Simon van Rysewyk *Editor*

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Editor
Simon van Rysewyk
Department of Philosophy and Gender Studies
School of Humanities
University of Tasmania
Hobart, TAS
Australia

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For Elina, and all people who struggle with pain

Contents

Chapter 1
A Call for Study on the Meanings of Pain

Simon van Rysewyk

> She told me that the high point of her life was playing the organ for her church choir. She lived for the twice-a-week practices and Sunday performances. Now, with pain immobilizing her elbow, she could no longer manage the keyboard. Her days held nothing that she looked forward to. The constant aching had robbed her or any hope. Life seemed empty of everything except pain. When I asked her if she had explained this to the staff of the clinic, she replied that they had not asked. Her medical history, as one might expect, read exactly like the history of an elbow (Morris 1991, p. 275).

Pain is a complex personal experience, with the widely accepted definition of pain advocated by the International Association for the Study of Pain defining it as an "unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" (International Association for the Study of Pain 2005). This definition rejects the traditional view that pain is caused by tissue damage alone (Sternback 1968; Mountcastle 1974), and replaces it with the claim that pain is associated with perceived bodily damage, thus supporting multiple causes and mediators. Nociception refers to the unconscious neural process of encoding noxious stimuli. In contrast, pain is a conscious personal experience that varies with the organism. In normal adult humans, pain links with meaning, appraisal, learning, emotional and cognitive experiences and responses (Melzack and Casey 1968; Hale and Hadjistavropoulos 1997; Arntz and Claassens 2004; Avila 2013; Gatchel et al. 2007; Price and Barrell 2012; van Rysewyk 2014). Several pain interventions are based on psychological mechanisms, with evidence supporting their beneficial role in pain management (e.g. Nicholas et al. 1992; Morley et al. 1999; Jensen et al. 2001; Butler and Moseley 2003; Louw et al. 2011).

S. van Rysewyk (✉)
School of Humanities, Department of Philosophy and Gender Studies,
University of Tasmania, Private Bag 41 Hobart, Tasmania 7001, Australia
e-mail: simon.vanrysewyk@utas.edu.au

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Although significant improvements in our understanding of pain have been made through preclinical and clinical scientific research, pain is often poorly recognized and poorly treated in the clinic (Craig 2009). Advancements in pain neurobiology are necessary to attain a more complete view of the nature of pain and to optimize its treatment (e.g. Tracey and Mantyh 2007; Wager et al. 2013; Nijs et al. 2014). However, such developments are insufficient without dedicated study of the psychosocial factors that determine qualities of pain experience and pain-related outcomes (e.g. Walsh et al. 2004; Kirwan et al. 2007; O'Brien et al. 2010; Hadjistavropoulos et al. 2011; Avila 2013; van Rysewyk 2014; Edwards et al. 2016). As David Morris recognizes in Chap. 22, "An understanding of pain, even in its most basic logico-scientific dimensions, cannot entirely float free from human motivations, human satisfactions, and human twists."

This book acknowledges calls in the literature for research scientists and clinicians to recognize biopsychosocial approaches to pain (Hadjistavropoulos et al. 2011). These calls parallel the growth of patient-centered organizations and advocacy groups that seek to integrate patients into the process of prioritizing research needs and creating alliances wherein patients and researchers partner together to accomplish research goals. Although biopsychosocial and patient-centered approaches to pain are well-supported by evidence (e.g. Gatchel et al. 2007; O'Brien et al. 2010; Hadjistavropoulos et al. 2011), preference for neurobiology continues to overshadow research and clinical attention to psychosocial factors of pain such as meaning (e.g. Morris 1991, 2001, 2010, 2013; Price and Aydede 2006; Price and Barrell 2012; Thacker and Moseley 2012; Avila 2013; van Rysewyk 2014).

This interdisciplinary book is the first to report in-depth scientific research dedicated to the *meanings of pain*. Situated within the wider context of a biopsychosocial framework, this book aims to improve understanding of the link between perceived meaning and pain, and to stimulate further research in this area. The intended audience of the book is research scientists, clinicians, patients with pain, and caregivers. To improve understanding of the meanings of pain in the target audience, this book studies several aspects within this area. These aspects include, common meanings of pain across types of pain, extended pain-related feelings and their meanings, meanings of pain associated with patient-clinician interactions, interactions between brain activity and meanings of pain, qualitative methods suited to studying meanings of pain, and meanings of pain in rodents and non-human animals. These aspects, together with relevant chapters in the book, are introduced below.

To my knowledge, no book in the pain literature presents research solely on meanings of pain together with a research call to study such meanings. Bustan (in press) focuses on the complexity of human suffering and pain, with attention in the book partly devoted to analysis of the meanings of suffering and pain. In the scientific literature on consciousness, Price and Barrell (2012) develop a research program with a focus on conscious experience and experiential meaning, but only one chapter of that book applies this integrative approach to pain experience and its common meanings. The call in this book is methodologically compatible with

"Neurophenomenology," a research program developed in the 1990s to study the neuroscience of consciousness (Varela 1996). However, very few empirical studies of pain have been conducted based within this program (e.g. Grace 2003; Rainville and Price 2004; Kerr et al. 2011; Valenzuela-Moguillansky 2013) and few theoretical pain publications have used it to develop theories and qualitative models about the meanings of lived pain experience (e.g. Giordano 2010; Fink 2011). Also, the focus of this book is on meaning, not consciousness (for the latter, see Garcia-Larrea and Jackson 2016). Thus, this book offers the first comprehensive treatment of the topic in the pain field. As such, it stands to make unique contributions towards study of the meanings of pain, and particularly towards understanding relationships between such meanings, the brain, and clinical practice.

Readers can take this introduction in parallel with, or independently of, reading the book. Chapters are mutually reinforcing, and interwoven with the same concerns. Despite the overlapping structure of the book, chapters are topically arranged. Chapters 1–5 focus on relationships between pain experience, meanings of pain, and the brain; Chaps. 6–11 present several qualitative methods suitable for studying meanings of pain; Chaps. 12–15 address extended pain-related feelings and their meanings. Relationships between meanings of pain and clinical practice feature in Chaps. 16–20. Chapters 21 and 22 are about studying and understanding meanings of pain in rodents and non-human animals. The 36 international book contributors approach meanings of pain from diverse research perspectives, including health psychology, psychophysics, philosophy, phenomenology, psychiatry, humanities, and cognitive and behavioural neurobiology. Many chapters are interdisciplinary, combining multiple perspectives.

1 Pain Experience and the Primary Meaning of Pain

Psychophysical studies of first ("protopathic") and second ("epicritic") pain using investigator-participants and studies of patients with pain reveal common meanings within the experiences of different types of pain. William Landau and George H. Bishop conducted self-experiments to study the qualitative differences between first and second pain, and found that first pain was sharp or stinging, well-localized, and brief, whereas second pain was dull, aching, throbbing, or burning, poorly localized, and longer lasting (Landau and Bishop 1953). In his own self-experiments, Head (1920) found that first pain was associated with temporal summation, spatial spread, and an increase in arousal. It was later discovered that the qualities of first pain, including the increase in "arousal," is the result of C-nociceptor activation, whereas A-nociceptor activation leads to second pain.

These findings were confirmed in studies combining psychophysical and phenomenological designs using investigator- and naïve participants. The unpleasantness of first and second pain was found to be associated with a common meaning of *immediate intrusion* or *attack upon the body*, despite the observed qualitative differences between these types of pain (Price 1972; Price et al. 1977; Staud et al. 2001).

Neuroimaging studies have identified neural correlates associated with temporal summation of second pain (Staud et al. 2008). This core meaning of pain was sometimes accompanied by immediate and extended negative feelings of “anxiety,” “fear,” “annoyance,” and “depression” (Price 1972; Price et al. 1977; Staud et al. 2001). The meaning of felt intrusion and negative feelings has been identified in cancer pain, neuropathic pain, and several types of musculoskeletal pain (e.g. Price 1988, 1999, 2000; Price et al. 1987; Jennings 2013; Osborn and Smith 2015).

It is important to note that this core meaning of pain does not always mean physical harm or impending physical harm, although it often does. It can also mean being personally overwhelmed or consumed by the pain, as some neuropathic patients have reported, and negative extended feelings of isolation and distress. This situation is often magnified when we consider how resistant pain is to clear linguistic expression. Patients may metaphorically describe their pain as if their skin was being burned or stabbed. Despite a longstanding debate regarding the use of metaphors within healthcare, our understanding of their application and therapeutic value remains unclear. In his chapter, Mike Stewart explores practical methods for eliciting metaphors from people in pain in order for them to create meaning and discover recovery strategies. Healthcare professionals may also use metaphors to develop empathy and create a shared understanding of pain.

A traditional view of feelings is that they are but “sensations or emotions of the soul which are related especially to it,” as Descartes put it, and thus are features only of the self and not of the world. However, in an intriguing study, Tabor et al. (2013) provides evidence that pain can change the meaning of an external stimulus. In this study, participants had to estimate the distance to a switch on a table. The investigators varied whether or not the switch would instantly stop a stimulus being delivered to their hand (set to the participants pain threshold), and whether or not they were required to reach for the switch. When participants felt pain and were required to reach for a switch that would deactivate the stimulus, they perceived the distance to that switch to be closer when they were in pain compared with the non-pain conditions. Thus, pain not only involves a meaning of intrusion of self, but that through my pain I connect to the world. When I am in pain, the world as I perceive it can change its meaning. A person in chronic pain who feels despair, desolation, and dread may begin to perceive phenomena in the world as animated with these same negative feelings such that the world becomes perceived in a despairing, desolate or dreadful way. Most chapters in the book further explore this neglected dimension of pain.

The sensory qualities (e.g. aching, dull, burning, stabbing, crushing) that occur during pain are necessary but insufficient to produce the core meaning of intrusion in pain experience, for sensory qualities can occur without any meaning of intrusion or threat. Thus, sensory qualities and meaning are separate factors in pain experience. To support this argument with several examples, patients who have had brain surgery to relieve intractable chronic pain often report they still experience the sensory qualities that typically occur during normal pain, but that these qualities are no longer painful (e.g. Rubins and Friedman 1948). In one study, following yoga therapy for chronic pain, one patient observed, “I feel more relaxed. I have pain, but

I don't feel it—it's there, but I am more relaxed" (Moody et al. 2010). As a final illustration, the burning sensory qualities following eating spicy foods are described by some people as painful, by others as not painful (Price and Barrell 2012).

Second, the psychophysical or physical context surrounding pain experience may co-create a meaning of intrusion or threat, in parallel with sensory qualities and cognition. In one psychophysical study, Arntz and Claassens (2004) informed participants through verbal suggestions to believe that a very cold metal bar placed against their neck was either hot or cold. Participants who believed the bar was hot rated it as more painful than participants who believed that it was cold. Further, meanings of tissue damage mediated pain intensity scores. These findings support the claim that meaning mediates the qualities experienced in pain, and that perceived tissue-damage in particular is an important meaning that partly determines pain intensity.

In a follow-up study, Moseley and Arntz (2007) placed a −20 °C rod on one hand of participants while altering the meaning participants believed of warning about, and visual attention to, the stimulus. A red visual cue meant *hot*, and *more tissue damaging*; a blue visual cue meant *cold*, and *less tissue damaging*. For warning about the stimulus, the stimulus occurred after the cue or concurrent with it. The authors found that stimuli associated with a red cue were rated as hot, the blue cue as cold. The red cue was rated as more unpleasant and more intense than the blue cue. For stimuli associated with the red cue only, rated pain was more unpleasant when the stimulus occurred after the cue than when it did not. Pain was rated as more intense, and the stimulus as hotter, when participants looked at the red-cued stimulus than when they did not. This study corroborates the central finding of Arntz and Claassens (2004) and shows in addition that warning and visual attention moderates the consequences of meaning when a meaning signifies bodily-damage. Thus, the context of the stimulus can exert differential effects on the sensory and emotional qualities and their meanings in personal pain.

In a final illustration of this point, pain unpleasantness can be mediated by meanings of the immediate physical and social consequences of having pain. For example, in women in labour, the immediate positive meanings of having a baby compared with avoiding pain during labour may partly decrease the unpleasantness of labour pain (Price et al. 1987). The pain of childbirth, as one obstetrician advised an expectant mother, is "good pain." In contrast, the unpleasantness of cancer pain can increase through interaction with the psychosocial context surrounding pain, including thoughts and images about the location of the tumour and the consequences of having this particular type of pain (Price and Barrell 2012). In Chap. 15, Chantal Berna argues that *intrusive cognitions in chronic pain*—that is, mental images associated with a meaning of intrusion or threat to the person in pain—offer a unique window for understanding pain experience, including meaning, emotional and cognitive reactions, and the perceived consequences of the pain condition. In clinical settings, patients aware of their own intrusive cognitions can receive targeted interventions using a range of psychological techniques to improve pain outcomes.

2 Extended Pain-Related Feelings and Meanings

Beyond the immediate primary unpleasantness of pain, “secondary” pain-related negative feelings may occur that are more cognitively mediated and based in reflection, imagination and memory (Price 2000). These extended feelings involve meanings about concern for the long-term consequences of pain. This concern includes perceived challenges in bearing with pain over time, how pain will interfere with one’s sense of well-being and activities, and other aspects of one’s life (Price 2000). The example of pain conveyed in the quotation from Morris (1991) illustrates the interaction between the different phases of pain and extended pain-related negative feelings. In this quotation, the statement “The constant aching had robbed her of any hope” shows how the sensory qualities and immediate primary unpleasantness of pain directly lead to meanings of disruption and concern for the long-term adverse consequences of pain (Price 2000; Vlaeyen et al. 2016). Her life had lost its meaning.

Perceived meaning in life is a clinically underestimated but important factor in adapting to the challenges of living through chronic pain. Jessie Dezutter, Laura Dewitte, and Siebrecht Vanhooren provide evidence linking meaning in life with the functioning and well-being of pain patients. Meaning-related issues need more clinical attention during patient intake, treatment and therapy. The importance of reconstructing meaning in adapting to chronic pain and the positive effects of meaning-centered therapy for other types of patients (cancer patients) requires developing meaning-centered therapies for pain patients as well. This meaning-centered therapy might alleviate pain and pain-related suffering. The authors touch on the rich relationship between meanings of pain and religion. More research is needed to understand interactions between meanings of pain and socio-cultural systems such as law, art, and literature (Morris 1991, 2001, 2010, 2013).

The Fear Avoidance Model (FAM) represents how the belief that low-back pain (LBP) means spinal damage can lead individuals into a cycle of fear and avoidance, which in turn sustain pain and pain-related disability. Available evidence supports FAM; however, randomized controlled trials of FAM have observed only modest effects sizes for reductions in LBP-related fear and disability. Limitations of the model in its current form may impede its clinical utility and applicability to all individuals with LBP and high pain-related fear. In particular, while the FAM conceptualises pain-related fear as a “phobia” driven by the underlying belief that pain signals damage, it is possible that “non-phobic” processes also trigger pain-related fear and avoidance. In this chapter, Samantha Bunzli, Anne Smith, Rob Schütze, and Peter O’Sullivan explore personal explanations and narratives related to the beliefs underlying pain-related fear, the common factors associated with these beliefs, and how fear may change over time. Of note, they consider how individual variance in qualitative data relates to scores on quantitative measures of fear. From this analysis, they derive an alternative model to represent the lived experience and meanings of pain-related fear, one representing “common sense,” rather than only “phobic” processes. Incorporating a “common sense” representation into future versions of FAM may improve its clinical utility and stimulate further research. If and how the experience of control over pain affects one's ability to derive meaning from pain experience is a possible study question.

In his chapter on pain-related feelings, Drew Carter applies philosopher Peter Hacker's distinctions between types of feeling to clarify the different types of extended negative feeling and their meanings that can appear during acute pain experience, especially in "secondary pain affect" (Price 2000). Carter highlights relationships between pain catastrophising and secondary pain affect to show that extended pain-related feelings need not always be negative, but can involve positive feelings of gratitude and amusement. In line with many authors in the book, Carter identifies our memories, long-standing hopes and fears, loves, or, more philosophically, what things mean to us in pain experience, in moral terms (Edwards et al. 2014). Health care practitioners can address the deleterious effects of feelings that instantiate secondary pain affect by empathetically reassuring patients of the nature of their pain, and keeping the hope alive that pain can be relieved.

3 Meanings of Pain in the Clinic

The patient experience narrated in Morris (1991) reveals that the patient's medical history excludes mention of the patient's lived experience of pain, its meanings and related feelings, through which she lives day in, day out. Medical evidence may not measure patient experiences, meanings, and outcomes, or include diverse patient groups, or personal information about comorbidities associated with pain. For patients included in the medical evidence base, quantitative information can be perceived as lacking meaning or unintelligible in relation to personal experience. In contrast, narratives and stories about pain, including patient accounts of pain experiences and meanings, clinical encounters and therapies, cautionary tales, and common sense, seem to offer meaningful and actionable information (Morris 1991, 2013; Frank 2015). Biomedical penetration into the depths of pain can render personal experience of pain unintelligible with a skepticism that corrodes the immediate needs of human action. A clinician who fails to account for the experiences and meanings of pain in a patient's history may be unable to experience that spontaneous sense of familiarity that enables his less biomedically inclined colleague immediately and personally to better relate to his patients and their particular experiences. A common complaint from pain patients is feeling a lack of opportunities to explore the personal meanings of their pain experiences with healthcare professionals (e.g. Butler and Moseley 2003; Teh et al. 2009; Thacker and Moseley 2012; Cedraschi et al. 2013).

Patients expecting to share personal experiences and meanings of pain in the clinic may face resistance from healthcare professionals. Patients with pain may encounter this resistance in various ways, sometimes as a kind of unreality in their everyday descriptions of pain experiences. It may seem as though patients are not *really* in pain, not as they describe it. Thus, patient reports of pain presented without clinical evidence of nociception may lead some health care professionals to treat such reports as imaginary or made-up, indicative of personal weakness, or malingering (Werner and Malterud 2003; Mendelson and Mendelson 2004; Cowley et al. 2009). Some clinicians use the term "subjective" in a pejorative sense to reject reported pain experiences as unreal, even in the presence of pain-related feelings of distress and depression. Patients may feel forced to fight with health care professionals for the care they have a right to receive. These negative clinical experiences can evoke meanings of belittlement and isolation in patients. Such meanings are associated with excitation of the nociceptive system and increased pain (Butler and Moseley 2003; Thacker and Moseley 2012).

The traditional biomedical approach to the person living through chronic pain, in whom no remediable source of nociception can be discerned, has proven unsatisfactory to clinicians and patients. When confronted with the *aporia* or puzzle of pain and the uncertainty that attends pain phenomena that do not accord with the biomedical imperative, validation of another person's experience of chronic pain may well be challenging and even threatening to the social capital of both clinician and patient. The need for mutual validation of the person experiencing chronic pain and the clinician pledged to provide information and treatment requires reframing of the traditional biomedical encounter. John Quintner and Milton Cohen assess the puzzling dynamics of the clinical encounter and attempt to show how both patients and health care professionals can achieve mutual validation of their predicaments through dialogical discourse, mutually negotiated narratives and social prospection. These strategies may reveal novel ethical possibilities for practicing clinicians and students in this challenging field.

To inform medical decision-making and facilitate patient outcomes, Karin Säll Hansson, Carina Elmqvist, Gunilla Lindqvist, and Kent Stening urge health care professionals to integrate phenomenological narratives and stories about pain into health care in parallel with consulting the medical evidence. Professional care structures should not make health care professionals feel torn between meeting patient needs for existential support and the demand of meeting high clinical workloads. The authors illustrate how narratives and stories can provide shared structure that allows patients and medical professionals to make decisions that feel meaningful, accurate, and clear (Hansson et al. 2011). Many patients use psychological strategies in everyday life in order to live meaningfully with persistent pain; but, according to the authors, this is not enough. They challenge healthcare professionals to "dare to open up and accept personal and deep conversations with patients" about their pain experiences and the lived consequences of persistent pain.

Giving meaning to persons with chronic pain is an integral part of accepting the reality of long-term pain. Bronwyn Thompson (Chap. 18) provides needed insight into the processes of meaningful adaption used by resilient individuals who live well with chronic pain. Clinicians can draw on these insights when working with people who seek help for their pain. By clarifying diagnosis, helping people understand their symptoms, and helping them develop predictions about what they can and cannot do in daily life, clinicians can help people make sense of their situation. Successfully completing this process allows persons to rebuild a sense of self that incorporates chronic pain as a reality, but not necessarily a limiting factor.

Chronic pain's etiology is not reducible to the biological malfunctions of the organism, but also lies in the processes of somatization and psychologization. While there are numerous studies of de-personalization in phenomenology, re-personalization remains largely unexplored. Saulius Geniusas demonstrates how re-personalization motivates one to re-conceptualize some of the central distinctions entrenched in phenomenological literature on pain and medicine. These entrenched distinctions include the distinction between psychogenic and organic pain, illness/disease and healing/curing. Geniusas argues that besides marking the subject's withdrawal from the common world, chronic pain, due to its persistence across time, also resettles the person in a new world of meaning, which one now needs to inhabit. The therapeutic meaning of dialogue is also highly relevant: pain therapy must be guided by a conscious realization that not only pain itself, but pain management, too, has both de-personalizing and re-personalizing significance. As Geniusas puts it, "Without understanding the person's history, her insertion in the lifeworld, her relation to others, as well as her orientation towards her future, one cannot understand pain's personal significance."

Pain is a shared social experience. Vicarious experience of pain arises from heightened activity in the neural networks involved in pain experience. Consideration of neurophysiological mechanisms in relation to the lived experience highlights that vicarious experiences may cause distress in some contexts, but in others, enhances interpersonal relationships. When a parent vicariously reacts to a painful injury in their own child, for example, this may motivate potent feelings of protection and nurturing. Healthcare providers who embody the pain or emotions of their client may report that this enhances intuitive and/or compassionate care. However, as Melita J Giummarra, Lincoln M Tracy, Kurtis A Young, and Bernadette M Fitzgibbon note, distressing vicarious reactivity towards the suffering of others is likely to disrupt the capacity to deliver compassionate care and/or lead to clinical burnout. To emphasise the significance of the social context in empathic and vicarious responses, the authors' overview lived experience of vicarious pain from the perspective of a clinician who describes her experiences with both family members and patients in pain. The authors' link phenomenological lived accounts of vicarious pain experience with central and autonomic mechanisms. They also discuss the implications of vicarious reactivity for interpersonal relationships, especially within a clinical context. Awareness of patient and clinician sensitivities to others' pain should be considered in the design and delivery of clinical programs and interventions, to attenuate distress and enhance quality clinical care.

4 Towards Using Neuroscience to Study Meanings of Pain

To date, pain research has been the domain of scientists and clinicians attempting to understand the neurobiological mechanisms of pain in an effort to develop effective treatments for patients. Based on standard quantitative methods, the results reported in these studies have scientific and clinical value of their own. The gate control theory of pain (Melzack and Wall 1965) and the neuromatrix model of pain (Melzack and Casey 1968) motivated researchers and clinicians to adopt a more accurate understanding of pain as a complex personal experience modifiable through facilitatory and inhibitory nociceptive mechanisms, and treatable through biomedical and psychological interventions (Basbaum and Fields 1984; Melzack 1990; Merskey 1998; Asmundson and Wright 2004; Julien et al. 2005; Julien and Marchand 2006; Louw et al. 2011). However, only a handful of studies have assessed interactions between meaning, pain, and neurobiological activity.

Benedetti et al. (2013) investigated relationships between the meaning of pain, the opioid and cannabinoid systems, and pain tolerance. Participants had to tolerate experimentally induced ischemic arm pain for as long as possible. Group 1 was informed about the aversive nature of the task (*negative pain meaning*); Group 2 was informed that the ischemia would benefit the muscles (*positive pain meaning*). The investigators found that Group 2 had significantly higher pain tolerance compared with Group 1, and this effect was partially blocked by the opioid antagonist naltrexone alone and by the cannabinoid antagonist rimonabant alone. However, combined administration of naltrexone and rimonabant antagonized the increased tolerance completely. When pain had a positive compared with negative meaning, the opioid and cannabinoid systems were co-activated and increased pain tolerance. Creating positive meaning for patients with pain is an option in pain management (Dezutter et al. 2015; Finan and Garland 2015; Gruszczyńska and Knoll 2015).

The neural mechanisms that convert sensory stimuli into personal expectations of impending events are an important component of neurosensory processing. However, the difference between afferent processing of stimuli-induced neural activity versus mechanisms supporting the contextual meaning of a stimulus remains poor. To study this question, Lobanov et al. (2014) used functional magnetic resonance imaging (fMRI) in an expectation paradigm in which stimuli (cues) were presented with visual or innocuous thermal stimuli. Cues were meaningful because they predicted the administration of high or low painful stimuli. The investigators found that the cues activated unimodal neurosensory cortices, which was transformed into a pattern of activity associated with cue meaning. Cues signalling high-intensity pain produced greater activity in the left dorsolateral prefrontal cortex and anterior cingulate cortex, which is consistent with the graded encoding of the intensity of expected pain. In contrast, cues signalling low-intensity pain produced greater activity in the right intraparietal sulcus, which may indicate processes directing spatial attention to the stimulated body region in order to process the weaker, low-intensity pain stimulus. Taken together, these findings indicate that stimuli arising from different sensory modalities engage common neurosensory mechanisms that reflect the meaning of the stimulus. This meaning-related activity may play a causal role in neurosensory processing of afferent information.

Despite improved understanding of relationships between the brain and psychosocial factors in pain experience such as meaning, the high prevalence of inadequately treated pain shows how difficult it is to control pain (Melzack and Wall 1988; McMahon and Koltzenburg 2005). Some researchers and clinicians believe neuroscientific data is sufficient to fully explain and treat pain, but is this true? More directly, can replacing personal reports of pain with brain-markers from neuroimaging studies improve control of refractory pain? Can brain models help improve patient-clinician communication? The contributors of this book are united in the view that a better understanding of pain neurobiology is necessary to meet the challenges of pain management, but insufficient in the absence of study of the physical and psychosocial context of pain, including study of the meanings of pain using suitable qualitative methods.

In his chapter, Stuart Derbyshire investigates whether any measure of brain function theoretically could become the gold standard for pain measurement. According to Derbyshire, the answer must be negative because measuring pain phenomenology, including patient meanings of pain, through objective brain measures implies the attribution of impossible features to physics, such as perspective, time and memory, and the attribution of implausible features to personal conscious experience, such as having a determined trajectory through time. The physical and psychosocial context of pain is hidden from view when pain experience is reduced to a pain-brain relationship.

On the assumption that the brain is necessary but insufficient for understanding pain experience, as Derbyshire suggests, what specific causal role does it play in producing pain? Grant Gillet argues that traditional neuroscientific views that treat pain as a sensory input are at best incomplete. Less than a somatosensory neural event, pain is more like a drive that signals a threat to the organism arising from an anomaly in harmonious neural function. The neuroplasticity of pain and its susceptibility to top-down (efferent) as well as bottom-up influences, make it obvious that clinical practices focusing on blocking or suppressing pain signals are not well advised. Pain must be managed in multidisciplinary ways that work at several levels to moderate the pattern of neural excitation in individual patients.

Magali Fernández-Salazar discusses important interactions between neuronal states, pain and pain-related emotions with a focus on non-reductionistic studies, compared with reductionist studies. According to Fernández-Salazar, chronic pain is a continuous learning state in which aversive emotional associations are continuously created with incidental events. Here, “emotion” is defined as an integrated neurobiological and functional adaptive process capable of generating physiological and experiential changes in constant interaction with neural systems and the external environment. The interaction of internal (neuro-mental) and external (environmental) dynamic networks may modulate the intensity and the experiential qualities of chronic pain. Fernández-Salazar also analyses emotional components that are part of the lived experience of chronic phantom limb pain. Phantom-limb pain might be associated with an increased functional correlation of brain regions involved in the processing and integration of sensory, emotional, cognitive and socio-cultural components. The distinction between sensation and perception is essential to understand the complexity of the neuro-mental processes of chronic pain, including phantom-limb pain. In the experiential representation of phantom limb pain, body-perception may contribute to the development of an emotional circuit in the brain leading to pain that may in turn transform into chronic phantom-limb pain.

Suggestions from some pain researchers to replace self-report of pain with brain-markers is compatible with Eliminative Materialism, a philosophy which asserts that there is nothing more to pain than brain mechanism. This is because pain, as conceived in our common sense folk psychology, does not really exist. Eliminativists draw inspiration from our intellectual history that shows that any theory can appear successful or beneficial even when it is false. However, as Simon van Rysewyk notes, pain education programs show that contemporary pain neuroscience theory and folk pain psychology can co-exist. Thus, elimination of folk psychology of pain is merely one possibility on a continuum comprising many theoretical outcomes. Further, history cannot protect eliminative materialism from the unjustifiably promissory nature of its claims.

Pain can signal the presence of danger in the immediate environment, and paying attention could contribute important information concerning the nature of the threat, its impact and consequences, and enable avoidance of bodily injury. Health care professionals, for example, are usually protected and remote from personal danger and trained to care for patients. Context and personal dispositions might stimulate a more sensitive response in perceivers. If one comes to empathize with the other person's pain, there is potential for intervening on their behalf. Still, the task of pain communication in clinical and non-clinical settings can be challenging. People in general can be characterized as only "good-enough" perceivers rather than "perfectly accurate" in understanding personal experiences.

According to Aurore Meugnot and Philip L Jackson, current "one-brain"-based neurocognitive models do not fully describe the interactive mechanisms underlying pain communication between observers and persons in pain. They propose that neuroscientific developments based on ecologically naturalistic research paradigms and affective computing (e.g. virtual reality) are viable methods to study pain communication. Technological breakthroughs help us understand the cerebral basis and the complex multi-dimensional nature of pain communication, which relies on sensory, cognitive, affective, and social information. A better understanding of pain communication in terms of caregiver and patient phenomenology may help promote empathetic interactions and improve clinical pain management.

5 Qualitative Study of the Meanings of Pain

The research presented in this book to support study of the meanings of pain derives from a small, but growing evidence base (e.g. Price and Aydede 2006; Price and Barrell 2012; van Rysewyk 2014; Bustan in press). Some of this supporting evidence consists of quantitative or analogical laboratory study. Such research typically occurs in academic research or clinical settings, using precisely defined healthy university student participants or patient groups. To optimize internal validity, analogical studies may exclude important psychosocial factors or variations in clinical care that might confound study outcomes (e.g. Gatchel et al. 2007; Hadjistavropoulos et al. 2011). A major consequence of this approach to the study of pain is that lived pain meanings and pain-related outcomes that patients consider meaningful are excluded from the scientific evidence base (Williams et al. 2000; Price and Aydede 2006; Dworkin et al. 2008; Osborn and Rodham 2010; Price and Barrell 2012; Thacker and Moseley 2012; van Rysewyk 2014; Bustan in press).

Analogical studies predominantly assess participant experiences and outcomes by assessing the same domains across all study participants. However, patient lived meanings or experiences do not typically form the basis of an original research study in a medical journal (Greenhalgh et al. 2016). Few studies have asked participants (or clinicians) to narrate in their own words the qualitative changes in pain experience, health-related quality of life, and overall improvement (or worsening) of pain that they judge meaningful. Few studies have investigated the contextual factors that mediate common meanings of pain in personal experience and pain-related outcomes, for individual patients and across types of pain, and how these interact and change over time. Further, even fewer analogical studies have studied interactions between meaning, pain, and brain activity (e.g. Benedetti et al. 2013; Lobanov et al. 2014). It is fair to say that the meanings implicit in behavioral and neurophysiological responses are missing from much of the pain evidence base (Price and Aydede 2006; Price and Barrell 2012; Thacker and Moseley 2012; Avila 2013; van Rysewyk 2014).

Evidence from qualitative studies conducted in research or clinical settings can complement and expand on the conclusions inferred by analogue investigations of pain (Price and Aydede 2006; Osborn and Rodham 2010; Hadjistavropoulos et al. 2011; Price and Barrell 2012; Thacker and Moseley 2012; van Rysewyk 2014; Toye et al. 2016). In contrast to analogical research, qualitative research does not aim to understand personal experience as a real "thing," which necessarily can be generalized to other populations of people (Osborn and Rodham 2010). Instead, qualitative research recognizes an interpersonal world that is describable in terms of the shared meanings persons attribute to it from within lived experience. The "shared world" that is the target of qualitative research is not a world distinct from the "real world" of quantitative research, but simply the same world differently described.

Thus, in qualitative research using interview methodology, participants do not adopt predefined theoretical categories but communicate their own descriptions of personal experiences. Such studies often ask a question such as, “What it is like to feel chronic pain?” or, “What is it like to feel anxious about something?” The participant directs attention to his or her own experiences under training from an experienced researcher, and learns to exclude personal beliefs, opinions, and a theory about what that experience is. This particular method attempts to preclude descriptions that are biased by either the participant’s or the researcher’s personal interests. Furthermore, the task of the participant is not to determine whether the stimulus really occurred, or whether the personal experience is real. Instead, the participant introspects on or attends to his or her own experience and describes it, but avoids formulating a theory or opinion about it. Participant data are not transformed through statistical analyses into average quantities; rather, comparisons between the descriptions of one participant are made with descriptions of other participants in the study (or compared with relevant data from other studies), and the investigators attempt to find *common meanings* of the experiences reported under the specific conditions of the study. The Experiential-Phenomenological Method (Price et al. 2002; Price and Aydede 2006), for example, aims to discover the common meanings within specific types of conscious experiences such as pain, anger, and anxiety, and interrelationships between the common meanings within these types of experiences.

In clinical contexts, health care professionals can use both medical evidence and patient data about lived meanings to help shape personalized decision-making (Morris 1991, 2001, 2013; Thorne et al. 1997; Frank 2015; Snow et al. 2016). Clinicians can recommend therapies to patients based on their professional understanding of patient lived meanings. They can compare how a particular patient with pain relates to other patients they have managed or heard about from past patients, colleagues or teachers. This approach is, in the words of Samantha Bunzli and colleagues “consistent with the epistemological standpoint that shared patterns of experiences are at the core of clinical knowledge and that the application of clinical knowledge is individualised for each patient” (Chap. 13; also, Thorne et al. 1997).

Patients may learn novel and unexpected insights about pain that helps them to understand information that quantitative evidence from medical databases cannot replicate. We relate to our own experiences in an intimate way because we live through or perform them. Other objects or events in the world we may observe and engage with in an impersonal way, but we do not intimately experience them in the sense of living through or performing them. Even data from patient surveys may not fully capture such intimacy. This new learning may inform shared decision-making with clinicians, researchers, friends or family members, and improve patient outcomes (Charon 2007; Toye et al. 2016). However, one challenge facing many clinicians and patients is that they lack the means to understand the role of narrative and meaning in clinical decision-making (Morris 2001, 2013; Charon 2007; Frank 2015).

Although qualitative methods share many methodological features, there are important design and theoretical differences between them. It is not part of the aim of this book to describe and compare such similarities and differences relative to the aim of a specific study, but the reader may consult with individual chapters in this book to form an understanding of this aspect. Price and Barrell (2012, 1–5; 7, 8) and Osborn and Redham (2010) in addition are useful introductory guides that focus on pain. Qualitative methods presented in this book to study meanings of pain include analysis of concepts from a western philosophical perspective (Chaps. 2, 5 and 15), Interpretative Phenomenological Analysis (Chap. 8), philosophical phenomenology (Chaps. 9 and 10), the Experiential-Phenomenological Method (Chap. 11), self-experimentation (Chap. 11), qualitative modelling (Chaps. 12 and 14), longitudinal or cross-sectional surveys (Chaps. 8 and 13), or questionnaires (Chaps. 7, 10, 14, 16, 20 and 21), and scientific phenomenology (Chap. 18). Interventions for treating pain in which lived meanings of pain play a contributory or central therapeutic role feature in most book chapters, but especially Chaps. 13, 14 and 16–20.

Sherrill Snelgrove explains why phenomenological approaches are suitable to study how pain appears to a patient through personal experience, and the embodied nature of pain. Although advocates of “big data” have been critical of qualitative studies with relatively small sample sizes, increasingly there is recognition in the field for the contribution of a single case-study approach to both theory and practice. Longitudinal or mixed method studies also can make valuable additions to the field, but are neglected by investigators (Price and Aydede 2006; Osborn and Rodham 2010; Dezutter et al. 2015; Vlaeyen et al. 2016). Snelgrove describes Interpretative Phenomenological Analysis (IPA) (Smith 1996; Smith et al. 2009), an ideographic research method, and reports data from her study using IPA on the lived experience and meanings of non-malignant chronic low back pain (CLBP). IPA has been used in several highly cited studies of pain (e.g. Jordan 2007; Osborn and Smith 2006; Smith and Osborn 2007; Snelgrove 2013; Osborn and Smith 2015).

The main benefit of IPA lies in its reflective, in-depth iterative and inductive design that may be generalizable to similar patient groups and sub-groups with pain. According to Snelgrove, the complex and diverse meanings of CLBP as revealed in her IPA study suggests that clinical assessment of pain be informed not only by quantitative and behavioural methods, but also by patient narratives to describe the phenomenology of suffering and its diverse meanings. To facilitate this end, psychological “talking therapies” such as Cognitive Behavioural Therapy should be included in clinical settings to give meaning to persons with chronic pain and build resilience.

Personal pain experience is the starting point for the study of the meanings of pain, but pain experience shades off into more unconscious phenomena. As the founder of phenomenology Edmund Husserl (1859–1938) proposed, we are only vaguely conscious of experiential qualities on the margin of attention, and we are only implicitly aware of the wider horizon of felt qualities in the world surrounding personal experience. Following Husserl’s phenomenology of attention, Agustín Serrano de Haro distinguishes between pain that occupies the foreground of consciousness and captures attention, from pain that shares attentional focus with other concurrent personal experiences. According to de Haro, pain captures attention because one’s own body defines the basic or zero level for exercising attention. Using phenomenology to study attentional structures of pain may inform a theoretical basis for non-pharmacological therapy for pain, especially interventions based on distraction techniques. The use of pain assessment scales and questionnaires in clinical settings may benefit from discriminating between different attentional forms of experiencing pain.

The question of investigators introspecting on their own personal pain experiences in pain studies has received little attention in the literature. Study of this question may have been impeded by ethical reservations about the many points at which self-interest may lead us to introspect on qualities through our biases that might unfairly influence professional decision-making and perception. Despite this concern, Simon van Rysewyk and Carl L von Baeyer (Chap. 10) offer three reasons why investigators can introspect on their own pain as co-participants in their own pain studies. One, there is historical precedent for investigator participation and co-participation in scientific pain research using introspection as a study method. Two, general concerns about variability in self-report based on introspection on pain experience derive from true fluctuations in personal pain experience, not simply error in its scientific measurement. Three, the availability of the Experiential-Phenomenological Method (Price and Aydede 2006), a mixed research method for the study of common meanings within human experiences, allows investigators to co-participate with naïve participants in their own studies by passively, not self-interestedly, introspecting on personal pain experiences.

Smadar Bustan assesses three major constraints for studying pain and pain-related suffering, and argues that, following Cassell (1991), achieving a fuller scientific understanding of pain will require ongoing research of the meanings of pain and suffering. Through use of standard qualitative and quantitative research methods, the study of "pain meanings" can complement knowledge of pain self-report, observable pain behavior and pain neurophysiology. In particular, personal challenges patients face during the development of their pain and pain-related suffering can be assessed using questionnaire, survey and interview methods. Bustan proposes that any ambition of science to obtain a final scientific theory of pain is an impossible goal. When pain persists over time, personal meanings of pain also change. Understanding these changes involves continuous study, especially for improving clinical understanding of chronic pain.

Ian Edwards models the physical and psychosocial context of pain within a larger landscape spanning a range of structural, policy, educational and clinical issues. Philosophically, this landscape consists of normative and non-normative territories creating a moral tension that can have deleterious effects on the well-being and sense of identity of a person with chronic pain. Edwards describes a qualitative reasoning model—*the Ethical Reasoning Bridge*—which may assist clinicians and patients to navigate this complex, interpersonal ethical landscape. Through this model, persons with chronic pain can develop narrative capabilities and learn sensitivity to the meanings of their own personal pain experiences. Qualitative modelling may also identify "a wider moral space" in which they can begin to resolve the moral dilemma they face in having to comply with the normative expectations of others at the cost of denying their own lived pain experience.

6 Studying Meanings of Pain in Rodents and Non-human Animals

Contemporary pain research in rodents has shown that the factor that produces the largest amount of variability in rodent responses to noxious stimulation is the human investigator. Mogil (2009) found that groups of rats showed differential results to noxious stimulation depending on which investigator conducted the experiments. Like humans, rats presumably are sensitive to the context surrounding pain experience. Like humans, rats presumably combine meanings with sensory qualities and the experienced context of pain (Price and Barrell 2012).

Michel Barrot, Eric Salvat, and Ipek Yalcin reveal that research methods have recently been developed in behavioral neuroscience that differentially combine reflexive and non-reflexive measures, enabling, for the first time, investigators to probe the complex sensory, emotional and cognitive phenomenology of pain in rodents. Aspects under study using these new methods include the core meaning of pain as intrusion or threat, the anxiodepressive and cognitive consequences of pain, and pain empathy. This development combining reflexive and non-reflexive measures could improve the translational value of preclinical research.

Despite the widespread reliance on animal models underlying medical understanding of human pain, understanding how non-human animals respond to physical and psychosocial factors in noxious contexts remains poor. David Morris distinguishes human pain from the pain of animals and concludes that animal pain is unknowable, an instance of what he terms *the otherness of the other*. Under-treatment of pain in racial and ethnic minorities suggests that beliefs about the meaninglessness of animal pain presuppose deeper anthropocentric and biomedical biases in responding to the *otherness* of non-human animals. Knowledge based on "animal models" used to understand and to treat human pain is as questionable as knowledge based on human models used to understand and to treat animal pain. The difficulties of understanding animal pain would advise caution in clinical applications of research based on animal models. Morris concludes: "we will not effectively address human pain until we have already adequately addressed the *other-ed* pain of animals. Respect for the otherness of the other—animal or human—is essential in pain research and clinical care."

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Chapter 2
Pain and the Dangers of Objectivity

Stuart W.G. Derbyshire

Abstract There is considerable hope and expectation that objective measures of brain function will soon replace subjective measures as the gold standard of pain measurement. Currently, there is considerable debate as to whether that gold standard will include the cortex or will focus on subcortical structures. This chapter looks beyond that important debate to ask whether *any* measure of brain function could, in principle, become the gold standard for pain measurement. Perhaps surprisingly, the answer is no, measures of brain function cannot, in principle, replace subjective measures as the gold standard for pain measurement. Essentially, the answer is no because measures of brain function measure objective physical changes, which is the wrong thing to measure if the aim is to capture subjective pain experience. Trying to read pain subjectivity through objective brain measures leads to the attribution of impossible features to physics, such as perspective, time and memory. It also leads to the attribution of implausible features to subjectivity, such as subjectivity having a determined trajectory through time. Part of the trouble arises from treating pain as a private experience when the roots of pain lie in a socially negotiated subjectivity. That socially negotiated subjectivity is lost when experience is reduced to brain function. Doubtless, the brain is *necessary* for pain, and all subjective experience, but the brain is not *sufficient*, the social negotiation is also necessary.

1 Introduction

Distinct medical diagnoses often turn on the evaluation of an objective measure. Lung cancer, for example, appears on a radiograph as a white area and, if the area is cancerous, the region will display increased activity in a flurodeoxyglucose (FDG) scan, which will then prompt a biopsy for a final diagnosis (Rivera et al. 2013).

S.W.G. Derbyshire (✉)
Department of Psychology and A*STAR-NUS Clinical Imaging Research Centre,
National University of Singapore, Singapore, Singapore
e-mail: stuart.derbyshire@nus.edu.sg

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Such a process is paradigmatic of the biomedical process where diagnosis proceeds without reference to the emotional or other subjective state of the patient. What the patient thinks or feels is important because the patient is a human being and should be treated as such, but the job of diagnosis is to look through that and observe the broken mechanisms beneath.

Pain, therefore, can appear as an irritation in the diagnostic process, a symptom of something broken in the body but not important in itself. In the latter half of the 20th century, however, many clinical observations and experiments challenged the view of pain as merely a symptom of pathology (Beecher 1956; Melzack and Wall 1965). Patients vary considerably in the pain they experience from similar evidence of disease or injury (Melzack et al. 1982) and can experience pain without any apparent disease or injury (Barsky and Boris, 1999; Wessely et al. 1999; Mayer and Bushnell 2009). Moreover, the attempt to find an underlying nervous system process to account for pain intensity ran into several problems, including the fact that activation of mechanoreceptors, or "touch fibres," could sometimes generate pain (Cervero and Laird 1996). The fact that patients might not report pain when injured, might report pain when not injured, and the difficulty of tightly coupling pain experience to a specific "pain system" gradually eroded the idea that pain could be treated only as a symptom and the idea that pain could be objectively measured. Thus, pain began to be viewed as a problem, or a disorder, in its own right and as a disorder defined by the subjective report of the patient. This view of pain as a subjective disorder was captured by the IASP (International Association for the Study of Pain) definition of pain in 1991.

[Pain is] an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage… pain is always subjective. Each individual learns the application of the word through experiences related to injury in early life (Merskey 1991).

It was not long, however, before the IASP definition was challenged. The focus on language and subjectivity seems to deny the possibility of pain for the fetus and newborn infants, animals and possibly patients entering into dementia (Anand and Craig 1996). Consequently, there were efforts to redefine pain as an inherent neurobiological process involving cortisol release and activity in certain parts of the brain (Giannakoulopoulos et al. 1994; Anand and Craig 1996; Lowery et al. 2007). In addition, the increasing use of imaging techniques, especially fMRI, to investigate pain gradually led to an understanding of pain as involving activation in a characteristic set of brain regions, which became known as the "pain matrix" or "pain signature" (Apkarian et al. 2005; Tracey and Mantyh 2007).

Special effort is now being made to find the regions of the pain matrix that are specific to the experience of pain and to use the pattern of activation as a "biomarker" for pain (Schweinhardt et al. 2006; Wager et al. 2013). That biomarker, it is hoped, can then be used to diagnose pain and to potentially test new pharmacological products. Those efforts have generated intense debate regarding the meaning of "pain matrix" versus a unique "signature" for pain (Hu and Ianetti 2016), the reliability of any fMRI based biomarker for pain (Letzen et al. 2016; Woo and Wager 2016) and even whether the so-called "pain matrix" has anything to do with pain at all (Ianetti and Mouraux 2010; Mouraux et al. 2011). The recent startling discovery that patients born congenitally insensitive to pain nevertheless activate the "pain matrix" in response to noxious stimuli provides a considerable challenge to the idea that pain matrix activation can be used to diagnose pain (Salomons et al. 2016).

The technical debates about the reliability of fMRI as a pain measure and the exact content of any biomarker for pain are important, but are not the focus of this chapter. This chapter aims to examine the underlying principle of *any* effort to provide objective diagnostic criteria for pain, regardless of the technical difficulties. As a simple analogy, it is accepted that fever can be measured with a thermometer in the mouth or ear, and that reliable changes in thermometer readings provide an acceptable measure of treatment efficacy. If the world of thermometer manufacture were plunged into chaos and thermometers stopped agreeing with each other and stopped accurately indicating temperature, then changes in thermometer readings would cease to provide an acceptable measure of treatment efficacy. However, that would be because of practical difficulties with the measurement of temperature, measurement of temperature would remain in principle a good means of diagnosing fever and a good measure of treatment efficacy. The question posed here is whether measures of brain activity, or structure, or chemical composition, can similarly be accepted as, in principle, a good means of diagnosing pain and a good measure of treatment efficacy.

The short answer is no, brain imaging cannot provide a good means of diagnosing pain. Fever is an increase in body temperature, and temperature is exactly what working thermometers are intended to measure. Therefore, thermometers are an excellent means of diagnosing fever and that logic holds even if all the thermometers in the world suddenly stop working. In contrast, pain is not a change in brain activity, hemodynamics or chemistry, which is what most brain imaging tools are designed to detect. Therefore, brain imaging is a poor means of diagnosing pain and that logic holds even if all our brain imaging technology works perfectly. Now let us look at that logic in more detail.

2 Dilbert's Error

Largely, the debate unfolding here is another version of the "hard problem" (Chalmers 1996). For those unfamiliar the hard problem is that the universe consists entirely of matter, we humans consist entirely of matter, matter has no awareness and yet we are conscious (Chalmers 1996). How? Calling that problem "hard" considerably understates the severity of the issue, which is where some of the trouble begins. The problem is exceptionally difficult and solving it will likely mean destroying much of what psychologists and neuroscientists currently hold as the central tenets of their disciplines (Fodor 2000, 2007; Tallis 2004, 2012). Right now, however, it seems that psychology and neuroscience is in some sort of denial about the hard problem. In pain research, for example, there is now widespread expectation that the field is close to replacing subjective reports of pain with objective measures of brain activity (Tracey and Bushnell 2009; Wager et al. 2013; Davis et al. 2015). This expectation remains despite the obvious gap between measures of brain function and pain subjectivity and intense arguments about the relevance of the pain matrix to pain (Iannetti and Mouraux 2010; Sullivan et al. 2013; Salomons et al. 2016). Similarly, there is widespread expectation that behavioural problems, such as addictive disorders, will yield to neuroscientific understanding despite ongoing uncertainty about the nature of addiction, the role of volition and the uncertain relationship between brain activity and addictive behaviour (Heilig 2015; Derbyshire 2016). Psychiatry has been awaiting the neuroscience revolution for many decades but is still unable to clearly demonstrate the effectiveness of pharmacological treatments of depression (Valenstein 1988; Kirsch et al. 2008). In short, it is expected that the hard problem will eventually be resolved by continuing to look at the brain, albeit with more technically demanding, fine-grained and innovative approaches (Churchland 1986, 2002; Koch et al. 2016). That expectation misconstrues how hard the hard problem really is.

One reason why psychology and neuroscience might be so relaxed about resolving the hard problem is that the problem itself can be stated remarkably succinctly and simply. In a hilarious Dilbert cartoon (Fig. 1), Dogbert asks Dilbert if he thinks the chemistry of the brain controls what people do. Of course, replies Dilbert. Then, Dogbert points out that such a position leaves us unable to hold people accountable for their actions. Dilbert resolves this by arguing that people have free will and we can hold them accountable for actions they freely choose. Now Dogbert smells something fishy and asks if free will is a part of the brain. Yes, says Dilbert, but it is the part of the brain “that is out there just being kind of free.” Dogbert goes in for the kill, “So, you’re saying the “free will” part of the brain is exempt from the natural laws of physics?” Dilbert is forced to assert that obviously the free will part of the brain is exempt from the natural laws of physics or else we couldn’t hold people accountable. The cartoon concludes with Dogbert asking if the free will part of the brain is attached or just floating nearby.

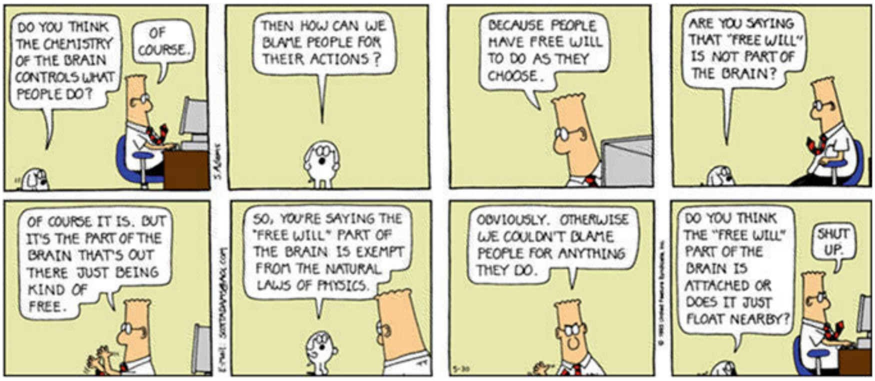

Fig. 1 Dogbert forces Dilbert into an error, but where is Dilbert’s error?

Thus, in a mere eight panels of a cartoon, Scott Adams manages to convey the central issue of the hard problem: how do we get subjectivity out of physics? The cartoon poses that question through an error made by Dilbert, so where is Dilbert's error? Dogbert, and many contemporary psychologists, view Dilbert's error in trying to extract free will from the brain. From there, the logic is compelling. If free will cannot be extracted from the brain, then free will is subject to the natural laws of physics just like all material things, which annihilates free will because material things do not will. Having annihilated free will, it is a small step to annihilate subjectivity entirely because it is our subjectivity that informs our will and, in any case, material things are no more subjective than they are wilful. Material things just are.

If we wish to rescue free will and subjectivity then we must find a different error for Dilbert. Perhaps Dilbert's error appears right at the beginning, when he concedes that the chemistry of the brain controls what people do. It is that concession that leads inevitably to the end of free will because chemistry and physics do not will. Thus, to rescue free will and subjectivity, we must deny Dogbert's premise and deny that the brain controls what people do. If we can successfully deny that the brain controls what people do, then the scope for brain imaging providing a measure of subjectivity, including the subjectivity of pain, becomes at least more remote.

3 Physics Doesn't Do That Kind of Thing

One solid reason for rejecting the brain as providing subjectivity is precisely because, as a material object following the laws of physics, the brain cannot provide the kinds of things subjectivity provides. When a person suffers an infection, the immune system releases pyrogens which are carried to the hypothalamus in the blood stream and which then raises the set point for core body temperature in response. Thus, hypothalamic activity can provide a direct indication of core body temperature, which is also recorded by a thermometer. Subjectivity, the perception of being hot or cold, however, is different from the temperature of the body. We can legitimately state that the thermometer and the hypothalamus provide a measure of temperature, but not a measure of feeling. We objectively measure temperature and subjectively feel hot, to subsume both within the activity of the hypothalamus, or the rise of mercury in a thermometer, illegitimately subsumes the subjective under the objective.

A simple trick to demonstrate the difficulty of subsuming the subjective under the objective involves two bottles of differently colored water, red and blue, for example. Then, in front of at least one other person, place one bottle in front of the other, and ask which bottle is in front of the other. The trick lies in ensuring that the other person is looking at the bottles from the opposite perspective to you—i.e. for you, the blue bottle is in front of the red but, for them, it is the other way around or vice versa. Typically, the other person will look confused and eventually ask, “From whose perspective?”

The material world does not have “perspective,” only subjective creatures have perspective. The spatial relations among objects are not objective relations, but subjective relations that change according to the position of the subjective observer. Conscious agents pick out spatial relations because conscious agents can identify boundaries. The boundaries that we pick out, however, do not transform physical space such that each object now becomes a point of view stipulating its surroundings. The blue bottle is in front of the red bottle for *you*, not for the bottle. The blue bottle is not in front, behind, to the left, right or in any spatial relation with anything because to be in a spatial relation requires having a particular point of view. In addition, bottles most emphatically do not do that kind of thing. Bottles just are and, without subjectivity, they are not even bottles because a bottle requires a spatial relation separating the bottle from its surroundings.

A similar trick can be done with memory. Take a look at the picture below (Fig. 2).

Most obviously, the car has crashed into a tree. How can we be so certain? In large part, we are certain the car crashed into the tree because we are familiar with how cars typically look when they have not crashed, they do not look crumpled, and we are familiar with how cars and trees typically interact. We know that cars move, quickly, while trees do not, and we know that when solid items collide at speed something has to give. What gives is the metal of the car, producing the crumpled state we observe above.

We see the car as having crashed into the tree because of knowledge that we share with others, which has a recognized meaning consistent with personal experience, and with other known associations. We do not see the car as having crashed into the tree because the crumpled car contains a sort of memory of its previous non-crumpled state. Although unlikely, it is not impossible that the car was deliberately manufactured in a crumpled state and merely placed by the tree. Also unlikely, but not impossible, is that the tree was placed on wheels and driven into the car. The car-tree alignment that you observe in the photograph does not deliver the past car-tree alignment such that you know the prior arrangement of the car and tree. That is because the car-tree alignment is just physics and physics does

Fig. 2 A car crash? Seems likely, but you do not observe the car crash and the car does not retain any memory of the crash for you to use

not carry along memories of prior physical states. One state of physicality does not provide details about causality or previous or subsequent states of physicality or the timing between events. If you think that is wrong, then you might be heading into a great deal of lunacy because, logically, you will be forced to concede that every past event is retained within every current part of physics.

The moral for neuroscientists chasing subjectivity into the brain is this: what holds true for the physical world out there also holds true for our physical brains. The inability of the physical world to spatially separate one object from another means that you cannot find spatial relations in the physics of the brain. In addition, the inability of the physical world to retain memories means that you cannot find memories in the physics of the brain, or, for that matter, temporal relations. Synaptic activity does not contain previous activity and is not about anything in respect to any other spatial or temporal event or thing.

The moral for pain neuroscientists is this: the spatial relations of pain, where a pain is felt in the body, cannot be found in the brain. The implications of pain, what it means for the person's well-being, whether it is connected to something that just happened, or happened years ago, or is seemingly disconnected from anything at all, equally cannot be found in the brain. The subjectivity of pain, how it feels, cannot be found in the brain. Trying, nevertheless, to stuff subjectivity into the brain does bad things to subjectivity and turns it into something it is not.

4 Subjectivity Isn't Like That

Putting subjective experience, such as pain, into brains either forces brains to have properties they do not have, such as perspective, memory, knowledge and so on, or it has to force subjectivity to be something it is not. Again, the analogy with the thermometer might be instructive. The thermometer contains within it some of the body temperature; some of the energetic activity constituting body temperature is transferred to the thermometer. Suggesting that the thermometer also picks up some of the subjective feeling of heat, however, is a tremendously strange suggestion because thermometers do not feel. One way to avoid that strangeness is to embrace it and argue that, regardless of how strange it may seem, thermometers do feel. That is the pan-psychic resolution of the hard problem—everything feels, at least a little bit (Chalmers 1996; Velmans 2000). The generally more preferred way to avoid that strangeness is to deny subjectivity and argue that any experience of heat is simply an expression of temperature that is every bit as objective as temperature (Churchland 2013). This resolves the hard problem by turning subjectivity into a determined object, making it concrete and definite instead of abstract and undecided. Thermometers might lose their strangeness, but only at the cost of subjectivity becoming very strange indeed. The elements of subjectivity that physics cannot provide, such as time, have to go.

If pain really is to be found in the brain, measureable as a property of brain activity, then pain must become determinable both going backwards *and* forwards in time. Backwards in time, the past is not problematic. The past really is determined, concrete, and decided. In principle, we can unravel the past and know it precisely. In that sense, the past can be treated as a determined object.

Forwards in time, the future is problematic. For physics, the future is just as determined, just as concrete and definite, as the past. In principle, we can unravel the future of a physical object and know it precisely. For physics, the future can be treated as a determined object.

Human beings, in contrast, are not like that. Looking backwards, Stuart is fully determined with the past events of his life, his thoughts and feelings, forever concrete and definite. Going forwards, however, subjectivity is not concrete and definite. Stuart on Friday is not the same as Stuart on Monday. Stuart on Friday could only imagine the Stuart on Monday because the Stuart on Monday is uncertain. Stuart on Friday, for example, might imagine Stuart on Monday finishing this chapter but this finished chapter is then only a possibility that may, or may not, be a reality on Monday (it was not). Stuart on Friday contains some, but not all, of the features of Stuart on Monday. Moreover, the features of Stuart on Friday cannot be used to precisely predict the features of Stuart on Monday; future Stuart is never a strict identity, but an undecided becoming.

Denying that the future is undecided might seem an odd thing to do, but it is necessary if the aim is to make subjectivity a physical property that can be objectively recorded in brain activity. It is necessary because physics is as determined going forwards as it is going backwards, which means that time is not meaningful for physics. McTaggart (1908), for example, precisely argues that there is no such thing as time, that time is an "unreality." In essence, he argues that on Friday, Stuart on Monday is in the future. On Monday, however, Stuart will be present and on Wednesday, Stuart on Monday will be past. Consequently, from the standpoint of today, *in the future*, Stuart on Monday will be future (still to happen), present (happening) and past (happened). Nevertheless, Stuart on Monday cannot be simultaneously future, present and past and thus, McTaggart argues, that time itself is unreal (see also Tallis 2012).

The mistake is, as already discussed, to turn future Stuart into as concrete an entity as past Stuart and to treat past, present and future Stuart as the same Stuart passing through three phases. The possible future is not the actual future; the future Stuart only becomes real when he arrives. Until then he is merely a possibility. Subjectivity does not provide the strict identity between past and future that physics provides.

In summary, treating the brain as the source of pain subjectivity leads us towards believing impossible things about physics. Those impossible things are that physics contains perspective, memories, time and causality. Treating the brain as the source of pain subjectivity also leads us towards believing implausible things about people. Those implausible things include the idea that there is a strict, concrete, human identity following a predetermined trajectory. A question obviously follows: if the brain is not the place to look for pain subjectivity, then where?

5 Where Else but the Brain?

We should not look for the explanation of behaviour in the depths of the brain or the soul but in the external living conditions of persons and most of all in the external conditions of their societal life, in their social-historical forms of existence (Luria 1979, p. 23).

> I contend that many of the most interesting and important human cognitive achievements, such as language and mathematics, require historical time and processes for their realization…Acquiring a natural language [also] serves to socialize, to structure culturally, the ways in which children habitually attend to and conceptualize different aspects of their worlds (Tomasello 1999, p 48).

The essential reason why looking outside the brain is necessary to understand pain, and all subjectivity, is because pain is not private (Sullivan 2001). Although it is obviously a private individual that feels pain, the content and meaning of pain comes from outside the person in pain. An infant might cry, grimace or flail; a caretaker might look for the cause and connect stimuli to responses through words, actions or an emotional connection depending on the circumstance and age of the infant. In this way, the negotiation and creation of subjective experience begins.

The social nature of experience might be rendered more obvious by considering something other than pain or similar perceptual experience. In an essay considering the deficits suffered by children with autism, Gregory Hollin asks the intriguing question as to whether a person praying in isolation is engaging in a social act (Hollin 2014, and see Fig. 3). According to one view, solitary prayer is an individual act because it is performed alone. Prayer, however, even if done in isolation, involves stereotypical acts such as kneeling, holding the hands together, closing the eyes, that an individual is unlikely to spontaneously perform without prior instruction. In other words, although the act is performed alone, the act does not belong to the individual, but is a part of the communal history introduced to the individual. The same is also true for perceptual experiences. The individual does not feel private feelings because he did not, by himself, create the terms and content of their feelings. The terms and content of feeling are "borrowed" from others until

Fig. 3 A person praying alone. Are they engaged in a solitary act, or a social act? Solitary, if you focus on the person being alone, but social, if you focus on where their behaviour originates

they eventually belong to the individual; but the individual feeling never loses its social content.

At least some neuroscientists are willing to consider the notion that knowledge has a social component and so searching for knowledge in the brain might generate problems. Far fewer, however, are willing to accept that essential sentient experiences, such as pain, also require a social explanation (Zeman 2001). Instead, the original grimace or flair is seen as expressing an already existing mental state of discomfort, which may be elaborated, but is not created, through interaction with others (Anand and Craig 1996; Tallis 2005; Grahek 2007; Devor et al. 2015). The difficulty with that view is that even the vaguest and elusive sensory experience has content that has to be isolated and separated in order for it to be experienced (Sullivan and Derbyshire 2015).

To argue that some core aspect of pain is given directly by brain activity, as a raw state of sensation that *just is*, is problematic. No words are allowed to describe such a sensation because they provide structure and meaning, which are prohibited. There can be no structure, no substance, and so the state of sensation cannot access the support it needs to exist. In addition, even if we allow an experience that somehow escapes the subjective structure necessary for experience (which is impossible), that experience would be in immediate competition with a vast number of other raw sensations. At any given moment, an organism is bombarded with a vast number of stimuli that must be appropriately held together and apart in order for specific experiences to reveal themselves against a totality of being. That would be private experience, an experience that is everything, entire being, and so nothing, because experience necessarily requires the isolation of discrete moments and elements from the totality of time and space.

The escape from this totality is to understand subjectivity as becoming rather than as a discrete thing (Derbyshire and Raja 2011). The first moment in subjectivity is when the infant is grabbed by a connection between a behavioural state and an external state. Initially, the child is determined by the external flow of stimuli, producing fixed-action patterns and catastrophic reactions. A conscious, subjective, caretaker can construct voluntary attention by highlighting the relevant elements of the environment and thereby controlling, regulating and shaping differentiated and socially responsive patterns of behaviour. The initially spontaneous behaviour of the child is guided by the intelligence of others until the child is able to regulate itself and, instead of following a stimulus, the infant now anticipates and organizes its perceptual experiences (Hobson 2002; Greenspan and Shanker 2004). The previous external regulation by conscious caretakers becomes the child's own mental regulation, which now allows specific experiences to emerge from pure, private, being.

In this conception, the subjectivity of human beings lies not in the physical structures of the brain, which are determined, but in the varied and complex social interactions of human beings, which are negotiable. This enables escape from the necessity to force physics to have impossible properties such as perspective, memory and time. Perspective, memory and time are the collective properties of humanity, a result of the "cognitive handshakes" occurring across time and space, which are inherited by every socialized human being (Tallis 2005, 2012). This also enables escape from the necessity to force subjectivity to have implausible properties such as being determined from moment-to-moment. Freedom arises from the collective negotiation of how to organize and regulate the structure of human existence, which every human being is a part of (they are a part of the negotiation) and separate from (they embody that negotiation in their personal, physical, being).

Pain scientists cannot escape the need to study conscious experiences or subjectivity per se, which should not be problematic because the experience is the thing that requires explanation (Price and Aydede 2006). Nevertheless, many pain scientists view the study of the brain as the more objective, more scientific, route to understanding pain. The fundamental materialist position is that every experience and behaviour must be reflected in distinguishable patterns of neuronal activity (Zeman 2001). That position is undoubtedly true, the brain is undeniably part of the story, and so study of the brain should remain part of the attempt to provide a comprehensive understanding of pain. The problem lies not in the inclusion of the brain but in the view of the brain as providing, in itself, the comprehensive account of pain subjectivity.

6 Brains are *Necessary*, but not *Sufficient* to Understand Pain

My aim has been to boldly state the case against finding pain subjectivity in the brain. The reasons are two-fold. First, the relevance of the brain is considerably overrated, and there is unreasonable expectation and hope that better understanding of the brain will resolve a host of subjective and psychiatric problems (Andreason 1984; Valenstein 1988; Frith 2007). Second, by stating the case against the brain as boldly and directly as possible, it is hoped that a reaction will be generated to create discussion and refine the arguments. In boldly stating a position, there is the danger of overstating. Thus, to be clear, it is not being argued that the brain does not matter. Clearly, the brain is necessary for pain because normal human beings without brains do not feel anything at all. Stating that the brain is necessary for pain, however, is not saying very much. It can be accepted that the brain provides a physiological process necessary for subjective experience, a process which Mead (1934) suggested as analogous to that of pulling down and raising a window shade. If the shade is down, it is dark, and that makes vision difficult, but if the shade is up then everyone with normal vision can see and we can then study people with normal vision without further concern as to the operation of the shade.

There remains some argument about what the "shade for pain" involves. Certain lesions and brain abnormalities can sometimes result in a complete insensitivity to pain, or to a partial insensitivity to the emotional component of pain so that they are no longer bothered, or moved, by noxious events (Grahek 2007). These findings are broadly consistent with a body of data that supports the necessity of several cortical regions for normal pain experience (Tracey and Mantyh 2007). There is, however, substantial opposition to the view that cortex is necessary for pain. Some suggest that subcortical structures can support pain experience and recent, startling, empirical evidence implies that cortical responses to noxious stimuli are not specific to pain experience (Lowery et al. 2007; Iannetti and Moraux 2010; Devor et al. 2015; Salomans et al. 2016). Similarly, there remains considerable uncertainty about the role of brain dysfunction in neuropathic pain and argument as to whether certain non-specific pain disorders, such as fibromyalgia, involve brain dysfunction (Dennis et al. 2013).

These problems and issues remain part of the "hard problem," which is the problem of understanding how physicality relates to subjectivity. Right now, that problem looks intractable and, as stated at the beginning, likely much of what neuroscience and psychology takes for granted will have to be jettisoned before that problem is resolved. Here, I have argued for the strong claim that one thing that needs to be jettisoned is the idea that pain can be measured via brain activity or composition in the same way that a thermometer can be used to measure fever. Subjectivity cannot be measured like that because subjectivity is not a physical process and so cannot be physically measured.

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Chapter 3
Neural Plasticity and the Malleability of Pain

Grant Gillett

Abstract Pain is a product of our neural networks painstakingly formed through phylogeny and ontogeny. Neural pathways form within neural nets as a result of long term potentiation and other dynamic mechanisms that subserve learning and memory and are modified so therefore form a key part of what Foucault calls "a volume in perpetual disintegration," constantly reinforcing connections that capture points of experiential association and gradually dismantling networks that are no longer relevant to the organism's affordances (points of biological significance in a stimulus environment). Human pain, seen as an experience with a pivotal role in human interactions, and with a number of psychologically inflected varieties and meanings, is therefore not only a neural phenomenon, but also a moral one. It is moral in that it reflects influences from our engagement in a context of human adaptation that is discursive and interpersonal, one that is heavily inscribed by cultural stereotypes and practices that shape who we are and how we understand and give an account of ourselves. To be, in that sense, is to be humanly engaged in the world, including the world of the clinic and its mores whenever and wherever we enter into it.

1 Introduction: The Role of Pain

Pain has a number of adaptive roles that tell a relatively coherent story about its evolution as a higher-order pattern of neural integration, forming part of what John Hughlings-Jackson calls the "organ of mind" (Hughlings-Jackson 1887) which is, like other mental phenomena, a "triply indirect" representation of fundamental sensory-motor activity (there are sensory inputs, yoked or coupled motor responses, and inflections from other areas of the brain such as memory, speech mechanisms, and widespread linked collateral excitation from social cognition and so on). As

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G. Gillett (✉)
Division of Health Sciences, Bioethics Center, University of Otago,
PO Box 56, Dunedin 9054, New Zealand
e-mail: grant.gillett@otago.ac.nz

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such, pain carries information about current or imminent tissue damage and is therefore intrinsically responded to as drive or motivation: “this something is … important—and frightful” (Wittgenstein 1953). But, in addition to being a complex signal it represents a struggle—the agony—of enduring an aversive motivational state without giving into it so as it disables us and seeking a way to deal with it and remain humanly intact.

> But you will surely admit that there is a difference between pain-behaviour accompanied by pain and pain-behaviour without any pain?“—Admit it? What greater difference could there be?—“And yet you again and again reach the conclusion that the sensation itself is a *nothing*.”—Not at all. It is not a *something*, but not a nothing *either!* (Wittgenstein 1953, §304).

Wittgenstein is reacting to the thesis that pain is in me but something apart from me as an engaged psychological and moral being like any other object or event in my world. It is, however, not a sensation within me but rather a subjective inflexion of my whole mode of being (as a variety of suffering), and thereby highly significant to me. This already complex analysis of pain is reflected when we allow the neuroscience to inform our philosophy and our concern with human subjectivity as being vulnerable to suffering.

2 The Old Stereotype of Pain

The experience of pain is often used as an example of a mental attribute with qualities that defeat attempts to identify mental events with neural events. The philosopher, Galen Strawson, remarks: “The word ‘pain’ is just a word for a certain class of unpleasant sensation, considered entirely independently of any of its behavioral or other observable causes and effects” (Strawson 1994, p. 245) and “the private experience is the fundamental given fact, so far as our own language of pain is concerned” (Strawson 1994, p. 243). Those actually working with patients in pain are nearly so certain about its status as independent of the sufferer in that there is, typically, a sensory input from a damaged body part but much happens in transmission, the translation of neural state into conscious, communicable experience (that used to be called “introspection”), that tends to confirm Wittgenstein’s famous “beetle in the box” (Wittgenstein 1953, §293) argument about the common introspective view whereby if what I experience is totally inner and private to me and what you experience is similarly only evident to you, it is difficult to see how we establish a public, received sense, of pain and its characteristics?

In fact, certain paradoxes arise when we adopt the simple introspective view of pain:

(i) pain is subjective and affected by cultural context not just the nature of the physical insult;
(ii) you can learn to feel pain—“You learned the concept pain when you learned language” (Wittgenstein 1953, §384);

(iii) you can feel pain where you have no body—phantom pain;
(iv) motor centres are prominent in the neural substrate of pain;
(v) there is no consistent threshold for pain.

These features do not fit well with the idea that there is a certain quantum and quality of input detected and passed up the system more or less unaltered until it reaches consciousness as a *pain*.

3 The Contemporary Conception of Pain

The standard view regards pain as something that goes on ‘inside’ a subject and is reported as a sensory state of affairs that bursts into consciousness and is known incorrigibly as such by a normal subject just because of its feel. Philosophers tend to repeat this view: ‘Whenever you feel this you do have a pain’ (Kripke 1979) and, it is taken to ground the claim that a person who says ‘I am in pain’ and says it sincerely, cannot be mistaken. The paradoxical facts about pain are, however, more complex so that some argue that ‘there can be no true theory of pain’ (Dennett 1978/1981) and that we need to get real in terms of what neuroscience tells us about human pain. Pains are essentially awful—‘Pain is perfect misery, the worst of evils…’ (Dennett 1978/1981) but also hurting is tied up, of necessity, with certain kinds of affects, beliefs, motivational states and behaviour (Nelkin 1994).

Human pain, in fact, comes in three distinct flavours: (i) There is sharp punctate pain which is closely localized as to the time and place of occurrence; (ii) there is more disturbing pain “of slower onset, greater persistence and less certainly localized… it is this pain that is so difficult to endure and that readily evokes the cardiovascular and respiratory reflexes characteristic of pain” (Mountcastle 1968, p. 1425)—this ‘surface’ pain indicates an injury or threat of injury to the body arising externally; (iii) there is deep pain in organs or muscles that may be cramping, burning or aching and is also disturbing to the patient and difficult to localize, especially so because it is unaccompanied by the type (i) information that typically accompanies surface pain.

We know quite a lot about the neuroscience of this system: Pain of type (i) is carried by small myelinated fibres (Ad, a subtype of the A-fibres) in human nerves and it passes into the spinal cord where it travels to the brain along with pain impulses of types (ii) and (iii). Impulses responsible for pain of types (ii) and (iii) travel in unmyelinated C-fibres. This excitation reaches the spinal cord where it relays in an area called the substantia gelatinosa (SG). Here collaterals of Ad and other A-fibres to do with general somatosensation may inhibit the transmission of information arriving in the C-fibres (Melzack 1976, p. 226).

In commenting on transmission of pain through the substantia gelatinosa, Wall observes,

> No cell is ever found which simply relays the inputs onto the output. There are always small surrounding cells that modulate the action of the input on the output. Some of these small cells…exaggerate the effects of the input; others…diminish the effect. All of these cells are also influenced by fibres descending from the brain (Wall 1999, p. 51).

The balance between the informative or action-guiding aspects of pain and the affective/unpleasant, action-urging aspects is given by the total pattern which is clearly sensitive to events at higher neural levels where the spread of excitation (e.g. from thalamus to cerebral cortex) is not straightforward.

The classical pathway for pain enters the forebrain at the thalamus. As expected in the classical model, painful stimuli to normal volunteers show the thalamus to be activated. However, when patients in steady pain were examined, there was less than normal resting activity in the thalamus. This seemed ridiculous to classical thinkers but is, of course, exactly what is expected if descending control circuit are trying to limit the pain. The next station in the classical plan is the sensory cortex, but here the new results were chaotic, with some finding no change, some a decrease, and some an increase.…widespread scattered patterns of brain activity were found (Wall 1999, pp. 69–70).

Some of these "chaotic" connections seem to mediate the felt intensity and location of the pain and are associated with areas subserving primarily informative skin sensations, others serve emotional reactions and yet others are much more diffuse and primarily concerned with mental aspects of pain and its effect on behaviour "Quite the most revolutionary aspect of all the new data is the intense activation in structures previously labelled as having a purely motor function" (Wall 1999, p. 71).

This complexity is reflected in clinical presentations of pain and neuro-cognitive responses to it.

> Some patients show every sign of perception of their pain but are not moving or even planning to move, yet parts of their brain previously assigned to the motor step are intensely active. Could it be that we have made a fundamental error in expecting a sensory box separate from the motor-planning box? Could it be that we in fact sense objects in terms of what we might do about them? Could it be that we have erected an artificial frontier between a sensory brain and a motor-planning brain which does not in fact exist? (Wall 1999, p. 71).

Damage to the nervous system also reveals a great deal about the phenomenology of pain, as seen, for instance in defects associated with lesions in the dominant parietal lobe (mediating the symbolic organization of experience and behaviour): "A patient with such a lesion may retain a normal threshold to pain but no longer appreciate its destructive significance" (Mountcastle 1968, p. 1444). Such a patient could be said to 'feel' pain but not incorporate it into his reasoning or into intentional activity designed to avoid harm. But what could the pain "feel like" to such an individual? Not, we must conclude, like a primitive input with a certain invariant quality. These facts support some 50-year-old observations in which damage to areas of the brain serving affective or motivational function has profound effects on experience of pain:

> Bilateral lesions of the mediodorsal nucleus or bilateral frontal leucotomy may diminish the anguish of constant pain but such lesions also produce drastic changes in the personality and in the intellectual capacities of those subjected to them. The reactions of these patients to individual noxious stimuli may even be exaggerated, but they state that while their pain persists as before, it is no longer so disturbing and they may require little or no pain-relieving medication. With time there is usually some regression of the disorders in personality and intellectual functions associated with these lesions, but with it a recurrence of severe suffering from pain (Mountcastle 1968, p. 1445).

These observations confirm the close relation between the appreciation of pain and its motivational or affective characteristics well known from work in frontal leucotomy: “After the operation, the patient no longer complained spontaneously of pain and no longer appeared to be in distress, though when asked, he acknowledged that pain was still present” (Truex and Carpenter 1969, p. 588).

Here we are puzzled because the bald statement that pain (*sans phrase*) was still present just looks hopelessly inadequate. Ramachandran has done a great deal of work with phantom limb pain and outlines a number of clinical findings with that and related phenomena which demonstrate not only the plasticity of the neural assemblies subserving different sensations but also the extent to which pain, as we see it in a human being, is a result of diverse patterns of firing in diverse circuits designed to reveal what is happening to our bodies and whether we ought to be concerned about it—“an opinion on the organism’s state of health” (Ramachandran and Blakeslee 1998).

We are left with a picture of the neurology of pain in which we discern the operation of two core systems contributing to the holistic response of the organism. “Conscious awareness of pain is one part of a massive synchronized series of reactions associated with tissue damage. The reaction is a coordinated whole. It would be very unwise to assume that each component of this overall reaction, including pain, has its own separate and private mechanism” (Wall 1999, p. 67).

Of the core systems, one is traditionally called *epicritic* and informs us about the spatio-temporal and other properties of a pain event but is not driven by the affective qualities of pain (in fact it can be used clinically to diminish them through the gating system) (Wall 1978); the other mediates a number of *affective* reactions to pain (some very primitive and others highly integrated into those complex higher order and quasi-stable patterns of behavioural control that underpin personality). Both affect the conscious appreciation of the “badness” of pain. The affective system is not primarily concerned with detailed analysis and stimulus inter-correlation so as to provide an accurate conscious and action-guiding characterization of events and situations. In fact, even in general, non-affective perception, the brain uses an ongoing dynamic integration of neural activity to predict and construct models of states of affairs and events on the basis of: (i) integrated higher-order processing of sensory input, (ii) the results of motor coupling, (iii) stored data patterns (Hughlings-Jackson 1887; Friston 2010) allowing the tracking of objects, and (iv) propositionising so that it makes maximal use of the interplay between the organism and the environment (including the social environment and other conspecifics) (Hurley 2008).

Pain and its unpleasantness, therefore, has aspects partly operating through conscious mediation but also intruding upon and dominating conscious thought through their powerful role in our sense of ‘badness’ or biological threat whereby the organism as a whole is moved to react thus and so such that “the pain signals are everywhere” (Young 1979, p. 327). Its effects on us are therefore manifest and do not just affect inner experience and what we manifest influences both our appreciation of pain, but also grounds our discourse about what pain is. Thus pain, through its role in our talk about what is happening to us, commands the semantic convergence that ensures we are denoting something real in our studies and, as a norm, can be sure we are seeing it; as Wittgenstein notes: “Just try—in a real case—to doubt somebody else’s fear or pain” (Wittgenstein 1953, §303).

Brain imaging uses our most sophisticated current investigatory techniques to show that the pain is everywhere and that it is more than just a sensory phenomenon:

> Positron Emission Tomography (PET) and functional magnetic imaging (fMRI) have recently demonstrated a number of cerebral and brain stem loci responding to cutaneous noxious stimuli …the large number of available imaging studies have shown that many areas with recognized functions are frequently affected by painful stimuli (Hudson 2000, p. 2).

A significant number of these centres modulate the signals travelling to the neocortex and parts of the brain associated with consciousness but also have effects on emotion, motor activity and the response of the nervous system to certain drugs (Fields 2004). The neurology is therefore complex.

The affective dimension of pain comprises feelings of unpleasantness and emotions associated with future implications, termed secondary affect. Experimental and clinical studies show several serial interactions between pain sensation, intensity, pain unpleasantness, and secondary affect. These pain dimensions and their interactions relate to a central network of brain structures that process nociceptive information both in parallel and in series (Price 2000).

These researchers reaffirm Hughlings-Jackson’s (multi-level and widespread) integrative view of consciousness whereby nociceptive input is combined with contextual information and memory to provide cognitive mediation of the affective features of pain (Aguggia 2003). What is more the brain areas activated in functional studies of brain activity during experienced pain have motor as well as sensory and cognitive functions” (Wall 1999, p. 177). It is clear that these neurological features are to the fore where pain has come to be a chronic feature of the patient’s experience (Loeser 2000), and the picture of a whole-body response—bottom-up and top-down—becomes even more dynamic and shifting from here on in.

4 Pathways and Neuroplasticity

Pain, as is now evident, has an intrinsic protective and mentally complex warning and motivating role, such that pharmacology (aimed at simple physiological pathways) and the search for targetable neural mechanisms is often disappointing (Woolf and Mannion 1999).

In addition to the inherent complexity of neural signalling in pain, further complexity is added by mechanisms such as central sensitization, wind up, expansion of receptive fields, and persistence after blockade, all of which are involved in neural plasticity (Melzack et al. 2001). The famous gate-control theory of Melzack and Wall (1965) initiated a research effort on human pain that has swept away older more simplistic models (such as those held onto by philosophers) and traced out for us the changes induced in pain signals by modifications over time and experience at all levels of the nervous system from peripheral receptors, to the dorsal horn cells and up into the increasingly tortuous and ramifying higher nervous mechanisms in which neural and psychological categories become inextricably entwined and we struggle to describe what the science is showing us (Petersen-Felix and Curtolo 2002).

Various mechanisms operate at the varying levels of neuromodulation, and they operate in both short (experimental, and pharmacological) and long (clinical and psychological or even developmental) time frameworks to equip the organism with a form of adaptation through "an active process generated partly in the periphery and partly within the CNS by multiple plastic changes that together determine the gain of the system (Woolf and Slater 2000). This shifting dynamic pattern of neural adaptation is typical of the human psyche as complex inputs from the physical environment, the social context, discourse, and cultural mores change and demand to be included in the mix that our evolved nervous system has to integrate so that we can adapt to an ever-changing human world.

5 The Human Psyche and Adaptive Integration of Sensory-Motor Activity

One of the most striking phenomena associated with pain is phantom limb pain where there is no normal signal arising in a peripheral receptor and being conveyed centrally and yet there is intense pain—"the phantom hand becomes curled into a tight white-knuckled fist, fingers digging into the palm" (Ramachandran and Blakeslee 1998, p. 52). Having tried to eliminate this pain by various means he realised that a phantom was an abnormal persistent activation of centres deep in the brain that normally carry information from the arm and that the pain state arose from the predictive mismatch between the post-amputation pattern of excitation and the lack of normal input from the relevant limb (in the normal state of affairs integrated multi-modally at subcortical and cortical levels). He used this multi-modal interaction by accessing visual information in a “mirror box” with one of his patients who had intractable phantom pain to modulate the pain signal. The patient saw his intact arm and hand reflected creating an illusion that it was the amputated hand. The visual input from the illusory hand was then used to control (apparent) hand movement with a dramatic result: as the patient opened his hand, the pain disappeared. Ramachandran concluded:

> pain is an opinion on the organism’s state of health rather than a mere reflexive response to an injury. There is no direct hotline from pain receptors to “pain centres” in the brain. On the contrary, there is so much interaction between different brain centres, like those concerned with vision and touch, that even the mere visual appearance of an opening fist can actually feed all the way back into the patient’s motor and touch pathways, allowing him to feel the fist opening, thereby killing an illusory pain in a nonexistent hand (Ramachandran and Blakeslee 1998, pp. 54–55).

The term “opinion” in this passage indicates the holistic response (cognitive, affective, and motor) of the human organism to a pattern of neural activity normally associated with a threat of tissue damage. A personal and self-referential sense of injury and health is part of the picture as is the intimate connection between our sensory-motor capacities and the interpretations we register. In fact, painful and other proprioceptive sensations can be induced in phantom limbs merely by arranging for the subject to “see” an image of the phantom undergoing contorted (and sometimes impossible) movements in fact performed by the other limb (or a substitute):

> These experiments … flatly contradict the theory that the brain consists of a number of autonomous modules acting as a bucket brigade. …the idea that the brain behaves like a computer, with each module performing a highly specialized job and sending its output to the next module is widely believed. …this is not how the brain works. Its connections are extraordinarily labile and dynamic. Perceptions emerge as a result of reverberations of signals between different levels of the sensory hierarchy, indeed even across different senses (Ramachandran and Blakeslee 1998, pp. 55–56).

The fact that there is significant modulation of input by existing brain activity—cognitive, affective, and cross-modal—illuminates wider cognitive and conative effects found in the psychology of pain. It implies that the higher levels of neural integration—Hughlings-Jackson’s “organ of mind” is, in fact, a mechanism for mapping “encounters with the real” onto a culturally evolved matrix of meaning.

The matrix of meaning generates a braided river of experiences—streams of widely coordinated neural activity conveying a message about how things are between the organism and the world—through which one tells how things are with oneself. For humans that is discursively informed as the basis of an imago (image-ego) (Lacan 1977) the object we apprehend as we monitor our body states and try and make sense of them. The neural information supporting this constructed entity is no more than a pattern of “triggerings of our sensory receptors” (as Quine puts it) (Quine 1981) of which sense must be made according to the patterns of thought available to the subject. The sense made reflects a place in a lived subjective trajectory through life and the discourses in which it is immersed and which contain the resources available to give an account of oneself. That account is used to tell (in both senses: speak of and discern) how things are with me at this point in life. In that sense, as Daniel Dennett claims consciousness is literally with-others-knowing (con-scio) how life is.

The signals we give and the symbols and shared signs we use to communicate about ourselves firm up subjective states and those signals include *pain language*. Any sign is given meaning through its connections to others (“No, I am tired, not lazy”) and its connections, to life situations, (“Anybody would be tired after all that stress”). The signals and the signs from which our talk is constructed position one in the human lifeworld; so that “I am in pain” may be a cry of complaint (Wittgenstein 1953, §189). What else one does, along with such a cry, (“It feels sore when you press there.”) directs oneself and others to the source of the complaint; “pain behaviour can point to a painful place—but the subject of pain is the person who gives it expression” (Wittgenstein 1953, §302).

That discursive direction can be as simple as the indication above of the sore spot so that diagnosis can proceed or so that sympathy and solicitude can be focused or it can be as complex as poetry. Burns’ “Address to a toothache” is a memorable example

> My curse upon thy venom’d stang,
> That shoots my tortur’d gums alang …
> Wher’er that place be priests ca’ hell,
> Whence a’ the tones o’ misery yell,
> And ranked plagues their numbers tell,
> In dreadfu’ raw,
> Thou toothache, surely bearst the bell
> Among them a’
> O thou grim mischief-making chiel,
> That gars the notes of discord squeel,
> Till daft mankind aft dance a reel
> In gore a shoe thick,
> Gie a’the faes o’Scotland’s weal
> A Towmond’s toothache

Burns’ poem is an articulation of a drive we share with animals and in it, the psychology of pain is reflected. It reinforces the conclusion that pain is not a brute subjective or qualitative phenomenon that is merely recognized (incorrigibly) based on its qualitative characteristics but is rather an all-engaging state the appreciation of which is tied to experience, learning, and culture.

In our culture, for example, childbirth is widely regarded as a painful experience. Yet we hear reports of cultural settings in which the women show virtually no distress during childbirth and continue to work in the fields until the child is to be born. The husband then gets into bed and groans as though he were in great pain while she gives birth. The husband stays in bed to recover from his ordeal, the baby is brought to him, and the mother almost immediately returns to attend the crops

(Melzck 1976). However, even in animals, aspects of pain are acquired; for instance, in experiments on infant Scottish terriers, it was found that socialisation was required to connect pain and pain behaviour.

> We raised Scottish terriers in isolation from infancy to maturity so that they were deprived of normal environmental stimuli, including the bodily knocks and scrapes that young animals get in the course of growing up.…when these dogs grew up they failed to respond normally to a flaming match. Some of them repeatedly poked their noses into the flame and sniffed it…If they snuffed it out, they reacted similarly to a second flaming match and even to a third. Others did not sniff at the match but made no effort to get away when we touched their noses with the flame repeatedly. These dogs also endured pinpricks with little or no evidence of pain. In contrast, littermates that had been reared in a normal environment recognized potential harm so quickly that we were usually unable to touch them with the flame or pin more than once (Melzack 1976, p. 223).

These strange responses occurred despite the presence of an intact sensory system such that 'Intense electric shock elicited violent excitement'. The social aspects of pain experience described support Trevarthen's comment about intersubjectivity in human neuro-cognitive responses to pain: 'I suggest that in humans pain is fundamentally associated with the need to "tell" someone else that the pain exists' (Trevarthen 1979, p. 325). That is meat and drink to Wittgenstein's analysis whereby *pain* like any other concept is marked by a word stationed among others whose role must be learnt (Wittgenstein 1953, §257). In short, pain language picks one out as a subject of a certain kind of desert, that of a sufferer for whom solicitude and care are warranted and over whose fate, concern is appropriate.

The reliability or otherwise of bizarre anthropological accounts are not immediately clear, but they are consistent with published data on the clinical phenomenology of pain: "Fear generates anxiety and anxiety focuses the attention; the more attention is locked, the worse is the pain. There is therefore a marked correlation between pain and anxiety" (Wall 1999, p. 185). In hospice practice, it is well known that the perceived significance of a pain is extremely important in pain intensity and control. A patient will often complain that cancer pain has a 'gnawing' and unrelenting character and it may be quite refractory to pharmacological control, but with counselling about the pain, the contributions of muscle spasm and the role of anxiety, and so on, a patient can often return home and on a much lower dosage of drugs but with better pain relief than that with which she presented to palliative care. I recall a patient (during my neurosurgical practice) with disabling back pain who had been seen by numerous doctors but had found no relief. He entered my clinic on crutches. He believed that his pain indicated a progressive deterioration of his spine due to the grinding away of one vertebra by another because of a previous disc operation, and that this process would ultimately condemn him to a wheelchair. We discussed the basis of his back pain (muscle spasm, stress, nerve root irritation possibly) and he left the clinic with so much less pain that he forgot to take his crutches with him. Such observations force us to adopt a nuanced view of pain and its role in the human psyche.

The important fact that pain is appreciated because of its significance to the individual (rather than just experienced for what it is) is also illustrated by the (already noted) use of pre-frontal leucotomy for pain. Such patients may remark that although the pain is still there it does not worry them anymore (Rainville et al. 1997). They react appropriately to noxious stimuli (quite unlike patients with peripheral or spinal lesions who do not detect such stimuli) but make remarks like "The big pain is gone" to indicate that the "badness" or "unpleasantness" of the pain has been obviated (Wall 1961).

These observations support the claim that there is a variable relationship between pain and injury moderated a great deal by the needs of the individual and other affective factors such that pain has three phases. The first, immediate, response diminishes the pain to allow adaptive escape or response to threatened harm. The next phase is painful because it is the pain that 'announces the need to enter a mode of behaviour best suited to treat and cure the damage' (Wall 1961, p. 300). The third phase is also painful and induces inactivity to allow maximal repair and recovery from injury. An injured part must be nursed and metabolism directed to tissue reconstruction or healing. Therefore, a kind of tiredness and lassitude marks this third phase of the response. These three phases are not invariable but Wall observes that they are often seen in field and clinical practice with patients recovering from trauma (either accidental or surgical) and they underscore the role of pain as a signal and spur to certain types of behaviour convergent with the observation that pain is affected both positively and negatively by its perceived motivational significance or meaning to the patient. Once that thought is laid before us the potential for elaboration or aberration of "a dynamic process that is influenced by the effects of past experiences. Sensory stimuli act on neural systems that have been modified by past inputs" (Melzack et al. 2001, p. 157) including a complex "endogenous pain modulating network" that produces much of the variability in the sensation of pain (Fields 1988).

Many traditional views underestimate anticipatory and top-down effects on even quintessentially objective and value-neutral modalities like vision and hearing where cognitive and cultural aspects of experience are also evident. Unlike experiences mediated by brain pathways designed to transmit and analyse information that tracks and details affairs in the world around us, pain impulses "diffuse" themselves in order to excite reactions and responses such that the primary destination is not the perceptual and analytic areas of the cortex, but areas which convey the impact of the world upon the subjective body and set in motion the body's highly mediated reaction to contingencies (the touch of the real). A major feature of complex and mediated cognitive and conative reactions is that, whereas animal drives reflect a simple psychic economy adapted to the natural world, human drives reflect a transformation into terms adapted to a life-world where we tell ourselves and others what is happening and negotiate what should be done to meet the challenges we face.

Pain is a currency in social transactions communicated about by different subjects with a relatively fixed meaning, so that when I say "I am in pain" I mean something with the same predicative content as "You are in pain" or "She is in pain." Wittgenstein asks:

> How do words refer to sensations? … How is the connection between the name and the thing named set up? This question is the same as: how does a human being learn the meaning of the names of sensations?—of the word 'pain' for example. Here is one possibility: words are connected with the primitive, the natural, expressions of the sensation and used in their place. A child has hurt himself and he cries; and then adults talk to him and teach him exclamations and, later, sentences. They teach the child new pain-behaviour (Wittgenstein 1953, §244).

Wittgenstein's argument has some radical implications:

(i) One learns when it is appropriate to think and talk of oneself as being in pain;
(ii) This process of learning teaches one which bodily state "pain" refers to;
(iii) It is possible to learn this by learning that the occasions on which one evinces certain reactions and responses to a bodily state;
(iv) This state constitutes the truth conditions for "I am in pain";
(v) When I am in this state, I fall under the concept (pain);
(vi) Discourse of this kind is the basis of propositions about pain—*you are in pain*, *the cat is in pain, your pain seems worse,* and so on;
(vii) The discourse connects to other discursive moves like taking care, expressing sympathy, excusing lapses, and so on.

This last point makes evident the fact that articulating an experience or "being able to tell" what it is part of a network of transactions including reasoning, reflection, analysis of causes, mobilisation of appropriate responses, and so on, all of which contribute an understanding of what is going on. Thus, there is a close relationship between one's discursive grasp of a concept like pain and knowing what one is thinking or, feeling (consider the ambiguity of the word "tell"). On Wittgenstein's view, the child learns to tell that something is happening to him which causes him to react in certain ways—the ways that human beings react when injured—and that tells others how he is.

> What would it be like if human beings showed no outward signs of pain (did not groan)? Then it would be impossible to teach a child the use of the word "tooth-ache"—Well, let's assume that the child is a genius and itself invents a name for the sensation!
>
> … However, what does it mean to say that he has 'named his pain'? …When we speak of someone's having given a name to pain, what is presupposed is the existence of the grammar of the word 'pain'; it shows the place where the new word is stationed (Wittgenstein 1953, §257).

Wittgenstein explicitly appeals to the location of a word in a discourse as indicating the place of a concept in a conceptual structure (and therefore about the content of the concept) (Harre and Gillett 1994). When one can tell one is in pain, the pain experience is, as it were, given a role in human activity and our ways of dealing with each other. "I am in pain" immediately raises certain discursive possibilities: "What has caused the pain?," "How long did it last?" "Is it sharp or dull, burning, boring, aching, stinging, throbbing or nagging?," "Where do you feel the pain?," and so on. One has, as it were, articulated one's experience in a system of concepts by which human beings make intelligent, informed responses to what is happening to each other and convey the their current states in terms that both describe them and solicit the help of others in understanding and dealing with them. This all forms part of the grammar of pain (which has both culture-bound and universal aspects).

In order to tell (both senses) that one has a pain one must learn to do it correctly. One should not, for instance, call hunger, thirst, or mere disgruntlement "pain" (their behavioural manifestations may be the same in an infant). Expressions of pain must express or convey just and only instances where the concept of pain conveys the truth because one is rightly using the sign "pain" to denote one's present state. That then allows mastery of pain discourse such that others are not misled. "Being in pain" is manifesting an inner state, but the discourse can be used whether or not its inner accompaniment is present, as a device to signal something else and the normal inner conditions may not be properly detected especially in view of the malleability of pain in certain human conditions.

6 The Human Transformation and the "Surreal Montage"

> … with the word "pain"—The image of pain enters into the language-game (Wittgenstein 1953, §300).

"Pain" is a signifier and, as such, it has connections to a situation and the discourses that converge on and spread from that situation. Its signification (that which it conveys) is elaborated in those discourses. The signification it makes available has many levels to all those who communicate about that situation and the reality at its heart (Gillett 2005) is such that slips can occur. Subjective impressions and needs can intrude into the register where one tries to denote a bodily state and the sign ("pain") and the signification ("I am in a state of suffering") and the signified ("It is like a pain which will not go away"), between the signification and the situation ("The bodily state is more like an amplified awareness of something not being right because of irritation of nerves and an intermittent sense of pressure"), and between the signification as understood by one participant and as used by others ("I am in pain means you need something to dampen the pain signals causing your suffering" versus "I need to know it is not going to kill me"). I may feel deeply distressed or pained and be unable to take my attention off my pain, and you may not discern the extent to which that pain is being fuelled by some anxiety or misconception (*the cancer is gnawing into me*). You might acknowledge my pain, and unaware of its full genesis, take certain actions to mitigate it ("Just give him something to lessen it!") Another might see more clearly this pain montage and the elements of meconnaissance (or affect driven miscontrual) that exacerbate it, and begin a different style of work from that which you envisage (“The pain you are feeling is not so much the cancer growing as your body responding to a perceived menace”). Lacan, a post-psychoanalytic philosopher, is well aware of these *montages* (or creations of the human mind as it pieces multiple bits of information together), surreal and potentially distorted as they are and the gap between them and simpler animal-like organismic states (Lacan 1981). What is more, as they touch the core of our being, which pain always does, even if only transiently, we cannot see them without including ourselves in the frame, how we are threatened or need comfort, how we are presenting ourselves and what we should be making of it all. Such a montage depicts the self as challenged, threatened, not only organically, but also as a being prone to morbidity and mortality.

> My heart, my heart, I could be having another attack, this could be the end.
> You have had an attack—that is true—but your heart, like any other muscle must rebuild itself and no muscle in our body does that without pain. Given what you are doing that is the most likely explanation. Keep calm and carry on or you will do yourself an injury.[1]

This transaction is discursive, but typical of recovery from a myocardial infarction or any other physiological insult. Assessment, reason, knowledge, all moderate the feeling and one’s response to it, and the multiple synapses presenting that feeling to us adjust themselves to its representation within a system of constraints not merely biological, but also mental, moral, prudential, self-presentational.

7 Self-Worth, Suffering, and Social Mores

The psyche is a response not only to the sensory-motor and informational features of a given situation, but also to evaluations and demands associated with it. That implies that montages of the human psyche need to preserve self-worth in the moral community as well as organismic adaptation to anticipated sensory-motor and problem solving demands. Such demands include the need to cohere with an *imago* (image-ego) that is liveable with in a world of others. Such a thing is a product of the mirror world (where self is reflected and usually located sustainably among others), and that is an inherently evaluative context of praise, blame, excuse, and so on. Within that context, phenomena such as conversion, somatization, and intolerable suffering take shape and moderate a human being’s pain response.

In the anomalous cases mentioned, the signal from a damaged or compromised body part, or an area where suffering has been focused, is crafted (perhaps unconsciously) for display to others and to oneself under the influence of the diverse neural connections already identified. Among these are powerful influences related to signifiers associated with stigmata and the martyr. Thus, one might identify the discomfort in part of the body as the bodily signal for some life

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[1] The dialogue is imaginary, the findings are real. Transcutaneous laser therapy for MI.

situation in which one has had to bear up under suffering and carry its marks with courage and honour. The original condition might be, for instance, a life changing brain injury which has been followed by some post-injury transformations such that it is unclear to what extent the brain damage is causing impaired function originally and to what extent the response is perpetuating itself (psychogenic) (Gaetz et al. 2000).

The struggle that ensues as one copes with life devoid of the excuses and allowances made for the initial impairment or lauded for the way in which one has risen above that, produces a set of parallel inputs to the pain-signalling mechanisms of the brain that may be fiendish in their complexity and non-obvious to the sufferer. The intimation of mortality linked to proven myocardial infarction and the fortitude required to recover from it, and to persist with the changes to everyday life that sustain that recovery, is a clear case in point, where the actual pain accompanying any given physical or constitutional challenge (e.g. exercise) may be so like angina that it is difficult to distinguish (it may be genuinely, physiologically, indistinguishable from the neural signature of angina).

Pain as a malady of the soul has an individual configuration in each sufferer (Kristeva 1995) and its causes, triggers, mode of being experienced, and mechanisms of production will vary accordingly. Once it has a role as the sign of suffering in currency among us, the neural mechanisms shaping its realisation are more than adequate for its protean nature as a sign whose source is deeply problematic: “Pain is not a passive consequence of … a defined peripheral input … but an active process generated partly in the periphery and partly within … by multiple plastic changes” (Woolf and Slater 2000). That protean nature begets an ethical response that, like all such, is as nuanced as the situation that is being responded to (Gillett and Franz 2014).

8 The Ethics of Pain

Ethics, Foucault famously remarks, is largely a matter of connecting the subject to the truth. But, when the truth is as complex as pain, that connection may be singularly hard to get right (Foucault 1997). It is hard enough for the person who is trying to discern the truth through the convoluted process of reading one’s own body and its states; it is even harder when one tries to disentangle the state of one’s body, one’s proper response to it in the face of varying levels of discomfort, and the demands that the world may be creating on someone who suffers and must endure (well or badly) as part of a responsive equilibrium. For a human being, that complex dynamic all takes place in a mirror world pervaded by images created partly by human discourse where one must learn to tell what is going on without speaking falsely or doing injustice to oneself or others and where much is unspoken. Truth and falsity are not easy to discern in such fraught human situations, as Pilate so clearly saw, and doing justice to oneself, as an aspect of the struggle with the pain in one’s life, is a further complication that one can do without as one tries to integrate oneself and know oneself at the same time. For Plato, even this last was worthy of a life-long dedication but when it is added to by pain in its various guises —that "grim mischief-making chiel"—any man or woman, as Robbie Burns noted, can find themselves "dancing a reel"; a pursuit that may be demanding even for a saint.

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Chapter 4
The Emotional Perception of Phantom Limb Pain

Magali Fernández-Salazar

Abstract Chronic pain is a continuous learning state in which aversive emotional meanings are continuously associated with incidental events. In this chapter, I define “emotion” as an integrated neurobiological and functional adaptive process capable of generating physiological and experiential changes in constant interaction with neural systems and the external environment. The interaction of internal (neuronal) and external (environmental) dynamic networks may modulate the intensity and the experiential qualities of chronic pain, including its meaning and perception. Phantom-limb pain might be associated with an increased functional correlation of brain regions involved in the processing and integration of sensory, emotional, cognitive and socio-cultural components. The distinction between sensation and perception is essential for understanding the complexity of the neuro-mental processes of chronic pain, including phantom-limb pain. In the mental representation of phantom limb pain, body-perception may contribute to the development of an emotional and neuro-mental circuit in the brain leading to pain, which may elicit chronic phantom-limb pain.

1 Amputations and Phantom Limb Pain

Descriptions of phantom limb were first published in the sixteenth century. The surgeon Ambroise Pare is credited as having been the first to describe the clinical features of phantom pain (Paré 1551). However, it was surgeon Silas Weir Mitchell who first coined the term “phantom limb” (Mitchell 1872).

In Western countries, the main cause of amputations is peripheral vascular disease. It is expected that the augmentation of the number of amputations increase due to the growth of diabetes cases in the population (Jensen et al. 1985). At

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M. Fernández-Salazar (✉)
Institute of Diagnostic Radiology and Neuroradiology, Functional Imaging Centre,
University-Hospital of Greifswald, Walter-Rathenau Str. 46, 17475 Greifswald, Germany
e-mail: magali.fernandez12@gmail.com

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present, war and mine explosions around the world have also increased the incidence of traumatic amputations in individuals (Clasper and Ramasamy 2013).

Amputation is followed by phantom sensations, which can be painful, or not. These sensations are present in almost all patients. The phantom phenomenon may occur after the amputation of any part of the body, sometimes even after the amputation of internal organs. The complexity of the perception of a phantom limb indicates that the phantom image is produced by the brain, but we do not yet know all the underlying mental mechanisms. A series of peripheral and central mechanisms are involved in the generation of phantom pain. It is likely that the first events occur in the periphery, and then initiate a cascade of events in a central direction involving cortical brain structures. An important aspect of the phenomenon of phantom limb comes from the reorganization of the primary somatosensory cortex after amputation. This particular cortical reorganization takes place just days after the amputation and suggests a correlation between pain intensity and the degree of reorganization (Flor 2002, 2003; Flor et al. 2006).

Currently, phantom pain is a major global health problem because it is one of the most difficult chronic pains to manage. Despite ongoing physiological research in this area, there is very little evidence of long-term positive outcomes using available pharmacological treatments for phantom limb pain. In general, current treatments for phantom pain are based on analgesics and tricyclic antidepressants. Prescribed medication is effective in some patients, but many remain resistant, and many medications—especially opioids—produce harmful side effects (Sanzone 2016). Unfortunately, random treatments such as transcutaneous electrical nerve stimulation (TENS), hypnosis, feedback therapy (mirror box),[1] have little long-term efficacy in amputated patients with phantom pain. The effects on pain reduction are positive, but temporary. I believe the reason for these results is that the mental nature of chronic pain is neglected by phantom pain researchers. This problem includes the integration of psychological with physiological studies of phantom pain. I claim that the mental nature of chronic pain is the essence of phantom limb pain.

2 Characteristics of Phantom Limb Pain

The phenomenon of phantom limb is the persistence of sensory and motor perceptions in an amputated limb. After amputation, about 90% of the subjects perceive the existence of the missing limb (Melzack and Bromage 1973). Phantom sensations such as paresthesia, heaviness, heat, cold, or cramps, sometimes may be accompanied by the perception of very severe pain. Phantom pain may vary in

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[1] Experiments performed from a simple box with a mirror in the middle to cause a visual feedback in amputees (Ramachandran and Rogers-Ramachandran 1996; Ramachandran and Altschuler 2009).

intensity, frequency, duration of episodes and sensations. They fluctuate continuously from paroxysmal to more sustainable and from low to severe. The reported sensations are often described as sensations of tension, crushing, electric shock, twisting, or burning (Melzack and Bromage 1973).

The phantom often follows transformations usually within 6–12 months after the amputation. Its position and size can change. This is called *telescoping* (Harvie and Moseley 2014). A large number of phantom limbs become totally static and painful, sometimes in unimaginable positions. The positions of the phantom generally depend on the position that the limbs had before the amputation, for instance, during an accident, if an accident was the reason of the forthcoming amputation.

During my research at the Salpêtrière hospital in Paris and at the Institute of Neuroradiology and Diagnostic in Greifswald, Germany, I had the opportunity to interview more than 200 patients with chronic pain as well as 15 amputees with phantom limb pain. To my question about whether they dream of their body as intact (as it was before the amputation), or as it is after the amputation, most of the patients responded that they always dreamed of their body as it was before the amputation, in some cases even 12 or 15 years after the amputation. Other studies have shown similar results (Mulder et al. 2008). The responses of these patients reveal the existence of a neural representation of the body, which is at least partially genetically determined and relatively insensitive to changes in sensory input (Melzack and Bromage 1973). This also indicates the existence of complex interactions between the physical body appearance and the mental body representation.

At a mental and unconscious level, it also reveals the non-acceptance of the loss, even if most of those patients responded to having accepted their amputation. Phantom limb pain may disappear within weeks or months. However, it can also remain the same, intolerable and persist for the entire life of the individual. Many factors can influence the experience of sensation and perception of phantom pain; for instance, pain in other parts of the body, the use of alcohol, in some cases the use of a prosthesis, and very often emotions play an important role in the intensity of phantom pain. In the process of subjective perception of chronic pain, it is imperative to emphasize the difference between chronic physical pain and chronic mental pain; that is to say, the difference between physical pain and suffering, both can also be related forming a noxious circuit, as I explain in the following pages.

3 Distinction Between Chronic Physical Pain and Suffering or Mental Pain: The Interaction Between Neuronal and Mental Processes

We know that acute pain is necessary as a warning and signal for protection. Despite the acute sensation that hurts, we do not typically "suffer" from it. Suffering is a distressing personal, mental state that extends over time, in which the permanence of a pending state causes hope that this state ceases. In other words, suffering is a subjective state and therefore, an individual (private) state. Its quality and intensity depend on our character, our past, our memories, our educational level and beliefs. All this will affect the vision of our future. Suffering is present in all human beings and most likely to extent in some animals. “Suffering is the substance of all life,” said Schopenhauer (2014).

In chronic pain processes, consciousness is involved and the suffering caused by chronic pain can change the perception of our bodies, of our lives, and the whole perception of the world. However, the reverse may also be possible, as the circuit operates in both directions. A mental state of chronic suffering can also be the cause of chronic physical pain that creates a neuro-mind circuit.

Scientific understanding of chronic pain is poor, partly because we seek to study it only in the brain, neglecting its interactions with the environment, which form dynamic mental states. Chronic pain forms not only in the brain; it also forms elsewhere. External factors that modify our mental states are also responsible for intensifying pain and altering its experiential qualities. We also neglect the possibility that the suffering caused by dramatic life experiences of an individual can be the cause of chronic pain. This is not surprising, given that the same structures of the limbic system are involved in the emotional process (suffering) and in the perception of pain (Fasick et al. 2015). Study of the interactions between depression and chronic pain show that both disorders activate neuro circuits (e.g. the hypothalamic-pituitary-adrenal axis, the structures of the limbic system, the ascending and descending pain tracks) as well as neurochemicals (e.g. monoamines, cytokines, and neurotrophic factors), and are associated with psychological alterations related with the control of emotions (Robinson et al. 2009).

There is another model that can help understand the intrinsic relationships and communication between the neurophysiological process and external factors. The concept of allostasis supports this model. Allostasis describes a cascade of cause and effect factors that commence with primary stress mediators, such as catecholamines and cortisol, to primary effects, secondary and tertiary outcomes (Seeman et al. 2001). Allostasis has been studied in a group of patients affected by chronic pain and depression who accumulated allostatic load through internal and external stressors (Robinson et al. 2009). This study highlighted the importance of treating all manifest symptoms of a patient using different kind of therapies.

Neurotransmitters that modulate pain, dopamine, norepinephrine, gamma-aminobutyric acid (γ-Aminobutyric acid) (GABA) and serotonin, are also involved in the modulation of emotions, thoughts and mood. Serotonin is a stabilizer that helps the mind to return to its homeostatic state. Studies have shown that migraine attacks, their frequency and chronicity relate to serotonin dysfunction and agonists of the 5-HT1F receptor (serotonin) are effective in the treatment of migraine, and receptor activation GABA has an anti-nociceptive role in the modulation of pain (Sivilotti and Woolf 1994; Hasanein and Parviz 2014; Tso and Goadsby 2014; Zhang et al. 2014).

However, what is the importance of these studies, and what is their relationship to pain and suffering? The answer is that if the neurotransmitters associated with depression and mood changes are also associated with the presence of certain chronic pains (as shown by these studies), it means that there is a pain-depression comorbidity, and that mental pain (suffering) may also be the cause of chronic pain. Neural states; namely, internal physiological mechanisms of pain, interact with mental mechanisms that are processed in the brain and which are in constant contact with socio-cultural networks (Bartra 2014). If we think of mental states as emergent properties of brain activity, sensitive to influence by external environmental factors, we can think that pain is a neuro-mental state. However, such emergence needs robust correlation with a well-defined neurophysiological process in which consciousness must be involved. For now, we have not achieved the theoretical understanding to underpin this assumption, in part because we do not have the means to build an experimental model of consciousness that can lead us directly to the mind-body problem. Since consciousness remains a scientific mystery, a good way to continue study of the mental nature of chronic pain would be to analyze the relationship between the brain and the universe around us. It is through this neuro-mental synergy (internal-external networks) which, in my opinion, consciousness and mind emerges. Therefore, it is advised to study interaction between mental states and neural states in chronic pain using the proposed neuro-mental theoretical model below (Fernández-Salazar 2015; Fig. 1).

This pattern of interaction between pain and suffering opens study of pain consciousness, to the analysis of the relationship between the qualitative nature of subjective mental states of painful experiences and their neurophysiological mechanisms. Perception is a process that affects and is affected by the state of mind of the person. Thus, the active selective perception of pain can alter the mental state of a person and change their perception of pain. In that process is included all the external events that a person can perceive just before the cognitive process, in which will exist an explanation and understanding of those perceptions.

It has been suggested that interactions of pain with other somatosensory sub-modalities and visual information about the body offer the possibility of modulating chronic pain (Haggard et al. 2013). A good example is the mirror box created by Ramachandran and Rogers-Ramachandran (1996) that manipulates the brain of amputees and, in many cases, reduces phantom limb pain as well as motor imagery which has been defined as the act of mentally play an action without executing it (Jeannerod 1994; Sirigu and Duhamel 2001) also in other kind of chronic pain (Moseley et al. 2008).

These studies support the hypothesis proposed in the above model that mental states could control and modify physical states, demonstrating the intimate relationship between body and mind. The suffering caused by the mental image of having an incomplete or distorted body, in the case of the strange phantom positions, could provoke an aversive mental state able to increase phantom pain intensity. Therefore, mental noxious states could be a cause of phantom limb pain. I believe that if we continue to investigate this model we may become capable through physical-mental therapy to modify the harmful mental conditions that cause chronic pain, and we may be able to prevent phantom limb pain.

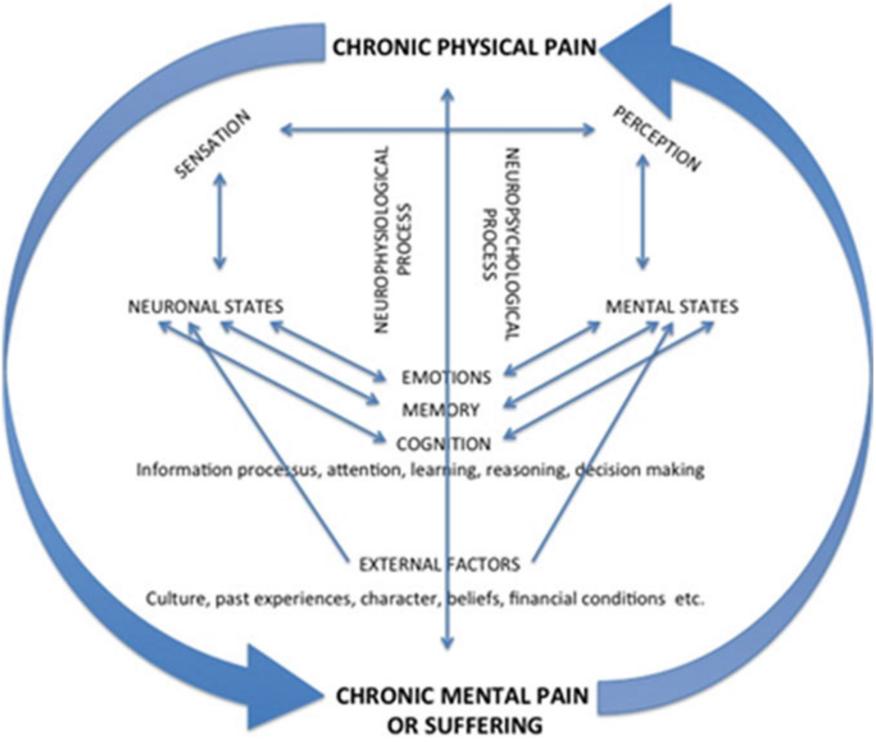

Fig. 1 Neuro-mental model of chronic physical pain and chronic mental pain or suffering. The process of pain involves unconscious nociception, and conscious pain. Emotions, cognition, memory, and external factors such as culture and social conditions influence our perception of consciousness of pain and its perception. Neural states interact with mental states in both directions, causing a noxious circuit that can start with mental pain (suffering) provoking chronic physical pain, or vice versa (Fernández-Salazar 2015)

4 Pain as Homeostatic Emotion

Physiological changes generated during the unpleasant emotional experience caused by pain are part of a defence system that alerts the body to be prepared to confront aversive situations through behaviour of attack or retreat. The theory of emergence expressed by Cannon (1914) says that the body is programmed to maintain an optimal level of activation and adjustment at the time to experience intense emotions caused by pain. Through homeostasis, there is a series of internal adjustments in order to find optimal levels. Emotions function to prevent a particular emergency.

The concept of homeostasis means a steady state of processes, which stabilize by the synchronization and the organization of self-regulating physiological mechanisms. Homeostasis allows the body to maintain its functional integrity in the internal environment (*milieu intérieur*), and the external fluctuating environment. Claude Bernard and Walter Cannon noticed that the constancy of the cell environment must be preserved and that the internal environment is key to this (Bernard 1859; Cannon 1926). Regulatory organs whose actions appear complementary and coordinated provide homeostasis in phantom limb pain. These organs (e.g. kidneys, lungs, gastrointestinal tract) interface between the external environment—where changes are permanent—and the interior environment, which must remain fixed. As Claude Bernard noted, the internal environment is the necessary condition to the "free and independent life." "The constancy of the internal environment is the prerequisite for independent living" (Bernard 1859).

The importance of homeostatic mechanisms involved in the control of chronic pain should be noted. In order to maintain the constancy of the internal balance of the body, it is important to consider the internal and external mechanical, thermal and chemical changes, as well as stimuli that cause pain. In the case of a nociceptive stimulus, the body is in an alert state, and the endogenous mechanisms that modulate the unpleasant sensation are activated. This occurs with some hormones, which have an analgesic effect, for example, oxytocin, which the paraventricular nucleus of the hypothalamus (PVN) releases. When the PVN is stimulated, it inhibits pain information that reaches the spinal cord producing an analgesic effect (Condés-Lara 2008, 2009). PVN neurons activated by noxious stimuli can suppress the activation of A-delta and C fibres, inhibiting nociceptive signals that may transform into pain, thus completing an endogenous analgesia system. This mechanism shows that the PVN, as other brain structures, participates in the mechanism involved in pain and analgesia. The same situation applies for other substances such as norepinephrine or serotonin (Fields et al. 2006).

These examples show the importance of homeostasis in controlling pain at an endogenous level. We talk about homeostatic "feelings" in reference to the perception of temperature, to itching, to distension, hunger, thirst, to touch and pain (Craig 2003). In the case of phantom limb pain, a process of internal regulation (homeostasis) occurs wherein an emotional component is essential. The emotion represents the amount of information received (pain) by which the body tries to adapt better to the level of the received stimulation. As Damasio (2000) puts it:

> The pervasiveness of emotions would be remarkable if only the "natural" and "acquired" inducers caused them. I submit, however, that what we call emotions and moods are not only caused by these easily recognizable kinds of stimuli but are also caused by the process of regulating life itself. Certain conditions of internal state, engendered by the ongoing processes of maintaining homeostasis and by the organism's interactions with the environment that are pertinent to homeostatic regulation, induce collections of responses that are formally comparable to the conventional emotions we have been considering (Damasio 2000, p. 18).

Emotions are inseparable from the states of pleasure and pain and represent the mechanisms of life regulation. They constitute a complex survival and adaptation system that is always linked to homeostasis, but also depends on social and cultural influences. As for acute pain, I prefer to consider it not as a whole emotion, but as a homeostatic emotional process with a negative connotation, but necessary and protective for the body. In contrast, chronic pain is an emotional process but is useless, aversive, and destructive to the body and manifests maladaptive homeostasis. If we compare pain and emotion, both consist of chemical and neural responses that aim to sustain life in an organism and have characteristic adaptive behaviours. Therefore, endogenous balance or homeostasis may decrease chronic pain and contribute to changing the contents of the emotions caused by pain and improving the quality of the life of individuals.

5 The Mental Representation of Phantom Limb Pain in the Brain

The neural representation of pain in the brain seems to be formed by a neuromatrix, which describes functional relationships of various sensory areas of the brain, cognitive, emotional and volitional (Melzack 1990). Phantom limb pain indicates that the neuromatrix activates, not only through peripheral receptors, but also intrinsically, so that the brain generates experiences without the need of a lesion to produce pain or a body-part to feel a body. There are no individualized centres or single tracks of "accurate representation" of pain in the brain. In fact, numerous experimental data in the fields of nociception indicate that a single burning stimulus activates several populations of neurons in different regions. In the brainstem, there are probably at least several tens of areas, which activate by that stimulus. These areas include the brainstem, and in the brain, hundreds of neuronal groups (including many thalamic nuclei, the hypothalamus, the amygdala, the hippocampus, the striatum and the cortex) which activate in parallel. There is no *pain centre* in the brain. It is probably the simultaneous activation of all these structures, which constitute the neural correlate of that pain (Bouhassira and Calvino 2009).

With these bases, pain is the subjective representation of a bodily injury which includes the sensory component, the *quale* (one can define *qualia* [plural of *quale*] as the phenomenal or qualitative aspects of our mental life that define what it is like to have a mental experience) as the core content of perceptions that we are sometimes unable to describe. For instance, what it is like to be in pain. However, what is the representation of the pain when it is not due to a physical lesion, as is the case of many types of chronic pain, such as fibromyalgia? The brain regions mentioned above also activate in spite of damage. There must be a kind of a mental representation of suffering or mental pain caused by the negative images, by memories, by the past and the present of the individual before mental pain becomes physical and transforms the neuronal networks. The representation of chronic pain without injury would be what each individual thinks about his/her pain; how they perceive it and the way he analyses or understands his suffering. Therefore, the meaning of this representation would be how it is like to be in pain. In the previous set of elements that includes pain, we face the mind-body connection.

To help identify the nature of phantom limb pain, the quality of chronic pain and its meaning needs study together with its neurobiological mechanisms, and the results integrated to produce a more complete understanding. I propose to study the possibility of a mechanism emerging from a neurophysiological and a mental phenomenon that have subjective and qualitative aspects. In this way, phenomenological and neurophysiological data can correlate non-reductively to form neuro-mental networks. Eventually, we can integrate the two perspectives: the objective perspective of chronic pain and the subjective perspective in a neuro-mental approach, i.e. both physical and mental at the same time. In this way, chronic pain is not only sensation, but also personal perception. This may "provide a richer and more precise description of the texture and structure of pain experiences, especially chronic pain experiences, and to relate pain to the brain" (van Rysewyk 2014).

I believe the distinction between sensation and perception is essential for understanding the complexity of the neuro-mental processes of chronic pain. Perception is more than the conscious and intuitive record of sensations. Perception is not only explained by the nature of the stimulus. In my view, the concept of perception must integrate mental and physiological approaches. It seems important to include consciousness in any definition of perception, even if we cannot accurately describe the phenomenon of consciousness of chronic pain.

Perception is physio-mental and cultural through which the use of the senses, the past of the individual, and his culture, link physical events with cognitive mechanisms. The cognitive process of perception includes attention (the selection of sensory information), interpretation (sensory information retained and transformed into impressions), comprehension (the meaning given to retained sensory information), storage (archiving in the brain sensory information understood and interpreted). The nature of perception is mental, and in the perceptive process, sensation turns into meaning and knowledge. In other words, the notion of perception implies that there is content and representation. In contrast, "pure" sensation may be organic, such as the sensations of hunger, thirst, satiety, nausea, muscle fatigue, orgasm, and tickling. However, it is not the same to have an empty sensation in the stomach as to have the mental representation of a meal, which informs us that we are hungry.

What is the meaning of chronic pain? The meaning of the physical painful representation could be the perceptual understanding of bodily injury. However, it could also consist in the aversive images that cause mental pain, and what we think these images mean. Pain has a fundamental component that characterizes it: the aversive emotion. Emotions are about something and thus, they have meaning. The meaning of pain could be bodily injury, or the illusion of a painful sensation, which one might call a false perception of pain, as in the case of phantom limb pain. It is not that phantom limb pain is false in its experiential qualities and meaning, but in the sense that I feel pain in my foot when the foot no longer exists. Thus, I would consider chronic pain as would I consider consciousness: both are neuro-mental phenomena. The emotional aspect of chronic pain is not just an organic emotional response, but also an intrinsic quality of the physical sensation and its interpretation.

As we know, with certain surgical procedures such as the prefrontal lobotomy or cingulotomy one can dissociate the cognitive component of the emotional aspect of pain. After surgery, when we ask the patient if he continues to be in pain, he responds that the pain is still there, with the same intensity as before the surgery and he is able to describe it. The difference is that after the surgery the patient is no longer suffering, he does not care about his nociceptive sensation; that is to say, although the intensity of the pain is the same, it does not matter to the patient because what is missing is the affective meaning of pain (Foltz and White 1962). This proves that the most alarming component of pain is the emotional aspect, i.e., the perception and its content, but not necessarily the sensation nor the nociceptive process. In these cases, patients have a nociceptive sensation, but not a perception of pain, and the sensation of *pain* does not cause them to suffer.

Chronic pain is a process in which the different components link in various ways to integrate as a whole, a complex and distinctive representation, which may be the consciousness of pain (Chapman 2005). In this sense, the distinction of the components required to do an analysis is not clear, because the painful experience integrates through the merger of these components. A priori, “each of its components reveals itself as physical and mental, as neurophysiological and conscious at the same time, and pain as a result would be a versatile event perceived by a sensitive individual” (Díaz 2007). As in the case of consciousness, the location of pain can be quite disconcerting. Irrespective of the type of pain, whether acute, chronic or inflammatory, the individual who perceives it normally refers to the location of the lesion. However, neuroscience tells us that the brain produces pain (Butler and Moseley 2003), although the latter is an organ with a deficiency of sensitivity to lesions, which in itself is a rather strange and almost ironic situation. One could say that this is half-true, since pain is indeed produced by this painless brain, but its perception comes from the outside; it is caused, in part privately, individually, especially through mediators such as psychosocial-cultural factors.

However, if we assume that pain is in the brain, it is because the nociceptive receptors arrive there. It is also in the brain that sensations and perceptions are received from outside the brain are subsequently integrated, although we do not yet have a good idea how this is produced, and even less how the distinctive quality of pain occurs; that is to say, its distinctive and unique *quale*.

In the mental representation of pain, when we speak of consciousness, either the consciousness of chronic pain or the awareness to perceive objects and all kinds of elements around us, it is not easy to distinguish between objects, mental representations, aversive images, the stimuli that cause these perceptions, the quality of these experiences and our social and cultural beliefs. It seems that it is precisely in the convergence of all these factors that chronic pain consciousness emerges (Chapman 2005).

The body schema, a part of consciousness, presents as “a system of motor function” as a set of mental representations that operate at the level of consciousness, a perceptual belief system of the body (Gallager and Meltzoff 1996). The body schema allows us to have knowledge of the position of our body in space. In contrast, the body image consists of a system of perceptions, attitudes and beliefs about our own body, what we think about the mental representations of our body (Gallager and Meltzoff 1996). The concept of self-image can be perceived constructively or destructively. These mental representations are not always part of conscious processing; they form part of the unconscious perception processes of the individual to the extent that they are sets of beliefs or attitudes. It seems then that amputation would cause a discrepancy between the representation of the body image and the body schema. The body image in the amputated patient would remain as it was before the amputation (probably because of the unconscious non-acceptance of the loss of one of its limbs), thus causing the change of body image. Mental images of an integral body will then be processed by the brain that tries to “fill” the amputated portion corresponding to the part of the body in the body schema represented in the somatosensory cortex. This would be one cause of the *existence* of phantom limb pain. The possibility that the chronic mental pain or suffering caused by the visual and constant reality of a missing limb, so the incompleteness of the self body image becomes unbearable, provoking a chronic physical phantom pain. The mirror box and virtual reality are used to modify the body schema through visual feedback, mostly resulting in decreased phantom limb pain (Ramachandran and Rogers-Ramachandran 1996; Ramachandran and Hirstein 1998; Ramachandran and Altschuler 2009). This works only temporarily since once the patient is no longer in front of the mirror box its visual reality always refers him to the actual physical image; that is to say, to the incomplete self-image. So, the phantom pain returns.

6 Conclusion

Chronic pain, especially phantom limb pain, is usually treated with expensive medications, which are associated with undesirable side effects. To the extent that chronic pain affects the whole person (body-brain-mind), clinical treatment should be varied and particularly focused on the aversive meaning of pain in a multidisciplinary and holistic perspective. All pains are different because each person has his or her own story; much of chronic pain depends on the personal history of the individual.

Scientific investigation of pain has important limitations. I am as sceptical as Damasio regarding objectivity in the neurosciences (Damasio 1994). On one hand, the results obtained are only approximations; on the other, results are sometimes ambiguous, and there are many ways to interpret them. In the case of phantom limb pain, the limits of science are especially marked because every patient is different and personal subjectivity influences interpretation of the experimental results. Therefore, it is very difficult to make objective analyses. In the study of large populations of patients, some particular cases are sometimes overlooked. However, these cases may hold the key to the sought after results.

Emotions and mental representations that amputees have in relation to their distorted body image after amputation must be studied in order to have a better understanding of the emotional dimension of phantom limb pain. There are several studies showing evidence of distorted body image in people with chronic pain, as well as evidence of distortion of the neural representations of the body image (Lotze and Moseley 2007). It could be possible that phantom pain is produced by the mental pain engendered by the non-acceptance of the loss of a body part and lack of acceptance of the amended body image. If that is the case, the brain does not cause mental pain; but conversely, the mind would provoke physical chronic pain able to transform neural networks generating phantom chronic pain.

Neuroscience has made significant progress in understanding the neurophysiology of pain. We know quite well the physiological mechanisms involved in the process of pain, but we continue to ignore some aspects of the emotional nature of chronic pain, especially regarding phantom limb pain. A non-reductive, multidisciplinary approach is needed. However, it could be that the mind is so complex that we will never understand its mechanisms. However, in chronic pain, evidence indicates that mind dominates brain, not vice versa. The key may lie in brain plasticity. The brain constantly rebuilds. Some studies have shown that it is mental activity that controls brain activity (MacIver et al. 2008), which may lead to inadequate plasticity in patients with chronic pain. However, if mental activity is controlled, it may balance neuronal activity, and reshape the brain by restructuring certain neural networks. Since the mind is an enigma, which for the time being seems mostly inaccessible, a good way to continue the study of the mental nature of chronic pain would be to analyse the relationship between the brain and the universe around us. It is such neuro-mental synergy (internal-external networks) through which consciousness and mind emerges.

The mind is an endogenous and exogenous oscillatory system emerging from the brain, from the constant interaction of the brain with the natural systems of our environment, and with socio-cultural networks. We need a body to receive external stimuli decoded in a perceptual process that takes place in the brain. But a body alone in the wild would be just a mass of fat, bone, water and muscle, unable to perceive external information, and a brain without mind (without the interaction of external networks) would be only a machine. Therefore, it seems essential to conduct holistic study of the mind, of the interaction between the brain and the environment. We cannot content ourselves with a reductionist approach; we need to stop looking for answers only in the brain; we must also look beyond, in our relationships with others, in the biotic and physical structure of our environment, in our emotional dimension.

The challenge in phantom limb pain is to determine the type of emotion felt, and understand how the meaning of the emotion is related to the quality of pain. From a practical perspective, the hope is to modulate the emotion caused by the loss in order to better control phantom limb pain. The type of emotion depends on the environment and circumstances when suffering arises. The quality of the emotion, however, depends on the personal perception that we have about pain as well as on the history of the individual, since we know emotions link to the mechanisms of memory. The emotion caused by suffering or mental pain will have a relationship with the type of the memories of the individual, which need to be revealed during clinical consultations. The control of those emotions will relate to the motivation of the individual in managing or eliminating physical pain, and of the capacity to identify and understand mental pain, by analysing the relationship between the perceptions that the patient has of his pain with the perception that he has of his environment. Such an objective requires advancement in our knowledge of the phenomenal mind using qualitative research methods. It is imperative that clinicians listen to patients, not only focusing on the list of his symptoms or experimenting with new medications. Understanding pain cannot be limited to knowledge obtained about neural structures and mechanisms using standard, quantitative methods. A deeper study of emotions, of consciousness, and mind and its correlation with the environment, in my opinion, will help resolve the problem of chronic pain and in particular phantom limb pain. We need to seek for answers not only in the brain, but also from studying relationships between the brain and the environment.

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Chapter 5
Is Pain Unreal?

Simon van Rysewyk

Abstract Some pain researchers are unconvinced that self-report of pain is reliable, and have urged its replacement with brain-markers of pain. This suggestion is compatible with a radical philosophy called *Eliminative Materialism*, which asserts that folk psychological claims and generalizations about the nature and causal powers of pain are false, and face elimination by a mature, neuroscientific theory of pain. Some eliminativists draw inspiration from our intellectual history, which shows that any theoretical claim can appear correct or beneficial even when it is false. However, the eliminativist accusation that pain folk psychology is explanatorily stagnant is mistaken, given that folk psychology has motivated important psychological and clinical research programs in pain science that have led to new knowledge and improved outcomes for some pain patients. Pain folk psychology is compatible with advances in pain neuroscience, as evident in successful patient education programs, which replace maladaptive beliefs about pain with adaptive folk beliefs informed by accurate pain neurophysiology. This chapter argues that the philosophy of Eliminative Materialism is one possible theoretical outcome on a continuum comprising many possibilities. The eliminativist needs to produce independent reasons for thinking that pain neuroscience will replace pain folk psychology in the way eliminativism thinks, which is a difficult task given that a central premise required for the outcome envisaged by the eliminativist is unknown. Facts of scientific history alone cannot inoculate Eliminative Materialism from the unjustifiably promissory nature of its central claims.

1 Introduction

Recently, arguments have been made for replacing or eliminating patient self-reports of pain using neuroimaging data. Apkarian et al. (2011) has claimed that pain assessment based on verbal self-report uses limited measures unsuitable

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S. van Rysewyk (✉)
School of Humanities, Department of Philosophy and Gender Studies,
University of Tasmania, Private Bag 41, Hobart, TAS 7001, Australia
e-mail: simon.vanrysewyk@utas.edu.au

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for discriminating between types and causes of pain, and for assessing the differential impact of interventions, inter-individual differences and prescribed medication doses. Wortolowska (2011) has stated that replacing pain self-report with neuroimaging data would improve the accuracy of pain measurement and treatment efficacy. A National Institutes of Health report (2011) pointed out that the anatomical and functional localisation of specific chronic pain conditions shows that treatment interventions can be assessed with specific brain-markers, thereby circumventing the need to collect and analyse patient self-report.

The use of brain-markers to replace or eliminate pain self-report is compatible with the strong view that there is nothing more to pain experience than brain mechanism. Philosophically, this assertion amounts to *minimal reductionism* about pain, which means that pain is "nothing over and above" brain mechanism (Polger 2011; van Rysewyk 2013). Minimal reductionism concerning pain contrasts with dualist and emergentist philosophies of pain according to which pains are dependent on the brain but are nevertheless somehow 'more than' the neurobiology on which they depend (e.g. Chalmers 1996).

One philosophy of mind which accepts minimal reductionism is *Eliminative Materialism* (EM) (Dennett 1978; Churchland 1981, 1989; Stich 1983; Hardcastle 1999). Eliminative materialists agree with dualists that pain and brain mechanism are not the same thing. However, unlike dualists, eliminativists claim there is nothing more to pain than what occurs in the brain. The reason pain is not irreducible to brain mechanism is not because pain is non-neurophysiological; instead, it is because pain—indeed, all mental states—as conceived by everyday common sense, *does not really exist.* EM denies that pain can be reduced to brain mechanism because pain is not real.

An important consequence of EM is that claims about the phenomenology and causal powers of pain are false and ultimately have no place in a correct theory of pain. This is at odds with our common sense intuitions that pains are personal experiences causally responsible for pain-related behaviours such as facial grimaces, limb guarding, crying out, and verbal self-reports. EM implies disquieting consequences about our common sense views of pain. This chapter carefully assesses arguments for and against EM with a focus on pain.

2 The Case for Eliminative Materialism

2.1 Theory-Theory and Folk Psychology

The central argument for EM begins with the idea that we use a *theoretical* framework to explain and predict human behaviour (Sellars 1956). In philosophy of mind, this idea is usually called the *theory-theory* (TT). TT views folk psychology (FP) as comprising specific theoretical claims and generalizations (and laws), described by our everyday common sense psychological words such as "belief," "desire," "recognition," "fear," "anticipate," "memory" or "pain". FP generalizations are thought to describe the diverse causal regularities and relations of FP claims.

FP pain generalizations have been documented in many studies using naïve participants (e.g. Williams and Thorn 1989; Eccleston et al. 1997; Aldrich and Eccleston 2000; Butler et al. 2003; Moseley 2007; Goubert et al. 2011; McCrystal et al. 2011). The following illustrative sample (1–7) lists simple to complex folk pain beliefs:

1. Pain generally hurts and is unpleasant.
2. Pains generally are located in a part of the body.
3. People generally want pain to stop as soon as they feel it.
4. A change in the intensity of a pain is generally influenced by a change in the weather.
5. Wounding generally causes pain, and when the wound is completely healed, pain usually stops.
6. If a physician cannot determine a physical cause for a person's pain, then a physician will generally not believe that a person is really in pain.
7. If a person wants his or her pain to stop and believes that the best way to get the pain to stop is to consult a physician, then a person will generally consult a physician.

Aldrich and Eccleston (2000) asked 61 naïve participants to sort 80 statements describing pain within our particular folk culture ("the culture of pain"). Eight pain FP claims emerged from the Q factor-based analysis:

8. Pain as abuse.
9. Pain as alien invasion.
10. Pain as coping and control.
11. Pain as homeostatic mechanism.
12. Pain as malfunction.
13. Pain as mental.
14. Pain as self-growth.
15. Pain as spiritual growth.

Aldrich and Eccleston (2000) derived common phenomenological themes from this list. One shared theme the participants identified was the idea that pain must offer personal meaning. Another set of themes consisted of how pain relates to self; specifically, whether or not pain can change the self.

TT claims that pain generalizations and claims like these operate in FP much like the generalizations and laws of *scientific* theories. However, the laws of FP are acquired more informally than scientific theories, as part of normal human development (e.g. Lewis 1970, 1972; Churchland 1981; Stich 1983; Hardcastle 1999; Roth 2012). For example, children who observe their parents showing fear and behavioral avoidance to back-stressing tasks, such as lifting heavy objects, may adjust their understanding of that situation ("back-stressing tasks are dangerous and can cause pain") and the behavioral effects ("avoidance of back-stressing tasks generally reduces pain") based on the generalization, "since back-stressing tasks can cause pain, and avoidance of these tasks generally reduces pain, it is best to avoid such tasks" (Goubert et al. 2011).

According to TT, the mental states referred to in FP are the states that feature in our everyday common sense mental explanations. TT asserts the view that, as theoretical claims, pains are not directly observed, though they are assumed to explain observable effects like pain facial expression, guarding, verbal self-report and other pain behaviours (e.g. Goubert et al. 2011).

In addition, TT asserts that everyday common sense attributes a number of features to mental states, such as causal and subjective features. For example, TT claims everyday common sense attributes two kinds of features to pains (e.g. Butler et al. 2003; Aldrich and Eccleston 2000; Moseley 2007; McCrystal et al. 2011). First, there are phenomenological or subjective properties. Pains are subjective experiences which depend for their existence on feeling them. Since pains are known by personally feeling and coming to know them in that way, they are private. The claimed privacy of pain seems to contrast with the *objective* nature of objects of standard perception. For example, the book on the table can be seen by others in just the way I see it, so is not private or subjective like personal pain. Second, there are causal properties. Pains are the kind of experiences that are caused in specific circumstances, and which reliably produce pain behaviours. Pain is causally connected to goal-directed behaviours that are helpful. Some causal roles pain can have are:

16. Perceiving pain might cause immediate protective behaviours.
17. Anticipating pain might cause avoidant and protective behaviours.
18. Expressing pain might cause palliative treatment from others.
19. Expressing pain might cause reassuring interpersonal interactions.
20. Labelling pain might cause a person to create a meaningful personal narrative.

These complex phenomenological and causal features of pain FP are the primary focus of pain EM that challenges their propriety and explanatory value.

2.2 *Elimination of Folk Psychology and Radical Theory Change*

The second central argument for EM begins with the claim that FP is mistaken about the nature of the mind. EM suggests that the theoretical framework of FP is a radically false misdescription of cognition and private mental states such as pain; thus, the claims of FP designate *nothing that is real* (e.g. Dennett 1978; Churchland 1981, 1989, 1996; Stich 1983; Hardcastle 1999; Roth 2012). To clarify this radical claim, it may help to make a distinction between *ontologically conservative* (retentive) theory change, and *ontologically radical* (eliminative) theory change (Savitt 1974). Ontologically conservative theory change happens when the concepts and claims of the old reduced theory are revised and relocated in the new reducing theory. The scientific wave theory of visible light, first proposed in the 1660s by Robert Hooke, was replaced roughly 230 years later by the theory of electromagnetic radiation (Baierlein 2002). A key event in the change from the old to the new theory of visible light was the Michelson-Morley experiment (1887), which led to the eventual rejection of the concept of the luminiferous ether, the claimed medium of light transmission, while the idea of wavelength was retained (Baierlein 2002). Moreover, at no point in the change did we come to say that visible light is not real. Instead, visible light was identified with electromagnetic radiation.

Alternately, the scientific theory of caloric fluid was rapidly eliminated from scientific theories of heat (Lyons 1985). There is nothing in the theories of static and kinetic friction (dry friction) that we can correctly identify with caloric. The theory of caloric fluid does not mesh with other parts of well-established physical science, and is thus far removed from anything we now claim about dry friction or electromagnetism that was once explained by caloric fluid. Accordingly, the dramatic progression from caloric fluid to modern explanations of heat was ontologically radical. Caloric fluid was eliminated from our ontology, and we came to understand that the concept is false: it designates nothing real.

EM predicts that an ontologically radical theory progression of this kind is expected of FP. Just as we came to understand that there are is no such thing as caloric fluid, so EM predicts that FP concepts such as pain will eventually be recognized as false concepts. Since there is nothing that has the subjective and causal properties we assign to pain it will likely turn out that there really is no such thing.

2.3 Folk Psychology and Explanatory Power

Advocates of EM have argued that any accurate theory should provide a research program that meshes with well-established science and which possesses considerable explanatory power (Churchland 1981, 1989, 1993, 1996, 2002, 2011). However, FP appears to be relatively *explanatorily powerless*, since there are many mental phenomena that FP cannot explain. For example, questions concerning memory and learning, motivation, dreams, coma, the dementias, pain disorders such as Congenital Insensitivity to Pain are entirely overlooked by FP compared with neuroscientific theories based on reliable markers between mental states and specific physiological states measured in both humans and animals. Since it is appropriate to support theories that offer the best explanations of mental phenomena in their domains, all other things being equal, then it is rational to endorse those theories, compared with the alternatives. Since neuroscientific theories satisfy this stipulation much better than FP, EM philosophers infer that EM is explanatorily superior compared with FP (Churchland 1981, 1989, 1993, 1996, 2002).

Indeed, the record of folk theories such as folk physics, folk biology, and folk epidemiology shows that they all turned out to be radically wrong (Churchland

1981, 1989). Thunder is not Zeus hurling lightning bolts; it is the sudden increase in pressure and temperature which produces rapid expansion of the air surrounding and within a bolt of lightning. Bubonic plague is not God's punishment for sin; it is a rat-borne bacterial infection. Pain is not a feeling in the nonphysical mind; it is the specific neurophysiological operations of a complex physical mechanism. Since folk theories generally turn out to be false, it seems unlikely that FP will prove to be true. Finally, since FP concerns a subject that is far more complex than any previous folk theory; namely, intelligent human behaviour, it seems unreasonable, all other things being equal, that this one-time folk theory really got something right (Churchland 1981, 1989).

3 Pain Eliminative Materialism

Philosopher Dennett (1978) proposes that the pain FP is radically false and ought to be eliminated. His argument draws on reports of clinical pain conditions which he characterizes as the *reactive dissociation* (RD) of pain emotion from its somatosensory aspects. Some surgical procedures, hypnotic protocols and drugs reduce or remove the negative emotion of pain (i.e. its characteristic unpleasantness) while retaining somatosensory-discriminative features such as pain intensity and pain locale. These reports come from pain patients who have had prefrontal lobotomy (e.g. Freeman et al. 1942; Hardy et al. 1947; Bouckoms 1994) or bilateral anterior cingulotomy (e.g. Foltz and White 1962; White and Sweet 1969; Wilkinson et al. 1999; Yen et al. 2005) as a final recourse for their debilitating chronic pain, from patients under the effects of hypnotic suggestion (e.g. Barber 1963; Rainville et al. 1997), and some opiates like morphine (Barber 1959). These patients typically report post-treatment that they can still perceive somatosensory features of pain following painful stimulation, but they no longer feel the experience to be unpleasant or aversive.

Dennett (1978) argues that the case of RD in pain patients radically falsifies pain FP. At issue is the core FP pain generalization, (1) "Pain generally hurts and is unpleasant" and the FP pain claim (1*) "Pain is always subjective and private." According to Dennett, an RD pain patient sincerely believes that (a) he is in pain, and that (b) his pain is not painful at all. Given (1) and (a), we may infer that he is in pain. However, this contradicts his belief (b) that is guaranteed to be true assuming (1*). Therefore, pain FP is contradictory. Since not anything with contradictory features can exist, it follows that nothing can be a pain; thus, pain FP designates nothing that is *real*. I will consider two objections to Dennett's pain EM.

Kaufman (1985) endorses Dennett's conclusion that nothing is picked out by pain FP, but disagrees that this justifies the elimination of pain FP. According to Kaufman, the correct conclusion to derive from Dennett's argument is that pain FP is simply in error to believe that the conjunction of (1) and (1*) is necessary. Specifically, pain FP is right to assert (1) as a true generalization, but wrong to assert (1*) as a true claim. Instead, Kaufman (1985) thinks they are both general statements. Thus, to avoid the threat of elimination posed by Dennett's argument, he suggests that the mistaken claim (1*) be modified and presented as a FP generalization. Replacing claim (1*) "Pain is always subjective and private" with the generalization (1**) "Pain is generally subjective and private" yields the new pain FP conjunction (1) and (1**), which is compatible with Dennett's argument (Kaufman 1985).

Conee (1984) and Guirguis (1998) have objected that (1) and (1*) are not actual parts of pain FP. The reports of the RD pain patients do not imply that pain is not real. Rather, according to Conee (1984) and Guirguis (1998), such cases reveal the complexity and intricacy of pain FP: what appears to be simple in everyday common sense thinking turns out to be more complex in scientific observation. Hardcastle (1999) also thinks that the physiological basis for pain is so complex that no one thing answers to our pain FP. Although Hardcastle (1999) describes pain FP as a "myth," she does not appear to think that pain is not real, but rather that it is much more complex than pain FP appears to think it is. This objection challenges a precise reading of (1*).

The RD pain reports show that the negative emotional features of pain are not necessary for an experience to be pain. Thus, a pain might involve somatosensory features rather than negative emotional features (e.g. Ploner et al 1999; van Rysewyk 2013). However, instead of undermining Dennett's argument for pain EM, this point might actually endorse its overall purpose. The purpose of Dennett's argument is not merely to show that pain FP is actually falsified by science, but also that the limit of what can be reduced or eliminated as a result of science is much nearer than we may intuitively think. Dennett's pain EM implies that, appearances to the contrary, intuitive judgments are insufficiently reliable to launch definitive predictions about whether in the future something (e.g. pain) will be reduced or eliminated as a result of scientific knowledge (Churchland 1981, 1989, 1996).

The remainder of this paper considers four objections to EM. I will focus the discussion on pain EM.

4 A Case Against Pain Eliminativist Materialism

4.1 Pain Folk Psychology and Explanatory Power

In response to the EM criticism that FP is explanatorily powerless, some philosophers have objected that this negative evaluation is incorrect. FP has actually stimulated a number of productive research programs in scientific psychology (Horgan and Woodward 1985; Greenwood 1991). Pain FP has had a similar effect in pain social and cognitive psychology for several decades (e.g. Sternbach 1986; Hadjistavropoulos et al. 2004; Karoly and Jensen 2013). I will argue that proposals to eliminate pain FP based on its alleged poor explanatory status are open to doubt. The following two cases substantiate this guarded assessment.

One case concerns FP generalization (4) that pain intensity is sensitive to changes in the weather. This generalization has been intensively investigated for over five decades. However, experimental results are mixed. De Figueiredo et al. (2011) conducted a meta-analysis of 247 abstracts of studies that investigated weather-osteoarthritis pain relations and found a strong correlation between weather changes and increased pain in osteoarthritis patients, especially changes in atmospheric pressure, but not in precipitation. Ngan and Toth (2011) found that weather-mediated changes occur for patients with neuropathic pain, manifesting as relief from Chinook winds, while cold temperature conditions provoked exacerbations in neuropathic pain intensity. However, other studies reveal no pain-weather relationship (e.g. Fors and Sexton 2002; Wilder et al. 2003; Smedsland and Hagen 2011). For example, weather variables have explained only a small amount of change in individual differences between patients in their weather sensitivity patterns. Gorin et al. (1999) found that while rheumatoid arthritis patients with higher levels of self-reported pain showed more weather sensitivity, weather variables accounted for only a small amount of change in pain scores. This pattern was true even for patients with the most pronounced pain-weather correlations. Hence, although weather sensitivity was shown, the effect sizes were not clinically meaningful. Similarly, Çay et al. (2011) found that the belief about the presence of weather-arthritis correlations was *stronger* than its statistical power. Thus, further study is warranted concerning the explanatory power of this FP generalization. In the meantime, caution seems to be the order of the day.

Many pain psychology studies demonstrate that pain FP beliefs and attitudes are correlated with the development of chronic pain and disability (e.g. Williams and Thorn 1989; Eccleston et al. 1997; Aldrich and Eccleston 2000; Moseley 2007; Leeuw et al. 2008; Main et al. 2010). Specific beliefs that set the stage for activity restrictions are associated with the development of chronic pain and related disability. These beliefs include the pain FP generalizations such as "hurt is generally harm" (i.e., if it hurts, something serious is broken), "pain is a signal to stop what you are doing" (i.e. if an activity results in pain, a person should always stop before an injury occurs), and "rest is the best medicine" (i.e. pain signals that a person should rest to recuperate the body). Integration of pain FP in clinical pain management and treatment has been shown to improve patient outcomes and reduce pain. For example, decreases in the belief that pain signals damage are correlated with decreases in patient disability (e.g. Elander et al. 2009; Molton et al. 2009; Jensen et al. 2001). Increases in perceived control over pain and decreases in pain catastrophizing and in the belief that one is disabled are also associated with decreases in self-reported patient disability, pain intensity, and depression (e.g. Jensen et al. 2001; Elander et al. 2009; Molton et al. 2009). Clearly, pain FP has stimulated important psychological research which has translated into genuinely improved patient outcomes.

4.1.1 Pain Folk Psychology and Patient Education About Pain

Inquiry into pain FP appears justified for its own sake, because informed pain clinicians can find new opportunities to intervene in modifying maladaptive beliefs concerning pain and replace them with adaptive folk beliefs informed by accurate pain neurophysiology. The success of education about the neurophysiology of pain (e.g. Pain Neurophysiology Education [PNE]; Therapeutic Neuroscience Education [TNE]) for patients with chronic pain is a case in point (Moseley 2003, 2005; Moseley et al. 2004; Clark et al. 2011; Louw et al. 2011; Nijs et al. 2011; Louw 2012).

PNE/TNE differs from traditional biomedical models of patient pain education in which pain is explained in terms of tissue damage or nociception. On this model, a patient reporting low back pain and limited movement might be shown a spine model by a clinician. The clinician explains to the patient that her low back hurts because of a "bad disc." However, phrases such as "bad disc" and traditional cognates such as "bulging/herniated/rupture/torn disc" increase anxiety in patients and fear of movement, which is a barrier to recovery (Moseley 2003, 2005; Moseley et al. 2004). In contrast to traditional biomedical models of patient pain education, PNE/TNE teaches patients "how the nervous system, through peripheral nerve sensitization, central sensitization, synaptic activity, and brain processing, interprets information from the tissues and that neural activation, as either upregulation or downregulation, has the ability to modulate the pain experience" (Louw et al. 2011, 2042).

In a PNE/TNE therapeutic session, therapists teach patients accurate neurophysiologic pain concepts using common sense metaphors ("pain as an alarm system") and narrative forms in which patient and therapist co-participate as interaction partners (Louw 2012):

Therapist: "If you stepped on a rusted nail right now, would you want to know about it?"
Patient: "Of course."
Therapist: "Why?"
Patient: "Well; to take the nail out of my foot and get a tetanus shot."
Therapist: "Exactly. Now, how do you know there's a nail in your foot? How does the nail get your attention?"
Therapist: "The human body contains over 400 nerves that, if strung together, would stretch 45 miles. All of these nerves have a little bit of electricity in them. This shows you're alive. Does this make sense?"
Patient: "Yes."
Therapist: "The nerves in your foot are always buzzing with a little bit of electricity in them. This is normal and shows….?"
Patient: "I'm alive."
Therapist: "Yes. Now, once you step on the nail, the alarm system is activated. Once the alarm's threshold is met, the alarm goes off, sending a danger message from your foot to your spinal cord and then on to the brain. Once the brain gets the

danger message, the brain may produce pain. The pain stops you in your tracks, and you look at your foot to take care of the issue. Does this sound right?"
Patient: "Yes."
Therapist: "Once we remove the nail, the alarm system should…?"
Patient: "Go down."
Therapist: "Exactly. Over the next few days, the alarm system will calm down to its original level, so you will still feel your foot for a day or two. This is normal and expected."
Therapist: "Here's the important part. In one in four people, the alarm system will activate after an injury or stressful time, but never calm down to the original resting level. It remains extra sensitive. With the alarm system extra sensitive and close to the "firing level," it does not take a lot of movement, stress or activity to activate the alarm system. When this happens, surely you think something MUST be wrong. Based on your examination today, I believe a large part of your pain is due to an extra-sensitive alarm system. So, instead of focusing of fixing tissues, we will work on a variety of strategies to help calm down your alarm system, which will steadily help you move more, experience less pain and return to previous function."

Studies have shown that PNE/TNE leads to some normalization of FP attitudes and beliefs about pain, a reduction in pain catastrophizing (Sullivan et al. 1995), and an improvement in physical performance (Clark et al. 2011). Following a single or multiple PNE/TNE session, pain patients are less likely to believe pain is indicative of tissue damage alone; less likely to seek care from others when in pain, more likely to believe one can control one's pain, and perceived themselves as less disabled (e.g. Moseley 2003, 2005; Moseley et al. 2004). Clearly, pain folk psychology is compatible with advances in pain neuroscience, as evident in PNE/TNE in which only some maladaptive pain beliefs are modified, and others eliminated. Thus, it is possible that pain folk psychology is replaced to a degree, with some folk beliefs persisting in modified form in the face of contemporary pain neuroscience. EM is only one possible theoretical outcome on a continuum with many possibilities.

According to supporters of pain FP, the folk theories pain patients hold are real because they produce genuine effects on how patients act in the world, and how they interact with caregivers and clinicians. These effects are also observed when patients receive clinical support to change their maladaptive pain beliefs, in some cases leading to attenuated pain and improved clinical outcomes, as in some clinical cases following successful PNE/TNE. Even if it is granted to EM that pain FP is theoretically incomplete, or fails to explain every feature of pain, it is hard to see how it must be therefore *radically* false (e.g. Horgan and Woodward 1985). Thus, the EM criticism that pain FP is explanatorily stagnant seems mistaken.

4.2 Pain Eliminativist Materialism is Self-Refuting

Some philosophers have argued that EM is self-refuting (e.g. Baker 1987; Boghossian 1990, 1991; Reppert 1992). The objection is that a capacity or activity that is somehow invoked by EM is *itself* something that requires beliefs. A reasonable choice for this activity is making an assertion. Plausibly, to assert something one must *believe* it (Baker 1987; Boghossian 1990, 1991; Reppert 1992). Thus, for EM to be asserted as a philosophy, the advocate of EM must believe that it is true. However, if the advocate of EM believes this, then there are beliefs and EM is therefore false. Similarly, to assert that there are no pains, the EM philosopher must believe that this assertion is true. If this is so, then there are beliefs, and EM is proven false.

In response to this objection, EM philosophers have observed that the mere idea that there are no pains is not *itself* contradictory (Churchland 1981, 1989; Ramsey 1991). Thus, the objection is not that EM is self-refuting. Instead, it is that the EM *philosopher* is doing something that refutes his or her own philosophy. In the previous example, the refuting act is making an assertion, as it is declared by the supporter of FP that we must believe anything we assert. However, this last claim is exactly the type of claim FP makes that EM is urging we should reject. According to EM, all of the diverse capacities that we now explain by appealing to beliefs do not *really* involve beliefs at all. All of the capacities we currently account for by invoking pains do not really involve pains. Thus, it seems that the self-refutation objection begs the question against EM.

4.3 Pain Eliminativist Materialism is a Premature Philosophy

Some philosophers claim that EM is premature, given its promissory nature (e.g. Fodor 1974, 1987; Horgan and Woodward 1985; Baker 1987; Greenwood 1991). EM claims that the correct theory of pain, when discovered by neuroscientists, will not reveal anything like the pains FP describes. Hence, for EM to work, an assumption needs to be made that neuroscience is going to turn out a specific way. But, why make that assumption before science gets there? Why infer an ontologically eliminative conclusion concerning pain, when a core premise required for that conclusion is unknown?

To the charge that EM is promissory in nature, EM philosophers have responded that this misconceives the nature of EM (Churchland 1981, 1989, 1996, 2013). EM is eliminative in *predicting* the future elimination of folk psychological pain from our post-neuroscientific ontology. Just as oxidative reactions as described within elemental chemistry bore no resemblance to phlogiston release, or dry friction to caloric fluid, continuing development in neuroscience will likely reveal that there are no such things as pains as understood by everyday common sense. This is not predetermination in action: rather, it is a theoretical expectation based on the historical and present success of science. Still, general uncertainty about how predictions will turn out does not inoculate EM from the highly promissory nature of its current central arguments. EM needs a stronger argument to justify its position. In the meantime, the most we can do is remain neutral on the issue, and adopt a wait-and-see attitude.

4.4 The Success of Pain Folk Psychology

The final objection I will consider against pain EM, which develops the criticism described in Sect. 4.1, is that it ignores the enduring *success* of pain FP, success that shows it offers a more accurate account of pain than EM recognises. Human beings are generally successful in using everyday common sense to predict the pain and pain-related behaviours of other people. For example, a person can form a maladaptive cluster of behaviours around pain FP (Williams and Thorn 1989; Aldrich and Eccleston 2000; Butler et al. 2003; Moseley 2007). Chronic pain patients may experience pain with no identifiable pathology, yet they may avoid beneficial activities because they fear that physical harm will occur. Pain clinicians are trained to help patients identify and reform this theoretical link by (e.g.) teaching about different kinds of pain (e.g. acute vs. chronic pain) and how pain may not necessarily signal bodily damage. As already described, patient education programs such as PNE/TNE have been successful in replacing some maladaptive pain folk generalizations and claims with adaptive folk generalizations and claims (e.g. Moseley 2003, 2005; Moseley et al. 2004; Elander et al. 2009; Clark et al. 2011; Jensen et al. 2001; Louw et al. 2011; Nijs et al. 2011; Louw 2012).

Kitcher (1984) and Fodor (1987), both supporters of FP, have observed that the success of FP is something like an inference-to-the-best-explanation argument in favour of FP and against EM. The best explanation for the success in explaining and predicting human pain behaviour, and in reforming maladaptive pain FP, in the case of PNE/TNE, is that pain FP is approximately true, and that there really are pains.

However, one EM response to this argument is to re-assert that any theory can seem successful or approximately true, even when it is false (Churchland 1981, 1989, 2002). Our intellectual history shows that human beings often discredit deviations and inconsistencies, ignore failures as unimportant, and typically assign more success to a well-known theory than it warrants (e.g. Gribbin 2004). Like the supporters of caloric fluid or luminiferous ether, we may be blind to the errors of pain FP until an alternative (e.g. neuroscientific) explanation is available (Churchland 1981, 1989, 2002). Since neuroscience is still a young science, we likely have only a faint understanding of what remains to be discovered about pain, and only a faint understanding how the discoveries will alter our pain FP. Although pain FP currently shows many functions beyond explaining and predicting, that fact does not change its theoretical status nor protect its generalizations and claims from elimination (Dennett 1978; Churchland 1981, 1993, 1996).

This logical point may be conceded to the eliminativist with a nod to Dennett (1978), who seems to arrive at a similar conclusion in his argument against pain FP. Nevertheless, the persuasiveness of this argument ultimately rests on the eliminativist making a convincing case for assuming that pain neuroscience or folk psychology turns out as EM *believes* they will, even when a core premise required for the envisaged outcome is simply not known, and may never be known. That case for EM remains to be made.

5 Conclusions

Suggestions from some pain researchers to replace self-report of pain with brain-markers is compatible with the philosophy of *Eliminative Materialism*, a theory which asserts that there is nothing more to pain than brain mechanism because pain, as conceived in folk psychology, does not really exist. Pain folk psychology continues to prompt important psychological research, which has been translated into improved outcomes for some patients with pain. But, eliminativists draw inspiration from our intellectual history, which shows that any theory can appear successful or beneficial even when it is false. However, pain education programs show that contemporary pain neuroscience theory and folk pain psychology co-exist. Thus, elimination of folk psychology as advocated by eliminativist materialism is merely one possibility on a continuum of many theoretical outcomes. Further, facts of history do not protect eliminative materialism from the unjustifiably promissory nature of its central claims. The eliminativist needs to produce independent reasons for thinking that pain neuroscience will turn out a certain way, a difficult task given that a central premise for the outcome envisaged by the eliminativist is unknown. Ultimately, recognition that all human knowledge about pain is temporary and susceptible to alteration fosters modesty about the truth of our folk and neuroscientific understandings of pain.

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Chapter 6
The Contribution of New Technological Breakthroughs to the Neuroscientific Research of Pain Communication

Aurore Meugnot and Philip L. Jackson

"You pain, my brain, I care" - EEVEE in the near future.

Abstract Pain is a universal experience of human distress but paradoxically eminently private. One can infer the level of pain in others based on varying sources of information making it difficult to accurately and systematically evaluate the actual experience of a person in pain. Yet, this is one of many difficult tasks healthcare professionals face every day. Assessing pain in others is further hindered by the fact that caregivers are humans, and humans cannot easily remain indifferent to other people's distress, and tend to avoid it. From the patient's point of view, available means of pain expression can be reduced, but they can also be voluntarily restricted when facing for instance distrustful professionals. From the healthcare professional's point of view, facing pain on a continual basis and communicating one's understanding and empathy can be difficult. Ultimately, beyond the individual feeling pain and another individual decoding the pain message, the patient-caregiver interaction itself crystallizes the complex phenomenon of pain communication. In this chapter, we discuss the perception of pain and its communication from the perspective of neuroscience. Firstly, we briefly review recent imaging studies on the cerebral responses to pain and pain in others. We point out neuroimaging evidence showing the varying involvement of regions of the "pain matrix" in the process of other's pain perception (also called pain empathy). Secondly, we discuss current neurocognitive models which provide a first step towards understanding pain communication at the level of the central nervous system, although they fall short at characterizing the interactive mechanisms

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A. Meugnot · P.L. Jackson (✉)
Ecole de psychologie, Université Laval, Quebec, Canada
e-mail: philip.jackson@psy.ulaval.ca

A. Meugnot · P.L. Jackson
Centre interdisciplinaire de recherche en réadaptation et intégration sociale,
Quebec, Canada

A. Meugnot · P.L. Jackson
Centre de recherche de l'institut universitaire en santé mentale de québec,
Quebec, Canada

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underlying this complex process, as the traditional one-brain approach used to date has focused on either the observer or the person in pain. We also review more recent neuroimaging studies on the phenomena of interpersonal synchrony. We argue that examining both individuals of a dyad together, and their interactions, is becoming necessary to address pain communication fully. Finally, we present new perspectives in the study of pain communication through the field of affective computing, which is making steady progress towards designing machines capable of detecting and reacting to behavioural and physiological markers of human emotions, including pain. We propose that the use of avatars offers a highly controllable experimental set-up to explore the mechanism underlying pain empathy and pain communication from both the patient's and the caregiver's perspective, as well as their interactions. Beyond designing intelligent and empathic tools to detect patients' experiences, these research initiatives may help promote empathic behaviour and thus meet the challenge of preserving our humanness in the contexts of pain and suffering.

1 Introduction

Pain is a universal experience of human distress, which stems from the interaction of different sensory, affective, cognitive and social features. The communication of this complex experience is especially challenging due to its subjective nature. In general, one can only infer the level of pain in others based on bodily information (e.g. facial expressions, posture) or verbal report and paralinguistic features (e.g. crying, moaning, screaming), making it difficult to accurately assess the actual experience of a person in pain. Yet, pain assessment is only one of the many difficult tasks healthcare professionals face every day. Unfortunately, it is now acknowledged that caregivers, including physicians and nurses, often fail to adequately estimate and treat patients' pain, especially people with communication limitations such as children, people with disabilities, or seniors (for a review, see Prkachin et al. 2007).

In recent decades, this unfortunate fact was paralleled by a widespread reflection aiming at broadening the narrow biomedical model of pain to include essential psychological and social dimensions. This biopsychosocial perspective of pain has inspired naturalistic pain communication models (e.g. Hadjistavropoulos et al. 2011) that address how pain information is communicated to others in the social environment. Such models appear particularly relevant to capture the complexities of pain communication in clinical contexts [i.e. within a patient-caregiver relation; (Craig 2009; Hadjistavropoulos et al. 2011)]. In fact, pain assessment is far from precise; it can be influenced by numerous biases linked to the patient such as gender and race, the caregiver (e.g. his physical condition), or even the relation between the two (e.g. distrustful or confident) (Grégoire et al. 2012). Thus, the conceptualization of pain communication provides a framework to study clinically relevant sources of discrepancies between pain management and patient's actual pain experiences.

According to Craig's proposal (2009), pain communication includes four steps. It must begin with an experience of pain accompanied by tissue damage, injury or disease (*self-pain perception* or *internal pain experience*), which is then described to another person (*pain expression* or *encoding*). Next, this *pain message* is understood by the observer (*other's pain perception* or *decoding*) who chooses a response following his or her appraisal (*reaction to pain in others*, e.g. pain management in the clinical context). Distress accompanying pain is generally conveyed using intended and consciously produced acts, such as speech. Verbal information is also accompanied by unintended actions, i.e. language prosodics, facial expression and body language, which may or may not be recognized by the observer. This model also includes complex inter- and intrapersonal factors modulating the different steps of pain communication. Actually, the majority of studies in various disciplines (Sociology, Psychology, Physiology, Neurosciences) are based on this theory of pain communication. Beyond the promotion of theoretical knowledge on this topic, in the clinical context, the overarching goal of pain communication research is also to examine innovative solutions aimed at the improvement of pain appraisal and management (Drwecki et al. 2011; Padfield et al. 2015).

Herein, we address the contribution of recent technological tools to neuroscientific approaches of pain communication. The advent of neuroscientific technologies offers a new research avenue for the study of pain communication and the factors interacting with the transmission of pain messages, by measuring the neural correlates of pain perception (both in the person reporting pain and in the observer) in different experimental contexts. Neuroscience is particularly interested in studying non-conscious processes of pain communication, and complements behavioral findings [i.e. self-reported questionnaire or behavioral tasks in which participants have to evaluate pain intensity in visual stimuli (Price and Aydede 2006)]. Note that, as the lion's share of neuroscientific evidence is related to physical rather than social pain, and, to avoid slipping into the interesting debate about the *physical* versus *social pain* model (Eisenberger 2015), we deliberately limit the focus of this chapter to physical pain. Firstly, after a brief review of the cerebral correlates underlying *self* (i.e. the person in pain) and *other's* (i.e. the observer) pain perception, the different cognitive and social mechanisms implicated in the modulation of pain communication and their underlying neurological bases will be presented. In particular, neuroimaging evidence demonstrating variation of brain activations during pain observation in another person (*pain empathy*) will be discussed as a potential factor interacting with inaccurate assessment of other's pain. Secondly, we highlight the ecological impact of neuroimaging studies on pain communication, as they tend to fall short at characterizing the interactive mechanisms underlying this complex process. Recent neuroimaging studies on interpersonal synchrony may illustrate how pain communication may be scientifically studied using standard methods and instruments. Thirdly, new perspectives in the neuroscientific study of pain communication through the field of affective computing and virtual reality will be presented.

2 The Neural Basis of Pain Communication and its Modulation

As mentioned above, pain communication is highly influenced by psychological and social factors. In routine clinical contexts, if a patient fails to convincingly express pain, it might imply that they have limited/reduced physical means with which to express pain, but it could also mean that they voluntarily restrict their expression when facing distrustful professionals. By examining neural activation changes associated with pain experiences, neuroimaging studies can complement behavioral and qualitative findings, and help to understand complex processes underlying changes in pain communication. After a brief overview of the neural correlates of pain perception, from both an internal (*self-pain*) and a vicarious (*other's pain)* experience, the neuroscientific contribution to pain communication will be illustrated by referring to neuroimaging studies. Notably, we will refer to pain empathy studies, which were specifically interested in the *observer's* brain changes following psychological and social factors modulating the other's pain perception.

2.1 The Neural Structures and Systems Involved in Acute and Vicarious Pain

In the past decade, actual acute experiences have been observed using several brain imaging and brain mapping techniques such as positron emission tomography (PET), functional magnetic resonance imaging (fMRI), electroencephalography (EEG), and magnetoencephalography (MEG). The commonest regions for self-pain perception include the primary and secondary somatosensory (S1, S2), the anterior and posterior insulae, anterior cingulate (ACC), and prefrontal cortices (PFC), as well as the thalamus (Apkarian et al. 2005). S1 and S2, located on the postcentral gyrus, are usually known for their role in the sensory-discriminative dimension of pain (pain location and intensity). The insula, which receives input from S2 and the thalamus (posterior insula) and tightly connects to limbic structures and the ACC (anterior insula), is usually associated with the affective dimension (unpleasantness) of pain. The ACC, which also has bidirectional connections with regions of PFC [e.g. the medial PFC (mPFC)] associated with the cognitive dimension of pain, seems to integrate both affective and cognitive components of a painful experience (Shackman et al. 2011; Shenhav et al. 2013). Yet, posterior parietal and prefrontal areas also participate in the different temporal stages of pain processing (Garcia-Larrea and Peyron 2013). This network of brain regions, conventionally termed the *pain matrix,* is largely (see Apkarian et al. 2005 for a meta-analysis; Garcia-Larrea and Peyron 2013 for a review), but not universally, accepted within the field of pain as specific to pain (Iannetti and Mouraux 2010; Mouraux et al. 2011).

The neural circuitry underlying other's pain perception has stimulated a growing body of research interest since the early 2000s (for a review, see Lamm et al. 2011). The cerebral correlates of facing others in pain have been largely examined in neuroimaging studies aimed at exploring the neural correlates of empathy. Thus, although a recent debate was introduced about the distinction between *pain empathy* and *other's pain perception*, as the latter one would not necessary include a prosocial reaction to other's pain (Prkachin et al. 2015), we propose to define *pain empathy* as the natural ability to perceive, understand and react (or intend to) to the pain of others. Robust evidence showed that seeing another person in pain activated some regions within the hypothesized pain matrix (for reviews see Lamm et al. 2011; Jackson et al. 2006). More precisely, a core network consisting of the anterior insula (AI) and adjacent inferior frontal gyrus (IFG), the somatosensory cortex and a region including the anterior midcingulate cortex and dorsal anterior cingulate cortex (aMCC/dACC) is associated with pain empathy. However, the brain overlap between the representation of self and vicarious pain is not absolute, and substantial differences have been found in the precise areas activated in each form of pain. For instance, in the ACC, self-pain activations are more posterior and ventral, while pain related activations are more anterior when observing others in pain (Jackson et al. 2006). Moreover, pain empathy is not restricted to a spontaneous sharing of other's pain experience, but also engages cognitive processes such as *perspective taking* and *emotion regulation* (see Decety and Jackson 2004; for a neurophysiological model of empathy), which are known to be associated with activation in the temporoparietal junction (TPJ) and the posterior part of the superior temporal sulcus (pSTS) (Zaki and Ochsner 2012).

2.2 The Modulation of Neuronal Correlates of Pain Empathy

While some researchers have explored the cerebral basis of actual or vicarious pain, other neuroscientists have examined whether the neural correlates of pain empathy would be affected by the varied psychological or social biases well known to modulate pain communication. A neuroscientific perspective may be particularly useful to complement behavioral findings (i.e. subjective measures) about the modulation of pain communication, especially as these biases are innately unconscious and implicit. The factors modulating pain empathy are presented below according to their source and the interaction between the sources, i.e. those linked to the person in pain, the observer or the relation between the two individuals.

Variables related to the *suffering person* include personal characteristics such as age (Latimer et al. 2011), sex (Simon et al. 2006; Coll et al. 2012), the ethnic origin of the person in pain (Xu et al. 2009; Avenanti et al. 2010; Contreras-Huerta et al.

2013; Mathur et al. 2010; Riečanský et al. 2015) or even the level of incomes presumed (Guo et al. 2012). For instance, Xu et al. (2009) examined the neural empathic activity when Caucasian and Chinese participants watched video clips of Caucasian or Chinese persons receiving either painful (i.e. with a syringe needle) or non-painful (i.e. with a cotton-bud) stimuli touch their cheek. The results revealed a reduced empathic pain activity in the ACC and left AI when participants viewed painful touch to the faces of other-race people compared with people of the same race. Since the anterior insula (AI) is involved in the integration and representation of interoceptive and affective information, and the ACC is identified as its motivational and action-related counterpart (Bernhardt and Singer 2012), race bias in these areas suggests a decrease in the affective sharing to pain in other-race facial expressions. In the same vein, Guo et al. (2012) demonstrated greater activation in pain empathy related regions (i.e. aMCC, insula and TPJ) for poor people compared with people in a good financial situation. This finding suggests that the empathic neural responses for pain are likely inhibited by the belief that wealthy people have enough resources and confidence to cope with physical pain by themselves. Furthermore, the brain response to other's pain may be modulated depending on whether the person in pain is considered responsible or not for his/her suffering (Akitsuki and Decety 2009; Decety et al. 2010). Note that neural activation differences between experimental and control group were sometimes demonstrated in the absence of significant behavioural differences (e.g. ratings of other's pain, Xu et al. 2009), which strengthens the relevance of a neuroimaging perspective to complement and contribute new data (and hypotheses) to subjective measures of pain empathy.

The changes of brain responses related to *the observer* are also well documented. Notably, the neural responses to other's pain were shown to be affected by the observer's personal characteristics such as sex (Yang et al. 2009; Preis and Kroener-Herwig 2012; Preis et al. 2013), the propensity to be empathic (Avenanti et al. 2009), his/her physical state (Coll et al. 2012; Meng et al. 2013), or by contextual factors such as situation appraisal (Lamm et al. 2007), attention (Gu and Han 2007), the cultural environment (Cheon et al. 2011, 2013) or the relation to pain (e.g. over-exposure to pain, Coll et al. 2016) and prior pain experience (Cheng et al. 2007; Preis et al. 2013, 2015), or even whether participants had been exposed to short-term media violence (Guo et al. 2013). In a seminal study, Coll et al. (2016) examined the neural mechanisms underlying a repeated exposure to someone in pain. They measured behavioural (pain detection task) and Event-Related-Potential responses to facial expressions of pain in healthy adults who were either repeatedly exposed to intense expressions of pain or to neutral expressions. As in previous behavioral studies (Prkachin et al. 2004; Prkachin and Rocha 2010), the participants were less inclined to consider moderate expressions of pain as painful after observing expressions of intense pain. Most notably, this behavioral effect was associated with a reduction in the Late Positive Potential (LPP) response, measured at centro-parietal sites to pain expressions following exposure to intense pain compared with participants exposed to neutral expressions. These findings were interpreted as an alteration of cerebral responses to pain in others, which would indicate that repeated exposure to vicarious pain leads to a decrease in the perceived saliency of pain expressions. Besides extending previous behavioral evidence of the effect of over-exposure to vicarious pain (Goubert et al. 2009), these findings are particularly of interest in clinical settings as healthcare providers are exposed to patients in pain every day. Future investigations should test whether this effect cumulates and/or persists over time (e.g. several sessions).

Moreover, other neuroimaging studies have begun to describe neuronal changes associated with factors linked to *the connection between the two individuals making up the dyad*, e.g. their affinities (Singer et al. 2006; Hein et al. 2010), their social status (Feng et al. 2015), or in the clinical context (i.e. patient-physician relation), the expectancy for pain relief (Jensen et al. 2014). In a recent study, using fMRI, Feng et al. (2015) explored the influence of social hierarchies on the empathic neural response to pain in others. Social hierarchies were established based on contingent skills in a perceptual task, which allowed ranking of participants. Then, participants were scanned while watching inferior- or superior-status targets receiving painful or neutral stimulation. The results indicated higher activations in the AI and aMCC when viewing painful stimulation applied to inferior-status targets. In contrast, these brain activations were significantly reduced in response to pain seen in a superior-status individual. Moreover, this heightened response towards inferior-status targets was accompanied by stronger functional couplings between AI and brain regions important for nociceptive and emotional processing (i.e. thalamus) and cognitive control (i.e. middle frontal gyrus). Once again, these findings indicate that social biases may shape the emotional sharing with others' pain, shedding light on the modulation of the complex processes underlying empathy for pain.

In line with studies based on subjective reports, neuroscientific data referring to the *decoding stage* of pain communication (*the observer's perspective*) support the idea that empathy for pain is more complex than a mere resonance with the target's painful state, and is modulated by multiple social or psychological biases either linked to the suffering person, the observer, or the relation between the two individuals. Overall, neuroimaging findings suggest that multiple levels of neural mechanisms involved in affective sharing and sensorimotor resonance with someone in pain are modulated by individual characteristics and social relationships, and, thus, would mediate the contextual biases interfering in pain communication already shown in behaviours.

Interestingly, few neuroimaging studies have focused on the modulatory factors of pain empathy arising from the dyadic interaction compared to those assessing the person in pain or the observer. This observation may also apply generally to pain communication research as the traditional one person/one-brain approach used to date has focused on either the observer or the person in pain, without considering the dynamic influence of one on another. Without denying the great progress achieved so far in building a neuroscientific functional model of pain empathy and pain communication, the following discussion will address the non-ecological aspects of neuroimaging studies in this field. These studies often fall short in studying the social interaction component of this phenomenon in ecological or naturalistic terms. Recent neuroimaging studies interested in the phenomenon of interpersonal synchrony offer a more naturalistic approach by examining both individuals of a dyad together and their interactions, and appear as an interesting model for the study of pain communication in all its complexity.

3 Towards Interpersonal Interaction Experiments in the Neuroscience of Pain Communication

3.1 Pain Communication Research: A Challenging Compromise Between Controlled and Ecological Paradigms

The neuroscience of pain communication is still at its infancy. Yet, this exciting new field yields exponential findings from both the perspective of the person in distress and the person offering help or comfort. That said, at least two important methodological gaps observed in pain empathy studies must be pointed out and discussed.

The decoding of pain is generally based on *multimodal* and *dynamic* information, stemming from visual (non-verbal) and verbal-report information, which are contextually embedded (Hadjistavropoulos and Craig 2002; Hadjistavropoulos et al. 2011). With some exceptions, neuroimaging studies on pain empathy have used mainly simple visual stimuli, i.e. *picture-based* experimental designs based on a series of independent short events, without feedback to the participant; for instance, extracted from the UNBC-McMaster bank (Botvinick et al. 2005). In fact, as for most early study of any complicated psychological phenomenon, simplified stimuli and tasks were needed to first isolate specific processes and localize the cerebral response of pain empathy, and such precise and well-controlled localization was necessary before studying more complicated ecological designs, more aligned to achieving a holistic understanding of the neural circuitry underlying pain empathy. Thus, while the recurrent use of such simple and tractable stimuli has allowed researchers to disentangle the complex neuronal and cognitive processes underlying decoding another's pain; nevertheless, they are overly artificial and may limit the ecological significance of the data (Zaki and Ochsner 2012). We advocate the development of a more ecologic and realistic set of stimuli, e.g. video clips of individuals in real-life situations. For instance, Latimer et al. (2011) used video clips showing infants undergoing real medical procedures to examine whether repeated pain exposure would affect nurses' ability to be empathetic (Latimer et al. 2011). Naturalistic and controlled paradigms are fundamentally complementary and researchers should choose either one or the other depending on their theoretical issue. The cross talk between these two approaches would be a productive way to characterize the neural systems supporting the different steps of pain communication.

The second limit of the current literature on the neuroscience of empathy for pain is that, in the tasks used, no interaction is possible between the observer and the person in pain, even in a paradigm in vivo (Singer et al. 2004, 2006), as the person in pain sat to the side of the observer (positioned in the scanner) who only saw his/her hand reflection in mirrors. As already said, simplified experimental tasks were necessary to establish an evidence base. However, to be consistent with the scope of a biopsychosocial conception of pain, which draws specific attention to the social (*interpersonal*) factors characterizing pain experience, more ecological experimental designs must be also developed in the future. More simply, in real-life, the observer and the person in pain continuously interact, and thus, the resulting perception can only be predicted by a suitable combination of intrapersonal and interpersonal features. To make this point more concrete, imagine a physician hearing a patient who is describing his painful distress. The patient thinks his physician is not sensitive enough when he is talking about his pain, and suspects the physician to underestimate his suffering. As the conversation unfolds, he may amplify his pain expressions in order to receive desired treatment. From the physician’s point of view, when facing a patient who never complains about pain, he/she may pay close attention to unintended cues such as facial expressions when he/she is examining the patient, to perceive whether he/she should prescribe pain-killers to the patient or not. This scenario illustrates the complexity of pain communication, which entails constant interactions between the individual feeling pain and another individual decoding the pain message characterizing pain communication. Accordingly, neuroscientists cannot sensibly remain agnostic about the necessity to integrate the interaction between two individuals as the core of pain communication paradigms.

3.2 Interpersonal Synchrony

Albeit from a different field than pain communication, studies on *interpersonal synchrony* have demonstrated a key role of interactive processes in social exchanges, as well as the relevance of using alternative methodologies enabled by technological advances (including neuroimaging, physiological markers or even virtual reality) to pinpoint online changes during social interactions. Interpersonal synchrony refers to the temporal coordination of behaviours that appears naturally during dyadic interactions. In other terms, people spontaneously and unintentionally align their actions with others. For instance, the synchrony between the speech rhythms of a speaker and the bodily gestures of a listener in a conversation is well documented (Schmidt and O’Brien 1997). Moreover, during a conversation, gaze contributes to speech understanding as well as turn taking with eye contact, enabling persons to be coordinated and synchronized.

From the framework of pain communication, it has been suggested that shared pain may also involve facial expressions mimicry responses in the observer (Yamada and Decety 2009; Mailhot et al. 2012). Further, interpersonal synchrony likely is a foundation for effective social communication and enhanced sociality. Indeed, synchronized actions would result in an array of positive outcomes, increasing liking and rapport (Hove and Risen 2009), blurring self-other boundaries (Miles et al. 2010), facilitating person perception (Macrae et al. 2008) or enhancing altruistic behaviour and cooperation (Valdesolo and Desteno 2011). The social functions of interpersonal synchrony are important relative to pain communication, especially in medical settings, as the degree of synchrony between the observer (e.g. the caregiver) and the suffering person (e.g. the patient) could indicate the degree of his affiliative response toward the patient's painful distress; that is, whether he is "in tune" with his patient. In clinical contexts, interpersonal synchrony would be a potential lever to enhance empathic behaviour among health care providers, but also among patients (as critically pointed out in Jackson et al. 2015a, b), and thus, to help meet the challenge of successful decoding of the patient's pain.

The neural signature of interpersonal synchrony has been investigated by isolating reliable correlates of dynamical brain changes that occur during social interactions (Tognoli et al. 2007). In social neuroscience, scientists have developed a technique, called *hyperscanning*, which simultaneously records brain activity of two persons while they are engaged in a social exchange. This technically challenging brain-to-brain method has been applied using fMRI and EEG, and enables examination of interindividual neural synchronizations associated with behavioural synchronies at the intra- as well as the inter-brain level (Montagne et al. 2001; Dumas et al. 2011; Tognoli et al. 2015). To date, most neuroimaging studies have used conventional sensorimotor synchronization paradigms (e.g. synchronous or asynchronous finger-tapping movements realized with a partner) to assess interpersonal synchrony. For instance, Tognoli et al. (2007) used EEG hyperscanning in participants who were instructed to perform a rhythmic finger movement with or without the visual feedback of the other participant's movement. The authors focused on the alpha-mu band, which is conventionally considered as an electrophysiological correlate of the human mirror neuron system (MNS) functioning. The MNS refers to a set of brain regions which have been deemed important for some motor behaviours as well as the observation of the same behaviour in another individual (Rizzolatti and Craighero 2004). They observed that when participants could see each other they coordinated their behaviour. More interestingly, the results indicated a particular oscillatory component (*phi complex*) of brain activity that either favoured independent movement (*phi1*) or, behavioural synchronization (*phi2*). The topography of the phi complex was consistent with neuroanatomical sources within the MNS. The authors proposed that the phi complex might be a neuronal marker of social interaction. Although hyperscanning presents challenges for data collection and analysis, as well as the implementation of naturalistic and yet controllable paradigms (Schilbach et al. 2013), it seems to more naturalistically model the way the brain acts to convey and decode pain.

Another innovative media to further explore behavioural and neural synchronization of social exchanges is the avatar platform. Research in computer sciences using virtual reality, social gaming and *affective computing* (the study of computational machines and software that can display and process human emotions) is making steady progress towards creating sophisticated characters able to detect and react to behavioural and physiological markers of human emotions (Gaffary et al. 2014). The enormous advantage of animation tools is that they are fully controllable compared with a real partner, while still realistic enough to be ecologically valid. For example, features of avatars can be changed to control some social biases, such as sex or ethnic origin. In a recent study using a finger-tapping paradigm, Cacioppo et al. (2014) examined whether a person may perceive that a virtual partner is synchronized with his/her movements, and would experience affiliative feelings toward this partner (Cacioppo et al. 2014). Participants performed fingertip movements with no specific instruction to align their behaviour with virtual partners. Unknown to the participants, the timings of the avatars' movements were either synchronous or asynchronous with those of the participants. The authors also used fMRI to investigate how regional brain activity was modulated by differences in synchronous stimuli during the task compared with asynchronous stimuli. Behavioral results revealed that synchrony by the virtual partner enhanced the participant's ratings of perceived interpersonal synchrony and social affiliation with the virtual partner. Importantly, the fMRI results indicated greater brain responses of the synchronous condition compared with the asynchronous one in cerebral regions identified as neural correlates of interpersonal synchrony (Fairhurst et al. 2013) including, the left inferior parietal lobule, the left parahippocampal gyrus, the ventro-medial prefrontal cortex (vmPFC) and the ACC. This approach seems encouraging, as the development of specific virtual platforms may be an efficient solution to overcome the methodological limitations described above and to study pain communication in a more "real-life" way.

In this section, we observed that some neuroscientific research on pain communication fails to capture the personal interactive dimension inherent to human social exchanges. Based on the current research interest in interpersonal synchrony, a methodological and conceptual leap from an *individual* towards a *dyadic approach* of pain communication is now necessary to fully capture the human intimacy of this complex phenomenon. In the next section, we will argue how virtual reality procedures may be highly relevant to address the phenomenon of pain communication, and present research interventions that may contribute to improve pain assessment in clinical settings.

4 The Use of Virtual Reality in Neuroscientific Research on Pain Communication

Affective computing studies the recognition and simulation of human emotions; for example, through virtual characters (also called *avatars*) that can recognize and mimic human affects (Picard 2003). In research settings, affective computing technology offers a flexible and controlled set-up appropriate in experimental and therapeutic contexts because avatars can be easily animated and systematically varied according to the experimenter's needs (Dyck et al. 2008).

Virtual reality may provide realistic three-dimensional environments created by computer graphics. Virtual reality has been already used in the field of pain to standardize how pain may be expressed by a patient and assess differences in how people rate pain in others (Hirsh et al. 2008, 2009; Stutts et al. 2010) and, more recently, in empathy (Bouchard et al. 2013; Jackson et al. 2015a, b). Virtual reality can be applied to control pain (Hoffman et al. 2011; Garrett et al. 2014; Jin et al. 2016). In one study, a virtual frozen world were designed to distract patients from their painful burns while receiving wound care (Hoffman et al. 2007). This approach seems clinically promising, as the authors reported reduced pain ratings following the intervention. As a research method, virtual reality may be an efficient solution to overcome the limitations mentioned above for studying pain communication in a more meaningful way.

Recently, several groups have created virtual platforms for studying social exchanges, such as pain communication, and pain empathy (Jackson et al. 2015a, b; Romano et al. 2016; Wittkopf and Johnson 2016). For instance, the Empathy-Enhancing Virtual Evolving Environment (EEVEE), designed by Jackson et al. (2015b), can be used in combination with objective neurophysiological markers (e.g. heart rate, skin conductance, and cortical excitability) for online assessment of pain empathy at behavioral and neurophysiological levels. EEVEE was developed around three objectives: (1) to provide an ecological way to study social phenomenon such as pain empathy or communication, i.e. an interactive and naturally looking, yet highly controlled social environment, (2) to identify correlates associated with the social phenomenon studied, and, (3) to use this platform as a tool for improving social communication and empathy.

EEVEE uses human avatars to produce distinct sets of emotional expressions based on the Facial Action Coding System (FACS) (Ekman et al. 2002; Prkachin and Solomon 2008). The FACS encompasses 46 facial Actions Units (AUs), each AU corresponding to the encoding of the contraction and relaxation of different muscles or muscles groups. Most importantly, EEVEE enables real-time recording of behavioral and neurophysiological reactions, e.g. emotional face recognition, heart and respiration rates, skin conductance. Ultimately, the avatar can interact with the participant by changing its facial expressions based on participant's behavioral and neurophysiological measurements through a multimodal interface that creates different scenarios, and implements different settings for changing the behavioural and emotional response of the avatar. Currently, EEVEE allows the

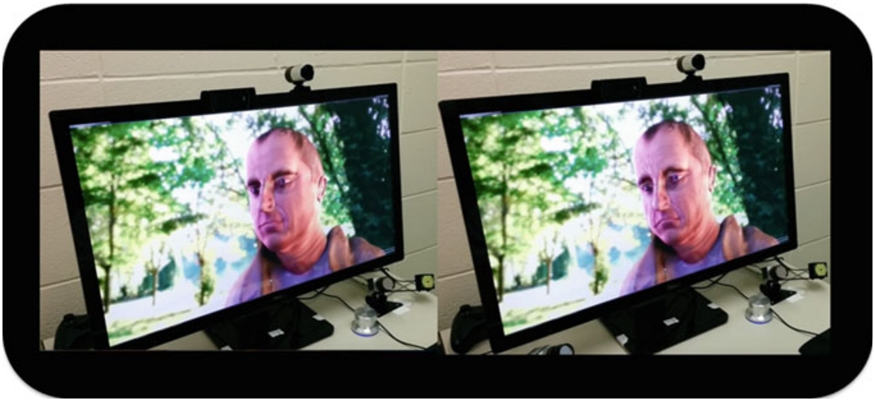

Fig. 1 Illustration of an avatar in a scenario configured with EEVEE. The avatar's facial expression can change based on a predetermined scenarios or the participant's behavioral and neurophysiological responses, including for instance gaze direction, facial expression, heart rate variability, changes in skin conductance and muscle contraction (EMG) (Jackson et al. 2015b)

production of varied avatars (i.e. different age, sex, ethnic origin) and has been validated for different intensities of facial expressions of basic emotions. Moreover, the platform actually proposes different environments in 3D (e.g. a hospital room and a park) (Fig. 1).

Future versions of EEVEE will allow users to change the avatar's gender, age, and ethnicity independently and yet to improve visual immersion. Actually, pilot experiments have been conducted to test the validity of the platform and examined whether the facial expressions of EEVEE's avatars are realistic to convey specific emotions (Jackson et al. 2015b). Preliminary studies were consistent with previous data (Kunz et al. 2012), confirming the validity of EEVEE. They also provided some key methodological information when using it for research on pain communication, discussed in the next section.

4.1 How Intelligent Avatars May Promote the Neuroscientific Study of Pain Communication

Virtual reality will certainly add value for research on pain communication. For instance, in the section above, we evoked the importance of the level of interpersonal synchrony in social exchanges as well as its positive outcomes, e.g. enhancing altruistic behaviour or facilitating the perception of another's mental state. Interactive avatars will enable researches to study whether the level of synchrony between the observer and the person in pain (e.g. matched gaze, facial and body expressions) may influence the empathic response to pain (*perspective of the observer*) or, pain perception (*perspective of the suffering person*), as well as their neural responses. It is reasonable to assume that a high level of synchrony of the observer's action with the suffering person may favour a better assessment of his or her pain; in other terms, may predict a better listening of the person's expression of pain. It seems of particular interest in the clinical context, as the level of temporal coordination of a caregiver with a patient may provide an objective marker of his or her capacity to empathize with the patient's pain, i.e. to recognize and share the pain in other. If the link between interpersonal synchrony, pain empathy and/or accurate pain assessment proves to be significant, intelligent avatars will make a suitable clinical and research tool to assess the ability of healthcare providers to synchronize with other's pain. Moreover, such virtual platforms could also help train caregivers to synchronize with others, improving their ability to detect and manage pain, especially in certain clinical populations (e.g. premature newborns, people with dementia). Concretely, different scenarios with the platform may be created using avatars with varied levels of facial expressions—as well as settings where avatars will change their level of expressions during the social exchange—to train healthcare professionals to detect and synchronize with *body-language of pain,* i.e. significant non-verbal clinical clues of pain (see Mantovani et al. 2003; Deladisma et al. 2007; Consorti et al. 2012; for prior research on this topic).

Another potential training exercise with intelligent avatars would consist in exploiting the neurophysiological and behavioral empathic responses of the caregivers to modulate the avatar's facial expression and communicative responses, to incite caregiver empathy. For instance, a caregiver could see a virtual patient, who suffers from chronic back pain, displaying different levels of facial expressions of pain (modulated according to a predetermined combination of neurophysiological parameters, e.g. gaze directed at meaningful facial areas, skin conductance showing elevated affective response). The avatar would then express relief only when the caregiver's responses would be compatible with a level of synchrony reflecting an empathic state. Other authors already tested practical interventions that may help nurses (Drwecki et al. 2011) or physicians to enhance their communication with patients. Adaptable avatar platforms like EEVEE provide a complementary tool to these cognitive approaches.

We have argued that methodological opportunities are offered by virtual reality to better understand the neuropsychological processes underpinning pain communication, and more generally social exchanges. Research on pain communication is now at a tipping-point and researchers should seek more ecological approaches to study this social phenomenon. Notably, new technological paradigms may help to uncover how behaviours may be modulated during dyadic interactions, as well as their neurophysiological basis. Such innovative initiatives as EEVEE should be encouraged in the future as they provide a rich experimental set-up to explore the mechanisms underlying pain communication from both the patient's and the caregivers's perspective, as well as their interactions. Note that a virtual platform should be developed in collaboration with scholars of artificial intelligence, who have expertise in machine learning paradigms allowing complex statistical analyses (Ashraf et al. 2009; Lucey et al. 2011; Bartlett et al. 2014; Girard et al. 2014; Sikka et al. 2015).

5 Conclusion

The inherent subjectivity of pain makes this experience difficult to access by others. Accurate pain evaluation is highly challenging but crucial for appropriate care delivery. Pain communication is highly influenced by psychological and social factors, linked to the suffering person, the observer, or the relation between them. Neuroscience provides a new window to increase awareness of how several psychological factors, either linked to the suffering person (e.g. age, visual quality, hands vs. facial expressions, visual perspective), the observer (e.g. age, gender, mental health, physical health, knowledge) or the interaction between them (e.g. link with the other [spouse, child], member of the same group, environment [hospital, war]), may separately shape pain communication. Until recently, neuroscience has focused either on the perspective of the person in pain (*self-pain perception*) or, on the perspective of the observer (*pain empathy*), and fell-short characterizing the interactive mechanisms underlying the transmission of a pain message. After 11 years of research on pain empathy, this field can continue to advance by promoting more ecological or naturalistic approaches that take into account both the perspective of the suffering person and the observer, as well as their interactions in relation to pain outcomes. While hyperscanning is a promising but exceedingly challenging method, technological tools such as affective computing and virtual reality appear as complementary and feasible methods. The use of intelligent avatars might provide an acceptable compromise between experimental control and ecological validity.

Overall, beyond designing intelligent and empathic tools to detect patients' experiences, these research initiatives may contribute to promote empathic behaviour in clinical contexts, helping caregivers to counteract the deleterious effects of over-exposure to pain; for instance, a tendency to underestimate the level of suffering. Ultimately, using naturalistic paradigms will be critical for modelling brain functioning during the course of pain communication, and thus help develop more ecological neurophysiological models of this complex phenomenon. The methodological adjustments towards more ecological experiments would also favour connections with other domains of research, especially the psychological literature, enabling evolution of current multidisciplinary models, and thus, contributing to our understanding of pain and the human mind.

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Chapter 7
A Scientific and Philosophical Analysis of Meanings of Pain in Studies of Pain and Suffering

Bustan Smadar

Abstract Carefully weighing three major constraints for elucidating pain and pain-related suffering, I argue that the study of their meanings in experimental and clinical research is necessary. This research program can further the understanding of pain self-report observable pain behavior in addition to physiological signals of pain, thus combining subjective and objective measures for better assessing the pain experience. Much of the information is derived from the encountered difficulties during the ongoing development of pain and related suffering questionnaires, in both the laboratory context conducting experimental studies with healthy volunteers and in the clinic with chronic pain patients. The chapter exposes the challenges of meaning acquisition while proposing, following Eric Cassell, that the study of pain recognizes both objective and personal meaning types. The chapter also explains why the ambition of science to obtain an exhaustive picture of pain is impossible, and that a continuous revision of pain meanings is necessary, especially for clinical studies of chronic pain patients. The methodological dilemma however remains, whether a direct approach is the most appropriate for understanding the state of the patient or is it rather an indirect gathering of information that may best depict individual pain and suffering.

Keywords Pain · Suffering · Meaning acquisition · Experimental studies · Chronic pain · Clinical studies · Questionnaire · Dilemma · Direct or indirect approaches

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B. Smadar (✉)
INSERM Research Unit U-987, Hospital Ambroise Paré, 9 Avenue Charles de Gaulle, 92100 Boulogne-Billancourt, France
e-mail: smadyil@gmail.com
URL: http://www.suffering-pain.com

B. Smadar
SND (Sciences Norms and Decisions) Research Unit, Philosophy Department, Sorbonne Paris IV, Paris, France

S. van Rysewyk (ed.), *Meanings of Pain*,
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1 A Scientific and Philosophical Analysis of Meanings

If there is a difficulty that keeps emerging regarding pain, it is in recognizing the lived experience of a seemingly invisible condition. For patients, this can cause difficulties in communicating as well as elucidating and diagnosing pain, all set against the risk of disbelief. Detecting the concealed is even more challenging in patients with chronic pain, whose pain extends over months and years, since it is not uncommon for these patients to report high levels of pain (8–10 out of 10) for long periods despite understanding that the value 10 represents “the highest pain imaginable”. Sitting across from chronic patients who I interviewed regarding their pain and related suffering, it was striking to find no tangible, apparent, physical expression to match the elevated scores and the descriptions of a torturous internal state owing to persistent nociception (“I am an invisible invalid”, a patient told me). Pain, unlike many other diseases and conditions, does not always have a demonstrable physical proof to attest for its etiology. Pain therefore obliges therefore obliges caregivers to turn to patients’ subjective narrations in order to reach a valid objective inference in addition to their knowledge of important preconditions known to trigger pain (post-surgical pain, post-stroke pain, chemotherapy induced painful neuropathies). Such dissociation between the unobservable but strongly felt illustrates the paradox of pain—that of *objectively attesting to a torturous condition without apparent evidence*—and the consequent necessity to rely on subjective self-report measures for ascertaining a diagnosis which lacks biomedical proof. Flor and Turk note in this respect that “in significant number of people reporting back pain, fibromyalgia syndrome (FMS), and headaches, among other prevalent conditions, no physical pathology can be objectively verified, despite advances in imaging techniques” (2011, p. 6) (Carragee and Hannibal 2004).

In the absence of an identifiable cause or external physical signs, the phenomenon of pain challenges the idea that objectivity in medical judgments must necessarily be based on empirical facts. A great deal of research in the clinic and in the disciplines of science and philosophy has therefore been devoted to the question of subjectivity of pains (Coakley and Shelemay 2007). Furthermore, the challenge involved in deciphering these private states is not only conceptual. It has crucial practical impact on the eventual distrust of third parties such as insurers and employers seeking reliable justifications and most importantly, on misinterpretation of symptoms due to medically unexplained pain conditions. The need for objective information to understand an elusive but undeniably excruciating reality led to an abundance of pain assessment methods (Turk and Melzack 2011). Among them, as we are about to see, are methods based on the observational-behavioral perspective, proposing a solution to the problem of understanding pain, and a recent perspective revaluating what is subjective and objective in pain thus proposing a shift in the way we conceive the problem.

When seeking accordance between external signs and internal conditions, one classical reference that initiated much research on pain responses is the behavioral perspective. Forty years ago, Fordyce’s behavioral approach to studying pain suggested changing the focus from subjective states to behavioral and thus observable manifestations of pain (Fordyce 1976; Main et al. 2015). Fordyce and colleagues were pioneers in applying the operant conditioning paradigm to chronic pain, leading to an important body of investigations that had a significant impact on the field (Sanders 2002). Essentially, operant conditioning proposes that behaviors are largely determined by their consequences and interactions with the surroundings. Applied to pain, observable conducts, including emotional responses, are thought to communicate a person's abnormal distress state and suffering (e.g. nonverbal responses like moaning or grimacing, verbal responses like complaint, frequency of medication intake or therapy and activity level compatible with pain such as sitting down or rest). It is important to note that operant conditioning is not purposeful, but is characterized by the fact that much of it is nonconscious or implicit, i.e. not consciously known to the patient or to an external observer. Thus, learnt behaviour is usually not shown to obtain a goal or a predetermined result but is the consequence of inadvertent learning (Becker et al. 2008, 2011, 2012). Overall, this approach has proven to be very effective in the rehabilitation of chronic patients and the reduction of their medication dependency thanks to the identification of specific behaviors and a tailored adaption of positive/negative reinforcements (Flor and Turk 2011, p. 399–410).

However, to what extent reinforcement contingencies control pain can only be determined in a careful behavioral analysis, which is the basis of behavioral treatments. Limitations come from assuming that maladaptive behaviour, which originates in acute pain, persist after the nociception is gone due to environmental rewards such as increased attention, care and legitimately reduced responsibilities. Describing observable relations that positively or negatively reinforce pain behaviors is believed to reflect a faithful picture of the hidden world of the pained. And yet, a sequential analysis of operant or non operant responses, as a basis for diagnosing the extent of pain and related-suffering without directly asking the patient for their reasons to engage in such behaviors, may be misleading (Flor and Turk 2011, p. 8, 61–67). Rest, for example, may not necessarily convey a desire to gain spouse or social empathy (Flor et al. 1987; Lousberg et al. 1992; Romano et al. 1992), but rather reflect a strategy for avoiding the undesired peak of paralysing pain. Behavioral observations, as objective measures, assuming to report the sense of a subjective experience could therefore lead to pseudo-explanations. This is because inferences may be based on performances and functional assessments and not enough on introspection on pain, as revealed through patient narratives and stories.

Several years later, Keefe and Block (1982) published their behavioral observation system, considered as the most systematic attempt to provide a pain behavior checklist. The reliability of the behavioral approach was demonstrated through a correlation between the subjective pain ratings and the observed pain conducts of the patients (Keefe et al. 1987). Paradoxically, this shows that the basis for pain detections remains patient-self report (Flor and Turk 2011, p. 238). This stance echoes similar conclusions in studies of subjective pain and imaging (Coghill et al. 2003). In addition, since no "third-person" observer can accurately and entirely know the pain of another and in the absence of an objective "gold standard" for a systematic study of pain and related suffering, the utility of "first-person", subjective, reports received support.

Following the requirement for objectivity in deciphering pain, a more recent attitude calls for a shift in perspective. The philosophical debate between "perceptual" and "representationalist" (Michael Tye) theories of pain, to which an entire book of essays was dedicated (Aydede 2005), led to conclusive suggestions by the scientist Donald D. Price and the philosopher Murat Aydede to treat "first-person" subjective reports as a form of objective knowledge. Price and Aydede claim that introspection ("first-person" approach) is not "scientifically and methodologically suspect" and should be integrated into the standard objective ("third-person" observer) practice (2005, p. 243). In associating individual descriptions with experimental patterns, the explanatory power of "first-person" reports is viable since it obeys the same scientific procedure of approving/rejecting initial hypothesis based on results, of finding common factors when encoding the specific pain descriptors and of comparing their interindividual differences. This experiential method, which the authors describe as phenomenological (reports of immediate experiences in the present-tense), is said to propose hypotheses that provide a basis for defining the pain and a practical outcome that can be tested using quantitative tools.

My aim, however, is not to advocate either perspective or even a different alternative since my philosophical-scientific-clinical work on pain and suffering brought me to the conclusion that their elucidation and assessment clearly necessitate combining subjective and objective approaches. These are aspects of pain with no one superior to the other. To the difficulties so far pointed out, I would add that the persistent desire to find a reliable objective anchor for their evaluation is vain without the benefit of "first-person" experience. Pain report and observable pain behavior in addition to physiological signals of pain define what pain is. But in this respect, what is currently missing to complete the picture is not only a clear idea of how people perceive and then communicate their pain (directly or through others observing them), but explicitly stating what it means to them. This chapter therefore proposes to *model pain and related suffering with the inclusion of meanings and personal concepts*, thus extending the literature in a direction that further integrates the *individual life world* into the standard, objective, approach. Much of the information presented in this chapter comes from difficulties pain patients encounter during the development of pain-related suffering questionnaires, in both the laboratory context with healthy volunteers, and in the clinic with chronic pain patients.

Regarding the notions of pain and suffering, they are drawn from our three-dimensional approach to pain measurement based on validated psychophysical research (Bustan et al. 2015; Brunner et al. 2017; Löffler et al. 2017). Traditionally, pain has been viewed as containing two dimensions, a sensory-discriminative (intensity) and an affective-motivational dimensions (unpleasantness). Considering that pain involves higher-order emotional and cognitive processes that go beyond unpleasantness, we extended the assessment of pain by introducing an additional dimension of "pain-related suffering". Suffering is a fundamental constituent of pain (Loeser 1980) and should therefore be included in clinical pain assessment, where pain and suffering are often confounded (Fordyce 1988; Fishbain et al. 2015). In addition to showing that we can measure the three pain dimensions, we conducted a qualitative study to examine the meaning participants attribute to "Intensity", "Unpleasantness" and "Suffering" (Bustan et al. under review). What I therefore refer to in this chapter is only the form of suffering yielded from, or in relation to, pain.

Almost thirty years ago, Clark, Janal and Carroll wrote: "The question 'What is pain?' is often answered, 'Pain is anything the patient says it is'. This is an extreme view, but if we could quantify such broad statements, we might be able to understand what the patient means" (Clark et al. 1989). To quantify is also to qualify by looking at the meanings attributed to numerically rated pain and suffering, as they did. Regarding suffering, taken here as a derivative mode of pain and not as the general multifaceted construct, it could be said that it reflects all the negative aspects in life related to the pain experience, even though conceptually the notion extends beyond pain per se and is more complex. In my philosophical theory on pain and suffering, the origin of the difficulty in obtaining a complete picture of the sufferer is assumed not to be only methodological, and cannot be resolved by using a better scaling system for determining and communicating one's pain intensity or distress signals. The difficulty lies, on the one hand, in the *evasive and invisible* nature of pain and suffering, and on the other hand, in the complex intersection between *the inner*, private, *world of the sufferer* and his *outer*—interrelational, social and cultural—*world*. Following these complex and multi-facetted percepts, we come to realize that pain is not only an unpleasant sensory, but also an emotional experience (Melzack and Casey 1968), and that suffering is a double-natured phenomenon, which expresses itself either as a *feeling* or as a prolonged *condition* (Bustan 2015, 2016). In this sense, a person may experience suffering as a passing *feeling* that will come to an end, but he or she may also experience a situation of endless affliction, such as the loss of a child or a chronic pain *condition* in the case of an incurable disease, making one's torment the basis of an everlasting reality. In my philosophical work (Fan Model), I define this last and fourth dimension as existential suffering, following the three other dimensions of physical, emotional or mental-cognitive suffering. Overall, my call for reviving the account of meaning guides four questions gathered together to lead the general inquiry and it is important to keep them in mind when reading this chapter: What is named by pain and suffering? How is pain and suffering best assessed? What is the contribution of meaning acquisition to the process of understanding pain and suffering? What is the benefit for the patients of pain assessment that includes meaning elucidations? These questions are addressed in turn below.

2 The Three Constraints in Meaning Acquisition of Pain and Suffering

In the medical and scientific literature, pain patients appear under numerous different designations. Their division into subgroups and the classification of their condition according to a consensually validated set of criteria assembling each of the relevant aspects—medical/physiological, psychosocial, and behavioral—provide a specific profile that labels and thus recognizes their plight (Merskey 1986; Turk and Rudy 1987; Williams and Keefe 1991). Such classifications appeal to the explanatory power of an established, rigorous scientific approach. At the same time, these in-depth classifications risk remaining inaccurate as long as they neglect to describe the meanings every individual attributes to his *own* pain and suffering experiences (Williams and Thorn 1989). What one conceives as imperfect may look impeccable to another, and seemingly, a person can qualify as tolerable the pain of a chronic syndrome his fellow might consider as excessive to the point of having prominent thoughts about death. The difference in appreciation lays in the sense the illness has acquired for each individual. In patients who view their chronic pain as a form of great injustice ("What have I done to deserve this?"), suffering is enhanced and so is the despair, creating possible resistance to various forms of treatment (Sullivan et al. 2008, 2012). Without identifying these subjective meanings, physicians cannot access the heart of the problem and apply non-invasive clinical procedures such as hypnotic analgesia (Erickson 1967; Barber 1996; Benhaiem 2006; Jensen 2011) biofeedback, neurofeedback, mindfulness or guided imagery, teaching patients to change the way they think and feel about their pain (Butler and Moseley 2013; Louw and Puentedura 2013). I tend to think that since the nature of the pain meaning is a central issue in clinical practices attempting to modulate individual pain perceptions, there are also gains to be made during routine pain examinations for personalizing treatment based on the recognition of the specific distress it involves (fear, sense of threat, loss of control, anguish, disruption, helplessness, incompetence, and so on).

Studying the meaning an individual attributes to his own pain experience could help adapt the right medication and potentially reduce drug intake in a patient. The identification of the negative component associated with the pain may facilitate targeting the right resources available for confronting it. For example, a sense of loss for *phantom* limb pain shifting into a favorable regained sense of control, may provide relief and reduced nociception that coincides with medication reduction. It is *a conceptual reorganization using meaning*, comparable to the perceptual reorganization occurring in the human brain as suggested by Ramachandran and Hirstein with the mirror box, where the mirror projecting the existing hand creates the illusion that the amputated hand has been returned (1998). Several studies confirm a reduction of phantom limb pain using the mirror treatment (Chan et al. 2007), although other studies have found no evidence for change (Brodie et al. 2007), However, the procedure seems to re-establish a sense of personal control over the phantom limb (Flor and Turk 2011, p. 513). Similarly, as my colleague Dr. Jean-Marc Benhaiem proposes in his hypnotic practice, in encouraging the patient to become aware of the sense he attributes to his pain, the patient can be engaged in thinking that his amputated leg is not a *loss* but simply an earlier *restitution* of a part of the body that would anyway be given back when the time comes. A change in the meaning associated with the vivid sensation of the missing limb when moving from loss to restitution can attenuate the sense of deprivation and facilitate the phase of mourning, so essential for better coping with the pain experience.

Looking back, the concept of meaning appears in the pain literature from its very early days. In his seminal work, anesthesiologist Henry Beecher emphasized the relation between the meaning of the wound and the pain experienced in war casualties, demonstrating that "the intensity of suffering is largely determined by what the pain means to the patient" (1956). The field indeed followed up with several standardized methods categorizing the various pain meanings, as with the display of pain descriptors in the McGill Pain Questionnaire estimating the quality and intensity of the pain experienced (Mehack and Torgerson 1971; Melzack 1975), or with the measurement procedure employing the Multi-Dimensional Scaling (MDS) (Clark et al. 1989). The field recognized the need to acknowledge the influence of meanings for understanding patients (Morris 1991, 2010, 2011; Arntz and Claassens 2004; Price and Barrell 2012; Thacker and Moseley 2012). However, this inquiry was not consistently integrated into the operant management of pain. The various MDS models, for example, were based on the idea that individual differences are important and can be structured mathematically to expose the individual perspectives yielded in verbal descriptors about pain and suffering. These procedures had methodological limitations that did not allow the capture of all the aspects, in particular those reflecting excruciating and unbearable pain. As mentioned earlier, we recently validated these more enhanced aspects under the third measurable dimension of pain-related suffering after having demonstrated that both pain and suffering are objectively measurable phenomena. At the same time, I have reason to believe that the challenge of analysing pain meanings is not only methodological and cannot resolve by using one global approach to uncover the overall descriptors of global pain in individual patients. Several issues bear on the topic.

3 The Inexhaustible Account of Meanings

One issue concerns the misleading ambition to obtain an exhaustive picture of pain without considering its manifold representations. This consideration requires a continuous revision of emerging meanings, either due to multi-dimensional profile of pain or, to the fact that the perception of pain evolves depending on its application within a context and in a given time frame (Moseley and Arntz 2007). We can assess pain, but not completely, getting closer and closer to it, by unravelling its transitory meanings without expecting, however, to obtain a finite list of qualifiers. In this respect, the program of identifying utterances in an exhaustive and finite way is doomed to fail because "meanings", as the American philosopher Hilary Putnam says, “are not objects in a museum” (1988, p. 119). The meaning of a concept may evolve as time passes by, so even though the term maintains an identity that carries on a core invariant (allowing to identify pain as being pain), its representations are not necessarily identical, stored as locked forms, but accumulate insights that add new layers to the former conceptual attributions. Putnam speaks, in this respect, of “enough continuity” that is kept “through change”, explaining the elasticity of a significance undergoing transformations by arguing that “meanings have an identity through time but no essence” (p. 11). The meaning of pain is therefore never fixed. Moreover, the challenge in assessing pain consists in finding a way to process the modulations of the meanings associated with this lived phenomenon. This is particularly relevant to conditions becoming chronic because in these circumstances, pain is often first thought of as a burden requiring strength and adaptable coping strategies on the way to recovery, before turning into a permanent condition representing a forever lasting, defeating threat.

The other alternative found in existing paradigms to this all-encompassing classification plan, consists in proposing a reductive account of pain meanings composed of *fundamental* features. But here again, the principle reason why a finite list falls short of portraying pain remains. According to Price and Barrell, “although the particulars [of meanings] are likely to differ radically across chronic pain patients, it is likely that they experience at least a partial commonality of meanings. If that is true, then it should be possible to assess their presence and perhaps even measure their magnitudes. A scientific analysis of meanings in studies of pain and suffering would be helpful in this regard” (2012, p. 179). The ability to reflect on the relevant range of meanings touches upon the requirement to obtain a reliable picture of the pain experience based on a commonality of meanings or similarity judgments which assure that the information is consistent with other cases when passing from the personal (subjective) to the general and shared meaning (objective). But in further proposing, following Price and Barrell (2012), three underlying fundamental meanings associated with pain-related suffering (interruption of life activities, difficulty to endure and concern for the future), other significances that do not fit into this classification are discarded and lost.

In short, the problem with these two positions—the all-encompassing and the reductive—is not so much a matter of finding the proper method to faithfully compute all possible pain and suffering meanings. The problem is that the interpretation of pain and related-suffering has no purely formal or a priori knowledge of the pain qualifiers to rely upon. If we are to understand pain and suffering in order to clinically treat both, the standardized quest should admit to the conceptual pluralism of pain meanings within a formal semantic framework while equally accepting the emergence of *unexpected and contextually bound* meanings that no global structure can predict (Karoly and Jensen 2013, p. 5; Bustan et al. under review). A better understanding of the subjective or personal aspect of pain can lead to better treatment. This might seem obvious but the methodological challenge of formalizing such *intuitive matter* is considerable and can only be obtained by recognizing personal meanings according to their *actual use*. Philosophically, this approach follows a long tradition that began with Wittgenstein’s declaration in

Philosophical Investigations stating that ‘meaning is use’ (1953 §43, 61). This claim has become a rule of thumb for linguistics and analytic philosophers (Putnam 1988, p. 113–120), implying that the same phenomenon can be described in many different ways depending on how we employ the term that expresses it. We can interpret pain as either excruciating or pleasurable, following its context and form of occurrence (sexuality/torture/illness), which demonstrates the immense epistemological gap created by the possible uses of the same word. At first, this rule may seem dynamic enough for obtaining a formal system of meanings, integrating the variety of pain descriptors with the different uses coming together to forge a concept. Yet this idea of use does not convey a purely linguistic construction that could lead to an overall categorization based on the causal relations of sensory, affective and cognitive properties evoked in the patient’s statements. For example, the semantic construction ‘a person directing others and exercising a high degree of influence over them’ refers to a leader and ‘a flying animal that is also covered with feathers’ to a bird. But, the descriptive statement “a sickening and miserable sensation of malaise” does not necessarily invoke or define pain even though it was computed as an item characterizing the second emotional dimension of pain (Clark et al. 1989).

When it comes to pain, the intuitive meaning of this private sensation obliges us to pay attention not only to “the practice of using it” in the language according to Wittgenstein (1966, p. 68), but also to its subjective account. Putnam explains that we no longer find with Wittgenstein a theory of causal relation of references (this is ascribed by that), with patterns that could facilitate, if I may add, the creation of a system of meanings to fit the enterprise of the scientific grid. He admits that “at one time, I myself had the hope that what Wittgenstein refers to as the use of words, or in this lecture as the technique of usage, could be completely surveyed and analyzed in a functionalist way; that is, that all the various referring uses of words could be neatly organized and depicted by something like a computer program” (1992, p. 166). Even with the flexible approach of meaning as use, a holistic or even functionalist account of meanings is not possible. The discussion, in fact, does not turn specifically around pain. Putnam rather speaks of interpreting private mysterious phenomena such as religious beliefs. He does not go into Wittgenstein’s famous and very frequently cited view regarding the obviousness of knowing we are in pain, which makes the phenomenon certainly meaningful to the individual but often obscure to others who cannot share his internal sensations (Wittgenstein 1953, §303, 317, 350). Due to its intimate nature, Wittgenstein argues, pain is difficult to interpret with certainty and translate into a logically consistent proposition that is understood by all. At the same time, the phenomenon does take on meanings and could be pointed at through its linguistic practice. “You learned the *concept* ‘pain’ when you learned language”, writes Wittgenstein (1953, §384), since having pain does not mean you acquire the concept of pain. It is necessary to pass through the mediation of using it in the language (public and shared, not a private one) to assure its understanding and communication.

Going back to the difficulty in obtaining the desired network of pain meanings because of its subjective and I would add intuitive character, Putnam demonstrates the novelty of this rule of thumb when assimilated to a game. Wittgenstein, he explains, “speaks of games as forming a family, as having a family resemblance, and he also uses the metaphor of a rope. The rope is made up of fibers, but there is no fiber running the length of the whole rope. There are similarities between one game and another, but there is no one similarity between all games” (1992, p. 167). In applying this key notion of family-resemblance, we may recognize different fibers (neuropathic, nerve or muscular pain conditions) running through the metaphoric rope of pain, revealing overlapping similarities (it is sore, it is excruciating) all referring to one single lived phenomenon. The meaning game therefore consists in looking for the resemblance uniting all the family members (the various pain conditions) while acknowledging their distinctive features (pinching, drilling, stabbing). This does not imply that the discrepancies in referring to pain are not real or true and should be disregarded in virtue of assembling similarities, but that altogether they form the concept of pain in an inexhaustible manner. None runs consistently through the full length of the rope. Expressing pain is therefore a never-ending game of perception and interpretation, where neither simply having it, nor inferring it from other sentences could assure a complete understanding of its evolving meaning.

4 The Dilemma: Enquiring Directly or Indirectly About a Patient’s Pain and Suffering

Along the same line, a second controversial issue regards choosing an implicit versus explicit approach for obtaining the clearest indications of pain and suffering, while keeping a necessary distance in order to avoid eliciting irrelevant responses. This is precisely the difficulty we encountered in the course of our ongoing development of the pain-related suffering questionnaire for chronic pain patients, aimed at assessing the impact of pain on all aspects of life eliciting suffering. The questionnaire is particularly relevant here because, as I said earlier, the underlying premise of integrating suffering in pain evaluation assumes that it could encompass emotional and cognitive qualities of pain, which the two traditionally evaluated dimensions of intensity and unpleasantness do not fully embody. The conceptual scheme of this third dimension refers to strong meanings such as misery, desperation or urgency (Melzack and Wall 1983) that are constitutive parts of acute and chronic pain but which the other two dimensions cannot convey. Sullivan and Ballantyne offer a similar argument in a recent overview (2016), advocating that suffering is more related to the meaning of pain than to its intensity and should therefore be included in chronic pain assessment, thus giving rise to numerous reactions in a scientific-clinical world still very much taken by the practice of numerically measuring the single dimension of the pain intensity (Okkels et al. 2016).

In the process of developing a questionnaire, a basic requirement for data collection consists in avoiding any effect of the investigators on the patients’ response to prevent biasing their pain and suffering behavior. Armed with this rule of method, the dilemma however remains, whether a direct approach is the most appropriate for understanding the state of the patient or is it rather an indirect gathering of information, as I am about to demonstrate, that may best represent individual pain and suffering. Eric Cassell, the American physician, has been leading a line of direct approach, "asking whether the patient is suffering and why. Even though patients often do not know that they are suffering, they must be questioned directly: 'are you suffering?' 'I know you have pain, but are there things that are even worse than just the pain?' 'Are you frightened by all this?' 'What exactly are you frightened of?' 'What do you worry (are afraid) is going to happen to you?' 'What is the worst thing about all this?' Once asked, patients have to be given the time to answer. The questions are purposely somewhat vague; they tell patients that they have permission to talk about things that usually no one wanted to hear before, and they do not specify what answers are expected" (1999). In his writings and especially in his canonical book *The Nature of Suffering and the Goals of Medicine* (1991), Cassell deplores the silence around the suffering of patients by doctors who feel uncomfortable asking these questions, unable to free themselves sufficiently for dealing flexibly with these concerns since they are afraid of lacking the capacity to provide the proper relief. His call for a change in attitude among physicians aims at recognizing the importance of personal expression and the meanings patients attribute to their experience so that caregivers can see the person behind the pain, beyond the physiologic mechanisms of the body or the disease (1991, p. xv).

However, clinicians who intentionally hold back from asking such direct questions consider that the best way to approach these sensitive matters is by loosening the bond between the pain condition and the consequent suffering. They claim that doctors are never disinterested by the patients' subjective experience and cannot maintain a cold look, remote from the obvious, apparent suffering. At the same time, directly asking a patient if he suffers is a mistake since the real challenge consists in trying to explore all the content and dimensions of suffering and its specificity for each person in order to detect particular patterns that the patient himself may not even consider. In addition, the risk of labeling what we seek to discover may inevitably lead the patient to respond to the questions in an inferred manner. An attitude that is discrediting and which adds up to deligitimizing pain patients who are often not taken seriously by non-pain specialists, thus developing a tendency to compromise the accuracy of their accounts in desperation for a diagnosis and a recognition of their pathology. Response bias in pain presentation is thus a complex matter (Robinson et al. 1997). There is always a hidden gain in a patient narrative, even unintentional. Bringing us back to Beecher, who observed, in his work at the Anzio Beachhead during the Second World War and at the Massachusetts General Hospital, the difference of the meaning severely wounded soldiers attached to their wound and concomitant pain sensations compared with postsurgical patients clearly stemmed from its relation to a potential evacuation from the battle field (1956). To settle the risk of resulting bias inducing a spectrum of unrelated physical or psychological qualifiers, a suggestion that is more in the spirit of meaning acquisition seeking a high degree of internal validity would consist of *adapting indirect measures all along*.

Regarding questionnaire development, the dilemma of using a direct versus an indirect approach for inquiring about pain and related-suffering involves integrating the term "suffering" into the questionnaire instructions or in the evaluation tool versus no mention of the targeted notion whatsoever. Identifying the level and nature of suffering may either consist in directly asking the responder to rate their suffering experience ("Please indicate to what extent you may be *suffering* if", for example, "the pain makes you feelangry/helpless/annoyed") or else collect the information on suffering in an implicit manner through a set of attributes coming together to reflect the subjective experience ("Do you have the impression that", for example, "the pain makes you feel angry/helpless/annoyed?"). Alternatively, the focus could also shift to introducing the term "suffering" in the measurement tool of the scale as we have done in our psychophysical studies (Bustan et al. 2015). Using a direct approach, we asked the participants to rate the Intensity, Unpleasantness and Suffering in response to the noxious stimuli using, for example, endpoints on visual analog scales (VAS) ranging from no pain, unpleasantness or suffering to extreme pain, unpleasantness or suffering. To ensure participants based the pain evaluation on their own pain and related-suffering concepts and representations, no previous definitions were given for the respective parameters.

Those who may, however, disagree with this direct approach warn against the use of a suffering scale to denote what we wish to assess, arguing that such explicit articulation might in itself affect the reliability of the answers. Instead, the picture of suffering is supposed to emerge from the sense provided by the items (expressions) chosen by the participants, unraveled by the various qualifiers that form a comprehensive perspective of this investigated phenomenon. And indeed, in the majority of cases, questions about pain states in the numerous evaluation instruments adapt the indirect approach as, for example, in The Pain Catastrophizing Scale (Sullivan et al. 1995), the role of perceived injustice in the experience of chronic pain questionnaire (Sullivan et al. 2008), and the Hospital Anxiety and Depression Scale (Zigmond and Snaith 1983).

This standard indirect approach, not only to questionnaire development, cannot however prevent us from wondering: "Can we obtain a more accurate picture of pain-suffering by compelling the individual attention to look at it directly?" This view supposes that knowing one's pain is intrinsic to the pain experience and could serve its understanding by others. It also insists on avoiding usurping the patient's authority to judge their suffering. Exceptionally, if a person is alexithymic and is thus unaware of his inner feelings [a trait comorbid with enhanced pain (Baudic et al. 2016)], detecting his suffering based on questions requiring him to distinguish and appreciate emotions and cognitions may be challenging. But in the majority of cases, introspection on pain and suffering assures exposure to their specific *mode of being* in a person. The return to self creates a proximity that allows for a literal expression without approximation. It opens the way for a clear articulation of suffering without having to derive it from *referring senses* in sentences that neither pronounce nor intentionally designate it. In addition, unlike the descriptors collected implicitly, direct enquiries do not require to make a detour by computing suffering as supervening on the various pain manifestations and no distance must be kept for evaluating the situation in an impersonal and supposedly more objective way.

Clearly, the suspicion regarding directly collected testimonies weighs not only on the intentions behind these reports, as mentioned earlier with the battlefield example, but also on their impossibility to exhaust all possible aspects, especially those that the individual may not admit to himself. Yet, what is at stake in this process of evaluation is not only epistemological, confronting scientific and philosophical stances on the question of how to best know these human conditions, nor is it simply methodological, seeking the most viable and effective approach to engage in the inquiry of deciphering the pain experience. The true difficulty with evaluating human pain and suffering in clinical circumstances concerns the need to expose how these phenomena appear in subjectivity without further hurting the sensitive individual when trying to recover maximal information. The view of suffering in pain is illuminating, but the possibility of penetrating this experience depends on whether a person has or has not integrated their chronicity, amputation or illness as part of their lived reality so the exposure to its meanings and consequences can be addressed. Admitting that the pain is part of me, of the person I have become, allows the digging into the open wound in search for personal senses of the agony and despair the subject would otherwise tend to dissimulate. Self-consciousness requires assuming one's own condition and coming to terms with the fact that pain is part of a daily reality. It allows describing a relationship with what inevitably coincides and is inseparable from my impoverished self. In this respect, a standardized approach looking for one objective tool to assess every patient on an equal basis might not be advisable as a normative rule. This thus raises the third possibility of using a direct (deliberative) analysis of pain-related suffering meanings for those who have fully integrated their illness but adopt a more indirect (evocative) form of evaluation for those who have not yet fully assumed their condition and who are therefore unable to report about what remains *ungraspable* for them. This point is stressed throughout Wittgenstein's argument that knowing I am having pain does not mean I know the pain, to which I would add: and that I could actually interpret it for explanatory purposes.

5 Two Types of Meanings for Deciphering Pain and Suffering

The third and last issue challenging the study of meanings of pain and suffering concerns the assumption that these phenomena should be thought of as underlined by two very different types of meanings. Together they illuminate the individual experience, thus requiring investigations to unravel both aspects. With respect to the aforementioned paradox of pain, the major contribution of the enquiry about both meaning types consists in filling the gap created by the invisible and thus imperceptible character of pain, making sense of an experience announced by an obvious physical event that may be missing a perceptible substance. Thus, despite the great confusion caused by the possibility of lacking a pictorial representation of pain (unlike the visible tumor), studying its meaning can provide a conceptual equivalence, a content matter, for transcribing both the felt sensation and the accompanying negative emotional-cognitive load. This process involves two types of meanings unfolded in the expression of pain and related-suffering:

The first and more *objective* type of ‘meaning as elucidation’, evokes the qualities of pain as symptom descriptors thus answering the requirement to provide a matter-of-fact knowledge that may be objectively evaluated. It can be acquired by identifying the specific qualities of the pain (continuous, intermittent, burning, sharp, cramping, surface vs. deep pain etc.) and the individual concept of suffering (for example, quoting a patient: “Suffering is to feel hurt, it hurts you, incapacitates your body and keeps you from living normally, and even if you have other things going for you, you cannot”). This first type transcribes the nature and reality of the phenomena according to the particular way a person expresses them (their mode of presentation). Typically, they are collected, albeit for the suffering aspect, by generic pain questionnaires such as the McGill Pain Questionnaire (MPQ) (Melzack 1975, 1983), the Neuropathic Pain Scale (NPS) (Galer and Jensen 1997) and the Multidimensional Pain Scaling (Clark et al. 1989).

The second and more *personal* form of ‘implied meaning’ reflects the internal value a person ascribes to his lived pain (annihilating, threatening, diminishing) and suffering (for example, quoting the same patient: “I suffer because of my health problems. This is not a mental suffering, rather physical suffering because it prevents me from carrying out my plans”). The latter meaning type cannot be substituted for the former as they are essentially different. If rigorously investigated, the notion of ‘implied meaning’ does not simply add another variable to the already complex elucidation of these phenomena. Rather, by expanding the examination of pain against the typology of symptoms and behaviors to include *subtle nuances* and *personal implications*, we may obtain precise information that is more compatible with the individual mode of experiencing pain and related-suffering. Thus, we are not simply speaking here of interpreting the aversive character of pain for unraveling its objective identity (meaning as elucidation), but of discovering the implied meaning it carries for oneself in life according to personal aspirations, conceptions and values. This may be accounted for when dealing with *what matters most for oneself* in the pain experience, exposing its singularity for the individual. For example, for a 50 years old patient I interviewed with neuropathic chronic pain eliciting permanent sensations of burning in her hands and a loss of equilibrium, it was—surprisingly enough considering the permanent burning pain—rather her declined sense of femininity that was repeatedly reported as determinant:

> I walk like someone who has been drinking. As if I have boots full of mud, like a cosmonaut. Even now. I lost my femininity because I cannot put high heels. Even with earrings, I drop them every time. Putting makeup lasts for hours. When I touch wool, it burns, as if I have no flesh on the skin. When I try to remove the Tampax, it is sometimes impossible. It burns me constantly, I do not feel my hands or the things that I touch. With my feet it is the same. I want to jump from a building. It lasts for 3 years now.

She adds, replying to my questions whether she considers herself as a person who suffers and what type of suffering is associated with her experience:

> I just told you, I am suffering. Emotionally, I lost my femininity, it is so bad one feels like crying all the time. But who can stand this physically, it is like I have two irons, I cannot stand straight and I have to force myself to do everything. I struggle. You see. I want to sleep because I cannot stand. Mentally, one suffers so much, everything is distorted by the disease. Here I am in front of you, I feel like in a fog and I feel that everything is wrong, I'm not here. As if I'm not here. I'm exhausted, I do not know what to do with my hands and instead of saying hell to everyone, I smile even though I am suffering. […] I fight against an evil, evil.

Thus, the first elucidation phase targets the objective qualifiers (burning, imbalance) and the way pain or suffering exhibit themselves for a more refined diagnosis of the condition. The second phase of implied meanings can teach us what really bothers the patient, thus providing relief by recognizing the obsessing burden (loss of femininity) and then working on reducing its impact by giving a new and more rewarding meaning. While working with chronic pain patients, I have noticed how important it is to look into both meaning forms. The first form can be said to be more 'rigid', often retaining the same significance across time while the second form varies from occasion to occasion according to the evolution of the illness and the personal situation. Thus, even if the incapacitating sense of burning pain (meaning 1) can be a dominant attribute for neuropathic chronic pain, it can be accounted for as either diminishing (meaning 2), annihilating (meaning 2) or rather manageable (meaning 2), depending on the patient and his condition.

Yet, the problem is that there are a few attempts to compute or categorize these meanings in the literature, either resulting in associating them with the first form of meaning as elucidation or, more rarely with the second, but not with both and not in a distinctive way. The only exception is Eric Cassell who raised the idea of using meaning to better understand patients over thirty years ago (Cassell 1991). Unjustly denoting the "sloppy" work of philosophers and in particular philosophers of language who define the term meaning in 16 different ways (philosophy like science evolves and moves forward to integrate new perspectives), he than selectively assigns meanings to the two categories of significance ("what something is") and importance ("contains the value element of meaning") (1991, p. 232). There is, however, no indication in his writings of how to apply this distinction *consistently*:

> "Another aspect essential to an understanding of the suffering of sick persons is the relation of meaning to the way illness is experienced. The word 'meaning'", Cassell explains in a summary article, "is used here in two senses. In the first, to mean is to signify, to imply. Pain in the chest may imply heart disease. We also say that we know what something means when we know how important it is. The importance of things is always personal and individual, even though meaning in this sense may be shared by others or by society as a whole. What something signifies and how important it is relative to the whole array of a person's concerns contribute to its personal meaning. 'Belief' is another word for that

> aspect of meaning concerned with implications, and “value” concerns the degree of importance to a particular person” (Cassell 1982).

Cassell’s inspiring insight of meaning as importance is similar to the earlier discussed second and personal form of “implied meaning”. But his claim that the basic meaning form is understood as a reference, a sign referring to an illness or an expression assigning a content matter naming pain (“it hurts”) seems however too narrow. It treats meaning as an object, assembling a standardized set that constitutes a sort of *inventory* of the pain properties, symptoms and correlated states. This indeed assures, as the physician points out, better identifiers for predicting the disease and providing a morexis (1991, p. 264), especially for pain patients who go through a myriad of physicians and unnecessary medical interventions, often hearing that they do not have a real disease, until a pain specialist finally recognizes their pathology.

At the same time, this first definition of Cassell closes the canon on the advantages of meaning as use, dismissing the possibility that the meaning of the pain complaint is not fixed, or prescribed, or predicative, but rather remains influenced by a sway of changing contextual factors, the way we employ words in the individual lifeworld. Interestingly, Cassell indeed admits to this point: “The kind of meaning that is the basis of this chapter is less stable, it may change from moment to moment as events, circumstances, utterances” (1991, p. 232). But the pattern he eventually adopts for interpreting the discourse of the patient relies on an ontological rule (“what is x”). I tend to think that this misconception comes from the tendency of the medical world to think of itself as universal, adopting a globally standardized approach applicable to all, even with meanings. Yet, we cannot describe pain meanings based on an open and formal system governed by the investigation of the invariants across conceptual changes (the definable thing depicting pain), when what we also seek to expose is the ongoing, situational and personal sense of the pain experience.

To recapitulate this third and last issue: pain meanings can be distinguished if we look attentively enough and acknowledge that there is something more than the scientific list of signs to account for, that they are dynamic and not fixed entities. The consideration of “meaning as use” shows that meanings are not just a list of properties implying what something refers to, but also reflect different aspects for different people with the same pain conditions but with very distinct sets of values. Overall, since the point is to acquire a better conceptual equivalence of the private world of the pained and to include personal meanings that shed a light on the particular way pain plays a role in one’s story, we need to go beyond the set of nociceptive and affective features coming together in a specific but quite mechanistic configuration in the various classifications procedures. This is better studied with the second meaning form, seen against a system of beliefs and concepts as well as in reference to the actual attendance of the subject to the direct experience (Williamson et al. 2015).

6 A Tool for Elucidating Pain and Suffering

The challenge is therefore to find the best paradigm for naturally yielding both meaning types. This is claimed to appear in the experiential-phenomenological approach of Price and Aydede (2005, p. 243–273), and although constituting a good basis for work this approach was not operationalized for clinical use. As a theoretical and practical tool for deciphering pain and suffering meanings, it must answer the needs of a large population of patients. It must be attentive to language, context, associated concepts and beliefs as well as the different pain conditions of patients in order to allow for the individual characterisation of pain and suffering. The merging of philosophy with science and medicine here is therefore essential as it seeks to highlight suffering and pain *as a lived event* including their multiple facets (e.g., situation, emotional state and cognition). Focusing on *circumstantial and contextual manifestations* will help to explain variations in a patient's distressed reaction to a repeated illness, why individuals differ in their responses to an identical malady, or why similar traumatic events play different roles in the experience of social groups.

In *clinical settings*, patients commonly rate their pain employing numerical ratings or visual analogue scales that classify pain on a scale ranging from "no pain" to "worst pain imaginable". Such ratings are often accompanied by a request to describe what they sense using adjectives as "dull", accompanied by the request to describe what they sense in using adjectives such as "dull", "sharp", "crushing", "fearful" or "excruciating", allowing the physician to assess the level and the type of pain (e.g., McGill Pain Questionnaire, Melzack 1975). These scales, along with other pain assessment tools that also evaluate the impact of pain (e.g., West Haven-Yale Multidimensional Pain Inventory; Kerns et al. 1985), help to communicate and quantify the subjective experience of pain. However, these scales do not convey the patients' full emotional state and, especially, the suffering resulting from the turmoil a person is undergoing. Although it is common practice, patients are not always able to relate to these key measurements (especially with the numerical scales of 1–10), considering it reductionist and inadequate for describing their experience (Williams 1996; Wlliams et al. 2000).

Our attempts in the *laboratory* with healthy volunteers to identify physiological and objective markers for acute pain and its related-suffering by measuring transpiration, heart rate, respiration and facial muscle activity explained some of the variability of suffering. But when combined with the pain-suffering ratings and qualitative data from questionnaires as well as interviews, a substantial increment in understanding the suffering component was achieved (Bustan et al. under review). What we come to learn is that psychophysics, measuring the sensations that are associated to physical changes, gives us the possibility to quantify our perception, but it does not expose the meaning attached to the subjective experience. This brings us back to the initial view expressed, calling for a combination of approaches for elucidating pain and related-suffering.

Another challenge for the development of a meaning acquisition tool consists of overcoming the frequent confounding between pain and suffering (Ricoeur 1994).

In shedding light on the nature of all three pain dimensions (intensity, unpleasantness and suffering), important information can be gathered on their extent and nature as well as their utterances. I also tend to believe that a systematic collection of both meaning types may avoid the frequent mix between pain and suffering in clinical practice, as noted by Fordyce (1988), and recently demonstrated in a statistical review by Fishbain et al. (2015), who examined 740 references addressing the expression of suffering in various patients' cohorts (chronic pain, advanced and terminal cancer, hospice group).

The matter is important because it may allow us to tackle two critical—but frequently overlooked—difficulties faced by medical staff today: first, patients' overrating pain and second, the negative correlation between reported pain and suffering states. Regarding the first, I assume that difficulties in clinical pain assessment such as frequently observed extremely high pain ratings could be related to not explicitly documented levels of suffering that often remain confounded with pain intensity and unpleasantness. In reality, it is unlikely that values of 8 or 9 out of 10 for people who endure pain over months and years reflects only chronic pain intensity. In analysing the different senses attributed to the individual experience, the "suffering" component of chronic pain can be assessed independently in the clinical setting. This characterization may have an impact on patient management, especially regarding a second common clinical finding of two emblematic categories following treatment: those who continue to suffer despite a significant reduction in the intensity of the pain, and those in whom the intensity of the pain remains high but who report no suffering. In better differentiating pain and suffering in chronic patients experiencing their conditions as a way of life by learning the specific meaning attributed to each aspect, we not only untangle the confusion between pain and suffering, but also categorize their nature.

In closing, while the focus of the current chapter was to present the importance of meaning acquisition for better understanding and assessing the lived experience of pain and suffering, there is clearly a need for accumulating empirical evidence in order to establish it in the scientific discourse. Recent findings in our laboratory show (Bustan et al. under review) that the three dimensions of pain-related suffering (physical, emotional, mental-cognitive) are all expressed by healthy humans in conditions of acute pain in a way that depicts the characteristics of suffering as an episodic *feeling*. However, existential suffering over the life span requires a sustained *condition* that can only be observed in mental and physical chronic illnesses in the clinical setting. Due to the dual nature of suffering (a feeling and a condition), the lack of one universal essence or ultimate element that an individual can easily identify from its manifestation plays an important role in the puzzles these phenomena raise today in philosophy and in the science of consciousness. Although in admitting to continuous variations in meanings a person attributes to personal pain, a rigorous operationalized conceptualization of the pain-suffering mosaic could create a strong basis for future investigations, possibly contributing a major step towards personalized therapy.

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Chapter 8
An Interpretative Phenomenological Analysis of Non-Malignant Chronic Low Back Pain

Sherrill Snelgrove

Abstract The aim of this chapter is to introduce the use of interpretative phenomenological analysis (IPA) in relation to understanding the subjective realities of individuals with chronic low back pain (CLBP). The chapter will begin with an overview of how phenomenological approaches may be of particular value in understanding how pain appears to a patient and ultimately the embodied nature of patients' pain experiences. This will be followed by an introduction to IPA, its theoretical background and ontological and epistemological claims. The rationale for exploring subjective experiences of people with CLBP will be expounded and the main findings discussed in relation to clinical practice. The chapter will conclude by exploring the ways in which findings from an IPA study may contribute towards a First-Person Neuroscience of Pain.

1 Introduction

This chapter is concerned with the use of Interpretative Phenomenological Analysis (IPA) to gain understanding of subjective meanings of chronic low back pain (CLBP). IPA is a qualitative, phenomenological research methodology, which is gaining increasing popularity in health and illness research (Smith et al. 2009). The growth of first-person qualitative methodologies stems from a growing disillusionment with the application of traditional natural science criteria to understanding human behaviour, as it fails to capture the totality of human experience (Osborne 1994). From the 1980s on, the supremacy of logico-empirical methods has been challenged by qualitative methodologies that aim to offer understanding and representation of phenomena from the individuals' perspectives, rather than an emphasis on prediction, measurement, control (Denzin and Lincoln 1994; Osborne

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S. Snelgrove (✉)
College of Human and Health Sciences, Public Health,
Policy and Social Sciences, Swansea University,
Singleton Park, Swansea SA2 8PP, UK
e-mail: s.r.snelgrove@swansea.ac.uk

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1994). Qualitative research recognises a commitment to viewing events, actions, norms and values from the perspective of those being studied (Bryman 1988). Thus, qualitative research lends itself well to research where a deeper, more intimate understanding of the phenomenon is required, rather than accumulation of facts, as in standard scientific, quantitative research. Questions such as "how," "what," "who" and "why" are appropriate for qualitative research designs, and may uncover unexamined assumptions with greater sensitivity than quantitative research (Murphy et al. 1998; Coyle 2006). In the context of health research, qualitative approaches are recognized as profitable for understanding how people make sense of and respond to illness, and facilitates "knowing how" to help with health and illness issues (MacKay 2005; Rapport and Wainwright 2006; Charalambous et al. 2008). Such methods explore beliefs and actions that underpin illness behaviours and facilitates "knowing how" to help with health and illness issues (MacKay 2005; Rapport and Wainwright 2006).

Phenomenological methodologies such as IPA are a variant of qualitative research and assume a human science approach to social research. As such, phenomenological approaches are concerned with in-depth questions about the nature of individual experiences and of particular value as they enable deeper understanding of how a phenomenon such as illness appears to a patient in personal experience, and ultimately the embodied nature of patients' illness experiences (Osborne 1994; Rapport and Wainwright 2006). It is worthwhile mentioning that despite the perceived value of phenomenological methods, criticisms have been directed towards an inappropriate application of phenomenological philosophy, lack of rigor in the terminology and a preponderance of similar phenomenological research methods only distinguishable by name (Crotty 1996; Paley 1997; Rapport 2004; Brocki and Weardon 2006; Paley 2014). However, by prefacing subjectivity, phenomenology has an affinity with the contemporary focus on holistic person-centered care which the traditional, positivist approach of natural and social sciences have difficulty accommodating (Mulhall 1998, 1994; Reid et al. 2005). The aim of this chapter is to detail the nature of IPA, appraise its main tenets as understood by the author, followed by an illustration of IPA in practice in relation to longitudinal CLBP research and implications for a "first-person neuroscience of pain" (Thacker and Moseley 2012; van Rysewyk 2014).

2 Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) has been making its mark in applied psychologies across disciplines (Hefferon and Rodriguez 2011). IPA was initiated by the psychologist Smith (1991, 1996) who set out to establish psychology as both an experimental and experiential endeavour (Smith 1996, 2011 Smith et al. 2009). In contrast to traditional theory building in psychology, the purpose of IPA is to understand how people make sense of a major transition in their lives through exploring the individual's "lived-experience" relatively unhampered by a priori conceptual or scientific criteria (Smith 2004). Although IPA is a relatively new approach, it draws on long traditions of interpretative and descriptive phenomenology to justify its methods (Smith et al. 2009). IPA theorists argue that its main strengths lie in its strongly particular or ideographic focus, clearly set out epistemological underpinnings and detailed, analytical, yet flexible guidelines (Reid et al. 2005; Smith 2011).

IPA has been proposed as a useful methodology for research into complex, ambiguous and emotionally laden phenomena such as chronic pain (Smith and Osborn 2014). The duration of chronic pain and associated potential for accruing layers of psychosocial issues, maladaptive coping strategies and illness related challenges are amenable to phenomenological inquiries, which seek to offer understandings not necessarily captured by large-scale epidemiological designs. The use of standardized questionnaires may be valuable tools for measuring associations between variables and offer valuable explanations for the adaptation or otherwise of chronic pain, but offers disembodied, narrow and partial pictures of chronic low back pain (CLBP) experiences (Busch 2005). Similarly, as essential as pain neuroscience studies are for our understanding of pain, they alone cannot inform us of the feelings and meanings of pain as directly appreciated by persons within their daily lives. In comparison, the pain staking detailed approach of IPA and its close empathic attention to the individual's version of events has the potential to reveal what is important to the patient and a close understanding of pain experiences, which may warrant further examination and help generate further research hypotheses (Smith and Osborn 2014).

IPA can be applied to a wide range of scientific inquiries and may be considered as complimentary to existing traditional scientific methods, including traditional, randomized controlled trials, rather than a substitute (Shaw 2001). However, IPA is not without its critics with main concerns relating to a lack of evidenced reflexivity and transparency surrounding the interpretative process (Brocki and Weardon 2006; Reid et al. 2005) and a lack of scientific credibility; that is, the methodological flexibility of IPA precludes meeting scientific criterion of replication (Giorgi 2011). In response to this criticism, Shaw (2001) points out that by ensuring transparency an IPA study can offer other researchers opportunity for replication. Although later reviews of IPA studies evidenced good quality research (Smith 2011), criticisms continue to target IPA's descriptive and interpretative approach, suggesting that all description may be viewed as interpretation and mediated according to context (Pringle et al. 2011). In defence, IPA theorists explain that IPA draws on elements of hermeneutics and descriptive phenomenology rather than being determined by them Smith et al. (2009). Its philosophical base has also been berated for its simplistic interpretation of phenomenological philosophy with little connection to phenomenological philosophy (Giorgi 2011). However, Smith et al. (2009) and Smith (2010) argue that IPA has a strong theoretical base and describe IPA as a predominantly interpretative endeavour, whereby phenomenon are illuminated by careful description which fits the descriptive purpose of phenomenological research.

Critique is important to acknowledge and is part of the scientific endeavour for advancement of rigorous qualitative methods. Nevertheless, IPA stands up well to criticism and is proposed as an alternative, inductive method to develop further understanding and knowledge of psychological phenomena previously studied by a positivist approach (Pietkiewicz and Smith 2014). It is distinguishable from a simple, qualitative, thematic approach by its association with Husserlian and Heideggerian Phenomenology and Ideography, which offer further direction, depth, and justification (Smith et al. 2009; Pringle et al. 2011). We now turn to IPA's philosophical underpinnings and its key unit of analysis: lived experience.

3 IPA and Husserlian Philosophy

Husserl described phenomenology as "The science of objective phenomena of every kind or the science of consciousness" (1917/1983). Central to Husserl's work was his quest to understand fundamental meanings or genuine perceptions of the world in order to understand how we as subjects gain knowledge of objects that make up our world (Maggs-Rapport 2001; Todres 2004). The objects that Husserl referred to may be real entities or immanent objects such as fantasies, dreams, and thoughts; in short, anything that presents itself to consciousness (Maggs-Rapport 2001). Husserl was not interested in the objects themselves and their properties; rather, he was interested in what makes it what it is. In other words, his inquiries centred on seeking out raw cognitions. Husserl's aim was therefore to establish a rigorous description of a phenomenon "To see things as they really are," primarily through intuition to gain understanding of its essence or essential properties and the perceptual processes undertaken to achieve this purpose. Furthermore, Husserl contended that our view of the world is always intentional and we impose meaning on an object to allow us to sustain recognition of objects in the world. Husserl refers to the "life world" or our "lived experiences" as a starting point for an inquiry. Husserl went on to describe a process of phenomenological reduction (epochè) to obtain knowledge of the essence of an experience. This involved bracketing out or suspending preconceptions and exploring the phenomenon in its various forms until reaching the pure untainted essence of the phenomena.

IPA engages with Husserl's work by its intense and reflective examination of articulated meanings, enabled by… "transcending" pre-suppositions and biases by adopting the phenomenological attitude; "bracketing" or suspension of these a priori influences (see below) (Larkin et al. 2006, p. 105). However, in contrast to Husserl's lofty ambitions to establish essences, IPA recognises this may be an impossible task and is rather less ambitious, with the main intention to reveal personal, subjective meanings, rather than universal essences (Smith et al. 2009). IPA thus fits closely with a phenomenology that seeks to understand the individual's experience of the phenomenon rather than seeking the essence or objective reality of the nature of the phenomenon itself (Caelli 2001).

4 IPA and Heideggerian Philosophy

In contrast to the descriptive phenomenology of Husserl, Heidegger focused upon human consciousness in terms of interpretation rather than description. Heidegger (1927/1996) explained that hermeneutic phenomenology is the discovery of the significance of perceptions that individuals themselves have shaped by "dasein" or, "being-in the-world." This approach claims "us" as having an inseparable relationship with our world and the objects within it. From this understanding of "being in the world," Heidegger also challenged Husserl's idea that absolute understandings or meanings may be reached through phenomenological reduction (Chadderton 2004). Heidegger claimed it is not possible to find an absolute and definitive perception of a phenomenon, as we are always part of the world. We cannot attempt to find untainted cognitions or perceptions as we already exist in the world "a priori" to conscious knowing and our experiences of our world shape our perceptions. Heidegger suggests our subjective worlds do not hide inside us, but are communicated, located and observable, in our relatedness to some meaningful context. For Heidegger, the role of language and speech is where revelation of meaning or "unconcealed-ness" of "being" takes place. Heidegger also indicates consciousness is always intentional and directed towards an object. On the other hand, Heidegger suggests that we are so immersed in our everyday experiences and "being-in-the-world" that many of our everyday behaviours are conducted without thought until a change occurs and it becomes an emergent reality. An example would be our breathing, an involuntary action that does not have to be consciously directed; it is only when we have a chest infection or similar that we become conscious of our actions. Heidegger also indicated we do not know the world just through "pure ego and consciousness," but rather by being in the world and engaging in activities that may be a priori to conscious knowing (Maggs-Rapport 2001). Another example here would be the infant who acts within the world prior to gaining consciousness of being in the world.

IPA is mainly interpretative and engages with Heidegger by recognizing that it is impossible to gain a "pure" view of reality as we cannot ignore the influences of language, culture, expectations and assumptions of both the researcher and researched that are integral to being "persons-in-context" (Larkin et al. 2006, p. 105). From this perspective, IPA acknowledges that any analysis is an interpretation, even a double hermeneutic (participant and researcher) of an individual's experience (Smith 2004; Larkin et al. 2006). By drawing on Heidegger's ideas, IPA theorists suggest it is only through sensitive, open-ended questioning and a careful reflexive methodology, including entering an iterative process of interpretation of an individual's accounting (hermeneutic circle), that we can gain adequate access to an individual's inner world (Biggerstaff and Thompson 2008; Smith et al. 2009).

5 IPA and Ideography

The third philosophical strand of IPA is ideography (Smith et al. 2009). This is very different from the nomothetic and quantitative approach that is also used to study psychological responses. Whereas nomothetic inquiries are concerned with producing generalizable facts informed by pre-existing theories, an IPA study is concerned with developing detailed description and interpretation of particular experiences in a particular context (Smith et al. 2009). On the face of it, the ideographic nature of IPA is consonant with the particularistic aims of van Manen's interpretative phenomenology where the aim is to distinguish what is unique and what is the nature or essence of a phenomenon to better understand what a particular experience is like (van Manen 2001). In contrast, IPA takes its ideographic commitment further by analysing each case in a sample in-detail and even writing up a single case study to facilitate detailed examination of personal lived experience.

To achieve its ideographic aims, IPA studies are characterised by small samples that may range from a single case study to five to ten participants with a minority of IPA studies having larger samples such as 45 (Reid et al. 2005). Smith and Eatough (2006) argue sample size is dependent upon the degree of commitment to the ideographic level of analysis, pragmatic restrictions, the richness of the individual cases and how one wants to compare or contrast cases and a case by case approach. Such intimacy enables the researcher to focus on nuanced meanings and facilitates in-depth understandings of participants' unique perspective of their experiences (Smith et al. 2009). Although external generalisation is limited, the ideographic approach of IPA and use of individual case studies may draw attention to unusual and interesting cases which contribute to understanding of a phenomenon, and may be a logical avenue towards establishing universal laws (Warnock 1987; de Visser and Smith 2006). It may even lead towards meeting Husserl's concerns with establishing the invariant structures of a phenomenon by developing a critical mass of cases (Smith et al. 2009). Nevertheless, in light of recent emphasis upon large-scale evidence and powers of external generalisation (Leeman and Sandelowski 2012), key concerns remain about the contribution of a single case study to advance knowledge. However, honing the analysis down to "case" may have wider implications for health-related topics. For example, de Visser and Smith (2006) conducted a single case study of masculine identity and social behaviour and concluded by applying the findings to wider issues of men's health related behaviour and compliance. Valyaen et al. (2016) urge the implementation of single-case experimental designs to help customize and develop new cognitive-behavioral interventions for individuals with chronic pain aimed at reducing the suffering of this group.

6 Lived Experience

Lived experience is the main unit of analysis in IPA, and yet it is a curiously nebulous term and a relatively unchallenged one. Indeed, most intuitively understand the concept of experience in a general sense. Nonetheless, a more precise understanding is required to present a comprehensive and clear account of its relationship to the sense-making process that is typically explored in IPA. For instance, uncertainty arises about whether lived experience as used in IPA and indeed other phenomenological approaches is similar to a more common understanding of experience; furthermore, is it a pleonastic term, that is, do we need the prefix "lived," after all, is not all experience by default "lived." It is also ambiguous; oft used interchangeably with "lifeworld," which is also part of the phenomenology lexicon to signify "a sense of lived life," or "the participant's world as experienced rather than as conceptualised, categorised or theorised" Schaefer et al 1999.

In an attempt to clarify what is meant by lived experience in IPA, Smith et al. (2009) draw on the work of Dilthey (See Rickman 1976) to conceptualise lived experience as significant experiences being at the forefront of our consciousness. This conceptualisation is similarly exemplified by IPA's take on Heidegger's concept of "dasein" or being-in-the-world (1962/1927), where our everyday behaviours are conducted without thought until a change occurs and they become emergent reality. For example, where the ill person loses their automatic unreflective understanding of being in the world and recognises that their everyday experience has changed. IPA researchers are interested in "this experience" and individuals' reflections upon the significance of what is happening rather than experiences per se (Smith et al. 2009). The following section illustrates the use of IPA in pain research.

7 The Research

Chronic pain is challenging for sufferers and clinicians alike and is economically costly to serve users and providers (Phillips 2009; Gaskin and Richard 2011; Rafferty et al. 2012). It is regarded as pain which may be continuous, cyclical or intermittent with no direct link to a life threatening condition and persisting after the point that healing would be expected to be complete (3–6 months) (Royal College of Anaesthetists 2003). The following research was conducted in response to a plethora of epidemiological, cross sectional studies of CLBP which did not accommodate the personal meaning or physicality of pain within personal and social contexts and over a period of time (Busch 2005; Osborn and Smith 2006). By exploring patients' subjectivity, it was hoped further insight would be gained into the needs of sufferers, which would inform both practice and research.

The study aim was to explore the meaning of CLBP as described by the patients themselves and extend understanding of the dynamics of living with chronic pain. Data were obtained from semi-structured interviews with a purposeful sample of 10 patients recruited from a medically led chronic pain clinic in the United Kingdom (UK). The participants were followed up on three occasions at yearly intervals over two years by a single researcher. Successive interviews allowed opportunities to get to know the participants and capture different elements of the individuals' pain experiences in addition to any changes and consistencies they experienced. In keeping with many IPA studies, a semi-structured interview schedule was constructed from an initial reading of psychological literature on chronic pain and discussions with individuals with chronic pain but who were not included in the research. The interviews lasted 45–60 min each and were tape-recorded and then transcribed. Interviews are especially useful for examining sensitive issues and the privacy afforded by a well set up interview will often encourage the participant to open up and talk. This requires a suite of interview skills to gain "insider information." Smith and Osborn (2014) suggest… "adopting a phenomenological attitude or a combination of strong empathic engagement and highly attuned antennae to probe further into interesting and important aspects…." (p. 41) and provide a representation closely grounded in what the participants say (p. 41).

Data were analysed according to Smith and Osborn's guidelines (2003). The data were engaged with closely using an iterative approach to ensure authentic representation of the participants' experiences and illuminating novel findings in addition to examining transcripts for negative evidence or contradictory statements. Super-ordinate themes and their supporting sub-themes were identified from each participants' account and patterns established horizontally across cases for each set of interviews. This process was repeated at each time point and then vertically to identify any consistencies and changes over time for each participant (Snelgrove et al. 2011). The aim was to maintain an inductive approach throughout without prematurely imposing a priori theories upon the data (Smith 2004).

Both an empathetic and heuristic approach to the analysis was taken that included a focus upon describing the pain experience for the participants but also a more critical approach that focused upon nuances in the data, particularly metaphorical devices and the discourse used by the participants to "position" themselves rhetorically during the interview. In order to achieve this level of analysis, it was particularly important to read the whole of the script several times at least in order to keep close to the data and understand the rhetoric in the accounts. These different levels of analysis are not viewed as being separate; rather, the "positioning" of the participants is viewed as a connection to the meaning of the experience of pain for these individuals (Smith 2004; de Visser and Smith 2006). Validity and credibility were established by a detailed methods section, sufficient presentation of data, carefully written narrative, reflexivity and triangulation procedures that included validity check of the themes with an independent researcher (Osborn and Smith 1998).

A full account of the consistencies and inconsistencies of participants lived experiences are found in Snelgrove and Liossi (2009), Snelgrove et al. (2011). In this chapter a sample of the participants accounts are presented which relate to their perceptions of unchanging lives and the intrusive nature of chronic pain, the ongoing challenges of immobility in their natural lives, changes to social roles and the daily struggle of managing CLBP. The accounts are illustrated by verbatim quotes that show how unrelieved pain can intrude into every sphere of participants' lives and that participants' beliefs about the nature of their pain relates to their management of pain.

8 The Constant, Intrusive, Painful Body

The pain was typically and repeatedly referred to as constant by the participants:

> I'm in pain constantly, every day of the week no matter how you position yourself-most people go to bed and just lie there and I can't do that. Nothing seems to work. I've tried Pilates and….. I've tried….can't put pressure on my back. I've tried different things; I've tried wheat pads that are no good [Sara, Interview 1].

The participants frequently prefaced the physicality of the pain; as pain experienced of and through the body; that is, embodied pain experiences. The sensory experiences of pain were a central feature of the accounts:

> I still have the same problem with my spine as I did in the beginning and it is a continual gripping feeling [Paul, Interview 2].

> I am in absolute agony, sweating with the pain and it is pressing down on my coccyx [Paula, Interview 3].

> You're never free of pain. I would love to have no pain just for a few hours, especially at night. It is dreadful. You are unable to go into bed and lie down like normal people and go to sleep [Eirlys, Interview 3].

Interestingly, any emotionality was positioned later on in the interviews or when participants were asked directly about their emotional well-being. For example, Don at interview two, intimates he has had more than enough of the pain:

There is never one day that you can say you take a tablet or you put this gel on and you can say that's nice, it's constantly there like and like I said some days you just think you've had enough.

The most commonly cited emotional responses were depression or a lowered mood as participants attempted to make sense of their pain with little resolution. However, participants' also referred to strong feelings of anger. For example, Paul is angry about his pain, which he regards as undeserved.

> I know I sound bitter but I did not ask for this curse upon my body, this living hell [Interview 3].

The pain, in this case, is represented as an undeserved punishment with Paul rejecting any culpability. According to Scarry (1987) the etymology of pain is poena or punishment, and it calls attention to a representation of pain as caused by agents external to oneself. As with Paul, participants reported a search for the meaning and cause of the pain. The male participants in particular expressed anger and frustration with the perceived disorganization of the health services and scepticism of health professionals.

> I got numerous letters saying I am on the waiting list and as I say, through temper I just rip them up. I've had numerous letters saying my name has been submitted to the list [Don: Interview 1. 'I hated Health Professionals telling me "Perhaps you have a low pain threshold." How could they measure the severity of pain I'm feeling? Bed rest was the treatment in the early years, but after trying physiotherapy it seems "there is nothing can be done" but to take medication and live with the problem [Paul: Interview 2].

Anger is a known consequence of frustration due to goal attainments being perceived to be blocked by pain Berkowitz and Harmon-Jones (2004). Whilst there is little information about the role of anger in the maintenance of chronic pain, anger has been found to be associated with catastrophising, a response strongly associated with amplifying negative pain perceptions and a predictor of depression and chronicity in pain populations (Berkowitz and Harmon-Jones 2004). Further studies show that frustration and anger are implicated in mental deconditioning or passivity that is observed in patients with chronic pain experiences. These emotions may override the original pain itself and contribute to maladaptive illness behaviours (Gatchel 1991; Pincus and Morley 2001).

These accounts present a picture of unrelieved and constant pain. The "painful body" is a prominent feature and challenges previous psychological studies that present CLBP as "disembodied experiences" (Osborn and Smith 2006). Participants strongly prefaced the physical pain with little initial and spontaneous reference to any emotional responses or social influences. Generally, any reference to negative emotional experiences were sequenced later on in the accounts or inadvertently referred to when describing very painful experiences. At first glance, this may be interpreted as a result of a focus on the sensory elements of the pain. However, this may also be part of a moral endeavour to establish the validity of their condition as a physical illness to establish authenticity for entry into the sick role (Kugelmann 1999).

> … 'according to the doctor …it was all in my head!' [Don Interview 2].

9 Unchanging Painful Lives and Fragmentation of Self

Participants spoke of pain inhibiting their activities so that they became observers of life rather than participating in life. There was a sense of lives standing still:

> My life is the same you know. All that changes are the seasons and the days. It is gradually getting worse. It is spreading to my knee, it is just not the pain it is the weird sensations, your legs become heavy and you got your knee grinding and clicking and you feel like your legs are three times the weight. It seems to be spreading you know the pain [Sara, Interview 2].

Sara's account typically indicated that her life was unchanging and accompanied by increasing and worsening pain. Sara's narrative is suggestive of a familiar and repetitive patterning of worsening pain, which contributed to perceptions of little change. Sara spoke of a sense of helplessness, the pain as an uncontrollable entity, feelings of heaviness and a weary observer of life. She represents the majority of participants whose accounts represented them as helpless onlookers as the pain invaded their bodies. This is also vividly illustrated by Mona:

> The pain is so severe it's like as if there's… I don't know have you seen that film alien? You know when that thing came out that's how my leg feels as if there's something in here and it wants to come out. I'm watching for it to burst open that's how bad the pain is [Interview 1].

A close inspection of the metaphor "pain as alien" demonstrates how participants perceived their pain as an external, threatening, object separate from a pain-free self (Snelgrove and Liossi 2009). This dualistic concept of self was present throughout the accounts and resonates with a Cartesian mind-body split. Such a subject-object distinction (self as subject and body as object) supports these accounts where participants distanced themselves from the pain and acted as detached observers of their own bodies. Osborn and Smith (2006) draw on the work of Vranken (1989) to explain that such data represent participants' efforts to protect their integrity by psychologically distancing themselves from the painful parts. From this perspective, pain is viewed as a "psychophysical dualism" (Vranken 1989, p. 442). An understanding of the participants' reports in this way indicates that for these participants' the accounts negated any suggestion of "acceptance" or engagement with the pain as conceptualised by McCracken et al. (1999). Rather, the participants are continually engaged in a psychological and physical battle with their "pain."

> Even when the painkillers take away that dragging pain away you got, its spreading to the joints in my knee…, my knees click and clack and my fingers do that [*demonstrates a movement]*, I'm clumsy, I can't do my daily tasks…I can't physically do it [Sara: Interview 1].

10 Changed and Problematic Relationship with the Environment

The participants' accounts of constant pain were accompanied by illustrations of a changed, problematic relationship with their everyday environment. The participants reported a repetitive and cyclical patterning of good and bad days that directed their daily activities.

> One day you feel okay the next day you feel bad [Sian, Interview 3].

However, there was little knowledge about what would trigger a bad day:

> And as I say some days I can't sit down on the toilet because some days the pain is in the cheeks of your bum sort of thing and well it's awful strange to explain it [Paul: Interview 1].

The onset of an episode of extreme pain was unpredictable and so to avoid this, any movement was deliberated and effortful even for the smallest task. All the participants continued to refer to adjusting one's body to minimise any pain on movement (Charmaz 1983). These protective behaviours and lack of spontaneity of movement fastened participants into a narrow range of activities to avoid pain. The physical limitations imposed by the pain meant that even basic movements such as sitting or getting up from a seating position required laborious efforts:

> I try and distract myself, I pull the jigsaw out and I will try to do some of that and I go down on my hands and knees and I bend over and because I am in that position I am all right. But then if I have to sit up, like if I have to go to the toilet, it is, wham, big time and perhaps I have no feeling at all in my back and I have to go to the wall and crawl up get up [Don: Interview 3].

11 Loss of Valued Roles and Changed Social Relationships

For all the participants, life with CLBP meant their social roles continued to be 'spoiled' because of an increasing loss of physical functioning and mobility. The participants continued to refer to "then" and "now" with little future orientation shown. Their descriptions indicated the degree of impairment caused by the pain and contributed to an overwhelming sense of loss of a previous, valued self and rejection of a present self:

> I cannot move furniture around now my daughter has to come around for that.
>
> Anything that is strenuous I cannot do. Ordinary vacuuming quietly, I do. I try to keep myself mobile. But the corners I cannot do [Sian, Interview 2].

Sian's sadness was evident as she spoke about an increasing inability to complete her housework and her growing dependence on her daughter. The mother had become the 'cared for' and the daughter "the carer." The corrosive nature of CLBP is illustrated by references to the increasing disruption of small daily tasks and which flagged up important changes in family roles and relationships. Increased dependency on participants' spouses led to strong emotional expressions in relation to loss of their role as the breadwinner.

> I have become the dependant instead of being the depended upon and this has affected me deeply [Paul, Interview 2].

The shame associated with loss of function and social roles has been previously reported (Smith and Osborn 2007) and helps understand how the physical limitations imposed by CLBP contribute to lowered self-esteem and frustration. At time three, Paul made further reference to his increasingly diminishing family role and described his shame and possible guilt as he watched his wife undertaking his responsibilities.

> It affects every part of your life and it affects all the family. It affects your sex life it affects every part of your life. I tell you what gets to me most is when I see my wife carrying the black bags out and I cannot do it; I go upstairs out of the way [Interview 3].

12 Loss of Social Life: Then and Now

Participants emphasized the difference between "then" and "now." These descriptions served as an index of the degree of impairment caused by the pain. Selectively remembered positive images were often evoked and compared with the present less favoured lives with little mention of any valued replacement.

> I used to be quite an active sports man. When I gave it up I started to follow them and even now they was at the final in X the other day and I thought I couldn't go in there just to stand there to watch the match as I would be constantly moving agitated and . . .so I got to the stage where I do not even feel like going to watch the rugby match [Don, Interview 2].

Don's account showed a typically developmental process of loss that was apparent across the data set. He described his transition from being an active sportsman to an onlooker, and then giving up altogether with an anticipated loss of any future.

13 Managing the Pain

Despite the inefficacy of treatments, for some participants there was a continued commitment to a biomedical paradigm, and biomechanical understandings of their pain. The power of the medical model was apparent as participants rejected any consideration of alternative therapies (Snelgrove and Liossi 2009). Paul likened his CLBP to a broken down car that could be "fixed":

> And all that time those people have seen me I feel like if it was a car with something wrong with it they would have found out how to fix it you know [Interview 3].

In keeping with a biomedical approach, medication was the main method of managing the pain for most of the participants. However, the medication was often inadequate and caused severe side effects that were viewed as troublesome as the pain itself:

> The problem is I'm on so much medication and of course I'm on morphine for the pain which means you get used to it and getting the dose increased. I try not to but of course you know if it doesn't work you take anything to try and stop the pain [Ahem], but that causes problems itself then that causes other problems so a vicious circle [Doris: Interview 2].

Despite the problems and inefficacy of the medication, any consideration of alternative therapies was often met with a negative response. For example, Paul rejected the offer of other non-medical therapies. He had been referred by the pain clinic doctor to a pain centre that offered therapeutic discussion sessions:

> I think it is held in the village of X. If it is a village hall where you go and have a cup of tea and talk about pain, what is the point? I can hardly sit here and talk to you (Paul: Interview 3).

The participants were more likely to use various personally derived, physical strategies in an attempt to relieve their pain. Participants attempted to distract themselves and learned to adopt certain positions to help functioning:

> The pain is there all the time but I think it's more so if I bend, if I stay vertical then I'm alright [Cara, Interview 2].

This restriction of movement and avoidance of certain postures implied participants often "lived around the pain" rather than "with the pain" by avoiding movements and in some cases any social activities that provoked pain or embarrassment (Borkan et al. 1995).

> However, if I got to go somewhere I get all tight about it. I went to…, and I had a tingle in my spine and I had to get away from the people. It is like a panic attack and once people start milling and I am afraid they will bump into me and that started to get me more panicky. I get panicky and I don't know why [Paul Interview 2].

Such avoidance behaviours led to an initial decrease in pain, yet it also precluded the possibility of developing any valued activities and restoring a valued sense of self. For example, Paul's resistance to any public outing was based upon an initial, adverse experience that fuelled his fear and reinforced further avoidance behaviours. The impact of this was a narrow existence and almost acrophobic lifestyle (Snelgrove et al. 2011). As with the CLBP participants in Osborn and Smith's (1998) study, there was a tension between the reality of coping with the chronic pain and the application of a primarily biomedical model to relieve the pain. This failure of the prescribed medication to fully relieve the pain when the pain was viewed as a biomechanical failure may have contributed to the participants' lack of a coherent understanding about their condition and the growing disenchantment with medical treatment.

14 Conclusion

The intimate and often harrowing accounts show how participants' lives were dominated by chronic low back pain and their constant endeavours to understand and manage it (Snelgrove et al. 2011). The participants attempted to make sense of their pain by perceiving it within a narrow paradigm of biomedical beliefs, a concomitant dependency on partially effective or even unsuccessful medication and medical treatments, and a narrow range of avoidant behavioural coping strategies.

Unfortunately, this served to perpetuate a comprehensive enmeshment of pain, illness and self-schemas as conceptualised by Pincus and Morley (2001) but also with a strong loss orientation.

15 Implications

By conducting an IPA of first-person data, we have gained a nuanced understanding of how people attempt to make sense of living with CLBP (Reid et al. 2005; Smith 2011). A purposeful, small sample has the advantage of enabling a detailed analysis of the data. Nevertheless, in keeping with qualitative research tenets a relatively small, purposeful sample indicates that any generalization of findings should be made cautiously with transferability and relevance in mind rather than positivist notions of generalizability (Smith et al. 2009). Although concerns remain about the status of small-scale qualitative studies in a world of "big data," there is increasing regard for the valuable and necessary contribution of a single case study approach to both theory and practice (Yardley 2008). Indeed, the strength of IPA lies in a reflective, in depth iterative and inductive approach facilitating unique perspectives that may be transferable to similar populations resonate, with other patient's experiences and contribute to theory building, clinical practice and knowledge. Rather than identifying an average statistic, the IPA data illustrates a range of individual responses about living with pain on a daily, momentary basis.

A main implication of this study was that it reinforced the need for "talking therapies" in the treatment of chronic pain. From the data participants' pain experiences were interpreted as being embedded in a predominantly biomedical model; where concordant pain beliefs limited their management of the pain to partially effective "medical only" treatments; rather than exploring alternative options such as talking therapies including Cognitive Behavioural Therapy (CBT) which has been used to successfully modify patient's responses and reduce disability (Vlaeyen et al. 1995; Morley et al. 2008). Furthermore, a first-person, qualitative approach to the study of pain may contribute to understanding why therapies may work or not work, but may also inform psychological studies that explore selective attention biases in pain. Inconsistent results from this line of research may be improved by initial robust qualitative data upon which to base further experimentation (Roelofs et al. 2004). Furthermore, our understanding of brain mechanisms may be improved by methodologically linking expressed pain feelings to neurobiological activity and provide a strategy by which to map brain data to descriptions of lived pain experiences and psychosocial morbidities (Benedetti et al. 2013; Robinson et al. 2013). IPA, with its emphasis on gaining rich, meaningful subjective data may be part of valuable, mixed-methods research designs by which to achieve a coherent and holistic approach towards researching chronic pain as a sensory, neurological and perceptual phenomenon (Thacker and Moseley 2012; van Rysewyk 2014).

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Chapter 9
Phenomenology of Chronic Pain: De-Personalization and Re-Personalization

Saulius Geniusas

Abstract This paper has four tasks. First, based on a phenomenology of personhood, it argues that the subject of chronic pain is not the body, conceived neurophysiologically, but the person, conceived phenomenologically. Secondly, it demonstrates that the processes of de-personalization and re-personalization make up the essential temporal structures of chronic pain experience. Thirdly, it offers an answer to one of the central objections raised against phenomenology of illness and pain, which suggests that phenomenology offers a solipsistic account of pain experience, which does not facilitate but impedes empathy and understanding. Fourthly, the paper maintains that the recognition of the de-personalizing and re-personalizing dimensions of chronic pain experience compel one to rethink some of the central distinctions entrenched in phenomenology of medicine, such as the distinction between organic and psychogenic pain, illness and disease or healing and curing. The paper concludes by addressing the therapeutic significance of dialogue.

1 Introduction

In what follows, I will understand phenomenology of pain as a form of pain research, which conceives of pain not as a neurological phenomenon, but as a lived-experience, and which aims to grasp the essence of this experience by following the methodological guidelines grounded in classical phenomenological principles.[1] By defining phenomenology of pain in such a manner, I depart from a widespread tendency to misidentify phenomenology as a form of introspection and

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[1] Here I rely on the essential principles of Husserl's phenomenology, and especially on how they are presented in Husserl (1983), §2–§4.

S. Geniusas (✉)
Department of Philosophy, Chinese University of Hong Kong,
4/F Fung King Hey Building, Shatin, NT, Hong Kong, SAR
e-mail: geniusas@cuhk.edu.hk

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to reduce this area of research to empirical descriptions of factual experiences. With the aim of revitalizing the phenomenological ambition to be an eidetic discipline, in the following investigation, I will defend the claim that the processes of de-personalization and re-personalization make up the essential temporal structures of chronic pain experience.[2] By defending such a claim, I will depart not only from those empirical accounts, which identify phenomenology with introspective psychology, but also from the dominant penchant in phenomenological literature on pain, which invites one to focus exclusively on pain's de-personalizing consequences. Indeed, while pain's de-personalizing effects have been repeatedly addressed in phenomenological studies of pain,[3] there is, to the best of my knowledge, not a single study, which thematized chronic pain as a process of re-personalization. I will argue that, so as to overcome this limitations, besides marking the subject's withdrawal from the common world, chronic pain also resettles the subject in a new world, which one now needs to inhabit. In short, my claim is that there is no chronic pain, which is not de-personalizing and re-personalizing.

Four introductory remarks are in place. First, there are different types of pain. In what follows, I will exclusively focus on chronic pain; namely, pain which persists for months or years, which extends beyond the expected period of tissue healing, and which refuses to be explained as a mere effect that follows from tissue damage. Secondly, the notion of pain is equivocal not only because there are different types of pain, but also because there are different sciences of pain, which conceptualize pain in significantly different ways. A neuroscientist understands pain as a neurochemical phenomenon; a psychologist, as a cognitive and emotive phenomenon; an anthropologist, as a socio-historical phenomenon. In the midst of these equivocations, phenomenology invites one to keep the established conceptions at arm's length and focus instead on how pain manifests itself not in someone else's, but in one's own personal experience. One is thereby invited to concede that the pre-scientific experience of pain is the very subject matter of diverse sciences of pain and that scientific determinations are meant to be nothing other than clarifications of pain experience. In my following analysis, I will understand chronic pain as an *aversive sensory feeling, which can only be given in first-hand experience, which can be (although need not be) triggered by tissue damage, and which must have three essential qualifications: it must be temporally extended, it must be localizable within the body, and it must be experienced indubitably*. Thirdly, I will

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[2] I do not claim that chronic pain is the only kind of de-personalizing and re-personalizing experience. Rather, to put the matter in those terms that Husserl employs in §3 of his *Ideas I*, chronic pain is a "particularization" (i.e., an instance) of a group of experiences (a group that also includes other experiences, such as depression and melancholia), whose *Eidos* consists of de-personalization and re-personalization.

[3] In this regard, see especially Scarry (1985). According to Scarry's central claim, while physical pain is inexpressible and "unmakes the world," the creation of verbal and material artifacts, which ultimately relies upon the powers of imagining, remakes the world.

focus only on pain as given from the first-person perspective. Fourthly, I will focus exclusively on human pain.

Within such a thematic framework, I will strive to accomplish seven goals. I will begin by subjecting the neurophysiological identification of the body as the subject of pain to a phenomenological critique. Secondly, with an eye on the phenomenological distinction between the lived-body and the physical body, I will argue that at the level of the body, chronic pain is to be conceived as the lived-body's protest against its "constitutive appropriation," i.e., the implicit and explicit sense it has been given in one's personal experience. Thirdly, I will contend that by enhancing phenomenology of the body with a phenomenology of personhood, one wins the insight that the subject of pain is not the body, conceived physiologically, but the person, conceived phenomenologically. Fourthly, I will argue that chronic pain is a de-personalizing experience in that it unsettles the fundamental relations that bind the person to his body, surroundings, others, and himself. Fifthly, I will argue that chronic pain is just as much a re-personalizing experience in that, due to its temporal nature, it forces the person to reconstitute those fundamental relations that pain disrupts. Sixthly, I will show how such a conception of chronic pain forces one to reconceptualise some entrenched distinctions in phenomenology of medicine: the distinction between psychogenic and organic pain as well as the illness/disease and healing/curing distinctions. Finally, I will conclude by addressing some further implications that are inscribed in the proposed phenomenology of chronic pain. The implications in question concern the presumably non-sharable nature of pain experience and the therapeutic significance of dialogue.

2 Can the Physiological Body be the Subject of Pain?

According to one of my claims, *the phenomenological concept of the person designates the subject of human pain, and more precisely, chronic pain*. Admittedly, this claim sounds trivial. Who else can the subject of human pain be, if not the person who has it? This claim, however, is set against one of the dominant approaches to chronic pain in medicine; namely, what Mariet Vrancken has labelled as the "somato-technical approach" (Vrancken 1989), or, what one could more appropriately call the exclusively neurophysiological approach, which identifies the brain as the location of pain, and which suggests that pain originates in the periphery, then travels through the pain pathways to the brain, until it is finally sensed in the brain as a copy of what took place in the periphery (cf. Thacker 2015). Supposedly, when a physician fails to identify an organic cause of pain, s/he must conclude that the patient's suffering is psychic, and that the patient is in need of a psychiatrist, not a physician.[4] In the framework of such an approach, to understand

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[4] Besides Vrancken's study, see Szasz (1975). Both provide a telling account of the reasons that motivate physicians to suggest to their patients that they visit psychiatrists. As a rule, these reasons

and treat pain, one must turn exclusively to the body, conceived as a system of chemical, electrical and mechanical functions, one must identify the neurophysiological causes that give rise to pain, and look for ways to eliminate their effects. Thus, according to the exclusively neurophysiological approach, the subject of pain is not the person, but the body, conceived neurophysiologically.[5]

Such a neurophysiological identification of the body as the subject of pain suffers from three fundamental problems. First, this approach is incoherent. The neurophysiological approach presupposes a mechanistic conception of the body. Yet, insofar as the body is conceived exclusively mechanistically, it cannot be conceived as the subject of any feelings; and if it is incapable of feeling, it is incapable of experiencing pain. Secondly, this approach proscribes both the recognition and the treatment of the so-called psychogenic pain—pain which does not derive from organic, but rather purely psychic causes.[6] If one begins with the assumption that the subject of pain is the neurophysiologically conceived body, one inevitably loses the capacity to recognize and treat psychogenic pain. Thirdly, this approach underestimates pain's deeper effects upon the person. FJJ Buytendijk emphasized this point especially strongly. Against Max Scheler, who in his *Formalism* maintained that pain is nothing other than a feeling-state and that therefore, the subject of pain is not the self (that is, the person) but the body, Buytendijk insisted that pain has its effects on the deepest levels of personality: "The more violent a pain, the deeper it penetrates, affecting not merely the 'body-self,' but our actual personality as well" (Buytendijk 1961, p. 114). More recently, Mick Thacker reiterated the significance of this insight when he wrote: "I remain unconvinced that brains are sufficient for pain…. I believe that the only entity sufficient for the experience and perception of pain is the person" (Thacker 2015, p. 3).

(Footnote 4 continued)

derive from the physician's failure to discover an organic cause of pain. Realizing this, patients commonly interpret such referrals as signs of the physician's disbelief that they are in pain (Szasz 1975, p. 92). This view is further corroborated by Arthur Kleinman as well as RA Hilbert, who suggest that "pain patients feel biomedical practitioners routinely delegitimize the experience of their illness, pressing them to believe that it is not real or, at least, not as serious as they fear it to be" (Kleinman 1994, p. 170).

[5] In phenomenological literature, James and Kevin Aho have recently emphasized this point: "in medical science the corporeal body is both de-contextualized and de-animated. Medical science does not treat persons as such; it deals with human organisms" (Aho and Aho 2009, p. 77). This point is further echoed by Alfred I. Tauber: "…we recognize that as the body is reduced to just so many materialistic parameters of measurement, the person inhabiting that body may be de-personalized, if not lost altogether" (Tauber 2002, p. 9).

[6] See Szasz (1975), pp. 93–99.

3 Chronic Pain as a Bodily Phenomenon

To return to Buytendijk, what exactly is the “body-self?” The bodily dimensions of chronic pain experience call for a more precise determination. It is one of my claims that the experience of pain, and especially chronic pain, is to be conceived as the body’s protest against the self. To clarify the meaning of this claim, it is necessary to briefly address the phenomenological distinction between *Leib* and *Körper.*

To think of the body as lived-body (*Leib*) is to thematize the body at the *pre-reflective* level of immediate experience. Following Husserl, I would like to provide this concept of the body with four fundamental determinations. First, the lived-body is the *zero point of orientation*: it is the *absolute here* to which the relative *here* and *there* relates. The lived-body is the perceptual organ of the experiencing consciousness. As Husserl puts it, “The ‘far’ is far from me, from my Body; the ‘to the right’ refers back to the right side of my Body…. I have all things over and against me; they are all ‘there’—with the exception of one and only one, namely the Body, which is always ‘here’” (Husserl 1989, p. 166). Secondly, the lived-body is *the organ of my will and the seat of free movement.*[7] “While extra-Bodily things are only moveable mechanically, the lived-body is “the *one and only Object* which, for the will of my pure Ego, is *moveable immediately and spontaneously*” (Husserl 1989, p. 159). A third central determination suggests that the lived-body is *the expression of the spirit*. “The Body is not only in general a thing but is indeed expression of the spirit and *is at once organ of the spirit*” (Husserl 1989, p. 102). Fourthly, Husserl also addresses the lived-body as the *bearer of localized sensations* (Husserl 1989, §36 and §40). It is the body that feels pains and pleasures, warmth and cold, tickles and irritations.

By contrast, to think of the body as physical body is to thematize it as the *reflective* level of experience. At this level, one understands the body (*Körper*) as an object extended in objective space and located in objective time. Interpreted as *Körper*, the body is a naturalistically conceived material thing and not a personalistically conceived animate organism (*Leib*). To be sure, my own physical body (*Körper*), for the simple reason that it is *mine*, is unlike any other object. Yet the *mineness* (*Jemeinigkeit*) of my physical body (*Körper*) already designates a modified (in Husserl’s words, *founded*) self-relation: in contrast to the lived-body (*Leib*), the physical body (*Körper*) is no longer the body that I am; it is the body that I *have*.

Drawing on Husserl’s analysis of bodily constitution, one could characterize chronic pain as the body’s inner protest against its constitutive appropriation. In this regard, four points require a special emphasis. First, although we feel pain in our lived-bodies, chronic pain no longer enables one to say that the lived-body is the *zero point of orientation*. In the usual flow of experience, the lived-body, while itself remaining non-thematic and non-objective, provides the self with contact with

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[7] While extra-Bodily things are only moveable mechanically, the lived-body is “the *one and only Object* which, for the will of my pure Ego, is *moveable immediately and spontaneously*” (Husserl 1989, p. 159).

all other material things. By contrast, the body-in-pain shows itself as a living wall, which blocks one's access to other objects of experience. Secondly, chronic pain brings into question the qualification of the lived-body as *the organ of my will and the seat of free movement*. Pain experience is *the lived-body's protest against the will*; it is its *resistance* that takes the form of freezing the lived-body's free movement,[8] chronic pain also renders questionable the qualification of the lived-body as the expression of the spirit. When a cancer patient asks the doctor to amputate his limb and thereby eliminate or at least alleviate his pain, it is hard to conceive of his body as an expression of what Husserl calls "the spiritual world." Fourthly, despite this threefold protest, the body-in-pain retains the sense of being the bearer of localized sensations. Such being the case, one can qualify chronic pain as the experience of the body's inner protest against the basic sense it has been given in one's personal experience.

4 A Blueprint of a Phenomenology of Personhood

Eric Cassell has argued that medical practice systematically suppresses what is specifically personal, and thus, at least in the framework that concerns health care, "we still do not know how to define a person" (Cassell 1978, p. 96). As we will soon see, without clarifying the notion of the person, one cannot determine the subject of pain. The regrettable situation of which Cassell speaks can be corrected by turning to Edmund Husserl's phenomenology; specifically, to the conception of the person he presents in *Ideas II*. According to Husserl, it is a matter of a category mistake to conceive of a person in a purely mechanistic way. To be a person is to be an embodied subject of cognitive, emotive, and practical acts. To be a person is to stand in an intentional relation to the surrounding world and in a communicative relation to others. These various acts that the person lives through build up the person's unique history, which up to a large degree determines the person's style of existence. This history, taken along with the cognitive, emotive, and practical acts, colours the subject's intentional relation to the world in a particular atmosphere, which *motivates* the person to project particular plans into the future.

It is important not to confuse motivation with causality. While causality rules over *nature*, motivation finds its place within the horizon of *understanding*. If, when I leave my apartment, I see dark clouds in the sky, I feel motivated to bring an umbrella with me, just as when I realize that I am running late for an important meeting, I feel motivated to catch a taxi. Motivation is a peculiar kind of non-mechanistic causality, which relies upon the person's capacity to discriminate between different possibilities, granting some more, others less weight. These

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[8] In this regard, with a reference to Heidegger's analysis of *Zuhandenheit*, one could liken the experience of pain to the lived-body's *unreadiness-to-hand*: just as a piece of equipment becomes noticeable when it no longer functions properly, so the lived-body becomes thematic when it is no longer an obedient servant of the will.

differentiations rely upon subjective expectations, and thus exclude objective necessity. Material things cannot choose to follow or not to follow mechanistic laws. By contrast, the person always remains free to choose certain plans over others as well as to engage in these rather than other activities. No matter how dark and heavy the clouds might be, I can always choose not to bring an umbrella with me; no matter how important the meeting, I might choose not to take a taxi. In short, a person is a subject of various cognitive, emotive and practical acts, as well as the subject of a unique history, which constitutes the subject's distinctive relation to the surrounding world and a distinctive communicative relation to others.

5 Chronic Pain as De-Personalization

It is my thesis that chronic pain emerges in the field of experience as a rupture at the very core of our personal existence. To determine this notion of pain as a rupture more precisely, it is important to distinguish between four characteristics.

First, chronic pain disrupts the usual relation between the self and the body. In the normal flow of experience, this relation is marked by the body's subservience to the self, yet chronic pain destabilizes this relation. And thus, patients suffering from chronic pain often experience their bodies with what the phenomenologically oriented anthropologist, Byron Good, has so appropriately called an "irrational sense of betrayal" (Good 1994a, p. 127): "I think it's against me, that I have an enemy," as some patients with chronic pain have proclaimed.[9] The body-in-pain is experienced as *paradoxical*: it certainly retains the sense of being *my own* body; and yet (as patients struggling with chronic pain so often point out), it has also become something alien, something that resists the self.

Secondly, by disrupting the usual relation between the self and the body, chronic pain also transforms the person's *self-relation*. It does this by taking away from the person the capacity to accomplish some of the most basic activities and by robbing the person of self-confidence and self-reliance. One can no longer confidently walk down the steps, carry a cup of coffee to the table, or shake someone's hand. Having lost self-confidence and self-reliance, one feels crippled.

Thirdly, chronic pain also disrupts the person's perceptual, affective, and conceptual relation to the world. Blepharitis blinds us, the migraine makes it hard to contemplate our thoughts; an asthma attack forces us to forget our affective relation to others. Chronic pain transforms the body into a living wall that stands between

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[9] Or as Brian—Byron J. Good's interviewee—puts it, "and then it goes back into my conflict about my body. Is it my body? Is it my thinking process that activates physical stresses? Or … is it the other way around?" (Good 1994b, p. 35) Consider also Gordon Stuart's, a thirty-three-year-old writer's, who is dying from cancer, observations: "The feeling there is something not me in me, an 'it, eating its way through the body. I am the creator of my own destruction. These cancer cells are me and yet not me. I am invaded by a killer…. Cancer makes us think of a lingering torture, a being eaten away from inside. And that is what it's been like for me" (Kleinman 1988, p. 148).

the self and the surrounding world: in the extreme case, the body-in-pain becomes the one and only perceptual, affective and conceptual object, whose sheer magnitude blocks the person's access to any other object.[10]

Fourthly, chronic pain unsettles the person's relation with others. First, one must stress the isolating nature of pain experience. Being in principle non-shareable, pain introduces a breach between the person in pain and everyone else. Secondly, the experience of pain lies at the limits of understanding. This point has been forcefully stressed in anthropological studies of chronic pain. As Arthur Kleinman has famously put it, "If there is a single experience shared by virtually all chronic pain patients it is that at some point those around them… come to question the authenticity of the patient's experience of pain" (Kleinman 1988, p. 57). Alternatively, in the words of Jean Jackson, "After a while, no-one believes you" (Jackson 1994, p. 138).[11] Thirdly, chronic pain renders *homo patiens* dependent upon others. Thus, the relation between the one in pain and others is fundamentally asymmetrical: the other—the very one who cannot understand me—is the only one who can help me overcome my pain.

In short, chronic pain is a rupture that unsettles four of our most fundamental relations: (1) the relation between the self and body, (2) the person's self-relation, (3) the relation between the self and the surrounding world, and (4) the relation between the self and others.[12] Pain is a de-personalizing experience, in these four fundamental ways.

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[10] See Sartre (1956), and especially the section "The Body as Being-For-Itself: Facticity" (pp. 404–445) and "The Third Ontological Dimension of the Body" (pp. 460–471).

[11] These references to A. Kleinman's J. Jackson's and B. Good's studies are meant to illustrate the philosophical fruitfulness of anthropological studies of pain. It is highly regrettable that to this day, neither the phenomenologically oriented anthropologists, nor the phenomenologically minded philosophers have shown interest in each other's works. In this regard, Katherine J. Morris' recent study (Morris 2013) is a noteworthy exception. This work reconstructs the main reasons that have led medical anthropology to consider phenomenologically relevant themes. This study also spells out the main phenomenologically resonant themes that have emerged from anthropological studies of pain.

[12] I readily admit that these four kinds of disturbance are not unique to the experience of pain; they also aptly characterize other forms of affliction, such as illness. Yet chronic pain does not affect the body the way illness does. *While illness affects the whole body* (and thus we would never say that our head, or our lower back is ill), *chronic pain is always located within the body* (and thus it is always our head or our lower back that is in pain). Due to its localizability, chronic pain marks the relation between the self and the body as profoundly and irreducibly paradoxical. One the one hand, the body in pain could be characterized as both subject and object. On the other hand, the body in pain could be further said to be both subservient and insubordinate to the self.

6 The Challenge of Solipsism

At this point, I would like to briefly turn to Tania Gergel's critique of the phenomenology of medicine, which equally applies to phenomenology of pain.[13] As Gergel sees it, one of the fundamental goals of the phenomenology of medicine is "to give an account and help us understand illness as it is experienced by the ill individuals themselves" (Gergel 2012, p. 1104). Yet, as Gergel sees it, the phenomenological emphasis on the disruptive effects of illness (as well as pain), does not facilitate, but rather impedes, the capacity to understand and relate either to illness, or to ill individuals. "Far from enabling empathy and understanding, if the true conception of illness resides in the ill individual's personal experience of the phenomena, we might well ask how it can ever be truly communicated and understood by another" (Gergel 2012, p. 1104). As Gergel sees it, this is not only a methodological difficulty that hinders phenomenological studies of illness (and pain); it also impedes phenomenology's central ambition to facilitate a dialogue between patients and healthcare practitioners. If illness is confined within the boundaries of experience, then we inevitably come to confront *the challenge of solipsism*: besides the subject of experience, the experience of illness turns out to be inaccessible to anyone else.

How legitimate is this critique? Does phenomenology truly maintain that the concept of illness *resides* in the ill individual's personal experience in such a way that it would elude interpersonal understanding? This is a highly misleading qualification of the phenomenological standpoint. The suggestion that the concept of illness *resides* in the experience of the patient is an instance of *psychologism*, which was the central target of Husserl's critique in his Prolegomena to the *Logical Investigations*. It would be much more appropriate to qualify the phenomenological perspective as a standpoint, which aims to ground the concepts of illness and pain in experience, yet not to bind them within personal experience. Among other things, this means that illness and pain are not reducible to the physiological conception of the mechanisms that underlie the organism's functioning. Rather, illness and pain are rooted in experience.

Gergel's (2012) characterization of phenomenology of illness (and pain) is a good illustration of the kind of widespread misinterpretation of phenomenology of pain that I mentioned at the beginning of this paper. Supposedly, the task of phenomenology of pain is that of offering an empirical description of the experiences pain-patients live through. This is far from the truth. The task of phenomenology of pain is no different from the task characteristic of any phenomenology. The task is to provide insight into what is essential about experience (in this particular case, pain experience). My claim that the concepts of pain and illness are grounded in experience suggests that particular experiences of illness constitute the phenomenal basis that underlies an eidetic description of the essential structures characteristic of pain and illness.

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[13] See Gergel (2012, pp. 1102–1109).

7 Chronic Pain as Re-Personalization

On the one hand, chronic pain de-personalizes the self in four fundamental ways. On the other hand—and this is the theme I want to address now—chronic pain is a deeply personal experience. Although Max Scheler famously called pain "death in miniature," there is a significant difference between the two. In contrast to death, chronic pain is something that one can and inevitably does respond. These responses to pain are constitutive in two different ways: they co-determine the feeling of pain; they also form the person one becomes. How shall I respond to pain? I cannot help, but must choose a way; and the way I will choose will not only co-determine my experience of pain, but also from the person I will be.

Arguably, the responses to pain are essentially of three different types: *bodily, emotive,* and *cognitive*. First, consider how our muscles tighten and our posture changes in response to both chronic and acute pain. Such bodily responses almost immediately become part of pain experience. As seen from the phenomenological standpoint, it would be a crude mistake to understand such responses only as physiological reflexes. Exclusively physiological explanations fail to take into account the role of the body's memory.[14]

Secondly, with regard to emotive responses, consider how fear, panic or anger can aggravate the experience of pain. For instance, consider the patient who interprets the pain in his chest as an impending heart attack. The emotions that accompany this interpretation significantly exacerbate his pain experience. Alternatively, consider the patient who had an expanding metastatic lesion of the femur (from cancer of the lung). "It was only when the patient was reassured that his leg was not going to be amputated … that his pain became controllable" (Cassell 2001, p. 381).

Thirdly, with regard to cognitive responses, consider a patient diagnosed with metastatic carcinoma of the prostate in the lumbar spine. This diagnosis triggered severe pain attacks, which only worsened with time and which led the doctors to diagnose the patient as chronically ill. However, the disease could not explain the reason for such severe attacks of pain. These reasons were triggered by the patient's independent discovery that survival is shortest when the metastatic disease affects young men and that metastatic disease has no cure. Clearly, the patient suffered the pain in his body; yet just as clearly, this pain was up to a large degree of cognitive rather than of physiological origin.

One could make a more general claim: If I interpret my pain as an expression of an incurable disease, as a test or punishment, my cognitive responses affect the manner in which I live my pain; in a direct way, my interpretations modify my experience of pain. This means that bodily, emotive and cognitive responses up to a large degree make up the painfulness of pain.

These diverse responses to pain are not only co-constitutive of pain experience; these responses also re-personalize the self. Recall my earlier claim that pain is de-personalizing in that it unsettles four fundamental relations: (1) the relation

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[14] See Fuchs (2008, pp. 65–81).

between the self and body, (2) the person's self-relation, (3) the relation between the self and the environment, and (4) the relation between the self and others. Yet, the particular emotive and cognitive reactions to pain enable the subject of experience to form anew these four fundamental relations. Thus, if one "gives oneself up" to pain, or "pits oneself against" it; if one "endures," "tolerates," or "enjoys" pain; if one seeks pain or makes efforts to escape it; if one interprets it as a penalty or atonement, or a means of purification or correction—these diverse responses to pain enable one to establish a particular kind of relation to one's body, one's self, one's environment, and other selves. By constituting these four fundamental relations, the responses to pain form the person one becomes.

So far, I have emphasized the projective nature of pain experience: the manner in which I respond to pain, will form the person I will be. However, the responses to pain are also expressive of the person's past: these responses also rely upon the person I already am. In this regard, Thomas Fuchs' research into the bodily memory of pain (*Schmerzgedächtnis*) is informative.[15] According to Fuchs, a bodily reaction, which at first glance seems to be nothing more than a mechanical reflex, once analysed more closely proves to be a response determined by the body's prereflective memory. It is the body's past experiences that largely determine the way in which the body chooses to respond to similar experiences in the future. Our bodily, emotive and cognitive responses to pain rely upon our past experiences. Moreover, they also rely upon our interpretations of our experience, which in their own turn rely upon and incorporate the experiences of others.

In the literature on chronic pain, it was Emily Dickinson who forcefully stressed the forgetfulness of pain:

> Pain has an element of blank;
> It cannot recollect
> When it began, or if there was
> A time when it was not.
> It has no future but itself,
> Its infinite realms contain
> Its past, enlightened to perceive
> New periods of pain.

In Dickinson's famous lines, everything is presented from pain's point of view with no reference to the person suffering pain. Although such a characterization of pain highlights pain's dominating nature, the price one thereby pays for pain's personification is the complete impersonalization of the subject of pain. However, it is undeniable that the manner in which one suffers one's pain is largely determined by one's involuntary and unconscious recollection of the past as well as involuntary and unconscious anticipation of the future. Thus, despite the overwhelming

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[15] See Fuchs (2008).

timelessness of pain, which Dickinson captures so powerfully, it would be phenomenologically illegitimate to confine pain within one temporal dimension; namely, that of presence. Largely due to the temporality of pain (due to the manner in which memory and anticipation affect pain experience), the subject of pain cannot be conceived either as disembodied consciousness, or as a physiological body; rather, this subject is the person, the embodied subjectivity.

Pain, and especially chronic pain, is a highly complex phenomenon. To make sense of it, one needs to take into account not only the body's neurophysiological structure, but also the person's immersion in the lifeworld (*Lebenswelt*)—the world of everyday experience, filled with perceived, affective and practical properties. More precisely, without understanding the person's history, self-understanding, relations to others, and life-long goals, without recognizing the significance of the person's bodily, emotive, and cognitive responses to pain, one can only have a limited understanding of pain experience.

8 Psychogenic and Organic Pain

I argued earlier that one of the chief limitations of the exclusively neurophysiological approach to pain concerns its failure to recognize the existence of psychogenic pain. Such a form of resistance to the neurophysiological approach has its limits; moreover, it can also lead to misunderstandings. To be sure, chronic pain can be triggered either by organic or psychogenic causes. It is, however, crucial to add that chronic pain, which derives from organic causes, is never only organic, just as chronic pain, which derives from psychogenic causes, is never only psychic. Put otherwise, it is crucial not to misinterpret the distinction between organic and psychogenic pain as a distinction between physiological and psychological pain—a misinterpretation which would immediately re-introduce the schism between body (the subject of physiological pain) and mind (the subject of psychological pain), while leaving it unexplained how these presumed "subjects of pain" (that is, body and mind) relate to each other. The phenomenological identification of the person as the subject of pain is meant to recapture the living unity that binds the mind to the body as well as denounce the tendency to treat them as independent spheres. Thus, first, to claim that the person is the subject of pain is to suggest that this subject is also *embodied*, *ensouled* and *encultured*. However, if so, then secondly, when it comes to chronic pain, there is no such thing as purely physiological pain or purely psychological pain. Rather, purely physiological, just as purely psychological accounts address only parts of a larger whole, and this larger whole—namely, the person—is not reducible to the sum of its parts. No matter what the causes of pain might be, the concrete bodily, emotive and cognitive responses enable the person to invest the physiological tissue damage and psychological traumata with a sense or meaning through which the person's unique experience of pain is formed.

In the case of chronic pain, pain and suffering walk hand and hand. This means that for pain to become chronic, the subject of pain must either *somatise* psychological traumata or *psychologise* tissue damage. Here somatization refers to the expression of personal and social distress in an idiom of bodily complaints, while psychologization refers to the expression of bodily distress in an idiom of psychic complaints (cf. Kleinman and Kleinman 2007).

In this regard, the work undertaken in medical anthropology is quite telling. First, I have in mind the work of Arthur Kleinman and Joan Kleinman, who conducted research on the widespread outbursts of neurasthenia in China after the Cultural Revolution, and argued that these outbursts were instances of somatization.[16] The political framework did not legitimize critical discourse on the Cultural Revolution, and thus, pain and illness provides the only safe way to express the personal meaning of this revolution. Other phenomenologists have offered studies of nerve-related illnesses in South America, especially in Brazil,[17] and analogously argued that under particular regimes, physical and mental illness provided the only safe way to express the effects of poverty. In short, due to the temporality of chronic pain, and processes of somatization and psychologization that it makes possible, just as psychogenic pain is never merely psychic, so organic pain is never merely physiological.

Phenomenologically informed anthropological studies of pain provides ample evidence to support my claim that chronic pain is neither purely physiological, nor pure psychological. Here we are faced with human experience, which is at one at the same time physiological, psychic, cultural, historical, social and personal. This is the reason why so often either purely physiological or purely psychiatric treatments of chronic pain prove ineffective. Chronic pain is a mosaic of physiological, psychic, cultural and social factors, all of which obtain their unity in the framework of the personal meaning that the patient invests in her pain.

The temporality of chronic pain, conceived as the phenomenological basis of somatization and psychologization, proscribes the possibility of explaining such a complex phenomenon as chronic pain with a reference to its origin. Just as chronic pain is not reducible to its origin, so its treatment cannot be reduced to its origin's treatment. For if it is indeed true that responses to pain—bodily, emotive, and cognitive—are part and parcel of the very experience of pain, then chronic pain is never purely physiological or purely psychological. What this established distinction conceals is nothing less than the personal meaning the subject suffering from chronic pain has invested her pain with.

9 Illness/Disease and Healing/Curing

Recall the conceptual ambiguity mentioned in the Introduction: the concept of pain means something significantly different for the physician or psychologist, historian or sociologist. One could lament this ambiguity and identify it as a cause that

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[16] See Kleinman and Kleinman (2007, pp. 468–474).

[17] See Scheper-Hughes (2007, pp. 459–467).

underlies much confusion in pain research. Furthermore, one might argue that to reduce this conceptual ambiguity, one need introduce into pain research a distinction similar to the one that we come across in phenomenology of illness. Here, I have in mind the distinction between illness and disease. According to this established distinction, while the concept of disease stands for actual pathology and pathophysiology, the concept of illness refers to the patient's experience. Correlated with this distinction, there is another established distinction between healing and curing: just as one cannot cure illness, but only the disease, so one cannot heal disease, only illness.

Yet, just as my foregoing analysis invites one to give up the distinction between physiological and psychological pain, so it also brings into question the validity of the illness/disease and healing/curing distinctions, which one could characterize as the most established distinctions in the phenomenology of medicine in general. We find this distinction in the works of Edmund Pellegrino, Paul Tournier, Viktor Kestenbaum, Arthur Kleinman, Byron Good, Alfred Tauber, SK Toombs, James and Kevin Aho, among others.

Why is this distinction important? Arguably, it was introduced with the aim of providing phenomenology of illness with its *raison d'être*: While disease constitutes the subject matter of neurophysiology, illness is a distinctly phenomenological concept. Yet, I would argue that this distinction leaves phenomenology with an artificially confined domain, which it must transgress.

Consider in this regard Eric Cassell's description of how the patient personalizes the disease. A patient who develops life-threatening disease will soon know the worst that can happen. Normally, those who know the worst expect the worst. Moreover, those who expect the worst act in a way that brings the worst. We face here a self-fulfilling prophecy, brought about by the person's reaction to the disease.[18] Put differently, through the bodily, emotive, and cognitive responses, the person has an impact not only on illness, but also on the actual disease process. Just as the person's bodily, emotive and cognitive responses to pain change the course of pain experience, so these responses also affect the disease. Alternatively, as Cassell puts it, "by virtue of their behaviour—for example, the doctors they see, medications they take changes in life pattern from sleep to food—they change the expression of the pathology and the behaviour of the disease, as a result of the person they are" (Cassell 2001, p. 382). In short, if the person's bodily, emotive and cognitive responses have pathophysiological consequences, then phenomenology of medicine cannot be limited to the analysis of illness, but must also address the disease. Moreover, if the person's feelings, thoughts, and behaviour modify the behaviour of the disease, then to change the course of the disease, one must directly confront the patient's bodily, emotive, and cognitive responses to pain and illness. To do so, however, is to supplement curing with healing.

In phenomenology of illness and pain, one commonly comes across the following standpoint: "In order to heal the patient, it is not enough to cure the disease.

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[18] See Cassell (2001, p. 382).

The medical establishment must also take the necessary precautions that the process of curing the disease does not have adverse consequences for the patient." Phenomenologically informed studies of illness and pain expressed this thesis and attitude with the help of the distinctions between illness and disease as well as healing and curing. When I claim that the recognition of the person as the subject of pain brings these distinctions into question, I mean that just as curing the disease constitutes a part of the process of healing the patient, so healing the patient constitutes a part of curing the disease. In this regard, Eric Cassell's late work is highly significant. As he once put it, "we are of a piece—anything that happens to one part affects the whole, what affects the whole affects every part" (Cassell 2001, p. 371).

10 Conclusion

Consider the most common claim put forth in the phenomenological literature on pain; namely, the claim concerning the fundamentally non-sharable nature of pain experience. This insight, whose phenomenological origins lead back to Carl Stumpf's account of pain as a feeling-sensation (*Gefühlsempfindung*),[19] played a central role in Scheler's reflections on pain, specifically in the context of his stratification of the emotional life.[20] According to Scheler, it is the non-sharable nature of pain that distinguishes it from similar phenomena, such as grief and despair. More recently, this insight also played a significant role in Elaine Scarry's classical study *The Body in Pain* (Scarry 1985), where she took pain's non-sharability to mean that the experience of pain shatters language and is in principle non-expressible.[21]

How exactly is one to understand pain's non-sharability? Along with Scheler (cf. Scheler 1973), I would interpret this claim as a contention that the *experience* of pain is non-sharable: I cannot live through your pain, just as you cannot live through mine. Pain introduces a breach between what is my own and what is not my own. If, impossibly, I were to experience your pain, this would prove to be the most egoistic act imaginable, for it would amount to appropriating your body and rendering it my own. The experience of pain delivers the body-in-pain as *my* body; *pain individualizes*.

However, while the *experience* of pain is non-sharable, it nonetheless is always possible (although by no means easy) to bring this experience to expression. By saying this, I am arguing against one of Elaine Scarry's claims (Scarry 1985); according to Scarry, pain's non-sharability means that the experience of pain shatters language and is in principle non-expressible. Scarry's arguments to the

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[19] See Stumpf (1907, 1917)

[20] See Scheler (1973, pp. 328–344).

[21] See Scarry (1985, pp. 3–11).

contrary notwithstanding,[22] it is important to emphasize that we do have at our disposal various languages of pain—autobiographic, medical, literary and scientific, to mention the four most significant categories. In fact, Scarry's own book is one particular way of bringing pain experience to expression. Moreover, it seems to me that Gergel's critique of phenomenology of medicine, which I have addressed above, applies to Scarry's contention that the experience of pain brings about the collapse of language. If pain indeed were immune to expression, then one could legitimately qualify it as a solipsistic experience, which lies beyond empathy, sympathy, and understanding.

Yet, the experience of pain *is* expressible, and considering its diverse expressibility, I would like to conclude with some reflections on the therapeutic significance of *dialogue*. Ever since its birth in the Parisian hospitals during the French revolution, the history of clinical medicine has been a history of the decline of dialogue and the upsurge of the technically mediated "discourses on tissue." The discovery of the stethoscope in 1819, of the X-ray in 1895, of the CAT scan in the 1980s and of the MRI in the 1990s has progressively rendered direct discussions between doctors and patients obsolete. The capacity to listen to the poundings of the heart, to penetrate the patient's skin and gaze directly at the organs, to observe the one millimetre cross-sections of these organs and finally the three-dimensional pictures of organs in "real time," has certainly enabled the physician to understand the patient's body incomparably better than the patient understands it herself. Nonetheless, this unprecedented and continuously evolving technical capacity to disclose the secrets of the human body helps medical praxis at the neurophysiological level. It appears to be of little use when it comes to the medical profession's obligation to confront pain's personal dimensions.

As S. Kai Toombs has argued in her *The Meaning of Illness*, the patient and the physician experience and conceptualize the patient's affliction in fundamentally different ways. While the patient conceives of pain as a lived experience that affects her lived-body, the physician thematizes it as a collection of physical signs and symptoms that disrupt the normal functioning of the patient's physical body. For this reason, far from representing the same reality, for the patient and the physician, the phenomenon of pain represents two distinct realities. To overcome this "ontological gap," it is necessary that "the physician explicitly attend to the lived experience when devising therapeutic goals (Toombs 1993, xvi). With Gergel's critique in the background, I would like to supplement Toombs' noteworthy investigation with a suggestion that both the patient and the physician, besides inhabiting different realities, are also motivated to overcome the ontological gap that separates them. Thus, the patient, besides living through pain at the level of immediate experience, is also aware that the biomedical understanding of pain

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[22] No one else has maintained as strongly as E. Scarry that pain, unlike other feelings, resists verbal objectification: "Thus Sophocles's agonized Philoctetes utters a cascade of *changing* cries and shrieks that in the original Greek are accommodated by an array of formal words (some of them twelve syllables long), but that at least one translator found could only be rendered in English by the uniform syllable 'Ah' followed by variations in punctuation (Ah! Ah!!!!)" (Scarry 1985, p. 5).

holds the promise of liberating her from affliction, and thus is motivated to trust pain's biomedical treatments. So also, the physician is motivated to understand the patient's pain not only as a symptom of disease, but also as a de-personalizing and re-personalizing experience, for the liberation of the patient from pain's dehumanizing effects constitutes one of the central goals of his professional praxis.

Only through dialogue can the patient and the physician overcome the ontological gap that separates them. Especially in the context of such afflictions as chronic pain, which typically is experienced in the absence of any detectable tissue damage, living dialogue between physician and patient obtains its preeminent therapeutic significance. What is especially called for is *listening*. What exactly is listening? It is not just a matter of hearing the patient's words, but also recognizing the meanings that inform these words, as well as the meaning with which the person has invested her pain. It is not just a matter of identifying symptoms, but also recognizing the specific meaning they have for the patient, the specific relation the person has towards her pain. It is not just a matter of understanding the person's relation to her pain. It is also a matter of how it affects the person's relation to others and to her own future plans. It is not just a matter of understanding the person's current condition, but also how her understanding of this condition is formed by her past. Without understanding the person's history, her insertion in the lifeworld, her relation to others, as well as her orientation towards her future, one cannot understand pain's personal significance. Moreover, without understanding the de-personalizing and re-personalizing dimensions of pain experience, one cannot offer chronic pain patient effective treatment.

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Chapter 10
Pain Experience and Structures of Attention: A Phenomenological Approach

Agustín Serrano de Haro

Abstract A general principle of the phenomenology of pain states, in agreement with everyday knowledge, that normal human experience oriented towards one's environment is distorted and its direction reversed whenever an unexpected pain arises. In my paper, I intend to shed some light on this descriptive principle by considering it in terms of Edmund Husserl's account of attention as a universal factor in conscious life, articulated in three main levels: attentional focus; co-attention, which necessarily accompanies the salient focal appearance; and finally, inattention, which is to be identified not with unconsciousness, but with the conscious horizon and background of whatever appears to experience. My essay accordingly draws a distinction between those physical pains that occupy the foreground of consciousness and violently monopolize the focus of interest, on the one hand, and on the other hand, other physical pains that allow some co-attention and therefore do not subjugate the attentional focus. There are even pains that due to their weakness or insignificance do not attract co-interest and do not interfere with the articulation of present experience. Concerning the first type, it nevertheless seems true that not even this "invasive pain" is capable of annihilating every other present experience, so that consciousness would be entirely reduced to "being in pain" and pain would be the sole content in these temporal phases. With regard to the quest for a general model of why pain captures attention, I finally propose that the lived body does not operate in conscious experience as a foreground, middle ground or background. Instead, one's own body is not only the "absolute here" for any spatial direction and the "zero point" of orientation, but is at the same time the "zero level" for exerting attention, the level from which one acts and upon which bodily pain impacts.

A. Serrano de Haro (✉)
Institute of Philosophy, Consejo Superior de Investigaciones
Científicas (CSIC), Madrid, Spain
e-mail: agustin.serrano@cchs.csic.es

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1 The Threefold Structure of Attention

As soon as physical pain appears, current normal human activity changes. Disruptively or not, pain is promptly felt and attended. This common fact seems to be altogether obvious and uncontroversial. Psychological accounts of human behaviour and phenomenological descriptions of lived experience have both remarked upon such elementary evidence; namely, pain demands attention, and, in quite a few cases, pain even captures attention and monopolizes it. Both theoretical approaches could also agree with the statement that, “a theory or model of how and why pain captures and maintains attention has not been developed” (Eccleston and Crombez 1999, p. 357).

The significant methodological differences between psychological research and phenomenological analysis should briefly be described. The former focuses on factual reality and relies on experimentation and measurement in order to gain empirical statements of variable generality. The latter, a discipline within philosophy, searches for a structural description of conscious experience, for example, of what it is like to be in pain, discerning patterns of possible types of experience and setting aside the question of the empirical distribution of these types in this or that or any population. Phenomenology is committed to a first-person perspective. It does not invoke any physical or physiological structure underlying the “phenomena” that appear, the data of experience. Instead, what is of interest is how the subject experiences what he/she is aware of through perception, memory, or feelings. However, at the same time phenomenology is exclusively focused on universal claims concerning experience; that is, verifiable laws that do not permit exceptions—such as “there is no pain without a lived body” (against Descartes and Putnam), “without temporal extension” (against the empiricist tradition of instantaneous contents of mind), or “without attentional modifications.” Finally, “the experiential-phenomenological approach” comprises a diverse range of experiential methodologies based on phenomenology for the scientific study of conscious human experience (Price and Aydede 2006).

In the following pages, I intend to shed some further light on the relationships between pain and attention by considering Edmund Husserl’s account of attention as a universal factor in conscious life. No present conscious experience may be so simple, so atomic, as not to include a plurality of simultaneous awarenesses, a multiplicity of “contents” that coexists in it. Attention in a generic sense is a primary principle governing the articulation of this simultaneous complexity. Through it, each present content is offered with different prominence or different importance to the conscious subject. From the point of view of subjective experience, preferential attention and interest can be identified; from the point of view of that which is experienced, the interest has its reflection in the degrees of prominence with which the object or the matter appears.

The founder of phenomenology, Edmund Husserl (1859–1938), distinguished at least three distinct levels of attention coexisting in every conscious experience in normal adults: attentional focus, co-attention and inattention (Husserl 1976, pp. 56–

60, 71–73, 185–187; 1984, pp. 419–425). Attentional focus makes something the centre of my interest and brings it into the foreground of appearance; that is, it becomes the most relevant correlate of the present experience: the thing, feature or issue that at this moment matters above all else to the subject of the experience. A tennis player is aware, for example, beyond anything else, of the direction and speed of the ball that he must immediately hit and of how he wants to return it. Therefore, this basic theme on which the focus falls stands out and is highlighted; it appears in a prominent, preferred, distinct way.

In contrast, co-attention is similar, not to the illuminating central beam of attentional focus, but rather to a "cone of light" that confers on the primary presence illuminated by attentional focus the immediate environment of sense within which it appears. Co-attention necessarily accompanies the salient focal appearance and articulates its environment as a consistent totality of sense: thus, both the entire tennis court and the opposing player moving on the other side of the net are co-present to the gaze that is fixed above all on the trajectory of the ball to be hit. However, not even these two simultaneous attentional fringes exhaust normal conscious attention of something. No matter how focused the tennis player may be on the match, in every moment he preserves a diffuse, peripheral, almost inert awareness of the other nearby courts, of the background noises, of the tennis club itself in which he is playing. Even this city, which is his, is announced in the horizon as a landscape beyond the court's fence. In truth, inattention is to be identified not with unconsciousness, but with the conscious horizon and background of what appears to experience. The player is aware in a passive manner of all this vast and complex area situated in the attentional margin, which does not currently attract his interest, which does not need his participation in order to be conscious. This does not make inattention irrelevant or suppressible. In line with Husserl's extraordinary thesis, the constant awareness of the world as the all-encompassing presence, in which the centre of subjective interest and the environment is inserted, arrives in this marginal form, inattended, in all experience; the certainty of the world as unique global reality pervades my experience at every moment through conscious inattention.

According to Husserl, focus or centre of interest, co-attention and inattention coexist in every conscious present, so that none of these forms can subsist without the others. The three levels form a continuity in experience and a fluid communication runs between them. The coherence with which I capture the context of my experience depend on this structure, which is at the same time fixed and flexible, with constant changes from the foreground to co-interest and to inattention, and vice versa. However, it should not therefore be supposed that the information that the person has from himself/herself at each moment of the experience, the "knowing" of the state of his own body, necessary relies on one or another of these levels. As we will see, pain seems to emerge from yet another, even deeper attentional plane.

However, in my view, this threefold articulation permits, with regard to painful experiences, a useful preliminary distinction that Husserl did not work out. Subsequent phenomenologists have only begun to deal with it (Leder 1984, pp. 255–258; 1990, pp. 70–79; Grüny 2004, pp. 28–49; Serrano de Haro 2010). There are, on the one hand, frightful physical pains that occupy the foreground of consciousness and violently monopolize the centre of interest. Other painful occurrences, on the other hand, do not dominate the attentional focus and still allow some free co-attention; finally, there are still other physical pains that due to their weakness, familiarity or lack of relevance do not even dominate co-interest and may pass by in the mode of inattention, scarcely interfering with present interests. Such a threefold typology—focal, co-attended and inattended pain—seems to be intimately related to the intensity of pain as it is felt by the person in pain, and can fruitfully help to conceptualize degrees of pain (for example, it is impossible to undergo severe pain without at least having to co-attend to it).

The three differentiated forms are not self-contained compartments in which to distribute the enormous variety of painful body situations. For theoretical purposes, it is much more relevant to consider how the intrusion of pain into one of the integrating fringes and as one of the types affects in turn the attentional structure in its tripartite whole; that is, it also conditions and affects other attentional fringes. The typology does not claim to impose a name or label on each pain according to the degree of attention that it draws. It deals instead with analysing how this pull impacts the other simultaneous forms of attentional consciousness, in such a way that it can clarify, among other basic questions, whether an extreme pain is capable of cancelling all other simultaneous awareness, of abolishing any co-attention and inattention. I will therefore first present this triple descriptive schema (2–4), and I will subsequently turn (5) to the general question of why pain captures attention.

2 Invasive Pain

Intense acute pain attracts the focal point of attention and immediately alters the arrows of co-attention, of co-interest. A sudden sharp pain in the tennis player's chest, according to the well-known example of Drew Leder,[1] an onset of migraine, a violent blow of any origin, bring with them this global transformation in conscious experience: they invade the attentional centre, detaching attention from previous occupations and focusing it on the event that has occurred, on the painful affection. In addition, even these words offer too mild a description. The violence of pain first pulls the attention and then forces it to stay fixed on the suffering point or area; it remains focused, concentrated, absorbed on the "there" of pain, as if the focus of attention and the focus of pain were a single focus.

The disruption of intense pain has a marked tendency to monopolise conscious life. All the rest, everything that up to an instant ago occupied my present moment of experience, suddenly moves to a second or third plane of interest. The previous

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[1] The references that I mentioned previously to the attentional planes of the tennis player do not come from Leder's *The Absent Body*, but rather are my responsibility.

articulation of interest and of co-interest is broken down, almost en bloc, causing the entire context of sense of the previous activity to fall at once literally into inattention, and its continuation is no longer viable.

The abrupt pulling of the focus of attention, with its simultaneous impact on the other planes, is, in my judgment, a tendency of any lived experience of intense pain, although it certainly admits different degrees of magnitude of the affliction. For this reason, I now examine with more precision what happens, in the midst of extreme pain, within the scope of the co-present and of inattention. This problem is of special theoretical interest.

The great study by Elaine Scarry, *The Body in Pain* (Scarry 1985), appears to defend the thesis that the absorption of attention by pain can be complete; the person who suffers the invasion of pain, as in the cases of torture to which Scarry gives priority, would not experience anything else, nothing distinct, not even in the margins of his/her consciousness: "Pain annihilates not only the objects of complex thought and emotion but also the objects of the most elemental acts of perception. It may begin by destroying some intricate and demanding allegiance but it may end (as it is implied in the expression *blinding pain*) by destroying one's ability to see" (Scarry 1985, p. 54). Scarry speaks thus of "world dissolution," in harmony with Hannah Arendt, who also qualified the situations of extreme pain as "loss of the world." In some way, the painful lived experience would consume everything, effecting an "obliteration of the contents of consciousness," which, stated in terms of a phenomenology of attention, would entail a powerful exception to the simultaneous three-dimensionality of the planes of consciousness previously sketched.

I would nevertheless like to defend the position that even in midst of the brutal domination that the painful affliction imposes, consciousness continues to be a field broader than the mere feeling of pain, a scope a bit more plural than pure suffering. In order to be able to live in "a pure scream of pain," the experience has to retain a slightly greater dilation, which barely has any influence, but which theoretical analysis can recognise. It is effectively true that because of the onslaught of pain, the phenomenal delimitations between the co-present environment (the second plane) and the background or horizon (the third plane) are contracted, restricted, weakened. The immediate context of sense is flattened and tends to converge, to become merged with the further background of sense; pain reigns supreme, and it appropriates any other prominence standing out against a merely inane objective background. However, even though that minimal remainder of contrast is flattened and irrelevant, it does endure and has to endure. In support of this affirmation, let me put forward an autobiographical testimony of great drama, one that is also very expressive of the conceptual nuance that I want to use in opposition to the thesis of total obliteration.

The "tabes dorsalis" or consumption of the back was well known in medical practice of the 19th century as the terminal form adopted by neurosyphilis. The writer Alphonse Daudet, who suffered it in his own body, offered an overwhelming testimony of suffering. In his notes, he writes of the "atrocious surprises" that the pathology produced (Daudet 2007). Occasionally, without warning, a sudden discharge of extreme pain could assault him in the midst of a stroll down the street or, catch him in a moment of calm reading at home. He not only lost motor control of his body, but the perceptive axes of spatial orientation also disappeared; no proper field of intuition and experience subsisted any longer.

However, in his account of these episodes, the attack did not bring with it the complete disappearance without a trace of the spatial environment in which he found himself. The awareness of being in Paris, or else in the thermal spa of Lamalou, did not completely vanish. Certainly, the pragmatic and experiential environment of the patient lost recognisable form; it was disarticulated and entered into disintegration. But, "in the midst of" the successive and insufferable stabbing pains, as he himself describes, the table of the room and the book he was reading survived for him. Although no longer the meaning of the phrases recently read but rather only a general echo, tied to one or another individual word; a type of worn and confused sketch of the whole that a moment before he was capturing. Without identifying before and behind, right and left, a consciousness of external reality remained as a globality without articulation, as a distant or lost world. Thus, a shred of the co-attentive and inattentive order of a moment ago continues to be experienced, even if this same residuum is experienced in retraction, as if it too were threatened.

Therefore, rather than a literal loss of the world and rather than an integral absolute of pain, what is produced is a disintegration of the specific components that give form and meaning to reality; the horizon is veiled—as Daudet also notes (Daudet 2007)—but under this veil, like an encompassing fog, it continues to appear. The Spanish and French languages do not use a phrase similar to "blinding pain," but they do use (as does English) the striking expression of "seeing stars," especially in cases of violent blows. To the sufferer who no longer attentively "sees" anything, who no longer experiences more than his pain, "something" appears, an unconnected reality, with hardly any materiality or shape. It is about celestial bodies ("stars") that have nothing to do with my existence; I am not looking at them, but they do fly over me and, in this anomalous mode, appear to me.

I would like to add a second consideration with regard to the problem posed. The only awareness in extreme pain, over and above this supreme pain, is not merely something like stars that indicate reality. What also seems necessary is an added presence of one's own body, which is preserved and which extends a bit beyond the focus of suffering. I am thinking, in this regard, about the phenomenological law that Frederick Buytendijk formulated, that any painful suffering always has a location in the lived body. Unlike bodily deficiencies (fatigue, sleepiness, hunger), which are essentially unitary or global, any pain hurts here or there, in this area, in this direction (Buytendijk 1948, p. 22). This location will be more or less vague, more or less oscillating, will or will not correspond to the organic cause, but the pain is experienced as located in principle, as situated in the corporeal space that I feel inside. The onset of migraine, biliary colic, a piercing pain in the knee absorbs my consciousness equally, but such domination does not annul the distinctive affected location of each one of these situations. The acute pain justly suctions the intimate presence of the body towards its site, towards that determined focal point of the body that is not erased. It is not as if my entire body were hurting, nor as if the extreme suffering in that location adopted a qualitative aspect that corresponded to the whole body as a unit and impeded me from distinguishing where it was hurting me. The here or there of a painful affection, this partiality that is experienced as such, is recognised thanks to a certain tenuous, muted presence of the rest of the body.

Consequently, a “coenesthesia,” perhaps also residual, coexists with the painful lived experience; it flanks it and contributes to its virulence. In these situations, the remaining non-painful part of my body seems to passively reinforce its unity; it retracts its delimitations of organs, areas, prominences, and is compacted in a single tension of contrast with the afflicted area. However, in any case, while I live subjugated by the focus of the pain, the undifferentiated remainder of my body continues to tick along for me, marginal, unfocussed, inattentive. A slight remainder of one’s own body is also needed in order to be entirely in pain, that is, in order to feel how pain is invading almost all of my total sensibility.

This second exception to the phenomenon of pain completely capturing attention should not be confused with the previous one. They are not to be understood as “two contents” of consciousness—the residuum from the world and the remainder of one’s own body—that cooperate or reinforce one another. Each one floats on its own, and the second forms a part not so much of the external world as of the same corporeal reality that has exploded in pain.

To my understanding, this analysis does not require new complements. In an acute pain crisis, no other stimulus of the environment and no other bodily affection are in play. Any other possible factors either do not reach the threshold of consciousness (the negligible degree of inattention), or they are submerged in the suffering and contribute to it (thus, the lighting of the room, the noise of the street, “hurt” no matter how little they are noted), or they remain in that unconnected shred of reality. The second possibility coincides with the so-called “allodynia” in medical approaches: “pain due to a stimulus that does not normally provoke pain” (IASP 2016). The third takes us back again to this peculiar phenomenon of “seeing stars.”

Given that the monopoly of attention by extreme pain admits being conceived as an increasing process, it is curious to suggest the following hypothesis concerning a final overcoming of the two provisos that I have indicated. In addition, this ultimate flooding, this obliteration, with attention now entirely consumed by the pain, would seem to lead to the limit at which the painful crisis brings with it the loss of consciousness. If the tendency to capture any form of attention and to eliminate any other object does indeed come to its culmination, a situation would still not arise in which absolutely everything is now pain, since an instant before this happens, fainting occurs, and so there is no longer any awareness at all, not even of pain itself. This is certainly no consolation, and in any case, this internal relationship between obliteration and fainting would need a more careful examination.

3 Co-Attended Pain

This first model of the painful alteration of the attentional structure merits being called "invasive" disturbance or "totalized pain," although, as I have indicated, the totalisation is an immanent tendency that is never completed. Let us now consider a second model. There is no lack of situations of notable and, where applicable, increasing pain that, however, do not lead to subjugating the focus of interest. Instead of absorbing the central axis of attention, a tension is produced between the different requirements, a struggle between motives that fight to occupy the foreground and to displace the rival motive to the second plane. The headache strongly felt in the middle of a work meeting, abdominal or tooth pain in the course of a social event that one does not want to leave, or any pain that plagues an athlete in a competition from which he/she refuses to withdraw, are suitable examples. However, I want to use as a paradigm another autobiographical story that we owe to another great man of letters. It deals with the myocardial infarction that the Catalan writer Josep Pla suffered in his home, and that he survived to tell about (Pla 2002).

The cardiac alarm occurred unexpectedly to Pla in the early hours of the night in the solitude of his country house. It was noted immediately, and immediately misinterpreted as a respiratory disorder; a product of the change of weather and of poor digestion of his supper. The writer's narration moves through a long night of suffering while he simultaneously sought home remedies. The disturbing impact of the pain, which was not at all slight, coexisted with a series of actions and activities aimed at escaping from or at least alleviating the pain: deliberate changes of position, substitutions of body support—the bed, a chair, a couch, the floor—in a deliberate attempt to sleep. In addition, ruminations took place, aimed at identifying the cause of the pain, at detecting the origin of the phenomenon in the body. Note that all these initiatives and actions justly require focal attention, which is still governed in part by subjectivity; the pain itself does not guide them. It is true that the pain is the theme that occupies attention and that this attention is in turn conditioned, shaken by the pain. However, it is not invaded, expropriated, captured. The totalised pain of the first model was reflected in the initial words of Daudet's story: "What are you doing right now? Suffering" (Daudet 2007). The invasion of suffering does not leave room even for initiatives that discern how to stop or counter the attack of pain; only writhing with pain is possible, the convulsion of the body toward or away from itself and against itself, that is not even a deliberate change of posture. Conversely, the severe pain of the second model corresponds well with the definition of it proposed by Pla: "I have to confess also that *I was not at any time dominated, overwhelmed by the pain*. I never lost mental consciousness" (Pla 2002, p. 366). The ego who suffers the pain is not at its mercy and can still guide his/her attention.

This second model does not require the ego to concentrate the co-attention in responding to its own pain. As noted in the other examples of the headache in society or the athlete in competition, the ego may have to distribute attention and co-attention between the pure pain and the response to the social or personal situation in which it is found. The rider of a bicycle at great speed who is surprised by the violent sting of a wasp on his back feels that his focal attention suddenly diverts. In turn, he feels an urgent need to maintain at least co-attention on his vehicle and on the road in order to avoid a certain accident, which would be even more painful. In this second general type, the pained ego does not lose, in sum, his/her communication with the specific order of sense, with the area of action in which his existence is situated. Stated in terms of a phenomenology of the field of consciousness, co-attention is not broken down, the simultaneous awarenesses—for example, of the curve the bicycle is approaching—is not distorted, the perceptive horizon is not ruptured.

A clean break in the body schema of the ego is not produced in this form of suffering. The location of the focus of suffering presents a greater specification and precision, that discriminates the affected area with respect to its ramifications and area of influence; one does not, then, experience only the contrast between an affliction exacerbated in one area and all the rest of the body, numbed, with barely any prominence or distinction. The severe but not total pain delineates a type of immanent topography that can be described from within. It is true that few patients are capable of the detail that Pla demonstrates: "Shortly after lying down, with the book in my hand, I noticed that in the high part of my chest a kind of very painful bar was formed, right above the area of the heart, and that in the back part of the trunk a parallel bar was formed, as painful as the front one" (Pla 2002, p. 363). However, it is also well known that neurophenomenology as a scientific orientation based on phenomenology trains patients and study participants to improve both their bodily sensitivity and their ability to describe their bodily experiences (Varela 1996).

4 Inattended Pain

In the second model, the pain alternates between claiming focal attention and demanding only co-attention. This characteristic tension is not resolved, and fear arises with the concomitant concern for a possible increase in intensity that would transform the current pain into invasive pain. However, at the same time, the severe pain of the second model, which could be characterized as "aggressive," can also be distinguished by the other extreme of the attentional structure, by the lower extreme of the more tolerated pains that flow between co-attention and the inattention. The very pains that ease up, that begin to decline, the burn or contusion on a descending curve, the headache leaving, also the dull, more or less familiar pains, would fall into this third type. There is no longer a threat on the first attentional plane, such pain is compatible with an active task centred on other matters, but even so, the pain makes itself noticed and the co-attention realises it and returns with some frequency towards it. It would also seem that the pains that open the way, that materialise with greater clarity, that are already something more than a simple background discomfort, could be situated in this wide band between co-attentive and inattentive.

The lower limit of this third model is mild or bearable pain, which can flow in mere inattention; it is there, on the horizon or in the margin of consciousness, and does not impose; I notice it, but it does not protrude. The sore muscles in the legs after a long walk (sometimes called "pleasant pain"), the plugged-up feeling that begins to provide pressure in an ear or the murmur of a tooth that begins to give signs of discomfort, are experiences that only stand out if the subject directs explicit attention or co-attention towards them. That is, if the ego pays attention to them. These lived experiences call weakly for attention, barely draw on it and do not interfere in the simultaneous tasks: it is the ego, in this case, that takes the initiative in focusing on them and emphasising them. Here the normal, usual presence of the body does not undergo a significant alteration that indisposes it for action; the point of pain is integrated more or less peacefully in "the special colouring of this instant of life," as the Mexican phenomenologist Antonio Zirión likes to say (Zirión 2002).

This third model, by uniting borne or bearable pain along with mild pain, would present a notable range, which corresponds in part to the principle that the three attentional dimensions do not have fixed limits and communicate with each other fluidly. In some ways, mild pain is closer to simple discomforts, to body phenomena like the numbness of a limb, an uncomfortable posture, a rather unpleasant itching or pressure. These events do not twist the normal dynamics of attention, since they do not disturb the continuity of the first and second operative planes. In my view, those who have only experienced this mild level of pain would not know what it really is to suffer pain, what hurting in one's own body really consists in. However, between this benign figure and the pain that dominates in co-attention (second type), it is advisable to recognise not-so-benign figures of the last type that are projected on the co-attention, insinuating or housing a possible threat.

It does not have to be said that a single individual pain is able to pass through, during its temporal course, the complete scale of attentional models, or a more or less broad section of it. The principle that no individual pain is experienced, throughout its duration, in a single and invariable attentional form is a phenomenological law. Such conscious constancy is not possible; it would not allow understanding how the painful lived experience grows or how it declines.

5 The Ego

The three interdependent planes of the field of consciousness are not Husserl's only contribution to the general analysis of attention. In his mature phenomenology, the attentional factor is a basic reason for recognising the existence of an ego in the heart of conscious life. The ego is the subject of attention, the agent or manager, to put it this way, of the attentional deployment, that directs interest towards a thematic centre or issue, withdraws it or diverts it to another theme, holds the threads of the co-attention. It is the ego that "lends," with certain freedom, "its" attention, as language wisely puts it; it is limited to conferring it for a time on one or more phenomena. To this same ego, to the subject of the experience, incessant invitations or stimulations arrive from the environment and from the background that urge the ego to turn his/her attention towards this or that which is conscious but inattended. The inattended passivity is thereby conceived as a field of affections that invite or urge the ego, that move towards the ego, so that the subject who pays attention is never an absolute and unconditional master of the focus of interest, but is conditioned by that which affects him/her. In light of this approach, how is it possible to understand that in invasive pain an actual expropriation and alienation of the attentional dynamic is produced? How is it that the ego can become and remain dispossessed of attentional control?

A fundamental part of the answer to this question points to the body. I refer not so much to the organism or to the visible physical reality as to the *lived body*, to the body of the subjective agent lived "from within": the corporeality of the ego, who is carrying out a job and manages the necessary utensils or who is engaging in a sports activity or holding a conversation with some friends. Without the body, the action of the ego is unthinkable. However, none of these actions puts the body in the centre of interest; none converts it into the direct theme of the subject's attention. The energetic manipulation of the carpenter, the mobility of the tennis player, the intervention of the speaker are concentrated on the work in fabrication, on the direction of the ball or on the meaning of the words that he/she wants to pronounce, not on the body that grasps the tool or that pronounces the sounds. According to the schema indicated, the body of the ego does not offer itself as the permanent object of co-attention either, as if an attentional beam weaker than the principal one and dependent on it had to take note of its presence, of its status, of its possibilities. As long as the action lasts, corporeality is presupposed without ever needing to become a co-protagonist standing out in relief within the field of intuition. In a certain sense, the body only appears in the inattended margin of the experience, in the passive background of perception, and here it shows itself, in addition, to a small degree. Some part of my body visually appears, and I marginally perceive, as if out of the corner of my eye, my hands, my general posture, the colour of my skin. In addition, the embodied agency in the experience and the control of the ego over the body do not depend on the familiar phenomenal presence of the figure of my body in the inattended background of perception. I move without needing to see myself.

In conclusion, with the body not being in the first or second, or even the third attentional level as a marginal awareness, the corporeality of the ego is found instead beyond, in "the zero plane" of experience. This plane defines the viewpoint of the agent, that makes his/her intervention possible and from which all the attentional complexity opens up. In a parallel way to Husserl's emphasis on the body as "the zero point" of spatial orientation, the "absolute here" from which what is near and far, on the right or left, above and below, before or behind is defined, the body occupies a type of zero plane of attention that actively deploys the other attentional forms while its agency is kept safe from the focus of interest.

In my way of thinking, this privileged position of the body, this unique intimacy with the operative ego, helps us to understand the attentional alterations that pain brings with it. Pain reverses the attentional dynamics as a whole, since it makes it "centripetal"; that is to say, it turns it back on one's own body, on the embodied subjectivity (zero plane) that normally exercises its powers “centrifugally”.[2] The absolute here of the body as a reference oriented to any spatial position is also a carnal, affective, sensitive density, which in pain reveals its vulnerability, violating the very ego of the experience. The zero plane of experience and of attention is a carnal subjectivity that feels its body while it acts in the world. Through this connection in principle, through this radical twinning of the ego that governs attention on the one hand with the body in which the ego lives on the other, pain is never restricted to provoking a change of content and a movement in the direction of the attentional focus. Even in the inattentive form, the appearance of a bearable pinprick is not similar to a background noise, to a background landscape, to which I can if I want attend. Pain incorporates a warning signal; it encloses a possible threat, such that if I do not attend to it soon, later I may not be able to attend to it well. Corporeal sensitivity is part of the identity of the ego; in fact, it is the conscious “substrate,” the intimate “base” of perceptual and personal activity (Husserl 1952, pp. 275–280). It is because of this connection that the co-attended form of pain produces the split between the body affection, that aversely pulls on the attentional axis, and the body ego that wants to preserve its power to control attention, precisely in order to combat that very affection. The centripetal direction of the pain towards the ego and the centrifugal direction of the attention of the ego cross each other and mutually block each other. In addition, of course, invasive pain generates an almost complete bending of the zero plane from which attention emanates, a turning back on itself in which the focus of the suffering swallows the focus of interest from within the experience. The pain crushes the attention of the ego, it bends it over itself, because it exacerbates it, discharges it, while closing off any operative centrifugal channel of interest.

6 Conclusion

The threefold attentional structure that operates in each experience can be expressed in a diagram of this type (Fig. 1).

This outline is applicable not only to the visual perception from which it seems to be primarily extracted, but also to any type of perception, and in reality to any form of objectifying awareness (memory, fantasy, judgement), as well to emotions and volitions. Any conscious experience of the ego possesses this complexity or richness. A primary contribution of my paper is that physical pains can be located in one or another of these three levels. They can be classified according to the quantity and quality of the attention they pull, and thus as focal, co-attended or inattended pains (Fig. 2).

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[2] The notions of centripetal and centrifugal direction of the experience were elaborated by Drew Leder in the texts cited previously.

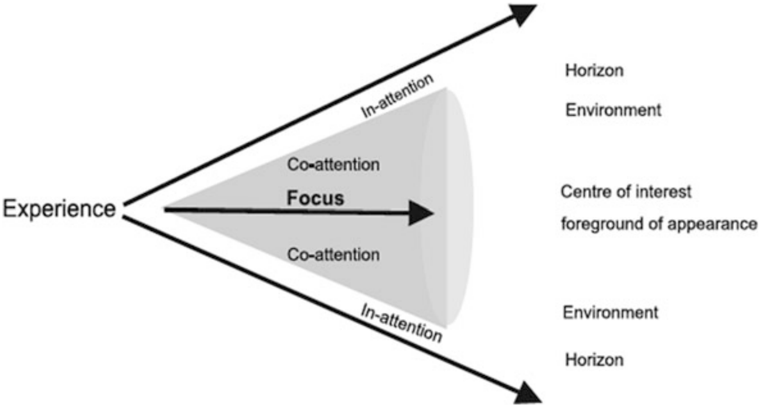

Fig. 1 Threefold structure of attention

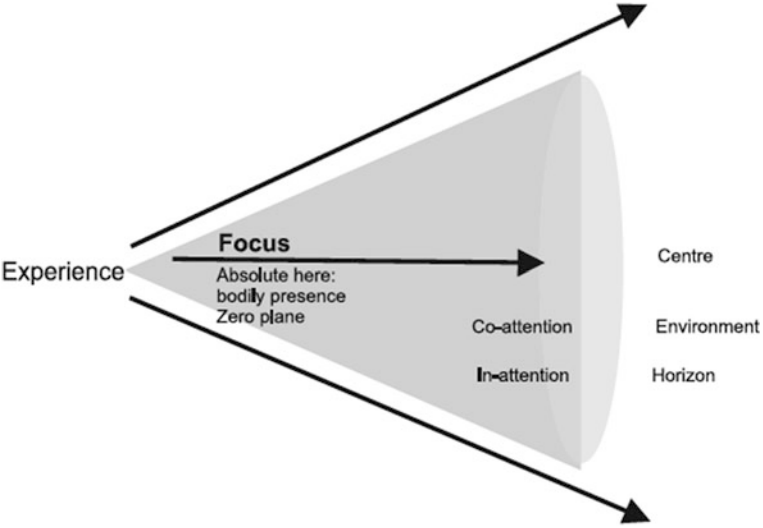

Fig. 2 Body as zero plane of attention

A second contribution concerns, however, the profound disruption of the attentional structure that focal pain brings with it and that accompanies, as an uncertain threat, co-attended pain. Pain is not another presence, another datum among the multiple data that coexist in the present, but rather an event that involves an immediate shock to the general structure of the experience. This impact of physical pain has essentially to do with the privileged position the body has in any experience of the ego. In fact, although the body can be the object of attention (such as when washing) and of co-attention (such as when changing clothes), and is always in awareness in an unattended manner, at each moment it is informed by a

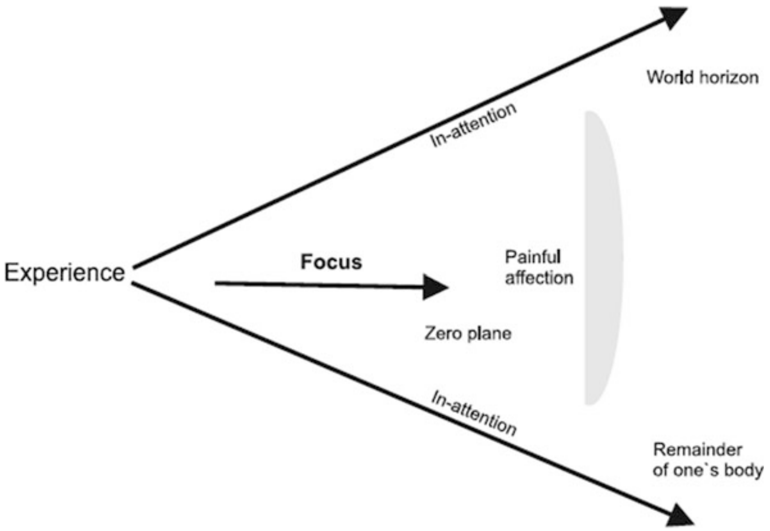

Fig. 3 Disruption of attention in invasive pain

special, unique attentional dimension that is still more radical. One that is, so to speak, "before" the foreground; the appearance of pain has its place in this "zero plane," and from there, pain can leap to the foreground, unbalancing and disturbing any attentional structure. These theoretical nuances are more difficult to reflect visually, but one can turn to two diagrams that are based on the previous one. The first diagram presents the constant, silent presence of the body in normal experience (Fig. 2), while the second presents the global alteration by invasive pain (Fig. 3).

In accordance with these phenomenological considerations, a first conclusion seems to be clear. Research on why pain captures and consumes attention has to advance through a better description of the ego, manager and agent of the attentional deployment. This lived body is sensitive, and sensitivity has to be acknowledged not only as belonging to the ego who experiences in the first-person, but also as having its own autonomy, its own ability to attract, urge, pull and even monopolise focal attention.

This conclusion clearly notes the need for delving deeper in the phenomenological analysis of pain through its relation with sensitivity. The most promising idea in Husserl's thinking in this respect points out that somaesthetic sensitivity is, in principle, tactile. The intimate spatiality of my body reaches as far as my tactile affective field reaches; so that the other forms of sensations and sensitivity (auditory, visual) are somaesthetic due to their involvement in tactile sensitivity, due to their inseparability from the tactile field. Husserl expressly indicated that any physical pain is, in fact, an intra-tactile affection (Husserl 1952, p. 150), but the founder of phenomenology did not explore the possibilities or the difficulties that this approach generates. The works of Buytendijk, Scarry, Leder, Toombs, Grüny, Geniusas, among other names of importance, have not clarified why the field of tactile sensitivity defines the lived body and is the locus of pain.

In any case, the phenomenological focus that I just sketched can have certain practical and, in particular, clinical interest. The patient's pain assessment scales that are used in medical practice: verbal description, numeric, visual analogical scales, and those of painted faces, could be complemented on the basis that the intensity of pain always involves a relation with the rest of the field of experience. What is not painful within the current experience, what has another attentional status, is revealed as important for determining the scope of the pain itself. However, the usual scales are limited to classifying and assigning a value to the painful experience and tend precisely to omit this greater complexity. The "pain diaries" do take into account, of course, the relationships between pain and daily activities. This theoretical model of the three or rather four dimensions integrating the attentional structure, in a changing and precarious balance, can serve as a conceptual instrument of support when analysing the information and data that the patients transmit in the diaries. Something similar may be said with regard to non-drug treatments for pain. The so-called "techniques that improve distraction" deserve having a more elaborated, more subtle, theoretical model, which fundamentally has to respond to a phenomenological inspiration. This last element can contribute to strengthening these techniques, although it also contributes clarity about the limits that make it impossible "to be distracted" entirely from pain.

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Chapter 11
Should Investigators Introspect on Their Own Pain Experiences as Study Co-Participants?

Simon van Rysewyk and Carl L. von Baeyer

Abstract The question of investigators introspecting on their own personal pain experiences in pain studies has received little attention in the literature. Study of this question may reflect ethical reservations about the many points at which self-interest may lead us to introspect on personal experiences through personal biases that in turn impair professional decision-making and perception. Despite this valid concern about research co-participation, we offer three reasons why investigators can introspect on personal pain as co-participants in their own pain studies. First, there is historical precedent for investigator participation and co-participation in scientific pain research using introspection as a study method. Second, general concerns about variability in self-report based on introspection on pain experience partly derive from true fluctuations in personal pain experience and perceived interests in self-reporting pain, not simply error in its scientific measurement. Third, the availability of the experiential–phenomenological method, a mixed research method for the study of human experiences, allows investigators to co-participate with naïve participants in their own studies by encouraging passive introspection on personal pain experiences.

S. van Rysewyk (✉)
School of Humanities, Department of Philosophy and Gender Studies,
University of Tasmania, Private Bag 41, Hobart 7001, Australia
e-mail: simon.vanrysewyk@utas.edu.au

C.L. von Baeyer
Department of Clinical Health Psychology, University of Manitoba,
Winnipeg, Canada

C.L. von Baeyer
Department of Pediatrics and Child Health, University of Manitoba,
Winnipeg, Canada

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1 I Had a Strange Experience Recently

In the fall of 2013, I (CvB) acquired a walking treadmill.[1] I raised my desk and placed the treadmill under it, allowing me to walk while I work. I quickly learned to walk, think, and dictate text to the computer with little cross-task interference. Walking at 2–3 km/h, I could comfortably cover 5–10 km a day, get some exercise, burn a few hundred calories and do some writing. This happy outcome lasted for about 6 weeks.

Then this arrangement fell apart for what seemed like a ridiculous reason. When I walked on the treadmill for progressively shorter periods, a powerful aversive sensation would build up in the soles of my feet. With every step, it felt as if I had one or more pieces of small, sharp gravel in my shoes. I kept stopping to inspect my shoes and socks and never found anything that could account for the sensation. Yes, perhaps there were tiny irregularities in the insoles of my shoes or inside my socks, but there was nothing like the sharp gravel my soles were reporting to my brain. I would rate the pain intensity at 3/10 and the unpleasantness at 8/10. The pain would stop a few minutes after I stopped walking on the treadmill, but would return more quickly and strongly each time I resumed. Interestingly, the problem never occurred during ordinary walking. I could easily walk 5 km outdoors without experiencing these aversive sensations in the soles of my feet.

At this point, two months after installing the desk treadmill, some serious negative thinking set in. Whenever I thought about using that computer, I told myself, “I wasted $1200. I’ll never be able to use this treadmill. I’ll have to go back to sitting at a desk. So much for my fitness plan,” and similar discouraged thoughts. I tried to figure out what was wrong and what to do to make it better, but got nowhere. When I did attempt to walk on the treadmill while working, I could not concentrate on the work at all: my mind was almost fully occupied with the sensation in my feet and with those negative thoughts. Realizing this led to a vicious cycle of increased negativity: “What an idiot—I ought to be able to focus on my work!”

After several weeks of this struggle, I finally remembered what should have been obvious to me as a pain researcher and as a person who has observed quantitative sensory testing in both clinical and research settings. I was experiencing neural sensitization to the prolonged and regular repetition of identical physical stimuli produced by walking on the treadmill.

In what has been called the “Chinese water torture” (which is probably not Chinese in origin and was described in Europe in the sixteenth century), a small drop of water falls at regular intervals on the restrained victim’s forehead, becoming

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[1] Section 1 of this chapter is adapted from von Baeyer CL. Sensitization and catastrophizing: Introspection confirmed experimentally. *Pain Research Forum*, 25 February 2014. Accessed from http://painresearchforum.org/forums/discussion/37588-sensitization-and-catastrophizing-introspection-confirmed-experimentally on September 15, 2016. The material is shared under a Creative Commons License (https://creativecommons.org/licenses/by-nc-nd/3.0/).

agonizing after a while. This is a classic example of sensitization. I realized that putting my feet down in a mechanically regular pattern had the same effect. The feelings in my feet corresponded to the classic phenomena of sensitization including allodynia (interpreting a normal touch as painful) and windup (progressively stronger response to the same stimulus).

With this insight, the cure was obvious: I had to vary the stimulus. This turned out to be easy. When the sharp gravel sensation starts, I kick off my shoes and continue walking in my socks or bare feet; if I am already barefoot when the sensitization begins, I put my socks and shoes back on. I vary the speed setting on the treadmill so that my footfalls occur at different intervals. I vary the way I walk, placing weight on different parts of my feet. Sometimes I just stand for a while. These actions vary the frequency, location, intensity and quality of the stimuli on my feet, thus reducing the sensitization. Because of these minor changes, I can continue my work with little interference. The sensitization still occurs, but I notice it only if I direct my attention toward my feet. The mild sensations (pain 1/10, unpleasantness 2/10) do not bother me because I know what to do. In other words, the sensitization is not amplified by catastrophizing and helplessness.

Coincidentally, the day after I wrote the above, an article by Salomons et al. (2014) was published online in the journal Pain, providing experimental confirmation of what I learned through direct experience. In this study, repeated thermal stimuli were applied to participants' forearms, producing hyperalgesia. Half the participants were given a cognitive intervention to reduce their stress response to the painful stimuli by identifying negative cognitions and reappraising the situation. In comparison with a control condition, the cognitive intervention led to reduced unpleasantness ratings. The authors concluded, "Reduction in secondary hyperalgesia was associated with reduced pain catastrophizing, suggesting that changes in central sensitization are related to changes in pain-related cognitions. Thus, we demonstrate that central sensitization can be modified volitionally by altering pain-related thoughts."

2 Meanings of this Experience

Three features of this experience can be mentioned that help describe its meaningfulness. First, the experience was characterized by a variety of worries or anxieties. There was the occupational-anxiety that, "I'll have to go back to sitting at a desk…," and the punishment-anxiety, "What an idiot—I ought to be able to focus on my work!" or, "I wasted $1200. I'll never be able to use this treadmill." These anxieties resulted from wanting the pain to stop, feeling foolish for not knowing how to achieve this or even knowing what caused the pain, and then producing self-critical and anxious self-statements. This recursive pattern is termed "pain catastrophizing," defined as self-focused exaggeration of the danger of pain, feelings of helplessness, and an inability to stop pain-related negative thoughts during, following, or in anticipation of pain (Sullivan et al. 1995). Pain catastrophizing reveals that pain involves much more than an aversive bodily sensation. It presents psychological tensions derived from a complex mélange of emotional, cognitive, and social sources.

Second, pain motivates thinking about what must be done to relieve or stop it, then acting to achieve this. At first, I was uncertain about what exactly that might be: "…perhaps there were tiny irregularities in the insoles of my shoes or inside my socks." Unsure, "I kept stopping to inspect my shoes and socks," but "I never found anything that could account for the sensation." Eventually, I realized that my pain was caused by sensitization. Normally, pain has a stake in eliminating itself, as it were, and motivates a person to think and act in investigative ways to achieve pain relief. Pain is an intrusion; so, how ought I to resolve it?

Recognizing through introspection that a variety of anxieties were in play also involves recognizing that particular types of pain anxiety may be more meaningful than others. Trying to find a solution to personal pain motivated by thoughts of self-punishment is one thing; initiating a train of thought and investigative action to best serve patients or research is another. Pain-related anxiety that helps us decide the right thing for others seems more meaningful and productive than the punishment anxiety, which goads us for not being smarter.

The final feature to highlight is that I was a participant in my own pain investigations. The pain that I had was part of my personal experience: I was at once both passive observer and active investigator. To learn why I had it, I thought intently about what I ought to do to achieve relief. Of course, in most psychophysics experiments, investigators learn about pain experience from data collected directly from study participants, not themselves. Participants provide information to investigators in verbal reports while thinking about—'introspecting on'— their own pain experience as directed by the investigators within the context of a study. Most scientific investigators view this traditional paradigm as scientifically objective and correct. They might have ethical reservations about including themselves as co-participants and using self-introspection as a scientific method. The multiple points at which self-interest may unfairly bias professional decision-making and perception presumably inform this reservation. Self-interest can lead us to experience qualities through our biases. Biases have numerous origins, including the past or present literature, imagining how something works, and self-interest in supporting one's theories and one's past results. Investigators become susceptible to bias when they form their hypotheses and design and conduct their studies, and there are many ways they can transfer their biases to study participants. This particular concern about introspection led to classical introspectionism being discredited as a psychological research program in the early twentieth century (Boring 1953).

Despite these valid concerns about investigator-introspection, we (SvR; CvB) now offer three reasons why investigators can introspect on their own pain experience as co-participants in their own pain studies. We describe one methodology that usefully incorporates investigator-introspection, the experiential–phenomenological method (Price and Aydede 2006). A noteworthy feature of this method is that investigators co-participate in their own studies by encouraging *passive*, not self-interested, introspecting on personal experiences.

3 Three Reasons for Investigator-Participation and Introspection

3.1 Historical Cases of Investigator-Participation in Pain Research

In the early twentieth century, scientists commonly viewed self-experimentation an essential part of medical research. Self-exposure to untested interventions was believed the most ethical way to assess human responses to those interventions, and to catalyse further research (Dresser 2013). Some of this research helped to found new scientific fields. Respiratory physiology was one such field, formed in the 1920s through self-experiments conducted by scientist John Haldane and colleagues. In 1984, physician Barry Marshall ingested Helicobacter pylori, which helped to establish the link between H. pylori and gastric pathology, and in 1992, self-experiments conducted by Mike Stroud and Ranulph Fiennes in Antarctica advanced understanding of nutrition in extreme conditions.

Self-experiments to study pain experience have been published by Sir Head (1920), Woollard and Carmichael (1933), Landau and Bishop (1953), Price (1972), Price et al. (1977), and Staud et al. (2001, 2008), to name only a few significant investigator-participants who studied pain. William Landau and George H. Bishop conducted standard psychophysical research on themselves to study the qualitative differences between “first pain” and “second pain” (i.e. “double pain”; later termed epicritic and protopathic pain) (Landau and Bishop 1953). Initially, Landau and Bishop identified through introspection the differential experiential qualities between first and second pain, followed by scientifically informed speculation about the mechanistic difference between the two types of pain. They discovered that first pain was sharp or stinging, well localized, and brief, whereas second pain was dull, aching, throbbing, or burning, and poorly localized, and longer lasting. The qualities of second pain were felt when skin C-nociceptors were stimulated.

These findings were subsequently confirmed by Price (1972) based on researcher and naïve participant introspective reports. Temporal differences between first and second pain were introspected on and mechanistically explained in terms of central temporal summation in studies by Price et al. (1977), and Staud et al. (2001, 2008), using investigator- and naïve-participants.

Conducting self-experiments to study referred pain, collaborators Herbert Woollard and Edward Carmichael observed that 300 g of weight placed on the right testicle produced slight discomfort in the right groin, while 650 g on the right testicle caused severe pain on the right side of the body. They confirmed that injury to the testicles caused pain to be referred throughout the body. For instance, as the weight on the testicle increased to over 900 g, they reported pain "of a sickening character" not only in the groin but also spreading across the back (Woollard and Carmichael 1933).

Self-experimentation on pain has on occasion led to surprising results. The psychologist B. Berthold Wolff self-experimented in his pain psychophysics laboratory, varying thermal pain which was produced at that time by briefly shining a strong light on a spot on the forearm blackened with candle black for a calibrated time and intensity of exposure (Hardy et al. 1940). On one occasion, Wolff pushed the button to deliver the noxious stimulus, but then something unexpected happened: he screamed with pain, which was brief but intense and filled his whole body. He described it as the most intense whole-body pain he had ever experienced. Wolff later discovered that the light stimulus had been knocked off its correct aim, and had missed his forearm altogether and instead diffused onto the opposite wall where it created a very strong flash of light throughout the normally dark room. Wolff speculated that, as he was expecting to feel pain, the unexpected flash of strong light had the same effect, producing an experience of pain.

It is unclear if investigators today independently conduct self-experiments or co-participate in their own pain studies. The convenience of recruiting participants from university classes and the internet may have made self-experimentation or co-participation of pain seem somewhat redundant to researchers. The Declaration of Helsinki advises on conducting ethical research using patients and healthy volunteers, although it is unclear if this is reason enough for challenging independent self-experimentation or investigator co-participation. In self-experiments, the researcher is both investigator and single participant, so the requirement for informed consent could be waived. Still, there is clear historical precedent for scientific investigators successfully observing and analyzing their own experiences of pain. The results of such published self-experiments have been integrated into the body of knowledge of pain, and replicated in numerous studies using naïve participant introspective reports and standard scientific methods.

3.2 General Concerns About Self-Report Based on Introspection

Objections to investigator-participation and self-introspection as a scientific method partly derive from general concerns about the reliability of verbal self-report based on introspected pain. Apkarian et al. (2011) have claimed that pain assessment based on verbal self-report uses limited measures unsuitable for discriminating between types and causes of pain, and for assessing the differential impact of interventions, inter-individual differences and prescribed medication doses. Wortolowska (2011) has stated that replacing pain self-report with neuroimaging data would improve the accuracy of pain measurement and treatment efficacy. Related to Wortolowska's concern, a philosophically inclined scientist may complain that pain scientists who endorse pain as a personal, private experience also follow the demands of established scientific research methodology that upholds the objectivity of evidence and publicly verifiable results. So, how is the pain scientist objectively to know pain when it is necessarily personal?

The first point to make in response to claims that self-report based on introspection of pain experience is unreliable is to acknowledge that self-report of pain is indeed variable. But variability of pain self-report is due to true fluctuations in pain experience itself, and not just to measurement error, as Apkarian et al. (2011) claim (Robinson et al. 2013). The observation that self-report uses limited measures unable to discriminate between types and causes of pain is correct if verbal self-report is limited to pain intensity. But the location, sensory qualities, and temporal features of pain can also be self-reported using existing assessment tools, all assisting in differentiating between types and causes of pain and assessing the differential impact of interventions, inter-individual differences and prescribed medication doses (Flor et al. 1992; von Baeyer 2006; Hoffman et al. 2007; Schiavenato and Craig 2010). There is evidence supporting the reliability and replicability of several self-report pain scales in the pain literature (e.g. Rosier et al. 2002), and a large proportion of the variability in self-report of pain is predictable (e.g. Staud et al. 2003; O'Leary et al. 2016). Thus, predictability of self-report of pain based on introspection suggests that the observed variability is not all erroneous.

Wortolowska (2011) argues for replacing pain self-report with neuroimaging data on the assumption that neuroimaging is more reliable than self-report. However, few data assess the reliability of neuroimaging measures (e.g. Letzen et al. 2016; Woo and Wager 2016), much less compare the reliability of such measures with the reliability of self-report (Robinson et al. 2013). Letzen et al. (2016) studied the test-retest reliability for functional brain connectivity (fcMRI) of pain-related brain regions, and self-reported pain (through visual analogue scales [VASs]) during a thermal pain task in 32 naive participants. Intraclass correlation coefficients for fcMRI values varied widely (range = −.174 to −.766), and intraclass correlation coefficients for VAS scores ranged from .906 to .947. Overall, self-reported pain was more reliable than fcMRI data.

Seemingly forgotten by Wortolowska (2011) is the practice in standard pain neuroscientific research of anchoring neuroimaging data in relation to self-report or behavioural measures. In preclinical animal pain research, reliance on behavioural measures predominates, but animal studies indirectly reveal something about the personal experience of pain in humans, so some results from these studies await confirmation in studies using humans introspecting on their own pain experiences (Price and Aydede 2006). Available evidence supports the reliability of self-report of pain and its use in current pain neuroscientific research. However, the reliability of neuroimaging data is currently unknown (Rosier et al. 2002; Staud et al. 2003). Finally, it is relevant to note that the validity of neuroimaging of pain was established by correlating brain activity with self-report of pain (Coghill et al. 2003).

Linguistic competence slowly emerges in the course of normal human development (Craig 2006, 2009; Stanford et al. 2005). It is not fully available to all individuals; including neonates, infants and young children, individuals who do not have the language of the pain caregiver, and those individuals with acute, chronic or acquired cognitive or physical disabilities (Hadjistavropoulos et al. 2011). Even individuals with effective linguistic and social skills can find it difficult to describe personal pain (Hadjistavropoulos et al. 2011). This is partly because pain is a complex personal experience that involves somatosensory, negative emotional and cognitive features. In the future, neuroimaging could be used as a proxy measure of pain in patients with compromised ability to provide verbal self-report of pain, such as persons with neurological impairment, infants or very young children, or adults with dementia (Davis et al. 2012; Robinson et al. 2013).

Psychological studies show that pain self-report may confound pain experience with the need to influence those people attending to what the person says (Craig 2009; Schiavenato and Craig 2010; Hadjistavropoulos et al. 2011; McCrystal et al. 2011). The audience may not be disposed to care for the person in pain; people may respond by ignoring the person in pain, punishing them for the pain report, or exploiting them because they are vulnerable (Craig 2009; Schiavenato and Craig 2010). Some pain patients have skill in negotiating the social complexities of health care settings, whereas others require devoted clinical attention (Jensen et al. 2001; Elander et al. 2009). Arguably, variability in self-report data not only derives from true fluctuations in personal pain experience, but also from a person's perception of the consequences of providing the self-report.

To answer the philosophical scientist about how pain science can objectively know pain when it is a personal experience is to reply that pain science has been studying pain for many decades already, using established scientific methods to generate reliable and replicable data about pain. Much pain research has successfully correlated the fundamental attributes of pain experience to mechanism; for example, neuron categories and pathways essential for pain (Bushnell et al. 1983; Price 2000; Price et al. 2002; Price and Barrell 2012) and the mechanisms of pain reduction and the effectiveness of pain-reducing treatments (e.g. Melzack 1984). Still, a philosophical dualist may not be satisfied with this: "Sure, personal pain depends on brain activity, and pain science has measured it and has come to know it; but at the end of the day, pains are knowable only through personal experience, which is private to the individual. Pain science knows brain correlates of pain, not pain itself" (e.g. Chalmers 1996).

It is not brain activity alone, but brain activity as related to personal pain experiences that is the focus of much pain research (Price et al. 2002; Price and Aydede 2006; Price and Barrell 2012). Pain science has undertaken a combined research project of scientifically relating pain experience to mechanism without rejecting an objective methodological approach in collecting data about personal pain. This point is evident in psychophysical experiments that use paradigms of discrimination, detection and direct scaling (e.g. psychophysical rating scales, quantitative somatosensory testing, and post-experiment questionnaires), and in studies that associate self-report data with data derived from similarly designed neuroscientific studies (Price and Aydede 2006; van Rysewyk 2014). In such studies, participants detect and make qualitative judgments about perceived qualities of sensations, feelings, emotions or cognitions, based on quantitatively controlled stimuli.

3.3 The Experiential–Phenomenological Method (Price and Aydede 2006)

The experiential–phenomenological method (EPM) is a mixed research method for the study of human experiences such as anger, anxiety, and pain (Barrell and Barrell 1975; Price and Barrell 1980, 2012; Price et al. 2002; Price and Aydede 2006). Based on phenomenology and psychometrics, it aims to discover common meanings ("common factors") of experiences and relationships between such common meanings and brain activity (Table 1).

Although the results obtained from the horizontal phase have scientific value of their own, the full meaning of these results requires integration with neuroscientific and psychophysical methods and data. A unique feature of this method compared with contemporary methods to study human experience is the involvement of investigators as co-participants introspecting on their own personal experiences.

The horizontal phase consists of 4 stages: (1) questioning and observing; (2) describing experiences in the first-person; (3) understanding experiences through finding common experiential meanings (factors) and their interrelationships; (4) application of quantitative methods to test generality and functional relationships between common factors (Table 2).

In stages 1–3, researchers are the subjects or participants of their own research questions. Stage 4 employs conventional psychometric methods (e.g. psychophysical ratio scales) to test the study hypotheses in other human participants (i.e. non-researcher subjects).

In Stage 1 of the horizontal phase, "questioning and observing," the researcher or group of researchers acting as co-participants pose a general open question to themselves about their experiences following administration of the experimental intervention; for example, "What is it like to experience the unpleasantness of laboratory pain, such as immersion of the hand in a heated water bath?" (Price and Aydede 2006) In responding to the study question, participants adopt a passive stance to what appears in personal experience without theorizing, explaining or

Table 1 The experiential–phenomenological method (Price and Aydede 2006)

Method task	Method phase
Identify common factors within experiences	Horizontal (first-person) "phenomenal structure"
Identify common factor interrelationships	
Identify common factor-brain relationships	Vertical (third-person) "brain structure"

Table 2 Stages of the "horizontal phase" in the experiential–phenomenological method (Price and Aydede 2006)

Horizontal phase stages	Study participants
1. Question and observe	Investigator-participants
2. Describe from a personal perspective	
3. Find common factors and their interrelationships	
4. Use psychophysical methods to test generality and functional relationships between common factors	Non-investigator-participants

otherwise judging the meaning of the experience itself. Active forms of introspection can filter qualities of experiences through personal biases, altering the meaning of the qualities experienced. In contrast, passive observation requires impartial acceptance of what appears in experience. Indeed, biases can be part of what is passively observed by the participant. Including investigators may help minimize the impact of investigator biases, especially when several investigator-participants are included in a study. Study results could be compared across participants and checked for possible biases. However, since it can be difficult to passively attend at the moment one is experiencing something, especially during an aversive or surprising experience, passive introspection often involves immediate retrospective attention to what has just been presented in experience. This form of passive observation has been used in certain forms of psychotherapy (Perls et al. 1951).

The features of experience relevant for passive observation are internal qualities of experiences rather than external causal stimuli that are correlated in some way with pain feelings, sensations or pain-related thoughts. Thus, the focus of Stage 1 is not to investigate *why* pain might occur (i.e. to study the properties of the eliciting noxious stimulus), but *how* pain is presented to the participant in the form of qualities of sensations, emotions, and thoughts that convey certain meanings. This approach is in line with phenomenology and contrasts with prior conceptions of pain that represented pain in terms of causal stimuli (Sternbach 1968; Mountcastle 1974).

In Stage 2, "describing experiences in the first-person," investigator-participants generate personal accounts of their pain experiences; for instance, "My hand was immersed in a 47° C water bath when intense burning and throbbing occurred in my hand. Feel bothered by this and distressed. Is it going to get stronger? Concern. Hope my hand isn't going to be scalded."

During the course of the study using this method, commonly experienced meanings or factors may begin to emerge. This marks Stage 3, "understanding experiences through finding common factors and their interrelationships." Thus, a subject report, "Is it going to get stronger? Concern. I hope my hand isn't going to be scalded," can be concisely described as, "I think and feel concern for future consequences related to this pain." "Feel bothered by this and distressed" can be characterized as "I have a feeling of intrusion related to this pain." These categories

simon.vanrysewyk@utas.edu.au

of characterizations lead to the formation of *definitional hypotheses* (experiential factors commonly present during a pain) and *functional hypotheses* (common factor interrelationships) agreed upon by the investigator-participants. In Price and Aydede's (2006) hypothetical pain study, sample definitional hypotheses could be:

- "an intense burning throbbing sensation in the hand"
- "an experienced intrusion or threat associated with this sensation"
- "a feeling of unpleasantness associated with this felt intrusion or threat"

Sample functional hypotheses could be:

- "felt unpleasantness should increase as a function of experienced intrusion or threat"
- "experienced intrusion should increase as a function of the intensity of burning, throbbing sensation"

Next, the definitional and functional hypotheses are used in standard quantitative testing (e.g. psychophysical testing) using naïve participants (e.g. university undergraduate students) with no knowledge of the hypotheses of the study. This is Stage 4, "application of quantitative methods to test generality and functional relationships between common factors." In our hypothetical pain experiment, participants would rate not only pain sensation intensity and pain unpleasantness, but also their sense of felt intrusion or threat and concern for future consequences.

Investigator-participation might be a useful way for investigators to connect with naïve participants as coequal partners in all phases of pain research: co-researching ideas for new study designs; shaping the funding, conduct and dissemination of studies; co-assessing protocols for their impact on patients with pain; guaranteeing participant-focused studies of pain experience (Woolf et al. 2016). Such 'authentic engagement' between investigators and naïve participants is respectful of patients, which could prove especially meaningful to vulnerable persons with chronic pain. It will help pain scientists study aspects of pain experience and outcomes that are meaningful to patients based on their lived experiences of pain and help choose methodologies that optimize data collection and validity.

Using neuroscientific techniques such as fMRI and EEG, the final "vertical phase" attempts to correlate the results of the initial horizontal phase with brain activity to establish possible causal relationships. Dynamic patterns of brain activity that co-vary with the different common meanings of pain could be identified. Finally, in stand-alone neuroscience studies, previously published pain meanings and their interrelationships may be used to design pain neuroscientific experiments ("front-loading phenomenology") (Gallagher and Sørensen 2006). Conveniently, "front-loading phenomenology" avoids the need to train research participants.

One constraint affecting traditional pain psychophysics studies that correlate personal reports with brain activity is the timing of data collection. In psychophysics experiments, experiential data are usually obtained either in intermittent periods or at the end of an experiment, and rarely simultaneous with brain data collection (e.g. Price 1972; Price et al. 1977). This experimental practice reduces the amount of personal pain and brain information obtained by investigators (Price et al. 2002; Price and Aydede 2006; Price and Barrell 2012). Further, pain can last several seconds, a time-scale that can upset a participant's personal sense of timing and affect overall precision of experiential pain data. The method of neurofeedback may help to address this particular challenge. Very briefly, neurofeedback enables a participant to search for relationships between simultaneous presentations of experiential qualities and brain activity. Brain activity concurrent with experience (e.g. a pain) is visually represented on a computer screen via a brain-computer interface. The participant tries to control this brain information, simultaneous with personal experience, increasing or decreasing it to a specified threshold level (e.g. reduced pain magnitude), with a reward when this threshold is achieved (e.g. pain relief). deCharms et al. (2005) found that chronic pain patients were able to attenuate painfulness only when levels of pain magnitude and brain activity were concurrently available to personal awareness.

4 Conclusion

The question of investigators introspecting on their own personal pain experiences in pain studies has received little attention in the literature. We offer three reasons why investigators can co-participate in their own pain studies: (1) there is historical precedent for investigator participation and co-participation in scientific pain research using introspection as the study method; (2) variability of self-report based on introspection of pain derives not merely from error in pain measurement, but also from true fluctuations in pain experience; (3) the 'experiential–phenomenological method' (Price and Aydede 2006), a mixed research method for the study of human experiences, allows investigators to co-participate with naïve participants in their own studies by passively, not self-interestedly, introspecting on personal pain experiences.

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Chapter 12
The Moral Experience of the Person with Chronic Pain

Ian Edwards

Abstract There is an ethical landscape associated with the understanding and management of the person with chronic pain, which spans a range of structural, policy, educational and clinical issues. This ethical landscape has normative (what one ought to do…) and non-normative (what one actually does…) terrains. Healthcare providers and patients alike encounter a moral tension between these normative and non-normative ethical terrains. This moral tension, if unrecognized and unresolved, can have damaging effects on a person's sense of 'self', sense of agency and therefore their ability to effectively participate in actions and activities required towards better health. The Ethical Reasoning Bridge is an ethical reasoning model that conceptualizes how healthcare providers can negotiate this normative and non-normative ethical landscape in terms of their decision-making in clinical practice. The use of narrative reasoning can assist healthcare providers to support patients to develop narrative capabilities (speaking, acting, telling and imputing personal responsibility for actions). If healthcare providers can learn to negotiate the normative and non-normative ethical terrains which form the landscape of chronic pain ethics, we can assist persons with chronic pain to develop narrative capabilities, and also identify 'a wider moral space' (Kleinman in What really matters: living a moral life amidst uncertainty and danger. Oxford University Press, Oxford, 2006) in which they can begin to resolve the moral dilemma they face in having to comply with the normative expectations of others at the cost of denying their own lived experience.

I. Edwards (✉)
School of Health Sciences, University of South Australia,
GPO Box 2471, Adelaide, SA 5001, Australia
e-mail: ian.edwards@unisa.edu.au

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1 Introduction

What does it mean to talk about the moral experience of the person with chronic pain? And would the answer, assuming that there is such an experience, have any relevance in either clinical or ethical decision making in the diverse range of issues (physical, psychological, pharmacological, ethical and practical) which arise in the clinical management offered by various health care providers?

McGee et al. (2011) conducted a study in which focus groups were convened in five major cities in the United States. These focus groups consisted of key stakeholders thinking about the issues involved in the management of persons with chronic pain. These stakeholders included persons with chronic pain, healthcare providers, insurance and pharmaceutical representatives, law enforcement officers and advocacy groups. Arising from these in-depth conversations was the recognition and description of a landscape of 'chronic pain ethics'. This ethical landscape included recognition of a range of structural, policy, educational and clinical issues resulting in the following call:

> … chronic pain ethics needs to be focussed upon and framed by the experiences of people living with chronic pain. A moral foundation is required, based in an understanding of the suffering experienced by people whose (pain) experiences have been invalidated, who continue to encounter a culture of stigma and distrust, and find their dignity undermined by a system and a society that appears disinterested in taking a stand for the care and consideration to which they are entitled (McGee et al. 2011, p. 1383).

In this chapter I will argue that the moral experience of the person with chronic pain forms part of a larger landscape of a chronic pain ethics which has normative ("what one ought to do") and non-normative ("what one actually does") terrains and, furthermore, that it is in understanding the relationship between these two moral 'poles' that ethics, commonly understood as the regulation of professional duties, obligations and behaviours, can also be seen as having a valuable role in the therapeutic and agentive process for—and with—the person with chronic pain (Edwards et al. 2014).

As suggested above, the normative parts of this ethical landscape are often its most familiar and recognized parts, having to do with the duties and obligations of healthcare providers, as laid out in the respective professional guidelines, standards and codes of conduct in each discipline. Even so, meeting these ethical obligations is not necessarily straightforward and can sometimes take healthcare providers to uncomfortable places. Regardless of health discipline or practice setting, we can be exposed, as healthcare providers, in our attempts to deal with the suffering and tragedy of others; experiencing stress ourselves and, at times, feeling incompetent to deal with what is being asked of us. A leading physician, writing in his capacity as both a doctor and, at the time, as President of the American Academy of Pain Medicine, told of his ethical distress—indeed, his torment—at the suicide of his patient (Webster 2014). He had been caught between his patient's cries for help, and not coping with ongoing, intractable pain and his perceived professional obligation to reduce, over time, his patient's opioid medication. The physician stated unequivocally that his patient never overused his medication, neither showing signs of abuse nor addiction. Yet he felt compelled to reduce his average daily dose, telling his patient in the face of his concern, "It will get better." Ironically, his response to his patients suffering, he lamented, was diminished by his own fear of receiving regulatory sanctions, together with the stamp of unethical practice, if he did not comply with current policies of opioid management (Webster 2014). Even good practitioners can let their patients down. None of us is quarantined from this possibility; caught in a tension of competing, even conflicting normative ethical obligations, and doing less than we might otherwise like to do if circumstances were somehow different. The notion of persons with chronic pain having normative ethical obligations is less clear or obvious compared with health practitioners but is, nonetheless, real and discussed below.

The non-normative parts of this ethical landscape surrounding chronic pain provide a context for understanding how the experiences of both healthcare practitioners and patients are enmeshed in and shaped by larger social and political factors at work in both healthcare systems and wider society. The conclusions of McGee et al. (2011, p. 1383) regarding the experience of people with chronic pain: "whose experiences have been invalidated," "who continue to encounter a culture of stigma and distrust" and "who find their dignity undermined by a system and a society" bear testimony to this point. Yet it is important to recognize that the "normative" and the "non-normative" forms of chronic pain ethics are part of the same larger landscape. The moral experience of the person with chronic pain, although involving the exploration of a person's lived experience, and therefore unique and individual is, nevertheless, also an expression of wider healthcare, and social, cultural and political systems that impact the sense of agency of both patients and health care providers, who each desire better care for persons with chronic pain. The challenge for both healthcare providers and persons with chronic pain alike is to learn how to negotiate their way in this diverse ethical landscape by understanding the different kinds of inquiry, decision-making and action necessitated by it.

2 The Moral Injury to the Self in War

A century ago, during World War 1, the medical practitioner and psychiatrist WH Rivers treated men from the trenches in France who were suffering what was then termed "shell shock." This term conveyed the "erroneous but culturally legitimizing idea that physical trauma, such as concussion, from bombardment with high-explosive munitions was responsible for the symptoms" these men experienced (Kleinman 2006, p. 204). These symptoms were varied in severity and scope but included paralysis, mutism, psychological deafness, nervous tics, stuttering, panic attacks, nightmares, sleep disturbances and amnesia (Barker 1992).

It became apparent to these sufferers, their doctors and other interested parties such as politicians and higher-ranking officers in the armed forces, that these symptoms:

> served the highly practical purpose of removing the soldier from the extreme danger of the war zone. The diagnoses were (*therefore*) stigmatized and sufferers were popularly regarded as malingerers, cowards or madmen (Kleinman 2006, p. 205).

Rivers argued that these disorders were not due to physical head trauma but arose from psychological trauma and that this did not make them “any less legitimate forms of pathology deserving humane care and technically competent treatment interventions” (Kleinman 2006, p. 205). Rivers treated men, mostly officers, who, he believed, were:

> experiencing neurotic symptoms because of conflicts between inner feelings, largely unconscious, of self preservation and societal and military values that required them to be brave and steadfast in the trenches, where they could neither flee nor fight but had to passively persevere under shelling (*described by one writer as being like “hurricanes of steel”*) that appeared to kill soldiers randomly and over which they could exert no control at all (Kleinman 2006, p. 208).

Rivers helped his patients (mainly British army officers) face what was really at stake which was, in his opinion, the resolution of a moral dilemma: they were conflicted between their deep and instinctual need to survive and their fears of disgracing themselves in the ultimate test of manhood as normatively defined by their British society at the time. The challenge for these men lay in their attempts to maintain or retrieve a good and moral self in the untenable position that their society had placed them. It may not be surprising for readers to learn that many U.S. veterans of wars in Afghanistan and Iraq, who are sufferers of Post Traumatic Stress Disorders (PTSD’s), also “feel morally tainted by their experiences, unable to recover confidence in their own goodness” (Brooks 2015).

Rivers approach to treatment then could be described as “ethnographically informed” (Kleinman 2006, p. 210) in that it involved helping patients gain insight and self-knowledge (the latter he termed “autognosis”) not only about their own psychological state but also about the social, cultural and political context which had shaped the conditions for their moral dilemma. Interestingly, it is now increasingly recognized that the suffering experienced by Afghanistan and Iraq veterans due to PTSD’s, is to be overcome, at least in part, by framing this suffering in terms of the moral dimensions of their experience and not just the psychological ones (Brooks 2015; Sherman 2015). In some rehabilitation programs, for example, veterans are assisted to reflect on their experiences and recognize just how much choices are limited when one is faced with a random, tragic situation; and to then reconsider how responsibility and blame for terrible things should be apportioned (Brooks 2015; Sherman 2015). Treating the pathological effects of memory as in PTSD, involves therefore an understanding of the politics of violence and trauma and the vital question of how to live a moral life under such dangerous conditions (Kleinman 2006, p. 213). Therefore, these approaches mirror, to some extent, Rivers’ approach to the WWI soldiers he treated.

In her novel, “Regeneration,” Pat Barker recounts a series of therapy encounters between Rivers and his pacifist patient, the poet Siegfried Sassoon, which would, in part, lead to Rivers’ conclusion that:

> …it was prolonged strain, immobility and helplessness (*in the confinement of the trenches*) that did the damage, and not the sudden shocks or bizarre horrors that the patients themselves were inclined to point to as the explanation for their condition. That would help to account for the greater prevalence of anxiety neuroses and hysterical disorders in women in peacetime, since their relatively more confined lives gave them fewer opportunities of reacting to stress in active and constructive ways. Any explanation of war neurosis must account for the fact that this apparently intensely masculine life of war and danger and hardship produced in men the same disorders that women suffered from in peace (Barker 1992, p. 222).

Rivers’ early observation that underlying the ongoing problems of these men from the trenches was an unresolved moral dilemma regarding the integrity of the self was also accompanied by the insight above, expressed in the context and language of a century ago, that the conditions of “prolonged strain, immobility and helplessness” formed the genesis of these problems these men experienced. This then enabled him to generalize this finding to others and their experiences. In addition, in turn, this points us to the experience of the person with chronic pain and the possibility of it, too, having moral dimensions and for not entirely dissimilar reasons.

3 The Moral Struggle for the “Self” in Chronic Pain

Rivers understood that norms in the social world could be expressed in and become “part” of the body such that:

> Cultural values could guide our gestures, our posture, and even our emotions and our sense of who we are in the direction of what the group regarded as good and desirable. Thereby, we become normal and moral human beings—normal and moral in the eyes of a particular group or society, that is (Kleinman 2006, p. 226).

In his phenomenology of perception, Merleau-Ponty (1962, p. 7) would later offer a concept of the body where bodily comportment “not only identifies the body as “mine” but also reflects the body as a social and cultural entity.”

A number of studies using an applied phenomenological method known as Interpretive Phenomenological Analysis (see Larkin et al. 2011), and which explored the lived experience of persons living with chronic pain, were critically appraised by Smith (2011) and by Edwards et al. (2014). The collated findings of these critically appraised studies provided a picture of the person with chronic pain as caught in a tension. On the one hand, they experience the need to describe their condition in objective, pathological and/or biomedical terms (Snelgrove and Liossi 2009; Smith 2011; Snelgrove et al. 2013) firstly, as a way of legitimizing their being-in-pain, then as a means of distancing themselves from their condition, and finally, as it was acquired (and perpetuated) through no fault of their own. On the other hand, there is the need to acknowledge the reality of their pain and their own lived experience, which they describe as an "elusive," "deceptive" and unseen (Snelgrove and Liossi 2009; Lavie-Ajayi et al. 2012), which erodes their sense of "self" and its relationships with others, including family members, friends and health professionals (McParland et al. 2011; Relieving Pain in America Report 2011; Lavie-Ajayi et al. 2012).

Lavie-Ajayi et al. (2012) termed this tension "narratological distress," defining it as an internal battle between two unwanted narratives. Participants in Lavie-Ajayi et al.'s study related times when they would bow before the pressure of social norms; normative in the sense of "who they ought—or were expected—to be." They would:

> …surrender to the narrative of the absence of illness. Facing scepticism from family, friends and health professionals, they ask themselves to submit to the external narrative, which positions their pain as imaginary or as an exaggeration, paying the price of alienation from their own experiences and pain (Lavie-Ajayi et al. 2012, p. 199).

The price of resolving this narratological distress, in this particular way, was a debilitating alienation from one's "self," an outcome which has also been termed as "living with a body separate from the self" (Osborn and Smith 2006). It is a moral struggle to retain, or indeed retrieve, a "good self" (Osborn and Smith 1998; Smith and Osborn 2007; Relieving Pain in America Report 2011):

> I'm some waster, they should have someone who's impressive, to look up to but how can they look up to me with what I do all bad tempered and crippled, dossing about lying down every 10 min. All they see is a bit of a man…terrible" and "…You stop caring. …If someone else gets a pain you're not sad for them, you're glad that someone else knows how you feel […] that's awful" (participant 'Tony': Smith and Osborn 2007, p. 525, 526).

and,

> …my personality's gone, I used to be right bubbly and lively you know but it's, that's gone, and even my mum says that I have changed, she never really says in what way, she says I have gotten more snappy and more nasty. You want the old Alice back but you can't" (participant "Alice": Osborn and Smith 1998, p. 72).

It is also salient to return to the experience of Iraq and Afghan war veterans (Sherman 2010):

> Yet, what moved me as I listened to soldiers, especially those recently returned, is how desperately they wanted to feel their old civilian selves. Or, at least, they wanted to feel more porous boundaries between being a soldier and a civilian—whether as a parent, a child, or a colleague in the work force; keeping their different selves fully separate was just too numbing.

It is apparent that it is not only healthcare providers who find themselves in the normative landscape of chronic pain ethics: others too are "obligated" to comply with normative expectations, including their own learned expectations, of what it is to be a "good" or "worthwhile" person in their life situations. But, as we have seen, the demands of doing this can come at the cost of denying what is happening in their own lived experience and bodies, as in the loss or separation of their previous "good selves." Kleinman suggests that "norms" and their demands upon persons can be deleterious—it certainly was for the officers treated by Rivers in WW1—and that norms may need to be refashioned, so that there is "a wider space for others to build their own moral careers, where they have alternatives to established norms and ways of being normal" (2006, p. 215). This suggests a need to understand and value the non-normative parts of the chronic pain ethics landscape, where norms can be questioned rather than merely complied with.

4 Narrative Identity and Capability in the Work of Paul Ricoeur

While it is beyond the scope of this chapter to comprehensively describe the current approaches to the management of persons with chronic (non-carcinogenic) pain, it is worth noting that so-called "pain education" provides a way, at face value, of resolving the moral tensions for the chronic pain sufferer described above. In "pain education," the aim of explaining pain is to shift a person's conceptualization of pain from "that of a marker of tissue damage or disease to that of a marker of the perceived need to protect body tissue" (Moseley and Butler 2015, p. 807). By assisting a person to realize that their pain is real and not imagined and that they are not neurotic, crazy or a malingerer can be very helpful indeed, modifying a person's pain experience and functional abilities for the better (Moseley and Butler 2015). However, the evidence and efficacy of this approach is still maturing (Moseley and Butler 2015). Gallagher et al. (2013) in a study, which acknowledged that pain education did not always achieve positive outcomes, demonstrated that this education process was more effective when delivered in the context of metaphor and story. Arguably, this suggests some utility in stories where persons can consider information in the context of others' experiences and how those experiences may "speak" to their own experiences and the development or trajectory of their particular "self."

The hermeneutic phenomenologist Paul Ricoeur reminds us that the "self" is constituted in relation to "others" (Ricoeur 1992). And so it can be appreciated that a moment of cognitive learning, as can occur in pain education, takes place in the larger history of a person's story and the development of a "self" which is constituted "culturally and socially." Ricoeur argues that it is in this set of social and cultural interactions that the potential for a person to discover new capabilities (such as learning and agency) is facilitated or extinguished (Ricoeur 2006).

Situating this discussion once more in the context of a landscape of chronic pain ethics, I propose that there is a role for healthcare providers to recognize and facilitate, where possible, the project of persons with chronic pain in retrieving or discovering new and more flourishing versions of their moral "selves." This is an ethical enterprise, and it requires that the healthcare provider leave the territory of normative ethics (and its focus on professional obligations and the regulations of these) and move into the area of non-normative ethics. With Kleinman, I suggest that narrative reasoning provides a means of creating a “wider moral space”; what he also calls “local moral experience” (Kleinman 2006), so that persons can recover a moral sense of themselves, in the ethical or moral landscape created by the tensions of normative moral obligations, and the inability to meet these without significant personal (and health) costs.

For Ricoeur, it is narratives which allow human actions to be truly apprehended and rendered intelligible to others (Dauenhauer and Pellauer 2012). This is based on the analogy that we make sense of our own personal identities in much the same way as we do of the identity of characters in stories (Dauenhauer and Pellauer 2012). In narratives, there is a unifying process where we come to understand the characters by way of the plot that ties together what happens to them, the aims and projects they adopt, and what they actually do (Dauenhauer and Pellauer 2012).

Ricoeur argues that every action (in terms of a change in the world) involves initiative that in turn requires a bodily agent possessing capabilities and vulnerabilities who inhabits some concrete context and situation (Ricoeur 1992). He describes four fundamental human capabilities: (1) speaking, (2) acting (doing or making), (3) narrating (or telling), and (4) imputing action to some person or persons as worthwhile or not worthwhile (Ricoeur 2006).

This notion of capabilities has particular significance in the context of non-normative ethics and the person with chronic pain. The capabilities described below constitute active processes in the formation of a “self” which importantly also become a means for establishing a recognition of persons; and in the first instance that of “self-recognition” (Ricoeur 2006, p. 17).

The first basic capability is the capacity to speak: “I can speak.” Speaking is itself a kind of action since the speaking subject is able to designate himself/herself by the use of specific linguistic processes, thus expressing intentionality in the phenomenological sense of expressing one’s relations with the world (Ricoeur 2006, p. 18).

The second capability is the capacity to act. The subject may recognize himself or herself as the “cause” or “initiator” of an action, leading to the assertion: “I did it; I am the one who did it” (Ricoeur 2006, p. 19). Thus, the subject also becomes an *agent* capable of answering the 1st person oriented question relating to the “who” of an action, as distinct from the 3rd person question regarding the “what” of an action, and the reporting of an event as its merely occurring (Ricoeur 2006). To the agent can be ascribed the capacity to designate themselves as the true authors of their deeds. In other words, the action belongs to the agent who appropriates it and calls it his or her own.

Thirdly, there is the capacity to tell: to tell stories about events and characters, including oneself. This connection between plot and character leads to the notion of a narrative identity (Ricoeur 1992, 2006). Narrative identity provides a temporal dimension to the notion of identity (and formation of “self”) (Ricoeur 1992). Until the story is finished, the identity of each character or person remains open to revision(s) and therefore, in order for a subject of action to assign an ethical value or qualification to his or her personal life, this subject (or agent) needs to be able to "gather this life in the terms of a narrative identity"(Ricoeur 2006, p. 20). MacIntyre refers to this as "the narrative unity of a life" (MacIntyre 2007).

Ricoeur differentiates between two aspects of identity. There is the self's *idem*-identity (Latin) which gives the self, among other things, its spatio-temporal sameness (Ricoeur 1992; Dauenhauer and Pellauer 2012). That is, its sense of continuity. There is also the *ipse*-identity which is what accounts for the self's unique ability to initiate something new and ascribe this to a "self," be it oneself or another, as the agent (Ricoeur 1992; Dauenhauer and Pellauer 2012). A narrative identity relies on a dialectical relationship between "sameness" and "selfhood"; that is, a constant movement between the maintenance of the continuity of a life and its capacity (self-initiated) for change (Ricoeur 1992, 2006).

Fourthly, there is the capability to hold oneself accountable; to impute moral responsibility for an action(s). What does this add to the notion of agency and "authorship" described above in the capability for action? Imputation is a Kantian notion and refers to a judgment by which a person is declared to be the author (freely taken) of an action which is then regarded as his/her moral fact or deed (Bok 2001). This speaks, therefore, of the capability to accept or bear the consequences of one's own acts. All narratives have ethical dimensions and narratives call for us to evaluate their characters as such. The "promises" or "assertions" of a narrative present characters in such a way that evaluations of what they do or suffer become part of the (self) interpreted meaning of an experience or event(s) (Ricoeur 1992; Dauenhauer and Pellauer 2012).

Ricoeur's analysis of a personal narrative identity is central to his hermeneutic phenomenology of the self, expressed here in the first-person: Since my personal identity is a narrative identity, I can make sense of myself only in and through my involvement with others and through the exercise of my capabilities. I do not simply enact a role, function or practice that has been assigned to me (in contrast to post structuralist ideas) but can initiate new actions and choices. Although I can be evaluated in any number of ways, ultimately, it is the ethical evaluation, which is, over time (and generally speaking), the most important evaluation; one made in the light of my responsiveness to others (adapted from Dauenhauer and Pellauer 2012). The narrative unity of my life (its virtue in Aristotelian terms) is made up of the moments of its responsiveness or failure to respond to others, with the intention (telos) that my responsiveness will bring about a better life with and for others (Ricoeur 1992; Gillett 2009; Dauenhauer and Pellauer 2012).

Understanding and working with patients' narratives have been taught by several authors in the health field: Medical and nursing education (Charon 2006; Greenhalgh 2006; Carel 2012); medical ethics (Brody 2002; Frank 2004); psychiatry and ethics (Kleinman 2006); psychology (White and Epston 1990). It is not my purpose here to reiterate the "how to" of various approaches to using narrative. However, these approaches have in common the notion that narrative reasoning (or practice) can help persons see themselves and their situations in ways not constrained or shaped by the dominant and normative narratives that they are seemingly enmeshed in. Healthcare providers have as part of their training and practice, skills in asking questions and interpreting responses and, therefore, are in a position to use narrative reasoning should they choose to do so. Whilst the biopsychosocial approach in healthcare, with its aim of being more holistic and patient centred than its antecedent, the biomedical model, has become widely accepted, both the inclination and the skills needed to implement this approach remain much less evident (e.g. Epstein and Borrell-Carrio 2005; Morris and Wilson 2008; Karp 2012; Singla et al. 2015; Overmeer and Boersma 2016). For example, even when the value of narrative reasoning is appreciated, as a means of understanding the lived experience of a patient in the biopsychosocial approach, its translation to and use in clinical practice is not:

> While likely not practical in routine clinical practice, the use of patient narrative in clinical therapy and research (i.e. "narrative medicine") can provide valuable insight into the human pain experience (Vetter 2012, p. 154).

The use of narrative reasoning in clinical practice, from either a clinical or ethical decision making perspective, becomes an issue of what questions—of the patient or themselves—practitioners consider important and what interpretive lenses they use to receive the answers to those questions (Edwards et al. 2014). How healthcare practitioners understand the necessary movement, even from moment to moment within a session, in reasoning and decision making between diagnostic and procedural forms of reasoning and those forms of reasoning needed to understand another person's belief(s) and lived experience, is also relevant in the importance practitioners place on using narrative reasoning.

5 The Ethical Reasoning Bridge

One conceptualization of what it means to navigate between these different forms of reasoning in healthcare practice and which assists the practitioner to traverse the normative and non-normative terrains of the chronic pain ethics landscape can be found in our reasoning model "The Ethical Reasoning Bridge." The Ethical Reasoning (ER) Bridge is an ethical (and clinical) reasoning framework derived from research of the decision making of expert physical therapists (Edwards et al. 2004; Edwards and Delany 2008) and describes a movement between normative and non-normative ethics. It further develops an idea, originally expressed by KM Hunter, who described the inquiry task of the medical practitioner as crossing a bridge where, on the one side, information is sought about a case which is universal (or normative) and shared by all or most patients and, on the other, information is sought which is unique to this particular patient case (Jones 1997).

On either side of this metaphorical bridge, are pylons, which are constituted, in an epistemological manner, by different conceptions of knowledge and the particular logic associated with them. On the normative ethics side of the bridge are assumptions about knowledge and truth which also underpin the empirico-analytical (or positivist) paradigm of quantitative research (Higgs et al. 2007). That is, knowledge or truth is rationally or objectively known, universal (or generalizable), measurable and predictive. This understanding (or epistemology) of knowledge is illustrated by the diagnostic act of taking blood pressure which involves the interpretation of an objective, measurable, predictable and generalizable finding. In turn, it involves a normative logic concerning what blood pressure values one "ought to find" and what one "ought to do" in response to this outcome. Physiotherapists, similarly, use this logic in assessment of such things as joint range of movement and muscle function. In ethical terms, use of these normative assumptions represents a "deductive" logic or reasoning in so much as we apply a universal or generalized ethical approach (e.g. utilitarianism), or ethical principle (e.g. respect for autonomy, beneficence, non-malfeasance, or justice) to a particular ethical dilemma in order to make a judgment or "test" as to its "fit" for answering the diagnostic ethical question, "what is at stake ethically in this situation?" (Edwards et al. 2011, p. 1657). To this end, Fox has described normative ethical problem solving, exemplified by, but not confined to, the four principles, as "a rigorously rational, formal, largely deductive mode of argumentation" (1994, p. 48). The question of "what is ethically at stake?" on this side of the ER Bridge, is therefore answered in terms of the collectively (normatively) agreed professional and ethical duties and obligations of a community of practice.

On the non-normative side of the ER bridge, the process of understanding lived experience of illness and disability (including pain) uses a narrative (or inductive) form of reasoning which "generates" rather than "tests" hypotheses. A different set of underlying assumptions regarding knowledge or truth is also used. On this side of the bridge, truth and reality are context dependent, leading to multiple realities and the idea of knowledge as a social construction (Edwards et al. 2011, p. 1657). Narrative reasoning involves understanding the manner, therefore, in which a person "edits" and "re-tells" their story (and thus their narrative identity) as an interpretation of personal experience over time (White and Epston 1990). Narrative reasoning also recognises that the meaning(s) people attribute over time to their personal situations may also be constitutive of their perceived self-identity, sense of agency and actions (or inactions) (Brody 2002; Kleinman 2006; Mattingly 2010). In other words, a person's (or indeed community's) interpretation of their experiences not only shape their decision making and actions but may lead to what Nussbaum (2006, p. 73) refers to as "adaptive preferences," where the expectations for change, in ethical terms such as equity and justice, may adapt or "atrophy" due to the prevailing and inhibiting influences in their particular context.

Narrative reasoning can therefore assist in also understanding the social determinants or "unjust background conditions," as termed by Nussbaum (2006, p. 73), which might either shape or constrain a person's (or group's) sense of moral agency. The assumptions underpinning this account of reality and experience therefore acknowledge how a person's sense of moral identity and agency is, in part, shaped by various discourses (e.g. historical and power relations) and social determinants (see Edwards et al. 2014, for further discussion).

The reasoning movement "to and fro," across the ER Bridge, not only requires skill on the part of the healthcare provider in being able to both move between and use these fundamentally different reasoning logics, but also an ability to make a shift in their perceptual "posture" (Edwards et al. 2004, 2014). A practitioner's normatively oriented intentionality,[1] when listening to and examining a patient, is to look for what they recognize (e.g. a doctor looks for the signs and symptoms of a particular disease entity). This leads to a categorization and ordering of the features of a presentation (clinical or ethical) with an emphasis on recognizing what is known and what—in a normative sense—is expected or ought to be found (Edwards et al. 2011; Kahneman 2011). Phenomenological (narrative) thinking requires putting this logic to one side (bracketing as it were) in order to understand, paradoxically enough, the person/patient as someone (a self) who is not "diagnosable" or "reducible" to a clinical (or ethical) pattern (Frank 2004; Komesaroff 2008). Instead, in phenomenological and narrative terms of the "self," what occurs is a project of mutual recognition between practitioner and patient. Ricoeur characterizes the challenges in achieving mutual recognition as "a struggle against the misrecognition of others at the same time that it is a struggle for recognition of oneself by others" (Ricouer 2005, p. 258). This can typify the clinical encounter and, in many respects, the stigma (suggested by McGee et al. 2011) which is commonly faced by the patient with chronic pain:

> I have a Masters degree in clinical social work. I have a well-documented illness that explains the cause of my pain, but when my pain flares and I go to ER, I'll put on the hospital gown and lose my social status and identity. I'll become a blank slate for the doctors to project their own biases and prejudices onto. That is the worst part of being a pain patient. It strips you of your dignity and self-worth (Participant in Relieving Pain in America Report 2011, p. 19).

There are inevitably differentials of power and rank in a clinical encounter, and so it is the healthcare provider who has the mandate to "cross and recross the ER Bridge" between the normative and non-normative sides in order to also "see" and "hear" the patient with a non-normative intentionality and situate this in the knowledge and obligations of their role as healthcare providers. This crossing and recrossing the ER Bridge can lead to a mutual recognition and "brings self-recognition to fruition" (Ricoeur 2006, p. 22). Self-recognition (and agency) becomes possible with the exercise of one's capabilities (to speak, to act, to tell, and to impute responsibility) (Ricoeur 2006).

The story near the beginning of this chapter about the pain physician and his patient's suicide was a very honest and personal expression of this healthcare provider becoming caught in a tension between his complying with his perceived obligations (in relation to opioid management) and listening to the cry of desperation from his patient. It is a normative (obligation-based) and non-normative (lived-experience-based) moral tension that he experienced. However, he is able to exercise capabilities of speaking, acting, telling and imputing responsibility as a

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[1] Intentionality here is a phenomenological term which does not refer to a practical intention to 'do something', but instead to the proposition that we have a conscious relationship with an object—externally or in mind or memory—which we interpret and develop meaning about (Larkin et al. 2011).

way of using this story to question the then current policies of opioid management and its ethical implications for physicians and patients; importantly with a purpose of calling for change.

We should, as healthcare providers, endeavour to assist persons with chronic pain (our patients) to develop these same narrative capabilities as a means of resolving the moral dilemma that they face; between the normative expectations placed upon them and the less visible but real imperative of acknowledging their own lived experience and the effects this has upon the integrity and health of their "selves." Narrative approaches in healthcare and ethics in healthcare have been previously described by a range of authors as mentioned earlier. This chapter describes, more particularly, how healthcare practitioners can understand both the influence and relationship of particular forms of reasoning and problem solving—diagnostic/procedural together with narrative/phenomenological— in professional practice. It is in developing awareness of and skill in using these different forms of reasoning that allows practitioners to traverse both the normative and non-normative ethical terrains of the landscape that is chronic pain ethics. Normative ethics has a focus on compliance with established duties, obligations and values. Non-normative ethics considers what Kleinman (2006) calls "local moral experience" and allows for the possibility of questioning existing norms and values in the light of a person's lived experience. Learning to traverse these normative and non-normative terrains assists practitioners to not only recognize better the influences which shape their own practice but also support persons with chronic pain, who feel caught in this tension and experience this as a moral dilemma, to change or widen the interpretive lens with which they view their moral "selves."

Current research continues to provide evidence in ways to better teach and encourage healthcare practitioners to use biopsychosocial approaches in the management of persons with chronic pain (Overmeer and Boersma 2016). The addition of a moral component: learning how to work with the moral experience of the person with chronic pain, and how this may influence outcomes, requires further research and evaluation.

6 Conclusion

The moral experience of the person with chronic pain is constituted in a dilemma which occurs as an inability to resolve the tension between normative expectations of others (and themselves) regarding expected attitudes and behaviours in the face of ongoing pain and the non-normative realities of the actual lived experience of that pain and its effects on the "self" and its relationships with others. This moral experience is an important part of the landscape of chronic pain ethics and its understanding has a utility and value for both practitioners and patients. In portraying chronic pain ethics as a landscape, which is wider than the commonly understood conception of professional ethics as a regulation of behaviour, non-normative ethics, then, becomes a means by which the moral agency of the person with chronic pain becomes a new and important focus. Narrative approaches in health have been widely described and advocated. In this chapter I outline a model of reasoning and decision-making, the Ethical Reasoning Bridge, which describes how practitioners can traverse the normative and non-normative ethical terrains, and in doing so, can begin to assist their patients to do so for their contexts. However, the role of narrative reasoning in the conduct of daily healthcare practice and, in particular, the development of narrative capabilities with patients, in order to enhance their sense of agency, remains under researched.This chapter is a revised and modified version of the following paper: Edwards et al. (2014).

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Chapter 13
Chronic Pain and Meaning in Life: Challenge and Change

Jessie Dezutter, Laura Dewitte and Siebrecht Vanhooren

Abstract A chronic pain condition affects all aspects of life. Chronic pain patients are not only confronted with enduring pain, but also with the detrimental psychosocial consequences of their condition such as job loss, marital problems, and social isolation. Much effort is required in finding the best way to cope with their aggravating situation. Research, policy, and care seem to focus predominantly on the physical and psychological aspects of the lives of chronic pain patients, with limited attention for the existential dimension. This is remarkable because chronic pain often threatens patients' perceptions about what is meaningful to them and the amount of meaning they find in their daily life. Experiencing chronic pain often requires a revision of one's life goals and expectations and can trigger an existential search for meaning in life. Hence, the impact of a chronic condition is not limited to patients' biopsychosocial functioning but affects the existential domain as well. Patients wonder how their life can be meaningful if they experience chronic pain and they are often less able to engage with those aspects of their life that gave their life meaning because of the pain. Despite the significance of experiencing meaningfulness for the functioning of pain patients, those themes seem often neglected in the work of treatment providers and care professionals. In this chapter, an introduction is given on the concept of meaning in life with attention for meaning making, searching for meaning, experiencing meaning and meaningfulness as part of sense of coherence. Furthermore, this theoretical framework is applied to the chronic pain condition and empirical findings are offered showing that meaning in life is related to the functioning and the well-being of pain patients. Finally, clinical implications and suggestions for implementation in care are discussed.

J. Dezutter (✉) · L. Dewitte · S. Vanhooren
Research Group School and Developmental Psychology,
University of Leuven, Tiensestraat 102 bus 3717, 3000 Louvain, Belgium
e-mail: jessie.dezutter@ppw.kuleuven.be

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1 Pain is *Not* a Simple Sensation

One of the major aims of medicine is the alleviation of pain. In order to develop methods to relieve pain, clinicians and scientists try to provide an objective and empirically based definition of “pain.” Finding a straightforward consensus definition that pays respect to the personal pain experience is extremely difficult because pain is a complex phenomenon. In the twentieth century, science and physicians needed a better grip on pain experience in order to make valid diagnoses and prescribe effective treatments. Based on the biomedical model prevailing in scientific medicine at the time, the focus was predominantly on the *sensation* of pain (Lima et al. 2014). Pain was approached as a sensory response in need of medical attention, and pain experience was reduced to neurophysiology. This definition offered clinicians and researchers focus in their search for understanding pain, and provided a starting point in the development of pain treatments. This physiological approach, however, does not encompass pain in all its complexity.

Although the progress of medical science offered new pain treatments like opioid analgesics, muscle relaxants and nonsteroidal anti-inflammatory drugs, the biomedical model seemed unable to provide adequate guidance for successfully living with chronic pain when alleviation of pain is very difficult, or no longer possible (Thomas 2000). Presently, physicians, care professionals and researchers affirm that chronic pain is not only a physiological, but also a psychological, and social phenomenon. Rooted within this idea, several new models and theories, like the *gate theory* (Melzack and Wall 1965) emerged in the late twentieth century and showed how psychological and social processes can modulate and influence pain experience. Pain is no longer perceived as a one-dimensional, purely physiological body process, but as a sensory, emotional and cognitive experience, which involves immune, endocrine, emotional and behavioral responses (Moreira-Almeida and Koenig 2008). From a one-sided focus on the objective symptoms, emphasis now in pain research shifts to the person who is experiencing the pain (Bendelow 2013).

The multidimensionality and the complexity of chronic pain are clearly visible in its impact on the lives of patients. Recent studies show that experiencing chronic pain has a devastating effect on both intrapersonal and interpersonal functioning (Breivik et al. 2006). For example, studies reveal high levels of comorbidity between chronic pain and depression. In a literature review summarizing 42 studies, the prevalence of major depression in patients with chronic pain ranged from 13% up to 85% depending on the specific setting (for example, pain clinics, orthopedic clinics, primary care clinics) (Bair et al. 2003). Chronic pain has also been associated with an increased risk of suicidal behavior. Stenager et al. (2014) found that chronic pain patients had a 3.76 increased risk of suicide attempts. In addition to psychological functioning, the social context is also influenced by the chronic pain condition. For instance, existing studies indicate that sexual and marital satisfaction often decline after the onset of a pain condition (Flor et al. 1987). In line with these findings, a European study showed that 27% and up to 43% of the pain patients reported a reduction of the ability to have sexual relations and to maintain family relationships (Breivik et al. 2006). This is also apparent in the experience of social isolation that is regularly mentioned by pain patients (Snelling 1994). The inability to work outside home and to attend social activities due to the pain condition often lie at the foundation.

The pain condition, however, does not unidirectionally affect the broader functioning of the pain patient. Accumulating research evidence points to the bidirectionality of the effects indicating that the psychological and social context also affects the pain experience itself. This fits within the biopsychosocial model of Turk and Okifuji (2002) that views illness as a dynamic and reciprocal interaction between the physiological processes, psychological aspects, and social contexts. All those aspects will shape the patient's response to the pain (Turk and Flor 1999). Patient beliefs such as pain-related fear or pain catastrophizing, for example, play a central role in how chronic pain is perceived and experienced (e.g. Hanssen et al. 2014; Niederstrasser et al. 2015). Depressive feelings might intensify pain complaints and depressed patients are at risk for developing chronic pain (Bair et al. 2003). Researchers in the field of cognitive neuroscience agree that cognitive and affective modulation of pain is possible and recent studies focus on the social modulation of pain (Krahe et al. 2013). Pain processing is influenced by social aspects such as the presence of social and emotional support of the pain patient (e.g. Montoya et al. 2004).

An intriguing experimental study conducted by Wiech et al. (2008) shows that the experience of pain is even involved in another aspect of human life; namely, the existential or spiritual domain. In her study, twelve religious and twelve atheistic healthy persons were randomized to a "religious" condition and a "secular" control condition. The participants in the religious condition received several painful electrical shocks to the back of their hand. During this painful stimulation, they looked at a painting with a religious connotation (Virgin Mary by Sassoferrato). The participants in the control condition received the same painful stimulation while looking at a painting without a religious connotation (Lady with an Ermine by Leonardo da Vinci). At the end of the trial, participants rated the intensity of the pain. The results indicated that the religious participants indicated less pain when looking at the religious painting compared with the secular painting, whereas the atheistic participants reported the same pain intensity regardless of whether they looked at the religious or the secular painting. Wiech and her co-workers stated that those results seem to indicate that a religious belief might act as a framework allowing individuals to engage in pain modulation processes. This statement is intriguing and innovative because it refers to the existential or spiritual domain, which is often neglected in the scientific discourse with regard to (chronic), pain (see also Siddall et al. 2015, for an overview).

The lack of attention for the existential or spiritual aspects of pain patients' life is remarkable, given that a chronic pain condition affects the core of human functioning so deeply. The confrontation with enduring pain often pushes existential questions forward. Becoming a pain-conflicted person, for example, regularly calls into question the meaning of life itself (Thomas 2000). Chronic pain often threatens patients' perceptions about what is meaningful to them and the amount of meaning they find in their daily life. Experiencing chronic pain often requires a revision of one's life goals and expectations (Pinquart et al. 2009), and can trigger an existential search for meaning in life. In addition, patients are often struggling with the deeper meaning of having continuous pain and the reason for suffering (Thomas 2000; Bullington et al. 2003). Existing ideas on theodicy, locus of control, and vulnerability are challenged. In sum, both the themes of finding meaning in the pain situation as well as ultimate meaning in life are important aspects in the experience of pain patients.

2 Pain and Meaning Making: A Profound Challenge

Trying to cope with such a severe stressor as chronic pain is a highly demanding task. The fact that the pain is enduring and that a cure or treatment is non-existent, makes it particularly challenging. Some scholars argued that in situations characterized by so-called unsolvable or irreparable stressors, such as chronic pain, problem-focused coping or emotion-focused coping might not be the most adaptive option (Mikulincer and Florian 1996; Park 2010). This is in line with the findings of Turner et al. (1987) that pain patients who mentioned pain as their primary stressor used fewer problem-focused forms of coping. Furthermore, McCracken et al. stated that problem-oriented strategies are not enough when dealing with chronic pain (McCracken 1998; McCracken and Eccleston 2003). Consequently, coping then often involves trying to make sense of the event and attempting to transform the meaning of the stressful experience (Park 2005).

In the past decades, several scholars in a wide range of disciplines have described how meaning is involved in adjusting to highly stressful events (e.g. Janoff-Bulman 1992; Bonanno and Kaltman 2001; Joseph and Linley 2005). Park (2010) integrated these rich insights in an overarching meaning making model. This model provides a theoretical framework for understanding how chronic pain patients may cope with their condition through meaning. The model distinguishes different levels of meaning. The most abstract layer of meaning is a general orienting system *(global meaning)* which includes beliefs, goals, and a subjective sense of meaning. This global meaning system provides individuals with a framework to interpret life experiences and to manage daily events (Reker and Wong 1988). The confrontation with stressful events can result in a discrepancy between this global meaning and the perception of the situation (*appraised meaning*). The impact of chronic pain on a patient's beliefs with regard to, for example, controllability or fairness in life, but also religious beliefs on the existence of a benign divine being, comes under pressure. The beliefs that were originally part of the patient's global meaning seem now difficult to reconcile with his or her chronic pain condition. A pain patient, for example, may have always held the idea that he or she is in control of life, but now he or she feels as if the pain controls life. In addition, motivational aspects of the global meaning such as plans, life expectations and goals can be shattered in the light of the pain. Patients often need to reformulate their goals because the pain inhibits the attainment of simple tasks and prior purposes in life. Both daily goals such as grocery shopping or cleaning the house, as well as long-term goals, such as pursuing a specific career, often need adjustment. At the affective level, this often results in a decrease of the patient's subjective sense of meaningfulness.

According to the model, pain patients will feel challenged by the impossibility to attain the original beliefs and goals. This is accompanied with intense levels of distress, which will initiate *meaning making processes* in order to reduce the discrepancy and the distress. In line with the theorizing of Brandtstädter and Renner (1990), meaning making can on the one hand involve changing the very meaning of the stressor in a process of assimilative coping, e.g. re-evaluating the pain as a challenge instead of a threat. On the other hand, meaning making can also involve changing one's global beliefs or goals to improve the fit between the appraised meaning and the global meaning, which is termed accommodative coping, e.g. reformulating personal beliefs, or goals. The products of these meaning making processes are *meanings made* (Park 2010). Park states that *meanings made* are the results, or changes, derived from the attempts to reduce discrepancies between the appraised situation and the global meaning. Many different meanings can be made such as feelings of having made sense, acceptance, benefits found, and post-traumatic growth (e.g. Davis et al. 1998; Calhoun and Tedeschi 2006). When individuals achieve these products of the process, reductions in discrepancy are assumed and, accordingly, the intense feelings of distress will disappear (Park 2010). When meaning is made, the meaning-making attempts are expected to decrease and, over time, meaning made should be related with a better adjustment to the chronic pain condition.

Empirical evidence for the benevolent role of meaning making can be found for patients with a broad range of health conditions such as cancer; HIV, multiple sclerosis, and stroke (see Park 2010, for overview). Little attention, however, is paid to making meaning when confronted with chronic pain. Graham et al. (2008) studied the role of anger expression and meaning making in a group of 102 outpatients from a chronic pain centre. The patients were randomly assigned to an anger expressing condition or to a control condition. In the anger expression condition, the patients were instructed to express their anger in a constructive way whereas in the control condition, they were instructed to write about their goals in a non-emotional way. Compared with control group participants, patients assigned to constructively write about their angry feelings showed improvement in perceived control over pain and depressed mood over a 9-week period. Importantly, this association was particularly strong if anger expression led to meaning making. Another recent study (Dezutter et al. 2017) attempted to clarify how pain patients cope meaningfully with the goal violation they experience due to their pain condition. In this study, 125 chronic pain patients were questioned three times over two years. The patients reported on the level of goal violation they experienced due to their pain condition, as well as on the use of meaning making processes (i.e. positive reappraisal and downward comparison), and life satisfaction. The results pointed out that downward comparison might function as a meaning making process resulting in a decreased experience of goal violation over time, followed by an increase in life satisfaction.

3 Experiencing Meaningfulness Despite the Pain

Park (2010) explained that global meaning consists of three aspects, namely beliefs (cognitive component), goals (motivational component) and a subjective sense of meaning (affective component). The latter aspect, also called meaningfulness, is also a key concept in Antonovsky's (1987) salutogenic paradigm. Antonovsky challenged the existence of two clearly distinct statuses of "health" and "illness." He argued that individuals move back and forth on an "'ease-disease" continuum during their lives. With his new paradigm, he aimed to shift the focus from pathology to salutogenesis with a strong interest in the psychological strengths or factors that can stimulate "ease" or health. In his theory, Antonovsky introduced *sense of coherence* as "a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence" (p. 19). Antonovsky described sense of coherence as a measure of an individual's capacity to use various coping mechanisms and resources when faced with a stressor. Individuals with a strong sense of coherence are assumed to effectively handle stress and protect their health, despite extremely challenging circumstances. After interviewing concentration camp survivors, Antonovsky concluded that individuals' ability to stay healthy despite severe circumstances is related to the way they view their life and their existence (Eriksson and Lindström 2005). He assumed that three aspects are important in this life view: the ability to understand what happens around them (*comprehensibility*), the ability to manage their situation (*manageability*), and their ability to find meaning in their situation (*meaningfulness*). Antonovsky (1993) stressed that sense of coherence is a dispositional orientation, not a personality trait or a coping mechanism, and it refers to the ability to perceive your situation as comprehensible, manageable and meaningful. For chronic pain patients, high levels of sense of coherence might imply that they, (a) are able to reach a satisfying comprehension of their situation faster, (b) have the tools to more easily manage their chronic pain situation, and (c) are able to find meaning in and make sense out of their pain situation. Based on these assumptions, pain patients with a strong sense of coherence should be better equipped to adapt to their chronic condition. Thus, theoretically, chronic pain patients with high levels of sense of coherence should show more optimal functioning compared with their counterparts who lack a sense of coherence.

Some studies seem to affirm this hypothesis. In a sample of fibromyalgia patients, women with a stronger sense of coherence experienced greater well-being than those with a weaker sense of coherence (Söderberg et al. 1997). In an observational study of Norwegian patients with various musculoskeletal pain conditions, a strong sense of coherence was associated with higher levels of life satisfaction (Anke et al. 2013). In a sample of rheumatoid arthritis patients, negative correlations were found between sense of coherence and measures of anxiety and depression (Schnyder et al. 2000). Antonovsky also assumed that a strong sense of coherence would play a role in the maintenance or the improvement of individual's physical health. Most studies, however, seem to focus primarily on well-being and mental health, pointing to a positive association between sense of coherence and psychosocial and psychological health dimensions. The associations with physical health, on the other hand, are less clear. Benz et al. (2013) came to a similar conclusion in a prospective cohort study of 335 osteoarthritis patients. They found that sense of coherence was able to explain significant variance in psychological aspects like social and emotional functioning, but not in physical aspects like stiffness, pain and physical functioning.

Similarities can be seen between the salutogenic paradigm of Antonovsky and the meaning-making model of Park, especially with regard to the aspect of "meaningfulness." Park also referred to meaningfulness as the affective component of global meaning. Furthermore, both the meaning making model as well as the salutogenetic paradigm assumes that meaningfulness is an important factor in coping with a stressful event. Antonovsky, as a medical sociologist, focused predominantly on health maintenance whereas Park, as a clinical and health psychologist, on psychological coping and adaptation. Comparing both models, one might wonder if or how sense of coherence and meaning making can be related to each other, especially for chronic pain patients. As Antonovsky mentioned that sense of coherence refers to individuals' ability to handle stressful situations and their appropriate application of coping strategies, it might be associated with the use of meaning making strategies for situations when no solution or repair seems possible. This would mean that chronic pain patients with a strong sense of coherence would more easily engage in meaningful coping strategies, which might lead to better adaptation to their condition. In addition, experiencing meaningfulness can also be seen as a possible product of the meaning making processes; namely, as a *meaning made*. It might be that this achieved meaningfulness can function as a source of personal strength in confrontation with future stressful events incorporating the reciprocity of the relations in the meaning making model. However, research investigating both sense of coherence and meaning making in chronic pain patients is lacking.

4 Searching for Meaning: A Possible Road to Change

Experiencing meaning is not necessarily an either/or experience (either experiencing meaning or not). The model of Park already pointed out that experiencing meaning can change over time. Pain patients can, for example, cease their job, which offered them a major source of meaning. Some patients, however, are able to reprioritize their life goals in a process of meaning making and succeed in creating something new that is meaningful to them (e.g. joining a patient organization as a volunteer). The old and inaccessible source of meaning (job) is gradually replaced by a new source of meaning (volunteer in a patient organization). It is thus possible that one specific source of meaning is (temporarily) cut off while other sources or new sources of meaning are still available. Vos (2015) stated, “people usually experience multiple specific meanings from various sources of meaning” (p. 886). Individuals do not tap into only one source of meaning, but usually deploy different sources of meaning. Those meaning sources vary across individuals, and can change due to specific life events (like a chronic condition), or during the life span. For a pain patient, the available meaning sources of employment, social relations and leisure time activities can all come under pressure due to the pain condition. At that moment, a simple shift to another available meaning source is probably not possible. As Park (2010) describes, a more profound search for new meanings and prioritizing different purposes in life will be necessary.

Viktor Frankl, psychiatrist and survivor of the Nazi concentration camps, also assumed that meaning is of crucial importance to men. Based on the horror Frankl experienced in the camps, he concluded that everything can be taken away from men, from belongings and health to loved ones, but nobody can take away men’s will to experience meaning. Frankl (1963) described the process of “will to meaning” as a search process. He defined searching for meaning as “the primary motivational force in man” (p. 121), and a natural, healthy part of life. Steger et al. (2006) adopted this aspect in his conceptualization of *meaning in life* by proposing that meaning in life consists of two components, namely Presence of Meaning and Search for Meaning. *Presence of Meaning* is defined as “the extent to which people comprehend, make sense of, or see significance in their lives, accompanied by the degree to which they perceive themselves to have a purpose, mission, or overarching aim in life” (Steger 2009, p. 682). It refers to the comprehension of oneself and the surrounding world, the understanding of how one fits into the world, and the clarity of one’s goals and desires (King et al. 2006). Presence of Meaning can be regarded as a highly desired psychological *quality* (“my life is meaningful”) (Steger et al. 2008). *Search for Meaning* focuses on how individuals develop their sense of meaning in life and is defined as the strength, intensity, and activity of people’s desire and efforts to establish and/or augment their understanding of their lives. It refers to the *process* of how individuals develop their sense of meaning in life (“how can I make my life more meaningful?”) (Steger et al. 2008).

As explained before, experiencing meaning (Presence of Meaning) is considered as an important resource for adjusting to an illness (Antonovsky 1993; Park 2010; Sherman and Simonton 2012). Breast cancer patients, for example, with a strong global meaning showed better physical and psychological functioning at a 4-month follow-up assessment (Sherman et al. 2010). Experiencing meaning in life was also related to lower distress and greater well-being in Italian and American cancer patients (Park et al. 2008; Scrignaro et al. 2014). Finally, meaningfulness was positively related to psychological well-being in spinal cord injury patients (deRoon-Cassini et al. 2009) and osteoarthritis patients (Smith and Zautra 2004). The role of Searching for Meaning is, however, less clear. In the general population, some studies linked Search for Meaning to less well-being (Steger et al. 2008) and less life satisfaction (Steger et al. 2009, 2011) more hopelessness and more anxiety (Scrignaro et al. 2014a). Conversely, other studies found Search for Meaning to be positively related to open-mindedness and curiosity (Steger et al. 2008). Evidence for the impact of searching for meaning on adjustment when confronted with a medical stressor is very limited (see Scrignaro et al. 2014a). The majority of studies seem to focus on searching for event-related or illness-specific meaning (i.e. how one tries to make sense out of the event or find meaning in the event), rather than considering the broader construct of searching for a general meaning of life (e.g. Kernan and Lepore 2009).

5 Meaning in Life Profiles and Adaptation to Chronic Pain

Although searching for meaning is often seen as a natural reaction to an absence of meaning, empirical studies showed that Search for Meaning and Presence of Meaning are only moderately related and are actually distinct from one another (Steger et al. 2008). In addition, several scholars (e.g. Steger et al. 2008; Cohen and Cairns 2012) pointed to a better understanding of the dynamic interplay between Search for Meaning and Presence of Meaning as an important research aim. Several scholars pointed out that, as already mentioned above, patients' functioning on an existential level (such as experiencing and searching for meaning) is important in the adjustment to chronic pain. Elliott et al. (2002), for example, stated that "cognitive activity associated with optimal adjustment… is often conveyed in constructions of personal meaning and purpose" (p. 133). Other scholars (e.g. Janoff-Bulman 2004; Park 2010) stated that optimal adjustment could be facilitated by re-establishing a sense of meaningfulness for patients. Based on the findings in healthy populations that Presence of Meaning and Search for Meaning are two distinct aspects, and that both might have a profound role in adjusting to chronic pain, Dezutter et al. (2013, 2015) tried to investigate this complex interplay in chronic pain patients. Two studies were set up to investigate (a) if specific naturally occurring meaning in life profiles existed among chronic pain patients, and (b) if these profiles are related to better adjustment to chronic pain.

In the past, studies addressing the relation between Presence of Meaning and Search for Meaning, and their links to adjustment, adaptation or well-being have utilized a variable-oriented approach (Kiang and Fuligni 2010; Steger et al. 2011; Cohen and Cairns 2012). Variable-oriented approaches concentrate on the relationships among variables through associations and modeling (Schnabel et al. 2002). Such approaches are not able to investigate the ways in which multiple variables are configured *within* individuals (De Fruyt et al. 2002). The person-oriented approach is conceptually different, with a focus on identifying groups of individuals within a sample, each group being composed of respondents who score similarly on the variables of interest, and whose pattern differs from the other groups identified (Scholte et al. 2005). Unlike the variable-oriented approach, in which only statements about the direction and strength of associations between variables can be made, the person-oriented approach allows investigators to make statements regarding how categories of individuals typically function, as well as about the similarities and differences between those categories. These two approaches are complementary in that both lines of research add to our understanding of adapting to chronic pain.

Based on recent insights in the potentially intertwined relation of the two meaning dimensions (Cohen and Cairns 2012; Steger et al. 2011), we assumed that the identification of specific Meaning-in-Life profiles (derived from different levels of Search for and Presence of Meaning) could further our understanding of how pain patients experience meaning. Our first research question focused on whether specific meaning profiles can be distinguished among chronic pain patients and, furthermore, whether specific groups of patients who have similar configurations or profiles can be delineated. Our second research question focused on how the meaning experience of chronic pain patients is related to adjustment. If distinct Meaning in Life profiles among pain patients can be delineated, do these profiles then differ with respect to the quality of the patients' psychosocial functioning? More precisely, are some meaning profiles closer to "optimal" with regard to psychosocial functioning and adjustment in comparison with other meaning profiles?

In a first cross-sectional study, 481 chronically ill patients (M = 50 years, SD = 7.26) completed measures on meaning in life, life satisfaction, optimism, and acceptance of their chronic condition (Dezutter et al. 2013). Cluster analysis was used to investigate the existence of naturally occurring Meaning in Life profiles. The results pointed to four distinguishable profiles. Cluster 1 was labeled "*Low Presence Low Search*" and consisted of patients scoring low on both Presence of Meaning and Search for Meaning. These patients were characterized by very low experience of meaning and no search for meaning. Cluster 2 was labeled "*Low Presence High Search*" and consisted of patients scoring low on Presence of Meaning and high on Search for Meaning. These patients did not experience meaning in their life but stated that they were highly engaged in Search for Meaning. Cluster 3 was labeled "*High Presence High Search*," and consisted of patients scoring high on both Presence of Meaning and Search for Meaning. These patients were searching for meaning but also experienced meaning at the same time. Finally, cluster 4 was labeled "*High Presence Low Search*" and consisted of patients scoring high on Presence of Meaning but low on Search of Meaning. These patients experienced meaning in their life and did not search for it. Furthermore, each profile had specific associations with adjustment to their pain condition (i.e. optimism, life satisfaction, acceptance). Specifically, the two profiles in which meaning was high (High Presence High Search; High Presence High Search) showed also higher levels of adjustment, whereas the profiles in which meaning was absent were characterized by lower levels of adjustment. Furthermore, the results provided some clarification on the nature of the Search for Meaning process by distinguishing between adaptive (the *High Presence High Search* cluster) and maladaptive (the *Low Presence High Search* cluster) searching for meaning in life. Searching for one's meaning in life seems not to be maladaptive per se. A search that is rooted in experienced meaningfulness was clearly linked with good optimal functioning among pain patients. However, searching for meaning when there is no "ground" to start from turned out to be very detrimental for the patient.

In a three wave longitudinal study, 273 Belgian chronic pain patients were followed during two years (Dezutter et al. 2015). We assessed the Meaning in Life dimensions (Presence of Meaning and Search for Meaning) and indicators of adjustment (depressive symptoms, life satisfaction, pain intensity, and pain medication use). In this sample, the four original Meaning in Life profiles emerged as well as a fifth moderate cluster (*Moderate Presence Moderate Search* cluster). Again, each Meaning in Life profile was associated with a unique adjustment outcome. Profiles that scored high on Presence of Meaning showed more optimal adjustment. The profiles showed little change over time and did not moderate the development of adjustment indicators over time, except for life satisfaction.

6 Clinical Implications

Several theoretical models, such as the meaning making model and Antonovsky's salutogenesis, point to the important role that meaning may play in the functioning of chronic pain patients. Increasing empirical evidence affirms this assumption so that now initiatives seem needed to implement this knowledge into practice. Frankl already translated his insights into the clinical practice by developing logotherapy. Logotherapy is an existential psychotherapy that focuses on the search for meaning as the primary motivation of humans. Unfortunately, there are little empirical studies available testing the impact of logotherapy for chronic pain patients (e.g. Khatami 1987). Wong (2012) elaborated further on the concept of logotherapy and developed the meaning-centered therapy, as a combination of logotherapy and existential therapy. A similar trend is visible in treatment programs including existential perspectives in cognitive-behavioral therapy (CBT). These treatment programs seem to yield positive outcomes for pain patients. Gebler and Maercker (2012), for example, set up a clinical trial including 113 pain patients and follow-up at six months. They compared two treatment programs; namely a classic CBT program and an existentially oriented CBT program. The results indicated that patients in the existential-oriented CBT program reported lowered pain-related disability than patients in the classic CBT program. Breitbart (2003) developed and refined the meaning-centered therapy based on the existential concepts of Wong and the logotherapy of Frankl. The therapy aims to help people developing and maintaining a sense of purpose, which can be an effective way to alleviate suffering. Breitbart et al. (2010) found benevolent effects of meaning-centered therapy for advanced cancer patients. In a study of 90 patients with advanced solid tumor cancers, the patients randomly assigned to the meaning-centered group psychotherapy reported significant improvement in anxiety, spiritual well-being and sense of meaning during a two-month follow-up assessment. No improvement was present for patients assigned to supportive group psychotherapy (Breitbart et al. 2010). Similar results were found in a study of 120 people with late-stage cancer who had six months or less left to live, according to the prognosis given by their physicians. These patients were randomly selected to receive seven sessions of meaning-centered psychotherapy or massage therapy. After their last treatment session, people receiving meaning-centered psychotherapy reported an improvement in their quality of life and spiritual well-being, and reported feeling less burdened by physical symptoms such as pain. In contrast, no significant benefit was observed in patients receiving massage therapy (Breitbart et al. 2012). As research points out that meaning in life is an important issue for the functioning of chronic pain patients and may play a central role in the adaptation to a chronic pain condition, meaning-centered psychotherapy might also stimulate pain patients in their coping and acceptance process.

For primary health care providers, a patient's meaning in life might be an aspect that needs monitoring. Special attention should be paid to patients with a lack of experiencing meaning. Earlier studies (Dezutter et al. 2013, 2015) showed that a considerable portion of chronically ill patients find it difficult to experience meaning in life and seem stuck in a maladaptive search or do not attempt to search at all. Such patients might need clinical help, tailored to their needs and focused on finding and obtaining meaning in life amid major health-related adversity. Developing meaning-oriented interventions that facilitate positive outcomes after the onset of disability in line with the meaning-centered group psychotherapy in palliative care seems warranted. Furthermore, the routine monitoring of patients' meaning-related concerns can signal patients' decreases in presence and increases in searches for meaning, indicating the potential need for a referral to counselling or therapy. However, despite the relevance of meaning in life in general patient care and treatment programs, as emphasized by several scholars (e.g. Sulmasy 2002; Wong 2012), these topics are still often neglected within medical practice. The current time pressure in medical care as well as the predominant focus on biological and physiological processes might hamper this discussion in a medical setting. Furthermore, health professionals might feel inadequate to handle topics and questions on personal existence (Yalom 1980).

7 Conclusion

In this chapter, we gave an overview of theoretical models showing the importance of meaning when confronted with a debilitating condition such as chronic pain. Framed within the coping literature, meaning making was illustrated as a powerful mechanism in the adaptation process. Furthermore, the role of experiencing meaningfulness and searching for meaning were explained and empirical findings were discussed. Finally, possible translations to the clinical field were suggested with regard to either screening as to treatment or counselling. We hope that the overview of findings in this chapter can encourage clinicians to consider the challenging and changing aspects of meaning in life and recognize their important role in the coping processes of chronically ill patients.

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Chapter 14
The Lived Experience of Pain-Related Fear in People with Chronic Low Back Pain

Samantha Bunzli, Anne Smith, Rob Schütze and Peter O'Sullivan

Abstract Low back pain (LBP) is a leading cause of disability worldwide. One of the strongest predictors of LBP disability is pain-related fear. The fear avoidance model (FAM) describes how the belief that pain signals damage to the spine can lead individuals into a cycle of fear and avoidance, which in turn sustain pain and physical and psychosocial disability. A large body of research has supported the relationships proposed by the FAM; however, randomized controlled trials based on the model have reported modest effect sizes for reductions in fear and disability. Limitations of the model in its current form may be impeding its clinical utility and applicability to the wider population of people with LBP and high pain-related fear. In particular, while the FAM conceptualises pain-related fear as a "phobia" driven by the underlying belief that pain signals damage, it is possible that "non-phobic" processes also trigger pain-related fear and avoidance. In this chapter, we examine the lived experience of LBP and pain-related fear. We explore personal explanations and narratives related to the beliefs underlying pain-related fear, the factors associated with these beliefs and how fear may change over time. We consider how individual variance in qualitative data relates to scores on quantitative measures of fear. Finally, we offer an alternative framework to understand the lived experience of pain-related fear, based on "common sense" rather than only "phobic" processes. We will propose that incorporating a "common sense" perspective into future iterations of the FAM may extend its clinical utility and have implications for the next generation of fear avoidance research.

S. Bunzli (✉)
Department of Surgery, St Vincent's Hospital, The University of Melbourne,
Melbourne, VIC, Australia
e-mail: sbunzli@unimelb.edu.au

A. Smith · P. O'Sullivan
School of Physiotherapy and Exercise Science, Curtin University, Perth,
WA, Australia

R. Schütze
School of Psychology and Speech Pathology, Curtin University, Perth,
WA, Australia

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1 Introduction

Low back pain (LBP) is common. In the last 6 months, most adults will have experienced it or know someone who has (Walker et al. 2004). This means they will have developed their own beliefs and attitudes about back pain. For most people, back pain will resolve within 3 months, whether they seek care for it or not (Croft et al. 1998). However, 65% will still experience LBP symptoms a year later and 10% will experience chronic, disabling LBP (Croft et al. 1998). Low back pain is now the leading cause of disability worldwide (Hoy et al. 2014), and the prevalence of disabling LBP is rising (Hoy et al. 2012).

For many people LBP is scary. The spine is commonly perceived to be structure of the body; the structure linking our limbs to our core. It is also perceived to be the structure protecting the body's neural highway—the precious spinal cord. We need our spine in all our daily movements—breathing, sitting, walking, and lifting. What then, when the spine is "damaged," "injured," "worn"? What will link our limbs to our core, or protect our spinal cord? How can we "escape" back pain when it is involved in all we do?

Contrary to popular belief in the general population, people with LBP, and even in clinicians, the spine is a strong structure and serious structural causes of LBP are rare. Less than 1% of cases are caused by serious pathology such as malignancy or fracture that threaten the integrity of the spine (Deyo et al. 1992). There is a weak association between underlying pathology or structural abnormality and LBP disability: indeed an estimated 85% of people with disabling back pain will have no identifiable pathological explanation for the pain they experience (Deyo 2002). These patients are considered to suffer from "non-specific" LBP (referred to henceforth as LBP), a multidimensional condition involving a complex interaction between biological, psychological and social ("biopsychosocial") factors (Waddell 2004).

Current models of LBP suggest that what people believe and do about their LBP exert a strong influence on how long it will last and how disabled they will be by it (Turk et al. 1983). The strongest, most predictive of these beliefs are fear avoidance beliefs associated with pain-related fear (Picavet et al. 2002; Swinkels-Meewisse et al. 2006).

In 1996, Waddell famously stated: "Fear of pain and what people do about pain may be more disabling than pain itself" (Waddell 1996, p. 2821). This followed the emergence of early fear avoidance models (FAMs) that suggested that in a subgroup of individuals, LBP disability could be explained by a vicious cycle involving cognitions and behaviour that occurred irrespective of underlying structural pathology (Lethem et al. 1983; Philips 1987). Drawing on the phobic literature in psychology, these early models equated pain-related fear with kinesiophobia: "an excessive, irrational and debilitating fear of physical movement and activity" (Kori et al. 1990, p. 37).

From these roots, Vlaeyen and Linton (2000) and Vlaeyen et al. (2016) proposed their FAM of chronic pain, which remains the leading cognitive behavioural model

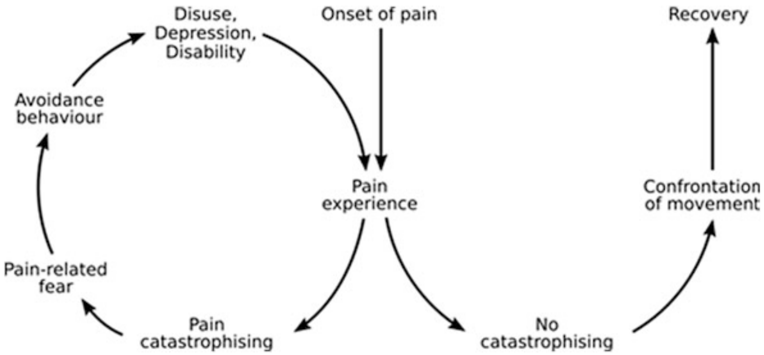

Fig. 1 Fear avoidance model, based on Vlaeyen and Linton (2000)

of LBP disability today. According to FAM, beliefs about the meaning of pain can lead to pain-related fear and the avoidance of activities and movements associated with pain. Fear avoidance in turn leads to disability, disuse and depression, which heighten the pain experience. The experience of increased pain reinforces fear and avoidance behaviour prevents opportunities for positive exposure. A vicious cycle of pain and disability ensues (see Fig. 1).

A decade and a half later, the associations proposed by the FAM have been supported by a large number of quantitative studies (Zale et al. 2013). Fear beliefs are one of the strongest modifiable predictors of LBP disability amongst people without LBP at baseline and people with acute LBP at baseline (Jensen et al. 2010; Picavet et al. 2002). Reductions in fear beliefs are associated with reductions in pain and disability (Lüning Bergsten et al. 2012; Wertli et al. 2014a), making it an important target for intervention. However, important limitations of the FAM may impede the clinical utility of the model.

Firstly, while the FAM is based on a phobic model of pain-related fear, fear beliefs are common and appear to be culturally endorsed. A large postal survey of the general population of New Zealand found that 50% believed LBP means the back is damaged; 89% believed ignoring pain could damage the back; and 71% believed there is an ongoing weakness in the back following LBP (Darlow et al. 2014). Evidence suggests that half of individuals presenting with LBP will have elevated pain-related fear (Sieben et al. 2002; Ostelo et al. 2007). Thus, fear is a common occurrence in the clinical context. However, not all individuals presenting with LBP have high fear. We know little about why some individuals with LBP develop a cycle of pain-related fear and associated disability. Understanding how individuals with high pain-related fear make sense of their LBP can provide novel insights into how fear develops, persists and responds to intervention. Such insights may extend the current FAM and help guide targeted, patient-centred interventions.

In this chapter, we will start with a brief history of the "problem" that is LBP. We will follow with an examination of the lived experience of LBP as described in the qualitative literature. We will then focus on the subgroup of individuals with LBP and high pain-related fear. We will explore how this subgroup makes sense of their LBP experience—examining their personal explanations and narratives related to the meaning of pain and how these might evolve on the pathway to high fear. We will consider how variance in qualitative data between different individuals relates to scores on quantitative measures of fear. Finally, we will offer an extended framework to understand the lived experience of pain-related fear, based on "common sense" rather than only on "phobic" processes.

2 The "Problem" of LBP

In nineteenth-century Europe, medical investigators observed a poor relationship between the reports of patients' LBP experience and observable signs of pathology. During this time, clinicians faced a problem about what pain means and how their patients' symptoms should be interpreted (Brodie 1837). Considerable debate prevailed in the following decades between proponents of a neurological explanation for LBP, based on the notion of spinal "concussion" (i.e. an underlying organic explanation for LBP), proponents of a "neuro-psychological" explanation of LBP in which the motives of the sufferer were called into question due to an emergence of compensation schemes, and proponents of a "psycho-somatic" explanation for LBP, according to which LBP was the somatic conversion of a problem primarily located in the psyche. For a detailed sociological account of the history of LBP the readers are referred to May et al. (1999).

> We are, perhaps, familiar with those interesting cases (…) in which there is no evidence of a pathologic or anatomic lesion, by any of the scientific tests at our command, but in which the patient complains of persistent pain at some point of the spinal column, attended with the various manifestations of "shock" (Grant 1898, p. 956).

The contemporary problem of LBP appeared from the 1930s onwards when technological advancements greatly improved the range of "scientific tests at our command." X-rays meant that a definitive diagnosis of an organic pathology was possible and the emergence of an Orthopaedic specialty made surgical interventions increasingly available. However, the results of these scientific tests were most often ambiguous or negative. Thus, the assumption remained that LBP was predominantly mental in the absence of objective organic evidence (May et al. 1999).

Today, the range of highly sensitive imaging investigations available is extensive. These have implicated a variety of patho-anatomical structures of the spine in LBP including (but certainly not limited to) disc degeneration, disc herniation, modic changes linked to bone oedema in vertebral endplates, foraminal and spinal stenosis with nerve pain (Albert et al. 2008; Merckaert et al. 2015). While significant associations between LBP and some patho-anatomical "changes" such as disc degeneration and disc herniation have been reported, these changes are at a population level (Cheung et al. 2009), are high amongst the symptomatic population, and are poor predictors of future LBP (Endean et al. 2011).

To date, for many patients and clinicians the absence of proof of a “disordered spine” infers the presence of a “disordered mind” (Bunzli et al. 2013; Synnott et al. 2015). The underlying belief that LBP is a patho-anatomical disorder and should be treated within a biomedical model continues to prevail. In the last decade, there has been an exponential increase in the use of spinal injections, disc replacement surgery, spinal fusion surgery and opioid medication (Deyo et al. 2009). This is in spite of evidence that only 8–15% of patients will have an identified patho-anatomical diagnosis that can explain their pain (Deyo 2002), and consistent results from clinical trials that no biomedical approach is clearly superior and all have at best small to moderate effects (Ostelo et al. 2005; Artus et al. 2010). Indeed, despite dramatic technological advances, disabling LBP has now reached epidemic levels (Waddell 1996; Hoy et al. 2014).

However, significant advances in LBP have been made. There is now indisputable evidence that LBP is a multidimensional disorder and that disability is closely linked to cognitive and behavioural aspects of pain rather than just sensory and biomedical ones (Turk 2002; Boersma and Linton 2005; Sullivan 2008). Strong evidence links LBP disability to cognitive and psychological factors such as back beliefs (Waddell et al. 1993; Foster et al. 2008), distress (Banks and Kerns 1996; Linton et al. 2010), catastrophising (Sullivan 2012; Wertli et al. 2014b) and fear (Vlaeyen and Linton 2012; Zale et al. 2013). These factors have social, behavioural, neuro-muscular and neuro-biological consequences, highlighting the inextricable link between the mind and the body (Campbell and Edwards 2009). Interventions targeting these factors through a range of strategies may reduce disability (Moseley 2004; Ostelo et al. 2005; Vibe Fersum et al. 2013). However, many clinicians find it difficult to identify and treat bio-psycho-social risk factors in their patients. It appears that the centuries old dilemma continues to this day: clinicians continue to face uncertainty about what the pain means and how their patients’ symptoms should be interpreted (Synnott et al. 2015); while patients continue to feel stigmatised and battle to legitimise their pain experience (Sullivan 2001).

3 The Lived Experience of LBP

A deeper understanding of the lived experience of LBP may assist both clinicians and sufferers in moving away from a purely biomedical model of LBP towards a more biopsychosocial paradigm. For such knowledge to be useful, we must understand which aspects of the LBP experience are shared by people in similar situations, and which aspects are particular to the lived experience of an individual person. This is consistent with the epistemological standpoint that shared patterns of experiences are at the core of clinical knowledge and that the application of clinical knowledge is individualised for each patient (Thorne et al. 1997). Quantitative methodologies can provide some insight into the patterns and correlations that characterise the LBP experience at a population level, but direct our focus away from individuals in their context. Qualitative approaches on the other hand can reveal patterns amongst the experiences of individuals-in-context and reveal processes for applying aggregate knowledge to individual cases (Thorne et al. 1997).

With the aim of revealing aggregate knowledge about individuals' lived experiences of chronic, disabling LBP (CLBP), we conducted a review of the qualitative literature. We used a thematic synthesis approach (Sandelowski and Barroso 2007) to pool findings from 18 studies that had explored the lived experience of CLBP using a variety of qualitative methods, into a qualitative metasynthesis (Bunzli et al. 2013). We identified three main themes from the included studies: (1) The social construction of CLBP, in which a biomedical explanation for pain was deemed critical for legitimising disability; (2) The psychosocial impact of the nature of CLBP, in particular feelings of anxiety and distress in light of an unpredictable future; and (3) Coping with LBP, describing patients' strategies to control their omnipresent and unpredictable pain that threatened their sense of self.

Common to all three themes was the tension created when expectations of a linear diagnosis-treatment-cure pathway were met with diagnostic uncertainty.

We captured this tension in a model of "Biographic Suspension," borrowing from the notion of biographical disruption. Biographical disruption, well known in the sociology literature, describes how the experience of a chronic illness disrupts the structures of everyday life (the daily accepted routines and personal habits), and the beliefs upon which these structures rest (Bury 1982). However, unlike biographical disruption that characterises other chronic illnesses such as diabetes or HIV, in CLBP, there appears to be an underlying hope that once the pain is gone, life will get back to normal. We describe three dimensions of suspension: Suspended Wellness, Suspended Self and Suspended Future.

"Suspended Wellness" describes the importance that people with LBP place on the outward appearance of pain in the attempt to legitimise their pain as "real." Glenton (2003) captures this concept well in their observation that while one is fighting to prove they are sick, they cannot get better. In this way, the pathway to wellness is suspended until legitimacy is achieved.

"Suspended Self" captures the psychological effects of pain described by people with CLBP. Feelings such as anxiety, depression, anger and frustration amount to a sense of "not being me" when experiencing pain. The present "suspended self" is seen as a temporary imposter while awaiting the return of the former, pain-free "true" selves.

"Suspended Future" describes the day-to-day struggle to control pain experienced by people with CLBP. An uncertain prognosis, combined with unexplained and unpredictable fluctuations in pain inhibit short, mid and long-term planning. A tangible future is suspended until the receipt of a viable prognosis.

We propose that these three dimensions represent lives lived on hold for people with CLBP. Lives with the "pause" button pressed until the "play" button returns them to their former pain-free lives. By conceptualising CLBP in this way, we highlight the importance of: (1) acknowledging the impact CLBP has on the lives of sufferers; (2) providing patients with diagnostic explanations grounded in biopsychosocial principles that resonates with their individual experience and lays the foundations for building pain coping strategies and pain self-efficacy; and

(3) providing them with strategies that enhance pain controllability in order to return to valued life goals and activities. We argue that only once this has occurred, can individuals stop searching for futile biomedical explanations for their pain, can they embark on the pathway to wellness, regain a sense of self and begin to make plans for the future.

4 What do People with CLBP and High Fear Believe About Their Pain?

Within this context of a life lived on hold with CLBP, is a subgroup of individuals who experience high levels of pain-related fear. For these individuals, beliefs about the consequences of pain and painful movement trap them in a cycle of fear and disability. For example, the belief that painful movement might cause damage to the spine and spinal cord can lead people to avoid bending or to brace their tummy muscles to protect their spines as they lift, or to take time off work to rest their backs. The problem is that these behaviours can make pain worse. Try clenching your fist for half an hour—how does your wrist feel? Imagine how your back would feel after years of bracing your back and tummy, of restricting movement in your spine.

While a large body of evidence has highlighted strong associations between fear of movement and LBP disability, little attention has been given to the beliefs underlying fear of movement and how these beliefs evolve on the pathway to pain-related fear. While quantitative prospective studies have provided some insights into the role of, for example, pre-morbid unhelpful beliefs about the back and the later development of fear of movement (Jensen et al. 2009), they are restricted to a priori assumptions. To improve our understanding of the cycle into fear, calls have been made for the next generation of research to explore the "personal narratives and explanations for the acquisition of fear, and beliefs about movement and avoidance" (Pincus et al. 2010, p. 744), focusing on the individual as the unit of analysis (Vlaeyen and Morley 2005). By adopting a qualitative approach to answer this call, we can move beyond a priori assumptions and explore patterns in individuals' experiences that trap them in the fear avoidance cycle.

We therefore embarked on a qualitative investigation to explore what people with CLBP and high fear believe about their pain. An Interpretive Description framework specifically developed for health research was selected (Thorne et al. 1997). Interpretive Description aims to yield practical knowledge that can inform clinical practice through an inductive approach, while explicitly accounting for the theoretical and practical knowledge that the health researcher necessarily brings to the study (Thorne 2008). The research team comprised of a PhD candidate with ten years of experience as a musculoskeletal Physiotherapist, and her supervisors, two Physiotherapists and a Clinical Psychologist with clinical and research expertise in chronic pain. A detailed description of the methodology of this study can be found in Bunzli et al. (2015a, b). In brief, we employed purposive and theoretical sampling to recruit participants with a range of experiences of pain-related fear, seeking care from diverse primary and tertiary settings in a state capital of Australia.

We recruited 36 individuals with CLBP who scored highly on the Tampa Scale of Kinesiophobia (TSK) (Miller et al. 1991), which is a measure of "Fear of movement and physical activity that is (wrongfully) assumed to cause (re)injury" that has been widely used in the literature to identify highly fearful candidates for fear-reduction interventions (Vlaeyen et al. 1995; Lundberg et al. 2011). The final sample was 69% female with an average of 42 years of age. The mean duration of LBP was 7 years and the average score on the TSK was 47/68. As the sample comprised only of individuals who were given the study information by their treating practitioner and contacted the researchers, the representativeness of this sample is unknown. It is possible that the participants differed in important ways to the wider population of people with CLBP and high fear, for example, they may have had higher health literacy and been more able to seek, understand and utilise LBP information (Briggs et al. 2010).

Semi-structured interviews were conducted face-to-face (n = 34) or over the phone (n = 2), lasting approximately 60 min. Concurrent data collection and data analysis employing inductive techniques, allowed for new directions to be explored as they arose.

4.1 Beyond "Damage Beliefs": The Heterogeneous Beliefs Underlying Fear

In the course of our investigation, an interesting finding emerged. While all our participants were highly fearful and described their fear of movements associated with the threat of pain, not all participants (wrongfully) assumed movement or physical activity would cause (re)injury despite scoring highly on the TSK. Our qualitative analysis of interview data identified two predominant beliefs underlying the participants fear: (i) the belief that performing a painful movement would cause damage to the spine and/or (ii), the belief that performing a painful movement would lead to increased suffering/functional loss. Consistent with our expectations, many participants believed that pain meant damage was occurring to the spine:

> "There is something about the back, it is that fear of my god, I don't want to do something to my spine because if I hurt my spine I am not going to be able to walk. I am not going to be able to mobilise and what if I am an invalid and I can't do anything?"

Many of the participants endorsed pain as a threat to the structure of the spine. Many described their fear of doing more damage or overloading already weak spines:

> "It is falling apart. It is an old person's spine. 80 year old's spine. Which is upsetting. The future scares me. Big time, because I feel that I will get worse. And then I may be confined to a wheelchair or I will have a walking frame earlier than might be the case."

For these individuals, the avoidance of activities perceived as threatening was believed to be a way of mitigating damage to the spine. However, some participants explicitly refuted the idea of painful activity causing damage to the spine, believing instead that painful activity would result in increased pain and suffering:

> "I am mainly just scared of the pain, that the pain will get worse. Not so much of my back because I know that exercise won't make it worse, but I am scared that if I do the wrong movement, the pain will get worse. 'Cause I know how bad the pain is and I don't want to aggravate that area because I know that will cause the pain."
> "It just means pain, I don't think I am going to end up in a wheelchair or anything like that, I don't think it will do any permanent damage, it just feels painful, I can't walk it off, there is nothing I can do to make it better once it is there, so I avoid it".

For others, a flare-up of pain meant they could not achieve valued life goals. These participants described their fear that pain would impact on valued functional goals, both in the near and far future:

> "Well the doctor said ignore it and get on with things. But I know if I bend over and pick up that pen, that pen is going to irritate me for the next half an hour. Why would I do that? If it is going to irritate me for half an hour when I could have an hour pain free why would I do that? I can achieve a lot in half an hour if I am not in agony".
> "There is something in my mind going if I wake up tomorrow and I am in that much pain and I can't walk, what do I do? Because I have got to function for my family".

The belief that painful activity will increase suffering and/or functional loss is consistent with the suggestion that pain is "more than a sign of bodily harm; it is an obstacle to be coped with in the daily pursuit of valued activities and goals" (Crombez et al. 2012, p. 477). Negotiating the dynamic between achieving important functional goals and controlling pain requires considered decision-making. The individuals in our study negotiated this dynamic by the avoidance or modification of feared, pain-provoking movements.

While it must be acknowledged that self-reports of behavior can differ from actual behavior, these findings have potentially important implications. The findings suggest that fear reduction interventions need not only target beliefs about the damaging effects of pain, but may also need to focus on providing individuals with pain control strategies linked to personal functional goals. The failure of many fear reduction interventions to explicitly target pain control may help explain the modest effect sizes and high dropout rates reported in intervention studies to date (Leeuw et al. 2008; Linton et al. 2008; Woby et al. 2008).

4.2 *What does the TSK Actually Measure?*

These qualitative findings also raise the question: What does the TSK actually measure? While widely believed to be a measure of "fear of movement and physical activity that is (wrongfully) assumed to cause (re)injury," a significant proportion of participants in our study did not report being fearful of (re)injury with threatened movements and physical activity, in spite of scoring highly on this measure.

Despite its widespread use, there has been some debate in the literature as to what construct(s) the TSK measures (Lundberg et al. 2009). Originally, it was designed as a 1-dimensional scale of Kinesiophobia: “an excessive, irrational and debilitating fear of physical movement and activity resulting from a feeling of vulnerability to painful injury or re-injury” (Kori et al. 1990). Applied to the context of CLBP, it is more widely considered to measure fear of movement and physical activity that is (wrongfully) assumed to cause (re)injury (Vlaeyen et al. 1995). Factor analytic studies have favoured a 2-factor model of the TSK, in which the broader construct of fear of movement/(re)injury is represented by two subscales (Goubert et al. 2004; Roelofs et al. 2004). The Somatic Focus (TSK-SF) subscale comprises of items such as “My body is telling me I have something dangerously wrong” and “I wouldn’t have this much pain if there weren’t something potentially dangerous going on in my body.” The Activity Avoidance (TSK-AA) subscale comprises items such as “Simply being careful that I do not make any unnecessary movements is the safest thing I can do to prevent my pain from worsening” and, “I’m afraid that I might injure myself if I exercise.” However, psychometric studies have failed to agree on a definition of these subscales. The TSK-SF has been described as “the belief in underlying and serious medical problems” (Clark et al. 1996) and, “the belief that pain is a sign of bodily harm or damage” (French et al. 2007). The TSK-AA has been described as “the belief that activity may result in (re) injury or increased pain” (Clark et al. 1996) and, “the belief that activities that promote pain should be avoided” (French et al. 2007). The failure of numerous factor analytic studies to arrive at a consensus has limited the clinical utility of the TSK subscales.

We saw an opportunity to gain novel insights into this debate by using our qualitative data to assess the construct validity of the TSK and its subscales. We set out to explore how variance between individuals’ qualitative interview data related to elevated scores on subscales of the TSK. To do this, we analysed interview transcripts for each participant in the qualitative study, asking the question: Does this person predominantly believe that painful activity will result in damage (damage beliefs)? Or, do they believe that painful activity will increase suffering and/or functional loss (suffering/functional loss beliefs)? Each transcript was classified as damaged beliefs or suffering/functional loss beliefs, based on the salience of the theme in each transcript, rather than the frequency of endorsement. “Quantitizing” qualitative data in this way has been applied previously in mixed methods studies (Borkan et al. 1991; Sandelowski 2000; Price and Aydede 2006). The reliability of the classification process was checked by independent analysis of transcripts by two members of the study team. Through this process we were able to reliably classify participants into the damage beliefs group (n = 14) and participants who explicitly denied damage beliefs and endorsed suffering/functional loss beliefs (n = 17), into the suffering/functional loss beliefs group. Beliefs are likely to function on a continuum, and indeed a minority of participants (n = 5) were classified as both damage and suffering/functional loss beliefs. Through closer analysis in-group discussion we were able to identify a predominate belief driving avoidance behaviour in each of these five individuals. For example, in two cases, individuals believed pain was a sign of damage, but in describing their experience, appeared to be more concerned about the functional rather than damaging consequences of performing a painful activity. Therefore, these two cases were classified in the functional/suffering loss belief group. Extracts supporting the classification of each individual can be found in the publication Bunzli et al. (2015b).

Once each individual transcript had been classified, we explored associations between the two belief groups and itemized scores on the TSK. Using independent *t* tests, we evaluated differences between groups on the total TSK scores and TSK subscales identified in the literature. Using the Mann–Whitney *U* test, frequencies of each ordinal response item were also evaluated between the beliefs groups. The endorsement of each item was reflected by a median score of >3.

We hypothesised: (1) Individuals in the damage beliefs group would score significantly higher on the TSK-SF and lower on the TSK-AA than individuals in the suffering/functional loss beliefs group and (2) Individuals in the suffering/functional loss beliefs would be more highly ranked on the TSK-AA items, while individuals in the damage beliefs group would be more highly ranked on the TSK-SF items.

In support of our first hypothesis, results from our analysis revealed that individuals in the damage beliefs groups scored significantly higher on the total TSK score and more strongly agreed with items on the TSK-SF than the suffering/functional loss beliefs group. This finding lends construct validity to the existence of a TSK subscale describing the belief that pain is a sign of damage.

Contrary to our second hypothesis, there was no difference in item endorsement between groups on the TSK-AA. To gain insight into the lack of discriminative ability of the TSK-AA we conducted a closer examination of the itemized analysis and found that 4 of the items in the TSK-AA that were equally endorsed by both groups contained the word "injure." While future investigation into how individuals with CLBP interpret the word "injure" is needed, we speculate that individuals in the damage beliefs groups and suffering/functional loss beliefs group may interpret the word "injure" in different ways. While individuals in the damage beliefs group may interpret the word "injure" as "damage," this is unlikely to be the case amongst individuals in the suffering/functional loss beliefs group who explicitly denied damage beliefs in the interview and did not endorse other items in the TSK that associated pain with damage or "danger." Instead, it is possible that individuals may have interpreted the word "injure" in this context to mean "increase pain."

Ambiguously worded items may in part, explain the poorly defined construct(s) of the TSK and TSK subscales. As approximately half of the participants in our study did not endorse damage beliefs, our results do not support the widely accepted definition of the TSK as a measure of fear of movement/(re)injury. Our results do however support a 2-factor model of the TSK, with one factor being the TSK-SF.

To be valid and applicable, it is important that questionnaire items measure what they are supposed to and are fully understood. Therefore, exploring how patients understand and interpret words used in questionnaire items is important part of the psychometric validation of pain questionnaires. This study highlights the role that qualitative methods can play in providing unique insights into the psychometric properties of a questionnaire that lie beyond the reach of quantitative tools. Indeed, quantitative techniques such as factor analysis, internal consistency and construct validity are able to highlight problematic items, but are not sensitive to how individuals interpret items.

The positivist approach taken in this study allowed us to increase the clinical utility of the qualitative findings. While in the process of reducing qualitative data, some of the depth and meaning of the participants experiences was lost and it must be emphasised that beliefs exist on a continuum rather than being dichotomous, this approach allowed us to contribute to the existing literature exploring the psychometric dimensions of a widely used measure. To date, such an approach has been underused in psychometric studies and in the pain literature [a notable exception can be found in Pool et al. (2008)].

5 How do Beliefs Underlying Fear Evolve?

Returning to our qualitative data, we sought to understand how beliefs evolve on the pathway to pain-related fear (Bunzli et al. 2015a). Why did these individuals enter the cycle of high fear? The common theme we identified amongst all 36 participants was a LBP experience that did not make sense. For all participants the experience of LBP as unpredictable, uncontrollable and/or intense was threatening to them:

> "When my back was completely bad, 10/10 pain, I got scared then, thinking what is going to happen am I going to be in a wheelchair and yeah when it gets that bad and I can't walk then that is when I do get really scared".

> "There is no set pattern when it is going to happen. And I can do things today that won't trigger it, tomorrow I do exactly the same things and it will trigger it. So nothing causes it and I can't control it. That is what is so frustrating and scary".

In an attempt to make sense of the threatening meaning of LBP, participants with damage beliefs described drawing on past personal experiences of LBP, societal beliefs about LBP, and consulted health professionals in search of diagnostic certainty. Diagnosis of an underlying cause of pain was central to understanding how it could be "fixed." However, most participants did not receive a clear diagnosis and the lack of explanation left them confused. Others did receive a diagnosis of underlying pathology, but commonly misinterpreted diagnostic labels such as "degeneration" (a normal age related process that has a poor association with pain) as meaning that their back was damaged and "breaking down." Confusion also arose with the realization that the diagnosed underlying pathology could not be fixed:

> "The injury is bone on bone. You know they can do hip replacements and all that sort of thing, why can't they do anything for your spine?"

In their attempt to make sense of LBP experience and achieve pain control, participants with suffering/functional loss beliefs described drawing on past personal experiences of LBP and consulted health professionals. However, the repeated experience of "failed" treatments and their consistent failure to achieve valued functional goals meant they were unable to make "sensible" decisions about what to do with their LBP.

> "That's the point that I couldn't understand like I am doing everything they want me to do. I am doing physio, I am moving and trying all this and the pain isn't dying. This is crazy". "I don't know what to do, it doesn't make sense to me".

That sense-making processes may play a role in the cycle into pain-related fear is a novel proposal that contrasts with the "phobic" processes in the FAM. However, an inability to make sense of LBP has been described in previous qualitative studies of the LBP experience. Lillrank (2003) describes "the riddle of the puzzling pain" and Campbell and Guy (2007) describe the "bewildering situation" of unmet expectations of LBP treatment. There is also some evidence from the wider chronic pain literature that individuals who cannot make sense of their symptoms are more likely to catastrophize about them (van Wilgen et al. 2008).

In a qualitative longitudinal study involving people on sick leave for injury-related chronic musculoskeletal pain, O'Hagan et al. (2013) found that individuals who could not make sense of their pain were more likely to experience it as threatening, as they were unable to predict the outcomes of their actions. Following participation in a multidisciplinary occupational rehabilitation program, those individuals who returned to work described a new understanding of their pain that enabled them to predict the course of their symptom exacerbations and the outcome of coping actions, providing a sense of control that reduced the threat surrounding pain (O'Hagan et al. 2013). The levels of pain-related fear experienced by participants in the study by O'Hagan et al. are unknown. However, the study raises the possibility that sense-making processes may not only be involved in cycling into fear, but may help reduce pain-related threat and thus be implicated in cycling out of fear.

6 The Cycle Out of Fear

A clinically useful framework to understand the cycle out of fear is lacking in the current literature. While the FAM suggests that confrontation of movement and activity despite pain will lead to recovery, it lacks clear detail as to how this can be achieved (Crombez et al. 2012). To gain novel insights into the cycle out of fear, we followed our original sample of 36 individuals with CLBP and high fear at baseline over a 4-month period, during which time they participated in "usual care." We conducted semi-structured interviews with 31 of the original 36 participants exploring their experiences of fear over time and their personal explanations for changes in any fear. We specifically aimed to identify individuals who experienced an improvement in pain-related fear and identify factors associated with an improvement in fear. A detailed description of this study can be found at Bunzli (2015).

Amongst the 18/31 participants who experienced an improvement in fear, the overarching theme identified was gaining control over the pain experience. Improvers reported a range of interventions and "gaining control" appeared to occur through a range of pathways. These included:

1. Gaining control over the somatic aspects of the pain experience:

> "It doesn't worry me when the pain flares up now. Because it is not as bad. I was starting to think am I going to end up in a wheelchair. But I am not like that now. It is just not having that excruciating pain anymore".

2. Gaining control over one's responses to pain through the development of a mindful acceptance of the presence of pain in their lives:

> "I have realized that you can't let the pain dominate your life. You've just got to keep going and when it turns up say 'gidday, how are you' and continue on".

3. Gaining control through developing an understanding of pain linked to the strengthening of locus of control beliefs:

> "I went from being terrified of hurting myself anytime I moved to realizing that moving was the very thing I needed to do…What I have learnt about chronic pain is that it is a result of your behavior as much as it is the result of something going on inside you. It is not necessarily the fact that something is busted, it is that you are continually hurting yourself without moving properly"."I would never have attempted to touch my toes because I thought I would hurt myself. When he got me to do it on the first day… it wasn't just that I had done it. I could have done it and it hurt like buggery. But my back wasn't hurting. And I had done it on my own, without him. He was just standing there. It changed my mind set instantly. Everything made sense".

The opportunity for "mastery experiences" in which participants could apply self-management strategies during a flare-up, appeared to be an important step on the pathway to improvement in fear. Such experiences instilled hope and confidence that future flare-ups could be controlled.

In support of the central importance of "gaining control" in the pathway to fear reduction, the experiences of non-improvers were characterized by poor pain controllability:

> "Nothing has really changed. Nothing at all. I have stopped going to the physiotherapist and all of that because it wasn't working. It is just that I was getting such minimum relief".

That different pathways to fear reduction may exist, and that gaining control over the pain experience may be a key ingredient on these pathways, are novel suggestions not currently captured in the FAM.

7 Making Sense of Pain-Related Fear

In the first part of this chapter, we have reported findings from our qualitative investigations exploring the lived experience of CLBP and of pain-related fear over time. We have highlighted that the current FAM does not account for:

1. Multiple beliefs underlying pain-related fear
2. Sense-making processes in the cycle into fear
3. The role of gaining control over the pain experience in the cycle out of fear.
4. Different pathways to fear reduction

In this next section, we will draw on an alternative health behavior model, the common sense model (CSM), illustrating how it may be a useful lens to understand the lived experience of pain-related fear. We will propose that the CSM may be a useful framework to extend the current FAM, increasing its clinical utility.

7.1 The Common Sense Model

How patients make sense of a chronic illness experience influences how they respond to it, what they do about it and how long it will last (Leventhal et al. 2011). The CSM (Leventhal et al. 1980) has been widely used in the health literature to understand how sense-making processes influence responses to chronic illnesses such as diabetes, heart disease and osteoarthritis (Donovan et al. 2007; Paddison et al. 2010; Knowles et al. 2016). The CSM describes a 3-stage process occurring at a cognitive and emotional level when one encounters a health problem:

1. The individual attempts to make sense of their symptoms by forming a "representation" about them. The representation is comprised of five dimensions of meaning that have consistently been identified in studies exploring meaningfulness of perceived health: identity, cause, consequences, time-line and cure/controllability of the symptoms.
2. Based on this representation, the individual may have an emotional response to the symptoms and will decide what they should do about them.
3. The individual appraises the outcome of the action, and this appraisal feeds-back into the representation.

Due to a continuous interaction between cognitive, behavioural and contextual factors, the representation is constantly updated to influence on-going behaviour (Leventhal et al. 1980) (see Fig. 2). Representations are therefore "lay" representations, embedded in the context of broader personal experience (Coutu et al. 2007).

Stage 1: **Interpretation Phase: Creating a Representation of LBP**

When an individual experiences LBP, they will attempt to make sense or "interpret" the meaning of their symptoms using their pre-existing knowledge

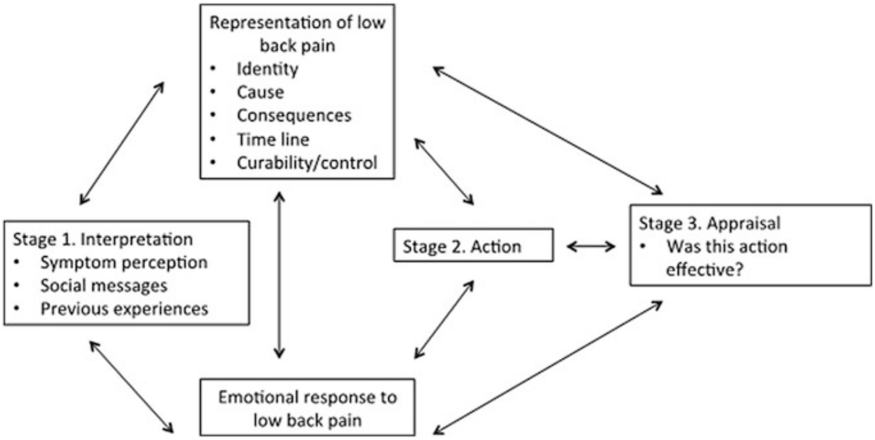

Fig. 2 The common sense model (based on Leventhal 1980)

(schemas) about LBP. These meaning are influenced by the individuals' previous experiences of LBP, both direct and vicarious, and are constantly and continually updated with new information from sources such as the media, clinicians and by the perception of actual sensations (Leventhal et al. 2011). The result of this interpretation will be a "representation" of their LBP experience. The representation will consist of beliefs associated with

1. The "diagnostic labels" used to describe the symptoms
2. The "causes" of pain, including what triggered the painful episode and flare-ups in pain
3. The time course of pain (acute, episodic or chronic) and whether it is stable, recovering or deteriorating
4. The consequences of pain, such as tissue damage, suffering and functional loss
5. The control they have over pain including external locus of control beliefs (i.e. that their pain can be controlled by powerful others such as clinicians) and internal locus of control beliefs (i.e. that their pain is within their own personal control).

Stage 2: Developing an Action Plan

Based on the representation, individuals will set goals and develop an action plan to guide their behaviour (problem-based coping). In parallel, the representation of LBP may elicit an emotional reaction, in which case individuals may take action towards preserving emotional equilibrium (emotion-directed coping) (Leventhal 1980). In particular, beliefs that an illness has severe consequences, and is experienced as unpredictable in nature, and out of one's control are thought to strongly affect negative emotional responses to illness and increase suffering (Moss-Morris et al. 2002).

Stage 3: Appraisal of Action: Assessing the Gap Between the Current Situation and Target Goal

A self-regulatory process follows, in which individuals appraise the outcome of the behaviour and this appraisal feeds back into the representation of LBP. If the outcome is expected and in the direction of the target goal, the usefulness of the representation in making-sense of LBP, the *coherence*, is high and the behaviour will be maintained. If the outcome is unexpected and distances the individual from their target goal, the LBP representation is *incoherent* and the individual lacks clues as to how they should readjust behaviour (Leventhal et al. 2008).

These three stages continue until the behaviours are deemed successful. The three stages interrelate in a dynamic and on-going way and therefore the process is regarded as self-regulatory. In this way, while representations of LBP (and the beliefs they are comprised of) may vary greatly between individuals and even within individuals at different points in time, the *process* of "making sense" of LBP will be similar for all people (Petrie et al. 2007).

7.2 Understanding the Cycle into Pain-Related Fear in People with LBP

According to the CSM, fear and avoidance may be viewed in some individuals as a "common sense" problem-solving response based on their representation (meaning) of LBP. If one believes that performing a painful activity could cause their spine to "break," or "crumble," it is "common sense" to avoid or modify the painful activity. If one experiences "stabbing" pain in their back every time they bend forward, it is "common sense" to avoid or modify bending forward. As long as the outcome of avoidance is expected (e.g. no further "damage" and/or no pain "flare-up" by avoiding the painful activity), the "representation" is deemed to be "useful" i.e. coherence is high, and avoidance behaviour will be maintained, despite having negative long-term consequences. The CSM raises a further possibility that pain-related fear may be generated and/or perpetuated by a lack of a coherent representation in order to make sense of the LBP experience.

We have documented that an inability to make sense of the LBP experience appears to be a common theme amongst people with LBP and high pain-related fear. Some of the participants in our study described uncertain diagnoses and prognoses. Some described unpredictable flare-ups, and all held beliefs in the damaging and/or suffering/functional consequences of pain and low levels of perceived control over their pain. All participants described a discrepancy between their expected versus their "lived experience" outcomes of the actions they took. This occurred in relation to their seeking of a diagnosis for their pain, their attempts to control pain and/or avoid its consequences. When this discrepancy was repeated through time, the representation was recognised as ineffective in guiding problem-solving behaviour (Bunzli et al. 2015b).

According to the CSM, in the absence of a useful cognitive representation to make sense of pain and guide problem-solving behaviour, behaviour will be driven by the emotional response. In the case of "threatening pain" i.e. where pain is perceived to have severe consequences, is unpredictable and/or uncontrollable, this emotional response is likely to be fear (Moss-Morris et al. 2002). As proposed by the current FAM, fear avoidance behaviour preserves emotional equilibrium by reducing fear in the short term (Vlaeyen and Linton 2000). However, it may reinforce incoherency regarding the identity, causes, consequences, time-line and/or the curability/control of the symptoms by preventing opportunities for positive exposure and adaptation in the long term. A vicious cycle is then implicated in which fear avoidance behaviour reinforces an incoherent LBP representation that in turn reinforces pain-related fear. This commonly results in increasing levels of disability, as valued life activities and goals become avoided, leading to escalating depression and distress and placing their lives in a state of "suspension."

It is possible that in the early stages of LBP associated with tissue injury, fear avoidance behaviour is a "common sense" solution to avoiding further injury and allowing for tissue healing to occur. However, in cases where pain is not related to injury or where pain persists beyond the time taken for tissue to heal, fear avoidance may be an emotional response to an incoherent LBP representation.

7.3 Understanding the Process of Fear Reduction

According to the CSM, a coherent LBP representation may be defined as the combination of diagnostic certainty (identity dimension) that is able to explain symptoms (cause dimension) and prescribe procedures for controlling/resolving the symptoms (timeline, control dimension). When this is combined with the experience of having control over the symptoms, including a reduction in pain intensity and reduced goal conflict (consequences, control dimension), a coherent LBP representation guides effective problem-solving behaviour that reduces the threat of LBP and therefore fear. Amongst the participants in our study who experienced an improvement in fear, we described how altered understandings of pain or "representations" enabled them to predict the course of symptom exacerbations and engage effective coping actions, providing a sense of control and reducing threat.

However, in addition to coherency as a mediator of fear-reduction, the CSM suggests an alternative mechanism of fear-reduction, through changing the individuals' emotional response to an incoherent representation. We have stated before that fear is a typical emotional response to a symptom perceived to be unpredictable and/or uncontrollable and to have severe consequences (Eccles et al. 2013). Through the acceptance of the uncertainty and unpredictability associated with pain and the "letting go" of negative thoughts about the consequences of pain, it may be that the emotional impact of an incoherent representation is reduced. This is consistent with Acceptance and Commitment Therapy (McCracken et al. 2005) and mindfulness-based approaches that focus attention away from pain and its consequences, towards value-directed behaviour. While these approaches focus on reducing fear avoidance behaviour rather than changing beliefs, it is conceded that belief change happens along the way (McCracken and Vowles 2014). The effectiveness of these approaches in reducing fear amongst individuals with high pain-related fear at baseline is yet to be established. However, in the qualitative accounts of participants in our study, we identified "acceptance" as one construct associated with improvements in pain-related fear.

8 Implications for Future Research

By exploring the lived experience of pain-related fear in people with CLBP, we have yielded novel insights that can inform the next generation of fear avoidance research seeking to ease the burden of disabling LBP. Future research is required to explore the validity and clinical utility of incorporating a CSM perspective into future iterations of the FAM. Future prospective studies employing quantitative methodologies may examine the relationship between LBP representations and pain-related fear. According to the CSM, all people have a pre-existing schema of LBP. Thus, the capacity of representations to predict pain-related fear associated with LBP disability amongst the general population can be explored.

Future studies are required to investigate the potential mediating role of "coherency" or sense making in fear reduction. Such studies should examine if and how the experience of control over pain influences one's ability to make sense of pain. The role of perceived control in fear-reduction interventions is currently poorly understood. Where Acceptance and Commitment Therapy and other mindfulness-based approaches recommend that pain controllability should not be a target of treatment, an intervention explicitly targeting pain control, Cognitive Functional Therapy, shows promising effects for fear reduction (Vibe Fersum et al. 2013). Findings from a qualitative investigation involving patients with CLBP undergoing Cognitive Functional Therapy suggest that improvements through Cognitive Functional Therapy may be mediated by alterations in pain representations and improvements in perceived control (Bunzli et al. 2016); however, this hypothesis remains to be tested through mediation analysis embedded in future studies of Cognitive Functional Therapy.

Further research is needed to investigate the relative importance of establishing coherency versus learning to accept an incoherent representation in fear reduction. Mediation analysis from a randomized controlled trial involving participants with chronic pain found that increased perceived controllability, rather than increased acceptance of pain, mediated improvements through Acceptance and Commitment Therapy (Wetherell et al. 2011). It may be that equipping some individuals with acceptance and mindfulness strategies assists them to control their worry about the consequences of their actions enough for them to pursue valued life goals. The achievement of desired outcomes may mean that the behavioural strategy is appraised as effective, feeding-back into the representation and reinforcing coherency. Embedding qualitative and/or mixed methods approaches such as that described by Price and Aydede (2006) into future trials of Acceptance and Commitment Therapy may assist in understanding the construct of improved control in this context.

Finally, research is required to explore how the lives of people with LBP can improve by equipping clinicians with a better understanding of the lived experience of pain-related fear. Recognizing pain-related fear as a "common sense" response, rather than always being a phobic response, is potentially less stigmatizing for patients, and may shift how clinicians perceive and communicate with their highly fearful patients who may be struggling with a threatening pain experience that they can't make sense of.

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Chapter 15
Conceptualising Secondary Pain Affect: The More Personal and Elaborate Feelings

Drew Carter

Abstract I aim to advance the conception of what pain scientist Price (2000) terms secondary pain affect, a dimension of pain thought to comprise "emotional feelings directed toward long-term implications." I analyse some of the many feelings involved in an experience of pain and aim to demonstrate three things. First, I aim to demonstrate how Peter MS Hacker's philosophical distinctions between different types of feeling help to differentiate the different types of feeling that conceivably comprise pain and, in particular, secondary pain affect. Pain researchers need something like Hacker's sensible taxonomy or way of thinking about different types of feeling so they can ask meaningful questions and research their phenomena of interest rather than phenomena that may be closely related, but actually intrinsically different. Second, I aim to demonstrate how pain catastrophising can conceivably relate to secondary pain affect and how secondary pain affect need not solely comprise negative feelings. Finally, I aim to demonstrate how pain can contain moral dimensions by drawing on our memories, long-standing hopes and fears, loves, and, more broadly, what things mean to us. I conclude with some implications for redressing pain in clinical practice by attempting to counter pain catastrophising and to decrease negative secondary pain affect.

1 Introduction

There is a theoretical gap in the scientific literature on pain. "meaning" and "context" are often discussed as shaping experiences of pain, but these terms are rarely expanded on. They are often used vaguely. Efforts to clarify conceptually what "meaning" and "context" signify for pain experience, and therefore what implications follow for clinically treating pain, have been fairly basic. They have tended to produce sketches rather than detailed pictures. Sketches are useful in developing theory and establishing an evidence base, but, beyond this initial phase of development, detailed pictures are

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D. Carter (✉)
School of Public Health, University of Adelaide, Adelaide 5005, Australia
e-mail: drew.carter@adelaide.edu.au

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needed to more precisely articulate our theories of pain, and for more sophisticated testing and targeted treatment of pain. It is for this reason that, in this chapter, I aim to advance and spur further work on the conception of what pain scientist Donald Price terms *secondary pain affect*. I take Price's work to provide a preeminent example of a theory of pain in which pain's meaning and context shape pain experience. Price's concept of secondary pain affect initiates a research pathway for more precisely conceptualising cognitive and temporally-extended feelings related to pain. This chapter applies Price's concept to provide a more detailed picture of what pain's "meaning" and "context" can include.

Price (2000) theorises that pain comprises a purely sensory dimension in addition to two further dimensions; namely, "moment-by-moment unpleasantness" and "emotional feelings directed toward long-term implications" (p. 1769). To refer to the latter, Price coins the term "secondary pain affect" (p. 1769). The former I would term *primary pain affect*, if only for the reason that this term is already implied by Price's term of *secondary* pain affect (Price himself uses the term *unpleasantness*). Price presents empirical evidence that, like pain sensation, primary and secondary pain affect each involve distinct neural pathways.

Price distinguishes primary from secondary pain affect as follows. While primary pain affect involves *some* "relation to meanings of the pain and to the context in which pain presents itself" (p. 1769), secondary pain affect "is based on more elaborate reflection related to that which one remembers or imagines. This involves meanings such as perceived interference with one's life, difficulties of enduring pain over time, and the implications for the future. Pain is often experienced not only as a threat to the present state of one's body, comfort, or activity but also to one's future well-being and life in general" (p. 1769).

Primary pain affect comprises "an overall sense of intrusion and threat to the physical body and self" (Price 2000, p. 1771). It is conceptualised as comparatively immediate, being oriented to the present, as well as comparatively direct, involving only basic interpretations of a situation, namely "primitive meanings of intrusion or threat" (Wade et al. 2011, p. 318). By contrast, secondary pain affect is conceptualised as being less immediate, often being oriented to longer-term implications for the future, for instance. Secondary pain affect is also conceptualised as being comparatively indirect, being shaped by interpretations of a situation that are more individual and elaborate; namely, interpretations that are shaped by an individual's hopes for the future, memories of the past, and perspective on the present, especially in what it means for oneself.

Price and others (Melzack and Wall 1988; Morris 1991; Price and Bushnell 2004) emphasise how "the meaning of the situation" (Melzack and Wall 1988, p. 15) shapes the experience of pain. This makes the experience of pain "highly personal" (Melzack and Wall 1988, p. 15) in the sense that what pains one individual may not pain another in the same way or to the same degree depending on its meaning; that is, depending on how it is personally evaluated or appraised (Nelkin 1994).

In this chapter, I elaborate some feelings that belong to a particular experience of pain. In doing this, I aim to illuminate the range and depth of feelings that secondary pain affect can be thought to comprise in human beings. This helps to foster a conception of secondary pain affect that is sufficiently rich or non-reductive; namely, a conception in which human pain and emotion remain recognisable. Presenting such an expanded conception is one of the unique contributions of this chapter. I also aim to refine the conception of secondary pain affect by identifying the distinct *types* of feeling that it comprises. In this regard, I then apply Hacker's (2004) philosophical distinctions between different types of feeling. Then, I reflect on how secondary pain affect conceivably relates to pain catastrophising, an increasingly studied phenomenon that has been found to worsen pain. Pain catastrophising has been conceptualised as "a tendency to magnify or exaggerate the threat value or seriousness of pain sensations" (Chaves and Brown 1987), cited in Quartana et al. (2009). On this conception, pain catastrophising always distorts or distends "the meaning of the situation" (Melzack and Wall 1988, p. 15), and in this respect it clearly bears some connection to pain affect. Finally, I highlight implications for clinical practice, examining how health practitioners might conceivably redress the deleterious effects of feelings that instantiate secondary pain affect.

2 Hacker's Distinctions Between Different Types of Feeling

Hacker (2004) follows philosopher Wittgenstein (2001, §127)[1] in asserting that the task of philosophy "consists in assembling reminders" about the ways in which we intelligibly speak and act. In Hacker's (2004) words, philosophy's task "is to describe the conceptual structures in terms of which we articulate our experience and its objects" (p. 199). In other words, philosophy's task is to trace the ways in which we intelligibly speak and act. Philosophy's task is to *elaborate* these ways or, put differently, to elaborate the *distinctions* that condition or structure our intelligible locutions and acts. These distinctions usually lie far in the background of our everyday lives, hidden from view. Philosophy's task, then, is precisely to *explicate*, "to open out (what is wrapped up)," "to spread out to view, display" (Oxford English Dictionary). It provides a "*a clear view* of the use of our words … A perspicuous representation" (Wittgenstein 2001, §122). Philosophy's task is to *remind* us what we mean by our words and actions, not to *reform* our use of words and actions. In this sense, philosophy "leaves everything as it is" (Wittgenstein 2001, §124).

The practice of philosophy, so conceived, helps us to be clear about what we mean by our words and actions. We need to be clear about what we mean by our words and actions—about what counts for us as *emotion*, for example—for at least two reasons. First, we wish to avoid asking questions that are actually nonsensical,

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[1] The symbol § is often used to refer to the numbered notes that comprise Wittgenstein's (2001) *Philosophical Investigations*.

questions that do not make sense, but may appear to prior to careful inspection. In other words, we wish to avoid sitting at an empty loom, weaving without thread (Wittgenstein 2001, §414). Take the following two questions as examples (Gaita 2002, p. 53 ff):

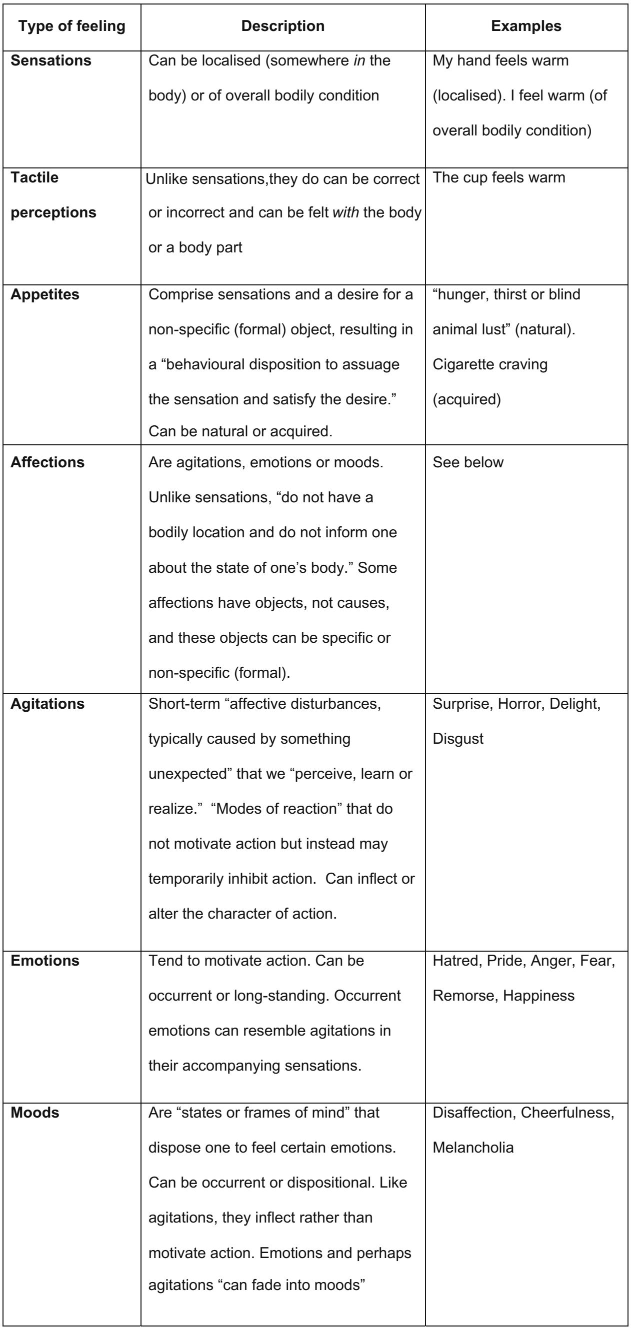
> Do stones feel pain when I kick them?
> Can you have a pain in your pocket?

These questions are devoid of sense by virtue of what we mean by "pain," "stone," and "pocket." Nothing could count for us as both "a stone" and "in pain" by virtue of what counts for us "a stone" and as "in pain." So too it is with a pain in your pocket. "But perhaps you can have a pain in your pocket!"—of this thought, Gaita (2002, p. 56) writes, "Only a very small child… could even think it, and then only inchoately, for… one could think it only if one had failed in quite fundamental ways to have mastered the concept of pain." There is an important sense in which "it belongs to the concept of pain that pains cannot be in one's pocket" (Gaita 2002, p. 56). It is for this reason that we never ask for evidence that you cannot have a pain in your pocket. Learning a concept—learning how to speak and act in ways that mean something to those around you—differs from learning about the world through accumulating evidence in one form or another. McGee (2016, p. 15) draws attention to "Wittgenstein's well-known dictum that only of a living human being and what resembles (behaves like) one do we say that it has sensations." The fact that we naturally attribute pain, sensation and consciousness only to "a living human being and what resembles (behaves like) one" actually "scaffolds" or undergirds our concepts of pain, sensation and consciousness, among others (Carter 2013).

Second, we need to be clear about what we mean by our words and actions because we wish to avoid investigating one thing when we think we are investigating quite another. As Hacker (2004) puts it, "Unless one is clear what precisely counts as an emotion, one may find oneself investigating phenomena, e.g. appetites, which are only tangentially related to the emotions" (p. 199). This second reason will become clearer as I further expound Hacker.

It is for these two reasons that Hacker distinguishes between different types of feeling (see Fig. 1). He does not *define* any technical or formal terms, but rather *observes* some distinctions that we typically make when articulating our experience. His gives us a clearer view of some of our concepts, as those are manifest in the things that we say and do.

- **Sensations** can be localised, or of overall bodily condition. For example, *my hand* can feel warm from holding a hot cup of tea (a localised sensation), or *I* can feel hot from having run 10 km, or from having developed a fever (a sensation of overall bodily condition). Equally, *my hand* can feel sore and weak from having used a power drill all day (a localised sensation), or *I* can feel sore and weak from having worked all day (a sensation of overall bodily condition). These sorts of locutions are readily intelligible to us.
- Sensations differ from **tactile perceptions**. The latter can be correct or incorrect. For example, the shower water feels very hot on my feet, but this is only because my



Type of feeling	Description	Examples
Sensations	Can be localised (somewhere *in* the body) or of overall bodily condition	My hand feels warm (localised). I feel warm (of overall bodily condition)
Tactile perceptions	Unlike sensations,they do can be correct or incorrect and can be felt *with* the body or a body part	The cup feels warm
Appetites	Comprise sensations and a desire for a non-specific (formal) object, resulting in a "behavioural disposition to assuage the sensation and satisfy the desire." Can be natural or acquired.	"hunger, thirst or blind animal lust" (natural). Cigarette craving (acquired)
Affections	Are agitations, emotions or moods. Unlike sensations, "do not have a bodily location and do not inform one about the state of one's body." Some affections have objects, not causes, and these objects can be specific or non-specific (formal).	See below
Agitations	Short-term "affective disturbances, typically caused by something unexpected" that we "perceive, learn or realize." "Modes of reaction" that do not motivate action but instead may temporarily inhibit action. Can inflect or alter the character of action.	Surprise, Horror, Delight, Disgust
Emotions	Tend to motivate action. Can be occurrent or long-standing. Occurrent emotions can resemble agitations in their accompanying sensations.	Hatred, Pride, Anger, Fear, Remorse, Happiness
Moods	Are "states or frames of mind" that dispose one to feel certain emotions. Can be occurrent or dispositional. Like agitations, they inflect rather than motivate action. Emotions and perhaps agitations "can fade into moods"	Disaffection, Cheerfulness, Melancholia

Fig. 1 Different types of feeling (Hacker 2004)

feet are cold from having walked in the snow; in fact, the water is only lukewarm. My perception of the water being very hot is incorrect, but the sensation of having very hot liquid fall on my feet is not incorrect, for it makes no sense for us to say that my sensation is incorrect (other than by meaning that my perception is incorrect). In other words, nothing counts for us as an incorrect sensation. This distinguishes sensations from tactile perceptions. So too does the following: localised sensations are felt somewhere *in* the body, but not *with* the body. For example, we make sense of the statement "I feel pain in my hand" but not "I feel pain with my hand." By contrast, we can perceive things with the body and with body parts. For example, I feel the heat of the water with my feet, or I feel the hardness of the table with my hand.

- **Appetites** differ again. They comprise sensations and a desire for a non-specific or "formal" object, resulting in a "behavioural disposition to assuage the sensation and satisfy the desire" (Hacker 2004, p. 200). For example, I feel thirsty. This feeling comprises some dryness in the mouth and a desire for something to drink, resulting in an inclination to get rid of the dryness and to have something to drink. Just getting rid of the dryness, perhaps by swilling some water, will not get rid of the thirst. In this respect, an appetite comprises more than just sensations and the desire to assuage those sensations; it encompasses a desire for a non-specific object (e.g. something to drink). Furthermore, appetites can be natural or non-natural. For example, "hunger, thirst or blind animal lust" (Hacker 2004, p. 200) contrast with a cigarette craving insofar as the latter is "acquired" (p. 200).
- Finally, Hacker distinguishes **affections**. His term "affections" is unfortunate, since it is intended to encompass emotions and moods that run counter to our typical uses of the word "affection," such as hatred and disaffection. In this regard, affect may be a better term. Unlike sensations, affects "do not have a bodily location and do not inform one about the state of one's body" (Hacker 2004, p. 200). For example, we do not ask where in the body is the pride, nor take a chest swollen with pride to inform us about the chest. For Hacker, three types of affect are typically distinct.

  - **Agitations** are short-term "affective disturbances, typically caused by something unexpected" that we "perceive, learn or realize" (Hacker 2004, p. 201). Examples of agitations are surprise, horror, and delight. They are "modes of reaction" (Hacker 2004, p. 201) that do not motivate action but instead may temporarily inhibit action. They can also inflect or alter the character of action.
  - **Emotions** do tend to motivate action. For example, we act *out of* anger in a sense that we do not act *out of* surprise, though we may act in a certain way because we are surprised. Emotions can be occurrent or long-standing. For example, contrast a fear with which one is gripped while poised on a precipice with a fear that sees one avoid heights over the course of many years. Occurrent emotions, unlike long-standing ones, can resemble agitations in their accompanying sensations. For example, the sensations of a churning stomach can

accompany both remorse, considered as an occurrent emotion, and disgust, considered as an agitation.

- Like emotions, **moods** can be occurrent. For example, I feel cheerful at the moment. Moods can also be dispositional. For example, one may feel cheerful or melancholic in a way that endures over time and shapes one's approach to things. Moods are "states or frames of mind" (Hacker 2004, p. 201) that dispose one to feel certain emotions. Like agitations, they *inflect* rather than motivate action, being "exhibited in the manner in which one does whatever one does" (Hacker 2004, p. 201). Emotions, and perhaps also agitations, "can fade into moods," since "boundaries between emotion, agitation and mood are not sharp" (Hacker 2004, p. 202). Some affects have objects, as distinct from causes. For example, I can feel cheerful *because* of something, then happy *about* something. In this case, the mood (cheerfulness) has a cause, whereas the emotion (happiness) has an object.[2] Objects can be formal or specific. For example, contrast my longing for company with my longing for *your* company. When anyone will do, the object of my longing is formal, but when only you will do, the object of my longing is specific.

I now apply Hacker's distinctions to illustrate the different types of feeling that can conceivably belong to an experience of pain and, in particular, comprise secondary pain affect. I enumerate some feelings that belong to a particular experience of pain, then I tendentiously classify them using Hacker's distinctions in addition to Price's scientific model of pain and contemporary models of pain catastrophising. Again, the purpose of this undertaking is to foster a conception of secondary pain affect that can accommodate the range and depth of emotions connected with pain in human experience. First, it is helpful to examine some current thinking on pain catastrophising.

3 Pain Catastrophising

Pain catastrophising has been conceptualised as "a tendency to magnify or exaggerate the threat value or seriousness of pain sensations" (Chaves and Brown 1987) cited in Quartana et al. (2009, p. 2). Pain catastrophising has been found to increase measures of both primary and secondary pain affect (Wade et al. 2011). There is some work (Geisser et al. 1994) cited in Sullivan et al. (2001) to suggest that pain catastrophising influences pain affect, but not pain sensation.

Wade et al. (2011) provide empirical support for the hypothesis that pain catastrophising worsens secondary pain affect independently of primary pain affect. Wade et al. (2011) studied 310 patients with chronic and severe osteoarthritic knee

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[2] Hacker is unclear on whether moods can have objects or only causes. See also de Sousa (2013), who distinguishes moods from emotions precisely by their lack of an object: "Objectless emotions share many properties with other emotions, especially in their physiological and motivational aspects, but they might more properly be classified as moods rather than full-fledged emotions. Moods typically facilitate certain ranges of object-directed emotions, but they form a class apart."

pain, using the Pain Catastrophising Scale (Sullivan et al. 2004) and Pain Experience Analog Scales (Harkins et al. 1989; Price et al. 1983) to measure catastrophising, pain sensation, pain-related unpleasantness (primary pain affect), and pain-related negative emotions (secondary pain affect). A multivariate approach was used to statistically test for hypothesised relationships between catastrophising and the three dimensions of pain (on four competing models of how those dimensions interact). The authors found that catastrophizing and unpleasantness made "separate and nearly equal parallel contributions to suffering" (p. 317). That is, measures of suffering increased both when measures of pain catastrophising increased and, independently, when measures of primary pain affect increased.

Wade et al. use the word *suffering* to refer to the "unique psychological component distinguishable from immediate pain unpleasantness" (p. 314). They measure it by measuring ongoing pain-related feelings of depression, anxiety, frustration, anger, and fear. Wade and colleagues take these feelings to "define" the "long-term cognitive or reflective processes that are related to the meanings and implications that pain holds for one's life in general"; namely, secondary pain affect (p. 314). I later challenge whether secondary pain affect ought to be conceptualised purely in terms of negative feelings, let alone solely feelings of depression, anxiety, frustration, anger, and fear.

There are two different models of pain catastrophising: the cognitive-appraisal model and the attention-bias model. I follow others (Quartana et al. 2009) in observing that these models are compatible with one another. On the cognitive-appraisal model, pain catastrophising comprises both primary and secondary appraisal. Primary appraisal concerns "whether a potential stressor is irrelevant, benign-positive or stressful-negative," whereas secondary appraisal concerns "coping options and the extent to which they will be successful or not" (Quartana et al. 2009, p. 5). The meaning of threat, of which pain catastrophising constitutes a magnification or exaggeration, is a product of both primary and secondary appraisal.

On the attention-bias model, pain catastrophising is primarily understood, not in terms of appraisals of potential stressors and of coping options, but in terms of "information processing biases" (Quartana et al. 2009, p. 5). On this model, pain catastrophising comprises comparative inabilities "to suppress or inhibit pain-related cognitions," to disengage one's attention "from both pain cues and painful stimuli," and to "utilize disconfirming evidence that pain cues were not necessarily followed by pain experiences" (Quartana et al. 2009, p. 5). A pain cue is something from which one expects pain to follow, e.g. the sight of something heavy falling on one's foot.

The cognitive-appraisal and attention-bias models of pain catastrophising can be mapped onto the three domains of pain catastrophising measured by the Pain Catastrophising Scale: rumination, magnification and helplessness (Sullivan et al. 1995). This helps describe further the models and to draw out their compatibility with one another. Rumination on the threat is a form of attentional bias. Magnification of the meaning of threat is an instance of primary appraisal. Deeming oneself helpless before that threat is an instance of secondary appraisal. We are now in a position to enumerate and classify the feelings that belong to a particular experience of pain.

4 Anatomy of a Painful Experience: Mia in the Emergency Department

Imagine that a young woman, Mia, falls badly while competing in gymnastics, dislocating her knee. She does not know whether she has sustained further injuries. In severe pain, Mia is rushed to the emergency department, where she experiences a maelstrom of negative feelings. These feelings endure over the course of many hours; they co-occur, like water in water, surging in intensity, reappearing and receding in Mia's reflective awareness.

Below, I analyse some of the many feelings that belong to Mia's experience of pain. In this respect, the analysis represents something of an *anatomy* of a painful experience; that is, an "artificial separation of the different parts" of a thing, undertaken "to discover their position, structure, and economy," that is, to discern something of their organisation (Oxford English Dictionary). This is also compatible with Wittgenstein's conception of "analysis" in philosophy (Wittgenstein 2001, §90). The below analysis also represents an imaginative undertaking aimed at fostering, in relation to human experience, an adequate conception of pain and, in particular, of secondary pain affect. The pain in question is severe and acute, not mild or chronic. This better examines secondary pain affect, which may tend to be more prominent in the case of severe pain (Price 2000). It also illustrates that secondary pain affect need not be conceived as primarily a dimension of chronic pain, as may otherwise be thought the case.

Mia experiences a distinctive sensation in her knee. This feeling has no object; it is not about or directed toward something, like a fear of heights is. Moreover, the feeling accords straightforwardly with Hacker's conception of a localised sensation. It has a bodily location—Mia can point to where it is—and it informs Mia about the state of her body: something is wrong with her knee.

Mia also feels exhausted, physically and emotionally. The feeling of physical exhaustion accords with Hacker's conception of a sensation of overall bodily condition. This feeling can be conceptualised as integral to Mia's experience of pain as to constitute a (sensory) dimension of that pain. Alternatively, the feeling can be conceptualised as merely consequent upon, and properly distinct from, the pain. I invite consideration of the former. Mia's feeling of emotional exhaustion can be considered an occurrent emotion in itself. Again, this feeling can be conceptualised as integral to Mia's experience of pain as to constitute an (affective) dimension of that pain; specifically, secondary pain affect. Alternatively, Mia's feeling of emotional exhaustion can be conceptualised as merely consequent upon, and properly distinct from, the pain. Again, I invite consideration of the former. Indeed, this invitation applies throughout my analysis. It is conceivable that Mia's feeling of emotional exhaustion follows from, or is exacerbated by, pain catastrophising; specifically, a negative appraisal of her ability to cope. Equally, the converse is true: it is conceivable that Mia's feeling of emotional exhaustion leads to or exacerbates a negative appraisal of her ability to cope.

Debate exists as to whether emotions are distinct from one another. On one view, emotions differ only in intensity (being more or less intense) and valence (being positive or negative), with the valence depending on whether the object of emotion inspires pleasure or displeasure, approach or avoidance behaviour, and (neurological) calm or excitement (Rainville 2004, pp. 118–119). On an opposing view, emotions differ in ways that cannot be elaborated by reference only to intensity and valence. This second view accords with how we typically treat emotions in our everyday lives. For example, instances of remorse and anger may share the same intensity and valence, both being intense and negative, but typically, we still take them to constitute discrete and different emotions. Like Hacker and Wittgenstein before him, I heed the distinctions found in natural language and, as such, conceptualise human emotions as being typically distinct and different from one another. This is reflected throughout my analysis.

Mia experiences feelings of surprise, amusement and horror, in addition to a feeling of sadness. The object of each of these feelings means how easily it happened; that is, how easily the injury was incurred. This object is specific, as opposed to merely formal, insofar as it does not merely refer to a class of things. The object here is the specific ease with which something very specific happened, as reflected by the words "how easily *it* happened, how easily *the* injury was incurred." Mia's feelings of surprise, amusement and horror can be classified as agitations with reference to Hacker's distinctions. They are short-term "affective disturbances, typically caused by something unexpected" that we "perceive, learn or realize" (Hacker 2004, p. 201). They are "modes of reaction" (Hacker 2004, p. 201) that do not motivate action so much as they may temporarily inhibit action, as well as inflect action. By contrast, Mia's feeling of sadness, having the same object, can be classified as an occurrent emotion. Both the agitations and this occurrent emotion can be classified as instances of secondary pain affect: they are not sensations, but affects, and they do not accord with Price's conception of primary pain affect, for they comprise a sense of something beyond mere "intrusion and threat" (Price 2000, p. 1771).

Mia also feels trapped by the pain. Again, the object of feeling here is specific and the feeling can be classified as an agitation. But this feeling is best conceived as instantiating primary pain affect, as opposed to secondary pain affect, because the feeling comprises a comparatively immediate, direct and, in these senses, "primitive" (Wade et al. 2011, p. 318) meaning of "intrusion and threat" in relation to Mia's body and self (Price 2000, p. 1771). By contrast, a feeling of being trapped by pain that is "based on more elaborate reflection related to that which one remembers or imagines" (Price 2000, p. 1769)—a feeling that connects to reflection on one's hopes and fears about the shape of one's future life—would best be conceived as an instance of secondary pain affect. It is conceivable that Mia's feeling of being trapped follows from, or is exacerbated by, pain catastrophizing; specifically, rumination on her pain. Equally, the converse is true: it is conceivable that Mia's feeling of being trapped leads to or exacerbates rumination on her pain.

Mia feels isolated from others. The object of this feeling is formal, in that Mia feels isolated, not from any one person in particular, but from other people in general. This feeling can be classified as a mood and, moreover, one that is occurrent rather than dispositional, being a product of current circumstances rather than typical of Mia herself. This mood of isolation can be classified as an instance of secondary pain affect. It comprises a tendency to feel emotions such as the yearning below.

Mia yearns for love, for communion, for someone to abide with her where she truly is, in the realm of experience she has entered. She yearns for connection with others. Morstyn (2009, p. 239) reflects that times of “intersubjective unity” with his wife following his bone marrow transplant “provided enormous relief and were vital to my emotional survival.” The object of this feeling of Mia’s is formal, in that Mia yearns for someone’s love, not the love of a specific person. This feeling of yearning can be classified as an occurrent emotion and as an instance of secondary pain affect (It can also be conceptualised as merely the flipside of Mia’s feeling of isolation and not a distinct and different feeling. However, it need not be conceived this way, since it is possible for someone to feel isolated without *yearning* to overcome this felt isolation, and vice versa: someone can yearn for love without feeling isolated. The two feelings can come apart). It is conceivable that Mia’s yearning for love follows from, or is intensified by, pain catastrophising; specifically, a negative appraisal of her ability to cope.

Mia fears that the pain will never end (Clark 2005); that she will be called on to adapt to this new state of being but be unable to. Mia also fears that no one at the hospital is taking overall responsibility for her, and that she could thereby slip through the world’s final safety net. Both feelings can be classified as an occurrent emotion and as an instance of secondary pain affect. The object of Mia’s fear that the pain will never end and that she will be unable to adapt to this is specific, whereas the object of Mia’s other fear is formal, in that this fear would be assuaged by *any* appropriate person stepping into the breach. Insofar as Mia’s fears are unrealistic, they reflect pain catastrophising, especially magnification of the threat that the pain is taken to constitute and a negative appraisal of her ability to cope.

Mia is grateful to some of her carers for their pity, for their acknowledging her suffering and not trivialising it or otherwise evading it, for their doing her a kindness in a spirit of kindness, for their approaching her as more than a damaged machine (Copp 1974; Morstyn 2009). This feeling of gratitude has a specific object and can be classified as an occurrent emotion and as an instance of secondary pain affect. This gratitude outlives the pain. Mia still feels gratitude years later: the occurrent emotion fades into a long-standing emotion (Hacker 2004, p. 202), and at some point no longer constitutes a dimension of pain like secondary pain affect.

Mia also feels grief and compassion (Copp 1974) for humankind, for those who must have suffered such pain and worse. These two feelings share the same formal object and can be classified as occurrent emotions and as instances of secondary pain affect. Like Mia’s gratitude to some of her carers, Mia’s compassion outlives her pain, fading into a long-standing emotion and at some point no longer constituting a dimension of pain like secondary pain affect. It is conceivable that Mia’s grief and compassion follow from, or are intensified by, pain catastrophising; specifically, rumination on her pain.

Mia feels sympathy for “how hard life had been” for her uncle, in particular, for why he had “acted the way he did” (Copp 1974, p. 493). Mia’s uncle had become an alcoholic after a motorcycle accident, for reasons Mia is only now understanding. This feeling of sympathy has a specific object and can be classified as an occurrent emotion and as an instance of secondary pain affect. Like Mia's gratitude to some of her carers and her compassion for humankind, this sympathy outlives her pain, fading into a long-standing emotion and at some point no longer constituting a dimension of pain like secondary pain affect.

Wade et al. (2011) take secondary pain affect to be defined by ongoing pain-related feelings of depression, anxiety, frustration, anger and fear. By contrast, in the above analysis, I classify as instances of secondary pain affect particular feelings of amusement, gratitude, compassion, and sympathy. I do this to invite consideration of the possibility that secondary pain affect need not solely comprise the feelings listed by Wade or, more broadly, feelings that are conventionally considered negative. This possibility has received too little attention by researchers and clinicians. So too has the role of secondary pain affect in constituting acute as well as chronic pain. Secondary pain affect can be conceptualised as a potentially significant dimension of acute as well as chronic pain, and with the above analysis I have sought to illustrate this.

5 Implications for Clinically Treating Pain

If the above anatomy is plausible, especially with regard to its objects of feeling, then the following might obtain. Secondary pain affect can draw on memories, long-standing hopes and fears, loves, and, more broadly, what things mean to us. As such, it comprises feelings whose range of objects is indefinitely vast. Likewise vast are the depths in us that pain can engage. These personal depths include our need for love and for some resolution of fundamental, often moral questions, including who and what we are, why we are here, what life is, and what the place of pain in life is. These questions can be part of pain's meaning and context. Experiences of pain can invite, and potentially even be alleviated by, some personal resolution to these questions.

Though health care practitioners may be given little access to the feelings of their patients, they can conceivably redress the deleterious effects of those feelings that instantiate secondary pain affect by, where possible, honestly reassuring the patient. Reassurance is promoted as a non-pharmacological technique for managing acute pain (Macintyre et al. 2010, p. 297), but reassurance of what exactly? Practitioners can reassure the patient of the nature and extent of their condition, countering pain catastrophising; specifically, magnification of the threat that pain is taken to mean, for now and in the future. Practitioners can reassure the patient that they *can* cope and get through this, countering pain catastrophising; specifically, a negative appraisal of one's ability to cope. Practitioners can reassure the patient that they can look forward to the pain improving following a particular course of treatment, countering a fear of never-ending pain, which can involve pain catastrophising, especially magnification of the threat that the pain is taken to constitute and a negative appraisal of one's ability to cope. Finally, practitioners can reassure the patient that they are not alone, that they can safely surrender to the good care in which they are enfolded, that they are looked upon with compassion as a fellow human being in need, and that a particular individual health practitioner has taken responsibility for them, possibly mitigating a fear of falling through the safety net that hospital-based care may engender in the patient.

Patients can be educated to counsel themselves along the same lines. These lines are consistent with Mantel's (2013) injunction, born of personal experience as a patient: "What healers need to do is muster their own resources of personality and professional knowledge and address the fear as well as the pain: to provide reasoned reassurance, information, and above all, hope" (p. 12). As a priority, health practitioners might also enlist hospital chaplains and the patient's loved ones to reinforce, not replace, their own efforts, as well as to redress those feelings that potentially lie beyond the health practitioner's reasonable willingness or capacity to engage with.[3]

6 Conclusion

I have undertaken an imaginative "anatomy" of a painful experience to foster a conception of pain, and, in particular, conceptions of secondary pain affect and pain catastrophising, in which personal experiences of pain remain recognisable in their human richness and depth. The painful experience analysed was acute rather than chronic to illustrate how secondary pain affect not otherwise be conceived as primarily a dimension of chronic pain. I have endeavoured to demonstrate how Hacker's distinctions between different types of feeling and different types of affect (which is itself a type of feeling) help to distinguish different types of feeling that conceivably comprise pain and, in particular, secondary pain affect. In this way, I have used Hacker's distinctions to refine the conceptualisation of secondary pain affect. I have invited consideration of the possibility that secondary pain affect need not solely comprise feelings of depression, anxiety, frustration, anger, and fear or, more broadly, feelings that are conventionally considered negative. Secondary pain affect can also conceivably comprise positive feelings, such as amusement, gratitude, compassion, and sympathy. Finally, I have touched on some implications for redressing pain in practice by attempting to counter pain catastrophising and to decrease negative secondary pain affect, especially through reassurance.

This chapter is largely limited to conceptual elaboration and clarification. The concepts and conceptual relations that it elaborates and clarifies should be applied in empirical testing, to assess the validity of more refined theories of pain and of the

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[3] The value of all this can exceed its *instrumental* benefit for the patient in terms of improving their pain; namely, via decreasing pain catastrophising and negative secondary pain affect. This can also be valued *inherently* by all involved for what it means. In other words, we need not be consequentialists about the value of such redress.

effectiveness of concomitant pain management techniques. Future investigations should also include the use of qualitative methods to catalogue and pattern the most common and deleterious feelings that instantiate secondary pain affect.

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Chapter 16
Mental Imagery in Chronic Pain: An Access to Meaning Beyond Words

Chantal Berna

Abstract *Mental images* are cognitions, which take the form of sensory experiences in the absence of a direct percept. Images can be opposed to verbal thoughts, i.e. cognitions in the form of words. From the perspective of clinical cognition, verbal thoughts and mental images are different phenomena, with mental images having tighter connections to emotion than verbal thoughts. Recently, cognitive psychology research has focused on *spontaneous mental imagery*, i.e. involuntary intrusions of often vivid mental images that appear in one's mind. Spontaneous mental imagery is now viewed as an important part of psychopathological processes across psychological disorders, a potential emotional amplifier and a therapeutic target in its own right. Pain is a personal experience, so exploring and understanding the patient's thoughts about pain might contribute to therapeutic success and favour personalized care. In the field, thoughts about pain have been mostly studied as verbal thoughts. Yet, a growing literature is investigating thoughts about pain *in the form of imagery*. Studying chronic pain patients' mental imagery provides unique insight into their personal experience, integrating information about somatosensory perceptions, emotional experience and meanings of pain. The study of imagery in pain also gives insight into possible reinforcing mechanisms of pain, and a basis for a powerful, individualized therapeutic approach through different mental imagery therapy techniques. This chapter describes current knowledge about mental imagery as intrusive cognitions in the context of pain, considers the neuroscientific investigations that have been undertaken, and discusses the therapeutic potential it yields.

C. Berna (✉)
Service D'anesthésiologie, Centre d'antalgie, BH 06, Centre Hospitalier
Universitaire Vaudois, UNIL, Av. Du Bugnon 46, 1011 Lausanne, Switzerland
e-mail: chantal.berna-renella@chuv.ch

C. Berna
Department of Psychiatry, Massachusetts General Hospital, Boston, MA, USA

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1 Introduction

1.1 What are Spontaneous Mental Images?

Mental images are cognitions, which take the form of sensory experiences (in any modality) in the absence of a direct percept (Pearson et al. 2015). Images can be opposed to verbal thoughts, i.e. cognitions in the form of words and verbal language. From a clinical cognition perspective, it is assumed that verbal thoughts and mental images are different psychological phenomena (Paivio and Begg 1974; Kosslyn et al. 2001; Hagenaars et al. 2010), with the latter having tighter connections to emotion (Holmes and Mathews 2010; Mathews et al. 2013). Cognitive psychology research has recently focused on *spontaneous or intrusive mental imagery,* i.e. involuntary and often vivid mental images that appear spontaneously and uninvited to the mind (Hackmann et al. 2011). Such images are recalled from sensory memories and can be a re-experience of the original input, or a new combination of different experiences. They typically relate to emotional experiences. Spontaneous mental imagery is now considered an important part of psychopathological processes across psychological disorders (Hackmann and Holmes 2004), a potential emotional amplifier (Holmes et al. 2008), and a therapeutic target in its own right (Holmes et al. 2007; Hackmann et al. 2011).

1.2 Exploring Thoughts About Pain

Studying patients' thoughts and beliefs is central to cognitive-behavioral models of pain. These models propose that the pain experience and pain-related suffering result from a dynamic process involving emotions, thoughts, and behavioral responses that in turn interact with sensory phenomena (Sharp 2001). Within clinical settings, ongoing assessment and monitoring of patients' pain beliefs is key to providing appropriate and comprehensive personalized care, as well as building a therapeutic alliance. Thoughts about pain have been mostly studied in the form of *verbal thoughts,* with axes of study focused for example on catastrophizing, worry, and coping (e.g. Eccleston et al. 2001; Sullivan et al. 2001; Jensen et al. 2007).

More recently, a growing literature has started to investigate spontaneous and intrusive thoughts about pain *in the form of imagery* (Carruthers et al. 2009; Berna et al. 2011; Philips 2011; Gillanders et al. 2012; Gosden et al. 2014). An adapted cognitive behavioral framework has been proposed to integrate these cognitions (Berna et al. 2011, 2012). This chapter will review how such images might provide a unique insight into patients' pain experiences, integrating information about somatosensory perceptions, emotional experience and meaning. Neuroscientific studies into mental imagery as a process relevant to chronic pain discussed. Finally, two different therapeutic imagery approaches to pain, positive guided imagery and imagery transformation, are presented and assessed.

1.3 Spontaneous Imagery: A Unique Insight into the Personal Pain Experience

Following reports of spontaneous intrusive imagery linked to pain in the clinical context (Barber and Bejenke 1996; Winterwowd et al. 2003; Jamani and Clyde 2008; Pincus and Sheikh 2009), research has recently focused on these cognitions. Interviews of patients with irritable bowel syndrome (N = 109) before hypnotherapy identified spontaneous pain-related imagery in nearly half of the population (Carruthers et al. 2009). The report of an image was not linked to symptom severity, quality of life or depression, but it was more common in anxious patients, and was a positive predictor of outcomes following hypnotherapy. The treatment followed a standard hypnosis protocol; that is, not using these specific images. Still, most responders to hypnosis reported new, positive or neutral images linked to their disease after treatment.

Interviews in patients with chronic pelvic pain (N = 10) collected more detailed accounts of spontaneous mental imagery associated with pain, using a cognitive framework (Berna et al. 2011). The patients' most meaningful images (identified as such by the patient) were presented. All images had a strong negative emotional valence and an association with avoidance. Patterns of behaviour were identified where the patient avoided either pain or pain-related triggers. The attached negative emotions ranged from fear or anxiety, as previously proposed (Jamani and Clyde 2008), to guilt, sadness, anger, disgust or helplessness. Furthermore, among 59 patients with chronic pain interviewed in a rehabilitation setting, 78% reported spontaneous images linked to pain (Philips 2011). Exposure to the most meaningful image led to increases in negative emotions and pain reports. Finally, a postal questionnaire study in patients from a chronic pain centre (N = 83) found an association between the presence of mental imagery (23%) and emotional distress (Gillanders et al. 2012). A follow-up study interviewed patients reporting mental imagery (36% of N = 105) on a second postal questionnaire, exploring the emotional valence (distressing in 83% of participants) and confirmed heightened emotional distress compared with responders who had no imagery reports (Gosden et al. 2014).

In summary, it seems that in a large proportion of patients with chronic pain, intrusive imagery reliably links to qualities and meanings of pain experience. The prevalence of these images is higher in interview settings than postal questionnaires, which could be due to a clearer definition of imagery in a face-to-face encounter. Patients report multiple images, yet are able to identify one that is most meaningful to them, which in general has a negative emotional valence. Voluntary exposure to such an image leads to negative emotions and increased pain, and triggers avoidance (i.e. patients assume specific behaviours to avoid pain or other triggers of the images, often involving decreased activity). Patients who report such intrusions seem to have heightened emotional distress compared with those who do not; although this conclusion stems from postal questionnaires studies, where report bias could have been a factor.

1.4 Themes of Spontaneous Imagery

Different thematic categories emerge from this literature. The following citations consider the first article proposing a theme, as these overlap across publications: images of the pain itself (possibly as a metaphor of threat or attack, objects or creatures reflecting sensory qualities, anatomical representations), oneself in pain, social interactions in the context of pain, projections about the future either in the form of worries or catastrophic thinking (Winterowd et al. 2003); memory of a pain-related event (possible trauma or surgery), coping imagery (Berna et al. 2011); negative self appraisals (Philips 2011); and abstract images (Gosden et al. 2014).

Spontaneous coping images in chronic pain patients are of specific interest, as they have not yet been studied systematically. Limitations of current interview tools might have hindered this area of research. For example, a frequently used scale to assess coping strategies in the context of pain, the Coping Strategies Questionnaire (Rosenstiel and Keefe 1983), does not make a distinction between verbal thoughts and mental images. Nevertheless, a classification of coping strategies did propose images as a separate category (Fernandez 1986). Furthermore, patients asked about their cognitions during acute dental pain reported imagery both as a way of coping and of catastrophizing (Chaves and Brown 1987). Moreover, participants in experimental pain studies used mental imagery before being instructed to do so, or, were more compliant with instructions to use imagery compared with using rational self-talk (Hackett and Horan 1980; Worthington and Shumate 1981). In other experimental pain paradigms, when instructed to use an imagery based coping strategy, many participants had their own images (Stevens 1985; Stevens et al. 1987). Our own research described the contents of spontaneous coping images reported by 8 out of 10 patients with chronic pelvic pain, proposing three thematic categories of meaning: allegoric treatment of an object symbolizing pain, imaginary treatment applied to the body, and supportive person (Berna et al. 2011). Further research needs larger samples to better characterize these images and their frequency.

1.5 Differences and Commonalities Between Mental Imagery and Metaphors

It is noteworthy that a specific and separate literature focuses on metaphors, i.e. voluntary mental depictions that are frequently used to describe or communicate patients' pain experience (e.g. Soderberg and Norberg 1995; Aldrich and Eccleston 2000; De Souza and Frank 2000; Schott 2004; Kirmayer 2008; Sim and Madden 2008; Semino 2010; Chap. 20, this book). Interestingly, besides simple verbal qualifiers such as "boiling" or "sharp," some of these depictions are extremely vivid and elaborate, leading to artistic representations (Pither 2002; Padfield 2003; Padfield et al. 2010; Carruthers 2011; Carruthers and Whorwell 2014). These more complex descriptions could represent patients' spontaneous mental imagery.

However, the literature on metaphors focuses on doctor-patient communication, and there is no information on the emotional impact or the potential intrusiveness of the depictions. Spontaneous Images come to mind involuntarily and not uniquely in a context of communicating about pain, while metaphors are mostly present in the patient's mind when describing their experience of pain. On the other hand, the intrusiveness and lack of control over the images reported in the interview studies regarding pain-associated imagery speak against these being merely metaphors with an aim of communication. Actually, most patients had never shared the most emotional images, and barely realized they were cognitions, and not facts (Berna et al. 2012).

Taken together, evidence from different chronic pain sub-groups support the claim that spontaneous images serve different roles in the pain experience, whether as an elaboration of meaning with emotional and sensory aspects, as a form of catastrophizing about the future, as ruminations about past traumatic events, or as a coping technique, representing a unique insight into patients' personal pain experience.

2 Neuroscientific Investigations into the Nature of Mental Imagery in Pain

2.1 Central Correlates and Physiological Impact of Pain Related Imagery

Neuroscientific investigations into mental imagery support cognitive theories, which suggest that intrusive and emotionally difficult images could maintain pain patients' distress. Mental imagery has been presented as a mental rehearsal, or a simulation of future and past events (Moulton and Kosslyn 2009). Images frequently occur in daily life (Killingsworth and Gilbert 2010). This process is embodied, meaning it involves physical and psychological aspects of the real experience (Niedenthal et al. 2005). In fact, mental imagery recruits activation in cerebral areas overlapping with those involved in actual sensory perception in a specific modality, with an additional core network of cerebral regions involved in imagery, across modalities (Kosslyn et al. 2001; McNorgan 2012). In parallel, emotional imagery can alter physiological measures in a similar way to real emotional experiences (e.g. Lang 1979; McNeil and Brunetti 1992; Cuthbert et al. 2003) and is used for the study of the neural networks involved in central emotional processing (e.g. Damasio et al. 2000).

Different studies have examined the neural correlates of imagined pain. Imagery tasks involving pain-related words compared with non-pain-related controls activate the anterior cingulate cortex (Osaka et al. 2004; Ogino et al. 2007; Richter et al. 2010), an area of the brain involved in pain processing and its regulation (Vogt 2005). Hypnotic suggestion of painful heat perception also recruited cerebral pain-processing areas (Derbyshire et al. 2004; Raij et al. 2005). The retrieval of memories from previous painful experiences activated similar neural areas

(Kelly et al. 2007), and imagining that non-painful touch was unpleasant (allodynia) also recruited such a network; however, this effect was only observed in participants who had experienced allodynia before (Kramer et al. 2008). Imagining pain from a first-person visual perspective, compared with a third-person perspective, led to stronger activations in the anterior insula, associated with higher reports of subjective pain and embodiment (Christian et al. 2015). The imaginary re-experiencing of a painful heat stimulus briefly after an actual experience led to very similar cerebral activations, with only the posterior insula being specific to the real experience (Fairhurst et al. 2012). There is even evidence of covert motor responses and postural adaptations associated with pain imagery (Lelard et al. 2013; Mochizuki et al. 2013). Hence, imagery linked to pain could lead to behavioral, cognitive or emotional changes, which might in turn increase pain. Furthermore, frequent co-occurrence of imagery with pain could favor the consolidation of a pain memory (Apkarian et al. 2009), and ultimately reinforcing nociception through a repeated "simulation of pain" (Berna et al. 2012).

2.2 Central Correlates of Mental Imagery Techniques for Analgesia

We know little about how mental imagery affects the central nervous system during pain perception in patients (Jensen et al. 2012). Mechanisms of analgesia induced by positive imagery are the subject of ongoing study in healthy individuals. The role of the descending pain inhibitory network as an anatomical pathway (involving endogenous opioids), as well as cognitive mechanisms such as distraction or reappraisal are currently being studied. In one study, the RIII reflex (i.e. the nociceptive flexion reflex, a muscle withdrawal in response to the activation of A-delta nociceptors, which is a measure of spinal nociception), was assessed in conjunction with pain ratings during positive imagery, compared with concentration on pain and a tactile discrimination task. Both the tactile discrimination and mental imagery tasks decreased pain ratings, while focusing on the sensation increased them. Although the tactile discrimination task reduced the RIII reflex, it was left unchanged by mental imagery (focusing on the sensation increased it), speaking against an activation of descending inhibitory systems by the mental imagery task (Ruscheweyh et al. 2011). Congruently, analgesia through imagery in a hypnotic state appears to be opioid-independent, as it is not blocked by naloxone (Moret et al. 1991). Yet, similar research without hypnosis would provide valuable further information. Finally, an EEG study of experimental pain modulation by mental imagery (inhibiting vs. increasing pain) demonstrated an association with heightened activity in the right inferior frontal and temporal regions. This result was interpreted as increased cognitive inhibitory control and retrieval of semantic information, i.e. retrieval of meanings of pain (Fardo et al. 2015).

In summary, an important neuroscience literature suggests that spontaneous pain-related images can amplify suffering. On the other hand, based on research in healthy populations, positive imagery could lead to analgesia through cognitive control, and possibly non-opioid mechanisms. We need more research on both control and clinical populations to qualify the nature of spontaneous intrusive images (for example, in relation to flashbacks in post-traumatic stress disorder) and to better understand how positive imagery affects pain processing.

3 Therapeutic Potential

There is a long history of therapeutic work with mental imagery in chronic pain. These approaches can be categorized broadly as *suggesting novel images* or *transforming existing images,* sometimes in conjunction with hypnosis (Barber and Bejenke 1996; Winterowd et al. 2003; Pincus and Sheikh 2009). These techniques can include exposure, i.e. approaching in imagination something that has a fearful meaning, whether an activity, a memory or a place.

3.1 Suggested Positive Images

Positive guided imagery is a psychological treatment technique used for pain relief, in which a therapist suggests specific or generic pleasant mental images that the patient should try to experience in their mind (Hart 2008). Most clinical imagery trials are script-based, using an imposed, standard image, for example, a meadow. Alternatively, positive images can be purpose-built with the patient in a voluntary, and engaged manner (Hackmann et al. 2011). A range of scenarios can be created, leading to positive emotions and meanings, distraction, relaxation and optimistic expectations.

Reviews and meta-analyses of guided mental imagery suggest positive imagery benefits patients with different chronic pain syndromes (Van Kuiken 2004; Roffe et al. 2005; Posadzki and Ernst 2011; Posadzki et al. 2012). However, it is important to note that these studies mostly analysed prolonged use of mental imagery in chronic pain patients. When used as a single intervention for acute pain control in the context of a medical procedure, the effects appear to be very small (Peerdeman et al. 2016). Nevertheless, procedural pain can be efficiently relieved by positive imagery used as part of hypnosis (Patterson and Jensen 2003; Dillworth and Jensen 2010). Since an isolated hypnotic induction does not lead to analgesia per se (Hofbauer et al. 2001), and suggestions with or without hypnosis can lead to similar levels of analgesia (Milling et al. 2005), one can hypothesize that hypnosis provides additional *interventions*, such as suggestions in conjunction with positive imagery, which may lead to improved pain outcomes.

Only a few studies have examined how to maximize the effects of guided positive imagery. For example, imagery with an external focus (e.g. pleasant scenery) seems to have heightened analgesic properties when compared with an internal focus (e.g. hand being numb) in healthy volunteers tested with experimental pain (Alden et al. 2001). Positive imagery suggested by a therapist might have better analgesic effects than imagery generated by the subject in acute pain, without differences in patients with chronic pain (Raft et al. 1986). In another study comparing two different imagery instructions in a sample of patients with fibromyalgia, while pleasant distracting imagery led to pain relief, this was not the case with imagery focused on the activity of their pain regulatory network (picturing endorphins and inhibitory neurons) (Fors et al. 2002).

In parallel, interesting questions of responder profiles to guided imagery interventions deserve to be further explored. Preliminary results suggest that greater imagery ability, heightened positive outcome expectancy, and lesser symptom load predict clinical response (Kwekkeboom et al. 2008). These findings confirm prior work in healthy volunteers on imaginative suggestibility (i.e. the ability to vividly imagine suggested things), a personality trait influenced by expectancy, motivation, absorption in imagery and fantasy proneness (Braffman and Kirsch 1999).

3.2 Work with Existing Images

Imagery transformation is commonly described in hypnotic (Barber and Bejenke 1996) and mental imagery techniques for pain control (Winterowd et al. 2003; Pincus and Sheikh 2009). Recently, such transformations have been conceptualized and used in the cognitive behavioral framework as “imagery rescripting” (Holmes et al. 2007; Hackmann et al. 2011; Arntz 2012). In this process, spontaneously occurring negative imagery as described above is identified, or the encounter with a metaphorical representation of pain is suggested. This image might trigger avoidance, which is then explored with the practitioner, unveiling meaning and emotional impact. This allows the patient to adopt a reflective stance and to create transformative elements that can be used to counter the negative meaning and affective value of the image (Hackmann et al. 2011).

While there is a literature of case reports (e.g. Jamani and Clyde 2008), systematic research on such techniques in pain is sparse. Reviews of clinical trials of hypnosis for pain (Patterson and Jensen 2003; Dillworth and Jensen 2010) only report one small trial (N = 17) using transformation of imagery (McCauley et al. 1983). Similarly, amongst trials of guided imagery in adults with chronic pain, only two studies used image transformation scripts (Lewandowski et al. 2005, 2011).

The first study (Lewandowski et al. 2005) is of particular interest to this chapter, as it assessed particular meaning attributions about pain over time in a mixed sample of patients with chronic pain. A content analysis of patients’ pain descriptions led to six thematic categories of meaning (pain is never-ending, relative, explainable, torment, restrictive, changeable). The impact of 4 days of guided imagery on the meaning attributed to pain was studied. Imagery instructions were, "Put your pain object in your hands… How would you change the shape… the size… Now change the colour… and its texture… Give it a different sound…"). In the imagery transformation group (N = 21), participants reported increased thoughts entering in the category of pain as a changing phenomenon, and decreased perceived permanence of pain after treatment (Lewandowski et al. 2005). In contrast, the control group did not show such changes over time. However, the statistical significance of these findings was not described in the study. Briefly, the second study by the same group used a similar imagery transformation intervention over the course of 8 weeks in patients with different chronic pain syndromes (N = 27). The main result showed a decrease of pain scores and disability over time (no control group), without a description of the actual changes in imagery or meaning of pain (Lewandowski et al. 2011).

In the cognitive behavioral therapy literature, only one study analysed the effects of this practice in a sample of patients with chronic or acute pain (N = 55), allocated randomly to imagery rescripting ("How would you rather see the image?" or "How would you prefer it to have been?") versus imagery rehearsal and crossover within a unique session (Philips and Samson 2012). The intervention group reported less negative emotion, appraisals and pain when evoking the rescripted image compared with reports when exposed to the initial image, and the same was found in the control group after crossover. These results are especially impressive given the brevity of the intervention (a single short session of rescripting). However, no long-term clinical impact on pain or thought processes was measured; therefore, this encouraging preliminary work would benefit from expansion. This article also provides interesting examples of spontaneous intrusive imagery and their rescripted versions.

4 Conclusion

The study of the meaings of pain entails assessing patients' thoughts. Thoughts can be in words or images. This chapter reviews how sponataenous mental imagery offers a unique insight into the personal experience of pain, integrating information about somatosensory perceptions, emotional experience (fears about the future, traumatic memories, grief…), coping and personal meanings. Despite holding such rich information, the study of this important cognitive process has been neglected, compared with the large literature on verbal thoughts about pain. Of note, Mike Stewart in Chap. 19 discusses overlaps and differences with the separate literature on metaphors. Few studies have systematically studied spontaneous imagery linked with pain. Thus, many questions remain to be answered more precisely; notably, risk factors associated with these cognitions, prevalence, neural mechanisms and links to the clinical evolution of chronic pain.

Further, since the meaning of pain can powerfully determine its perception (Price 1972; van Rysewyk 2014) exploring such psychosocial elements of pain holds potential for therapeutic interventions (Arntz and Claassens 2004; Benedetti et al. 2013). Therapeutic interventions using or addressing mental imagery are widespread, yet systematic research in the field is only in its infancy. Such interventions can suggest or develop novel images, or transform the patient's existing images. Of note, specific techniques involving motor imagery are in use for certain neurological conditions such as phantom limb pain or complex regional pain syndrome (CRPS), as highlighted by Magali Fernandez-Salazar in Chap. 4.

In sum, this chapter brings together literature from different fields, integrating research in cognitive behavioral therapy, nursing, clinical pain, hypnosis, and cognitive neuroscience, to provide a novel and unique view of mental imagery in pain. This perspective, suggests this topic remains understudied, given its important potential both in furthering our understanding of pain and its treatment.

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Chapter 17
The Challenge of Validating the Experience of Chronic Pain: The Importance of Intersubjectivity and Reframing

John Quintner and Milton Cohen

Abstract A fundamental tenet of Western biomedicine is the validation of a patient's predicament by the clinician through demonstration of a disease process underlying illness. For the person experiencing chronic pain, however, the absence of demonstrable pathophysiological evidence of disease is a challenge to the clinician's ability to discharge that role. What may not have been appreciated is that the reverse situation can also hold true, insofar as the patient cannot validate the clinician as possessing sufficient knowledge and expertise to relieve their pain. In an effort to understand and remediate this impasse, this chapter explores the dynamics of the clinical encounter through the lens of the French sociologist Pierre Bourdieu, and examines the effects on the players when dealing with the *aporia* of pain. Then, in the novel approach of reframing the *field* of the clinical encounter through considerations of intersubjectivity, empathy and prospection, ethical possibilities for clinician and patient to achieve mutual validation of their predicaments are canvassed.

1 Outlining the Problem

I can only believe that someone else is in pain, but I know it if I am. Yes: one can make the decision to say "I believe he is in pain" instead of "He is in pain." But that is all. What looks like an explanation here, or like a statement about a mental process, is in truth an exchange of one expression for another, which, while we are doing philosophy, seems the more appropriate one. Just try—in a real case—to doubt someone else's fear or pain (Wittgenstein 1953, §303).

J. Quintner (✉)
Arthritis and Osteoporosis Western Australia, Shenton Park, Australia
e-mail: jqu33431@bigpond.net.au

M. Cohen
St Vincent's Clinical School, University of New South Wales, Sydney, Australia

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Why is the management of chronic pain so unsatisfactory and frustrating for both the person experiencing pain and the attending health professional? The biomedical model of illness, which has long dominated Western healthcare, turns on the ability of a clinician to validate a patient's clinical presentation by demonstrating an underlying disease process through a commitment to obtaining empirically observable ("objective") evidence, leavened by the testing of hypotheses. In this context, "to validate" (from the Latin *validus*, strong) means to confirm, corroborate or substantiate. However, this criterion of validation breaks down in those forms of illness in which there is no demonstrable pathophysiological evidence of disease (Wade and Halligan 2004).

The predicament of the person experiencing chronic pain is an example *par excellence* of the inability of medical practitioners to validate that person's experience, as there may be no identifiable underlying cause. Thus, there is no specific treatment that will result in its resolution (Quintner et al. 2008). This leads to a crisis for both observer and observed. As Wittgenstein (1953) argues, whilst on the one hand, it is impossible for an observer to confirm the experience of pain of another person; on the other hand, it is equally impossible for an observer to deny that that person is feeling pain.

For clinicians whose training has been in accord with the strict rules imposed by the biomedical model of disease (Quintner et al. 2008), such a clinical presentation constitutes an impenetrable puzzle or an *aporia* (Derrida 1993). It is therefore understandable why physicians can become demoralized by their inability to provide validation when the context in which they have to practice is unfamiliar to them (Frank 2004). Furthermore, this failure of validation categorizes such pain sufferers as members of an "outgroup" (Robbins and Krueger 2005), and can result in them encountering societal disbelief (Newton et al. 2013) and stigmatization (Cohen et al. 2011).

This chapter will seek to understand why what should be a basic function of health professionals—the clinical management of people experiencing persistent pain—is not only unsatisfactory in terms of therapeutic outcomes, but also frustrating for both patient and clinician, each of whom is seeking validation from the other. Recognition of the *realpolitik* of how this clinical "game" is "played" can lead to some innovative approaches and strategies towards more satisfactory ethical and therapeutic outcomes for both parties. This opens novel avenues for clinicians to safely and ethically lead their patients towards a better understanding of their existential predicament, which itself is an important component of validation.

2 The Clinical Encounter

Central to this challenge of validation of the pain experience is the nature of the clinical encounter itself. In examining the dynamics of this fundamental interaction, a lead is taken from the writings of the French philosopher and sociologist Pierre

Bourdieu [1930–2012] (Colyer et al. 2015), as applied to clinical medicine by Frank (2002) and to medical education by Gomes and Rego (2013). The discussion turns on Bourdieu's concepts of *illusio*, *habitus*, *field*, and *capital*.

2.1 *Illusio*

The essence of a clinical encounter is dialogue, captured by Frank (2002) as "talk grounded in mutual desire to recognize and be recognized," as an example of a social "game." For this Bourdieu coined the term *illusio* (drawing upon its Latin root *ludere*, to play), to describe how a person could be caught up as a player in other people's social games. The medical consultation can be viewed as one such social game, which both parties are enjoined to take seriously, as the stakes can be high (Frank 2002).

Illusio can be viewed from the perspective of the kinds of discourse that typically operate in exchanges between clinician and patient. Although in practice they overlap, three standard forms of discourse—or "game"—can be identified. The "objective" discourse of factuality, as informed by science, is the basis of biomedical practice. The "subjective" discourse, which is the realm of personal expressiveness, has tended to be diminished in this context. The third form of discourse might be called the intersubjective or social that emphasizes negotiation towards shared meaning. To each of these forms of *illusio* the players bring their own *habitus* and *field*.

2.2 *Habitus*

According to Bourdieu, the *habitus* of an individual is the set of embodied habits, tastes, actions, styles and attitudes that are acquired through the process of growing up in families, communities and societies. These constitute a primer for how it is that people act and think, in accordance with that social context. In their *habitus,* people's experiences become embodied and through them they develop a "feel for the game," learning the rules that become second nature to them (Bourdieu 1994). Moreover, "these habits are not just individual ways of behaving, but include lasting decisions, values and judgments made by an individual that have been adopted in the course of his or her life" (Moran 2011).

In practical terms, *habitus* embodies our "know-how" in managing day-to-day life situations, and is a predictive model of our behaviours in response to certain circumstances that call for us to act (Gomes and Rego 2013). These authors argue further, in the context of medical education, that *habitus* "…is not the simple internalization of social rules, rather it is a dynamic interaction between individuals, social agents and social structure in order to enable acting-in-the-world" (hyphens added). In medical practice, *habitus* conditions clinicians' ways of "being, seeing, acting and thinking" (Emmerich 2013).

2.3 Field

It follows that clinician and patient each brings to the clinical encounter not only their own *habitus* but also this "mutual desire to recognize and be recognized." The encounter itself takes place in what Bourdieu (1975) termed a *field*, a structured space in which agents and their respective social positions are located. The position of each particular agent in the *field* is a result of dynamic interactions between the specific rules of the *field*, the agent's *habitus* and what Bourdieu termed the agent's *capital*, that refers to the kinds of resources agents bring to the social interaction or the products of those interactions (as discussed below).

Gomes and Rego (2013) draw on Bourdieu's concepts in relation to medical education: "Considering medicine as a socially structured space where social agents, namely physicians and those who intend to gain this title—medical students—meet and follow rules and principles of regulation specific to that occupation, it would appear that this profession can function … as a well-organised model for Bourdieu's field." An extrapolation to medical practice itself is clear, the *field* being constituted by its own story or "monopoly of categories of appreciation and of modes of operation."[1]

In Western medical practice, the rules of the game are usually unspoken, but well understood. Society expects clinicians to be trained primarily to apply basic scientific principles of diagnosis to the injured or diseased human body in order to return it to functional health. The patient is expected to present symptoms to the clinician, who then evaluates them in order to arrive at a specific diagnosis and plan a regimen of treatment. However, when these expectations cannot be met for the persistent pain sufferer, the fundamental assumption of the clinician's task appears to have been misguided from the outset.

Horton (2003) has shown how their use of language provides clues as to the way in which medical practitioners might bring to the *field* their *habitus* as a form of benevolent possessor of their patients. The word "patient" as a sufferer waiting for something to be done to alleviate suffering, and the way in which patients become "subjects" in research studies, exemplify these unconsciously adopted paternalistic attitudes that can strip sick people of their unique characteristics.

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[1] Bourdieu saw the locus of these interactions as being "a competitive struggle in which the specific issue at stake is the monopoly of scientific authority or … the monopoly of scientific competence in the sense of a particular agent's socially recognised capacity to speak and act legitimately (i.e. in an authorized and authoritative way) in scientific matters." [p. 20] Substitute "clinical" for "scientific," and these comments capture the *field* of the clinical encounter.

2.4 Capital

Bourdieu's concept of *capital* (1986) is the third player in the *illusio*, with *habitus* and *field*. This concept includes economic capital (concerned with material resources), social capital (an enduring network of mutual acquaintances), and cultural capital (the cultural competencies individuals develop through socialization and learn over time).

For health care professionals in contemporary society, prestige, reputation and fame have become valued forms of social capital (then referred to as symbolic capital), which can be incorporated as skills and knowledge, objectivised in books or tools, or institutionalized as degrees or certificates (Abel and Frohlich 2012). The historical outcome of health professionals' persistent search for accumulation of these resources is to entrench hierarchies that in turn require permanent vigilance to legitimize and maintain these social differences, or a continuous effort to conceal the origins of these asymmetries (Navarro 2006).

When such social capital becomes legitimized as part of a dominant culture, Bourdieu's concept of *symbolic violence* can come into play (Bourdieu 1990). Pringle (1998) explains how this concept relates to her particular medical specialty:

His account applies well to the field of internal medicine where, it may be argued, power and prestige are maintained through forms of symbolic violence, 'gentle, invisible … unrecognised as such, chosen, as much as undergone, that of trust, obligation, personal loyalty, hospitality, gifts, debts, piety, in a word, of all the virtues honoured by the ethics of honour (Pringle 1998, p. 98).

Horton (2003) also sees the unstated terms and conditions of the doctor-patient relationship as one that may be more appropriate as being between master and servant. Typical examples of "medical master" discourses in chronic pain include: the biomedical narrative, reducing the patient to a mere organism in the hands of a techno-scientific apparatus; the bio-behavioral story of pain as a conditioned response; the egotistic clinician narrative, where social standing and career goals overshadow patient needs; the ironic-sarcastic discourse, which though superficially friendly, barely conceals the clinician's contempt for the patient's explanatory story; and, above all others, the stigmatizing narrative by which the patient is declared an immoral *malade imaginaire* (Molière's "The Imaginary Invalid").

This form of discourse can also be seen as reflecting tension between the social or symbolic capital of the health care professional and that of the patient-person experiencing chronic pain. It then becomes understandable how the clinician's inability to relieve a patient's pain may threaten his or her social capital. However, an important aspect of social capital for people experiencing pain is very much linked to their access to reliable and up-to-date information to explain their pain, and therefore to clear assessment and treatment pathways, which is the provenance of health care professionals (Nielsen 2012). When such information is not conveyed appropriately, the patient's social capital becomes threatened and trust in the health care professional will be undermined. When it comes to the needs of persistent pain sufferers, all such master-servant narratives must count as unethical options for medical practice.

3 Pain as an *Aporia*

What is it about pain that disturbs the otherwise ordered rules of engagement in the *illusio* of the clinical encounter? The lived experience of being in pain is not only difficult to express in natural every-day language but also ultimately not communicable in these terms. As Scarry (1985) has shown, people experiencing pain have no language with which to express it and are constrained to use metaphor, often creatively. For clinicians, pain is too complex to be understood from the standpoint of linear causation or even from a desire to make sense of it using currently available frameworks of reference (Quintner et al. 2008). As a result, our attempts to develop explanatory models of pain bounce off a metaphysical brick wall, which constitutes an encounter with the *aporia* of pain.

An *aporia* (from the Greek meaning "lacking a path, a passage or a way") is a mystery or puzzle that encompasses the dual problems of neither knowing how one has arrived at a particular place nor knowing where next to proceed (Burbules 2000). As it is unlikely that pain can ever be demonstrated objectively (that is, to be seen as an observable "thing"), the clinician's experience becomes one of uncertainty, discomfort and doubt.

The person experiencing pain, encountering the same *aporia*, presents for investigation and treatment with the quite reasonable expectation that the clinician will be able to explain their lived experience using currently available medical scientific knowledge. However, when the clinician does not know how to proceed, the result for both parties can be a crisis of choice, of action, and of identity. The clinician's dilemma can lead to loss of empathy and even to feelings of resentment towards the person in pain (Cohen et al. 2011).

When confronted with their clinician's dilemma, the person experiencing pain is forced to share the very same doubt and uncertainty, thereby compounding their own discomfort, with potentially negative implications for the therapeutic relationship, the most serious of which is the risk of stigmatization of the patient (a form of "social suffering") within the health care system and poor integration of health services (Nielsen 2012).

4 Rapprochment

All the interventions that treat the body as an object, and that consequently understand pain as something inside the body, will never be enough for many patients … Sooner or later, what affects pain is the relationship between the patient and the clinician (Frank 2003, p. 619).

The discussion above has shown that the conventional *field* of biomedical discourse in usual Western medical encounters breaks down when confronted with the *aporia* of persistent pain, to the detriment of all players, irrespective of their *habitus*. To recall Frank (2002), neither party "recognizes or is recognized." Given the established nature of *habitus* and the unlikelihood of changing *capital*, perhaps it is the *field*—that "monopoly of categories of appreciation and of modes of operation"—in which there is potential for resolution and therefore for validation.

Some perspectives on reconstituting the *field* of the clinical encounter come from an examination of the roles of intersubjectivity and the "third space": empathy, and social prospection (Crisp 2015), or imaginability (Ruthrof 2014).

5 Intersubjectivity and the "Third Space"

In his most influential work, the philosopher Martin Buber [1878–1965] outlined two different approaches through which people can choose to relate to others: that of I-It or I-Thou (Buber 1958). The biomedical model of illness has traditionally employed the I-It approach or paternalistic model (Charles et al. 1997), where the patient is portrayed as a passive recipient of treatment, but from whom cooperation with treatment is expected. By contrast, echoing Buber's I-Thou approach, intersubjectivity refers to one's ability to interact with others in a reciprocal and mutually meaningful fashion (Grinnell 1983). Translating Buber's I-Thou approach to the doctor-patient relationship has profound ethical implications for both parties. Frank (2004) offers valuable insights into the practice of ethics-as-process:

> First, being ethical requires working with people who have never had to confront the realities of a hard choice until they face a clinical situation involving a choice no one should have to make … Ethics needs to shift its orientation from decisions to identities—that is, who I become as a result of making this decision. That I-in-becoming refers equally to clinicians and patients and families. Second, claims to autonomy should be tempered by the recognition that values are held only in relation to other values, both other values of one's own and other people's values (Frank 2004, p. 357).

The realization of intersubjectivity takes place within what Winnicott (1971) termed the "third space." Similarly, to the imaginative play of children, the "third space" can be likened to that in which the players are able construct a relevant culture for a particular purpose. In such an empathetic clinical encounter, clinician and patient seek to carve out a communal public space of signs and understandings created by their respective actions (Favareau 2002). In effect, this space constitutes a *field* of Bourdieu where the *habitus* of each player is respected (Emmerich 2013).

This form of clinician-patient interaction is also an example of Frank's "ethics-in-process," taking place in a virtual space that both parties have agreed to enter for creating a therapeutic relationship (Frank 2004). It functions as an "in-between" or transitional space between subject and object (Praglin 2006) where a truly ethical culture of clinical practice develops and each can live in the other's experience. This space can then become a zone of active exchange, where dynamic negotiation and testing of boundaries take place (Blair 2014).

According to Praglin (2006), the intersubjective space is "where one finds the most authentic and creative aspects of our personal and communal existence, including artistic, scientific, and religious expression." Through creative expression, situations can be resolved and new possibilities emerge. Thus, the clinician-patient relationship becomes a truly intersubjective one, when Buber's I-Thou dichotomy can be unified as "We."

6 Empathy and Prospection

Etymologically derived from the Greek *empatheia* for "in suffering or passion," empathy implies a shared phenomenology wherein the observer is able to accept and understand the expression of another person's emotional experience because it reflects that observer's own experience or capacity to appreciate such experience (Cohen et al. 2011).

Empathy represents the core ethical value of intersubjectivity, as it functions as a foundation for other acts that allow one to live in the experience of the "other" in an intuitive manner without the necessity of having to share the same experience at an emotional level, as is the case for sympathy (Stein 1917).

Evidence from neuroimaging studies accords with phenomenological descriptions (Gurmin 2007) and functional simulation proposals of empathy (Barnes and Thagard 1997; Gallese et al. 2002) that suggest that the act of observing others who are experiencing pain triggers activation of neural networks that have been implicated in the direct lived experience of pain (Decety et al. 2009).

Importantly, these networks include those that have been found to accompany the observation of strong negative emotional expressions such as disgust, fear, anger and sadness (Budell et al. 2010) as well as those associated with positive emotions such as joy (Takahashi et al. 2008). As these neural networks sub-serving emotions are shared, it is not surprising that empathic responses of both clinician and person-experiencing-pain will bias the attitudes, emotions, intentions and behaviour of both parties.

7 Prospection

One of the tenets of empathy is the ability to put oneself in the position of the other because of shared human biology and humanity. Crisp and colleagues (Crisp and Turner 2012; Miles and Crisp 2014; Crisp 2015) have developed this theme as *social prospection*, defined as "the capacity to mentally project oneself into the past or the future to consider alternative perspectives based on our past experiences."

In his important "contact hypothesis," Allport (1954) suggested that bringing together members of different groups under appropriate conditions could lead to more positive inter-group relations. Crisp and Turner (2012) expanded Allport's hypothesis to encompass “the planning, rehearsal, and enacting interactions with others—the ability to mentally time-travel that is necessary to transcend peoples’ tendencies to see out-groups as ‘them’, and to see a possible future in which they are also ‘us’.” In support of this proposal they have assembled evidence that by simply imagining contact with a member of an “out” group a person is engaging in conscious processes that parallel those involved in actual contact.

The potential benefits of a person imagining a positive interaction with an outgroup member include positive changes in attitudes and behaviour towards the member, as well as less overall anxiety for the person involved. In addition, they draw on research from other areas of behavioral science that shows that social prospection can enhance self-efficacy.

Evidence assembled by Miles and Crisp (2014) also supports the proposition that imagined contact is potentially a key component of educational strategies aiming to promote positive social change. Although this proposition has not been tested in relation to clinicians and their patients in pain, it has been shown on the one hand that only providing information does not change intergroup attitudes, while on the other hand that imagined contact could help to challenge existing attitudes and to “reduce anxiety and negative expectations about contact, while generating positive emotions like empathy” (Crisp and Turner 2012). Social prospection may be a novel template for reframing the clinical encounter in pain medicine.

8 Negotiation Towards Validation: Reframing the Problem

Validation was defined above as confirmation, corroboration or substantiation. That process for the person with chronic pain has two dimensions: the recognition and affirmation by the clinician of where-they-are-in-the-world, and a mutually agreed reframing of the person’s predicament. In order to help the patient come to terms with the fundamental change in their existential situation, the clinician needs to have a genuine interest in the patient as a person by the facilitation of a genuine dialogue.

9 Strategies for an Ethical Discourse

The conscious experiences of other people cannot be perceived, analysed, or defined as objects or as things—one can only relate to them dialogically. To think about them means to talk with them, otherwise they immediately turn to us their objectivised side: they fall silent, close up, and congeal into finished, objectivised images (Bakhtin 1963).

In contrast to monologic discourse, which pretends to be the ultimate word, finalized and deaf to the other's response, dialogic discourse is the willingness to become caught up in the other's *illusio*, at least provisionally (Frank 2002). From a dialogical standpoint, listening is the capacity to share what makes someone's story worth telling and worth hearing. The dialogical and profoundly ethical task is for each to see themselves as participants in the other's story to the extent that "each feels implicated in the other's life story, and feels that other's implication in his or her own story—and believes these stories matter, crucially" (Frank 2002).

Trevarthen (1979) suggested that in humans the experience of pain is fundamentally associated with the need to "tell" someone about it. For those experiencing chronic pain, where there may be no readily discernible lesion or process, the third space provides a unique opportunity for them to "tell" this to their clinician, and for both to use the process of dialogical discourse to reframe the problem in an attempt to comprehend their suffering.

10 Reframing the Problem Through Narrative

The biomedical narrative, which is based upon the discovery of underlying disease, cannot be the only one for the person experiencing chronic pain. By contrast, in order to meaningfully engage with their patients at a deeper level, clinicians may need to offer a continuous narrative that might lead the patient to an existential understanding of their condition and predicament. This proposition is supported by findings that patients with pain associated with cancer who disclosed highly emotional narrative material reported lower pain intensity and improved well-being (Cepeda et al. 2008).

One such narrative, which is biologically based, serves to make both parties aware that humans share fundamental properties in common with all living organisms and that the experience of being in pain can often be associated with a host of clinical features suggesting activation of evolutionarily conserved systems of stress or sickness response (Lyon et al. 2011). This narrative transcends dualistic thinking as it is made clear that both physical and psychological traumata can activate these systems. Moreover, the clinical problem can be reframed as one due to dysregulation of the mechanisms that control them.

11 Reframing the Concept of Validation

Another, older connotation of the word "validation" (from its Latin root) is "strengthen." This can itself add another ethical dimension to the role of the physician, through the act of "being with" the patient-experiencing-pain in the intersubjective space and negotiating an interpretation of the patient's narrative through dialogical discourse, the clinician is able to provide a satisfactory explanation of the patient's predicament and lay the groundwork for the patient to play an active role in addressing that predicament. The strength of this approach is that it increases the likelihood of adherence to prescribed therapy, and implementation of strategies of self-monitoring, self-management and self-efficacy.

However, it must be expected that such an approach may be resisted by agents of the dominant ideology, whose "task of teaching medicine leans towards cultural and social reproduction… that, in effect intends to perpetuate the existing *symbolic capital*" (Gomes and Rego 2013).

12 Conclusion

When confronted with the *aporia* of pain and the uncertainty that attends phenomena that do not accord with the biomedical imperative, validation of another person's experience of chronic pain may well be challenging and even threatening to the social capital of both parties. However, by accepting this risk and reframing this problem through the concepts of intersubjectivity, and using the strategies of dialogical discourse, mutually negotiated narratives and social prospection, a rapprochement characterized by both confirmation and strengthening can be reached in an ethical manner (Fig. 1).

Legend: Clinician and patient both grapple with the aporia of pain. Both face risks that can threaten their respective social capital. Through negotiation in the intersubjective (third) space, using strategies of dialogical discourse, the experience of the person in pain can be reframed and thereby validated.

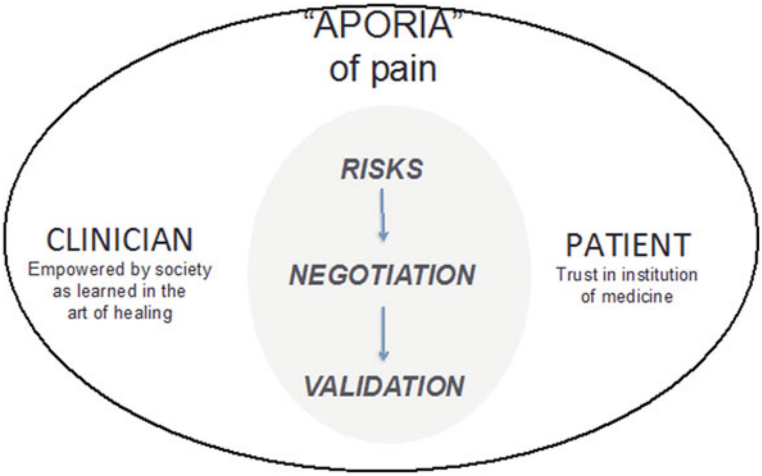

Fig. 1 Intersubjective (third) space negotiation

simon.vanrysewyk@utas.edu.au

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Chapter 18
Meanings of Chronic Pain in Patient Interactions with Health Services

Karin Säll Hansson, Carina Elmqvist, Gunilla Lindqvist and Kent Stening

Abstract Chronic pain causes suffering for patients and managing chronic pain is one of the most common assignments in the health service. Health care professionals can profoundly influence the meaning patients and their families attribute to pain experience. Patients with chronic pain may feel discredited and called into question by skeptical medical professionals. Patients may have to fight to receive entitled care and to suggest suitable treatments. To contribute to medical decision-making and improved patient outcomes, health care professionals should integrate phenomenological narratives and stories about pain into health care in parallel with consulting the medical evidence. Professional care structures should not make health care professionals feel torn between meeting patient needs for existential support and the demand of meeting high clinical work-loads. Narratives and stories can provide shared structures that allow patients and medical professionals to make decisions that feel meaningful, accurate, and clear. Many patients use psychological strategies in their everyday lives in order to live meaningfully with persistent pain; but, this is not enough. Healthcare professionals need "dare to open up and accept personal and deep conversations with patients" about their pain experiences and the lived consequences of persistent pain.

1 Introduction

Let's start with a patient's true story about an encounter at an Emergency department (ED). This narrative highlights some of the issues that will be discussed further in the chapter.

> A young woman arrived to the ED by ambulance one Wednesday afternoon. She has had a terrible pain for a week and had barely slept at all because of the pain. Several of her joints were subluxated after an examination a week earlier. She could barely walk to the bath-

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K.S. Hansson (✉) · C. Elmqvist · G. Lindqvist · K. Stening
Department of Health and Caring Sciences, Linnaeus University,
391 82 Kalmar, 351 95 Växjö, Sweden
e-mail: karin.sall_hansson@lnu.se

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> room, she felt sick and she vomited. It was very hard for her to drink and eat. Her lips were swollen and ulcerated and she was very, very tired. The young women had not dared to go to the emergency department. She was afraid of how she would be treated and she was afraid of being disbelieved. It was possible to read her three diagnoses in her journal; Ehler-Danlos syndrome (hypermobility), narcolepsy (sleeping disorder) and Mb Chron (an inflammatory bowel disease).
>
> The ambulance nurses told the registered nurse (RN) and the assistant nurse at the ED that the young women was so sick and pained that she was needed a real bed instead of a stretcher. The RN and the assistant nurse took good care of the young woman. She got a bed and a small plastic mug with water. The RN and the assistant nurse put her into a room and closed the door. One and a half hours later another RN arrived into the room. She said hello to the young women, her husband and her mother. However, the RN did not ask the young women about her pain or if she needed anything. She only said that the physician will arrive soon. The young women and her relatives stayed in the room for another two hours before the physician arrived. He tried to examine her. The young women screamed in pain. The physician said:
>
> "You are too sick to be here at the ED. It's better for you to go home! We can't do anything for you."
>
> The young women's mother objected and told the physician that they had done all they could at home! The physician said he would talk to his colleagues. He came back after 20 min and said, "There are no beds at all available for you at the hospital! It's better you go home!"
>
> The young women began to cry. Her mother refused to accept that there were no beds for her very sick daughter. The physician promised again to consult other colleague, this time an anaesthetist. The physician came back after some minutes and said, "We do not deal with such pain during this time of day!"
>
> The young women's mother did not accept this argument either. One hour later the anaesthetist came to see the young women at the ED. Having met and conversed with the young women he decided to put her in the intensive care unit. The young woman was then admitted to intensive care unit for a week and then she was three weeks at a medical unit.

As this story shows, healthcare professionals (HCPs) can negatively affect patients with pain and their relatives and contribute to their suffering. The young woman in ED suffered through the unreflective thoughts, actions, and lack of knowledge of the HCPs (Rehnsfeldt and Eriksson 2004). However, if a patient with chronic pain arrives at the ED, HCPs might feel unprepared and disempowered. There are several reasons for this. First, patients with chronic pain are not typically received at ED. Second, HCPs may think ED is an acute environment only and may feel unprepared to treat patients with chronic pain. Third, they are also concerned whether a patient with chronic pain may block patient beds. Fourth, HCPs describe some patients with chronic pain as "dramatic" or causing a "sinking heart" because they are unsure how they should treat them. Sometimes, HCPs avoid patients with chronic pain or take a deep breath outside the patients' room before entering to administer care (Gauntlett-Gilbert et al. 2012). Finally, while pain is central for the patient with pain, HCPs prioritize other symptoms such as signs of heart disease and other critical illnesses before patients with chronic pain (Bergman 2012).

Within emergency care, when there is no need for life-saving actions, patients and relatives often experience what we prefer to call an *interspace* in encounters with HCPs. An interspace includes a meaning of distance between patients and HCPs where patients paradoxically feel being in focus and at the same time not being in focus—a paradox of care. Professionals take serious responsibility for the medical aspects of medical care, but often forget to talk to the patient about how he or she feels and why, which can create an interspace, or worsen one that already exists. At the same time a HCP may feel torn between meeting patient needs for existential support and meeting the high demands of work. In this way an interspace reduces the optimal handover of information between both parties (Elmqvist 2016). A patient may feel he must fight to be a credible patient. Further, the environment in the ED may also be an important contributor to creating an interspace for the patient when for example the examination rooms are perceived to have a meaning of sterility and flatness (Elmqvist et al. 2011).

Patients with pain, especially those with chronic pain, are more at risk to be discredited by health care professionals than patients with other chronic diseases. A reason for this lies in the significant clinical challenge of accurately recognizing pain (Breivik et al. 2006; Craig 2009). Pain is far more difficult to measure and therefore manage than chronic diseases such as diabetes or heart failure (Garbez and Puntillo 2005). When patients with chronic pain arrive at the hospital they often feel disappointed (Gauntlett-Gilbert et al. 2012). When pain is not recognized by HCPs, it can increase patient suffering (Banz et al. 2011).

Due to personal experience, each living person has an intuitive understanding of what acute pain is like. Intuitively, we expect that it will eventually end. This isn't the case in chronic pain. Chronic pain constitutes a never-ending story for the one who suffers it. Chronic pain is now seen as a global public health problem which causes great suffering for those affected (Giordano and Schatman 2008). It constitutes a major health care issue in Europe, and is poorly understood and managed (Breivik et al. 2006; Craig 2009). Chronic pain is becoming more prevalent in the general population compared with different diseases or health conditions and mainly affects older female adults, contributing substantial comorbidities to this group (Freburger et al. 2009; Goldberg and McGee 2011). The European Federation of the IASP (The international Association for the Study of Pain) (EFIC) declaration from 2001 expressed that, "*very few people die of pain, many die in pain and even more live in pain*". So, "to live with pain", affects the patient's life as well as the relatives at every turn. To face doubt from HCPs can turn the life of the patient and family into a bitter struggle for recognition of lived reality. The reality of hospital functioning can provide challenging experiences for patients, which can include long waiting times and failure on the part of some HCPs to reschedule appointments (Cooper et al. 2008). Patients find it irksome when some HCPs arrive late to or cancel an appointment, especially when such changes are not communicated to the patient beforehand (Osterhof et al. 2014).

There is a need to accurately describe chronic pain patient experiences within health service settings, their expectations of such experiences, and what they mean to patients and clinicians. Although the specific experiences and what they mean will vary considerably across patients with chronic pain, it is probable that patients experience at least a partial commonality of meanings. These shared meanings may be generalizable to patient groups or sub-groups, and could highlight areas for improvement in patient care, as well describe important success stories. Patient and HCP quotations presented below are taken from a qualitative phenomenological study conducted in Sweden, which included interviews with eight patients with chronic pain about their experiences in the health service (Hansson et al. 2011).

2 Patient and Health Care Professional Expectations About Clinical Encounters

HCPs and persons with chronic pain have different expectations of each other, of clinical care, and what it means to live with pain. Patients with chronic pain want to be seen as *persons*, not as a hospital number or a patient with no name (Hansson et al. 2011). Patients expect to be treated by HCPs as human beings with self-worth. They want to be seen, heard and taken seriously (Jakobsson 2008), and to actively participate in their own healthcare (Hansson et al. 2011).

HCPs are expected to be professional, to understand how pain works, as well as being knowledgeable about what it is like to live with chronic pain. Patients expect to be asked to describe their pain in their own words: "*If you don't get the chance to say something yourself, then they can't know how you feel and how much pain you've got*" (Hansson et al. 2011).

Patients view medical evidence alone as insufficient for HCPs to understand what it is like to live through chronic pain from a personal point of view. Persons with chronic pain expect that HCPs should believe what is reported to them and to integrate these personal accounts with the medical evidence (Reynolds 2004). However, there is a patient expectation for a 'quick fix' that involves pain being quickly recognized, treated and relieved by HCPs, and that revolutionary discoveries will emerge to relieve pain in the same way. This expectation includes a desire to eliminate pain, to do the everyday activities others can effortlessly do, and that HCPs will say, "*that's what's wrong, now, we know what to do*" (Hansson et al. 2011).

It is important to patients that HCPs are supportive and are willing to communicate about pain; unfortunately, desired support and open-mindedness is often lacking in health service settings. Patients experience a lack of engagement with HCPs (Juuso et al. 2014) as well as a lack of meaningful communication with them (Grace 1995). Patients with chronic pain want to consult with a medical professional who is willing to really listen to them narrate pain experiences. As a result of these experiences, patients are forced to find support primarily within family and peer groups, both of whom in turn expect dedicated care from the HCPs (Ojala et al. 2015). Patients with chronic pain think HCPs need to have more knowledge about pain, and they expect HCPs to consult with more knowledgeable colleagues for alternative views. One patient stated: "*It's not good to have pain; you heal a lot slower if you have pain, it's been proved, and all nurses should know that*" (Hansson et al. 2011). Furthermore, patients view it as positive if HCPs admit to patients that they do not have sufficient knowledge about pain, and instead ask the patient to talk about his/her lived experiences of their pain and the meanings of such experiences (Hansson et al. 2011).

Patients may find it difficult to access HCPs for support when they need it. They have expectations of using email, voice messaging and landlines to directly communicate with HCPs (Upshur et al. 2010). Demands for medical care are increasing; yet, the resources available to meet these demands are shrinking. This problem has resulted in finding new ways to support patients. The use of Information and Communications Technology (ICT) in health service settings—*technology-based healthcare* (Fagerström et al. 2016)—can allow patients to communicate with their care manager when face-to-face contact with HCPs is not possible. ICT may be a convenient tool to supplement face-to-face communication with patients. However, patients prefer face-to-face contact as the first communicative option (Skuladottir and Halldorsdottir 2011).

From the point of view of HCPs, care of patients with chronic pain is difficult and frustrating. They think it is extremely challenging to provide pain management and to trust the patient's self-assessment of pain. HCPs think patients who do not complain about their pain are perceived easier to care for (Blondal and Halldorsdottir 2009). Some patients who do not look or act like they should be in pain, despite personal reports to the contrary, are difficult to believe (Reynolds 2004; Larsen et al. 2012).

HCPs consider patient education about pain a very important part of the treatment of pain to correct maladaptive beliefs about pain that patients may have developed. Furthermore, HCPs think it is important to assist chronic pain patients to widen their perspective about pain and help them to look away from only negative aspects of living with pain. Patients should learn to actively live with pain, rather than passively through its aversive and functionally disabling nature (Ojala et al. 2015).

3 Experiences and Meanings of Clinical Encounters

Persons with chronic pain describe clinical encounters with HCPs as mostly negative (Hansson et al. 2011). They describe not being accurately or sufficiently examined, inappropriate investigations and referrals, missing test results, and HCPs who lack knowledge of chronic pain. Furthermore, they often describe meeting with HCPs as upsetting, disempowering and a battle to be understood (Robinson et al. 2013). "*There's been many occasions when I've just sat down and just collapsed because I don't know what to do, I've just felt like a nobody suddenly*" (Hansson et al. 2011). On some occasions, patients observe that they are met with arrogance; they are questioned and seen as idiots. "*When the doctor took a test and couldn't* *get confirmation that the test was wrong then they became sort of frustrated and they looked at me as though I was nutty, that's how I felt*" (Hansson et al. 2011).

It happens the patients receive a pat on the back and the answer that there is nothing that can be done about the pain. Patients have also been told that pain is natural and that there are others who are worse off than themselves. "*I gritted my teeth and felt no you bloody swine. That's what I thought ... I couldn't manage to say anything.... I was in such pain and was so disappointed. I felt he didn't believe me. He hadn't a clue as to how much pain I had*" (Hansson et al. 2011). Sometimes, patients wonder if they would be in this situation if they had been correctly treated when they began therapy against pain (Larsen et al. 2012).

Some clinical encounters between patients and HCPs were experienced by patients as positive (Hansson et al. 2011). To be approached in a positive manner is seen as self-evident and as a natural human action. To be able to explain one's situation, to be asked how one feels, how the treatment is working, and what help is needed, are positive experiences. Receiving a diagnosis feels like self-confirmation and gains meanings of hope for the future. "*It was wonderful, I felt that I got my human dignity back, it was like coming to heaven, it was like coming back to life again*" (Hansson et al. 2011). A diagnosis is a huge relief (Larsen et al. 2012).

Patients desire accurate information about their diagnosis and consequences in terms they can readily understand (Cooper et al. 2008). If HCPs give good evidence-based explanations of their decisions, then it is easier for patients to understand and accept what the HCP decides. The key factors in patient-centered decision-making are to involve the patient and listen to their wishes and tailor information to the individual patient. Patients also trust HCPs who are perceived to have adequate knowledge about their pain and how to treat the pain (Eriksson et al. 2016). Unless a patient is perceived as a unique person requiring dedicated attention, patients find it very difficult to open up to nurses to tell her/his life story in the form of intimate thoughts, feelings and experiences (Gudmannsdottir and Halldorsdottir 2009).

Patients who meet the same HCPs every time feel it is easier for them to describe pain and how it changes over time (Matthias et al. 2010; Eriksson et al. 2016). Meeting new HCPs makes patient participation more difficult and can result in emotions of anxiety and frustration, and meanings of concern for the future (Hansson et al. 2011; Gonzales et al. 2015). Patients who feel disbelieved in reporting personal pain have a negative meaning of being passed over. This feeling and meaning is strong if HCPs do not regularly ask patients about their pain or follow-up on pain treatments. The patient may come to feel that they are not allowed to mention pain or pain-related topics (Grace 1995).

Eriksson et al. (2016) describes how professional disbelief may first appear in the acute phase, which transfers to chronic pain. In these situations, patients do not dare ask for pain management because HCPs look busy, walk quickly, and apparently have no time to talk. So, patients do not want to disturb HCPs; they think they have more important things to do (Faulkner 1995; Jakobsson 2008; Eriksson et al. 2016). A consequence of this is that the patient hesitates to ask for advice on pain treatment, and feels isolated from other people (Eriksson et al. 2016). For example, patients perceive that it is easier to approach nurses concerning prescribed analgesics than physicians, but they don’t have all the answers patients need. The nurse assistant talks to the senior nurse who then talks to the physician. HCPs often tell patients to wait for analgesics. In such situations, patients have to wait and “bite the bullet”, sometimes for several hours. If patients press further for more analgesics they risk denial. A case arose when a patient requested more analgesics, but HCPs hesitated and claimed that the patient asked for more analgesics too often (Eriksson et al. 2016). However, some HCPs are mindful of patient needs, and do counsel patients to take prescribed analgesics. This makes the patient feel understood. Patients feel safer and less frustrated if they are asked about their pain experiences.

When it comes to the treatment of pain, trust between both parties is of great importance (Jakobsson 2008; Matthias et al. 2010; Wuytack and Miller 2011; Eriksson et al. 2016). If the opposite occurs, patients may come to feel abandoned or neglected (Eriksson et al. 2016). More philosophically, the patient perceives the HCP, but the HCP doesn’t perceive the patient. I am close to the HCP, but he is not close to me. Such clinical encounters have the feature of impersonality, and this feature can originate a meaning of desolation in the patient. Desolation is the personal experience of the inevitable failure of the search for reciprocal love. Initially directed towards HCPs, desolation may develop into a felt emptiness towards the health service as a whole. Such patients reach out hopelessly into perceived oblivion for HCP contact, all the time perceiving that there is nobody to notice or care for them. However, there is hope. Reciprocity in a care relationship can partly be achieved when HCP and patient co-operatively understand what each other’s needs and strengths are (Snellman 2009).

All persons suffer in life depending on conflict or disruption to relationships or through personal illness, disease or pain. Patients with pain suffer when pain is perceived to interrupt, burden or permanently harm functional abilities and sense of well-being (Price and Barrell 2012). Pain-related suffering may differ based on whether pain is acute or chronic and on the meaning of pain as a personal burden that persists without meaningful relief (Price and Barrell 2012; Arman 2015). Persistent stress and anxiety can worsen pain and, over time, negatively affect personal well-being; that is, the person as a whole (Price and Barrell 2012). Pain-related suffering is also associated with depression, anxiety, hopelessness, frustration and anger (Breen 2002). Impaired relationships which disrupt or harm one’s sense of personal meaning, as described in this chapter, also contribute to patient suffering. Patients may struggle to cope with symptoms and to achieve balance in a life dominated by unrelenting pain (Berglund 2014). Some patients with chronic pain may suffer less than others due to a stoical attitude (Robinson et al. 2013).

4 Patient Strategies for Living with Pain

Patients need personal strength to manage challenging encounters within the health care system. Stubbornness is a necessary personal trait in order to get care, “*If it had been a person who wasn’t as strong as I am, then it wouldn’t have been easy. It’s* *terrible!*" (Hansson et al. 2011). Patients felt forced to use their own initiative and make suggestions to HCPs for alternative treatments (Hansson et al. 2011). At times they felt that HCPs do not make sufficient effort to help. "*You have to be a doctor yourself to know what treatment you should have. If I hadn't looked for help then I wouldn't even have got there*" (Hansson et al. 2011). The general perceived opinion is that "*you were lucky if you met a person who would listen*" (Hansson et al. 2011). According to patients, pain is a private experience; but there are obvious signs when someone is in pain. They expressed surprise that HCPs did not perceive these behavioral manifestations. "*That you're actually crying, that you are so tense // you're sending clear signals about having such pain and if you were to stop and look … you can't fake things like that*" (Hansson et al. 2011). If patients present in the clinic looking "*too healthy*", they are met with skepticism by HCPs (Hansson et al. 2011). Some patients feel forced to appear and behave in certain ways in order to be trusted by HCPs. For example, they do not appear sunburned, use make-up or look happy (Werner and Malterud 2003).

Patients think that they are entitled to receive treatment and medical information based on evidence, but such information may not be forthcoming because HCPs consider it inappropriate. However, with greater knowledge about pain, patients themselves could participate more in clinical consultations, and share clinical decision-making and planning. Participation entails being active oneself and calling attention to one's needs and openly expressing wishes about treatments. On the other hand, greater knowledge could have a negative meaning, because some HCPs might perceive patients with knowledge about pain as a threat to their professional expertise. In these situations, patients perceive they are nagging, whining, troublesome or selfish persons (Hansson et al. 2011). When patients try to draw clinical attention to their pain, they are afraid of being seen as a troublesome inconvenience. They are afraid of being perceived as argumentative and creating conflict within the health service (Eriksson et al. 2016).

Intimate and supportive communication between patients and HCPs is extremely important for patients. Sensitive clinical communication conducted in an informal, conversational manner fosters a sense of vested participation in patients (Cooper et al. 2008). HCPs can ask patients about pain in different ways. For example, patients may be asked to assess pain intensity with a numeric rating scale without adequate explanation of why. '*He doesn't seem interested… I haven't had any success when… saying how I feel about it or what it's like*' (Hansson et al. 2011). Pain assessment can create a strategic dilemma: "*if I register a five… I may then not receive enough pain relief and then I have to register a higher figure in order to get more*" (Hansson et al. 2011). Nurses in particular are perceived to have a key therapeutic role in the health system (Hansson et al. 2011). They are well-placed to clearly explain to patients what pain assessment scales are and their intended medical use (Eriksson et al. 2016).

Some patients may imagine the future as scary and dark and they feel reluctant to ask about HCPs or significant others the future because they are afraid. They want to continue living as they always have. It is important for HCPs to guide patients to narrate their concerns about the future and enduring pain and help them to accept this new life and the prospects of pain control. HCPs should encourage such patients to reflect on their life with pain and help them to make evidence-based decisions to achieve personal goals. HCPs must adopt a more empathic and caring approach to patients with pain (Bergman 2014)..

5 Towards a More Caring Approach to Pain Management

According to the world-view of natural science, human beings are neurobiological organisms, compelled by an ancient causality and relating to each other through mechanisms and laws that control us and every other thing. By contrast, in the shared world of personal experience, we are persons, acting in the world and relating to other humans through beliefs, intentions, feelings, and experiences. The second world describes concepts that refer to human ‘intentionality’, to use a term from the philosophical discipline of phenomenology. The term ‘intentionality’ means the quality of referring to, or describing, an object of personal experience. I myself am the object of my own painful experience; in my perception of pain in another person, the object of pain is someone else in the world neighboring my experience (The *Lebenswelt* or, ‘lifeworld’). An ‘intentional understanding’ describes the lifeworld in terms of the personal meanings implicit in our everyday lives and actions. Thus, an intentional understanding of pain is concerned not to explain pain in terms of neurobiology so much as to be ‘at home’ in it; describing common or idiosyncratic personal meanings about pain, showing why meanings of pain change over time and how they interact with the body and the lifeworld.

In good health, we take our lifeworld for granted and we seldom reflect on its meaning for us (Dahlberg and Segesten 2010; Ekebergh 2015). Within our lifeworld, our body is a lived body. This means that we not only have a body, we live our body and we experience the world around us through our body. Therefore, any change in our body, as for example pain, also means a change in our perception of our lifeworld as well as a change of our access to it (Merleau-Ponty 1945/2006; Dahlberg and Segesten 2010). To live with pain is not only to live with the pain itself; it is about relating a body with pain to the world. A body is more than its physical organs; a body is a lived body, as described above, and it needs to be understood in health service settings in terms of this wholeness. For a person with pain this wholeness appears if the encounter with HCPs intertwines the stories of the body with the soul and the world in order to create meaning for the patient (Merleau-Ponty 1945/2006).

Being viewed as a person and not just as a patient with pain involves more than consulting a patient’s medical record. It also entails showing sensitivity towards a patient’s lifeworld in which his or her lived pain is immersed (Dahlberg and Segesten 2010; Ekebergh 2015). “*It’s not just about how you cope with the day; you have to cope with the night as well*”. Patients felt that HCPs were self-focused on concerns within the world of their respective medical fields and disinclined to consider other physical problems that could challenge their expertise (Hansson et al.

2011). Again, patients wish to be regarded as persons; HCPs need to see the person behind the pain (Ojala et al. 2015).

Patients prefer open person-centered communication with an empathically supportive style that enables co-engagement (Ullrich et al. 2014). To communicate in this intimate and supportive way with HCPs is extremely important for the patient with chronic pain (Hansson et al. 2011). Good clinical communication includes developing a feeling of participation, appropriate language-use (e.g., for diagnostic information), and time for mutual listening and talking. It also includes getting to know the patient as a unique person and inspiring the patient to take part in this reciprocal process (Cooper et al. 2008). Patients prefer clinical encounters to have a conversational rather than exclusively biomedical tone. The meaning of biomedical information is rarely self-evident to patients. Patients and HCPs must decide together which information to consider and which to reject, and how to make shared decisions accordingly. Patient narratives can help structure conversations in the clinic, and provide meaningful pathways to decision-making.

HCPs that show empathy and understanding in this way are more effective in helping patients feel they are being taken seriously and not being called into question, either mentally or physically (Hansson et al. 2011). Treatments are not only prescribed medications; they could also include a management plan with individualized goals (Upshur et al. 2010). Ojala et al. (2015) suggests that chronic pain management must be personalized. Patients need to be taught to sensitively reflect on the total lived experience of pain instead of just the aversive sensation. It is important to include family members in this task. Such reflection can aid HCPs to build a management plan for treatment.

Fredriksson (1999) describes two different attitudes about dyadic interactions involving patient and clinician. First, “being there” is characterized by attentiveness to the other, where the patient fulfils a passive role solely attending to the clinician, whereas the clinician adopts an active role, treating the patient’s report of pain only as a means to the end of giving it a biomedical interpretation. Within the context of this chapter, we endorse a relation of “being with” the patient. This is characterized by a meaning of mutual receiving, in which HCPs are present in the encounter as medical professionals and human beings. Conversely, patients are encouraged to learn more about the science of pain without fear of professional push-back from HCPs. A version of this model of care is developed in more detail in Chap. 17 by John Quintner and Milton Cohen.

6 Conclusion

Clinical encounters between patients and HCPs reveal mutual expectations and strategies in play which can deeply affect the patient-clinician relationship, and patient outcomes. Our phenomenological exploration of these interactions has revealed a significant gap between patient expectations about medical treatment for pain and HCPs knowledge about pain control. Patients may have to fight for care and may struggle to navigate a perceived complex health service system. Patients with chronic pain suffer due to meaningful negative changes to their lifeworld. They are concerned about the future and enduring pain as a burden over time without meaningful relief.

Most importantly, patients ask for empathy and to be believed. They want to be seen as human beings *with pain* and not as *pain patients*. They expect HCPs to be professional, inclusive, to understand what pain is, and know how best to assess and manage it. HCPs should show sensitivity to psychosocial dimensions of pain, not merely the aversive sensation assessed with simple rating scales. From the HPC point of view, patients with chronic pain are often seen as 'heart sinkers.' If HCPs think the opposite way, such patients can have a very hard and 'heart sinking' life. However, if the HCP takes the patients point of view and learns from the patient in terms of his or her personal lifeworld and reflects on the information they receive from patients in this way, the encounter them would likely be more positive. HCPs can *be with* patients in a caring capacity by encouraging a shared conversation about pain and how to manage it. In clinical encounters, HCPs can encourage sharing of personal narratives and stories about pain in parallel with consulting the medical evidence. Narratives and stories may allow patients and HCPs to make shared decisions that feel meaningful and accurate to both parties. In turn, HCPs need support to manage feelings of being torn between meeting patient needs and the high work-loads.

Many studies reporting clinical encounters involving patients with pain are designed from a HCP point of view (Bergman 2012; Blondal and Halldorsdottir 2009; Clark and Iphofen 2005; Gauntlett-Gilbert et al. 2015). The present chapter contributes accounts of the lived experiences of patients in health service settings, but similar qualitative or mixed method studies are needed to corroborate these experiences and meanings, and to generate new research questions with a clinical focus. Phenomenological studies on this topic are disappointingly few, but the in-depth information they uniquely provide is not available to quantitative research methods.

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Chapter 19
Making Sense: Regaining Self-Coherence

Bronwyn Lennox Thompson

Abstract Chronic pain is a perplexing and confusing experience for both the individual and the clinician. As meaning-making beings, people struggle to make sense of an experience that disrupts the sense of coherence and assumptions about who they are and what they can do. Individuals who successfully make sense of their pain, and can integrate this new reality into their self-concept are able to move forward in life. Findings from a classical grounded theory are used in this chapter to show the importance of making sense of pain as part of a process of regaining self-coherence. The overall process shows that a critical aspect of accepting chronic pain is learning to re-occupy a self-concept that integrates the impact of chronic pain while allowing the individual to express important values through activities in daily life. Clinicians are encouraged to place emphasis on creating a space where being present, listening and explaining can occur so that people living with pain can begin to feel that the world, and their place in it, makes sense.

1 Making Sense, Regaining Self-Coherence

It is not immediately apparent that persistent pain is different from any other pain. The experience is located somewhere in the body, it has intensity, quality and dimension and of course, meaning. Whereas “normal” pain gradually fades into the background, disappears, this pain is different. The experience remains, intruding on awareness and raising questions. Until individuals make sense of this experience, life can feel incoherent.

Sense of coherence is an orientation to life that consists of *comprehensibility* (that happenings in life are rational, predictable and understandable); *manageability* (that resources are available to help); and *meaningfulness* (life changes are viewed

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B.L. Thompson (✉)
Department of Orthopaedic Surgery and Musculoskeletal Medicine,
University of Otago, 2 Riccarton Ave, Christchurch Central,
Christchurch 8011, New Zealand
e-mail: bronwyn.thompson@otago.ac.nz

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as challenges and should, therefore, be engaged with) (Antonovsky 1996). Unexpected or extraordinary events threaten an individual's sense of coherence and especially their self-concept, or the inferences individuals have developed about themselves (Baumeister 1997). Experiencing chronic pain is such an event. Regaining a sense of self-coherence is a primary concern for people newly diagnosed with a chronic painful condition, and I argue that making sense of chronic pain is an essential part of this process.

2 The Private to the Public

Michael Bury describes the chronic illness of rheumatoid arthritis as a *biographical disruption* (Bury 1982), an experience where the everyday life, habits, routines and expectations are challenged, and where states not usually attended to are brought into focus, need explanation and require a response. Using a sociological lens, Bury goes on to describe the insidious onset of rheumatoid arthritis. Individuals initially disregard the importance of symptoms such as a swollen finger or morning stiffness, believing them to arise from external factors such as gardening or housework. Bury points out that illness, in modern times, is considered to be external to the person and once treated, should resolve, leaving the self-concept relatively unchanged. When symptoms persist, conventional, externally-directed explanations fail, introducing a new and unfamiliar social scenario of uncertainty about what is happening, and where this may end (Bury 1982, p. 169–170). Previous assumptions about the self and the future are challenged.

Bury identifies that the initial stages of recognising an illness are often private (Bury 1982, p. 171). Pain is always personal and invisible, but when accompanied by tissue damage far more likely to garner social validation. Broken bones, blood, bruising and swelling elicit immediate responses from onlookers. Even images where limbs are shown in potentially tissue-damaging situations (for example, jammed in a door, cut by a knife) elicit neurobiological responses on observers closely matching those found in individuals experiencing pain themselves (Jackson et al. 2005).

Many things that are usually scarcely noticed are brought into awareness when pain persists. Chronic pain is not typically accompanied by visible tissue damage, and nothing may be visible on imaging (Balague and Cedraschi 2006). Instead, internal, private experiences must be articulated and revealed. The "what it feels like" to sit, walk, carry and even lie awake at night need description. The word of the person describing these things must be trusted. A common complaint of people living with fibromyalgia, a widespread pain condition, is that they appear well and feel judged because they "don't look sick" (Arnold et al. 2008), and their experience disregarded in the pursuit of "objective diagnosis" (Thacker and Moseley 2012). As a result of this appearance of normality, many people experiencing persistent pain feel stigmatised, isolated and uncertain.

At some point in the journey with persistent pain, the initial belief that an external factor is responsible can no longer be retained. The pain continues. The experience becomes more threatening, disruptive and mysterious. Answers are needed. Some individuals living with persistent pain will have already sought explanations from Healthcare professionals. They may have been advised that their pain is something that is similar to existing community beliefs: it is a response to tissue damage; it will settle with time; treatment will support the healing process. The over-riding message is that this pain is typical, and recovery is assured. When pain persists, however, doubts arise. Could it be that something else is to blame? Another issue in the tissues? Or, more insidiously, could it be that the person is somehow deviant, not adhering to treatment, not really wanting to get better, or perhaps over-representing the situation?

While these doubts may not be voiced, accounts from studies exploring the lived experience of chronic pain suggest that both the health professionals seeing these people, and the individuals and their families themselves may begin to doubt their own judgements (Lillrank 2003; Mengshoel and Heggen 2004; Newton et al. 2013). Making sense of pain includes both internal and external validation.

There are several different models to choose from when considering a theoretical framework. I have selected the Common-Sense Model of Illness (Leventhal et al. 1992) because it incorporates processes associated with receiving a diagnosis, as well as the illness itself.

3 Theoretical Explanations

Making sense has appeared as a theme in many qualitative studies of chronic pain (Aldrich and Eccleston 2000; White and Johnson 2000; Rogers and Allison 2004; Harding et al. 2005). Psychological theories also describe making sense as part of a process of coping with chronic illness. Leventhal's Common-Sense Model of Illness identifies this process as consisting of illness representations (sense-making), coping procedures and appraisals in response to internal or external stimuli or symptoms (Leventhal et al. 1992).

This model was first developed to explain treatment adherence and illness behaviour and identifies the factors thought to be involved in the ways people process information about their illness and how this is integrated with community views. The resultant appraisals thus guide coping endeavours. Leventhal's model describes individuals drawing firstly from their personal experience of symptoms, together with what they have absorbed from what has been said and is culturally accepted about the illness and integrating this with information drawn from significant others and respected sources such as health professionals. Leventhal claims that the process of making sense involves linking symptoms with diagnostic labels, and is automatic or intuitive. The illness representation usually includes information about *causal* factors; the personal *consequences* of the illness or its effect on quality of life or capability for everyday activities; the illness *identity* or what the diagnostic label means; and the *timeline* or beliefs about the course of the illness (Leventhal et al. 1992; Diefenbach and Leventhal 1996; Hagger and Orbell 2003).

The commonsense model has been applied to many health conditions including beliefs about the causes of hypertension (Pickett et al. 2014); self-management behaviour in medically-unexplained conditions (Leos et al. 2016); treatment seeking delays in people with colorectal cancer (Jensen et al. 2015); health professional's beliefs about psoriasis and the influence on clinical management (Chisholm et al. 2016); individual's understanding of post-traumatic stress disorder (Wong et al. 2011); diabetes self management (Scollan-Koliopoulos et al. 2011), and has been shown to influence disability and quality of life in adolescents with chronic fatigue syndrome (Gray and Rutter 2007).

With "Dr. Google" providing ready access to an overwhelming array of information on disease and illness, the process of becoming aware of even rare diseases is very different today from the mid-1980s. While more information is available, the quality and accuracy are variable (Fahy et al. 2013; Kitchens et al. 2014). Added to official repositories of health information published by consumer groups or professional organisations, individuals can write their own content through blogging (Ressler et al. 2012) and interactive patient forums (Ziebland et al. 2014).

As a result of the interactivity between information providers and receivers of internet-mediated information sources, individuals can ask questions, share their experiences and form highly individualised representations of their situation. The final authority on diagnosis and explanation, despite this, remains with health professionals, mainly medical practitioners (Darlow et al. 2013), and these accounts stand firm in the minds of individuals despite conflicting experience and alternative explanations (Darlow et al. 2015).

The Common-Sense Model provides a useful framework for considering the influences on personal beliefs about illness. Knowledge drawn from long-held beliefs and attitudes within community and family, and from healthcare providers continues to affect an individual's readiness to accept explanations for persistent pain. A process of matching occurs such that until a diagnostic label (complete with its associated halo of cause, consequences, identity and timeline) aligns with the individual's personal symptoms and information available, the search for a name to represent the experience will continue. Diagnostic labels are hard currency for people living with persistent pain.

4 Grounded Theory of Living Well

In this section of the chapter, I will draw from the findings of a classical grounded theory study of individuals identifying as "living well" despite chronic painful conditions (Thompson 2015). Participants in this study were people residing in the community who experienced persistent pain, had received one or more diagnoses of a chronically painful disorder (such as rheumatoid arthritis, ankylosing spondylitis, fibromyalgia, osteoarthritis), and identified themselves as "living well." Participants agreed to a one-hour interview with the author, who then used this information to generate a classical grounded theory in which the main concern was to *regain self-*

coherence through the process of *reoccupying self.* Within the process of reoccupying self, individuals completed phases in which they were involved in *making sense, deciding* and *flexibly persisting*. I will focus on the first process of making sense because individuals develop an understanding of their pain and its impact during this process.

Making sense involves three interlinked processes: (1) *Diagnostic clarity* in which a label encapsulating both personal experience and a name that could be used as a shorthand representation of the illness was confirmed; (2) *Symptom understanding* in which the pattern, variations, and fluctuations of symptoms were recognised such that the person could identify their usual pain (and conversely, unusual pain); (3) *Occupational*[1] *existing* in which future plans were put on hold, and many current activities were curtailed until the person became better able predict the effect of symptoms on functional performance.

5 Diagnostic Clarity

Receiving a diagnosis represents a major milestone, and participants in this study indicated that it gave them a sense of relief. Once given a name for their problem they were able to believe their symptoms were recognised, and they no longer needed to invest energy in searching for a diagnosis, although they may not always have understood or acknowledged the reality of living with long-term pain at that time.

While giving a sense of validation to the individual, diagnostic clarity also involves defining those symptoms that are part of the diagnosis, and those that are not. Adopting a diagnosis includes comparing personal subjective experiences with those that are vocalised both by themselves and others to form illness beliefs or representations (Carlisle et al. 2005; Lee et al. 2010; Glattacker et al. 2012). Individuals may share their experiences with others, seek verification from other people with the same problems (e.g. peer support groups, online networks), and obtain further information about the diagnosis in order to establish what is and is not expected (Smedley et al. 2015; Allen et al. 2016). Symptoms that are less frequently socially acceptable in conversation such as pain, depressed mood, anxiety and intimacy problems (including pain in genitals) may be less openly acknowledged (Seear 2009).

Diagnostic clarity aids in recognising and validating an otherwise invisible chronic pain experience. Diagnoses have social valence. That is, by obtaining a name for the problem, the otherwise invisible experience of symptoms is accepted as real and allows an individual to claim their experience as valid (Jutel 2009). There is a set of social sanctions and responsibilities that individuals can draw on

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[1] Occupation in this context refers to the everyday activities that people do as individuals, in families and with communities to occupy time and bring meaning and purpose to life. Occupations include things people need to, want to and are expected to do (WFOT 2010).

that, in turn, provide socially acceptable self-schemas (Bury 1982). For example, once a person is diagnosed with rheumatoid arthritis, pain and fatigue are recognised as common problems. As a result, those with rheumatoid arthritis can "give permission" to themselves to stop doing certain activities because the fatigue and pain they experience are now attributable to "rheumatoid arthritis" (Bury 1982; Charmaz 1995; McPherson et al. 2004; Lempp et al. 2006; Graves et al. 2009). Instead of feeling guilty for not continuing with activities, the diagnosis provides a socially acceptable reason for being unwell.

6 Symptom Understanding

While diagnostic clarity allows for a broad acknowledgement of symptoms and facilitates social validation, the meaning and pattern of symptoms as they impact the individual's daily life must also be established. By developing *symptom understanding*, participants in Thompson (2015) study described defining expectations associated with the patterns of symptoms that they could consider "normal." These expectations referred to what could they could expect from themselves in terms of occupational engagement (activity participation).

Individuals in this study noticed the *patterns, qualities and ongoing nature* of their symptoms to generate expectations. They became aware that certain activities, contexts, and emotions were associated with increases in pain, while reductions in pain were related to others. Those with highly variable pain had more difficulty identifying patterns, and consequently had more trouble developing consistent expectations. Symptom understanding was a personal and internal process, although was influenced by information obtained from others, for example, feedback from a health professional or family member.

Interestingly, although there is a wealth of information about the end result of developing symptom understanding (for example, associations between catastrophising and avoidance), the processes involved in developing this understanding have received less attention. The power of clinician's statements about the meaning of, for example, low back pain has been investigated (Darlow et al. 2015), as has the legacy of biomedical models in the general population (Baird and Haslam 2013), but the ways in which individuals develop an understanding of what symptoms mean in terms of daily life have scarcely been explored.

7 Occupational Existing

The routines and habits carried out in daily life both provide a means of reinforcing self-concept ("who I am") and of obtaining feedback from others and directly from occupational performance about the effects of pain (and other symptoms) on "what I can do." *Occupational existing* is a process identified in Thompson (2015) grounded theory in which individuals developed predictions about the impact of pain in their daily life. It is also the way individuals maintained their lives during the time they were *making sense*.

By engaging in the same set of occupations or daily routines, and as symptoms vary from day to day, individuals in pain developed an internal awareness of typical pain intensity for them, and “what it is like” to get up and get dressed for example, thus developing *symptom understanding*. *Diagnostic clarity* informed them of the range of symptoms to notice and the “acknowledged” pattern that they may experience. Previously ignored symptoms were identified as part of the disease process or diagnostic label they had received. Symptoms that were previously identified as highly threatening, for example, indicating serious pathology or cancer, were now disregarded because they can become reframed as a typical aspect of the diagnosis.

Some occupations or activities are relinquished as a result of chronic pain, or beliefs about the meaning of pain. For example, leisure activities (Ashby et al. 2012) and paid and unpaid employment (Löfvander and Engström 2004; Jakobsen and Lillefjell 2014). Studies exploring disability in populations of individuals living with chronic pain demonstrate the significant impact of psychosocial factors on what individuals do when their pain experience persists (Froud et al. 2014). Rather less attention has been paid to the impact of chronic pain on the sense of self, but the effects are no less profound.

8 Self-Concept

Self-concept develops over time and refers to the social roles, relationships, and relatively long-lasting traits, beliefs, and expectations individuals have of themselves in various contexts. Baumeister (1997) argues that the self-concept is not a single “unity,” but rather is a set of loosely connected beliefs about oneself, formed by feedback from others, but often contrary to the way others perceive that individual (p. 686).

When pain persists, the expectations an individual holds about him or herself are challenged; his or her self-concept is threatened. Hellstrom (2001) writes about “entrapped” selves, or the experiences of being isolated from normal life and the passage of time, having difficulty making predictions about the future and what it may entail, with gradual restrictions on the range of “possible” selves the individual can envisage. Morley et al. (2005) and Sutherland and Morley (2008) found that individuals could become enmeshed in a self-concept in which a future “hoped-for” self could only be envisaged in the absence of pain while the current self-concept represented a “feared-for” self. The discrepancy between “who I want to be” and “who I am now” contributed to depression and distress (Sutherland and Morley 2008).

The process of making sense of persistent pain involves reconciling the ideal self-concept with what is possible, given the presence of pain. The closer an individual’s self-concept can be towards an “ideal” self, as opposed to a "feared-for" self, the more likely that person will be able to accept the new reality and begin to develop plans for the future. In Thompson (2015) study, the phase of making sense initiated a process of letting go of aspects of self that could no longer be sustained. Later stages helped individuals redevelop a self-concept that incorporated valued aspects of self despite the pain, allowing them to eventually "re-occupy" a self-concept that integrated the meaning of chronic pain, making life—and the self—coherent once more.

In the case of a person learning to live well with persistent pain, achieving self-coherence involves making sense of what is, to many people including many health professionals, a felt meaningless experience. Having labelled the experience, differentiated between those symptoms that are and are not associated with the name, and developed an understanding of the patterns and fluctuations of the experience by participating in everyday occupational tasks, individuals begin to recognise their pain as something that may start to be comprehended. For many people, there are few options to manage the pain experience itself. For some of these individuals, over time, and as part of developing a new self-concept, life can regain meaning. In order to reoccupy a new self-concept in which meaning and manageability are retained the individual must modify how he or she goes about participating in valued actions.

9 Regaining Self-Coherence by Reoccupying Self

As health professionals working in the field of chronic pain know, a large number of people appear unable to experience a sense that life is manageable, comprehensible, and that the life they live can continue to have meaning in the face of persistent pain (Maly and Krupa 2007; Lachapelle et al. 2008; Lempp et al. 2009; Larsen et al. 2013). Their self-concept remains in tatters, as they find it difficult to relinquish things they used to be able to do easily while generating new, more achievable occupations, roles, and tasks. The ongoing search for pain relief, cure, or restoration of life as it used to be, is an important component of the illness of persistent pain (Eccleston and Crombez 2007; Van Damme et al. 2008; Flink et al. 2012).

Various authors have defined the alternative to this persistent search for "a return to normal" as acceptance (McCracken and Keogh 2009; McCracken 2010; McCracken and Velleman 2010; McCracken and Vowles 2014). Acceptance is, from within the Acceptance and Commitment Therapy (ACT) framework, willingness to pursue valued actions despite fluctuations in pain intensity. Studies have shown the positive influence of adding a values component to pain tolerance (Paez-Blarrina et al. 2008; Branstetter-Rost et al. 2009).

Values can be defined as "chosen concepts linked with patterns of action that provide a sense of meaning and that can coordinate our behaviour over long time frames (Dahl 2015)." Values develop over time and within a socio-cultural context. Values are thought to underpin occupational choices (Abrahams 2008; Persson et al. 2011), while feedback from occupational participation and social interactions shape self-concept (Abraido-Lanza 2004; Diehl and Hay 2010; Poulsen et al. 2011). Although self-concepts are prone to cognitive biases (Hanley et al. 2015), by clarifying values and using values to guide committed action, individuals experience greater tolerance to stressors including pain in both laboratory (Paez-Blarrina et al. 2008) and clinical settings (McCracken and Yang 2006; McCracken and Jones 2012; Gauntlett-Gilbert et al. 2013), even after three years (Vowles et al. 2011).

While making sense of symptoms involves diagnostic clarity, symptom understanding and occupational existing, individuals may need help to develop new ways of meaningfully expressing the values they were able to enact prior to pain onset in order to establish self-coherence. By finding alternative ways to maintain values-based actions despite their persistent pain, they are able to reoccupy a self-concept that can integrate the changes required to accept their capabilities.

10 Clinical Implications

If an important part of learning to live well with chronic pain is associated with making sense of the experience, and finding ways to return to active participation in values-based actions or occupations, then clinical management should address critical components of this process. I believe there are gaps in how therapy addresses issues of symptom understanding, and re-occupying the self-concept.

11 Diagnosis

Diagnosis may be delayed for individuals experiencing persistent pain (Seear 2009; Salvadorini et al. 2012), or a firm diagnosis may never be obtained (Kanaan et al. 2012; Eriksen et al. 2013). Women experience challenges when trying to "behave as a credible patient" (Werner and Malterud 2003). As I have discussed above, obtaining a diagnosis performs a valuable function from the perspective of both the individual living and his or her treatment provider/s. Without a definite diagnosis, individuals may continue to seek help in an attempt to verify the legitimacy of their illness.

Mechanisms underpinning experiences such as nonspecific low-back pain remain poorly understood, leaving individuals given the diagnosis in an awkward situation. Do they believe the messages conveyed in social media and even in health professional's clinics, that back pain arises from mechanical factors (poor lifting or posture)? If their pain fails to settle as expected, what then do they make of their problem?

Perhaps a clearly-defined and accepted diagnosis of "chronic pain" with accompanying public health messages about the problem would support its recognition amongst the general public. To this end, the call for persistent pain to be identified as a disease entity seems reasonable (Siddall and Cousins 2004).

12 Symptom Understanding and Occupational Existing

Recording symptom changes as individuals go about daily activities appears to have lost favour, yet individuals in Thompson's study describe monitoring their pain variations and using this information as they make decisions about day-to-day activities and coping strategy selection (Thompson 2015). This finding is not an isolated one, with Large and Strong (1997) and Strong and Large (1995) finding that maintaining awareness of pain forms part of managing activity levels; Audulv et al. (2012) indicating that integrating illness self-management involves "considering costs and benefits" (p. 338), and (Busch 2005) describing participants "embracing a conscious strategy to monitor prolonged pain as a continuous, manageable threat" (p. 400).

While some clinicians wince when shown a month's of daily pain recordings and potential influencing factors, guidance as to the factors that influence an individual's pain, and the effect that these fluctuations may have on tolerance, concentration and participation in highly valued activities seem to be prized by people living with persistent pain. Developing effective symptom monitoring approaches through technology (such as wearable recording devices or pain applications available for smartphones) may provide such guidance without requiring intensive clinical supervision. Even simple strategies such as monitoring sleep and pain intensity can provide insights useful to the individual (Kothari et al. 2015), who can then make better-informed decisions about managing daily activities.

Symptom variations may or may not be associated with particular tasks and contexts while pain intensity and fatigue have been shown to influence participation (Andrews et al. 2016). It is the loss of participation in meaningful activities that creates distress and treatment seeking (Ferreira et al. 2010). The task of understanding which activities are most affected by pain, and then of experimenting with a return to those activities seems to rest primarily with the individual living with pain. Practical guidance to structure returning to normal activities provides support for those people who tend to catastrophise, and is the specialist practice domain of occupational therapists. It is my contention that by providing support for returning to normal activities, particularly for those people vulnerable to catastrophising, individuals will be able to negotiate a new self-concept that maintains contact with previously valued occupations and roles, thus reducing both disability and distress.

13 Re-Occupying Self-Concept

Notions of integrating the effects of chronic pain with self-concept seldom appear in the chronic pain treatment literature. Processes to help people living with pain grapple with the implications of changes in their abilities have targeted cognitions, emotions and more recently, the relationship to thoughts and emotions (Skinner et al. 2012; McCracken and Vowles 2014). While these treatments contribute to revising the self-concept, directly addressing the lived experience of re-occupying the self-concept has not been a prominent feature in much clinical research.

Self-concept, as I mentioned in the introduction to this chapter, involves individuals making inferences about themselves within their social context, and as a result of reflecting on their typical ways of responding to internal and external demands. Revising what an individual can expect from him or herself when chronic pain becomes part of their lived experience is a process, and occurs over time, as described in the Grounded Theory of Living Well with Chronic Pain.

The feedback individuals who live with chronic pain receive from those around them, including health professionals, is often negative. Such experiences feed into the individual's "feared self" with resultant adverse emotional and behavioural responses described as early as 1979 (Armentrout 1979). Structured experiences in which individuals achieve success while being trained to monitor symptoms in a neutral or nonjudgemental manner provide opportunities for discovering that the "actual self" is closer to the "ideal" than the "feared."

Acceptance and Commitment Therapy (ACT) provides such a framework in which values direct actions, and where experiences are dealt with in a nonjudgemental or mindful way. By engaging in values-based action within daily life, and by recognising that the values underpinning the self-concept can still be achieved, albeit in different ways, those who need to live with persistent pain can indeed re-occupy a revised self-concept. Chronic pain can then have less meaning and less impact on daily life, and life can become more coherent.

14 Conclusion

In this chapter, I have considered the private experience of persistent pain as it is made public by those seeking help. I have shown that the onset of chronic pain represents a disruption to an individual's sense of self-coherence. Individuals try to make sense of their diagnosis, the pattern of their symptoms, and the effect on daily occupations and to integrate the changes wrought by chronic pain on the self concept in order to regain a sense that the world continues to be comprehensible, manageable and meaningful. People who live well with chronic pain successfully achieve these tasks, and are able to flexibly pursue values-based occupation in which their self-concept is expressed.

There is a great deal of research published about those who find it difficult to adjust to chronic pain, rather less is available to demonstrate the ways resilient people have adapted to their pain. The study of people living well with chronic pain is an emerging area of interest, but there is much more research needed, particularly to understand mid-level processes involved in coping well. Processes such as daily decisions about priorities and motivations for using coping strategies in the context of daily life have not yet been examined in detail. Understanding the approaches used by people who remain resilient can shed light on aspects of coping that are not readily apparent when studying those who have more difficulty with their pain.

I have also called for greater attention to what pain means to an individual's self-concept. The effect of persistent pain is to raise the spectre of the "feared self" (Kindermans et al. 2010, 2011). Rehabilitation in chronic pain management has addressed emotional wellbeing, physical capabilities and beliefs about the nature of pain, but has rarely discussed how an individual might reconcile the disparity between the person they are with pain (the "feared self"), and the person they most want to be (the "ideal self"). I argue that guided experiences where individuals can successfully express important values can be a useful approach to reduce this disparity, helping them to move towards occupying a new self-concept that incorporates the effects of pain.

People seeking help for their pain most value being listened to, and having explanations (Hansson et al. 2011; Dow et al. 2012; Sheridan et al. 2015). For clinicians to be able to provide the kind of healthcare that people living with chronic pain most value, clinicians must develop more than diagnostic or technical expertise: *human to human connection* and willingness to be present is needed to make space for exploring the implications of a diagnosis; the effect on valued occupations within daily life, and tracing the patterns and variations of pain and other symptoms over the course and contexts of each day. It is through the seemingly simple acts of listening, explaining and being present that people living with chronic pain can make sense of their experience and begin to feel that life is coherent once again.

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Chapter 20
Seeking Order Amidst the Chaos: The Role of Metaphor Within Pain Reconceptualisation

Mike Stewart

Abstract Communication is a fundamental component of rehabilitation. Without it, it does not matter what we know. The profoundly complex and idiosyncratic nature of pain experiences often requires the use of metaphoric expressions. Metaphors enable us to link the abstract to what is already known. We use metaphors when conveying experiences that are most resistant to expression. Pain is one such experience. In order to make sense of the distress and confusion that pain often brings, many people turn to metaphors. Healthcare professionals (HCPs) use metaphors to transfer abstract scientific knowledge into meaningful cognitions. However, whilst some metaphors are explicit in their execution, many remain characteristically concealed and many HCPs remain unaware of both the power of language and how best to use metaphors within clinical practice. Through exploring the implicit nature of metaphors clinicians, researchers and people in pain may develop strategies to bridge the communication divide and begin to make sense of their experiences.

1 Introduction

Living with pain is a distressing experience. Pain is a simple four-letter word that belies a myriad of subjective human beliefs and emotions. Far from the uncomplicated, cathartic expression of “Ouch!” that is commonly associated with an experience of pain, the distress that frequently accompanies persistent pain is characteristically wrapped within feelings of depression, anxiety, isolation, uncertainty and, chaos (Bullington et al. 2003; Linton 2005). From this chaotic blend of emotions comes a desire to seek meaning (Bullington et al. 2003). Mantel (2013, p. 8) states that, “Pain cannot easily be divided from the emotions surrounding it.

M. Stewart (✉)
Faculty of Health and Social Science, School of Health Sciences, University of Brighton,
49 Darley Road, Eastbourne BN207UR, East Sussex, UK
e-mail: mike@knowpain.co.uk

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Apprehension sharpens it, hopelessness intensifies it, loneliness protracts it by making hours seem like days. The worst pain is unexplained pain."

Gaining a meaningful understanding as to why things continue to hurt provides many people with a route back to a life that was self-determined and fulfilling. Biro (2010) suggests that pain is, "An all consuming interior experience that threatens to destroy everything except itself and can only be described through metaphor." All pain demands an explanation. The challenge facing many clinicians is how best to explain our current scientifically informed understanding of pain in a non-formulaic way that mirrors individual lived experiences.

The word metaphor stems from two Greek words, 'Meta' to transfer and 'Pherin' to carry beyond. In order to transfer the abstract, scientific concepts that form our present-day understanding of pain, researchers and clinicians frequently rely upon metaphors (Gallagher et al. 2013). As practice-based educators, clinicians frequently use metaphors to provide meaning through a variety of practical and cognitive experiential learning methods. The clinical psychologist Fordyce suggests that, "Information is to behaviour change as spaghetti is to a brick." When attempting to make sense of pain, information alone is often not enough. Instead, the shared meanings that are contained within our metaphoric expressions have an ability to facilitate a scientifically informed understanding of pain at a meaningful level. Metaphors have an ability to bring order out of chaos. However, they also have the ability to baffle, magnify worries and obstruct recovery (Stewart 2014).

When attempting to make sense of pain it is worth remembering Rosenbleuth and Weiner's warning, "The price of metaphor is eternal vigilance." Whilst searching for meaningful answers to painful questions, millions of people encounter health information that unwittingly accelerates their journey towards disease, depression and disability (Darlow et al. 2013). Healthcare professionals (HCPs) find themselves in a unique position within the lives of others. The advice and knowledge that they transfer can either enhance people's motivation to change, or can contribute to resistance through darkening an already bleak pain picture. Whilst metaphors can guide people on the road towards a meaningful and helpful reconceptualisation of pain, they can also hinder the journey by reinforcing unhelpful, threatening thoughts that steer vulnerable individuals towards a lifetime of worry (Stewart 2014).

Loftus (2011, p. 217) encapsulates the debate regarding the role that metaphors play within pain reconceptualisation by suggesting, "A powerful and enabling metaphor for one patient might be meaningless or even threatening to another." All pain, and the words we use to describe it, must be viewed within a subjective cognitive framework, which is bound together by our perceptual vulnerabilities. As Eccleston and Crombez (2007, p. 233) have so eloquently stated, "Pain is an ideal habitat for worry to flourish." Without an appreciation of the frequently concealed and implicit influence that metaphors have within healthcare; clinicians, patients and researchers will continue to unknowingly fertilise pain's vulnerable and fertile ground. Following several years of interviewing clinicians, researchers and people in pain; the healthcare journalist Judy Foreman (2014, p. 4) argues that, "There is an appalling mismatch between what people in pain need and what HCPs know." As the global epidemic of persistent pain continues to rise (Foreman 2014), it is time for us all to ensure that we are linguistically equipped to guide people towards a sense of resilience and robustness.

Through a discussion of the influence of metaphor on pain reconceptualisation, and with an emphasis on a variety of clinical applications when using metaphors within clinical practice, this chapter seeks to provide the reader with the following learning aims:

1. To explore current thinking regarding metaphor use within pain science.
2. To consider the varied impacts of clinician and patient generated metaphors within healthcare.
3. To explore the clinical application and potential therapeutic value of metaphors within clinical practice.
4. To develop creative methods for eliciting metaphors from people in pain in order to promote reconceptualisation and behaviour change.

2 Science and Metaphor

Metaphors are generally considered to be the domain of poetic, linguistic expressions. However, it is shortsighted to contain metaphoric thinking to artistic expression alone. When considering metaphor within science, Albert Einstein remarked that, “Combinatory play seems to be the essential feature in productive thought” (Singer 2001, p. 236). Our desire to make sense of the world through metaphor encompasses scientific reasoning. Some of science’s greatest paradigm shifts have stemmed from metaphoric thinking. From Newton’s translation of a simple apple to express planetary gravitation, to Max Plank’s inception of Quantum theory through vibrating cello strings acting like electron orbits, metaphor and science are intrinsically linked. Banville (1998, p. 40) argues, “Of course, art and science are fundamentally different in their methods, and in their ends. The doing of science involves a level of rigor unattainable to art. A scientific hypothesis can be proven—or, perhaps more importantly, disproven—but a poem, a picture, or a piece of music, cannot. Yet in their origins art and science are remarkably similar.” He concludes, “Art and science are alike in their quest to reveal the world.”

In order to promote an understanding of abstract scientific models, scientists use metaphors as well as equations and graphs. Table 1 illustrates a range of metaphoric expressions that exist within scientific thinking related to the human body.

The process of metaphoric transfer extends to the science of rehabilitation and pain. Melzack and Wall’s (1965) Gate Control Theory of Pain provides an excellent example of how a metaphoric expression can help explain an otherwise impermeable and abstract model for much of the population. Rathmell (2006, p. 1914) describes Melzack and Wall’s (1965) paper as, “the most influential ever written in the field of pain.” With this in mind, we can see how Melzack and Wall’s (1965) pain gate theory has transfused common consciousness regarding pain neurobiology. In a comprehensive, longitudinal analysis of pain gate theory’s adaptations

Table 1 Commonly used scientific metaphors

Scientific concept (body part)	Metaphor
Heart	Pump
Cell membrane	Wall
Brain	Computer
Eye	Camera
Immune system	Defence force
DNA	Blueprint code
Blood vessels	Highways
Nerves	Wires
Sound/light	Waves
Pelvic musculature	Floor

within educational texts, Semino (2011) found that, despite an updated understanding through Melzack's redefined 'neuromatrix' and 'neurosignature' metaphors, many educational texts continue to use pain gate theory (Melzack 1999, 2005).

This poses a widely held and well-documented dilemma regarding the application of metaphor within science and healthcare. Although strong advocates of metaphoric expression, Lakoff and Johnson (1980) warn that metaphors may obscure other lines of inquiry. Taylor (1984, p. 11) argues metaphors can be "seductively reductionistic," whilst Paivio and Walsh (1993, p. 307) see them as a "solar eclipse (which) hides the object of study, and at the same time, reveals some of the most salient and interesting characteristics, when viewed through the right telescope."

3 Clinician-Generated Metaphors

Loftus (2011, p. 213) argues that, "Most health professionals are largely unaware of the power of language to shape the ways in which they think about and understand their work." However, at present, metaphors appear to be in vogue across a multitude of health communication areas from cancer (Laranjeira 2013) to mental health (Turner 2014). This trend is also notable within pain neuroscience education and, as with any healthcare intervention, it is essential that metaphors be not regarded as the latest panacea. Instead, they need to be viewed within context and with a balanced awareness of their influences. We must endeavour to make best use of our current linguistic awakening in order to foster opportunities for behavioural change. However, we must also be mindful of the potential pitfalls and well-documented concerns related to the use of metaphors when helping others make sense of pain (Loftus 2011; Stewart 2014).

Although useful, some metaphors can obstruct the evolution of our comprehension by their literal permeations into common language. Sontag (1978) rejects the assumption that metaphors suit explanations of illness, and argues that they can misdirect our understanding. Critics feel Sontag's work is implausible and cannot apply to all human experiences as it reflects personal assumptions (Clow 2001). However, many theorists have argued that metaphors oversimplify human suffering and insinuate false ideas. This is evident throughout the literature with formulaic, clinician led pain explanations ranging from burglar alarms, to thermostats and computers (Butler and Moseley 2003; Moseley 2007; Semino 2011; Wilgen and Keizer 2012).

Whilst these comparisons might enable some people to successfully reframe their pain, they might further reinforce a biomedical regression for others by augmenting a body-mind partition. Hartley (2012) argues that whilst the information-processing model contained within the "brain as a computer" metaphor can help some people understand the complexities of neurobiology; it misjudges the idiosyncratic, adaptive properties of an individual's nervous system. For some, a cognitive shift towards "sensitive wiring" rather than damage or harm, may prove helpful. For others, such expressions may embed the unhelpful, unrealistic expectation that a simple "off switch" can be found with a resulting instant resolution of pain.

By incorporating a philosophical perspective into the biopsychosocial framework, we can begin to appreciate the categorical inaccuracy of the "brain as a computer" metaphor (Bennett and Hacker 2003; Thacker and Moseley 2012). The brain alone cannot provide a single source of meaning for the vast complexities that clinicians face when attempting to reconceptualise pain; but when faced with such entangled obstacles, it is easy to see how we might lose sight of the bigger picture. Metaphors provide a frame through which we paint unique cognitive landscapes. As clinicians, we must remain mindful of our eagerness to impose our brush strokes onto the canvases of others.

Table 1 highlights several examples where metaphors that are used to describe biological concepts create issues of reductionism and false assumptions. Edelson (1984) considers how William Harvey's seventeenth century metaphor of the 'heart as a pump' has permeated our understanding to such an extent that it has become somewhat literal. With a simplified, mechanistic view of the world, it is easy to see how an engineer's linear experience of dealing with pumps within day-to-day working life can lead to a simplified, mechanistic solution for a very complex human problem such as heart disease.

Equally, the permeation of the "floor" metaphor into our consciousness regarding the structure of pelvic musculature can lead to a misinformed and unnecessarily worrying view of its function. As HCPs, we understand the term pelvic "floor" as the muscular base of the abdomen, which attaches to the bony pelvis and can, like any other muscle, respond to exercise. However, when a desire to seek meaning is combined with limited understanding and compounded further by misguided thoughts and beliefs, we can understand how some people's perception of the pelvic "floor" can be worryingly misinterpreted.

Case study 1 highlights the cognitive flaw contained within the pelvic "floor" metaphor and how, by further exploring the language used, we may begin to better understand any perceptual gaps and move towards a more realistic and hopeful cognitive reconstruction.

Case Study 1: The Broken Floor

Patient:

"I'm really not sure why I'm here. I don't think physiotherapy can help me."

Physiotherapist:

"Can you please explain why you feel physiotherapy can't help?"

Patient:

"I've been told that my pelvic floor is broken." I must see a surgeon. I need an operation."

Physiotherapist:

"I see. I'd like to show you how physiotherapy and exercise can help. Do you mind if we try something?"

Patient:

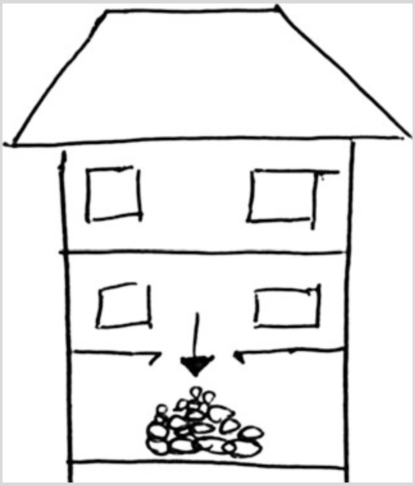
"Yes. Ok."

Physiotherapist:

"Would you mind using this pen and paper to draw what you think is happening?"

Patient:

"Yes. Here you go…"



Patient:

“Can you see? My pelvic floor is broken like the floor in this building. Exercise cannot help this problem. Surely I need reconstructive surgery to fix the floor?”

Physiotherapist:

“I can see what you mean, but exercise can help you. Although we call it a pelvic floor, the pelvic muscles don’t actually look or work like a floor within a building. Instead, we need to think about them like any other muscle in our body.”

Patient:

“Like the muscles in my arm?”

Physiotherapist:

“Yes that’s right. The muscles in your pelvis can become stronger and work better through exercise, just like the muscles in your arm.”

Rathmell (2006) suggests that metaphors are designed to be overused in order to create meaning. Collectively, we will of course continue to use the term “floor” to describe the pelvic musculature just as we will continue to use the term “pump” to express how the heart functions. However, both of these examples highlight the implicit impact that these seemingly enabling metaphors can have on an individual’s experience of pain and illness.

4 The Battlefield

Healthcare is often regarded as a battlefield. Historically, germ theory ushered in invasive and mechanistic metaphors to describe pain and disease within Western civilisation. Bourke (2014) suggests that since the word “painkiller” was first used in 1845, pain has been viewed in the West as an enemy that must be relentlessly fought and defeated. Wiggins (2012) calls for an end to military metaphors to describe disease. He argues that battle metaphors give the impression that the ‘war’ can be won with biomedical, interventional escalation. The permeation of military metaphors into the language of healthcare provides some context for how pain is viewed within the Western world. Neilson (2015, p. 8) suggests that negative expressions of military metaphors are used to the detriment of people in pain and HCPs—“Pain is also the context in which we feel pain, and that context need not be a clinicoapocalyptical one of damage, weaponry or live wires.”

Many people who live with pain fall into a cycle of short-term solutions, which often lead to an ongoing escalation in the arsenal of modern day healthcare. The language of healthcare and physical rehabilitation speaks of analgesic ladders, bed blockers and failed back surgery syndrome. People in pain frequently experience a build-up of passive healthcare interventions that often leads to false hope, amplified worries and entrenched beliefs (Eccleston and Crombez 2007). People climb the analgesic ladder from paracetamol towards opioids. Unavailing attempts at physical rehabilitation (the ground troops) frequently lead onto steroid injections (the tank division) and invasive epidurals (the fighter jets) before finally, the patient is facing the nuclear warhead option in the form of surgical intervention (see Fig. 1). Unfortunately, this war is not often won through modern, interventional medicine.

This broad, militarized metaphor lies at the heart of many healthcare models and drives passive dependency and an overreliance on interventional medicalized escalation (Wiggins 2012). Reisfield and Wilson (2004) believe that military metaphors lead us to assume that failure lies with the patient, and not the treatment. We see evidence of this within the medical term, "Failed back surgery syndrome." (Hussain and Erdek 2014). Equally, military metaphors might lead some clinicians to perceive themselves as incompetent soldiers when faced with repeated short-term solutions that fail to resolve persistent and chaotic problems. Practitioners and sufferers who go in pursuit of a specific diagnosis (the perceived enemy) often feel disappointed when tackling the multifaceted complexities of persistent pain.

When we consider the implicit and uncertain nature of pain related metaphors, we cannot fail to mention the influence of the media. In their search for meaning, people in pain readily discover health related articles that contain a plethora of misguided words and phrases alongside headlines that further reinforce the battlefield metaphor and oversimplify a complex and multidimensional problem. Words such as "tackle," "beat" and "jab" leap out from many headlines and suggest a swift, ruthless end to pain. The "fight" against cancer mirrors this predicament.

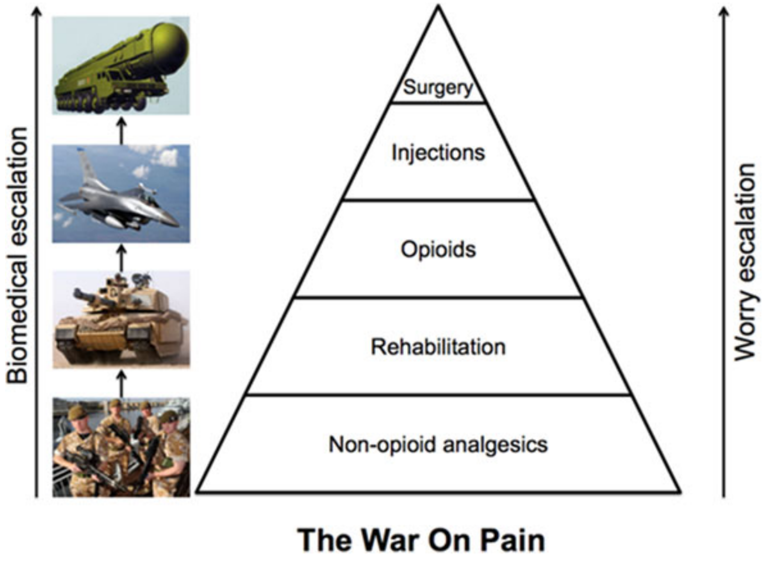


Fig. 1 The escalating battlefield of pain management

Sontag (1978) spoke on behalf of many people with cancer when she argued that living with cancer is a process, rather than a fight. Equally, a reframing of pain away from our cultural tendency towards fighting battles can lead us towards more optimistic approaches to pain management and the discovery of more self-determined solutions.

5 The Road Ahead

Unlike military metaphors, journey metaphors shift the focus away from a win, lose or fail notion. Journeys provide opportunities for optimistic explorations, whilst also acting as a realistic reminder of persistent pain's long and winding road. Reisfield and Wilson (2004, p. 4027) suggest journey metaphors advance reconceptualisation by offering "different roads to travel, various avenues to explore, and, always, there are exits to take." For example, "a light at the end of the tunnel" provides an optimistic cognitive reconstruction for a brighter future.

However, whilst they facilitate personal growth, Southall (2012) feels journeys often involve arduous battles along the way. This highlights an interpretative overlap between journey and military metaphors. Journey metaphors enable inventive opportunities for pain reconceptualisation, but remain susceptible to misinterpretation (Sontag 1978). Whilst one person's "bright light future" might be tinged with the realism of ongoing setbacks, others will perceive a permanent resolution. This unrealistic outlook is likely to heighten negative emotions should patients experience repeated poor outcomes.

There are many examples throughout practice where HCPs use journey metaphors to educate patients, establish agendas for rehabilitation and seek to foster behavioural change. Stones and Cole (2014) examined the use of online persistent pain diagrams. They found that, although many models made use of journey metaphors through cycles and flow diagrams (see Fig. 2), most focused on the need for cognitive change without displaying motivational guidance towards behavioural change. Forty-five of the fifty online educational diagrams examined by Stones and Cole (2014) depicted negative, vicious cycles that stopped short of displaying further, optimistic routes to recovery.

Throughout health communication, the vicious circle is repeatedly used to express the downward spiral of interrelated events that lead to disease, disability and depression. Van Damme et al. (2006) argue that this difficult to break, cause and effect cycle can further perpetuate a decline into psychological distress and physical disability. Although we can use the journey metaphor contained within the persistent pain cycle to highlight the commonly seen cascade towards illness, we must move beyond this perpetual loop and begin to signpost people towards educational discoveries that empower them to break free from this vicious cycle of events.

With this in mind, Stones and Cole (2014) produced an extension of the pain journey metaphor as shown in Fig. 3. By recognising the importance of reflection

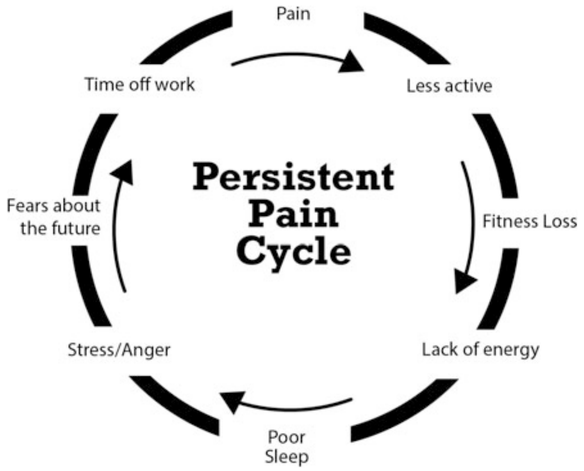


Fig. 2 The persistent pain cycle. Printed with permission from Stones and Cole (2014)

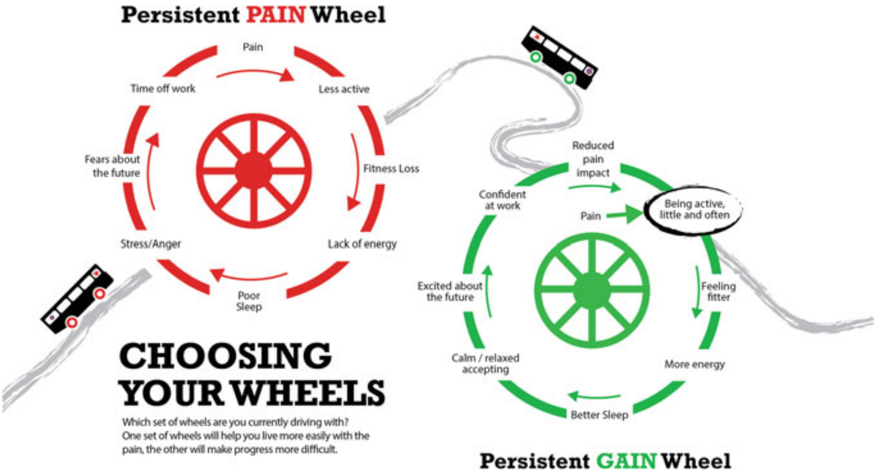


Fig. 3 Choosing your wheels. Printed with permission from Stones and Cole (2014)

and choice within a biopsychosocial approach to pain management, this hopeful diagram shifts the focus from a vicious to a virtuous cycle. Furthermore, by incorporating a widely used journey metaphor (the bus journey) within the model, the authors aim to facilitate change through an established metaphor used within acceptance and commitment therapy (ACT).

ACT uses a variety of journey metaphors to promote behavioural change. Professor Steven Hayes developed the bus journey metaphor as a central part of a 16-page educational booklet. This educational resource uses a bus journey to express the control and self-resilience that is often lost when persistent pain takes hold of the steering wheel. The bus represents the person's life containing their family and friends. The intruding driver represents the unwanted and controlling pain experience. This engaging metaphor provides a cognitive and linguistic safe-bridge for discussing acceptance of biopsychosocial factors that sit outside of an individual's personal control. How will you take back control? Where is your destination? What will you do when you encounter obstacles along your journey? Through reflective questioning and guided discovery, the bus metaphor encourages problem-based learning and facilitates dialogue regarding self-determined resilience and control (Hayes et al. 2004).

Solberg et al. (2012) used a solution-focused approach to improve self-management skills through the use of a journey metaphor. They discovered enhanced understanding of self-management approaches of chronic diseases when using the metaphor 'Captain of the ship'. The authors provided the participants with illustrations of a ship whereby they (the Captain) had to take responsibility for the voyage. They were asked to consider helpful strategies when 'hitting the reef' in order for them to arrive safely at the first harbour.

The author C.S. Lewis suggests, "A smooth sea never makes a skillful sailor." One participant in Solberg et al.'s (2012, p. 400) study reiterated this helpful metaphoric reminder of our need to confront challenges when faced with the self-management of any long-term condition: "Hitting a reef makes you prepared for facing some difficulties, and that makes them easier to overcome." However, whilst one participant found illustrations of the ship "hitting a reef" helpful when making sense of setbacks, others found the images infantile. Again, this highlights the impact that personal appraisals have on the therapeutic process. Behavioural analysis is needed alongside metaphor delivery if a complete, contextual picture is to emerge (Shinebourne and Smith 2010).

Figures 4 and 5 show a nautical journey metaphor used within practice to promote discussions regarding the loss of confidence and reduction of activity levels that people experience through fear avoidant behaviours related to pain. Once again, these images aim to help people in pain reflect on the need for a meaningful and enjoyable return to activities through a confident and graded exposure to movement. Just as the boat is designed for movement and adventure, so too is the human body. Boats that remain in port gather barnacles and become more difficult to function. By exploring the journey beyond the harbour walls, people in pain are encouraged, with adequate support, to consider both the importance of getting going and the finer details of the rehabilitation voyage ahead. How far do you want to go on your first trip? What will you do if you start to struggle? What happens when you have reached your destination? The extent to which an individual wishes to expose themselves to both physical and psychological challenges can be safely explored through these metaphoric images.

Boats are most safe when they are in port….

Fig. 4 A nautical journey metaphor

But that's not what they are designed for

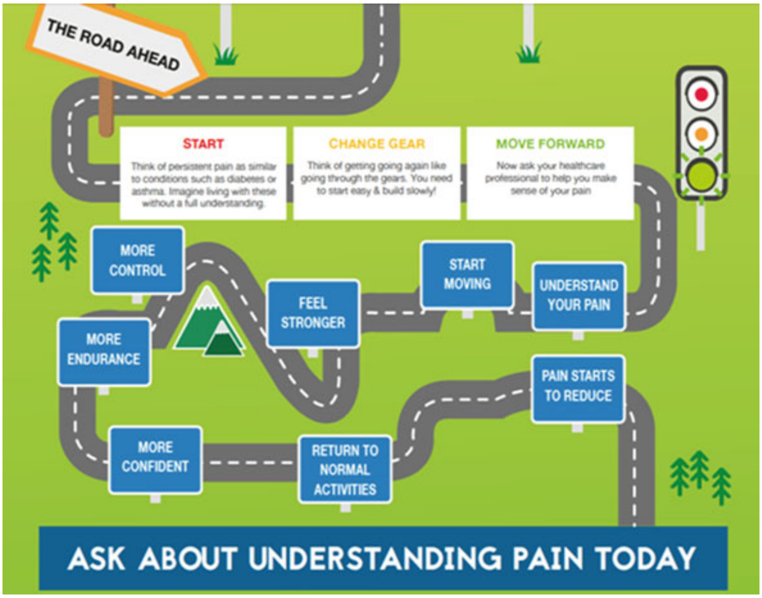
Fig. 5 A nautical journey metaphor

As clinicians, images such as these provide an opportunity to better understand where a person perceives their confident starting point to be along their journey from chaos to ordered control and resilience. Additionally, the metaphoric context of these images can be applied to the formidable reality facing both people in pain and HCPs when attempting to make sense of pain. The testing nature of a sea voyage mirrors the dynamic relationship that exists between the amount of challenge that is required within practice to bring about change, and the extent of facilitatory support necessary to achieve this.

Daloz (1999) argues that as people grapple with the difficult and threatening process of learning, it is essential for educators to understand the constantly shifting relationship between challenge and support. Whereas too much challenge and too little support will likely lead to disempowerment and negative associations (sinking of the ship, retreating back to the safety of the harbour), adequate support and sufficient challenge will guide empowerment and confidence to sail into the unknown.

With an appreciation of the need to move beyond current cyclical healthcare models, the following patient education poster (Figs. 6 and 7) aims to represent the desire for people to search for a meaning for their pain. By using a road network, we may begin to facilitate both a cognitive and behavioural shift that seeks to explore new pain management pathways beyond the frustration and despair that many people encounter on the persisting, interventional healthcare loop (Eccleston and Crombez 2007). This loop is shown as a roundabout within the metaphoric

Fig. 6 Taking back control: know pain patient education poster



Think of persistent pain as similar to conditions such as diabetes or asthma. Imagine living with these without a full understanding.

Think of getting going again like going through the gears. You need to start easy & build slowly!

Now ask your healthcare professional to help you make sense of your pain

Fig. 7 Taking back control: know pain patient education poster

context of people's pain journey (Fig. 6), with different, untried exits to explore leading to a hopeful, yet challenging road ahead (Fig. 7).

Amidst the cluttered complexities that pain experiences bring, we must all remember to pause and reflect on just how challenging the process of rehabilitation can be. Visual journey metaphors such as those shown above highlight a multitude of chaotic influences that impact on the journey towards recovery. Such images not only provide guidance for HCPs and people in pain, they can also act as a means of collaborative, problem-based learning when attempting to discover obstacles (bumps in the road, mountains to climb) along the recovery journey whilst revealing new, unexplored pathways.

Hayes et al. (2004) suggest that a key component of psychological flexibility is the ability to gain perspective and view pain within the larger context of its multifaceted and challenging journey. With this in mind, ACT uses the "Welcome to Holland" metaphor in order to foster reflective discussion towards acceptance and behaviour change. Case study 2 shows the clinical application of this metaphor.

Case Study 2: Welcome to Holland

Clinician:

"I want you all to imagine that later on today we are all going to board a plane and enjoy a two week holiday in the Caribbean. Think about how this might make you feel. What things will you need to pack for your journey?"

Patient 1:

“Great! I’ll need my sun-cream, shorts and sunglasses.”

Patient 2:

“I will need my sandals and a sun hat.”

Clinician:

“Ok. So you’ve got everything you need for the Caribbean. You board the plane, have something to eat and fall asleep. When you wake up you find that the plane has landed and the Captain announces, “Welcome to Amsterdam! The current temperature is 5 degrees Celsius with a chance of heavy rain. Have a pleasant stay.” What would you do next?”

Patient 1:

“I would not be happy! Why am I not in the Caribbean? I would head straight to the airline’s manager and demand to be put on the next flight.”

Clinician:

“What if the next flight leaving Amsterdam is five days away? Sometimes living with pain can be like this. Have you ever found yourself stuck in a situation where you don’t want to be?”

Patient 1:

“Yes all the time, but my experience of living with pain is not like suddenly finding myself in Amsterdam. My pain is a chaotic and war-torn place.”

Patient 2:

“Yes I agree. However, people continue to live in war zones. They find ways to adapt, as we must whilst working out how to overcome our pain. I would buy a coat, find a hotel and visit the tourist information desk.”

Case study 2 highlights how HCPs can use stories and journey metaphors to facilitate discussion and promote peer-assisted learning. Ashwin (2002) suggests that by providing opportunities for learners to support each other within educational settings, clinicians can encourage communication skills and critical thinking. These nurturant effects help steer people towards self-directed learning discoveries and self-management strategies. Harden and Crosby (2000) argue that, “The move to a more student-centred view of learning has required a fundamental shift in the role of the teacher. No longer is the teacher seen predominantly as a dispenser of information or walking tape recorder but rather as a facilitator or manager of the students’ learning…The more responsibility given to the student, the greater the shift in the teacher role.”

6 Dialogical Metaphors

As practice-based educators, clinicians aim to guide people through an awareness of facilitational and coaching skills. This is an important factor when using metaphors to help others make sense of pain. Loftus (2011, p. 229) calls for a dialogical approach to metaphoric expression within pain management. He argues that a monological, didactic approach, “restricts perspective and narrows our vision.” Instead, conceptual thinking is needed for effective biopsychosocial management (Warmington 2012). Tompkins and Lawley (2002) feel a more tailored, collaborative approach is needed when using metaphors within healthcare. They suggest that training is needed to help clinicians identify patients’ own use of metaphors. Autogenic (patient-generated) metaphors have also been suggested by Hejmadi and Lyall (1991). Unfortunately, whilst these suggestions might facilitate patients towards a worthwhile pain reconceptualisation, they remain as speculative opinions and more research is needed.

Dewey (1933) argues that, “Education is not an affair of telling and being told, but an active and constructive process.” By casting people in pain as passive recipients of information, HCPs risk disengaging patient learning opportunities and closing windows on self-determined behavioural change. The philosopher Socrates reminds us of our facilitatory responsibilities as practice-based educators by suggesting that, “To find yourself, you must think for yourself.” Continual, guided discovery through Socratic exploration of the patient’s understanding of pain is an indispensable component of therapeutic pain reconceptualisation through metaphor.

Colameco (2012) suggests that by resisting the urge to give advice, we can guide people towards their own conclusions through Socratic, guided questioning. To achieve this when using metaphors to explain pain, we must see patients as learners and help them to question their own experiences. This requires an ability to remain non-judgmental, to resist giving advice and to remain somewhat naïve (Hinchliff 2004). Colameco (2012) considers the following three types of Socratic enquiry:

3 types of Socratic Question:

1. **Information seeking questions**: What happened?
2. **Analysis questions**: Why do you think this happened?
3. **Synthesis questions**: Based on our discussion how do you see this now?

With these questions in mind, we will now explore the clinical application of a two-way, dialogical metaphor within practice-based pain education.

7 The Chinese Finger Trap

Historically, pain was seen as an experience which should be passively endured with terms such as, “A touch of lumbago” leading to a swift, uncomplicated continuation of activities and recovery. Bourke (2014) argues that advancements in

Fig. 8 The Chinese finger trap

Western medicine have also brought an expectation of a complete pain resolution for many. This eradication of pain is sought through technology and an ongoing struggle to seek the ‘magic bullet’ treatment option. In their qualitative study to explore how individuals with fibromyalgia make sense of their illness experience, McMahon et al. (2012, p. 1358) found that metaphors were used to express feelings of being trapped inside their body and trapped within a perpetual healthcare loop with participants, “engaged in an enduring struggle against the challenges of fibromyalgia.”

HCPs encounter a dilemma when meeting people in pain who seek a continuation of their struggle to find a simple, instant solution to their complex pain experience. In order to highlight the shortcomings of this ongoing struggle for recovery, clinicians frequently engage in unidirectional advice giving that relies upon traditional, didactic teaching methods of educational delivery (Quintero 2014). This somewhat blunt, one-way approach to behavioural change often leads to retreat and disengagement from the learning process (Daloz 1999).

Instead, we should seek to engage people in experiential learning methods which aim to foster dialogue and self-discovery. When attempting to facilitate behavioural change, we must consider Albert Einstein’s reminder that, “Learning is experience. Everything else is just information.” Case study 3 shows how the Chinese Finger Trap experiment is used within practice as an engaging, conversational metaphor for behavioural change and psychological flexibility (Fig. 8).

Case Study 3: The Chinese Finger Trap Experiment

Patient:

“I can’t understand why my pain has not gone away. I am doing all I can. I have tried all of the treatments and medications that I can find. Some of them help for a few weeks but then the pain returns. I am determined to get rid of my pain and will continue to fight it.”

Clinician:

"Living with pain can be hard and can seem unfair at times. It sounds like you're trying your best, but don't feel like you're getting very far. Do you mind if we try something to help you make sense of this frustrating situation?"

Patient:

"I'm at the end of my tether and willing to try anything."

Clinician:

(Hands Chinese finger trap to patient)

"Please place both of your index fingers into either end of this tube. Insert them far enough inside so that you become quite stuck. Then, without touching the tube with any of your other fingers or thumbs, try to remove your index fingers from the tube."

Patient:

(Trying to escape the trap)
"It's impossible! The more I pull my fingers apart, the more the tube tightens and the more I become stuck!"

Clinician:

"Yes. So what have you learnt? How are you going to find your way out of this situation?"

Patient:

"I see now. If I relax, twist and move my fingers towards each other, then I can gradually make my way out."

Clinician:

"Yes that's it. Now you've got it. What do you think this means for your experience of living with pain?"

Patient:

"I suppose the harder I struggle, the more I feel frustrated, tense and trapped. Maybe I need to be more flexible and explore other ways to feel better?"

The Chinese finger trap experiment shows how a clinician can use metaphors to create a sense of order from the fluctuating myriad of chaotic and confusing pain experiences. Rather than embarking on an educational pathway where the healthcare professional passively leads the patient down a purely information based journey, the Chinese finger trap provides an active narrative space for discussion regarding psychological flexibility, behavioural change and acceptance. Through this engaging, experiential learning method, we can begin to stick Fordyce's cognitive spaghetti to the behavioural brick.

Through a combination of verbal and physical metaphors, we can begin to influence meaningful pain reconceptualisation via a shared participation that links metaphoric expressions to lived experiences. The author E.M. Forster argues that, "Spoon feeding in the long run teaches us nothing but the shape of the spoon." With an appreciation of Socratic questioning and an ability to guide rather than tell, HCPs and people in pain can make use of a variety of multimodal and engaging metaphors, stories and parables in order to promote self-efficacy.

When considering a range of metaphor do's and don'ts, Nguyen and Umemoto (2012) suggest that metaphors should be left unfinished. By taking metaphors far enough to engage discussion, but not so far that they might negate an active contribution from people in pain, we can begin to explore a more collaborative means of pain reconceptualisation.

8 Patient-Generated Metaphors

Although they remain frequently implicit, metaphors influence how we facilitate others and how others attempt to reach out to make sense of their experiences. We turn to metaphors when conveying experiences that are most resistant to expression (Geary 2011). Pain is one such experience. Metaphors can provide a bridge between subjective experience and clinical descriptions (Loftus 2011). With this in mind, we must appreciate the extent to which people in pain use metaphors to express their experiences. We must also develop communication skills that create a path towards therapeutic gains. For those who find their experience of pain difficult to communicate, it is important to consider how we might elicit their own patient-generated metaphors so as to develop a shared understanding and foster empathetic connections.

In their qualitative study entitled, "I feel so stupid because I can't give a proper answer…" Clarke et al. (2012, p. 4) found that older adults who live with pain used metaphors and similes to convey their distress. When asked to explain a feeling of embarrassment when being unable to explain his pain to HCPs, one participant stated, "I don't have the vocabulary and I haven't got the medical vocabulary. I don't have the jargon to explain what I'm feeling." However, when given enough space and time during the interview, the same participant drew upon his experience of working within the dairy industry to metaphorically describe his experience of pain as a "sort of bubbling" sound like you might hear within a refrigeration pipe. By recognising the importance of linking lived experiences to bodily sensations, and by using a narrative approach to clinical encounters, metaphors enable us to link the abstract to what is already known.

Shinebourne and Smith (2010) argue that patient-generated metaphors act as a linguistic "safe bridge" through which people can express emotions that are too distressing to communicate literally. With a limited ability to detect when people are attempting to cross this bridge through metaphoric expression, HCPs risk squandering opportunities for a meaningful reconceptualization of pain and ultimately, a safe and confident return to physical activities. As clinicians, we must strive to identify our patients' own metaphors in order to explore meaning, and to foster empathetic and therapeutic connections. Gray et al. (2005) argue that for health psychology to remain relevant to the lives of people in pain, clinicians must seek a narrative approach that focuses on preserving the context in which stories and metaphors are told.

However, whilst patient-generated metaphors permit access to personal narratives, it is essential that we remain aware of their intrinsic ability to obstruct and regress the therapeutic process (Haigh and Hardy 2011). Continual, Socratic exploration of the patient's understanding of pain is an indispensable component of pain reconceptualisation when using metaphor.

In their recent qualitative study exploring patient perceptions about pain, Darlow et al. (2015) found a variety of negative assumptions existed amongst those with low back pain (LBP). Participants expressed feelings of vulnerability, protection and uncertainty. The authors concluded that clinicians need to approach consultations with an appreciation of these beliefs as people with LBP display an attentional bias towards threat information that supports their perceptions of danger. With a meaningful reconceptualisation of pain as a threat output (Moseley 2003), clinicians can begin to acknowledge the implicit threat contained within their words and metaphoric constructions.

Throughout their study, Darlow et al. (2015) use direct quotes from people living with LBP. Whilst these comments highlight a range of anxious and worrying beliefs, the words used by the participants to express their pain experience also unveil the frequent use of patient-generated metaphors within healthcare consultations. Table 2 highlights these comments and proposes the variety of expressive safe-bridges that might be in use.

Within psychotherapy, the use of patient-generated metaphors is widely recognised as an effective method for eliciting change through the exploration of narrative (Kopp 1995; Tompkins and Lawley 2002). With an increased therapeutic detection of these subtle linguistic nuances, HCPs may begin to make sense of the lived experiences of people in pain. Furthermore, they may utilise people's metaphoric safe-bridges so as to foster empathy and self-efficacy.

For example, people who express feelings of loss of control as those shown in Table 2 can, with skilled guidance, consider a range of strategies to help regain control. This involves further exploration of their chosen metaphor with therapeutic facilitation (Kopp 1995; Tompkins and Lawley 2002; Southall 2012). What strategies might they use to turn the amplification down? Which methods might they consider when next frozen in one place?

Case study 4 provides a practical example of how HCPs can make use of patient-generated metaphors:

Table 2 Patient-generated metaphors and their safe-bridges from Stewart (2015)

Patient-generated metaphor	Expressive safe-bridge
It feels like it's crumbling. Like my back is crumbling and it can't support me	Body as a broken machine Life is falling apart Seeking support beyond biomechanical development
I have to think about how I get down, use my legs as opposed to my back as a winch, or else I will do myself an injury	Body as an adaptable machine
The spinal part of my back, it can go as quick as sneezing	Body as a broken machine "Gone" and "Went" as an expression of loss beyond biomechanical failure (Stewart 2014)
I guess just the worrying about it just kind of amplifies that a little bit	Desire to regain control through change in the 'volume' of experience
I've finally come to a place where I can manage it, I feel rather good about that	Pain experience as a learning journey Optimistic cognitive reconstruction (Reisfield and Wilson 2004)
I couldn't sit, I couldn't stand, I couldn't bend, I was frozen in one place	Loss of control Stalled journey metaphor Strategies to 'unfreeze' required
It's almost like it's whipping me, saying 'no, lie down'	The language of agency (Biro 2010) An external, insidious force inflicting harm
It was so sensitive that if I misbehave with my back…then, again my back will go rebellious	Loss of control and resilience Battlefield metaphor with the spine as an attacking, external entity (Bourke 2014)

Adapted with permission from Darlow et al. (2015)

Case Study 4: Making use of Patient-Generated Metaphors

Patient:

"It's so frustrating. I just feel like I'm going round in circles without any answers."

Clinician:

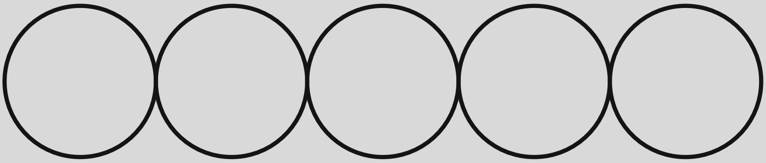
"Living with pain can be very frustrating. I'm interested in something you've just said. Do you mind if we try something?"

Patient:

"Yes ok."

Clinician:

"You just said that you feel like you're going round in circles. If I were to draw what that looks like would it look like this?



Patient:

“Yes. I suppose so. I feel as if I am trapped in an endless loop.”

Clinician:

“If a friend of yours said that they were going round in circles, what would your advice be? What things might you suggest that they could do to change the situation?”

Patient:

“I would advise them to pause and think about how they might free themself from the cycle. Maybe they could create an opening and find another way out. They could also reverse the cycle or find a lever that might slow it down and eventually stop the spinning. You know, like slowing down a Waltzer ride at the fairground?”

Clinician:

“That sounds like a good plan. Without a good understanding, pain can be confusing and chaotic like a Waltzer ride. Shall we explore some ways to help you take back control?”

Patient:

“Yes. That sounds like a great idea!”

The educator Daloz (1999) suggests that, “Like guides, we walk at times ahead of our students, at times beside them, and at times we follow their lead. In sensing where to walk lies our art.” Case study 4 highlights the need for such flexible facilitation and coaching skills within practice. A more traditional, didactic approach to patient education might have acknowledged the patient’s use of metaphor whilst employing a telling, rather than a guiding approach to reconceptualisation (“You certainly sound like you’re going round in circles. Let me tell you what to do…”). However, by using a collaborative approach and a conversational style, we can begin to make better use of such patient-generated metaphors and reflect upon a creative range of behavioural change strategies.

Furthermore, case study 4 highlights several key considerations when using metaphors to facilitate meaning. Firstly, rather than imposing our own schematic interpretations on other people’s lived experiences, we must seek an invitation prior to attempting any new and unexpected practice methods. By asking, "Do you mind if we try something?" HCPs aim to explore interest and curiosity, within the patient's control. In addition, Kopp (1995) argues that, when utilising such two-way dialogical metaphors for therapeutic gain, clinicians should frame the discussion within a third-person context. By suggesting, "What advice would you give to someone else in this situation?," we can begin to help others step outside the confines of their personal experience and facilitate change through a more comfortable and more empathetic advisory scope.

The importance of imagery and drawings when using metaphors to help people make sense of pain is also evident within case study 4. Scarry (1985, p. 32) suggests, "Whatever pain achieves, it achieves in part through its unsharability, and it ensures this unsharability through its resistance to language. To have great pain is to have certainty; to hear that another person has pain is to have doubt." No matter which sense we use, most attempts to express our perceptual experiences fall short of the mark through words alone. Think about how we might express our love for another person or how we might attempt to describe our experience when drinking wine. How does one describe what scrambled eggs tastes like, or smoke smells like, without comparing them to something else?

Metaphors, particularly visual representations of metaphoric expressions, permit a means of shared communication that move beyond words. Images extend the boundaries of our linguistic restraints in order to grant interpersonal access to inner feelings and beliefs. They also enable a sense of connection from within an otherwise isolating and chaotic internal pain experience. Words are limiting, but art elicits an emotional response (Kenny 2004).

In their study to discover if photographic images of pain can improve communication in pain consultations, Padfield et al. (2010, p. 144) argue that, "Verbal metaphors remain formulaic, offering the individual little opportunity to express how they feel, or to contextualise the symptoms within a personal narrative. Furthermore, a well-documented stasis exists in many pain consultations as a result of physicians and patients searching for different meanings."

In an attempt to bridge this chasm, the authors used a booklet of 64 photographic images, which had been collaboratively produced with patients to visually express their pain. These images were left in clinic waiting rooms and the participants were asked to choose any image that they felt represented their experience of pain. The purpose was to foster discussion with HCPs during the clinical encounter. Following the completion of a questionnaire the results showed that 86% of the participants related at least one image to their pain. 67% felt the images had facilitated dialogue, whilst 82% of the HCPs reported improved communication. Padfield et al. (2010, p. 149) conclude that these metaphoric images offer, "a narrative space for people to step into, the possibility of some kind of identification and empathy with the other…some kind of slippery surface for further narrative."

Finally, the dialogue shown within case study 4 also highlights how, by actively listening through a narrative approach and by pausing to further explore a particular patient-generated metaphor (going round in circles), HCPs can develop innovative methods to elicit verbal accounts of lived experiences (like living on a Waltzer ride). By utilising the power of linguistic ownership that the patient now has, we

Remember... Living with persistent pain can be like a rollercoaster ride. Good, long-term planning will make it less bumpy!

Less like this... & more like this!

Fig. 9 Excerpt from Know Pain Patient Education Booklet

can begin to extend their metaphoric thought into constructive action as Fig. 9 from a patient education booklet shows.

9 Eliciting Patient-Generated Metaphors

As previously discussed, pain is an isolating and frustrating internal experience that is resistant to expression. In their qualitative study, Dow et al. (2012, p. 143) discovered ongoing frustration in the narratives of people living with pain. They suggest that communication and therapeutic bonds may improve if, "the frustration of living with an invisible, debilitating condition that is hard to diagnose and treat is explicitly acknowledged by the health professional." Such essential displays of acknowledgement can be achieved through metaphoric expression (Kopp 1995; Loftus 2011). However, whereas some people in pain will create their own metaphoric terms to express their experience, others require further guidance from supportive clinicians. This highlights a need for HCPs to develop facilitation skills.

For those people who find it challenging or impossible to generate their own metaphoric outlets for expression, we must consider creative ways in which we might elicit inner feelings and beliefs in order for us to better understand their experience. Through a range of innovative practice methods, HCPs may evoke expression and develop communicative bridges by making use of existing metaphors that can be found within art. We can also apply commonly used metaphoric expressions that have already been uttered by people living with pain.

Figure 10 shows a selection of patient-generated metaphors. These have been designed to be used with people who are struggling to express their pain. As Padfield et al.'s (2010) photographic images enabled improved communication, the metaphor menu (Fig. 10) aims to awaken expression, foster empathy and develop a shared understanding by unshackling pain's linguistic constraints. Through the patient-led choice of a particular metaphor from the menu, and the subsequent exploration of the chosen expressive safe-bridge, both the healthcare professional and the person in pain attempt to find a collaborative, narrative space. This communication aid aims to further understanding and promote discussion regarding self-directed strategies towards behavioural change and recovery.

Case study 4 shows the clinical application of one of the patient-generated metaphors found within the metaphor menu (It's so frustrating. I feel like I'm going round in circles without any answers). Case study 4 also highlights the need for serious playfulness and creativity when attempting to breach pain's internal and unshareable barricades.

With this need for divergent and innovative practice methods in mind, Chan (2013) explored creativity and critical thinking in traditional and problem-based learning groups. A sample of 100 student nurse perceptions following problem-based learning tasks within semi-structured focus groups was used. Chan (2013) found increased critical thinking and problem-solving skills when using the metaphors contained within poetry and song lyrics to foster empathy and understanding regarding patient case studies.

Song composition and lyrical analysis can also enable people to explore different learning possibilities and foster collaboration. The metaphors contained within poetry and song lyrics are also capable of unveiling hidden feelings (Chan 2013). They provide people with associative outlets for experiences that are resistant to expression. People frequently turn to the metaphors that are contained within song lyrics and poetry to help them make sense of a myriad of human experiences. We have songs, which relate to our personal, internal experiences when in love or when grieving the loss of a loved one. We have poetry to assist our expressive needs when reflecting on a wide range of human experiences. Why should our experiences with pain be any different?

When asked, "If your pain was a song, which song would it be?" people who have struggled for years to express their pain can suddenly find a facilitatory outlet to communicate their experience beyond the formulaic constraints of our imposed metaphoric descriptors (stabbing, shooting, burning). One patient who had only been able to describe her pain as "stiff" through standard subjective questioning chose the lyric, "My body is a cage, but my mind holds the key." Such experiences highlight how clinicians can facilitate dialogue and elicit patient-generated metaphors. Such expressive safe-bridges can represent a cognitive shift towards a holistic, embodied experience of pain that moves beyond a dualistic mind-body divide (Demertzi et al. 2009; Semino 2011). Further research is needed to explore the use and therapeutic value of such creative methods within practice.

METAPHOR MENU

Sometimes, pain can seem impossible to describe. We often use metaphors to help us make sense of difficult experiences. Here is a selection of metaphors that other people have used to talk about their pain. Please read through them, choose any that mean something to you, then talk to your healthcare professional about them.
Thank you

"I guess just the worrying about it kind of amplifies things a little bit."

____

"I couldn't sit, I couldn't stand, I couldn't bend, I was frozen in one place."

____

"I'm really struggling at work. I need to hold my own again."

____

"It feels like it's crumbling. Like my back is crumbling and it cannot support me."

____

"Every time I try to get back on track, things just keep going off the rails."

____

"It's so frustrating. I feel like I'm going round in circles without any answers."

____

"I just wish somebody would tell me what to do. I'm in the dark here!"

____

"It's an absolute mess. It feels like everything is so tangled up these days."

Fig. 10 The metaphor menu

10 Conclusion

Metaphors pervade all aspects of everyday life including our language, thoughts and actions (Lakoff and Johnson 1980). They enable us to link the abstract to what is already known. Metaphors provide us all with shared expressive phrases for dialogue that can lead to emotional relief and behavioural change, but they can also accelerate the process towards disease, disability and depression and hinder meaningful reconceptualisation of pain (Stewart 2014). Hurwitz (2003, p. 10) argues that, “pain not only hurts and demands relief, it also scares, baffles, enrages, isolates, resists medical treatment and demands interpretation.” As clinicians and practice-based educators, we have a professional and moral duty to guide people in pain towards a meaningful, scientifically informed understanding so that we might empower them towards recovery. Our metaphoric expressions, and those uttered by people in pain, can assist us all when attempting to seek order amidst the chaos of distressing and uncertain pain experiences.

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Chapter 21
The Social Side of Pain: What Does it Mean to Feel Another's Pain?

Melita J. Giummarra, Lincoln M. Tracy, Kurtis A. Young and Bernadette M. Fitzgibbon

Abstract This chapter gives an overview of the current state of the neuroscientific basis of empathy and the experience of vicarious pain; that is, an explicit sensory experience of pain when observing another in pain. We summarise the central and autonomic mechanisms that are associated with vicarious pain experience from studies using electrophysiology, electroencephalography, transcranial magnetic stimulation and functional Magnetic Resonance Imaging. While this research has given us fantastic insight into the neural mechanisms giving rise to vicarious pain experience, the mechanisms are not well contextualised in relation to the daily lived experience. We discuss the importance of social roles and context in vicarious experiences to provide insight into the aspects of life in which vicarious sensations may arise. For instance, when a parent vicariously reacts to a painful injury in their own child, this may motivate protection and nurturing. Healthcare providers who embody the pain or emotions of their client may report that this enhances intuitive and/or compassionate care. However, distressing vicarious reactivity towards the suffering of others may also ultimately disrupt the capacity to deliver compassionate care and/or lead to burnout. While several qualitative studies have characterised the experience of secondary trauma, and to a lesser degree emotion contagion in clinicians, there has been a lack of qualitative and mixed methods research in this field. In an attempt to emphasise the significance of the social context in empathic and vicarious responses, we give an overview of lived experience of vicarious pain from the perspective of a clinician who describes her experiences both with family

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M.J. Giummarra (✉)
Faculty of Medicine, Nursing and Health Sciences, Department of Epidemiology & Preventive Medicine, School of Public Health & Preventive Medicine,
Monash University, 99 Commercial Rd, Melbourne, VIC 3000, Australia
e-mail: melita.giummarra@monash.edu

L.M. Tracy · K.A. Young
Faculty of Medicine, Nursing & Health Sciences, School of Psychological Science,
Monash University, Wellington Rd, Clayton, VIC 3800, Australia

B.M. Fitzgibbon
Faculty of Medicine Nursing and Health Sciences, Central Clinical School, Monash Alfred Psychiatry Research Centre, Monash University, Melbourne, VIC 3000, Australia

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members and patients in pain. In concluding, we draw parallels between the phenomenological lived account of vicarious pain experience and neurophysiological mechanisms, and discuss the implications of vicarious reactivity for interpersonal relationships, especially within a clinical context. Ultimately for our understanding of both the mechanisms and consequences of vicarious pains sensations future research should take advantage of mixed methods designs to triangulate the neuroscientific mechanisms with the lived experience.

1 Introduction

> So far as I sympathise with you I annex your consciousness… as though my nerves could somehow be made continuous with yours in such a way that a blow which fell upon your frame would convey a sensation to my brain

(Stephen 1882, p. 237).

We witness friends, loved ones, and strangers succumb to injury or express their pain and suffering every day. Most of us will empathise with a person's experience of suffering by resonating with their *emotional* state through affect sharing and/or empathic concern, while also recognising that they are in pain. For as many as a third of us, however, witnessing such incidents actually brings about the experience of explicitly painful vicarious sensations. Vicarious pain sensations are almost universally described as having neuropathic sensations (e.g. tingling, sharp or shooting/radiating), or as having feelings that indicate enhanced sympathetic arousal (e.g. my heart was racing, I was instantly sweating, I had pins and needles), concurrent with the subjective experience of an embodied *feeling* of pain for another.

Vicarious experiences of pain are consistent with the original term *Einfühlung*, from which the English word *empathy* was derived (de Waal 2010). The nineteenth century German philosopher Robert Vischler first used *Einfühlung* to describe the process through which we enter into, and feel, the emotions of others (e.g. the feelings of an artist) by observing their behavioural or external manifestations (e.g. through a piece of art, music, or literature). When entering into the emotions of another who is experiencing and/or expressing pain, the concept of *Einfühlung* also aligns with Preston and de Waal's (2002) more modern *shared representations* model of empathy, whereby shared neurophysiological processes are activated during both first-hand and observed experiences. It is not entirely clear, however, whether vicarious reactivity arises out of enhanced empathy (i.e. being objectively "better" at understanding or *feeling* the other's experience) or compassionate concern (i.e. not only understanding that the other person is in pain, but embracing feelings of love and care towards them).

In psychological sciences, major advances in the development and use of neuroscientific methods over the past 20 years have significantly advanced our understanding of the neural mechanisms underlying human experience and behaviour.

Empirical neuroimaging methods serve to *understand* the neural networks underlying specific processes, the psychological or behavioural manifestation of disruption to those neural networks, and the development of interventions that target specific neural mechanisms or networks in order to modulate a range of human experiences of behaviours. For instance, delivering Transcranial Magnetic Stimulation (TMS) to the dorsolateral prefrontal cortex to modulate symptoms of schizophrenia (Li et al. 2016), depression (Duprat et al. 2016) and migraine pain (Rapinesi et al. 2016).

Our fascination with understanding the neural basis of emotion and complex processes as empathy has resulted in a swathe of studies, including those examining the basis of vicarious pain. In particular, these studies have predominantly focussed on attempting to characterise the neurophysiological mechanisms that give rise to the experience through highly controlled experimental designs (for an overview, see Fitzgibbon et al. 2012; Ward and Banissy 2015). Various sophisticated neuroimaging and recording techniques have been used to identify the neurophysiological mechanisms associated with vicarious pain. The results, which will be summarised below, show that vicarious sensations arise from heightened activity in similar brain regions involved in feeling the respective sensation, and suggest that vicarious phenomena correspond to the automatic and disinhibited tendency resonate with the sensory and emotional experiences of others, consistent with *Einfühlung*. However, little attempt has been made in any published studies to examine the experience of vicarious reactivity within the context of one's *intra*personal (e.g. with respect to psychological traits or prior experience) and *inter*personal (e.g. social or professional role) lived experience. Little is known about how the tendency to experience vicarious sensations affect one's social behaviour from day to day or across the lifespan. For instance, does the tendency to feel vicarious sensations, particularly vicarious pain, influence career choices, such as steering one towards or away from the "caring" professions of nursing or medicine, or impact on social behaviour (for example, are you more likely to run to the aid of someone who is acutely injured, or will you be more likely to make donations to alleviate the suffering of others)? Moreover, do these experiences arise in the first instance because you had previously had a series of terribly painful procedures (e.g. dental procedures) and you then become more attuned to these experiences in another? Below, we consider some of these aspects of the lived experience of empathy and vicarious pain; however, first, we give an overview of the neurophysiological mechanisms of empathy, and vicarious pain, and the key role of inhibitory control when appraising the feelings of another.

2 The Neuroscience of Empathy

Empathy involves a strong affective component, whereby one understands the unpleasant painful experience of another through shared emotional states (Fan et al. 2011; Reniers et al. 2011). Several functional imaging studies have found that witnessing and imagining others in pain activates the affective-motivational brain regions that process painful experiences including the medial/anterior cingulate cortex and the anterior insula (Singer et al. 2004; Jackson et al. 2005; Lamm et al. 2011), albeit to a lesser degree than during an explicit personal pain experiences (Wager et al. 2013; Cui et al. 2015). Nevertheless, neural activity in shared networks is thought to facilitate empathic understanding of another's pain.

Just as personal experience of pain elicits strong motivational states such as those that serve to protect oneself from further injury or pain (Melzack and Casey 1968), witnessing another in pain also elicits motivational states including feelings of compassion, whereby we seek to alleviate the distress and pain of others (Decety and Chaminade 2003), or avoid exposure in order to diminish one's own distress (Bernhardt and Singer 2012). Empathic concern and compassion are also tied to greater social connectedness, and are predictive of the likelihood of engaging in prosocial helping behaviour (Hein et al. 2010; Bastian et al. 2014).

Alongside affective appraisals, witnessing another in pain elicits sensorimotor representations of another's state, which is thought to facilitate empathic understanding (Braadbaart et al. 2014). In a meta-analysis of fMRI studies, Lamm et al. (2011) revealed that activity in the sensorimotor brain regions tends to only arise when one views explicit visual cues that another is in pain; i.e. picture or film-based experimental paradigms portraying injuries. Moreover, using electroencephalography (EEG), several studies have found that viewing others in pain elicits greater activation in the primary somatosensory cortex, with a significant increase in the amplitude of the P45 somatosensory-evoked potential (Bufalari et al. 2007), and greater mu suppressions over the primary somatosensory cortex (Cheng et al. 2008).

Inhibitory mechanisms have been investigated in studies using TMS and Nociceptive Flexion Reflexes. During TMS, a magnetic field passes through to the brain, and the electrical current alters neural excitability in superficial areas of the brain like the primary motor cortex. TMS produces observable motor responses in the corresponding muscle when applied to the primary motor cortex, which can also be measured as a motor evoked potential in the extremity muscle. The amplitude of the motor evoked potential is thought to reflect corticospinal excitability. In the context of empathy, Avenanti et al. (2010) used TMS and found that witnessing a painful needle prick procedure into the hand brings about *reduced* corticospinal excitability (i.e. smaller MEP), suggesting that the observer had inhibited their mirrored processing of the painful procedure. The Nociceptive Flexion Reflex (NFR) is a withdrawal reflex to nociceptive stimulation, whereby a greater NFR indicates heightened corticospinal excitability, and engagement of descending mechanisms to enact a protective withdrawal response from the noxious stimulus. Vachon-Presseau et al. (2011) measured nociceptive withdrawal responses to an acute painful stimulus while participants viewed images of painful scenarios and facial expressions of pain. They found that the NFR was enhanced when observing images of persons in pain, compared with facial expressions, particularly in those with greater empathic concern. Together these findings reflect increased sensorimotor simulation of the experience of others, and the engagement of inhibitory and/or self-protective withdrawal behaviours consistent with the observed painful experience. This is fundamentally similar to any time you have watched a graphic painful scene in a film (e.g. the scene in the film *127 hours*, where Aron Ralston amputates his own arm after it became trapped under a boulder) where you simultaneously feel like your body has become "frozen," however you may also have automatically grasped your own arm as if to protect it from harm.

Witnessing another in pain also elicits spontaneous autonomic arousal. Several studies have found that witnessing others in pain elicits greater pupil dilation (Azevedo et al. 2012), startle reflexes (Leiberg et al. 2012), heart rate deceleration and increased respiration rate and skin conductance (Craig 1968). These responses all prime an orienting response in the observer, and prepare them for action, while also facilitating vicarious learning about sources of danger. In a classic study, Craig (1968) exposed participants to pain by asking them to hold their hand in a cold water bath. He then asked them to witness another person undergo the same procedure, and then finally to imagine themselves in that situation. Observing or imagining pain was associated with a faster respiration rate, heart rate deceleration and increased skin conductance, compared with baseline. Taken together, when we witness another in pain, the autonomic and central nervous system is aroused in preparation for action. Importantly, rapid sympathetic and emotional arousal towards others in pain appears alongside inhibitory autonomic processes (e.g. heart rate deceleration), to prevent over-arousal.

The activity in shared neural networks during pain empathy is lower than during a direct pain experience (Craig 1968; Bufalari et al. 2007; Wager et al. 2013). This reduced activity is thought to reflect the engagement of inhibitory control, preventing excessive emotional arousal, which is crucial to the regulation of emotion when faced with the pain and suffering of another (Decety 2010). Emotion regulation is a higher-order cognitive process that enables one to alter their emotional state in response to ongoing demands, typically conceptualised as an adaptive response to diminish the impact of negative emotion (Cisler et al. 2010). For instance, this may mean the dampening one's own emotional distress through reappraisal of another's pain (e.g. although my wife is in excruciating labour pain, she will soon hold a much anticipated newborn in her arms so this pain does not mean "danger"). Inhibitory control, and emotion regulation, arise through increased activity in the ventral and dorsal prefrontal cortex, inferior frontal gyrus, and the dorsal horn of the ACC (Ochsner et al. 2002; McRae et al. 2012). Failure to engage inhibitory control mechanisms within these regions is associated with excessive emotional arousal, psychological distress (Decety 2010; Williams and Hasking 2010), and greater self/other confusion (Murray et al. 2015). Maintaining a distinction between oneself and others is an important component of empathy as it provides a barrier against becoming disproportionately distressed by the suffering of others (Decety and Jackson 2006).

2.1 Vicarious Pain and the Mechanistic Role of Inadequate Disinhibition

Self/other confusion and poor inhibitory control appear to play a crucial causal role in vicarious pain states. These mechanisms have recently been described by Ward and Banissy (2015) in the "self-other" and "threshold theory," respectively. The self-other theory proposes that vicarious states arise because of diminished capacity to distinguish oneself from others, and/or to disinhibit the processing or representation of others in relation to the self. Persons prone to vicarious sensations may have broader representations of the self which in turn lead to the "inclusion" of other's sensory and emotional experiences into their own body representation; i.e. when "who" is truly being touched becomes unclear (Banissy et al. 2009). For example, a recent experiment by Maister et al. (2013) examined whether viewing a model being touched, or not, would modulate the self-attribution of morphed facial images in vicarious responders. The morphed images presented varying degrees of both the participant's own face and that of the model from 0 (100% model) to 100 (0% model; 100% participant). After witnessing the model being touched (but not after "no touch" trials), vicarious responders reported that 20% more of the images showed their own image suggesting that vicarious touch attenuated the division between self and other.

The difficulty in distinguishing oneself from others is thought to play a key role in eliciting suprathreshold disinhibited activation throughout so called mirror systems for pain (Osborn and Derbyshire 2010) or touch (Blakemore et al. 2005) giving rise to states of vicarious pain or touch, respectively. Vicarious pain has been found to correspond to greater and more widespread activity in all areas of the sensory and affective brain regions involved in processing pain (i.e. ACC, insula, primary and secondary somatosensory cortices), when viewing images of others in pain, compared with non-responder controls (Osborn and Derbyshire 2010). In particular, activity in the secondary somatosensory cortex typically only arises during an explicit experience of pain, but not when viewing others in pain (Wager et al. 2013; Cui et al. 2015), which suggests that the vicarious pain state reflects the genuine feeling and not just the thought of pain.

Despite evidence of hyperactivity in neural regions associated with personal pain, vicarious pain responders have been found to have reduced neural activity in frontal brain regions, which are integral for attentional control and emotion regulation, when appraising painful scenarios. Fitzgibbon et al. (2012) measured electrophysiological activity in amputees prone to vicarious pain, non-responder amputees and non-amputee controls while they viewed images of body parts in painful or non-painful situations. A significant decrease in the amplitude of event related potentials was revealed in the vicarious pain responders, compared with non-responder amputees and controls, when appraising the sensory qualities (i.e. pain intensity) of the images, but not when identifying the limb depicted (control condition). This reduced activation was evident in early component frontal and late component parietal sites involved in attention and inhibition. Given that viewing emotional images typically results in an increase in ERP amplitude (e.g. see Mu et al. 2008), the reduced activation in vicarious pain responders may reflect the failure to engage inhibitory control networks in the frontal brain regions. Similarly, using TMS, Fitzgibbon et al. (2012) found heightened motor evoked response when amputee vicarious pain responders viewed painful procedures, suggesting that the ordinary inhibition of simulated motor activity did not occur. More recently, Giummarra et al. (2016, submitted) found that vicarious pain responders had reduced activity in the inferior and medial frontal gyri when viewing angry and sad emotional expressions in an emotional face matching task. Again, given that these neural regions play an integral role in the regulation of emotion and empathy (Decety and Chaminade 2003; Kim et al. 2009), these findings suggest that the tendency to experience vicarious pain arises due to impaired inhibitory control specifically when appraising emotional and/or sensory states that represent threat or suffering.

Ultimately, dysfunctional self-regulation is proposed to underlie vicarious states of pain, which ought to be measurable through activity in the autonomic nervous system. Indeed, we have found that vicarious pain responders have lower heart rate variability (HRV) when experiencing cognitive stress, compared with non-responders (Nazarewicz et al. 2015). This finding was specific to the variability between heart beats in the high-frequency band (HF-HRV), whereby lower HF-HRV reflects reduced capacity of the nervous system to adapt to changing circumstances or threat via the parasympathetic nervous system (Rajendra Acharya et al. 2006; Thayer et al. 2012), and reduced ability to adaptively regulate emotion (Appelhans and Luecken 2006). This finding suggests that poor parasympathetic control may not only be mechanistically linked to vicarious pain states, but these experiences may also be predictive of other poor long-term outcomes, including depression, cardiovascular disease and early mortality which are associated with low HRV (Kemp et al. 2012; Thayer et al. 2012; Huikuri and Stein 2013).

Consistent with evidence of poor inhibitory control in vicarious pain responders, disinhibited cardiac reactivity has also been revealed in this group. During exposure to short film clips of sporting injuries, heart rate acceleration was observed in vicarious pain responders with anxiety traits, whereas heart rate remained steady in non-anxious responders, and non-responders showed a marked "adaptive" deceleration in heart rate (Nazarewicz et al. 2015). Heart rate acceleration is typical of a direct pain experience (Tousignant-Laflamme et al. 2005), providing further support for the subjective experience that these vicarious sensations are perceived to be painful.

Increased physiological activity in response to perceived threat indicates activation of an aversive motivational circuit, triggering reactions ranging from orienting to flight/fight, as per the defensive cascade model (Lang et al. 1997; Van Diest et al. 2009). However, the same neurophysiological activity may elicit "tend and befriend" behaviours, depending on social context (Taylor 2006). To better understand the association between vicarious reactivity, physiological reactivity and trait tendency to be compassionate towards others (Giummarra and Fitzgibbon 2016, submitted) administered a comprehensive battery of questionnaires that measured each of those traits to 276 participants. In this study, we found that vicarious reactivity—i.e. the tendency to experience vicarious pain, touch and/or taste—was not directly associated with compassionate concern. This was consistent with findings from previous studies, which observed no association between vicarious pain and trait empathy (Derbyshire et al. 2013; Vandenbroucke 2013; Vandenbroucke et al. 2014, 2015). However, there was a small indirect relationship between vicarious responding and compassionate concern via the tendency to be more physiologically reactive (i.e. trait anxiety, anxiety sensitivity and physiological suggestibility). This evaluation of trait characteristics concurs with the neuroimaging research described above whereby there seems to be a mechanistic role of supratheshold reactivity in both vicarious states and compassionate concern. Moreover, several studies have found a positive association between state affective empathy and vicarious pain (Derbyshire et al. 2013; Vandenbroucke 2013).

3 Context and Social Roles in Vicarious Experiences

Nearly all of the neuroscientific studies described so far have used strictly controlled experimental designs in order to understand associations between brain activity and the personal experience of vicarious pain (Osborn and Derbyshire 2010; Godinho et al. 2012). However, given the tightly controlled and limited nature of experimental design for functional neuroimaging, these studies can rarely take into consideration other factors that modulate empathic responses. For instance we feel heightened empathic resonance towards those who are similar to us (e.g. in-group members compared with out-group members; Molenberghs 2013), and with whom we can identify, such as those with similar racial features (i.e. skin colour or facial features; Avenanti et al. 2010; Cheon et al. 2013). Moreover, other appraisals, such as the judgement whether or not someone is to blame for their misfortune, play a role in the degree of empathic concern and related neural responses towards that scenario. For instance, when a person who has contracted AIDS from a blood transfusion, compared with intravenous drug use (Decety et al. 2009).

While applying empirical approaches allows for the advancement of conceptual frameworks through hypothesis testing, these methods are limited given that multiple contextual factors cannot be incorporated into the study design. Thus, although we can understand the relationship between broad trait and experiential constructs through empirical, hypothesis driven research, we suggest that you can only truly understand experiences of empathy and vicarious sensations as we live through them as subjects. To do this requires appreciation of mixed methods approaches that triangulate central and peripheral nervous system mechanisms with personal lived experience, social context and subjective appraisal (e.g. see Aydede and Price 2006).

Empathic concern is heightened when the other person is a loved one compared with a stranger (Taylor et al. 2000; Forsythe et al. 2012). There is a fundamental evolutionary need to be more emotionally and empathically reactive towards the members of your own social group and family, which appears to have especially evolved in women, to ensure the survival of the group (Taylor 2006). We suggest that the biobehavioural social desire to protect loved ones is phenomenologically consistent with the experience of vicarious responding given that vicarious pain is associated with disinhibited neurophysiological reactivity, the association between vicarious responding and compassionate concern is mediated by arousal-related traits. These correlates imply that vicarious pain may in fact be a manifestation of the "tend and befriend" social response.

In our previously published study, which validated the empathy for pain scale (Giummarra et al. 2015a), we also asked participants to offer a description of their experiences when witnessing surgical procedures, visiting a patient or seeing another who had been accidentally injured. Participants were classified as being a vicarious pain responder if they reported experiencing vicarious pain for any of the scenarios. We examined the type and frequency of words used to describe reactions to the painful scenarios, after filtering out common English words that were not of interest such as "a," "as," "am." For vicarious responders (n = 104; 798 words after filtering), the most common words, in order of frequency, were: feel or feeling (n = 121, 15.2%), person (n = 41, 5.1%), pain (n = 41, 5.1%), help (n = 31, 3.9%), like (n = 23, 2.9%), see (n = 21, 2.6%), away (n = 20, 2.5%), surgery (n = 20, 2.5%), procedure (n = 17, 2.1%), and empathy (n = 16, 2.0%), see Fig. 1a. For non-responders (n = 306, 1642 words after filtering), the most common words included, in order of frequency: feel (n = 244, 14.9%), person (n = 126, 7.7%), help (n = 104, 6.3%), surgery (n = 74, 4.5%), procedure (71, 4.3%), pain (n = 58, 3.5%), watch (n = 56, 3.4%), want (n = 50, 3.0%), need (n = 49, 3.0%), uncomfortable (n = 44, 2.7%), and see (n = 43, 2.6%); see Fig. 1b.

The major differences in word choices, based purely on word frequency analysis indicated that vicarious pain responder descriptions focused on feelings, sympathy,

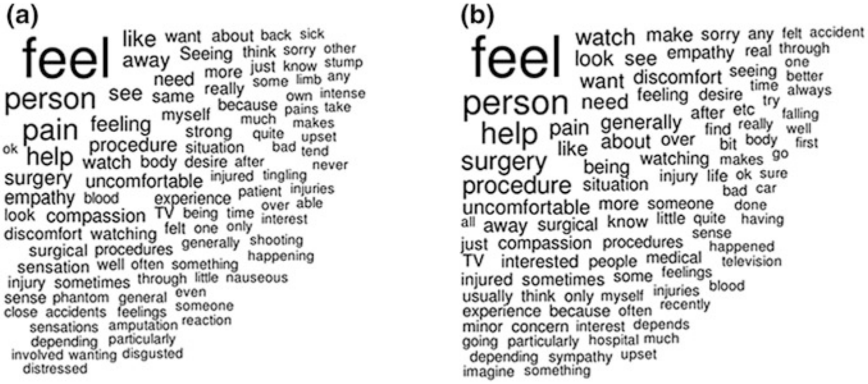

Fig. 1 Word map demonstrating the most common words used to describe experiences when witnessing pain in another by **a** vicarious pain responders, and **b** non-responders. In each figure, word frequency is represented by increasing word size

compassion and painful sensations, whereas non-responders focused on feelings, compassion and the more procedural elements of the experience as an observer. Vicarious pain responders offered some of the following descriptions of their first-hand experience when witnessing another in pain:

> I feel compassion, a need to help or get help, and usually pain or sensation in a similar area (Male, 36 years old).
>
> I am aware of stabbing pains through my body, odours and colours (Female, 53 years old).
>
> I feel a tugging/discomfort in the area that the procedure is being carried out… I watched a C-section once and felt as though someone was tugging/cutting my abdomen even though I knew that the woman couldn't feel any pain. There was also a lot of blood and so I got quite faint (Female, 23 years old).
>
> If I see a person with sutures or a cast or bandages or anything suggesting a wound, I will have intense shooting pain down the back of my legs and down the back of my arms. It will come in waves, will have an electrical quality and will last as long as that injured person is in my view (Female, 46 years old).
>
> I feel the surgery myself… I never watch programs like 'hospital shows/ER programs' as a deliberate act. I've personally been through too much to subject myself for that. I worked in the medical system for many years. I have seen too much as an employee too. I was able to cope with patients (I am NOT a nurse) in the work situation but following my own major trauma I am unable to now (Female, 52 year old amputee).

Non-responders also frequently described their experiences as involving a sense of compassion, but did not mention embodied pain or distress, including:

> I may be surprised or shocked, I would seek help… possibly feel bad for them, feel compassion and feel uncomfortable looking at the injury (Female, 22 years old).
>
> It feels as though my heart skips a beat, and I want to offer assistance. I don't feel squeamish or repulsed, just focus on what needs to be done to help (Female, 35 years old).
>
> When I see a person being accidentally injured, particularly if it is a person I know who is being injured, I often feel annoyed or frustrated at the misfortune that has befallen that person, because there is often nothing to be gained for anyone from the situation. I feel compassion for the victim of the accidental injury, and feel compelled to help the person (Male, 21 years old).

These examples highlight the broad range of empathic reactions when witnessing another undergo a painful procedure or experience. Both vicarious pain responders and non-responders express deep compassion towards the suffering of loved ones, consistent with the fact that we are biologically wired to care for those in our intimate social networks and family unit. However, many also expressed compassion and/or distress at witnessing pain in strangers, raising the question about what makes us not only feel compassion for another, but what makes us want to care for a stranger? And could vicarious reactivity play a role in this decision?

Some vicarious pain responders described the fact that having a traumatic experience themselves made their vicarious pain unbearable. We previously found that vicarious pain responders with symptoms of PTSD were more likely to have disabling chronic pain (Giummarra et al. 2015b), suggesting that central sensitisation may play a role in eliciting vicarious pain states. At a less extreme end of the spectrum, Derbyshire et al. (2013) also found that prior sensitivity (i.e. tooth sensitivity) was associated with an increased likelihood of reporting vicarious tooth pain when presented with images of people eating frozen sweets. Evidently prior experience and sensitisation are likely to play a role in disinhibited reactivity and vicarious pain.

There is some evidence that people who are drawn to work in the caring professions, like nursing, are motivated to do so because of an "innate" motivating sense of compassion and empathic concern towards others in need (Eley et al. 2012). Historically, in the days before anaesthesia, surgeons quite literally needed to be sympathetically sensitive to every feeling expressed by their patient during an invasive surgical procedure (Bourke 2014). More recently, we acknowledge that expression of empathy remains clinically important for the benefit of both the healthcare provider and patient (Decety 2014). Clinician empathy is commonly defined as a three-faceted concept. It refers to the ability of a clinician to (a) understand the patient's situation, perspective, and feelings, and their attached meanings; (b) communicate that understanding and be able to check on its accuracy; and (c) act on that understanding with the patient in a helpful (and therapeutic) manner (Mercer and Reynolds 2002). Benefits of an empathic clinical relationship include increased reporting of symptoms and concerns from patients, increased diagnostic accuracy from the physician, increased patient compliance, and subsequently increased quality of life for the patient (Squier 1990; Coulehan et al. 2001; Kim et al. 2004; Neumann et al. 2007; Blatt et al. 2010; Halpern 2010; Hojat et al. 2011).

When health professionals have been in similar situations to their clients these experiences may then be used during clinical encounters with patients. For example, when physiotherapists have sought physiotherapy treatment for an injury themselves and experienced an unpleasant clinical encounter as patient (e.g. experienced pain due to the physiotherapist progressing through a movement or stretch too quickly), then this can feed back into their own careful and empathic handling of patients (Daykin and Richardson 2004; von Baeyer 2014). Consequently, the clinician adapts their approach to provide a higher level of patient care in a more empathic manner.

In the box below, we present a detailed case summary of a clinician who reports that she had always been prone to experiencing vicarious pain. This case beautifully highlights that her vicarious sensations are useful both when evaluating and treating the patient for physical therapy, but that when a family member is injured the experience is much more salient. JK typically feels sensations that mirror her patient's injury somatotopically; that is, the location where she perceives vicarious sensations is the same as where the patient's pain or injury is localised (patient's right hand = JK's right hand).

JK's experiences are largely consistent with the findings that are emerging from a study that we are currently conducting in which we are examining empathy and vicarious pain in clinicians and clinical students (Tracy and Giummarra 2016, under prep.). In our study, participants who reported that they experience vicarious pain (n = 49) were asked to indicate on a manikin where on their body they would typically feel the strongest vicarious sensation if they witnessed a professional athlete fracture their right leg. The majority (n = 22, 44.9%) indicated that it would arise in a location that was somatotopically consistent with the imagined injury location, with most localising the pain just below the right knee; see Fig. 2. However, a small proportion indicated that these sensations would arise in the contralateral leg (i.e. mirrored; n = 10), a more central visceral location (n = 9), the chest (n = 4), or head (n = 3). Altogether, mirrored vicarious reactivity in a clinical

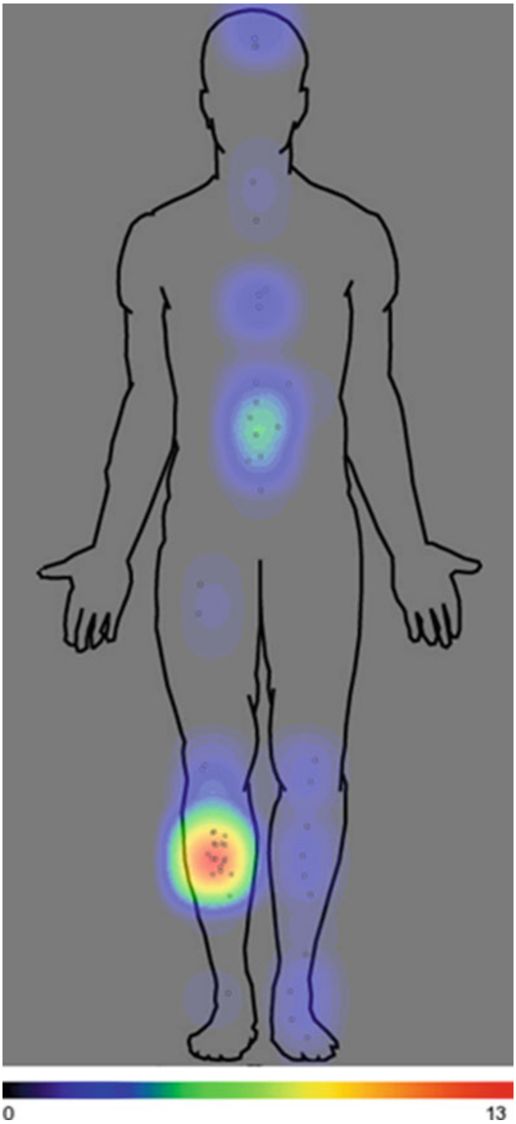

Fig. 2 Heat map representation of the location of the strongest vicarious pain sensation experienced by clinical students and clinicians if they were to witness a footballer fracture their right leg (n = 49 vicarious pain responders)

context may both facilitate localising the source of pain in another, and provide a continued link between clinician and patient to ensure that interventions and manipulations are clinically effective; however, empirical research is required to substantiate these insights.

Vicarious responding in clinical practice: A case summary JK is a private practice hand therapist who for the last 20 years has treated a number of clients/injuries in city and rural contexts including post-surgical, over-use and sports injuries and referrals from general practice. JK describes herself as a creative individual who first trained in prosthetics as a medium between her love of pottery and her need to work closely with people. JK reported that she had experienced vicarious sensations for as long as she could remember; however, they became more obvious as she began to work clinically, particularly with amputees. For JK, the experiences occur when she is "present, engaged and interacting with a person or procedure," occur in the exact location of the sensation of another and, while not necessarily causing intense pain, describes the feeling as that of tension and/or pressure. Her vicarious experiences are not the same from person-to-person, and the experience varies according to a number of situational factors including the patient's specific experience, the level of familiarity with the patient or injury and severity.

In cases of vicarious experiences in response to close family or friends, or very severe accidents, JK reports overwhelming autonomic responses that last for several minutes. For instance, after her step-son was bitten by a newly adopted family dog, JK was overcome with sensations including "sweating, mouth-watering, psychedelic curtains" and felt as if she would faint. These autonomic experiences do not occur when she works clinically, and her vicarious experiences in the clinical setting are a useful tool, as they help her to tailor her manipulations or modify patient posture/movement to enhance their treatment needs. JK even reports feeling that she has a higher level of "intuition" where she can pre-empt the diagnosis/cause of the presented symptoms, has a sensitivity towards detecting whether a patient is under/over reporting their pain or, if the patient has additional social or emotional issues that may be involved. As JK describes, "They might say they need treatment for tennis elbow, but I'll look at them and know that it's probably more radial." JK therefore views her vicarious sensations in her practice as a physical therapist to be related to superior simulations of the client's experience which, in turn, facilitate her therapy and leads to improved patient outcomes.

Empirical neuroscience has shown us that even though physicians appear to be better at simulating the experiences of a patient subjected to a painful procedure, such clinical experts also typically demonstrate greater regulatory control over the limbic system to effectively dampen the experience of distress (Cheng et al. 2007; Decety 2010). When health care providers report high levels of empathic concern and vicarious distress; however, they are more susceptible to poor clinical encounters due to countertransference (i.e. when the therapist transfers their own emotional feelings back towards the client; Marshall and Smith 1995), secondary traumatic stress (Robins et al. 2009), emotional exhaustion and burnout (Halifax 2011). It appears that there is a fine line between being overly involved, or overly distant as a physician whereby physicians who can appropriately manage their own affective responses and empathic concern at an optimal level are able to display greater expression of empathic concern while reducing their risk of emotional burnout (Decety and Meyer 2008; Davidov et al. 2013; Ho et al. 2014; Williams et al. 2014).

Studies of empathy and vicarious experiences in the clinical context has attracted the greatest balance in scientific approaches, including both qualitative methods of inquiry and neuroscientific methods (i.e. fMRI, TMS). The findings across these studies enable us to not only understand the neural mechanisms that support clinical practice (e.g. greater engagement of neural regions involved in inhibitory control and emotion regulation), but also the role of complex personal (e.g. having stressors at home) or organisational (e.g. lack of supervisor support, too many demands) factors that impact on the capacity to regulate emotion contagion and maintain empathy for patients in pain. The triangulation of findings across scientific methods in the clinical context has been valuable as it can lead directly towards translational solutions for improving work culture, support or training for staff to maintain optimal performance at work.

4 Conclusions

Vicarious pain states appear to be associated with enhanced reactivity towards threatening and unpleasant emotional and sensory experiences of others, which fundamentally arise from disinhibition, and a reduced distinction between self and other, but seem to lead to enhanced compassionate concern. The qualitative insights from published studies and the experiences that we have presented, suggest that the immediate and long-term behavioural consequences of vicarious pain states will most likely differ vastly depending on the social context, and the circumstances in which the vicarious state arises. In particular, when we are faced with pain or suffering in immediate family or social group members, empathic concern is likely to be heightened compared with seeing a stranger in the same situation. Vicarious simulation of a loved one's experience seems to enhance the capacity and desire to tend to their needs. In a clinical context, vicarious sensations may be an intuitive way of simulating the client's experience, which is fundamentally beneficial and rewarding. However, if vicarious states are coupled with embodied suffering and feelings of distress, the health care provider is likely to be at greater risk of burnout and psychopathology. Altogether, these types of insights are challenging to gather solely through highly controlled empirical hypothesis driven research, but are immediately apparent in qualitative methods of inquiry. On the contrary, empirical research allows us to uncover and confirm the neurophysiological and trait characteristics underlying vicarious pain experiences thereby allowing us to test the universality of the lived experience and to ultimately make substantial advances in conceptual frameworks underlying vicarious experiences (e.g. Threshold Theory and Self/Other theory).

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Chapter 22
Tests and Models to Study Pain in Animal-Based Translational Research

Michel Barrot, Eric Salvat and Ipek Yalcin

Abstract Nociceptive reflexes are predominant in traditional "pain" tests using rodents. However, pain is not a nociceptive reflex, but an unpleasant personal experience associated with a complex sensory, emotional and cognitive phenomenology. Modern research methods in behavioral neuroscience have now enabled preclinical pain researchers to develop procedures which differentially combine reflex and non-reflex based measures, thus making various aspects of pain experience experimentally accessible in rodents. These aspects include the aversive component, anxiodepressive and cognitive consequences of pain as well as pain empathy. Rodents are also highly sensitive to their environmental context, and can accordingly attribute different contextual meaning to different experimental situations. This chapter summarizes classically used nociceptive tests, but mainly focuses on the recent developments highlighting the possibility to address the complex experience of pain in rodents.

1 Nociception and Pain

Translation of pain research between clinic and animal research laboratories requires consideration of the difference between pain and nociception. According to the International Association for the Study of Pain (IASP), while nociception refers to the neural process of encoding noxious stimuli, i.e. stimuli that are damaging or threaten damage to normal tissues, pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage. Thus, the encoding of noxious stimulation (nociception) must be distinguished from the resulting aversive sensation and interpretation (pain). This distinction avoids the inappropriate attribution of an emotional or cognitive

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M. Barrot (✉) · E. Salvat · I. Yalcin
Centre National de La Recherche Scientifique, Institut Des Neurosciences
Cellulaires et Intégratives, Université de Strasbourg, Strasbourg, France
e-mail: mbarrot@inci-cnrs.unistra.fr

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meaning due to unconscious reflexes or to elementary mechanisms that are peripheral, spinal and sub-cortical.

Nociception includes processes through which a noxious stimulus is detected by the peripheral nervous system, encoded, transmitted and unconsciously processed by the central nervous system. Such detection is ensured by peripheral molecular transducers (ionic channels) on nociceptive neurons whose cell bodies are located in posterior (human) or dorsal (rodent) root and trigeminal ganglia. The afferent signal is then processed by a complex network within the posterior/dorsal horn of the spinal cord (Todd 2010) or its brainstem equivalent. This nociceptive processing is under the influence of non-nociceptive sensory information, and of descending controls originating from the brain. Nociception also includes reflex responses protecting the organism, as well as part of the unconscious cerebral processing of the information. On the other hand, pain is a conscious experience, which is multidimensional and subjective. It requires cortical processing and the interpretation of nociceptive information as consciously aversive. While nociception and pain are closely linked, both clinical and preclinical evidence support the idea that they may in some cases be dissociated one from the other.

When relevant, nociception and pain contribute to survival (Le Bars et al. 2001). They offer an alarm system, allowing an adapted immediate response, as well as future avoidance strategies or improved responses through aversive associative learning. Despite this physiological function, it is necessary to silence this alarm system when the lesion or its risk are either anticipated or identified, or when pain becomes chronic or dissociated from an actual lesion. This requires adequate treatments with anaesthetics or analgesics, whose development may benefit from preclinical tests and models (Mao 2009, 2012; Mogil et al. 2010; Negus et al. 2006). In healthy subjects and in most patients, pain is verbally expressed and evaluated, which is not possible in rodents. Thus, so-called “pain” tests in rodents are in fact mostly nociceptive tests, based on reflex responses, and the preclinical measure of pain itself is still extremely challenging (Mao 2012; Barrot 2012).

2 Nociceptive Tests in Rodents

Nociceptive tests in rodents use thermal, mechanical, chemical or electrical stimuli (Le Bars et al. 2001; Barrot 2012). The choice of the test is a critical step in an experimental design as the various nociceptive modalities are partly independent and can be experimentally dissociable (Delmas 2008; Scherrer et al. 2009).

Some of the available tests rely on the latency of avoidance behaviour, which is often either a paw or tail withdrawal reflex, in response to a stimulus (usually nociceptive) of fixed intensity. This concerns for example the thermal tests of tail flick (D’Amour and Smith 1941), hot plate (Woolfe and MacDonald 1944; O’Callaghan and Holtzman 1975), or radiant heat (Hargreaves et al. 1988), which can be conducted in mice or rats. Tail flick, which is based on the reflex latency following exposure of the tail tip to a heat beam or dipping the tail in a hot bath at fixed temperature, is highly sensitive to opiates and has been widely used to evaluate analgesics. This response is a spinal reflex; however, it is also under the influence of descending pathways. In the hot plate test, whose temperature is often set at either 52 or 55 °C, the measure is usually the latency to first paw withdrawal or paw licking, but jump can sometimes be also considered in mice. In the 1980s, a test has been described that allowed differentiating the nocifensive response of each hind paw in a freely moving rodent. It is the radiant heat test, sometimes referred to as the Hargreaves' method or Plantar® test. In this test, the animal is placed on a glass surface and the heat source is placed underneath the considered paw, the test automatically detecting paw withdrawal. This test is useful for models of unilateral pain, and for testing topical application of proalgesic or analgesic substances. Heat-based tests are often set to observe a withdrawal or licking response within 5–10 s. Short latencies, i.e. more intense heat, may be preferred when expecting analgesic responses; whereas longer latencies, i.e. less intense heat, will favour detecting a nociceptive impact in models of pain. Similarly, the response to nociceptive cold can be tested by using a cold plate (Bennett and Xie 1988; Choi et al. 1994), but obtaining reliable and sensitive measures may be more difficult than with heat.

Some other tests are based on the stimulus intensity necessary to induce an avoidance behavior. The stimulus is then variable, either continuous or incremental. An advantage of these tests is the possibility to assess the hypersensitivity associated with allodynia, i.e. pain due to a stimulus that does not normally provoke pain (IASP definition), which may sometimes be clinically more relevant than hyperalgesia (increased pain from a stimulus that normally provokes pain). These tests include the ones assessing mechanical response thresholds, such as the von Frey filaments, the analgesimeter from Randall and Selitto, or more recent tests using strain gauges. While these tests are all appropriate for studies in rats, the von Frey filaments remain the only reliable one in mice. These filaments of various diameters are usually applied to the plantar surface until they bend, exerting a calibrated pressure. The filament of lower diameter inducing a behavioral response indicates the mechanical threshold value (Chaplan et al. 1994; Barrot 2012). The other tests of mechanical sensitivity are mostly used in rats. The Randall and Selitto analgesimeter (Randall and Selitto 1957; Kayser et al. 1990) allows exerting an increasing pressure on the paw. The measured parameter is the threshold, in grams, leading to either paw withdrawal or to vocalization. This test however implies maintaining the animal in a non-natural posture, which requires expertise, but it provides reliable and stable measures allowing repeated testing. The recent development of apparatuses using strain gauges (Hu 2006; Luis-Delgado et al. 2006; Barton et al. 2007) offers easier and faster tests to assess nociceptive mechanical thresholds. Concerning thermal thresholds, computer-controlled dynamic cold/hot plates cover a wide range of temperatures, allowing determination of thermal nociceptive thresholds in freely-moving animals (Hunskaar et al. 1985; Yalcin et al. 2009, 2011b). However, it is more time-consuming than the classical hot plate and poorly adapted to pharmacological testing. The response to foot-shocks can also be used, but usually as a control for other behavioral procedures using electrical stimuli, such as learned helplessness, fear conditioning or active/passive avoidance tests.

Finally, some nociceptive tests rely on the observation and quantification of specific nocifensive responses; for example, in the acetone test, the formalin test or other tests using irritant or inflammatory agents. The evaporation of an acetone drop induces a cold sensation that does not evoke behavioral responses in non-painful rats. It thus enables assessing the presence of cold allodynia (Choi et al. 1994) in models of pain. This test can be implemented in mice (Smith et al. 2004), but it is slightly more challenging in this species since naive mice often respond to acetone. Various chemical agents can also be used to induce responses that can be counted; the distinction between test and model is then partly erased. The formalin test, which can also be considered as model of inflammatory pain, is the most common one (Dubuisson and Dennis 1977; Tjolsen et al. 1992). Intradermal formalin injection into the paw induces paw withdrawal, licking and biting responses that can be counted. In this test, biphasic responses are observed, the first responses corresponding to the direct stimulation of nociceptors and being sensitive to local anaesthetics, while the second phase of responses implies inflammatory mechanisms and central sensitization and is sensitive to analgesics. To study visceral pain, various irritating agents can also be delivered by intraperitoneal or intracolonic ways, producing quantifiable abdominal contractions (Le Bars et al. 2001).

3 Pain Models in Rodents

For many decades, basic research on pain and preclinical therapeutic research relied on nociceptive tests conducted on non-painful naive animals. While this strategy has allowed progress in our knowledge of nociceptive mechanisms, benefits in terms of new treatments for pain have proved far more limited (Negus et al. 2006). A combination of pain models to current tests was necessary to advance the field.

In tissue damage, autoimmune disease or exposure to irritating agents, the immune system can release mediators of inflammation that activate and sensitize the nociceptive system (Marchand et al. 2005). A large number of inflammatory pain models are thus based on the administration of substances leading to an immune response, or on the direct administration of mediators of inflammation (Bendele 2001; Holmdahl et al. 2001; Negus et al. 2006; Neugebauer et al. 2007; Bevaart et al. 2010; Billiau and Matthys 2011; Bolon et al. 2011). We already cited formalin, but for more sustained models, the complete Freund adjuvant extracted from mycobacteria or the carrageenan sulfated polysaccharides extracted from algae, are more often used. Their intraplantar injection leads to allodynia and hyperalgesia that last from hours to days. Delivering complete Freund adjuvant, carrageenan, carrageenan/kaolin mix, or zymosan extracted from yeast, into the knee or into the ankle joint is used to model monoarthritis (Neugebauer et al. 2007). Various models of chronic pain from inflammatory or autoimmune origin also exist, allowing studies over weeks to months, but they raise obvious suffering-related ethical questions. However, losing the pathological relevance in models may also become unethical when it reduces the validity and translational value of results.

Such long-term models may thus be important to specifically study the time-dependent aspects of the considered pathologies and the mechanisms underlying pain chronification and long-term associated pain comorbidities. They are also important for a relevant testing of pain-relieving compounds that are developed against chronic clinical conditions.

Neuropathic pain is caused by a lesion or disease of the somatosensory nervous system. It can be consecutive to a section, lesion or compression of a nerve, to a central lesion affecting the spinal cord or a specific brain region, to diabetic polyneuropathy, to some viral infections affecting the nervous system, or be of iatrogenic origin, as in the case of anticancer treatments. A large number of models of neuropathic pain have thus been developed in rodents (Sorkin and Yaksh 2009; Colleoni and Sacerdote 2010; Jaggi et al. 2011; Barrot 2012). They reproduce nerve or central lesions, trigeminal or post-herpetic neuralgia, diabetic or chemo-induced polyneuropathies. However, many models of peripheral neuropathic pain rely on ligation, compression or partial sections affecting the sciatic nerve. Indeed, this nerve is easy to access, and the nociceptive tests are easily conducted on hind paws. While hyperalgesia may be present in these models, mechanical or cold allodynia remain the most studied symptoms.

The largest part of animal-based research concerns inflammatory and neuropathic pain. However, there is growing research interest in musculoskeletal pain, such as fibromyalgia which remains challenging to model, and in pain comorbid with other pathologies, whether genetic, neuromuscular or neurodegenerative, such as Parkinson’s disease (PD) or multiple sclerosis (MS).

Fibromyalgia is a chronic widespread musculoskeletal pain syndrome which is more pronounced in women than men. Its pathophysiological bases haven’t been identified yet. In rodents, it has been modelled through either repeated insults to the muscle, such as injections of mildly acidic saline solution into the gastrocnemius muscle, or by submitting animals to stressors (Sluka and Clauw 2016). These models induce a widespread hyperalgesia, more pronounced in females than males, which concern the skin, muscle and viscera, without notable tissue damage or inflammation. Moreover, they are associated with the presence of anxiety- and depression-like behaviors, which are hallmarks of fibromyalgia (Sluka and Clauw 2016).

Among neurodegenerative disorders, PD is characterized by tremor and rigidity, but is also accompanied by non-motor symptoms which include neuropsychiatric disorders and pain (Poewe 2008) and can start occurring prior to the motor symptoms. While there is still a paucity of animal-based studies addressing this question, allodynia, hyperalgesia and exacerbation of other pain (neuropathic, visceral) can be detected in neurotoxin-based and in genetic models of PD (Rosemann et al. 2010; Jagmag et al. 2015; Park et al. 2015), even though the nociceptive sensory symptoms may sometimes be masked by the slowing down of reflexes (Tassorelli et al. 2007). In patients, MS is characterized by inflammatory demyelinating lesions of the central nervous system, resulting in motor and sensory impairment, as well as in central neuropathic pain. MS animal models rely on autoimmune or viral encephalomyelitis or based on toxic-induced models of demyelination (Pachner 2011). In these models, studies assessing pain aspects remain rare. However, they show that nociceptive responses are variable, depending on the disease time-course (Khan and Smith 2014), which is likely due to confounding motor impairments at the peak of motor deficit in these models. In fact, for both PD and MS models, present studies have only addressed reflex nociceptive responses, with no attempt yet to evaluate more complex aspects of pain.

The association of models to sensory tests proved to be useful to research efforts for understanding nociception. While necessary, this effort remained insufficient in modelling the complex pain experience reported by humans (see below).

4 Beyond Nociception: Toward Indexes of Pain in Rodents

Despite current criticisms about the clinical relevance of some models and tests in rodents (Langley et al. 2008; Craig 2009), these models and tests have allowed indubitable progress in our knowledge of the physiological and anatomo-molecular bases of nociception and pain. Difficulty in translating this progress into therapeutic benefits for humans has led researchers to improve tests and models as well as develop new ones more closely aligned with human pain experience; in particular, with its emotional component. Indeed, together with neuronal sensory signalling, pain is also associated with endocrine and immune mechanisms (Chapman et al. 2008), and more importantly with emotional and affective aspects, that are essential to the experience of pain.

During the past decade, research efforts have partly focused on searching for more objective and quantitative indexes of pain compared with evoked response, or at least for indirect parameters reflecting complex pain states in the animal, in order to go beyond the simple nociceptive reflexes evoked by existing tests. This search has partly drawn on experimental strategies developed in other fields of neuroscience research.

One experimental strategy to get closer to modelling human pain experience in rodents, especially chronic pain experience, is to let the tested animal choose between avoiding or approaching environments associated (or not) with pain experience. Tests of active avoidance or of place conditioning (Sufka 1994; Johansen et al. 2001; King et al. 2009), as described in next paragraphs, allow integrating the aversive component of pain, and, for those using place conditioning, they may indirectly evidence the presence of spontaneous pain. Indeed, in chronic pain patients, spontaneous pain is often more debilitating than the alterations in evoked responses.

Some years ago, Dr. Porrecca's group showed that it is possible to unmask spontaneous pain in a rodent by alleviating the tonic aversive state of chronic pain, using non-rewarding analgesic drugs such as clonidine or lidocaine (King et al. 2009; Qu et al. 2011). This test relies on the rewarding effect of ongoing pain relief and on a conditioned association between this pain relief and the environment where it was induced. Thus, a spinal administration of clonidine or, the administration of lidocaine in the rostral ventromedial medulla, can induce conditioned place preference in models of chronic pain, either neuropathic or inflammatory, but not in naive animals. However, such a strategy requires great technical expertise in behavior as well as large numbers of animals, which strongly limits its widespread use in laboratories. For example, it is likely inappropriate for initial drug screening. Testing direct avoidance may be simpler. It implies either evoked place avoidance responses to direct mechanical stimulation (LaBuda and Fuchs 2000), or temperature preference on plates displaying a temperature gradient along their surface or allowing the choice between surfaces of different temperatures (Moqrich et al. 2005). In this case, there is still an access to the aversive component of pain, but not to spontaneous pain.

Another strategy consists in considering the emotional component of pain through its revealed facial or vocal expression. A pain grimace can indeed be recognized and scored in rats and mice exposed to acute pain (Langford et al. 2010; Sotocinal et al. 2011). However, and similar to the human pain facial expression observed in the clinic, this grimace is not necessarily maintained when pain becomes chronic, which is the situation for which alternatives to nociceptive tests is needed the most. Evaluating pain through ultrasound expression in rodents has also been explored (Calvino et al. 1996; Jourdan et al. 2002; Han et al. 2005; Wallace et al. 2005; Kurejova et al. 2010). This parameter remains however poorly reliable, and here again it does not seem presently appropriate for evaluating spontaneous pain in a context of chronic pain.

Beside the somatosensory and affective components of pain, anxiodepressive consequences which often accompany chronic pain could also be evaluated (Suzuki et al. 2007; Benbouzid et al. 2008; Yalcin et al. 2011a, 2014; Yalcin and Barrot 2014). The most frequently performed tests to evaluate anxiety-related behaviours are exploratory-based approach/avoidance conflict tests, such as the open field, the elevated plus maze or the dark-light exploration test. The novelty-suppressed feeding test, which is based on a conflict between the drive to eat and the fear of venturing into the center of an open field, is used to address both anxiety-like and depression-like behaviours (Nestler and Hyman 2010). The most frequently used tests for assessing depression-related behaviours in rodents involve exposure to stressful situations and the measure of time spent in active versus passive stress coping, such as the forced swimming test or the tail suspension test. Another symptom observed in rodents displaying depressive-like behaviour is anhedonia, the lack of an animal's interest in pleasurable activities such as the loss of preference for a sucrose solution or lesser interest for social interactions. For instance, both sucrose consumption (Wang et al. 2011) and social interactions (Benbouzid et al. 2008) decrease in rodents with neuropathic pain. The splash test is another test which is used to evaluate indirect grooming behaviour, an important index of well-being in animals. For this purpose, a 10% sucrose solution is vaporized on the coat of the animal and the grooming behaviour is measured over a given time period. A recent study using fossorial and therefore naturally burrowing rats showed that this burrowing behaviour is reduced by peripheral nerve injury (Andrews et al. 2012). Burrowing is an evolutionarily conserved behaviour and alterations of such activity likely reflect the effect of chronic pain on motivation and general well-being. In all cases, it is critical to always control for motor and locomotor functions. Indeed, their possible impairment in models of pain might affect the animal's behaviour in anxiety and depression-related tests. Interestingly, the anterior cingulate cortex, which is a cortical region clinically critical in both pain and depression, is also responsible for the aversive component and for the anxiodepressive consequences of neuropathic pain (Barthas et al. 2015). Various other indirect measures of pain are now at the heart of an important research effort assessing autonomic responses, sleep dysregulation, cognitive deficits, or deficits in social interactions.

The possibility to access non-reflex indexes of pain in animals may be critical for translational research. Indeed, the various components of pain can in some instances be dissociated. For example, mice with lesions of the anterior cingulate cortex still display neuropathic mechanical hypersensitivity, while the aversive aspect of spontaneous pain (Qu et al. 2011; Barthas et al. 2015) and the anxiodepressive consequences of chronic pain are no longer present (Barthas et al. 2015). Conversely, neuropathic mechanical hypersensitivity is suppressed in mice with lesion of the posterior insular cortex (Benison et al. 2011; Barthas et al. 2015), while the aversive aspect of spontaneous pain and the anxiodepressive consequences of chronic pain are still present (Barthas et al. 2015). In other words, it is possible to experimentally suppress the affective aspects of chronic pain without impacting reflex responses, or reciprocally to suppress the reflex response without impacting the affective aspects of pain. It is then not inappropriate to consider that similar dissociation might also be possible when testing drugs for their pain-relieving action. In this case, combining easy-to-conduct nociceptive tests in models of pain for initial drug screening (higher throughput), to more elaborate animal measures of pain on developed lead molecules (better relevance), might be beneficial to drug development.

Importantly, the significance of this research now goes beyond the simple context of pain research. Thus, the anxiodepressive consequences of chronic pain developing over time offer an original model of depression, which differs from classical stress-based models. The study of these complex experiences should also help to mechanistically explain the transition toward chronic pain. A preclinical model impacting the quality of life of the animal should thus be viewed as highly relevant in modelling chronic pain. In this regard, the anxiodepressive consequences of neuropathic pain in mice are time-dependent (Yalcin et al. 2011a). Indeed, anxiety-like behaviours appear 3–4 weeks after nerve injury, while depressive-like behaviours develop later, around 6–8 weeks post-injury (Yalcin et al. 2011a). Based on these findings, results obtained from neuropathic pain models may thus differ depending on the considered stage of the pathology. It may then be hypothesized that the more complex symptoms (sensory, anxiety-like and depressive-like) observed after 6–8 weeks post-injury in rodents may more adequately reflect the chronic pain experience in humans.

5 Procedures for Pain Models in Rodents

Optimizing animal protocols for pain research relies on appropriately matching model, tests and procedures. The social environment of animals is among the important parameters to consider for conducting the experiments. While social isolation can strongly affect rodent behaviour (Fone and Porkess 2008; Wallace et al. 2009; D'Amato and Pavone 2012), nociceptive, pain and emotional responses can also be affected in group-housed animals sharing their cage with painful or non-painful cage-mates (Langford and de Williams 2014; Li et al. 2014; Martin et al. 2014). For example, social isolation in adulthood decreases heat sensitivity as well as sensitivity to opiates (D'Amato and Pavone 2012). These alterations are however more pronounced in rats than in mice, for which isolation does not appear as stressful, which also highlights the influence of species differences in sociability. Confrontational social interactions also impact nociceptive responses. Indeed, when a rodent experiences social defeat following physical attack, it results in a "defeat-induced analgesia," which is opioid dependent (Miczek et al. 1982). In a very different context, opioid-induced analgesia is also consecutive to the social reunion with physical contact of mouse sibling brothers, but not of unfamiliar mice (D'Amato and Pavone 2012).

Recently, it has been suggested that a form of empathy may exist in rodents. In this regard, a mouse witnessing a conspecific being attacked by biting flies will develop analgesia (Kavaliers et al. 2001), while male mice with visual contact and that are co-tested for a same noxious stimulus exhibit enhanced responses if the animals already know each other, but analgesia in presence of a conspecific stranger (Langford et al. 2011). Similarly, rats interacting with a cagemate in pain will develop hyperalgesia, which is not the case if the interaction is with a noncagemate (Li et al. 2014). Nociceptive controls are thus influenced by the social context and the actual relationship, such as familiarity or kinship, between animals.

The sex of the animal is also of importance. Too many studies are still conducted on male rodents only, while different nociceptive and pain sensitivities, mechanisms and response to pain-relieving drugs may be present depending on the considered sex (Sorge et al. 2015; Melchior et al. 2016). These sex-differences are however highly variable, depending on the considered model, nociceptive test and animal species. Nevertheless, females appear to be globally more sensitive to various pain conditions, either acute, inflammatory or neuropathic (Melchior et al. 2016). There is for example a stronger and longer lasting mechanical allodynia in female rodents with peripheral nerve injury (Melchior et al. 2016). Even when symptoms appear to be similar, the underlying mechanism may differ between males and females. Indeed, allodynia following sciatic nerve injury has been shown to be dependent on microglia in male mice, while it implies adaptive immune cells, such as T-lymphocytes, in females (Sorge et al. 2015).

The social parameters, the sex of the animals, and the time-dependent aspect of symptoms but also of treatments are thus aspects that are susceptible to alter nociception and pain. Furthermore, the choice of symptoms to be tested is critical.

For models of neuropathic pain, evaluating cold allodynia may for example be more relevant than testing responses to heat, and if mechanical allodynia is an important parameter, it remains imperfect. Indeed, tests measuring mechanical allodynia in animals are presently addressing static allodynia, i.e. to pressure, while dynamic allodynia (to stroke) is clinically predominant and can also be tested in rodents (Sasaki et al. 2008). Treatment, in terms of dose and duration, is also a sensitive step, particularly when trying to model the clinical use of a drug. A preclinical screening of pain-relieving drugs based on their acute analgesic response is unlikely appropriate if these drugs aim at relieving chronic pain in patients. While ethical and economic arguments would favour short term experiments, this may be to the detriment of clinical relevance, particularly when considering models of chronic pain and chronic pain treatments.

6 Conclusions

Nociception and pain is a major field of both medical and neuroscience research. Over time, numerous tests and models have been developed in rodents, which offer a toolbox that is useful to both fundamental and translational research. However, the search for parameters that would evidence pain instead of simple nociception, the study of complex states reflecting the quality of life, as well as the transition toward chronic pain, are important direction presently explored. These necessary methodological efforts rely on essential interactions between clinicians and specialists of behavioral studies in animals.

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Chapter 23
Animal Pain: The Limits of Meaning

David B. Morris

Abstract The biomedical literature on animal pain is thin, despite widespread reliance on animal models in pain medicine. The International Association for the Study of Pain distinguishes sharply between nociception and pain. Pain, says the IASP, is “always subjective” and “always a psychological state.” It traffics with meaning. This essay distinguishes human pain from the pain of animals and concludes that animal pain is largely unknowable: an instance of *the otherness of the other*. Biases against racial and ethnic minorities demonstrated in the undertreatment of pain suggest that dismissive attitudes toward animal pain reflect wider anthropocentric and biomedical difficulties in responding to *otherness*. The difficulties of understanding animal pain would advise caution in clinical applications of research based on animal models. It also suggests—in a speculative conclusion—that we will not effectively address human pain until we have already adequately addressed the *other-ed* pain of animals.

> I went to a concert upstairs in Town Hall. The composer whose works were being performed had provided program notes. One of these notes was to the effect that there is too much pain in the world. After the concert I was walking along with the composer and he was telling me how the performances had not been quite up to snuff. So I said, ‘Well, I enjoyed the music, but I didn’t agree with that program note about there being too much pain in the world.’ He said, ‘What? Don’t you think there’s enough?’ I said, ‘I think there’s just the right amount.’ John Cage, “Grace and Clarity” (1944, p. 93).

D.B. Morris (✉)
Department of English, University of Virginia, Byran Hall, PO Box 400121,
Charlottesville, VA 22904-4121, USA
e-mail: dbmkirk@me.com

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1 Pain: A Universal Experience?

The biomedical literature on animal pain is thin, despite widespread reliance on animal models in pain medicine to study nociception. The International Association for the Study of Pain (IASP) distinguishes sharply, however, between nociception and pain. “Pain is always subjective,” the IASP affirms. The distinction could hardly be clearer: “Activity induced in the nociceptor and nociceptive pathways by a noxious stimulus is not pain, which is always a psychological state…” (Merskey and Bogduk 1994, p. 210). The IASP in referring to pain automatically means *human* pain, as (presumably) did twentieth-century avant-garde composer John Cage in his curious remark, concerning the global quantification of pain, that the world contains “just the right amount.” These almost automatic responses raise the question of what (beyond nociception) we know, do not know, and cannot know about the largely un-discussed pain of animals.

Cage, steeped in Zen Buddhist ways (Larson 2012), perhaps meant his koan-like paradox to re-orient a companion whom he regarded as over-invested in rational judgments and in computational thought. The sum total of world pain is always unknowable. Who can say what amount is right or wrong? Moreover, Buddhist attitudes toward pain are embedded in a larger account of suffering, or *dukkha*, that ignores Western concepts of an individual ego (Russon 2016). Scraping by as an impoverished composer in New York City, Cage surely encountered enough destitution to absolve his paradox from a flippant denial of real-world misery. The first Noble Truth (a foundation of Buddhist thought) is the maxim that *suffering exists*. From a Buddhist perspective, an affirmation of life does not depend upon the global reduction of either pain or suffering. “Our intention is to affirm this life,” Cage wrote in 1944, amid world war, “not to bring order out of chaos nor to suggest improvements in creation, but simply to wake up to the very life we’re living, which is so excellent once one gets one’s mind and one’s desires out of its way and lets it act of its own accord” (p. 95).

Waking up (a traditional philosophical image for mind-altering inner illumination) implies for Cage letting go of judgment-driven, ego-based, instrumental rationalities that measure, say, which musical performance is better or how much world pain is too much pain. At least in his post-concert riposte, however, waking up did not extend to an explicit acknowledgment that animals too might be included in the sum of world pain.

“Pain is a universal experience,” so begins the blue-ribbon Institute of Medicine report *Relieving Pain in America* (2011), before instantly shifting to a human-centered focus and to computational thought: “Common chronic pain conditions affect at least 116 million U.S. adults at a cost of $560–635 billion annually in direct medical treatment costs and lost productivity” (p. 1). Statistics, while useful in sketching the dimensions of a social or medical problem, cannot of course capture the individual experience of pain. Human pain, whatever its brain-based correlates and biochemical substrates, is a subjective state, fluid, open to multiple environmental influences impossible to duplicate in laboratory settings. One powerful environmental influence today is the commonplace biomedical assumption that pain signifies tissue damage, communicated via nerves and neurotransmitters from the site of injury or inflammation to the brain. Nonetheless, even when the science that supports this near-eradication of meaning seems, like the law of gravity, scripted in the nature of things, human meanings are at stake. William James, pioneering psychologist and the only American philosopher with a degree in medicine, put it this way in *Pragmatism* (1907): “Human motives sharpen all our questions, human satisfactions lurk in all our answers, all our formulas have a human twist” (1975, p. 117). An understanding of pain, even in its most basic logico-scientific dimensions, cannot entirely float free from human motivations, human satisfactions, and human twists.

The pain that the Institute of Medicine report calls “a universal experience” is, of course, the pain of humans, universalized in a reflex gesture that excludes nonhuman animals. John Cage might nod: ego-centered, reason-based, computational mentalities allow many to assume that the only truly significant pain is human pain. The pain of animals—as our behaviours tend to confirm—is not something that most people feel an urgent need to understand and to confront; it yields no startling statistics about annual costs to the U.S. economy computed in billions of dollars. My purpose is not to offer a theory of animal pain but rather to *acknowledge* animal pain and to *address* some of the questions that it implies: at a minimum, to bring nonhuman animals into the discussion of pain. The pain of animals is not an isolated topic, with zero bearing on human pain, as the use of animals in biomedical research indicates. Most important, we will not effectively address the social, medical, and personal costs implicit in human pain, I believe, until we wake up to the pain of animals. That is, when our actions show that we truly care about animal pain, we will already have advanced to a state in which we effectively address the pain of war refugees, migrant workers, rape victims, homeless veterans, and untold millions of sick and hungry children. There are very strong human reasons, if I am correct, to think seriously about the pain of animals.

What little we know about the pain of animals is invisibly entangled in routine assumptions about differences between humans and animals. The IASP defines pain as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (Merskey and Bogduk 1994, p. 210). It is plausible that such a definition, stripped of any reference to psychological and subjective states, might apply to pain in animals, but it is hardly possible to discuss animal pain without asking what constitutes an animal. Here too responses are at best equivocal. The category *animal* exposes the anthropocentric twists and biases that underlie immemorial distinctions that separate animals from humans: *us* from *them*. Various historical eras and cultures characterize the distinction differently, basing the differences on reason, language, tool use, brain size, opposable thumbs, and similar biological endowments that presumably explain human superiority. All such distinctions, however, collapse under scrutiny. Lemurs have opposable thumbs; chimps use sticks as tools; and pigeons display cognitive behaviours. *Animal*, as a classification, spans a huge unwieldy kingdom of domesticated and wild creatures, from whales and snakes to genetically altered mice bred (or, in laboratory jargon, “built”) for use in experiments. Dogs belong to the subcategory of pets, which generally accords them kindly treatment, but humans breed dogs too for companionship, entertainment, herding, hunting, and sport: they are commodities, bought and sold, like the mass-produced stock of puppy-mills. Animal pain thus is inseparably bound up with the distinctive human uses and the self-interested human categories that we invent for animals. The pain of a rabbit torn apart by coyotes falls so far outside human self-interest as to be almost negligible. The insignificance of animal pain, however, is also an entirely commonplace social or individual judgment that depends upon placing humans and animals (at least as regards the experience of pain) into separate and carefully patrolled categories.

The assessment of pain in animals is an important and pragmatic matter in animal welfare not least because it is "required by the law of many countries and by many professional guidelines" (Bateson 1991, p. 827). Research into animal pain is nonetheless, as KMD Rutherford of the Scottish Agricultural College explains, "a difficult task" (2002, p. 31). It is tempting to circumvent the difficulties by claiming that pain in animals is a sensation, whereas pain in humans is a perception. Perception and cognition are certainly crucial to the human experience of pain, but animal cognition is a well-established fact. Zoologist and psychologist Sara J. Shettleworth describes animal cognition as "all ways in which animals take in information through the senses, process, retain and decide to act on it" (2001, p. 277). The eminent biologist and primatologist Frans de Waal (2016) provides a mind-spinning tour through the different modes of cognition demonstrated throughout the animal kingdom. Anatomy and physiology—as reflected in the distribution of nerves and in the complexity of brains—clearly affect the varieties of animal cognition across species, from the dolphin in the pod to the lobster in the pot, but cognition and perception constitute a slippery slope on which to construct valid differences between human pain and the pain of animals. Biological anthropologists, philosophers, and cultural theorists have begun to create a new border-crossing enterprise called animal studies, and the traditional iffy distinctions between humans and animals—often based on deeply flawed human-centered assumptions—underlie the serious, related set of inquiries that scholar Michael Lundblad (2004) calls "The Animal Question." What the unsettled state of the animal question makes unmistakable is that commonsense, legal, or scientific distinctions between humans and animals do not provide a reliable basis for decisions about animal pain.

Do animals feel pain? Of course they do. Our own human-centered leanings—often quite useful, when carefully examined (Daston and Mitman 2006)—are good enough to persuade most people that animals are not the mindless automata that Descartes imagined. Injured dogs will limp or howl; rabbits scream when badly hurt or killed. Many animals display pain-related behaviours that in humans count as strong evidence of pain, and we don't regard it as an anthropocentric flaw to recognize and to respond to signs of pain in a fellow human. Even a very rudimentary nervous system gives nonhuman vertebrate creatures the neurons associated with human pain, and veterinarians have even developed a post-surgical pain patch for dogs (Bekoff 2002). There are now multiple formulations for defining and assessing animal pain: scientists, for example, can match measurable changes in biology, in physiology, and in behaviour with the empirical observation of changes in apparent motivational state, as when a cow avoids an electric fence (Sneddon et al. 2014). Humans have long used pain, like food, as a tool in training animals, but the hard question remains how such animal pain *differs*, if it does differ, from human pain. Human pain comes in numerous varieties, from the stabbing pain of post-herpetic neuralgia, say, or the queasy, blinding pain of migraine, to the dull ache of deep muscle pain or the burning pain of a skin abrasion. Cancer pain may evoke emotions linked with cultural mythologies of illness and with prospective personal fears of death. Does animal pain reflect a similar range or evoke anything beyond a momentary sensation of discomfort?

Animal pain, almost by definition, cannot encompass the more complex cognitive and emotional dimensions intrinsic to human pain. Human pain, through and beyond its underlying neurobiology, is intricately bound up with meanings (Morris 1991, 2010, 2011). Art, religion, philosophy, and literature—among other sociocultural systems, such as slavery and judicial punishment—provide rich illustrations of the meanings that humans attribute to pain, from divine retribution or a mark of sin to a test of stoic reason or the passing of a kidney stone. The pain of childbirth, as one obstetrician advised an expectant mother, is "good pain." Good or bad, redemptive or punitive, medical or mysterious, pain is automatically imprinted with human meanings, including the widespread modern belief that pain is merely a symptom of tissue damage. Chronic pain—as distinct from short-term, stimulus-evoked, acute pain—may last for years in the absence of verifiable lesions (Bennet 2012), and biomedical researchers (focusing largely on chronic pain) have developed clinical instruments to study so-called "pain beliefs," including even a formal Pain Beliefs Questionnaire (Edwards et al. 1992).[1]

Human pain differs from animal pain, as the extensive medical literature on *pain beliefs* suggests, in that what we *believe* can significantly affect the pain we feel; especially beliefs about cause, control, duration, projected outcome, and conscious or nonconscious blame (Jensen and Karoly 1992). Such macro-level beliefs, operating via higher cortical processes distinct from a micro-level physiology, affect chronic pain, acute pain, and even the short-term pain of post-operative recovery. Moreover, such beliefs are often linked with powerful if inarticulate and even unacknowledged emotional states that accompany and infiltrate pain: anger at a negligent employer, fear of a medical catastrophe, hope for financial compensation, affection for an otherwise cold or indifferent spouse whom pain transforms into a loving caregiver. Specific pain beliefs predict pain intensity and social behaviour. Patients function better who believe that they have control over their pain, who believe in the value of medical services, who believe that family members care for them, and who believe that they are not severely disabled. Specific pain beliefs, in one such study, correlated directly with treatment outcomes. Samantha Bunzli and

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[1] On pain belief studies, see Williams and Thorn (1989), Shutty et al. (1990), Williams and Keefe (1991), Williams (1996), Pons et al. (2012), Tan et al. (2015), Arcury et al. (2015) and Williamson et al. (2015).

colleagues explore relationships between perceived control over pain and belief in Chap. 14.

"*The brain*," writes distinguished neurosurgeon John D Loeser, "*is the organ responsible for all pain*." "All sensory phenomena," he adds, "including nociception, can be altered by conscious and unconscious mental activity" (1991, pp. 215–216). The brain of course connects us to our environments, and research shows that numerous variables, from job stress to substance abuse, can influence pain in a complex biological and cultural mix.[2] Such variable biocultural influences are highlighted in a study showing that chronic low back pain patients in Japan proved less impaired (in psychological, social, vocational, and avocational function) than similar patients in America (Brena et al. 1990). The key point is that biomedical research—even in creating new animal models of chronic pain more responsive than the familiar tail-flick, hot-plate, and abdominal constriction tests—has produced strong clinical evidence that humans experience pain as inseparable from emotionally charged personal, social, and cultural meanings. True, researchers using "animal models" have recently begun to study chronic pain in genetically altered mice predisposed to anxiety and depression (Mogil and Crager 2004; Mao 2009, 2012), but anxiety, depression, and similar conditions in humans often involve specific sociocultural triggers. Two well-known pain specialists argue persuasively that patients will benefit if medical students are taught to focus less on the micro-level, cellular biology of pain and more on its macro-level psychological, social, and cultural components (Carr and Bradshaw 2014).

Meaning and belief are distinctive human products, and it thus would follow that the pain of animals (in whom cognition is *not* mediated through belief, reason, and language-based meaning) must go on in a profoundly nonhuman dimension. We cannot say precisely what animal pain is (or is like) but its fundamental *otherness*—its intrinsic difference from human pain—seems clearly established. This otherness, released from an us/them narrative of human disdain, is precisely what we need to address.

2 The Otherness of Animal Pain

The otherness of animal pain might be addressed indirectly through the famous question posed by philosopher Thomas Nagel (1974): what is it *like* to be a bat? His essay concerns the difficulties of obtaining reliable objective data about inner subjective experience, and bats—the world's only flying mammals—served as his surrogate for any nonhuman creature whose interior subjective life by definition cannot resemble human experience. Bats, that is, depend upon a sonar-based brain that guarantees perception utterly alien to ordinary human experience. Nagel

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[2] On the mix of cultural and biological influences on chronic pain, see Bates et al. (1993), Unruh (1996), Breitbart et al. (1996), Fillingim et al. (2009) and van Middendorp et al. (2010).

labours to work free from a limited, human-centered perspective on nonhuman experience. It just can't be done:

> Our own experience provides the basic material for our imagination, whose range is therefore limited. It will not help to try to imagine that one has webbing on one's arms, which enables one to fly around at dusk and dawn catching insects in one's mouth; that one has very poor vision, and perceives the surrounding world by a system of reflected high-frequency sound signals; and that one spends the day hanging upside down by one's feet in an attic. In so far as I can imagine this (which is not very far), it tells me only what it would be like for *me* to behave as a bat behaves. But that is not the question. I want to know what it is like for a *bat* to be a bat. Yet if I try to imagine this, I am restricted to the resources of my own mind, and those resources are inadequate to the task (p. 439).

Research integrating brain scans with psychophysical data may begin to generate reliable biomarkers of *human* pain, but such research cannot tell us what it is like to be a bat, or a badly injured bat, or a lab rat on a hot plate, or a horse beaten by its owner, or a whale shot with an explosive harpoon grenade. Steel canisters of a nitroglycerine-like compound threaded onto the tip of a harpoon explode when they penetrate about 18 in. into the whale. Such exploding grenades yield a poor rate of instantaneous kills (Norway and Iceland, but not Japan, use more expensive and efficient grenades). What is it *like* to be a whale shot with an inefficient, inexpensive exploding grenade?

Animal pain as a subject and as an experience will lie wrapped in confusion and in conflicting assumptions unless we acknowledge that animals—or at least certain higher vertebrates—experience emotion. Emotion represents one strong connection between human pain and animal pain, and the emotions of animals have recently come into sharper focus. According to biologist Marc Bekoff in *The Emotional Lives of Animals* (Bekoff 2007): "Scientific research in evolutionary biology, cognitive ethology, and social neuroscience supports the view that numerous and diverse animals have rich and deep emotional lives. Emotions have evolved as adaptations in numerous species, and they serve as a social glue to bond animals with one another" (p. xviii). Emotions are far more difficult to observe in wild animals than in domesticated species, and even rare scholars such as primatologist Jane Goodall (who studied chimpanzees in the wild for some 55 years) and renegade animal trainers with horse-whisperer rapport cannot give us an understanding of animal emotion *from the inside*. Animal emotion too possesses an intrinsic otherness, even if scientific journals and the popular press, as Marc Bekoff observes, regularly publish stories and reports on joy in rats and grief in elephants. No doubt similarities abound. Still, we do not know what a dog feels when starved and left to die. Anthropomorphic dancing penguins and singing bluebirds help to expose the presumption behind attributing identical complex human states such as love or loyalty to animals. Animal pain, while its underlying nociceptive and emotional processes may resemble the neurobiology of human pain, remains finally as *alien* as whatever interior states correspond to the sound-dense, upside-down, insect-centered life-world of a bat.

3 Animal Pain: Why it Matters

What does recognizing and respecting the alien quality of animal pain imply for us as patients, doctors, researchers, family members, citizens, and moral agents? A natural language (English, French, Arabic, for example) is our evolutionary and biocultural birthright as humans, dependent upon highly evolved cortical structures and an upward migration of the larynx, so that from an early age we can discuss what we feel with fellow speakers, exchanging information on interior states such as grief, love, and pain. Natural languages also facilitate our inclusion in cultures and subcultures that shape what we feel and believe, including our beliefs about pain. Language allows us to fake or pretend to have feelings, of course, but fraudulent claims of pain are instances of fraud, not pain. There is no alternative to using language in discussing animal pain—no mathematical formulas or pure Euclidean forms—so that it requires vigilance to make certain that our discussions avoid the anthropomorphic biases already built into various natural and professional languages. One particularly noxious anthropocentric bias (expressed in words, in expressions, and even in implicit micro-narratives) suggests that the pain of animals, all things considered, doesn't really matter.

What really matters, so this implicit anthropocentric and linguistic narrative goes, is human pain. Humans, according to a biblical narrative at the heart of Judeo-Christian culture, were assigned "dominion" over the animals. God, of course, assigns such dominion in Genesis, but it is humans who wrote down the words, who perpetuated the claim of dominion, and who extended it to an implicit right to inflict pain on animals in our self-interest. If animal pain will advance higher or urgent human interests, such as the war on cancer or tonight's dinner or a return on investment, then human needs trump animal pain. Human interests often turn out to be commercial interests—the profit of pharmaceutical companies, salary lines, professional advancement—since it is hard to imagine what interest beyond commercial profit could be served in slowly killing a whale with an exploding harpoon grenade. George Bernard Shaw, deploring the use of vivisection in medical science, wrote in his preface (1909) to *The Doctor's Dilemma* that are countless paths to knowledge, but only one path runs through deliberate cruelty. Philosopher H. Tristram Engelhardt, Jr., in an essay with the title "Animals: Their Right to Be Used," makes an ethical case (based on concepts of moral agency) in favour of medical experiments using laboratory animals (2001).

Is there in fact a "right"—as distinct from immemorial custom or from anthropocentric privilege—that gives humans a free pass to use animal pain for human purposes? If so, who bestowed it? God? The United Nations? There are distinguished animal-rights philosophers who would strongly dispute Engelhardt's conveniently human-centered argument that transforms other living beings into objects or property useful in the acquisition of experimental knowledge. The deliberate infliction of pain on a living creature, animal or human—for any purpose—would count for Shaw as cruelty. It did not matter to Shaw whether the creature is humanly re-classified as a "lab animal" used, say, to test an advanced computerized Rat Grimace Scale that can quantify rat pain through a menu of facial expressions

(Sotocinal et al. 2011). Rights, Engelhardt acknowledges, are created by humans—*for* humans, I would add—and presumably humans can therefore also create a twenty-first century biocentric "right" for animals to live free from human purposes, or at least free from the deliberate infliction of a pain that we simply do not and cannot comprehend.

A bias or presumption or narrative implying that the pain of animals is wholly meaningless—inconsequential, unworthy of notice, devoid of value—is a human assertion of meaning. Animal pain is assigned the meaning that it has no meaning. Meaninglessness, as one of the more toxic meanings that humans attribute to animal pain, is also an assumption that, historically, humans have attributed to the pain of enemies, slaves, women, children, minorities, and almost anyone (or anything) that, in their apparent absence from the centres of power, occupies the fluid category of the Other. The pain of the Other doesn't matter; it is inconsequential; legally, without standing: just plain meaningless. This unfortunate history is still ongoing, implicit in recent political disagreements about what manner and degree of prisoner-abuse constitutes torture, even as it underlies the military use of drones and definitions of collateral damage. The Other is by definition a site where pain does not figure into the discussion. Assumptions about the meaninglessness or insignificance of animal pain are profoundly meaningful in their implications, however, and intersect with urgent issues in ethics and in medical ethics.

Official codes and ethical guidelines can sometimes serve a secondary use in public relations. The various ethical guidelines regarding animal pain are riddled with professional self-interest, loopholes, and confusions. My individual ethical practice, hardly free from contradiction, leans toward "the ten trusts" that humans can make with the animal world, described by Goodall and Bekoff (2002), and sometimes I surely break trust. From an ethical point of view, however, what matters most (beyond individual self-correction) is a serious discussion of animal pain. Such a discussion can get the disagreements, confusions, and self-interested loopholes out into the open; it can articulate significant differences or points of conflict among the discussants; and it can identify possible areas of agreement, while also honoring the claims of minority positions (Bennet and Gibson 2006). Such a self-critical enterprise provides a crucial medium for waking up. If animal pain, as experienced by a lab rat or whale, may always proceed in a dimension inaccessible to human experience, what we think and what we say about animal pain is available for analysis, debate, and full discussion. Pain resides with the animals, but the meanings we assign to animal pain are a vital human concern.

The stakes are high in acknowledging the otherness of animal pain. Philosopher Ludwig Wittgenstein famously observed that if a lion could talk, we still could not understand, but a talking lion would cease to be a lion. Humans are the *only* talking animals, and natural languages give us a rich opportunity to talk about animal pain, including the reductive meanings that we attribute to it and the pragmatic ways in which we might be of help. Drugs are not likely to produce a panacea solution, since they now constitute a huge dilemma in the response to human pain. OxyContin, marketed to physicians in a multimillion-dollar, military-style campaign, has done great unintended harm, and its kindred opioid painkillers now account for more deaths annually in the United States than heroin (Zee 2009).

Drugs at least give us a significant measure by which to estimate the current status of animal pain. Black Americans, a recent study shows, are (relative to white Americans) systematically undertreated for pain, and this racial bias is related to false beliefs about biological differences between blacks and whites (Hoffman et al. 2016). Explicit false beliefs, however, are easier to correct than the soft systemic violence that—far more than overt racism—affects the unequal treatment of ethnic and racial minorities. Numerous studies confirm racial, ethnic, and even gender-based bias in the medical treatment of pain.[3] When humans systematically undertreat other humans for pain, at times on the basis of demonstrably false beliefs, at other times on the basis of simple otherness, it will take significant culture-wide change to undo the biases that encourage us not only to ignore the pain of animals but also to *justify* the continued neglect or deliberate callousness as somehow reasonable and right.

There is a valid human-centered and even clinical interest at stake in changes that re-address questions of animal pain. Concern for animal welfare, on a planet that sustains life through networks of interconnected global ecosystems, is finally inseparable from a concern for human welfare, and neither concern requires a full understanding of pain. We do not and cannot know what it is like to be an animal in pain, but such knowledge is not necessary in order to turn away from deliberately inflicted pain, cruel or routine, and instead to choose pain-relief and an avoidance of pain. A deliberate questioning of human biases and assumptions concerning animal pain are at least as necessary as additional research into nociceptive pathways and neurobiological processes. Meaning is always a human meaning. Animals feel pain in a realm *beyond meaning*.

John Cage at age 65 exhibited a portfolio of prints (*Seven Day Diary*) completed during an invited 1-week crash course on etching: “an activity,” he told interviewer John Ashbery, “that would be characterized by the fact of my not knowing what I was doing.” Ashbery, understanding Cage’s preference for chance events and aleatory patterns, then asked what the advantage was of *not knowing what you are doing*. Cage replied: “It cheers up the knowing” (Ashbery 1978, p. 69). A cheerful Cage-like affirmation of the *not-knowing* always at play in the otherness of animal pain—combined with a knowledgeable and serious twenty-first-century biocentric (as opposed to anthropocentric) program to address pain in *all* creatures great and small—may do far more to relieve the ignored, untreated, and undertreated pain of both animals and humans than countless validations of the (no doubt humanly useful) Rat Grimace Scale.

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[3] On the influence of race, ethnicity, and gender in undertreatment for pain, see, for example, DePalma (1996), Stephenson (1996), Morrison et al. (2000), Green et al. (2003) and Trawalter et al. (2012).

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