Exploring the experience of neuropathic pain following spinal cord injury: An

Interpretative Phenomenological Analysis study

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Abstract

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Research exploring pain following spinal cord injury (SCI) is largely quantitative, with very little known about what it is like to live with pain after SCI. In response to inconsistencies and the dearth of qualitative literature in this area, this study investigated the lived experience of neuropathic pain (NP), following SCI. This was conducted using semi-structured interviews with 16 people living with SCI-specific NP that had been present for a minimum of three months. Eight participants were inpatients in a rehabilitation centre, aged between 23 and 82, and eight were outpatients living in the community, aged between 26 and 77. Data from each sample were analysed separately using the qualitative methodology of Interpretative Phenomenological Analysis (IPA). For outpatients, three themes emerged: (1) the chasm between biomedical perspectives and patient needs and beliefs; (2) the battle for ultimate agency in life; and (3) the coexistence of social cohesion and social alienation. For inpatients, four themes emerged: (1) using metaphors to describe NP; (2) the spectrum of medication experience; (3) interpreting the hospital environment; and (4) thinking about the future. The results suggest that chronic NP is experienced in a biopsychosocial manner, and should be treated in such a way. In particular, participants felt that medication was heavily relied upon by healthcare professionals, despite limited efficacy, and articulated a desire for collaborative approaches to pain-management. Issues surrounding acceptance of NP, and its social impact, were also discussed. The involvement of significant others in pain management may improve communication and psychosocial outcomes. Promoting acceptance may be effective in facilitating psychological, and social well-being. Cognitive treatment incorporated with acceptance- and mindfulness-based interventions (MBIs) may encourage adaptive responses to, and interpretation of, pain.

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Finally, I want to extend thanks to my very special family for their continued support, love, and sacrifice, throughout the toughest, but most enjoyable, three years of my life so far.

Abbreviations

ACT	Acceptance and Commitment Therapy
ASIA	American Spinal Injury Association
CA	Content Analysis
CBT	Cognitive Behaviour Therapy
CNS	Central nervous system
CR	Conditioned response
CRPS	Complex regional pain syndrome
CS	Conditioned stimulus
CT	Computerised tomography
EEG	electroencephalographic
IPA	Interpretative Phenomenological Analysis
MBCT	Mindfulness-Based Cognitive Therapy
MBI	Mindfulness-Based Interventions
MBSR	Mindfulness-Based Stress Reduction
MCC	Mid cingulate cortex
MRI	Magnetic resonance imaging
NP	Neuropathic pain

RTA	Road traffic accident
SCI	Spinal cord injury
SoC	Sense of coherence
tDCS	Transcranial direct current stimulation
US	Unconditioned stimulus
QoL	Quality of life
WWII	World War II

Table of Contents

List of Figures

List of Tables

Declaration of Originality

I hereby declare that my thesis entitled 'Exploring the experience of neuropathic pain following spinal cord injury: An interpretative Phenomenological Analysis study' is the result of my own work and includes nothing which is the outcome of work done in collaboration except as declared in the Preface and specified in the text, and is not substantially the same as any that I have submitted, or, is concurrently submitted for a degree or diploma or other qualification at the University of Buckingham or any other University or similar institution except as declared in the Preface and specified in the text. I further state that no substantial part of my thesis has already been submitted, or is concurrently submitted for any such degree, diploma, or other qualification at the University of Buckingham or any other University or similar institution except as declared in the Preface and specified in the text.

Signature: **Date:**

Chapter 1 **Introduction to Pain**

Pain is described by Merskey (1979) as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage" (p. 249). Pain can be divided into acute and chronic pain. Acute pain may begin suddenly, is of short, limited duration of less than three months (The International Association for the Study of Pain; IASP, 1994), and is often an evolutionarily protective mechanism that forces action in order to prevent further damage (Craig, 1999). This is particularly effective in terms of learning pain-avoidance strategies. The IASP (1994) define chronic pain as any persistent pain over a period of three months or more, and not necessarily caused by tissue damage. Three months is the cut-off point as chronic pain is likely to have exceeded the expected healing time (Turk & Okifuji, 2002). Such pain, however, can be significantly debilitating, with potential consequences including psychological distress, fear, and disability (Eccleston, Crombez, Scotford, Clinch, & Connell, 2004; McBeth, Macfarlane, & Silman, 2002).

In evolutionary terms, pain is an adaptive, aversive mechanism serving a beneficial purpose; warning an individual to take action and seek treatment when something is physically wrong (Melzack & Wall, 1988). This may be particularly true for acute pain, which often has an identifiable cause, such as injury or disease, as well as an identifiable treatment (IASP, 1994). Chronic pain, however, may be considered a maladaptive experience, as it often does not appear to serve any beneficial function, and cause and treatment may be more difficult to identify. In addition, chronic pain may not

respond adequately to pharmacological treatment, particularly where there may be no organic cause (IASP, 1994), suggesting a need for an improved understanding of chronic pain in order to develop specific, effective treatments and programmes for it.

The widely accepted view of pain comes from the biopsychosocial model (Engel, 1977). This approach posits that pain arises from, and causes, a dynamic and complex combination of biological (such as physical damage), psychological (such as cognitive appraisals, mood), and social factors (such as responses from others), each of which plays a considerable role in the experience and treatment of pain. It is not possible, therefore, for pain to be separated into distinct components, and biological, psychological, and social factors (specific to the needs of the individual) should be addressed in order to reach satisfactory pain management.

Pain, therefore, is a complicated phenomenon, with multiple theoretical perspectives attempting to explain and understand it, including biological, cognitive, behavioural, cognitive-behavioural, and social perspectives. Many theories offer contributions to the understanding of pain in their own right, but many may also hold disadvantages, such as a lack of sufficient explanation of the pain experience. Biological theories explain how pain has a biological underpinning, whilst other theories explain how psychological and social factors contribute towards the experience of pain. This chapter will outline predominant theories of pain, in light of contemporary research and the biopsychosocial model.

1.1 Biological Theories.

Many early theories of pain arose with a biological perspective, including little or no psychological contribution, positing that bodily functions and nerve responses cause pain. In biological theories, the experience of pain is underpinned by biology, as it is an experience within the body, separate from the mind. Biological theories explain how pain is felt as a physiological consequence of bodily tissue damage (nociception). Arising from this damage, signals travel through A-delta and C polymodal nerve fibres from the injury to the brain. A-delta fibres are myelinated, meaning that pain signals are conducted at a faster rate than by unmyelinated C polymodal fibres, thus causing the sufferer to perform protective actions. These may include retracting from the painful stimulus, and are carried out in attempts to protect the body from further physical harm.

The earliest biological theories, including *Summation*, or *Pattern, Theory* (Goldschneider, 1920), and *Specificity Theory* (Dubner, Sessle, & Storey, 1978), suggest that pain perception follows specific patterns from the location of damage to the brain, as in hearing and sight. Specificity theory suggests that A delta and C polymodal fibres transmit touch and pain signals via specific pathways to a specific 'pain centre' in the brain. By contrast, Summation Theory, a neurophysiological model, posits that an area of the spinal cord holds a modulating dorsal horn that receives sensory input from the body, such as touch and vibrations, and relays that information to the brain. Summation theory argues that pain is experienced when repeated low-level stimulation occurs, travelling along A delta fibres, and builds up in the dorsal horn, until a critical threshold for pain perception is exceeded. When this threshold is exceeded the pattern of signals is then transmitted to the brain and perceived as pain. However, patterns of neural firing

are difficult to locate, and it may be difficult to specify how these patterns occur (Baxter & Olszewski, 1960).

Both specificity and summation theories are outdated, and there remains no evidence for a specific pain centre in the brain (Craig, 2003). Additionally, cases of Congenital Universal Insensitivity to Pain (CUIP), in which the sufferer is unable to feel pain, pose problems for this theory, particularly as A delta and C polymodal fibres remain intact despite the loss of pain perception (McMurray, 1975). Further, the brain is actively involved in the selection and abstraction of information from sensory input (Melzack & Katz, 2012), meaning that pain perception is not a result of information ascending to the brain alone, but a complex relationship between ascending and descending pathways. Such theories fail to explain why pain may exist where no injury occurs, as in phantom limb patients, and those with comparable injuries who perceive pain differently (Beecher, 1956). Beecher suggested that pain perception might be dependent on various other factors. Differences were found in requests for pain relief between soldiers and civilians, despite comparable injuries, suggesting that meaning attached to an injury may moderate the experience. This resulted in the introduction of psychological, social, and environmental factors in pain theories.

Melzack & Wall (1965) attempted to respond to deficits in previous theories by incorporating psychological factors, consequently advancing the *Gate-Control Theory*. Melzack and Wall suggest that the dorsal horn of the spinal cord acts as a gate that is regulated by cognitions, emotions, psychological and social states. Pain impulses are transmitted to the Central Nervous System (CNS). Before reaching the CNS, however, pain impulses travel to the gate in the dorsal horn, at which point, the gate may be

'open' or 'closed'. The state of the gate either facilitates or inhibits the transmission of pain impulses to the brain. Three spinal cord systems receive sensory input transmitted from painful stimuli: receptor cells in the dorsal horn, which modulate the patterns of sensory input; dorsal fibres that transmit information to and from the brain, influencing the gate; and the central transmission cells (T-cells), which activate perception and response systems to pain. Central to gate control theory is the suggestion that pain transmission may be modulated by psychological and social influences, such as beliefs about pain and the ability to cope with it, anger, depression, and happiness.

An individual is considered to be in a positive psychological state when the presence of endogenous opioids such as endorphins are noted (McCaffrey & Locsin, 2002). In this state, a person may interpret pain as less threatening, and as such the gate 'closes', thus inhibiting pain transmissions and acting as pain relief. In contrast, where an individual is in a negative psychological state such as fearful, sad or anxious, neural activity is promoted and they may interpret pain as more threatening, so the gate may be more 'open', allowing faster pain transmission through to the brain (Melzack & Casey, 1968). There is still no direct evidence for this 'gate', however, and it fails to explain individual differences in experiences (e.g. intensity) of the same pain (Melzack, 1999). Further, this model is still based around a simple stimulus-response process in which it is assumed that there is an organic cause of pain and views the mind and body as two separate entities.

Whilst Gate Control Theory highlighted the CNS as an essential component of the pain experience, Melzack (1999) argued the need for a deeper understanding of brain function in relation to pain, which led to the development of *Neuromatrix Theory*. The

neuromatrix is made up of three processing networks, working in parallel with one another in order to understand pain: the sensory-discriminative network, in which ascending neurons from the stimulus to the brain indicate the location and nature of the pain (such as quality and intensity); the motivational-affective network, in which the limbic system controls emotion regulation and behavioural responses such as retracting from painful stimuli; and the evaluative network, in which psychological evaluation of pain occurs, arising from the context, the individual's cultural values, and their current cognitive state. Each individual has their own unique neural networks within the neuromatrix, called the 'neurosignature', which is built in by genetic specification and modified by their own previous experiences of pain.

Neuromatrix Theory provides an explanation for the differences in pain experience, accounting for pervious physical, psychological, and social experiences, which may alter pain perception. Whilst neuromatrix theory of pain specifies individual pain perception, recent neuroimaging identifies that specific modules for pain do not exist. Rather, pain perception in the brain involves networks and the central nervous system (Bassett & Bullmore, 2009), demonstrating how the brain structure may undergo plasticity (altered networks) in cases of chronic pain (Baliki et al., 2006).

Biological theories place focus on mind-body dualism, and rely on stimulus-response processes, assuming that pain still has a biological cause. Thus biological theories fail to acknowledge how thoughts and physical damage influence the other, as well as how external influences such as cognitive appraisals, perceptions and past experience, behavioural responses and reinforcement, and social influences such as communication of pain and familial responses, impact upon the pain experience. Each of

these factors may influence pain perception and will be discussed further here.

1.2 Behavioural Theories.

Behavioural theories of pain build upon the shortcomings of biological theories, focussing upon behavioural responses to pain, such as somatic tension, muscle spasm, and exaggerated perceptions of pain, all of which can maintain pain. Such behavioural responses may be reinforced in a process of conditioning (Vlaeyen & Linton, 2012). *Operant Conditioning* (Skinner, 1937) denotes that behaviours are sustained or weakened by their consequences, which may involve reward or punishment. For acute pain, the response of withdrawing from a painful stimulus subsequently reinforces the avoidance of that painful stimulus in the future. Similarly, when pain occurs as a result of a particular behaviour, the individual may become fearful of engaging in that behaviour again, reinforcing the avoidance of behaviours that induce pain. Vlaeyen and Linton (2000) termed this the fear-avoidance model, which will be discussed later (page 16). Whilst avoiding behaviours that result in pain may offer benefits in terms of acute pain (Slade, Troup, Lethem, & Bentley*,* 1983), it may conversely exacerbate pain and turn it into a chronic problem (Waddell, Newton, Henderson, Somerville, & Main*,* 1993).

Pain conditions may be further exacerbated by the receipt of beneficial gains such as solicitous responses from friends and family, and financial benefits. This rewards serves to positively reinforce pain-avoidance behaviours in order to continue receiving such gains. In vivo exposure, in which patients are gradually exposed to the

stimulus, allows new, non-threatening associations to be made with pain, thus reducing fearful avoidance of activity of it, supports this model, with studies indicating reductions in fear and anxiety associated with pain (Bailey, Carleton, Vlaeyen, & Asmundson, 2010; den Hollander et al., 2010). This model, however, only accounts for development and maintenance of pain problems, whilst other factors such as fear, may determine the progression of chronic pain, as opposed to the personal behaviour alone (see page 16).

Classical Conditioning (Pavlov, 1927) posits that behaviour is learned through associations between paired stimuli. As pain is an important motivator in learning (threatening actual or potential bodily harm), it is considered an unconditioned stimulus (US) that becomes anticipated through knowledge of associations between neutral cues such as a particular movement (conditioned stimulus, CS). Where an individual repeatedly learns that CS causes them pain, they may withdraw from taking part in activities that cause the pain. This withdrawal becomes the conditioned response (CR) that may be more likely to occur where individuals fear the CS may occur, as they attempt to avoid the pain. Individuals gain information about associations between other stimuli and the US from direct experiences, through verbal instructions conveying negative information (Vlaeyen et al., 2009) and via observations that are sufficient to install fear (Goubert, Craig, & Buysse, 2011). For example, muscular tension may become a CR when induced by a fear of pain, whilst activity avoidance may become a CR through the observation of another individual engaging in the activity. Knowledge of associations may lead to hypervigilance, further reinforcing the CR (Vlaeyen & Linton, 2000). Such expectancies can, therefore, lead to increased perception of pain, and maladaptive coping efforts to avoid future potential pain.

Again, behavioural theories focus upon the impact of threat and fear upon responses to pain, therefore are concerned with the emotional impact of pain, but fail to acknowledge the influence of cognitive and affective factors, such as cognitive appraisals and meanings of pain, whilst also neglecting the social context. Behavioural theories tend to treat individuals as passive respondents, whose internal and social lives do not play a role. Pain behaviours may also be reinforced by the responses of the sufferer's immediate social network, such as solicitous responses, and may conversely play a role in the family's ability to cope with the sufferer's pain and consequent behaviours. As such, similar environmental contexts may produce a variety of responses to pain, rather than fear and avoidance alone. Such ideas are difficult to explain without utilising cognitive theories, as follows.

1.3 Cognitive Theories.

Cognitive theories focus on attention, appraisals, and distorted judgements that may provoke pain, and often refer to the individual's beliefs, self-efficacy, feelings of hopelessness and uncertainty, anxiety, and a lack of control, that then promote pain intensity and prevalence (Turk & Flor, 1999). According to Lazarus (1991), where pain is present in a situation where it should not be, or has no known origin, it may challenge pre-defined meanings of what should and should not cause pain. Past experiences are used as templates to determine appropriate emotional and behavioural responses in present situations. Where present experience challenges previous experience, distorted judgements of pain, such as exaggerated negative appraisals involving fear and worry,

may be induced, thus maintaining pain and preventing the use of more therapeutic

appraisals of pain (Lazarus, 1991). Examples of distorted thinking patterns are

highlighted in the following discussion of cognitive theories of pain.

One such distorted reaction to pain is *catastrophising*, in which exaggerated

negative and unrealistic appraisals, including worry and helplessness towards actual and

anticipated pain, are prominent. The high degree of stability that catastrophising has

(Sullivan, 2012), means that individuals may begin to fear that anything they do will

cause a flare up of pain, with this worry may often becoming more disabling than the

pain itself (Crombez, Vlaeyen, Heuts, & Lysens, 1999). The vast majority of the

available literature suggests that catastrophising is one of the most powerful predictors

of increased intensity of pain, psychological health problems and disability (Sullivan et

al., 2001; Keogh & Asmundson, 2004) with greater levels of catastrophising predictive

of a reduction in perceived quality of life and general health (Borsbo, Gerdle, &

Peolsson, 2010). Multiple investigations have established correlations between

catastrophising and psychological issues such as depression and anxiety (Sullivan &

D'Eon, 1990), as well as attachment styles, with high catastrophisers more likely to be

insecure and anxious (Tremblay & Sullivan, 2010). This work suggests that

catastrophising is a maladaptive cognitive coping mechanism, posing risks to pain-

related outcomes and psychological well-being, thus promoting pain's prevalence.

In contrast, however, Sullivan (2012) argues that catastrophising may play a

functional role, and is not always a predictor of psychological problems. He posits the

Communal Coping Model of Pain Catastrophising, in which exaggerated pain

behaviours are displayed as a means of coping and social communication, conveying

information in order to maximise the proximity of others, gain assistance, and elicit empathy. This theory arose from evidence highlighting the increased use of pain behaviours by high catastrophisers in the presence of a researcher, as opposed to reductions in pain behaviours when alone (Sullivan, Adams, & Sullivan, 2004). Further, a number of studies indicate that catastrophising is the central predictor of disability and depression (Nieto, Miró, Huguet, & Saldaña, 2011), emotional distress, and long-term pain intensity (Soderlund, Olerud, & Lindberg, 2000) in chronic pain patients. Results of these studies indicate that catastrophising may offer benefits in that it elicits solicitous responses and understanding from others. Whilst this may be beneficial in terms of preventing the exacerbation of an injury in acute circumstances, excessive reliance upon others in chronic pain situations, rather than upon individual autonomy, may risk the reinforcement of pain behaviours and the exacerbation of pain, as implied by behavioural theories. Catastrophising, therefore, appears to play an influential role in the experience of pain, psychological well-being, and the coping strategies adopted in chronic pain patients, making it an important factor to target in pain management.

A second distorted response to pain might be the belief that they are not well when they are in pain. Psychological adjustment to chronic pain may be dependent on the extent to which the future hoped-for self is conditional on the absence of pain (Pincus and Morley, 2001). Pincus & Morley propose *Self-Pain Enmeshment Theory*, in which a client might believe that to be 'healthy' is conditional on the absence of pain, thus whilst they are in pain they believe that they are in a state of bad health. If an individual's hoped for self-representation (ideal self) is dependent upon the absence of pain in this way, then these schemas are considered enmeshed and may influence each

other as a result of this. When self-discrepancies exist between the ideal self and actual self, these signify the absence of positive outcomes for the individual (Higgins, 1987), and are correlated with more severe pain, depression, and psychological distress in chronic pain patients (Waters, Keefe, & Strauman, 2004). For example, those whose self-perceptions are enmeshed with pain, and are more likely to suffer depression (Morley, Davies, & Barton, 2005), which may subsequently influence pain threshold and tolerance. Thus, cognitive states can worsen pain, which can then worsen cognitive states in a negative feedback loop.

Such enmeshment means that positive psychological adjustment to chronic pain is less likely, whilst the patient is at increased risk of psychological dysfunction, maintained distress, and illness behaviours (Pincus and Morley, 2001). Where enmeshment is not apparent (the self-schema is not conditional upon the absence of pain), the individual is likely to be more positively psychologically adjusted. Self-pain enmeshment has been associated with anxiety and depression (Morley, Davies, & Barton, 2005; Sutherland & Morley, 2008), as well as an increased risk of selectively processing pain and illness stimuli (Pincus & Morley, 2001). Whilst this model is valuable in appreciating differences in goals with regard to pain, it fails to provide ways in which pain sufferers might prevent enmeshment, or become 'un-enmeshed'. Such enmeshment may also lead individuals to search for inappropriate resolutions to their pain and enmeshment.

Eccleston & Crombez's (2007) *Misdirected Problem-Solving Model* (see Figure 1.) suggests that worry may be a mediator of pain that also functions to motivate problem solving behaviours in order to resolve the threat of pain. However, in the case

of chronic pain, looking for causes and treatments may result in the worsening of pain, as it often has no cause and may be resistant to treatment (Morley & Eccleston, 2004). Rather than trying to alter or 'cure' pain, the suggestion is that those with chronic pain should learn how to lead a high quality of life with pain present (McCracken, 1998). Importance is placed on the aim of pain acceptance; particularly due to increasing evidence suggesting that acceptance of pain is a predictor of reduced psychological distress (McCracken, 1998; McCracken & Eccleston, 2003). Prolonged efforts to 'solve' the problem of pain may cause the individual to become 'stuck' in a 'perseverance loop', in which they continuously aim to resolve their pain. When attempts fail, worry increases, causing further distress, hypervigilance, and demand of attention (Eccleston, 2001), which in turn motivates the individual to continue to seek solutions. This model is beneficial for those with a propensity to worry and frame pain in a biomedical perspective, but does not consider other cognitive factors that may influence one's behaviour, nor the social context of pain.

Figure 1. Misdirected Problem-Solving Model (taken from Eccleston & Crombez, 2007).
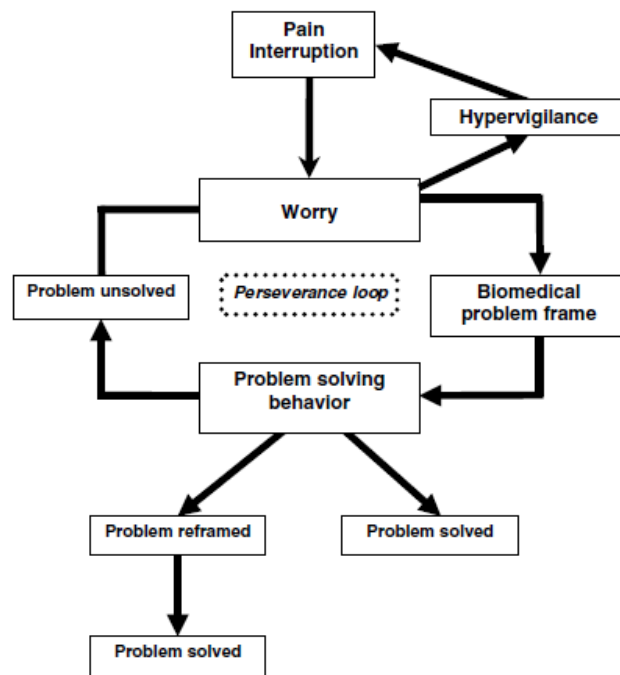
The Neurocognitive Model of Attention to pain, proposed by Legrain and

colleagues (2009), adds a cognitive aspect to a motivational model of attention (Norman

& Shallice, 1986), which suggests that attention is allocated to goal-relevant

information, whilst irrelevant information is inhibited. In the neurocognitive model, two

modes of attentional selection are proposed; bottom-up and top-down. Bottom-up

attentional selection is the capture of attention by novel and salient stimuli that contrasts

with other environmental stimuli. Pain automatically captures attention in this way,

ensuring that behaviour aimed at avoiding any bodily threat is prioritised. This has been

supported by neurological studies that show increases in activity in the midcingulate

cortex (MCC) in novelty detection (Downar, Crawley, Mikulis, & Davis, 2002) and

behavioural control (Botvinick, Cohen, & Carter, 2004). Top-down processing is an

intentional, goal-directed approach that prioritises information by its relevance to the

current situation and modulates the attentional load. In this, stimulus-specific neurons

are amplified or inhibited, depending on their relevance to the stimuli in the environment. In relation to chronic pain, when an individual distributes more attention to their pain, it is likely to be exacerbated, demanding further attention (hypervigilance), and consequently impairing performance in cognitively demanding tasks (Hart, Martelli, & Zasler, 2000). If more attention is invested in a cognitively demanding task, there is less risk of attentional capture by pain (Lavie & de Fockert, 2006).

Evidence supportive of the neurocognitive model of attention, has found that, in the presence of chronic pain, reductions occur in task performance (Eccleston, 1995), catastrophic thinking (Heyneman, Fremouw, Gano, Kirkland, & Heiden, 1990; Sullivan, Bishop, & Pivik, 1995), and the threat of impending pain (Eccleston, De Williams, & Stainton-Rogers, 1997). The neurocognitive model of attention, therefore, suggests that cognitive investment in a demanding distraction task is likely to reduce the risk of attentional capture by pain (Eccleston & Crombez, 1999), therefore reducing the intensity of pain felt. Verhoeven et al. (2010) found evidence to inform clinical practice through a study inducing experimental pain and using distraction in order to reduce it. Some participants were given a financial motivation distraction task of pressing a button correctly after hearing a tone. Others were given the same distraction task without financial motivation. A non-distracted control group was also used, with findings identifying reduced pain intensity in both distraction groups compared with controls. This provides evidence supporting the motivational model and neurocognitive model of attention and confirmation of the impact of attentional demands and resources on chronic pain.

Cognitive models are supported by a vast body of available literature, and offer insightful explanations for the persistence of pain. Such models, however, fail to account for behavioural variables that may influence the pain experience, and the social context in which pain occurs, which may play a role in reducing or exacerbating pain. Borsbo, Gerdle & Peolsson (2010) conclude that a complex interaction exists in the experience of pain, involving psychological factors, as well as behavioural and social factors. They suggest that, in order to develop an adequate pain management programme for the treatment of chronic pain, it may be meaningful for the evidence base to assess how cognitions and behaviours interplay to influence the experience of pain.

1.4 Cognitive-Behavioural Theories.

Cognitive-behavioural theories combine the cognitive perspective with behavioural perspectives, rather than limiting theories to just one approach, allowing for a combination of perspectives to inform pain theory and research. This provides further value to the study of pain, particularly in situations where recovery may be hindered by behaviour, such as in musculoskeletal pain conditions (Vlaeyen & Linton, 2000).

First, *The Fear-Avoidance Model* (Vlaeyen, Kole-Snijders, Boeren, & van Eek, 1995) posits that fear of pain arises from the interpretation of pain as a threat of on-going disease that signals the need to rest. In turn, this fear exaggerates pain perceptions (catastrophising), heightens attention and sensitivity to any stimulus that may induce pain (hypervigilance), leading to behaviours that aim to avoid pain, such as muscle tension, withdrawing from an activity or task, or social withdrawal. These behaviours

are carried out with positive intentions of preventing further damage, but, conversely, may promote chronic pain. Fear-avoidance works in a 'vicious circle' (Linton & Shaw, 2011), in that avoidance behaviours are motivated by fear, but serve to fuel the fear-centred and catastrophic thinking patterns further, which additionally increases pain intensity and reinforces avoidance behaviours. In turn, this may turn an acute problem into a chronic one (Vlaeyen & Linton, 2000), thus risking unnecessary consequences that may be avoided with adequate treatment of fear with acceptance or graded exposure.

The process of fear-avoidance may occur even in the absence of any nociceptive information, and may cause individuals to further isolate themselves from any kind of activity that may or may not result in pain. Vlaeyen & Linton (2012) suggest that pain avoidance can eventually take priority over other tasks and activities, such that individuals will withdraw from previously valued activities in order to avoid pain. This becomes the most debilitating consequence of fear-avoidance, limiting function, increasing disability, and resulting in social isolation (Schrooten & Vlaeyen, 2010). Studies of rehabilitation (Werneke et al*.,* 2009), and pain (Cleland, Childs, & Whitman*,* 2008; Fritz, George, & Delitto, 2001) patients suggest that elevated fear has a detrimental effect on outcome measures such as function and pain intensity, when compared with control groups. This suggests that fear and avoidance behaviours should be targets for pain management. A systematic review of nine studies, however, concluded that the association between fear-avoidance beliefs and outcome measures is supported by very little evidence (Pincus, Vogel, Burton, Santos, & Field*,* 2006) with another study suggesting that no significant association exists between fear and

disability (Sterling, Jull, & Kenardy, 2006), thus obscuring the ability of the fear-avoidance model to inform the management of chronic pain. Therefore, there is a need for further work to demonstrate this model's effectiveness in explaining the persistence of chronic pain, particularly in those who are not fearful and avoidant.

Crombez, Vlaeyen, Heuts, & Lysens (1999) suggest that the fear of pain, along with the increased levels of anxiety and depression that occur alongside it may be more disabling than pain itself. Sullivan, Bishop, and Pivik (1995) agree that fearful, catastrophic, and distressing thoughts associated with pain increase the risk of a delayed recovery. Chronic pain that persists as a result of such distressing and fearful thoughts may not be effectively managed by pharmacological treatment. This suggests that catastrophising and fear should be essential targets of pain management (Vlaeyen & Linton, 2000). However, for those who do not display distressing pain-related thinking, exposure-based interventions that target pain-related fear may not offer any benefit.

Cognitive-behaviour models of pain begin to integrate the dual physical and psychological nature of pain in a way that illustrates how cognitions and emotions can lead to persistent pain and increased disability. Unfortunately, however, these models may not be appropriate for pain conditions unrelated to behaviour, such as pain that is the result of central nerve damage (neuropathic pain), which may produce a more general form of distress or worry, as opposed to fear of particulars (Mineka & Kihlstrom, 1978). More work should be conducted to establish the variability of cognitive beliefs and pain-related behaviours over time, and in relation to specific pain conditions, rather than considering them as fixed variables at fixed time points. Further,

these models still do not account for any social influences on pain, such as social withdrawal and solicitous responses, which may influence the experience of pain.

1.5 Social Theories.

Previously discussed theories conceptualise pain in an individualistic manner, and as such, fail to highlight that pain occurs in a social context. Family theories use social measures in order to demonstrate that pain occurs in social contexts and environmental factors may serve to prolong pain. These theories argue that the family plays a role in the perpetuation of pain in a sufferer, and as such, it is important to include the family in the treatment of pain (Kerns & Otis, 2003; Kerns, Otis, & Wise, 2002; Lewandowski, Morris, Drauker, & Risko, 2007). In such social theories, pain is conceptualised as a two-dimensional, circular relationship, in that pain in a family member can affect the rest of the family negatively, and as such, may cause further distress in the sufferer (Gamsa, 1994; Lewandowski, 2004). Evidence supportive of this is provided by Kemler & Furnee (2002), who found that where adult males suffered with chronic pain, the household income decreased, meaning that spouses took on more employment and financial responsibilities to compensate. Such actions thus risk their own physical and psychological health, with partners of individuals with chronic pain likely to suffer higher rates of depressive symptoms (Feinauer & Steele, 1992). Theories put forward that attempt to explain pain through family functioning include the family systems theory, operant conditioning and the cognitive-behavioural transactional model. Each theory has a corresponding therapy.

Family systems theory posits that chronic pain remains present in a family because there is a need for it to fulfil psychological functions within the family (Kerns & Otis, 2003). Pain is seen as a stabilising factor associated with conflict or distress in some families who may have difficulties in resolving conflict, and is often perpetuated in order to avoid conflict in other interpersonal problems, such as marital dysfunction (Turk, Kerns, & Rosenberg, 1992), or excessive dependency on family members (Kerns, Otis, & Wise, 2002). By focusing on the pain complaints of the sufferer, other problems are essentially 'covered over' and avoided. Additionally, Cowan, Kelly, Pasero, Covington, and Lidz (1998) advocate that pain may serve to meet unexpressed needs of the individual, such as receiving care and nurturing, whilst Smith and Friedmann (1999) found that pain acted as a mechanism to regulate the distance between, and closeness to, family members. Pain, therefore, causes families to center on maintaining balance and coherence within the family, rather than growing and developing with others, and so may lead to isolation from the community. This may result in reductions in psychological well-being and social isolation for both the pain sufferer and their family. Friend and family pain education, therefore, may be a viable intervention for those with chronic pain, such that family members are able to understand and reflect upon their influence on pain.

The avoidance of familial problems is not the only factor causing pain to endure. Skinner's (1937) operant conditioning posits that, in relation to the social context, pain behaviours such as grimacing, are influenced by the social response from the family. Pain behaviours, such as facial expressions, are important opportunities for communication, and for an observer to better understand and manage pain (Chambers &

Mogil, 2015), and the Facial Action Coding System (Ekman, Friesen, & Ancoli, 1980)

has been developed to describe these expressions in terms of the emotions associated

with them. Such behaviours elicit responses from the family including positive (e.g.

solicitous responses, attention, sympathy) and negative reinforcement (e.g. ignoring

behaviours) of pain behaviours, and discouragement of behaviours associated with

wellness (Newton-John, 2002). This reinforcement strengthens the likelihood that the

same pain behaviours will be used again (Cowan, Kelly, Pasero, Covington, & Lidz,

1998).

   Positive reinforcement behaviours are seen as enjoyable gains, serving to

reinforce negative pain behaviours such as avoiding undesirable activities and work, and

thus reinforcing the expression of pain (Newton-John, 2002). Such pain-behaviours may

even persist when no nociceptive information is available to suggest that pain is present

(Lewandowski, Morris, Drauker, & Risko, 2007), and pose a risk of increased disability

(Romano & Schmaling, 2001). However, social interactions are complex, and family

responses are mediated by affective and cognitive factors, and as such, responses to

pain-behaviours may be inconsistent, changing over time or according to mood. Further,

the underlying assumption with regard to pain expressions and behaviours is that these

have an exact correspondence with emotions, which is not necessarily the case (Russel,

1994). This model fails to account for this cognitive perspective.

   The Cognitive-Behavioural Transactional Model (Turk, Kerns, & Rosenberg,

1992) is a response to the limitations of the operant conditioning model, adding the

cognitive perspective and focussing on the individual's prior responsibilities and the

challenges and stresses that pain imposes. The model posits that the family has a distinct

set of beliefs surrounding pain; these beliefs are used to cope with and respond to the pain problem. The family then appraises the success of their responses. Failed efforts are likely to increase the family's perceived threat of the pain problem, the sufferer's pain intensity, disability, and distress, thus these responses are less likely to be used again. Successful responses moderate pain and increase the confidence of the family, thus the use of these and similar responses is increased. This approach emphasises the importance of understanding the cognitive appraisals individuals ascribe to pain and how these appraisals affect each dimension of the pain experience. It is, therefore, important to educate family members of adaptive responses to pain, and to assess the beliefs and cognitions of both the pain sufferer and the spouse and how interactions and responses might be better managed.

1.6 Contemporary Work

Contemporary work is now moving towards the concept of coping with pain (McCracken & Eccleston, 2005), as opposed to searching for a cure, thus acknowledging cognitive appraisals of pain, as well as behavioural reinforcement. Reviews of concepts such as catastrophising and resting as a result of pain have established that such strategies prompt the increase of pain intensity and disability, whilst positive approaches to coping, such as social support and positive social comparison, are found increasingly beneficial (Jensen, Turner, Romano, & Karoly, 1991). *Acceptance and Commitment Therapy* (ACT; Hayes, Strosahl, & Wilson, 1999) and *Mindfulness-based interventions* (MBIs) are gathering increasing interest.

Such interventions are based upon *Relational Frame Theory* (Hayes, Barnes-Holmes, & Roche, 2001), which posits that humans develop relational frames that relate one event to another, and that this learning can transfer to other events that are not necessarily related. Those living with chronic pain may use avoidant coping strategies such as experiential avoidance (Ruiz-Párraga & López-Martínez, 2015), which occurs when the individual is unwilling to remain in contact with such experiences, emotions, and thoughts. Individuals will then take steps in order to alter the occurrence of such experiences, even where this may cause psychological, or behavioural harm (Hayes et al., 2004). One might attempt to supress, or avoid negative thoughts, which might actually have an opposing effect, becoming a cue to the avoided event, and thus causing the thoughts to increase in prevalence (Wenzlaff & Wegner, 2000). ACT and MBIs, therefore, do not aim to reduce the frequency or intensity of unhelpful thoughts (unless this is likely to achieve improved functioning), but to reduce the influence such thoughts exert upon behaviour. This involves improving psychological flexibility, which involves a number of sub-processes, summarised as behaviour that is open, aware, and active (Hayes, Pistorello, & Levin, 2012).

Evidence suggests that developing psychological flexibility and facilitating acceptance of pain can improve depression, anxiety, pain intensity, as well as psychical and psychological well-being (McCracken & Gutierrez-Martinez, 2011). Further, studies demonstrate medium-to-large effect sizes for pain-related outcomes including anxiety and distress, disability, work status, and physical performance (McCracken, MacKichan, & Eccleston, 2007; Vowles & McCracken, 2008). Acceptance of pain is also correlated with depression, pain-related anxiety, and physical and social disability

(McCracken & Zhao-O'Brien, 2010; McCracken & Gutiérrez-Martínez, 2011), highlighting the efficacy of ACT to improve outcomes in a biopsychosocial manner for those with chronic pain.

Mindfulness involves attempts to uncouple physical sensation from cognitive and emotional appraisals, and promote open, non-judgemental awareness of the body, through awareness and meditation (Kabat-Zinn, 1982). Relational Frame Theory understands mindfulness as a collection of processes functioning to undermine relational frames and verbal networks during evaluative relations (Fletcher & Hayes, 2005). By this, acceptance, cognitive defusion, and contact with the present moment (key aspects of mindfulness training) are seen to undermine the individual's relational frames, perceptions, and evaluative and judgmental interpretations of the event as negative. As such, this allows patients to process the event without imposing their perceptions upon it, increasing their tolerance for negative thoughts and emotions (Baer, 2003), and therefore reducing the likelihood of engagement in maladaptive coping responses (Lauwerier et al., 2012). These components are seen to underlie therapeutic change, enhancing well-being by increasing an individual's engagement with their pain, and encouraging acceptance.

MBIs offer improvements in depression and anxiety, disability, and catastrophising (Cassidy, Atherton, Robertson, Walsh, & Gillett, 2012), and demonstrate small-to-medium effect sizes on psychological outcomes (Bohlmeijer, Prenger, Taal, & Cuijpers, 2010). Such beneficial effects are documented to continue for up to four years post-intervention (Kabat-Zinn, Lipworth, & Burney, 1985). However, the mechanisms of ACT and mindfulness are, as yet, not fully understood. The above presented evidence

suggests that no singular approach to pain theory can explain the complex, multi-dimensional phenomena.

1.7 Conclusions

The problem of pain is a complex one incorporating biological, cognitive, behavioural, and social variables. Chronic pain is becoming increasingly common and has been described as a global challenge, which is best understood from a biopsychosocial perspective (Engel, 1977). This suggests that pain is affected by a complex interaction of psychological and social factors such as environment, coping, appraisals, which thereby impact the physical, psychological and social functioning of the individual. Few of the theories discussed, however, combine the individual variables in order to understand the phenomenon from this holistic, biopsychosocial standpoint. Following this model, it is suggested that treatment of pain should be in the form of a multidisciplinary programme assimilating contributions from biomedical, psychological, and social approaches, thus incorporating the use of analgesics, psychological interventions to restructure appraisals, behaviours, and beliefs about pain, and the consideration of the social context, thus reducing the impact of pain upon the individual (Turk, Swanson, & Tunks, 2008). However, in order to manage pain well, it is important to reach an understanding of individual pain conditions and their impact on the sufferer, in order to be able to prioritise aspects of the experience causing the most distress.

A vast body of evidence supports the effectiveness of multidisciplinary interventions in reducing pain and increasing function when compared with no treatment and standard care (Scascighini, Toma, Dober-Spielmann, & Sprott, 2008). However,

some patients may benefit from less comprehensive programmes, and as such, there may be a need to match patients to treatment strategies and goals specific to them. Indeed, some studies show no significant differences between multidisciplinary treatments and standard treatment in patients with low back pain (Jellema et al., 2005). Further, pain management programmes tend to be a 'one size fits all' development, and include numerous pain conditions such as musculoskeletal conditions, fibromyalgia, and rheumatology conditions (Cole et al., 2012). Such an intervention may result in different outcomes for each patient group, due to variations in pain aetiologies and impact. This indicates a need to understand each patient as an individual in order to deepen the knowledge of the main components contributing the continuance of their pain, as well as how best to manage each specific condition.

The majority of the literature available on pain focuses upon chronic pain due to its high direct and indirect costs to the individual (Fortner et al., 2003). However, much of the research and theory is conflicting as well as incomplete, reinforcing the need for research in order to understand the experience fully. Pain, however, can be difficult to measure and treat due to its subjective nature. Individuals experience pain differently, advocating that research should be directed to more qualitative, phenomenological influences (Anand & Craig, 1996). Further qualitative research is needed in order to gain a better understanding of the personal experience of pain and its psychological processes (Osborn & Smith, 1998).

Chapter 2 **Spinal Cord Injury**

Pain is a common side effect of many health conditions, one of which is spinal cord injury (SCI), which will be discussed further here. However, before discussion of pain after SCI occurs, it is important to understand what SCI is, and its impact on those living with it.

The spinal cord is a dense network of nerves that control the body's muscles and functions. Damage to the spinal cord, which is protected by the spinal column, results in paralysis from the affected area and below, and cannot be repaired. Paralysis is the loss of ability to control muscles and bodily functions (American Spinal Injury Association; ASIA, 2015). This may occur due to physical trauma to the spinal cord, or through non-traumatic means, such as a spinal tumour or other illness. Paralysis consists of a complete or partial loss of motor and/or sensory function, and with it comes a multitude of physical and psychological consequences. A loss of control of blood pressure may occur, as well as fatigue, pain, and sexual function (Dijkers, Bryce, Zanca, 2009). Some patients may require a ventilator in order to assist their breathing if they have a high neurological level of injury (discussed later). Patients are likely to be unable to walk, and will most likely be wheelchair bound for the rest of their life. This may reduce their ability for social, sport and employment participation, and may often result in a decrease in psychological wellbeing.

The spine consists of three major sections that are made up of small bones called vertebrae. Protected by this column of vertebrae is the spinal cord. From top to bottom the regions of the spine and their corresponding nerve levels are the cervical (8

vertebrae; C1 to C8), the thoracic (12 vertebrae; T1 to T12), and the lumbar (5

vertebrae; L1 to L5). At the base of this is the sacral (S1 to S5) and coccygeal areas,

where the bones are fused and therefore cannot protect nerves. The spinal cord runs

from the brain and ends between L1 and L2. Selections of nerves end in each region of

the column, corresponding to specific areas of the body. This is part of the central

nervous system, connecting the brain and the body together. Figure 2 shows the

relationship between the spinal column vertebrae and the spinal cord.

Figure 2. The relationship between the spinal column vertebrae and the spinal cord.
Reprinted with the permission of www.apparelyzed.com
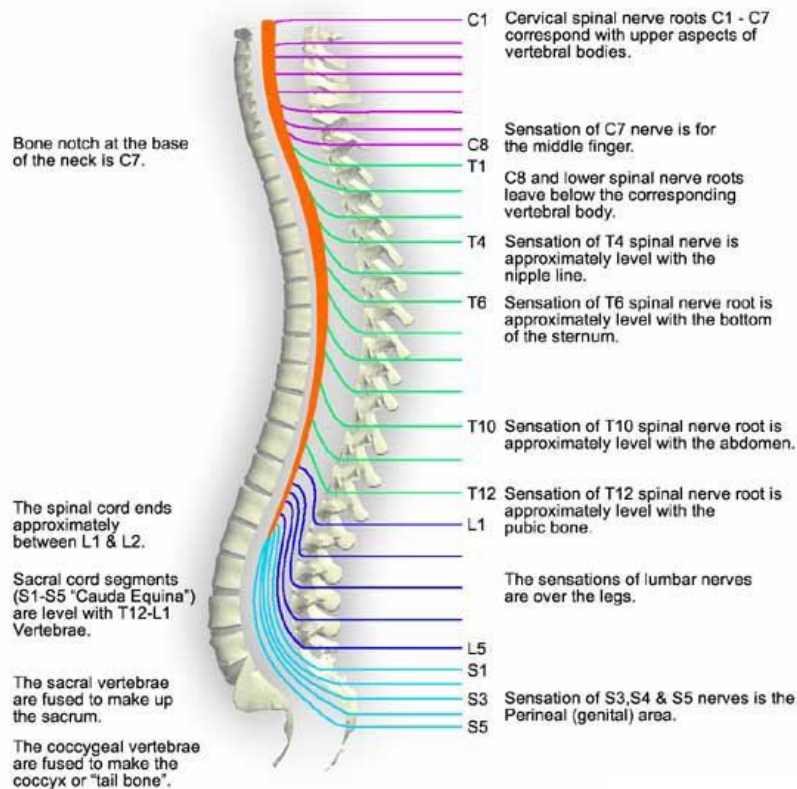
Image © www.apparelyzed.com

Damage to the bones can be repaired; however, damage to the nerves (a lesion)

of the spinal cord cannot. Where this lesion occurs dictates the neurological level of

injury, such as C6 or T4. Immediately after an injury, swelling occurs cutting off oxygen

and blood flow to the area of damage. At the same time, because the nerves can no longer reuptake them, glutamate neurotransmitters flood to the area and over-excite the nerves. This glutamate excitotoxicity opens channels to allow calcium to enter the nerve, which can induce neuronal cell death, the extent of which may be variable depending on the speed of emergency treatment (Belousov, 2012). Damage to the cord prevents signals and messages from being relayed below the level of injury and will result in partial or total paralysis of particular limbs, depending the level of damage to the affected area.

2.1 Types of Paralysis

Wherever an injury occurs, paralysis will generally affect that point downwards. Paralysis may be complete or incomplete (ASIA, 2015). A complete injury consists of a complete loss of motor (movement) and sensory (feeling) function below the level of injury, whilst an incomplete injury consists of some retention of motor and/or sensory function. A lesion that occurs at the cervical region will result in complete or incomplete tetraplegia (paralysis, or loss of motor function, of the torso and all limbs), whilst a lesion at the thoracic region will result in complete or incomplete paraplegia (loss of motor function affecting the torso and legs only). Injuries to the lumbar and sacral areas result in decreased control of legs but may still require patients to use a wheelchair. Figure 3 shows how the spinal cord may become damaged. Nerves do not have to be completely severed for a spinal cord injury (SCI) to occur, and an individual may break their spinal column without sustaining a SCI, as such damage may not damage the

nerves. Bladder, bowel and sexual function can all be affected by a SCI, along with a loss of control of breathing and body temperature, dependent on the level of injury.

Figure 3. How a spinal cord is damaged (AQA Victoria, 2013).
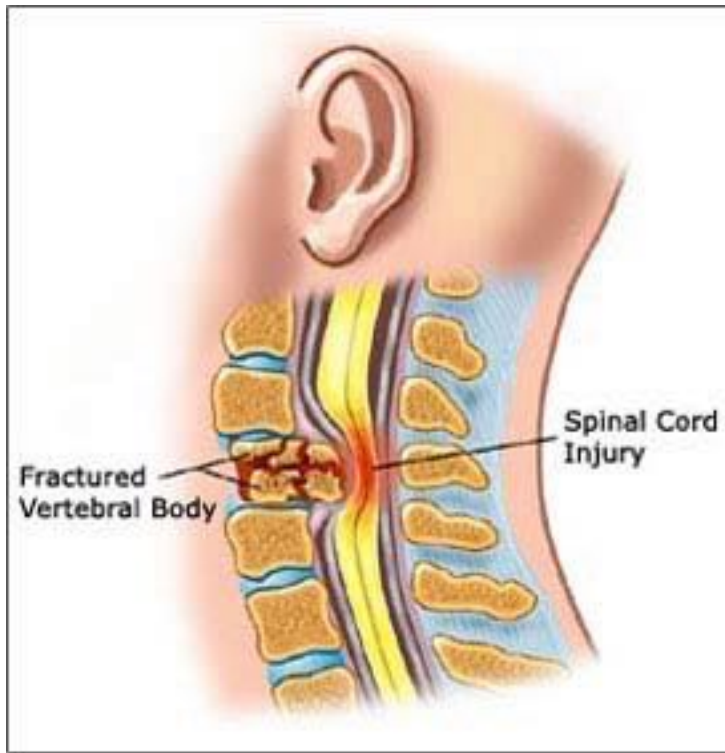
2.2 Cause and Diagnosis

Around 65% of SCIs are caused by traumatic events and injury to the spine (McKinley et al., 1999). The most common cause of traumatic SCIs (as a result of external events) is road traffic accidents, making up around one third of the traumatic SCI population (O'Connor, 2002). Violence accounts for 19% of traumatic injuries, falls account for 15%, and 1% occur due to sporting injury (McKinley, Jackson, Cardenas, & DeVivo, 1999). Other causes of SCI include non-traumatic events; non-traumatic causes of spinal cord injury make up around 35% of the spinal injured population (McKinley et al.,

1999). Such causes include degenerative conditions such as cancer, infections, osteoarthritis (degeneration of vertebrae) and disc degeneration, and vascular problems such as cardiac arrest or hypotension, both of which may prevent blood from flowing efficiently to the spinal cord (New, Rawicki & Bailey, 2002). Of all non-traumatic SCI, vascular problems cause 25%, cancerous causes make up another 25%, inflammatory illnesses and infections cause 20%, degenerative illnesses account for 18%, and the remaining 12% are made up of problems such as multiple sclerosis, toxins such as radiation, and problems arising from birth or early development (McKinley, Seel & Hardman, 1999). Differences in causes of injury may influence the way that such an injury is appraised.

In the event of a SCI, emergency treatment is given by restraining the spine and using a hard neck brace, as well as using a steroid (Methylprednisolone) in order to prevent any inflammation from spreading further along the spinal cord and causing further damage (Bracken et al., 1990). Diagnosis of spinal injury may include x-rays to identify problems in the spinal column, computerised tomography (CT), and magnetic resonance imaging (MRI), to generate images to detect problems such as blood clots compressing on the spinal cord. After swelling has decreased, a doctor or consultant will conduct muscle, light touch, and pinprick tests in order to determine the level and completeness of the injury based on the American Spinal Injury Association neurological impairment scale (ASIA) in which a patient can be diagnosed, below the injury level, with A (complete - total loss of motor and sensory function), B (sensory incomplete – sensory but not motor function preserved), C (motor incomplete – motor

function preserved, with low movement range), D (motor incomplete – motor function preserved, with high movement range) or E (normal).

SCI has been regarded as one of the most devastating and traumatic types of neurological impairment (Krause, 1998). Its rarity, lack of physical cure, the wide variability in the extent of motor and sensory damage, and the limited number of specialist SCI services in the UK, make it difficult to manage. However, physical debilitation is not the only consequence of SCI, and a range of secondary psychological complications such as depression and anxiety (Bombardier, Richards, Krause, Tulsky, & Tate, 2004), and a reduction in quality of life (Wilson, Hashimoto, Dettori, & Fehlings, 2011), also accompany the injury. These consequences can be psychological and social, reductions in daily activity, and pain, each of which are discussed further here.

2.3 Psychological and Social Side Effects

Before World War II (WWII, 1939-1945) mortality rates of individuals with an SCI were high, most living just weeks after their injury due to a lack of knowledge of treatment and care after SCI (Donovan, 2007). However, life expectancy is ever-increasing (Middleton et al., 2012), with 47% and 62% of individuals with tetraplegia and paraplegia, respectively, living up to 40 years after their injury, although this life expectancy is still lower than the general population (Strauss, DeVivo, Paulcdo, & Shavelle, 2006). This reinforces a need to focus on the resources of individuals with SCI, and to understand how to increase activity and social participation levels within this particular population (Ullrich et al., 2012), in order to enable them to continue living a high quality of life post-injury.

Individuals with a SCI may be more vulnerable to depression and anxiety. Rates of depression are reported in 35-38% of the population (Kennedy, Duff, Evans, & Beedie, 2003), and both depression and anxiety are likely to continue for at least the first two years after injury (Kennedy & Rogers, 2000). Potentially as a result of the increased risk of depression and anxiety, evidence also suggests that suicide rates are higher in the SCI population (Beedie & Kennedy, 2002; Charlifue & Gerhart, 1991). Problems with self-neglect and substance abuse are also reported as a result of difficulty adjusting to the injury (Macleod, 1988; Pollard & Kennedy, 2007). Additionally, life satisfaction is lower after injury, but significantly increases from two to five years post-discharge if the individual has social support and independence, and low levels of pain (van Leeuwen et al., 2012). These negative psychological consequences imply a need to provide adequate support to sufficiently aid adjustment to SCI and quality of life after injury.

Despite no existing treatment that can restore an individual's neurological function, vast improvements have been made in the care of those with a SCI (McMahon et al., 2009). Therefore, the ultimate goal in any rehabilitation centre for SCI is to increase a patient's independent function and to reduce the effects of their disabilities to a minimum (Vassend, Quale, Røise, & Schanke, 2011). Research suggests that positive adjustment to SCI is relatively high due to the frequency of adaptive coping strategies used by the injured individuals, such as acceptance and a fighting spirit (Kennedy et al., 2000), and the contributing stability of these strategies over time (Pollard & Kennedy, 2007).

2.4 Coping with SCI

Coping strategies employed by people with SCI are indicative of outcomes, more so than the severity of the injury itself (Kennedy et al*., 2000). The use of positive coping strategies may improve and maintain psychological well-being after an injury, and aid reintegration into the community after a lengthy stay in a specialised rehabilitation hospital. Factors that may be predictive of positive outcomes and adjustment after SCI include younger age and positive affect (Krause, 1998). Being young at the time of injury and having positive affect was associated with a perception of more future career options and living circumstances, whilst older individuals perceived fewer of these opportunities (Krause, 1998). On the other hand, maladaptive coping strategies such as drug use and denial (or lack of acceptance) are correlated with negative adjustment, anxiety, and depression (Kennedy et al*., 2000). The use of maladaptive strategies may be moderated by negative thoughts such as self-blame and denial (Mackay, Charles, Kemp, & Heckhausen*, 2011), suggesting the importance of coping strategy engagement upon outcomes and adjustment (Hanson, Buckelew, Hewett, O'Neal, 1993).

Much of the research focussing on adjustment following a SCI has centered on coping strategies and sense of coherence (SOC). SOC is found to predict positive adjustment to SCI. This is defined by Antonovsky (1987) as the belief that environments are structured and predictable, and that demands of tasks are worth the investment and engagement of the individual. Kennedy, Lude, Elfstrom, and Smithson (2010a) explored the long-term relationship between SOC and health outcomes of patients with SCIs. Higher levels of SOC had significant positive relationships with acceptance of injury, positive coping strategies and appraisals, quality of life and psychological well-being, at

one year post-injury. The study also found that low levels of SOC were significantly related to depression, anxiety, negative coping strategies and appraisals, poor quality of life and psychological well-being at one year post-injury. This suggests that a good SOC is beneficial in aiding adjustment to injury, as well as functional and psychological well-being, and that improving SOC may promote positive outcomes after SCI.

A further coping strategy is hope; Smith & Sparkes (2005) investigated how men with SCI due to sporting injury experienced and expressed different types of hope after their injuries. Of 14 men, 11 expressed concrete hope, oriented towards obtaining specific goals such as a cure for SCI. The authors argue that this type of hope is negative and inappropriate in persons with SCI, reducing their ability to restructure their identity, and causing them to focus on an unobtainable goal. The second most frequent type of hope, transcendent hope, in which the individual is open to novelty and change, was described by two men, allowing them to live in the present rather than focussing on the past or future (Sparkes & Smith, 2005). This form of hope was adaptive, empowering the men in adapting to an uncertain future. The last participant in the study displayed despair and an absence of hope, internalising that his life would never get better, and provoking fear in himself for the future. Transcendent hope is the most adaptive form of hope after a SCI, yet, in this study, was only adopted by a minority of the participant group. Collectively, this shows that many SCI patients may hold unrealistic hopes, suggesting a need to educate individuals regarding the irreparable nature of the injury, but also to reinforce openness to change and learning that life can still be lived well despite disability. Further research may attempt to understand the in depth experience of SCI, such that we may gain an understanding of why unrealistic hopes may occur.

The evidence presented here demonstrates that many individual differences, be they psychological, or social, interplay in dictating the effects of SCI on an individual and how they adjust to the injury. These factors are also likely to influence the level of pain an injured individual may be exposed to, and the extent to which they are able to reintegrate into the community and how much daily activity they are able to, or want to, engage in. This may then pose further threat to the psychosocial and physical well-being of the individual. There is a need, therefore, to deepen current understanding of such individual differences in order to further recognise what role they play in adjustment to injury. Obtaining such knowledge may be best taken from the perspective of the person living with SCI, who will be better able to identify which factors are experienced differently, and to what extent they impact upon their experience of the SCI.

2.5 Daily Activity and Living after SCI

As a result of these individual differences, engagement in daily living activity and reintegration back into the non-SCI (able-bodied) community may be affected. Due to the nature of SCI, the vast majority of patients have to learn to live from the perspective of a wheelchair-user. The rehabilitation stage of recovery after an injury involves patients learning how to carry out their usual everyday tasks with restricted use of their arms and/or legs. Donnelly & Eng (2005), however, found that 27% of their SCI community sample reported that pain affected the performance of most of their daily activities, often slowing such activities down or causing the person to cease engaging in them completely. Tawashy, Eng, Lin, Tang, and Hung (2009) indicate that activities of daily living, such as carrying out personal hygiene, made up 50% of all heavy activity

engaged in by participants with SCI. Heavy activity was defined as exhausting, requiring a lot of physical effort, and only able to be carried out for a short period of time. However, despite the fact that daily living activities were considered heavy activity, such heavy activity offered physical and psychological benefits. Reduced levels of pain intensity and fatigue were observed, as well as increased self-efficacy and quality of life, suggesting that whilst some activities may be more difficult than others to carry out, they also present benefits to the individual's health and well-being.

Whilst it may be significantly reduced after SCI due to a lack of motor control, physical activity can have multiple benefits in that it may maintain psychological and physical well-being (Hicks et al., 2003), enhance quality of life (Manns & Chad, 1999), ability to manage daily living activities, as well as reductions in stress and pain (Ditor et al., 2003). Despite the benefits, however, day-to-day living activities may be taxing for those living with SCI, meaning that many of the SCI population remain inactive after their injury. This may occur to the extent that costs such as injury, increased pain, illness, and a loss of independence may occur (Kerstin, Gabriele, & Richard, 2006). Increased pain may pose a specific problem for those with a SCI, as pain after heavy activity may cause fear, and prevent individuals from engaging in such activity again, as described by conditioning models of pain. This increased pain may also contribute towards the development of further physical and psychosocial problems.

2.6 Pain after Spinal Cord Injury

There is a large body of evidence to suggest that over 60% of individuals with a SCI suffer with chronic pain (Kennedy, Frankel, Gardner, & Nuseibeh, 1997; Rintala,

Loubser, Castro, Hart, & Fuhrer, 1998; Modirian et al., 2010), with a third of these

rating their pain as severe (Siddall, 2009) and the most difficult aspect of their SCI to

manage (Widerstrom-Noga, Duncan, Felipo-Cuervo, & Turk, 2002). Pain can be

debilitating, with the potential to negatively affect an individual's functional ability, as

well as their ability to return to work (Widerstrom-Noga et al., 2002), engage in daily

activities (Tawashy, Eng, Lin, Tang, & Hung, 2009), reducing their quality of life and

psychological well-being (Widerstrom-Noga et al., 2002). Pain, therefore, is a common

and significant consequence secondary to SCI, beyond that of the SCI itself (Dijkers,

Bryce, & Zanca, 2009), and its adequate understanding and management may mean that

quality of life can be improved.

  Pain following SCI is divided into nociceptive and neuropathic pain. Nociceptive

pain consists of somatic pain (touch), visceral pain such as internal organ disturbances

and urinary tract infections, and musculoskeletal pain due to damage in bones, joints or

muscles. A recent study (Dijkers, Bryce, & Zanca, 2009) concluded that prevalence

rates of pain varied so widely across 42 studies (26-96%) that a meta-analysis could not

be conducted. Neuropathic pain (NP) arises from damage to nerves, as a consequence of

a lesion or disease (Treede et al., 2008). These lesions damage dermatomes; skin areas

corresponding to sensory fibres of a single dorsal nerve root in the spinal cord, which

receives sensory signals in order to process them to the brain. Dermatomes and their

corresponding areas of skin are represented in figure 4, below.

Figure 4. Dermatome Correspondence Chart. Reprinted with permission from Apparalyzed (2013).
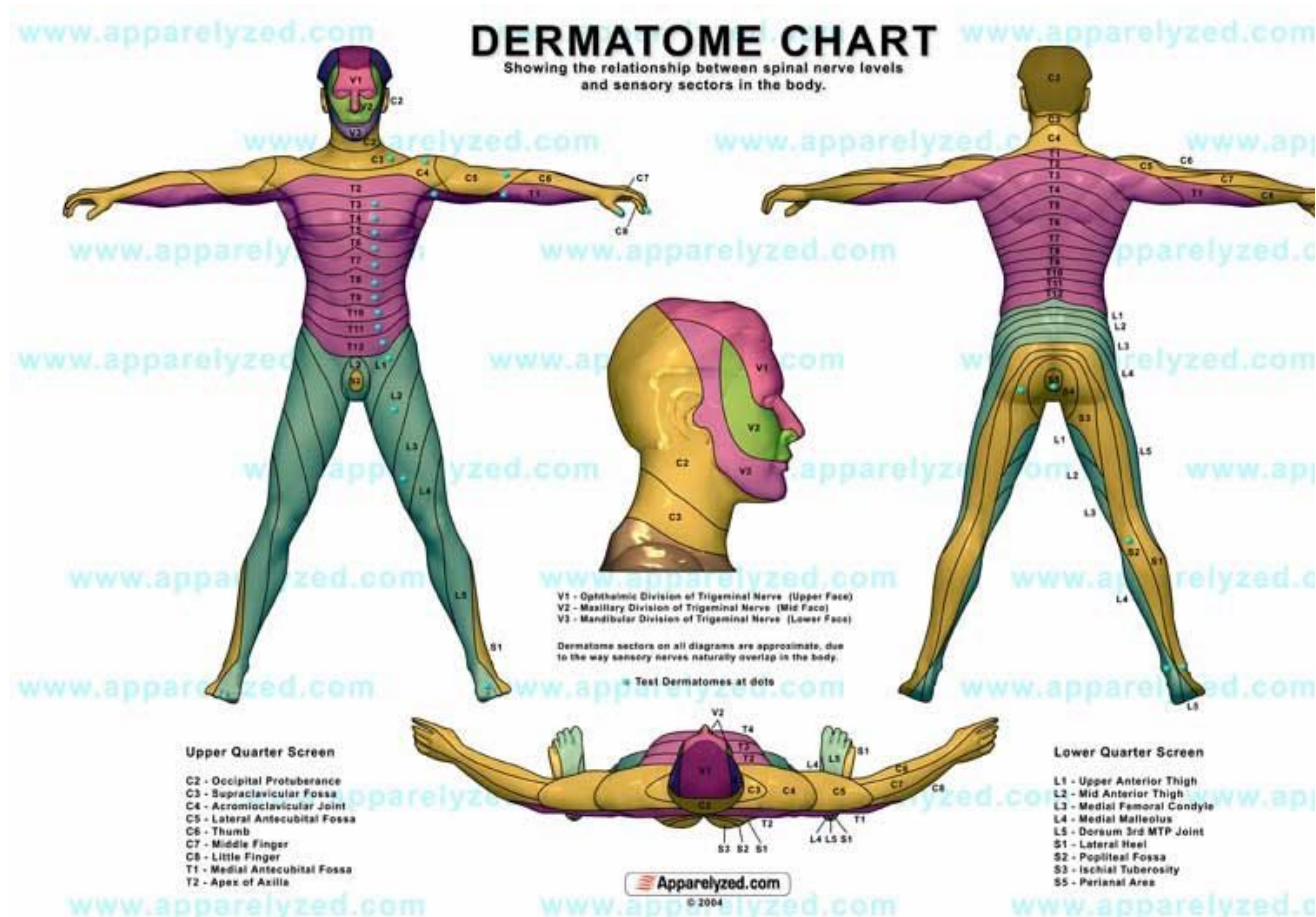
Neuropathic pain consists of at-level pain (affecting the area at the level of injury, plus two dermatomes above and below the level of injury), below-level pain (located more than two dermatomes below the level of injury), and above-level pain (more than two dermatomes above the level of injury), as defined by Siddall (2009). NP is usually constant, and is unrelated to posture or movement, but from spinal nerve damage which may lead to abnormal neuron firing patterns that generate the experience of pain (Widerstrom-Noga, Cruz-Almeida, Felix, & Adcock, 2009). Damage to the spinothalamic tract may play a role in the onset of NP, due to its function in the

mediation of pain and temperature sensations (Finnerup et al., 2009). Neuropathic pain is persistent, resistant to pharmacological treatment, and associated with secondary implications in psychological well-being, each of which will be discussed here. Neuropathic pain will, therefore, be the focus of this section.

Approximately half of the SCI population suffer with NP, which is most likely to be described as severe or excruciating (Siddall, McClelland, Rutkowski, & Cousins, 2003). Neuropathic pain is debilitating and persistent, often worsening over time (Modirian et al., 2010) and refractory to treatment (Warms, Turner, Marshall, & Cardenas, 2002). Sufferers of NP may also present with pain felt in response to stimuli that are not harmful (allodynia, Beric, 1990) and an increased sensitivity to nociceptive stimuli (hyperalgesia, Defrin, Ohry, Blumen, & Urca, 2001), making it an important area of study. This pain has been rated as severe and excruciating by 48% of participants with below-level pain, and 60% of participants with at-level pain (Siddall et al., 2003). In a study by Celik, Erhan, and Lakse (2012) the most commonly used words to describe NP included 'throbbing', 'hot', 'tiring' and 'tingling'. The potential consequences of such pain experiences reinforce the need for continued research and understanding of the phenomenon, and what can be developed for the management of such pain.

The progression of pain over time is a widely-researched topic, with studies indicating a worsening of pain post-discharge from a rehabilitation unit (Kennedy, Frankel, Gardner, & Nuseibeh, 1997; Jensen, Hoffman, & Cardenas, 2005). Further, at five years post-injury, NP had increased and was present in between 34% and 41% of the SCI population (Siddall et al., 2003), indicating that it is not an acute experience, but

one that persists and increases after discharge from hospital, potentially preventing adjustment to injury and outpatient life. However, conflicting evidence suggests that, rather than increasing, NP remains stable over time from hospital stay to one year post-discharge (New, Lim, Hill, & Brown, 1997), and from admission to a rehabilitation hospital to four-year follow-up after discharge (Vassend, Quale, Røise, & Schanke, 2011). Inconsistencies amongst SCI pain research imply a need for further study in order to fully understand the experience and the variables impacting upon its presence as well as its psychological impact upon the individual.

The importance and relevance of pain in SCI is highlighted in work suggesting that pain can impair physical and emotional function as seen in increased levels of psychological distress (Kennedy, Frankel, Gardner, & Nuseibeh, 1997; Craig et al., 2013). Persistent and increasing pain was found a risk factor for the development of depression amongst SCI individuals (Hoffman, Bombardier, Graves, Kalpakjian, Krause, 2011) and those with NP are likely to have higher self-ratings of depression if they suffer with pain, as well as lower self-ratings of mood and quality of life (Ataoglu et al., 2013). Additionally, depression and pain are rated as more severe when coinciding (Campbell, Clauw, & Keefe, 2003), with diagnosis and treatment of one being adversely affected by the other (Banks & Kerns, 1996). Ullrich et al. (2013) argue that pain and depression amplify one another, and that persistent pain and depression after SCI suggests that there are issues surrounding treatment and management. As such, increased understanding of NP after SCI and its implications in psychological well-being is necessary.

Responses to pain are also influential in the pain experience. Catastrophising is one such response that is strongly related to outcome measures of pain intensity and interference, distress, quality of life, physical function, pain-related disability (Raichle, Hanley, Jensen, & Cardenas, 2007). Catastrophising is also a strong, independent predictor of negative outcomes after SCI (Molton et al., 2009), with high levels associated with psychological distress (Nicholson Perry, Nicholas, Middleton, & Siddall, 2009). Nicholson Perry and colleagues (2009) suggest that identification of distress and catastrophising may subsequently aid in distinguishing SCI patients 'at risk' of negative long-term outcomes in relation to chronic pain, suggesting that adaptive coping and lower levels of catastrophising predict reduced pain intensity after SCI. Negative pain beliefs, such as being unable to function due to pain, are also predictive of pain consequences (Raichle et al., 2007). The extent to which an individual believes that their pain is under their control or the control of external forces (internal and external locus of control) can predict quality of life, physical function, community integration, and psychological distress (Boschen, Tonack, & Gargaro, 2003). This suggests that assessment of coping strategies adopted in response to NP may be influential in how pain is experienced. However, no work has explored coping strategies and their efficacy from the SCI patient's perspective, and it may be necessary to obtain this understanding in order to evidence the recommendation of particular coping strategies to others.

Whilst cognitive factors impact pain after SCI, social support and emotional factors are also implicated. Social support may provide encouragement for healthy behaviours after a SCI but the relationship between pain and social support is complex. Rintala, Hart, and Priebe (2004) found that persistent pain after a SCI was associated

with decreased social support, and increased pain and disability. In contrast, in samples

of pain patients without SCI, solicitous responses from partners may actually increase

pain severity and disability behaviours by unintentionally reinforcing their continuation

(Romano et al., 1995; Boothby, Thorn, Overduin, & Ward, 2004). The extent to which

these results can apply to SCI populations is unknown, but the evidence suggests that

although social support after SCI may be necessary, it may influence NP and the well-

being of the individual. Again, an in-depth understanding of NP may reveal more detail

surrounding its implications on the psychosocial well-being of the sufferer, therefore

informing future practice and pain management.

Pain also impedes social and employment participation, yet whilst SCI

individuals may need some degree of help from others, they tend to use strategies

available to them, such as planning activities in advance in order to avoid pain, to obtain

autonomy (independence, self-determination), and overcome barriers presented by pain

(Van De Ven, Post, De Witte, & Van Den Heuvel, 2008). Various authors present

conflicting views of which aspects of pain should be treated with priority, with Jensen et

al. (2010) suggesting a focus on cognitive influences, and Norrbrink Budh, Kowalski,

and Lundeberg (2006) suggesting a focus on the incorporation of education into a

multidisciplinary treatment programme to reduce pain severity. However, cognitive,

emotional, psychological, and social factors appear to affect one another in the

experience of pain after a SCI, suggesting that pain in this specific population should be

treated from a biopsychosocial perspective, emphasising the individual differences of

each patient. The evidence discussed here suggests that in order to improve management

of NP, a complete understanding of its mechanisms and impact upon the individual is

needed. No work has previously explored the patient's perspective and experiences of pain, despite the value that such evidence could offer to prioritisation of pain management outcomes.

2.7 Current SCI Pain Treatment

Pharmacological treatments currently dominate the available treatments for SCI-related pain (Cardenas & Jensen, 2006). Nociceptive pain can be treated with analgesics (painkillers) and anti-inflammatories, but no treatment is available for the causes of neuropathic pain (Siddall & Middleton, 2006). Instead, its symptoms can be treated with anticonvulsants such as gabapentin, opioids such as tramadol and morphine, and antidepressants such as selective-serotonin reuptake inhibitors. However, there is a lack of controlled trials into the effectiveness of antidepressant drugs on neuropathic pain, and consistent findings suggest that pharmacological treatments in general insufficiently relieve pain in the majority of the SCI population (Siddall, 2009; Widerstrom-Noga & Turk, 2003). Therefore, psychosocial management may be considered more appropriate, and an enhanced comprehension of NP's bearing upon the individual may inform such management.

Long-term use of pharmacological interventions is not desirable due to potential side effects such as exacerbated bowel dysfunction, blurred vision, fatigue, sedation, and dizziness, as well as risks including substance abuse and tolerance. A recent trial of pregabalin, another anticonvulsant, was considered effective over a placebo in the reduction of neuropathic pain as a result of SCI (Cardenas et al., 2013). Side effects such as dizziness and extreme tiredness occurred but were well tolerated by participants.

Despite this evidenced efficacy, Finnerup, Johannesen, Sindrup, Bach, & Jensen (2001) reported that of their sample, 77% of participants reported pain, with 43% of these treated with analgesics such as paracetamol, whilst only 7% were treated with anticonvulsants, despite them being considered to be most effective in reducing neuropathic pain (Widerstrom-Noga & Turk, 2003; Nicholson Perry, Nicholas, & Middleton, 2011). Evidence suggests that whilst analgesics may have partial effect on SCI pain this is not the most adequate treatment option for pain after a SCI long-term, and research exploring the views of those using such medications is warranted.

The current literature base for neuropathic pain suggests an incomplete knowledge of the mechanisms underlying it (Widerstrom-Noga, Cruz-Almeida, Felix, & Adcock, 2009), making its treatment difficult (Yezirski, 2009). As a result of this, treatment, pharmacological in particular, may come down to trial-and-error (Norrbrink Budh, Kowalski, & Lundeberg, 2006), with no existing treatments producing satisfactory pain relief (Siddall & Middleton, 2006). A study by Summers, Rapoff, Varghese, Porter, and Palmer (1991) found that associations between SCI pain and psychosocial factors are much stronger than associations between SCI pain and physiological factors, suggesting that an increased knowledge of the impact of NP on those with SCI may evidence more effective pain management.

Consistent research suggests an inadequacy of pharmacological treatments, whilst limited evidence has informed understanding of what it is like to live with NP, with most treatments rated as 'somewhat helpful' by patients (Warms, Turner, Marshall, & Cardenas, 2002). Patients report being 'dissatisfied' with the effects of a range of strategies such as analgesics and physical therapies (Cardenas & Jensen, 2006). By

exploring the experience of NP from the patient's perspective, it may be possible to

identify patient's priorities in terms of pain management, as well as the most important

aspects of the individual's unique experience. The evidence surrounding the impact of

NP on the physical, psychological, and social well-being of those with SCI highlights

the importance of targeting NP from the biopsychosocial perspective (Molton et al.,

2009; Nicholson Perry, Nicholas, Middleton, & Siddall, 2009). However, before

adequate NP management can be reached, a complete understanding of the experience,

from the patient's perspective rather than through quantitative work, is required.

2.8 Quantitative vs. Qualitative Research in SCI Populations

Currently, the evidence base surrounding pain following SCI appears to be dominated

by quantitative literature and an incomplete understanding of NP. Whilst much

quantitative work has been carried out amongst those with SCI, personal experiential

stories, particularly of their pain, appear to have been neglected in the literature base.

Some qualitative research has attempted to understand some aspects of pain, such as

memories of pain (Sparkes & Smith, 2008), experiences of pain management (Lofgren

& Norrbrink Budh, 2012), and acceptance of pain (Henwood, Ellis, Logan, Dubouloz, &

D'Eon, 2012). By understanding these experiences from a qualitative point of view, it is

possible to gain access, to some extent, to the personal worlds of those with SCI, and as

such, achieve a deeper understanding that can better inform the literature as well as

future treatment and support. None of the currently available literature, however,

focuses directly on the experience of pain after a SCI.

Lofgren & Norrbrink Budh (2012) used Grounded Theory in order to explore the

patient experience of SCI NP management, through the analysis of patient diaries and

interviews. Results suggested that a discrepancy exists between what patients are offered

from healthcare professionals and what they actually want. Many patients stated that

they used medication alongside other complimentary therapies such as massage and

relaxation, but these methods were often found by trial and error as opposed to being

provided or recommended by professionals. This suggests that healthcare professionals

may be uninformed regarding what patients want from care, and that qualitative work

exploring the experience of NP may inform future care. Further qualitative work has

explored memories of pain following SCI (Sparkes & Smith, 2008). Grounded Theory

47

was used to explore neuropathic pain acceptance post-SCI (Henwood, Ellis, Logan, Dubouloz, & D'Eon, 2012), in which increasing independence and evolving the pain view were seen as the driving forces of the process of acceptance. The results suggest that, as opposed to searching for a cure, early education to improve independence and knowledge surrounding NP could be beneficial to SCI patients in terms of pain-related outcomes, and improving acceptance. Previous work, however, has not explored what it is like to live with pain, without the imposition of topics such as acceptance (as in the studies discussed above).

Qualitative content analysis has been used to investigate the questions that those with SCI have surrounding pain (Norman et al., 2010). Results indicated a number of questions and resources used to answer such questions. Disappointment in the level of knowledge held by family doctors was articulated, suggesting that healthcare professionals without SCI-specific knowledge should be provided with specialist education when a patient sustains a SCI. Other studies (Henwood & Ellis, 2004; Norrbrink Budh, Löfgren, Hunter, & Ellis, 2012) have used focus groups to explore NP, with participants identifying commonalities in experiences, such as medication failure. Such evidence from qualitative studies identifies themes that may not have been identified by quantitative methods, thus allowing new avenues for future work to open and clinical implications to be reached.

Whilst no qualitative research has explored the meanings of pain after SCI, Davis & Novoa (2013) quantitatively assessed the efforts of those with a SCI to find meaning in their experiences, finding that more frequent searching predicts worse adjustment. Others state that finding meaning may increase perceived control (Taylor,

1983), and post-traumatic growth after an injury (Davis & Morgan, 2008). Such studies highlight the importance of the utilisation of qualitative methodologies for improving knowledge of particular phenomena.

The available qualitative literature surrounding pain after SCI offers a rich depth of understanding to be reached. Despite such depth, no previous work has explored the personal experience of NP. Such an understanding would offer valuable knowledge to the literature by highlighting patient experiences and preferences. This would also contribute towards effective healthcare delivery, and further inform and validate the development and utilisation of existing therapies. Whilst the majority of the literature base for SCI and pain uses quantitative methods, little research adopting qualitative methodologies is available. Qualitative research is important for the evidence base, enabling more in depth understandings of the relationships already established by quantitative research to be reached. Whilst qualitative work may not be generalisable, it has theoretical generalisability (Smith, 1996), in that it still has the ability to inform the evidence base, aiding in answering research questions as well as potentially opening up new areas for the development of future research.

2.9 Conclusion

Hughes & Paterson (1997) state that humans use language in order to make sense of bodily sensations, and that by interpreting how an individual uses language it may be possible to obtain some understanding of their experiences, even where it is not possible for the researcher to experience it subjectively. None of the previous work has attempted to understand the experiential impact of pain in individuals with a SCI. Neuropathic pain

is a particular problem for those with SCI, due to irreparable nerve damage, and the reduced ability to physically control it. It is important to obtain a deeper understanding of the pain suffered by this population, such that the effective development and delivery of pain management programmes tailored specifically to the needs of those with NP after SCI can be reached. Further, by utilising a qualitative approach, themes may emerge that have not yet been considered or studied, thus allowing such an approach to open new avenues and provide rationale for the quantitative study of particular themes.

SCI is a debilitating injury that brings with it a number of additional consequences, ranging from depression and anxiety, to social isolation. Literature surrounding such consequences is vast, and offers a number of clinical implications for their treatment. NP post-SCI, however, can be a significantly debilitating problem, posing increased risks to psychological well-being, and often described as worse than the injury itself. This provides great impetus for evidencing the experience. Pain after SCI should be treated from a multidisciplinary perspective utilising the biopsychosocial model, and yet pharmacological treatment options remain dominant in its management, whilst multidisciplinary PMPs offer limited efficacy. Further, it remains unclear as to how a SCI individual experiences their pain and if there are any aspects that may provoke or inhibit pain after discharge. Therefore, a need for qualitative analysis of the experience of pain in SCI after discharge is outlined. The most appropriate medical or psychological treatment may differ for individuals suffering chronic pain, thus an understanding of their experiences of NP after SCI may provide a knowledge base for what may aid in enhancing the quality of life, acceptance of NP, and pain management in this population.

Chapter 3 **Qualitative Methodologies**

Taking everything discussed in the previous two chapters into account, it is important to discuss the different available qualitative methodological approaches, their underlying principles, benefits, and drawbacks for the literature. Quantitative research rejects or retains hypotheses that are drawn up based on previous literature and is concerned with the relationships between variables. This uses step-by-step research techniques that are not open to flexibility (Silverman, 2010). In contrast, qualitative research is based upon obtaining deep, rich knowledge, and meaning. It does not seek to prove or disprove hypotheses; rather, it aims to answer open research questions. This is done through the analysis of transcripts, obtained from semi-structured interviews, observations, focus groups, and diaries. All research has an epistemological approach in which its stance on how people produce knowledge is identified. Quantitative research adopts a realist approach, with the goal to produce objective knowledge that is factual, empirical, and generalisable, whilst qualitative approaches vary in their epistemological standpoints.

There are multiple qualitative research methods that are concerned with the quality and meanings of experience. Some methods focus on the 'small q', using open-ended questions in quantitative research, and coding answers into categories for quantitative comparison. The literature available for 'small q' is already vast and focuses on the generalisability of data, whilst 'Big Q' methodologies explore lived experiences and meanings, at the same time as generating theories (Kidder & Fine, 1987). Each 'Big Q' methodology informs every aspect of the research process differently. In the present study, 'Big Q' methodologies are most appropriate for

attempting to understand individual experiences and key theoretical issues using a novel exploratory methodology, as well as for filling the gap in the evidence base, although each methodology differs, offering its own theoretical approach. This section will review the multiple similarities and differences existing among approaches, and explain how each is used in different situations when it is most appropriate. As a result of this review it will be possible identify the most appropriate methodology for the aims of the present study.

3.1 Grounded Theory

Grounded Theory (Glaser & Strauss, 1967) aims to develop new theories by standardising qualitative data. The researcher remains uninformed of the existing literature base until after the results have been found, and does not posit any hypotheses or research question. This uses a process of identification or coding of descriptive categories, interpreting instances that share features with each other, from words or phrases utilised by large samples of participants. These instances may occur across a range of categories and are likely to develop throughout the analysis. Grounded Theory continues data collection and analysis based on categories identified, theoretically sampling participants who can elaborate on or challenge these emerging categories. The researcher moves back and forth between collection and analysis in order to 'ground' the data. Throughout this analysis, memos are written and kept in order for the researcher to reflect on how the final understanding was generated, leaving a paper trail identifying how the theory was generated.

This approach generalises findings to all individuals who meet the sample

criteria instead of acknowledging the uniqueness of each individual account, and holds a

realist epistemological stance, meaning that similar themes will arise from data,

regardless of the interpreter. However, the subjectivity of the data interpretation means

that it may become difficult to detect and prevent researcher-induced bias (Bryant &

Charmaz, 2007). Charmaz (2003) and Strauss and Corbin (1990) present alternative

approaches: Constructivist Grounded Theory, and Straussian Grounded Theory,

respectively. Constructivist Grounded Theory challenges the original proposition that

objective truth can be reached, and argues that reality is constructed as a result of

interpretations of this reality, thus analysis aims to present multiple realities. Straussian

Grounded Theory uses literature before analysis in order to develop theoretical

sensitivity and hypotheses, whilst adding further structure to the analysis process.

This method aims to develop new theories, and therefore it imposes categories

upon the data, without focusing solely on the experience of the individuals speaking. It

aims to reach data saturation, in which no new categories emerge. Due to the

subjectivity of experience, however, reaching data saturation may be time consuming,

and may reveal many themes that are not relevant to other participants. Further, the large

amount of data obtained may make analysis difficult to manage.

3.2 Discourse Analysis

Discourse Analysis focuses upon the words used in talk or text, exploring what the

choice of language does in different contexts, how these choices obtain goals, and what

the consequences of using this language are (Edwards & Potter, 1992). It also analyses

the functions of turn-taking and power struggles evidenced through language. Discourse analysts posit that social actions are characterised and understood through the use of linguistic resources, and the concept of multiple realities, in which the same reality can be seen in different ways (Fairclough, 1992). Discourse Analysis involves reading transcripts of naturalistic conversations (not interviews) and categorising the data in terms of how language is used. The analyst also looks for patterns in how text and talk are organised, and how understanding, and social life are constructed. Quotes represent how individuals subjectively construct accounts of their personal world.

The use of naturalistic conversations for the purpose of Discourse Analysis may be beneficial, as participants are likely to guide the conversation rather than following a set interview schedule, and as such may be more likely to raise and discuss issues that are important to them. However, this methodology focuses on the use and functions of language used, and fails to acknowledge cognitive and affective reactions of individuals to an experience, and how they make sense of such experiences. The use of this methodology may offer insight into how the participant uses language but ignores the content of the speech itself, which may provide more detailed experiential information.

3.3 Thematic Analysis

Thematic Analysis (Braun & Clarke, 2006) is a large group-based approach to qualitative research that focuses upon the ability to generalise descriptive data and to support or reject theories. Qualitative data is coded by applying brief verbal descriptions to small chunks of a text, which is then analysed into a limited number of themes that

reflect the textual data and are related to the research question. Relationships across themes are then analysed, with the ability to offer quantitative information such as percentages of prevalence and occurrence of themes across participants (Howitt & Cramer, 2011). The researcher may then define and explain each theme in just a few sentences, applying them to each participant.

This approach prioritises description of the phenomenon of study, with the aim to find support for the research question, rather than studying language use or interpreting the subjective effect it may have upon the individual. Its focus remains upon large groups as opposed to the individual experience, which may differ from person to person. Its aims include supporting or rejecting theory, and the context of the participants is not usually considered which may involve researchers becoming too focused on a specific goal as opposed to remaining open to new themes, unrelated to the theory, that may emerge. This means that potentially valuable information may be lost during in the analysis.

3.4 Conversation Analysis

A fourth qualitative methodology is Conversation Analysis (Garfinkel, 1967), where the focus is upon naturalistic social interactions and the way individuals speak and organise their language. This type of analysis concentrates on elements that identify an individual's role within the conversation, such as turn-taking (Sacks, Schegloff, & Jefferson, 1974), sequencing and structure of interactions (including pauses, interruptions, and changes in intonation). It explores the structure of conversation and the roles speakers play in it, meaning that it has the ability to identify linguistic nuances

that may be overlooked by other approaches, rather than its content and meaning.

Due to the detailed approach to analysis, conversation analysis is a time-consuming methodology, requiring specific training. Further, its focus on language use means that content and meaning are not necessarily acknowledged (Schiffrin, 1994). As such, conversation analysis is not suitable for understanding the meaning of specific events that are individualised experiences or how people make sense of their experiences, which may be different for each individual.

3.5 Interpretative Phenomenological Analysis

Interpretive Phenomenological Analysis (IPA; Smith, 1996) is a rapidly growing approach to qualitative research that uses interpretation to understand "what personal and social experiences mean to the people who experience them" (Shaw, 2010, p. 178). A central tenet of the IPA approach is that it attempts to gain access to the participant's 'lived experience' as opposed to simply an 'experience'. In exploring the 'lived experience' it is suggested that the individual is aware of, interacts with, and assigns meaning to a situation, whilst an 'experience' may not necessarily hold meaning to, or be internalised by, the individual, merely passing their awareness (van Manen, 1990). For example, an individual in pain lives that experience, whilst a carer of that individual may only experience the pain without actually living it, holding some knowledge of it but not interacting with it personally.

In contrast to other qualitative methodologies, the aim of IPA is to engage with the reflections of individuals who have experienced something major in their lives, be it positive or negative. Smith's (1996; 2004) articles outline how IPA may be of benefit to the health psychology profession and literature, and qualitative research in psychology,

recognising that each individual may perceive the same phenomenon (such as chronic illness or pain) differently. As such, research should explore the meanings of experiences and how individuals make sense of them. He suggests that this qualitative approach can be used to complement existing quantitative literature, whilst identifying themes posited by participants that may not have previously been explored or even considered within quantitative work. IPA attempts to get as 'experience close' as possible, enabling research to begin to focus on new areas as a result of increased understanding. This type of analysis may also aid in re-evaluating existing theory (Newton, Larkin, Melhuish, & Wykes, 2007).

IPA researchers hold an 'epistemological openness', that occurs somewhere between being critical realists and contextual constructivists (Smith, Flowers, & Larkin, 2009). This means that the researcher is able to make clear their epistemological stance in relation to them and the phenomenon of study. IPA is a linguistically-based approach to research, but in a unique way that involves interpretation of meaning, as opposed to other purely descriptive and discursive approaches such as Grounded Theory, discourse analysis, and conversation analysis. In IPA, analyses reflect some extent of truth for participants (contextual constructivist), in that the experience is described, but this experience is also interpreted by a researcher (critical realism).

IPA is concerned with quality of experience, rather than causal relationships, thus any human experience can be subjected to an interpretative phenomenological analysis. In contrast to discourse analysis, it does not utilise predictions or pre-defined codes. Rather, its primary aim is to describe and explain events and experiences (Willig, 2008). It does not explore the way an individual speaks, but investigates the subjective

experience and meanings of a situation, and may, therefore, be an effective way of informing psychological interventions (Yardley, 2008). Smith & Osborn (2003) outline how IPA studies may be carried out, with emphasis placed on the data collection and analysis, but also stress that IPA can be flexible to the researcher. This methodology appears to be most relevant to the aims to the present study, as it attempts to discover meaning through interpretation of transcripts of first-person accounts, appreciating the experience of each individual. In this, the researcher becomes engaged in identifying themes and integrating them into meaningful clusters, outlining the most important aspects of participant's experiences of the studied phenomenon. IPA is based on the combination of the phenomenology, hermeneutics and idiographical philosophies, each complimenting each other rather than competing (Smith, Flowers, & Larkin, 2009). Each philosophy is examined here.

3.5.1 Phenomenology. One of the foundations of IPA is that of phenomenology, the study of conscious experience and how knowledge is understood by people. This identifies features essential to experiences, as suggested by common themes in accounts of individuals on the particular concept being studied (Zahavi, 2003). Husserl (1931) argued that reality is not independent from human experience; reality is how an individual perceives objects, people, and events. Husserl explained that essential features of an experience are found when a researcher focuses on the experience of another individual in its own right; by stepping away from their natural attitude and bracketing off (stepping away from or reduce) their own assumptions, opinions, and knowledge. This enables a phenomenological (objective) attitude to be adopted, which

will aid in being open to new information that may diverge from what is already known. For example, a researcher should accept that some individuals may not believe in going to counselling for psychological problems, even if the researcher believes that counselling is efficacious. Husserl suggests that being completely objective towards an experience prevents subjective assumptions from interfering with the understanding and description of an experience. This approach minimises interpretation and utilises a focus on objective description, disengaging from the experience in order to focus as objectively as possible on the concept in its phenomenological purity, without incorporating external theory.

Steps for carrying out descriptive phenomenology are defined by Giorgi & Giorgi (2003). First, a researcher must obtain a concrete description of the phenomenon of interest from a participant and bracket off their assumptions and theoretical knowledge about the phenomenon, adopting an objective approach towards understanding the phenomenon. The researcher reads and rereads the description to gain a familiarity with it, and then identifies phrases that capture different aspects of the phenomenon. The researcher is then able to describe the experience of the phenomenon by identifying the psychological significance of each phrase. IPA adopts the use of the phenomenological attitude through bracketing, but differs from descriptive phenomenology in that it acknowledges that it is not possible for a researcher to become completely objective towards a phenomenon. This is discussed in the following section.

3.5.2 Hermeneutics. Hermeneutics is the analysis, interpretation, and understanding of text, with emphasis on meanings. Heidegger (1962) argued that

individuals are constantly engaged with and involved in the world, objects, cultures, and relationships, and cannot always know what their preconceptions are until after they are presented with something new. Therefore, the researcher will see a phenomenon in light of their own preconceptions, so it is not possible to adopt a completely objective stance towards a phenomenon. Emphasis is therefore placed on interpretation of the views of others, and as such, is adopted by IPA. Researchers are encouraged to remain open to and aware of their preconceptions emerging during the processes of data collection and analysis (Gadamer, 1975), in order to bracket off these preconceptions and become at least partially objective (Smith, Flowers, & Larkin, 2009).

In hermeneutics, a process called the hermeneutic circle (Schleiermacher, 1998) is adopted in order to understand texts. This means that parts (such as words) can only be fully understood after understanding the whole (sentence), and the whole can only be fully understood after comprehension of the parts. Thus, in order to understand small excerpts of a transcript, it is important to understand the whole of the transcript. When the excerpt is understood, the whole transcript is further illuminated. IPA engages in the use of the hermeneutic circle, with the researcher constantly re-reading transcripts and analysing in light of understanding of the parts and whole (Smith, 2011a). Further, IPA also engages in the double hermeneutic, in which the researcher must interpret the participant's interpretation of an experience, potentially using their own view of the world, but also recognising that a participant's world cannot be directly accessed. Reflections of an experience are considered an individual's attempt to make sense of what is happening to them, and the researcher needs to investigate and interpret this in order to offer meaningful insights into the experience (Smith, Flowers, & Larkin, 2009).

IPA was developed with the aim of gaining a better understanding of the nature and quality of the phenomenon as it presents itself, by utilising description (phenomenology) and interpretation (hermeneutics) together in order to understand the meanings of experiences, and to be able to describe these meanings.

       3.5.3 Idiography. IPA engages in the use of idiography; this requires the researcher to focus upon the meaning of individual life, one case at a time, analysing each one fully before continuing to the next case. Each case is unique, and as such, each is analysed with a fresh view, in that themes found in one case are not carried over to the next case (Smith, Flowers, & Larkin, 2009). The researcher does not look for the same themes in each case, but appreciates and analyses each case in its own light (Smith, Flowers, & Larkin, 2009). Analysis works at the individual level, making specific statements about that individual. After each case is analysed individually, the researcher searches for patterns across the accounts, presenting shared themes (convergence), whilst highlighting the ways in which themes are experienced differently (divergence). The idiographic approach offers insight into particular instances, and is argued to illuminate the existing literature through "theoretical transferability" (Smith et al., 2009, p. 38). This means that, whilst the results of an IPA study cannot necessarily be generalised to a whole population, they can provide further depth of understanding of quantitative relationships, and offer explanations as to how and why such relationships may occur.

3.5.4 Conclusions. IPA utilises the views of phenomenology, hermeneutics, and idiography in a complementary manner, adopting hermeneutic reflexivity rather than scientific phenomenological reduction as a way of acknowledging preconceptions and judgements. This is done through the documentation of reflections, concerns, goals, reasons for particular analytical decisions, and major issues in the process of the research. Phenomenology is used in order to identify features central to specific experiences, whilst hermeneutics understands that it is not possible for experiences to be described completely objectively, and thus is adopted in order to interpret the interpretations of others. IPA places emphasis on the importance of the individual, adopting an idiographic approach to data collection and analysis. Analysis focuses on the similarities and differences across participants, gaining insight into the experience, rather than attempting to generalise data to the wider population. This combination of philosophies towards qualitative research makes IPA a unique methodology to follow, utilising strengths from a range of approaches in order to obtain a rich, detailed understanding of an experience from a perspective that gets as 'experience close' as possible.

Vital to the qualitative paradigm, and in line with the beliefs of IPA, reflexivity rejects that a researcher can become completely objective towards a phenomenon. Instead, researchers should reflect upon their position in relation to the research and to question and consider how they may have influenced the research process and the findings. This should be an ongoing process throughout the entire research project, right from subject choice, through to the write-up of the analysis in order to understand how and why decisions were made and results may have occurred. The two types of

reflexivity described by Willig (2001) include personal reflexivity, reflecting upon how the researcher's social background, interests, beliefs, and values contribute to the shaping of the research; and epistemological reflexivity, reflecting on the researcher's assumptions of how we know what we know and assumptions about the world. Each of these should examine how the research process has been influenced. Personal reflexivity and epistemological standpoint will be discussed at the end of each individual study.

3.6 Methodology of IPA

3.6.1 Participants and Sample Size. Smith & Osborn (2007) describe how to carry out and analyse an IPA study. The nature of IPA informs the research right from the start, thus informing the generation of the research question, the sample used, the method(s) of data collection, and the analysis of data. The research question should be an open one that aims to explore the experience of a phenomenon in its own right. Samples are based on purposive sampling, in which participants are recruited according to their relevance to the research question and similarities to each other in experiencing the phenomenon of study (Willig, 2001). Participants experiencing the phenomenon are considered experts in their experience, and are likely to provide lots of information regarding the experience of interest. This homogenous sample is likely to produce themes that are reflective of the population (Smith & Osborn, 2003).

Brocki & Wearden (2006) reviewed studies that used IPA, finding participant numbers varied between one and thirty, however Smith & Osborn (2003) suggest that there is no 'right' sample size. A review conducted by Smith (2011a) identified a number of studies considered as 'good', 'acceptable' and 'unacceptable'. Within the

studies considered 'good', sample sizes varied from one to 14 participants, with an average of nine. IPA has been effectively utilised in a single case study (Rhodes & Smith, 2011). However, Smith (2011a) states that it is not necessarily the sample size that determines a 'good' study, but the richness of the accounts, the prevalence of themes across the sample, and the discussion of these themes.

Turner, Barlow, and Ilbery (2002) describe striving to continue to attain data until data saturation occurs throughout qualitative research. This is the point at which information given by participants becomes repetitive and no new themes emerge. Due to the potential for everyone to experience a phenomenon differently, data collection and analysis within an IPA study could continue for a long period of time and data saturation could never occur (Smith, Jarman, & Osborn, 1999). This may be a risk factor for the research and its generalisability, but the idiographic nature of IPA means that data saturation is not a priority. Instead, samples of homogenous and articulate participants are used, in order to obtain meaningful perspectives on the area of interest. Additionally, time constraints of interviews, transcription, and analysis also prevent data saturation from being a priority (Smith & Osborn, 2003). After participants are recruited, interviews are carried out and transcribed verbatim; the process of both of these is explained next.

3.6.2 Interviews. In order to obtain rich data from a participant, exploratory, open-ended, and non-directive questions are posed during semi-structured, recorded interviews. These questions aim to facilitate a detailed account of the phenomenon of study. Interviews generally begin with an open, introductory question such as 'tell me

about your experience of pain'. Focused and specific questions may then be used to gain more information on topics of interest raised by the participant. Leading and closed questions that may cause a participant to answer in a particular way are never used. Osborn & Smith (1998) advise that the interview schedule does not dictate the exact course of the interview; questions may be adapted so that participants can tell their own story. Where participants raise topics of interest to the study, the researcher may probe into these areas, asking 'could you tell me more about that'. The semi-structured nature of the interview means that the schedule is open to change and can go in any direction the participant wishes to take it.

An alternative method of data collection is through the use of focus groups. This technique is argued to be suited to research where an accessible and homogenous group is available (Dunne & Quayle, 2001). Steps for using IPA in focus groups have been identified (Palmer, Larkin, de Visser, & Fadden, 2010) and demonstrated by McParland, Eccleston, Osborn, and Hezseltine (2010). Smith & Osborn (2003), however, argue that the purpose of IPA is to understand personal experience and this may not be obtained if research is carried out in groups, due to confounding variables such as demand characteristics. For example, discussing personal experiences of illness in a group may cause individuals to answer questions in ways that they think they should answer in order to maintain a good social appearance (social desirability bias; Fisher, 1993), whilst others may shy away from answering questions that they might be more likely to answer when interviewed alone. For example, questions regarding pain may be embarrassing for some people and as such, answers provided may not be entirely true. Subsequent analysis of this would, therefore, potentially be inaccurate and/or invalid.

3.6.3 Transcription. The first step of analysis in IPA is the transcription of recorded interviews. This is carried out verbatim. Unlike the Jeffersonian technique (2004), which studies the linguistic content of speech by transcribing information regarding tone and lengths of utterances, IPA transcription includes all words spoken and major prosodic features such as false starts, laughs, sighs, and interruptions (Smith & Osborn, 2007). The Jeffersonian technique may be suitable for conversation analysis, as it records other transcription conventions such as length of pauses, changes in intonation, but, aside from notable features, these are not considered necessary in IPA transcription. IPA studies the content and meaning of text, rather than how the speech presents itself (Smith & Osborn, 2007), therefore it is not important for all minor utterances to be transcribed, unless they contribute towards the understanding of the meaning behind the text.

3.6.4 Analysis. The next stage involves reading and rereading transcripts individually a number of times in order to become familiar with them. Smith & Osborn (2007) state that intensive and detailed engagement with individual transcripts is needed to gain insights. The researcher makes initial exploratory notes including associations, questions and comments, in the right-hand margin. These are carried out on a line-by-line basis, identifying words of interest (descriptive), tone, mood, metaphors, humour (linguistic), and interrogative (conceptual) interpretations of how the participant talks about and understands the issue of study (Smith, Flowers, & Larkin, 2009). As prescribed by Smith and colleagues (2009) further reading of the exploratory notes

involves 'chunking' notes and the generation of emergent subordinate themes that relate to what is said but are also theoretical and grounded in the data. For example, where a participant states that they feel anger at a particular phenomenon, this may be grouped with other similar statements and labelled into a cluster of 'emotions'. These themes map out the participant's cares and concerns regarding the phenomenon. Often, the researcher will go back to the data in order to explore new avenues, and as such, theme labels are open to change dependent on further interpretation and developed understanding of the parts and whole.

An article by Smith (2011b) discusses the concept of three 'gems' that may occur within IPA studies; these are secret, suggestive, and shining gems. He suggests that gems are small units of a text that are highly significant, illuminating a whole text and aiding the understanding of an individual's experience of a phenomenon. First, the secret gem requires lots of analytical work to understand and is not necessarily obvious to the researcher at first. This is highly important as they may often occur as a verbal slip due to psychological confusion, revealing a lot of hidden information. Participants are not necessarily aware of the meanings of what they are saying. An example of this is drawn from a study of anger and aggression (Eatough & Smith, 2006), in which a participant discussing her mother states that 'she was always my brother'. Analytical work revealed that the participant believed that her mother expelled her, favouring her brother in a new 'good' nuclear family. Second, is the suggestive gem, which participants have some awareness of, but some work is needed to understand these gems. Smith presents a suggestive gem in 'I'd dreamt about the devil', which, after some detective work, presents dialysis, an intense treatment, as the 'devil'. Third,

shining gems are obvious and often literally true, conveying high psychological impact that the participant is aware of and able to articulate. An example of a shining gem comes from a participant speaking of her son's circumcision 'Everybody's watching my son being chopped to pieces', capturing a sense of horror. Although Smith states that the idea of gems is a work in progress, he suggests that working on gems can offer valuable insight to the evidence base.

Once subordinate themes are identified, the researcher adds structure to the analysis by listing these themes and identifying patterns and connections amongst them. This forms clusters of subordinate themes with shared meanings, relationships, patterns, or conflicts. These clusters are then labeled descriptively. This is an iterative process; these themes should make sense in relation to the original text, so that the researcher may go back and forth between the text and themes to ensure that connections are compatible, potentially editing labels. A summary table should be produced, in which clusters and their subordinate themes are listed in terms of their overall importance and concern to the participant, with the most important at the top and the least important at the bottom. Indicative quotations and references (name, page, line number) that reflect each theme are included in the table. During this process, some clusters and subordinate themes may be dropped if it is found that they do not fit in with the structure or lack rich evidence. It is important to be aware that some clusters may be more focused than others, thus providing fewer subordinate themes. Due to the nature of interpretation and its subjectivity, it is only possible to achieve a sense of gestalt (good enough) for each case, rather than aiming for perfection, as different researchers may hold different interpretations of data (Smith, Flowers, & Larkin, 2009).

Smith & Osborn (2007) suggest that themes found in one case may be used to help orient further analysis. Where new themes emerge, the researcher should follow a cyclical process, going back to previous cases to see if they are represented there. When all accounts have been analysed, triangulation occurs, during which individual case tables are cross-analysed together in order to compare and contrast clusters across participants. Connections are made across each participant's summary table, through which clusters are organised into superordinate themes that should capture the majority of the data. According to Smith, Flowers, and Larkin (2009), each superordinate theme should be present across at least half of the cases. Again, this should be carried out in a cyclical process. A master table of superordinate themes and clusters is constructed as a graphical representation of the analysis. Analysis involves presenting the data, giving an extract to evidence the data, and a commentary of the account and how it fits into the theme.

Second and third researchers may be used as independent auditors (IAs) in order to establish the validity of the themes identified, as well as provide additional judgement on the analysis. In this, independent researchers may study a number of transcripts and discuss this reading with the first researcher, coming to an agreement on theme labels and interpretations. IPA does not aim for inter-rater reliability due to the individuality of experience, but independent auditors are enrolled to verify that IPA has been carried out correctly and themes are supported by the data. Ideally, a second researcher should check themes throughout every step of the analysis (Osborn & Smith, 1998).

After analysis, Smith, Flowers, & Larkin (2009) suggest that between three and five superordinate themes should occur, with two to three subordinate themes each, and

a minimum of four quotations for each subordinate theme. Each superordinate theme

and its corresponding subordinate themes are described and illustrated with rich

verbatim quotations in order to demonstrate examples of themes. Participants who

contrasted themes should be included, in order to evidence how themes exist, but

manifest themselves differently for each individual. Each superordinate theme is then

presented and discussed in terms of how they contribute, compare to, or contrast against,

previous literature. The outcome of IPA research enables a renewed insight into the

phenomenon of study, informed by the participants' experiences (Larkin, Watts, &

Clifton, 2006).

3.7 What makes a good IPA paper?

Smith (2011a) evaluated IPA papers studying the experience of physical illness. Of the

51 papers included, 14 were regarded as 'good'. Eleven of the papers studied chronic

pain and ten studied neurology, suggesting that IPA may be a well-established technique

for further understanding the particular problem of NP following SCI. The IPA

methodology has been also utilised effectively in the explorations of the experiences of

heart disease (Chapman, Parameshwar, Jenkins, Large, & Tsui, 2007; French, Maissi, &

Marteau, 2005), cancer (Reynolds & Lim, 2007), arthritis (Turner, Barlow, & Ilbery,

2002), and dermatology (Murray & Rhodes, 2005).

Each study was analysed and compared against others in order to establish what

makes a 'good', 'satisfactory' and 'unsatisfactory' IPA research report. As a result of

this analysis, Smith outlines each of the quality levels' criteria. 'Unacceptable' papers

may have been inconsistent with the principles and methodology of IPA, descriptive

(rather than interpretative), with a small number of extracts supporting each theme, no comment on the prevalence of themes, and a poor evidence base. 'Acceptable' papers should meet the principles of IPA, be coherent and interesting, use sufficient numbers of extracts in order to demonstrate themes and comment on the prevalence of themes. 'Good' papers meet the same criteria as 'acceptable' papers, but also offer clear focus, in-depth analyses of the topic, with strong interpretation that engages and enlightens the reader. A 'good' research paper may be recommended to an individual with no prior experience of IPA and should be rigorous in its indications of convergence and divergence as well as the prevalence of themes (using extracts from at least half of the participants in order to demonstrate themes sufficiently), and be interpretative as well as descriptive.

'Good' papers made up 27% of the corpus of Smith's analysis. Clarifying what makes a 'good' IPA paper claims importance in improving the quality of future research and the inclusion criteria of journals. In these papers, participant numbers varied widely, from one to 14. Smith's article suggests no recommendations of participant numbers, but states that each theme identified should be evidenced by quotes from at least three participants and a statement of the level of prevalence of the themes, or quotes from at least half of the participants. This further highlights the ways in which IPA should be carried out during the data collection and analysis stages of research.

3.8 IPA Research

IPA has been effectively utilised as a methodology for the study of numerous experiences; a vast body of studies of those with chronic pain, and those with spinal

cord injury have been subject to IPA. Each of these will be discussed further, in order to illustrate the appropriateness of IPA for studies with these groups. IPA studies exploring the experiences of chronic pain and SCI are discussed here in order to highlight the value of using IPA for the purpose of investigating what it is like to live with NP post-SCI.

 3.8.1 IPA in Studies of Chronic Pain. IPA has been successfully utilised to identify that sufferers of chronic, benign lower back pain experience a 'disengagement' from the area of the body in pain. This disengagement led to a change in the relationship towards that area, in that participants feel it was no longer a part of their 'self' (Osborn & Smith, 2006). These results provide experiential support for Pincus & Morley's (2001) Self-Enmeshment Model, as discussed on page 11. This theoretical transferability has the ability to provide supporting information to quantitative study, thus highlighting the importance of such a model of pain. This indicates the benefit of IPA to provide clinically relevant results that can be used to inform healthcare professionals of the prevalence of disengagement, and offer them guidance for practice.

 Smith & Osborn (2007) found that participants with chronic pain felt a sense of self-loathing, with negative emotions becoming so strong that as well as being directed inwards to the self, they directed outwards to other people around them. For example, individuals would be nasty or welcome the misfortune and pain of others, and often resorted to socially isolating themselves to avoid negative feelings activated by the presence of others. The social impact of pain is further clarified by an IPA study by Osborn & Smith (1998), who found that individuals with chronic pain found themselves

withdrawing from others due to feelings of being a burden and being unable to show their distress. Such studies emphasise that IPA studies can inform clinical practice and future research, and may be used to inform professionals of how pain may influence social isolation, enabling a focus upon the social aspects of pain in order to aid coping and adjustment.

Internet message boards for sufferers of Complex Regional Pain Syndrome (CRPS), in which individuals feel intense pain at the slightest touch to their skin, have been subject to IPA (Rodham, McCabe, & Blake, 2009). Focusing on positives, the use of humour, venting, and giving and receiving support were identified as the most important factors in coping with the condition. This result highlights a tendency of those with CRPS (who choose to use online message boards) to focus upon being positives rather than negative, a theme that may not have emerged from quantitative work. This also demonstrates the flexibility of the use of IPA, ascertaining that it is not only interviews and focus groups that can be subject to IPA.

Chronic pain is among the most widely researched area of physical illness that has undergone IPA analysis (Smith, 2011a). This suggests that pain may be an important factor in predicting psychological well-being and that many researchers find this concerning. In different participant groups, some themes have been comparable, whilst others have reinforced the individuality of different populations' experiences of the same phenomenon. IPA, therefore, is a beneficial methodology for the understanding of the same phenomenon in different populations, and may be used to inform the development of strategies for treatment, specific to each unique population.

3.8.1 IPA in Studies of Spinal Cord Injury. IPA has been successfully utilised in order to explore a variety of experiences following spinal cord injury, each of which will be discussed in more depth here, in order to illustrate the depth of information that may be obtained from such studies, and again, the flexibility of the IPA approach.

Kaiser & Kennedy (2011) used IPA to explore cognitive appraisals adopted by people with SCI. Ten inpatients at a rehabilitation hospital took part, and four superordinate themes emerged. These outlined the most important factors when making cognitive appraisals about a SCI, including: making sense of the traumatic experience, impact of the SCI, coping, and altered views of the self and life. These themes suggest that appraisals are complex, particularly after SCI, relating to the context of the injury, roles and relationships adopted, as well as the individuals themselves. Such evidence can be used to provide experiential support to previously existing theory, whilst offering depth to the current understanding.

Life after discharge from a rehabilitation unit has also been subject to IPA. Dickson, Ward, O'Brien, Allan, and O'Carroll (2011) found that post-discharge, individuals feel that they lose the sense of camaraderie gained as an inpatient, and may be ill-prepared for other people's reactions to SCI. The themes identified may influence the use or development of interventions that may aid community reintegration after a SCI, such that physical and psychosocial difficulties may be prevented. Boschen, Tonack, and Gargaro (2003), suggest that the use of peer mentoring schemes and supervised transactional phases can prepare patients for discharge, whilst patient and family education on SCI can offer realistic expectations. Continually assessing needs, and increasing social support and functional independence are also suggested

techniques. The suggestions made by Boschen and colleagues are supported by the results of Dickson et al.'s (2011) IPA study, thus bringing the issues that occur post-discharge to the forefront of clinician's and researcher's attention.

A significant event that may occur after SCI is childbirth, an experience that has been studied by Tebbet and Kennedy (2011). Key themes articulated by women with SCI were; preparing for childbirth, childbirth as a pleasurable event, childbirth as a unique experience, importance of support during the childbirth experience, and childbirth as a team effort with varied degrees of control. These themes illuminate how pregnancy and childbirth are experienced post-SCI, outlining where further support may be necessary, and describing the event as a pleasurable one; results which may not have been reached through quantitative study. The emergence of such unique themes evidence the power of IPA to open up new avenues for future work to explore.

In addition to the direct effects of SCI on the individual with the injury, themes identified through the use of IPA have demonstrated that the injury also directly affects the lives of siblings of children with an SCI (Akhtar, Kennedy, Webster, & Graham, 2012). Key superordinate themes that emerged included 'life interrupted' due to absent family members and unwanted intrusion, 'what about me?', due to feelings of being second priority and vulnerable, and 'my safety net', encompassing issues surrounding relationships and acceptance. This work has posited potential ways to enhance positive psychological well-being of siblings of children with SCI, such as increasing education on SCI, encouraging sibling visits to the hospital to increase involvement, and including siblings in the rehabilitation process to ward off fears and myths they may believe.

The IPA studies here illustrate how themes can emerge that offer benefit to both the literature base and in practice, demonstrating the advantages of IPA as a methodology to understand experiences. Each of the studies discussed provide further insight into what it is like to live with SCI, no previous work has explored what it is like to live with NP following SCI, despite its impact upon the psychosocial wellbeing of the sufferer. Whilst it may not be possible to achieve complete understanding of a subjective experience, utilising IPA offer the potential for a deeper understanding to be reached. IPA is an ever-growing qualitative methodology that is increasing in popularity and use within health psychology (Brocki & Wearden, 2006). The studies outlined above emphasise the flexibility of IPA, in that it may be used across a variety of patient groups, and through various mediums of data, from transcribed interviews, focus groups, or participant diaries, as well as its applicability to populations living with chronic pain.

3.9 Conclusions

IPA utilises the views of phenomenology, hermeneutics, and idiography in a complementary manner, adopting hermeneutic reflexivity rather than scientific phenomenological reduction as a way of acknowledging preconceptions and judgements. This is done through the documentation of reflections, concerns, goals, reasons for particular analytical decisions, and major issues in the process of the research. Phenomenology is used in order to identify features central to specific experiences, whilst hermeneutics understands that it is not possible for experiences to be described completely objectively, and thus is adopted in order to interpret the

interpretations of others. IPA places emphasis on the importance of the individual, adopting an idiographic approach to data collection and analysis. Analysis focuses on the similarities and differences across participants, gaining insight into the experience, rather than attempting to generalise data to the wider population. This combination of philosophies towards qualitative research makes IPA a unique methodology to follow, utilising strengths from a range of approaches in order to obtain a rich, detailed understanding of an experience from a perspective that gets as 'experience close' as possible.

Vital to the qualitative paradigm, and in line with the beliefs of IPA, reflexivity rejects that a researcher can become completely objective towards a phenomenon. Instead, researchers should reflect upon their position in relation to the research and to question and consider how they may have influenced the research process and the findings. This should be an ongoing process throughout the entire research project, right from subject choice, through to the write-up of the analysis in order to understand how and why decisions were made and results may have occurred. The two types of reflexivity described by Willig (2001) include personal reflexivity, reflecting upon how the researcher's social background, interests, beliefs, and values contribute to the shaping of the research; and epistemological reflexivity, reflecting on the researcher's assumptions of how we know what we know and assumptions about the world. Each of these should examine how the research process has been influenced. Personal reflexivity and epistemological standpoint will be discussed at the end of each individual study.

The methodology of IPA, including its commitment to the idiographic, and to ensuring quality and rigour in analyses, alongside the growing corpus of studies of

chronic pain and spinal cord injury that utilize the approach, suggest that this is a good

qualitative methodology for exploring subjective experiences and enhancing

understandings of what it is like to live with a phenomenon such as pain or spinal cord

injury.

Chapter 4 **Rationale**

As a result of its many direct and indirect costs to the sufferer, chronic pain remains the focus of research around pain (Fortner et al*., 2003). However, theoretical accounts of the mechanisms that cause pain to persist focus primarily on single features such as a biological basis (Melzack, 1999; Baliki et al*., 2006); behaviour (Vlaeyen et al*., 2009; Goubert*, Craig, & Buysse*, 2011); cognitive factors (Turk & Rudy, 1986; Pincus & Morely, 2001; Severeijns, Vlaeyen, & van den Hout*, 2004; Eccleston & Crombez, 2007; Sullivan, 2012); and family or social influences (Kerns, Otis, & Wise*, 2002; Kerns & Otis, 2003; Lewandowski, Morris, Draucker, & Risko*, 2007), despite the agreement that pain is a biopsychosocial phenomenon, and for the need for multidisciplinary pain management programmes (Engel, 1977; Osborne, Jensen, Ehde, Hanley, & Kraft, 2007). This reinforces the need for a more in depth understanding of the experience. Pain, however, is experienced subjectively, and it has been argued that research should be directed to more qualitative, phenomenological influences (Anand & Craig, 1996). Further qualitative research is needed in order to gain a better understanding of the personal experience of pain and its psychological and social processes (Osborn & Smith, 1998; Holzman & Turk, 1986).

Pain is a common side effect of many health conditions, one of which is spinal cord injury, with wide ranging studies documenting its presence in over 60% of the SCI population (Kennedy, Frankel, Gardner, & Nuseibeh*, 1997; Rintala*, Hart, & Priebe, 2004; Modirian et al., 2010). Occurring in locations that may lack motor and sensory function (thus potentially inducing further distress), NP is often described as the most

difficult consequence of the injury to manage (Widerstrom-Noga, Felipe-Cuervo, Broton, Duncan, & Yezierski, 2001), and the presence of NP after SCI may also pose significant risks to the sufferer's psychological well-being (Widerstrom-Noga, Duncan, Felipe-Cuervo, & Turk, 2002; Putzke et al., 2002). NP serves as a risk factor for the development of depression (Hoffman, Bombardier, Graves, Kalpakjian, & Krause, 2011), and reductions in functional ability after SCI (Widerstrom-Noga, Felipe-Cuervo, & Yezierski, 2001; Tawashy, Eng, Lin, Tang, & Hung, 2009). NP after a SCI is particularly difficult to treat (Yezierski, 1996), refractory to treatment (Warms, Turner, Marshall, & Cardenas, 2002), and often worsens after discharge from hospital (Kennedy, Frankel, Gardner, & Nuseibeh, 1997; New, Lim, Hill, & Brown, 1997; Vassend, Quale, Røise, & Schanke, 2011). It is, therefore, important to establish an in-depth understanding of what those with chronic NP following SCI want and need. This should be examined from the patient perspective, such that interventions can be better informed and developed, specific to their needs.

General pain management programmes (PMPs) aimed at those with chronic low back pain, for example, have been found less effective for those with a SCI (Nicholson Perry, Nicholas, & Middleton, 2011). This may be due to the different mechanisms underlying each type of pain, but also due to varying needs and requirements of each population. Competing demands, such as the need to manage pain, coming to terms with a life-changing injury, and often adapting to life from the perspective of a wheelchair, may increase the risk of distress. This implies a need for PMPs specific to those with SCI, treating their specific pain problems, rather than the problems that are experienced by non-paralysed populations, who may not have the same competing demands.

However, little research exists addressing the impact of SCI and its meanings and implications on an individual's purpose in life (Davis & Novoa, 2013). The evidence presented here suggests a need for a more complete understanding of the experience of NP after SCI and how it is experienced differently to general chronic pain populations, in order to improve current, and develop new, pain management interventions specific to spinal cord injured patients.

Hughes & Paterson (1997) state that humans use language in order to make sense of bodily sensations, and that by interpreting how an individual uses language it may be possible to obtain some understanding of their experiences, even where the researcher may not be familiar with it. No previous work has attempted to understand the experience of NP for those with a SCI, despite being a particularly distressing problem for SCI patients, due to permanent nerve damage and the lack of ability to exert physical control over it. Further understanding of this experience can allow those living with NP to feel heard, as well as informing the literature base, future work, clinical practice, and the development of SCI-specific pain management programmes. Such deep insight may be reached through the adoption of a qualitative approach that will allow participants to tell their stories and identify what is important to them.

IPA is a qualitative methodology that allows researchers to explore the meanings behind language, and has been applied in many areas of clinical significance, highlighting its practical impact as a methodology. Groups with chronic illness that have been studied using the IPA approach include those with heart disease (Chapman, Parameshwar, Jenkins, Large, & Tsui, 2007; French, Maissi, & Marteau, 2005), cancer (Reynolds & Lim, 2007), arthritis (Turner, Barlow, & Ilbery, 2002), chronic pain

(Marriott & Thompson, 2008; Osborn & Smith, 1998; Smith & Osborn, 2007), and spinal cord injury (Dickson, O'Brien, Ward, Allan, & O'Carroll, 2010; Dickson, Ward, O'Brien, Allan, & O'Carroll, 2011; Tebbet & Kennedy, 2011; Kaiser & Kennedy, 2011). These studies have informed the literature base, evidencing interventions and positing practical treatment suggestions specific to each population that may aid their coping abilities and benefit their psychological wellbeing.

IPA has not yet been used to explore the lived experience of NP from the perspective of people with SCI, despite its prevalence, negative impact upon adjustment to injury, quality of life, and physical and psychosocial function. Indeed, there is agreement that its mechanisms require further understanding (Widerstrom-Noga, Cruz-Almeida, Felix, & Adcock, 2009). The utilisation of IPA is considered important, particularly from the psychological perspective, in order to identify what the people living with the experience consider most important to them, as well as to highlight any secondary consequences and themes that may not have previously been investigated or even considered by quantitative work (Smith, 1996). Such explorations of the patient perspective may direct researchers and healthcare professionals to the areas of participant-identified importance (Yardley, 2008), thus evidencing the continued use, or introduction of, treatments and management techniques.

Neuropathic pain after SCI is a complex problem that needs to be understood from the patient perspective. The aim of this study, therefore, is to fill this gap in the literature base. This aim will be met by exploring accounts of participant's personal experiences of NP, and investigating how these accounts converge and diverge, such that themes of importance to those living the experience arise. The adoption of IPA

offers many benefits; whilst consequences of NP have already been identified by

quantitative explorations, it may be possible to identify which of these are considered

most important to those living with NP. Issues may arise that highlight what is missing

in the evidence base, and what requires more explorative work. Further, the emergence

of themes may provide additional, in-depth, support for pre-existing work to continue.

This work should, therefore, highlight what is important to those living with NP post-

SCI, what is worth exploring in future work, and interventions that may be developed

and employed in clinical practice.

Chapter 5 **Study One: The Experience of Neuropathic Pain after Spinal Cord**

Injury Post-Discharge from a Rehabilitation Unit

5.1 Research Aims

The present study utilises IPA in order to explore how individuals with a SCI experience pain on a deeper level than through quantitative self-reports alone. Outpatients are of particular interest to this study, as pain may be more likely to affect their daily lives in an environment that may be less wheelchair-user friendly than a specialised spinal unit in a hospital. As well as this, these outpatients may not have direct access to healthcare professionals and medication, and pain is likely to increase upon discharge. Outpatients are attempting to reintegrate into the community after a devastating injury, and the presence of pain may play an important role in helping or hindering this reintegration (Donnelly & Eng, 2005; Widerstrom-Noga, Duncan, Felipe-Cuervo, & Turk, 2002; Putzke et al., 2002).

5.2 Research Questions

The present study aims to provide some answers to the following research questions:

- How do outpatients with spinal cord injury experience chronic neuropathic pain?
- How do members of this population converge and diverge in their experiences?

5.3 Methodology and Procedures

5.3.1 Design. An exploratory, qualitative, interview design is adopted in this study, utilising IPA in order to analyse semi-structured interview data obtained from a small, homogeneous sample of individuals suffering with chronic neuropathic pain as a result of their SCI.

5.3.2 Participants. Participants were recruited through The National Spinal Injuries Center, Stoke Mandeville Hospital, Aylesbury, and the Spinal Injuries Association. Outpatients were chosen specifically due to existing literature suggesting that pain may increase after discharge from hospital (New, Lim, Hill, & Brown, 1997; Vassend Quale, Røise, & Schanke, 2011; Kennedy, Frankel, Gardner, & Nuseibeh, 1997), and that it poses an increased risk upon quality of life and reintegration into the community post-discharge (Donnelly & Eng, 2005; Widerstrom-Noga, Duncan, Felipe-Cuervo, & Turk, 2002; Putzke et al., 2002).

The inclusion criteria were developed in order for the sample to be recruited purposively, in that all participants were experts in the phenomenon of study, rather than being representative of the whole population, with enough cases to be able to examine the convergences and divergences within the group (Willig, 2001). This meant that participants would be 'experts'; able to give detailed experiential accounts of the phenomenon of study, and that the research question would be significant and meaningful.

Inclusion criteria were as follows: over 18 years old (no upper age limit), outpatients of The National Spinal Injuries Center, spinal cord injured for a minimum of one year, sufferers of chronic neuropathic pain for a period of over three months that they continue to experience (in line with IASP's definition of chronic pain), and sufficient understanding of the English language. Exclusion criteria included: any other known chronic health condition that may affect the pain experience, any significant cognitive impairment, mental illness or head injury, and articulation difficulties.

A total of eight participants were recruited, all from The National Spinal Injuries Centre (none were recruited from the Spinal Injuries Association). This sample size reflects the principles of IPA (Smith, Flowers, & Larkin, 2009) and previous IPA studies with SCI samples (Dickson, Allan, & O'Carroll, 2008; Kaiser & Kennedy, 2011; Nunnerly, Hay-Smith, & Dean, 2012; Tebbet & Kennedy, 2012). There is an increasing focus on small sample-sized investigations that are in line with the idiographic focus of IPA, and as such, the sample size for this study was considered acceptable for this study (Smith et al., 2009). The nature and timescales of the interviews allowed for abundant data generation and experiential richness, such that fewer participants needed to be recruited. Figure 5 shows the outpatient consort diagram.

5.3.3 Situating the Sample. Contextual details of each participant's individual circumstances are provided in Appendix A. Contextual details are provided in order to situate each participant and illustrate how each interview was dominated and made unique by each individual's experience. Table 1 contains demographic information.

Figure 5. Outpatient Consort Diagram.
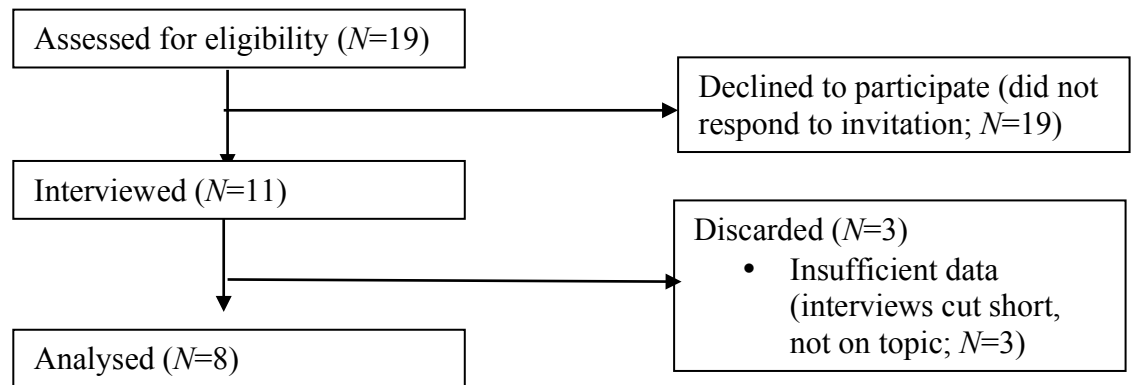
LIVING WITH NEUROPATHIC PAIN AFTER SPINAL CORD INJURY

Table 1. Outpatient Demographic Characteristics.

Participant*	Age	Employment status	Marital status	Cause of injury	Time since injury (years)	Level of Injury	Completeness of injury (ASIA Impairment level)	Pain location(s)	Average Pain Intensity
James	38	Part-time	Married	RTA**	2	T3-T4	Incomplete (B)	Left leg, chest, right shoulder	8
Daniel	26	Full-time	Cohabiting	Gun-shot wound	3	L1-L2	Incomplete (C)	Right leg	9
Harry	65	Unemployed	Married	RTA	32	C5-C6	Complete (B)	Right hip, back	8-10
Rebecca	44	Unemployed	Single	RTA	21	C4-C5	Complete (B)	Whole body	10
Dave	77	Retired	Widowed	Fall	15	T12	Incomplete (C)	Legs	5
Emma	42	Part-time	Married	Non-traumatic	1	C4-T9	Incomplete (D)	Legs, abdomen, back	3-4
Sharon	49	Unemployed	Divorced	Non-traumatic	1	C4	Incomplete (B)	Arms, right leg, whole body	6
Sean	31	Part-time	Single	Traumatic	10	C5-C6	Complete (A)	Abdomen, legs	4

* All names changed to preserve anonymity. ** Road Traffic Accident.

5.4 Materials

Letter of invitation (Appendix B). This provided brief, essential information regarding the study, inviting those interested to request further detailed information from the researcher.

Participant information sheet (Appendix C). This provided further detail of the study, including potential risks and benefits, confidentiality, dissemination plans, as well as funding and ethical review information.

Consent form (Appendix D). The consent form listed statements, next to which participants were required to sign their initials in order to consent to the requirements of the study, and to taking part.

GP letter (Appendix E). This provided each participant's GP with very brief information regarding their patient's participation in the study, the nature of the study, the date of participation, and contact details of the researcher, should they have any questions.

Friend/family member information sheet and consent form (Appendix F). The information sheet provided information regarding the study and what friend/family participation involved. The consent form provided statements requiring consent from the friend or family member in order for them to be present during the participant's interview.

Demographic questionnaire (Appendix G). Standard demographic variables were recorded including age, occupation, marital status, cause of injury, time since

injury, level of injury, completeness of injury, pain location, and a numerical rating scale for pain intensity. The total number of items was 13.

Interview schedule (Appendix H). The interview schedule was semi-structured and non-directive, prepared following guidelines proposed by Smith (1996). Open-ended questions were utilised in order to give participants the ability to lead the conversation, telling their own story with as much or as little information as they wanted. There were a total of six questions in the schedule.

Debriefing form (Appendix I). The debriefing form provided a reminder to the participant of the aims of the study, what would happen to the results, whilst reasserting confidentiality of personal data and anonymity of information provided. Details of the research team were provided in case of further questions or concerns after completion of the interview. Details of an independent contact point were provided in case participants felt particularly distressed by the nature of their interview.

5.5 Procedure

5.5.1 Developing the Interview Schedule. Following the principles of IPA (Smith, Flowers, & Larkin, 2009), interview questions were developed following consideration of a range of relevant literature surrounding living with pain, in order to explore each participant's own experience of pain after SCI. All questions were developed to remain open and exploratory in order to focus upon the meaning of the experiences to participants, as opposed to finding causality or differences. This schedule was piloted with members of the Spinal Injuries Association in order to assess timings and confirmed the suitability of the questions. The first question of the interview

schedule; "tell me about your experience of pain since your SCI" elicited lots of rich data, and allowed participants to set the parameters of the interview and discuss what was of importance to them. Further questions were raised by the interviewer, only after the topic had been established by the participant first, allowing the questions to remain grounded in the phenomenological account of the participant and reduce researcher influence upon the data.

5.5.2 Interviews. Spinal outpatient clinics at The National Spinal Injuries Center, Stoke Mandeville Hospital, and The Spinal Injuries Association were targeted for the recruitment of participants. The Spinal Injuries Association advertised the work, and directed those who were interested in the study to the principal investigator. Members of the direct care team at The National Spinal Injuries Centre provided those meeting the inclusion criteria with a letter of invitation to the study to read whilst being checked in to their appointment. If patients stated their interest in the study, they were provided with a detailed participant information sheet by a member of the direct care team within the department, and directed to the principal investigator (Jasmine Hearn).

In a private office at the outpatient clinic, those interested in the study had the opportunity to find out more about the research and discuss any queries and concerns. This meeting meant that potential participants were able to meet the researcher who would carry out the interview in person, before inviting them into their home. Those interested in the study were informed of the nature of the interview, and were told that they may have a friend or family member present during their interview, should they wish. Dates, times, and locations for the interviews to be carried out were organised at

the convenience of the participant, either during this meeting or after the participant had more time to consider their participation.

On the day, prior to the interview, the participant read and signed two consent forms confirming their understanding of the study. Both were counter-signed by the principal investigator; the participant and researcher kept one each. Where participants had reduced motor control of their hands, a friend or family member was allowed to sign the consent form on their behalf, with agreement from the researcher. Friends or family members present during the interview were also required to read a participant information sheet specific to them, informing them of their role within the interview. They then signed sign two consent forms confirming their understanding. A short demographic questionnaire was completed by the participants. Where participants had reduced motor control of their hands, the researcher completed the form for them by asking them the questions and responding with their answers. Interviews then took place.

Interviews followed a funnelling process, through which questions began very broadly, asking generally about pain following SCI. This aimed to ease participants into conversation, as well as building up a strong, trusting rapport between the participant and the interviewer. As the interview went on, questions became more and more focussed on the pain experience and how the pain affected specific areas of life for SCI individuals that were initially raised by the participant. Participants were given a strong role in how the interview developed, doing the majority of the talking with minimal interviewer contribution, and were reminded that there were no right or wrong answers.

The researcher remained aware that new topics raised by the participants may be the most interesting and valuable to the research, and took brief notes for memory in order to ask participants to elaborate on interesting topics raised. Due to the flexible nature of the interview schedule, where topics were raised that were of particular interest and not previously anticipated, minimal probes were used that did not lead the participant, such as "how do you feel about that?" or "can you tell me more about that?". Interviews lasted between 40 minutes and two hours.

5.6 Ethical Considerations

The study was granted full ethical approval by The University of Buckingham Research Ethics Committee and The National Spinal Injuries Centre Research Ethics Committee. The ethical approval forms are provided in Appendix J. The principal and chief investigator (Jasmine Hearn and Dr Katherine Finlay, respectively) gave full consideration of this research in accordance with The British Psychological Society Code of Ethics and Conduct (2009). All research in the NHS is considered by an independent group of people, called a Research Ethics Committee. This study was reviewed and given favourable opinion by London Bloomsbury Research Ethics Committee (ref: 13/LO/0558) and the Buckinghamshire Healthcare NHS Trust Research and Development Office (ID: RXQ/549). Ethical approval letters can be found in Appendix J. This study is registered with an International Standard Randomised Controlled Trial Number: ISRCTN01886640.

Participants were fully informed of the research in a face-to-face meeting prior to giving their consent and were offered ample time and opportunity to consider the study

and raise any questions or concerns. They were consistently reminded of their rights to withdraw without giving a reason, and that this would not affect their standard care. No physical risks were anticipated as a result of interviews taking place. Interviews were conducted at a time, date and location of the participant's choice. Seven of the eight final participants chose to have the interview in their own homes. This maximised accessibility and allowed the patients to feel comfortable throughout the interview, as well as to remain close to facilities suitable for each particular participant.

Due to the potentially distressing and sensitive nature of the interview, participants were given the option to have a friend or family member present during their interview. As recommended by Smith & Osborn (2003) and the IPA training undertaken by the researcher, the effects of the interview on participants were monitored closely, such that any potential for distress could be dealt with in a professional manner. This was done by offering breaks and reminding the participant that they may provide as much or as little detail as they wanted, as well as pause or halt the interview completely if they felt they were becoming too distressed to continue. The researcher gave participants a verbal debriefing after interviews, discussing the experience with the participant, in order to monitor for any adverse negative effects. A written debrief form was provided, including details of a clinical psychologist at Stoke Mandeville Hospital as well as an independent contact point, in case participants felt they needed to speak with someone regarding their distress.

As interviews were being conducted in participant's homes, the principal and chief investigators developed a lone worker policy. In order to protect the principal investigator's safety, the researcher checked in with the chief investigator prior to

interviews. This was done in the form of a phone call, informing them of the location and expected time scales of the interviews. After interviews were completed, the researcher then checked in with the chief investigator again, confirming the end of the interview and their safety. An inconspicuous 'safe' word was agreed upon, which could be used in case of emergency; it was not used.

Interviews were audio recorded with the consent of the participants and transcribed verbatim. Transcriptions included major dialogue expressions such as long pauses, gestures, false starts, or laughter. After transcription, all audio recordings were erased from the recording device. All patient identifiable information and their corresponding transcribed interview data files were stored separately on a password protected computer, whilst all manual audio files were kept in a securely locked filing cabinet, at The University of Buckingham Psychology Department. Any place names identified by the participants were replaced with descriptive information (e.g. local hospital, as opposed to the name of the hospital). All participant names, identifying features such as places names, and any person identified by the participant during the interview were changed at the point of transcription. Participants and named people were given generic pseudonyms in order to protect them from identification. This was also done in an attempt to 'bring the participant to life' during the analysis and discussion stage, thus retaining their 'realness' rather than them being another number. A key identifying which pseudonyms corresponded with each participant was stored securely and separately from transcriptions.

5.7 Analytic Strategy

Data analysis and interpretation were carried out in line with IPA's philosophical underpinnings of phenomenology, hermeneutics, and idiography, in order to understand how the content of participants' speech reflects the individual's experience of pain. Transcriptions included page and line numbers for ease of reference, and were printed on A4, with line spacing of 2.0 for the line-by-line analysis. Each page was then attached to an A3 sheet, ensuring a wide margin on the right for exploratory coding, and a smaller margin on the left for emergent themes. Each stage of analysis was carried out in different coloured pen, for ease of identification and organisation of notes.

Initial encounters with the text occurred during listening to and transcribing the interview data. This also involved close and detailed readings of the text in order to 'enter' the participants' world, and become actively engaged with the text. The aim was to gain a sense of the whole of the text, before going on to understand the parts (as described by the hermeneutic circle). Initial comments and notes were highlighted and made on the text. Further re-reading occurred, along with exploratory coding on a line-by-line basis, identifying descriptive, linguistic, and conceptual interpretations of how the participant talks about and understands the issue. These notes were logged in the right hand margin. A sample of the analytic process carried out on an extract of a transcript is available in Appendix K.

Initial exploratory notes were then cross-analysed, and 'chunked' into emergent themes of psychological concepts and abstractions that represented the text and labelled in the left margin. These emergent themes were then clustered by relevance and connections to each other and labelled. A table was then generated including names of

clusters and corresponding subordinate themes, along with page and line numbers of quotations evidencing each theme.

Clusters and theme labels were not considered fixed at this point, and were open to change in light of potential new information. The transcript was continuously re-read in order to ensure that themes were representative of the quotes provided. A sample of a summary table of clusters and themes can be found in Appendix L.

Each account was analysed in an idiographic manner (one by one), with the researcher remaining open to the new and engaged in a reflective diary, such that themes emerging from one transcript did not influence the themes emerging from the next. The researcher engaged in an iterative process, in which new themes arising in one transcript were amended and checked for in previous analyses. All participant summary tables were then cross-analysed, with clusters of themes compared against one another and further clustered into superordinate themes that were labelled, capturing the majority of the data from the transcripts, and as such, representing the important shared aspects of the experience across the individual transcripts.

A master table was then generated, including superordinate themes and their corresponding subordinate themes, along with representative quotations that were checked again for representation of the theme, as a visual guide to the analysis process (Smith & Dunworth, 2003). The most appropriate quotes were chosen from each participant reflecting the themes. This process was cyclical and iterative, requiring flexibility, in that themes were open to reworking and reorganisation, moving from close case-by-case interpretation to a further abstracted analysis of the shared experiences of the group as a whole. The master table of themes is available in Appendix M and

represents a mapping of the present analysis of chronic neuropathic pain after a SCI (Smith & Dunworth, 2003). As a result of the constant reworking of themes and data sifting, micro-divergences emerged and a second master table was generated, identifying divergences that were particular to certain participants only. This can be found in Appendix M.

5.8 Quality Checks

Guidelines for quality control ensuring rigour and good qualitative analysis were followed (Smith, 2011a). Independent auditors (Dr Katherine Finlay and Dr Imogen Cotter) were enrolled to ensure quality in themes, checking that interpretations were grounded in the data, by recommendation of Smith, Flowers, and Larkin (2009). This made the researchers aware of any errors, ambiguities, and opportunities that may not have been initially appreciated. The auditors discussed thoughts and interpretations in order to illuminate different areas of the experience that may have been more easily identifiable to them. Dr Katherine Finlay is the Chief Investigator involved in the research, and has been involved in previous pain-related research. Dr Imogen Cotter is a clinical psychologist at The National Spinal Injuries Center, with direct experience of working with spinally injured patients.

Both auditors took part in the first step, which involved presenting superordinate and subordinate themes with a selection of supporting extracts. For all transcripts, auditors were asked whether the extracts corresponded to the themes, and if so, to which theme they belonged, in the form of a card-sorting task. They also provided further

detail on themes or interpretations of the extracts and ensured that themes previously identified were validated by checks.

When all emergent themes were identified and labelled for the entire group, all extracts from each theme were taken from every participant and arranged, with each individual theme separated by page breaks. Both auditors read the list of extracts on each page, making notes and discussed with the principal investigator their own thoughts and interpretations of what the theme might be labelled. Auditors were then told the theme label and any discrepancies were discussed. This was in order to ensure themes were grounded in the data and interpretations were understood for every participant. Dr Katherine Finlay then did this same task when the cross-case analysis was carried out and all superordinate and subordinate themes had been generated.

The final superordinate and subordinate themes and relevant quotes were taken back to Dr Imogen Cotter, along with a nurse, a doctor, and a physiotherapist, all who work closely with the participant group, for qualitative feedback. All were asked to what extent they believed that the themes and quotes provided resonated with their experiences of working with the participant group. They also provided information on how they believed the findings of the research could be used to influence their practice.

Further to these quality checks, after the initial IPA weekend training session, the principal investigator then attended a one-day IPA Data Analysis Clinic, during which they had the opportunity to present a number of quotes from two clustered themes to a group of individuals from different backgrounds (textiles, counselling, education, health) who were also engaged in IPA research. The group read all quotes and made notes on what they thought the theme label should be. Thoughts and interpretations were

discussed among the group and agreements were reached. This helped to ensure that the themes were grounded in the data, analysis was carried out to a high standard, and that researchers from a variety of backgrounds were able to understand the interpretations made.

5.9 Writing up

Throughout the process of writing up the analysis, all themes were further reorganised, revised, changed and labelled as the write-up took place, at which point the decision of what would be included in the write-up was made. Utmost care was taken whilst striving to retain the meaning of quotes provided within the analysis section, some were edited in order to improve the fluency, for the benefit of the reader. Data deemed unnecessary to the understanding of the quote was omitted, such as false starts and short pauses, whilst some quotes were left unchanged where linguistic data was deemed necessary for the interpretation.

5.10 Validity

The researcher has remained sensitive to context throughout the analysis and write-up stages; the researcher endeavoured to provide interpretations that acknowledge the complexities of each participant's account. In addition, in line with IPA's commitment to rigour, sufficient detail and transparency have been offered with regard to sampling and the process of analysis in order to demonstrate the purposive and homogeneous nature of the sample, as well as the systematic approach adopted. Attention has also

been paid to identifying diverging experiences, in order to demonstrate the disconfirming case argued for by Yardley (2008). This aids in ensuring that all data have been taken into account, as opposed to just that which fits the researcher's perspectives and themes articulated by the majority of participants. This transparency towards validity is also aided by a methodological and procedural reflective account acknowledging the researcher's experience of and impact on the research process, provided at the end of this study.

5.11 Outpatient Results

Interviewing outpatients yielded a vast amount of data, with results that may be framed within the biopsychosocial model of pain (Engel, 1977). Participants spoke of varying aspects of pain, from the social and psychological interferences and influences, to the impact of the biomedical approach in their pain management. The vast amount of data obtained contributes towards an improved understanding of what it is like to live with NP after SCI as an outpatient, whilst also offering novel insight into the individuals' personal lives. The analysis here presents the key emergent themes under three broad, encompassing superordinate themes: (1) 'The Chasm between Biomedical Perspectives and Patient Beliefs and Needs', (2) 'The Battle for Ultimate Agency in Life', and (3) 'The Coexistence of Social Cohesion and Social Alienation'. Each participant voiced at least two of the superordinate themes, each of which will be discussed in further detail here. Superordinate themes were considered prevalent if they were expressed articulately by at least half of the participants (Smith, Flowers, & Larkin, 2009). Table 2 presents a visual aid to identify which of the themes each participant communicated.

The results are presented in such a way that the reader can follow particularly articulate participants' stories throughout each theme.

The superordinate themes presented here are not exhaustive; the present analysis highlights the most representative themes with high quality supporting quotations. Further, themes are not distinct; there is overlap between superordinate and subordinate themes, which suggests the interplay of various factors upon the global experience of chronic NP after a SCI, supporting the framing of the results in the biopsychosocial perspective. Each super- and subordinate theme will be discussed in turn, and presented with quotes representative of the themes.

Table 2. Master Table of Presence of Superordinate Themes for Outpatients

	James	Harry	Daniel	Rebecca	Dave	Emma	Sharon	Sean
The Chasm Between Biomedical Perspectives and Patient Beliefs and Needs	■	■	■	■	■	■	■	■
The Battle for Ultimate Agency in Life	■	■	■	■	■	■		■
The Coexistence of Social Cohesion and Social Alienation	■	■	■			■	■	

5.11.1 Superordinate theme one: The chasm between biomedical perspectives and patient beliefs and needs. This superordinate theme is presented here first, specifically as it was one that undoubtedly resonated across all participants, and represents the 'bio' aspect of the biopsychosocial model, illuminating how the biomedical approach and the neuropathic pain experience are entwined yet conflicting, often producing negative consequences. The biomedical approach appears to play a crucial role in the experience of NP, shaping the way in which outpatients experience it. What emerged from the data describes participants' concerns about an inadequate approach to the management of NP post-SCI. Participants perceived an unnecessary and excessive reliance on medication that often poses more consequences on the patient than the pain itself. This excessive reliance was accompanied by what appeared to be an unsupportive patient-staff relationship, with many participants feeling unheard and unable to contribute to their own care, as though healthcare professionals (HCPs) controlled their lives, and pain. This contributed towards the development of a 'chasm' between what patients wanted, and what they were offered. Table 3 shows the breakdown of the superordinate theme, and who voiced each subordinate theme.

Table 3. Master Table for 'The Chasm between Biomedical Perspectives and Patient Beliefs and Needs'

	James	Harry	Daniel	Rebecca	Dave	Emma	Sharon	Sean
Excessive Reliance on Insufficient Medication	■	■	■	■	■	■		■
Relationships with HCPs: Losing Faith		■	■	■		■	■	
Lack of Input into own Care	■		■			■	■	

5.11.1.1 Subordinate theme one: Excessive reliance on insufficient medication. The accounts of the participants tended to place a central focus upon the limits of the treatment they had been offered. Many participants shared a resentment of medication, which appeared to be the only available treatment option offered by the HCPs involved in their care. In fact, some chose not to adhere to their medication regime, or to alter it themselves, due to drawbacks such as the side effects that often became more of a problem than the pain itself. For Emma, the ineffectiveness of her analgesic regime, even at its highest dose, appeared to induce significant distress and desperation:

I would say eight, nine, ten [on the numerical rating scale of pain intensity][1]
where I'm crying and I feel like I'm in a pit of fire, actually I'm shouting at you
because I want you to try and help me with my drugs, and I'm on the phone to
my GP saying, "what can I do now? I'm in pain" …[2] *"we're increasing your*
drugs, you increase it every couple of days until you get pain relief" [role
playing GP]. Actually I'm on 1,200 [mg], I'm on top dose Gabapentin generic,
and it's not helping, what do I do now? (Emma: page 4, lines 94-97)

Emma describes great difficulty in achieving satisfactory pain relief, even at the highest

dose of pain medication "*I wasn't at a therapeutic level. So I increased it gradually …*

But then I thought well I'm here now taking two, three times a day. Surely I must be

getting some pain relief? And I wasn't." (Emma). Failures to relieve her pain induces a

desperation that then turns into anger aimed at HCPs, such as her GP, who she

repeatedly asks "*what do I do now?*" with little or no helpful response perceived. Emma

is searching for anything to relieve her pain, yet even the highest dose seems inadequate.

This may suggest that those with NP after SCI are only receiving support in the form of

medication, which provides limited pain relief. It may also be that Emma is unaware of

alternative pain management options potentially available to her. Emma's quotes

suggest that the medication she has been prescribed delivers limited efficacy for her

pain, and that further education surrounding NP and its management may be a

requirement for both patients with SCI, and the staff involved in their care.

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[1] Descriptive information provided by researcher.

[2] Indicates text removed to improve fluency of quote.

Whilst Emma's concerns lay with the ineffectiveness of her medication, Harry and Sean illuminate the negative experience of the biomedical approach further, voicing concerns about the potential for dependency and the psychological side-effects of their drug regimens:

… all these kinds of drugs, but, I've tried them, and I've rejected them. Because it makes no difference whether I have them and I'm not prepared to take high doses constantly, and be a zombie, and I'd rather put up with a bit of pain than take those drugs and have a blank mind. Because that's how they make you feel. It's like your thoughts are trying to fight their way through a thick lump of fog. You know so I'd rather have the days of pain and not have to take high doses of these tablets. And once you are on a high dose of course it's very difficult to get off them. So I don't want to go there. (Harry: page 6, lines 135-141)

It's usually side effects in some shape or form. I'd rather take none really so I take the minimum that I have to … when I first started taking Baclofen, I was on quite a high dose, I think it was 100mg a day, I would be getting drowsy by the afternoon so now I'm on 40 so. Usually with any medication there's some kind of, you know negative side effect or something that comes along with it. (Sean: page 2, lines 49-54)

For both, the extensive negative consequences of pain medication outweighed the potential benefits, or no benefit in Harry's case, resulting in conscious choices to adjust or abandon their regimes, with an apparent priority for preserving their psychological function, well-being, and clarity, over pain management. This is resonated in Harry's refusal to *"be a zombie",* implying his desire for the ability to think clearly, something that he is unable to do when he takes his medication. His metaphor highlights

the extreme, negative impact of medication on Harry's ability to think for himself. He discussed his thoughts having to "*fight their way through a thick lump of fog*", which simulates the image of a battle for conscious awareness, a battle that he was unwilling to engage in. Harry explicitly states that he would prefer to have pain than to have to take medication, suggesting that the implications of the medication are worse than the pain itself, and that he may appreciate physical or psychosocial pain management techniques, as opposed to medication.

Sean's comments suggest that negative consequences of all medication are inevitable, which inform his decision to take low doses or none at all, even where there may be potential for pain relief. This suggests that, although there may be some positive outcomes as a result of pain medication, for him, the potential risks far outweigh the benefits. Fears or worries about dependency were also an issue for Sean; "*I wouldn't want to become dependent on anything that possibly could assist but it's like the pros and cons really.*" (Sean). Both Harry and Sean's quotations indicate resentment towards the apparent reliance upon medication, and lack of other options.

Daniel also noted a reliance on, and ineffectiveness of, his medication regime. His main concern with his drug regime identified how medication did not only affect his physical and psychological well-being, but also created a negative social image for him. This concern lay with his altered sense of identity, caused by his need for medication. As well as this, Daniel had fears surrounding physical bodily damage:

> *It's just like you're taking the medication, makes you feel horrible as well.*
> *Makes you feel like you're some druggy or something, do you know what I*
> *mean? So it shouldn't mean you have to go to the chemist, and then they give*

you like some massive bag of drugs. It just looks, especially when it's, like a morphine-based drug as well. It just makes you feel horrible … (Daniel: page 8, lines 184-189)

It makes you feel like you're some … druggy, because it's like an opium-based morphine stuff. I think that's what it, gives people sometimes when they're trying to cut off drugs, do you know what I mean? So yeah, it makes you feel like, oh it just makes you feel dirty. I hate it … (Daniel: page 8, lines 193-195)

Daniel repeatedly comments on the negative impact on his sense of identity and self-concept produced by the medication. He implies that the large bag given to him containing his prescription may make others think he is *"like a druggy"*. Further, the effect of the medication makes him feel the same way. He compares himself to drug users who are *"trying to cut off drugs"* and this makes him feel *"dirty"*; his medication creates a new, undesirable, social image and he anticipated that others would perceive him in this way. Daniel was three years post-injury, which may have contributed towards the negative impact of medication. In contrast to Daniel's relatively short time since injury, Harry was 32 years post-injury, whilst Sean was ten years post-injury, which may indicate a potential reason for Daniel's anxieties. This new social image may pose a risk for debilitating consequences for his psychological well-being due to its stark contrast with his previous work within the army, which may have empowered him with a strong identity.

His concerns for the protection of his body also arose *"It's just going to get worse. Yeah I think it's going to … get worse and they'll just give me more medication, that's just going to damage your body more …"* (Daniel), potentially from his army

past, in which physical health may have been prioritised over psychological health. Despite Daniel's fears about the potential for damage upon his body, he continued to adhere to his drug regime, as his pain would be too much to cope with without it, suggesting that, whilst there are drawbacks of taking medication, it has benefits too. Despite negative consequences for his sense of identity, Daniel may have felt that the benefits outweighed the consequences.

Importantly, Daniel saw his pain worsening in the future, and voiced a lack of faith in the biomedical approach, and his limited choices for treatment. When asked how he believed his pain will affect his future, Daniel responded:

> *I'm scared, really scared. I always say that I'm not going to live long, I reckon I'll live till about 50, 55. Because of the amount of medication I take, that on your body, even the doctor says like "we're going to have to try and think of something because you can't keep taking all that medication because it's damaging your liver". Because obviously, your liver fuels everything, so yeah. I'm just scared, like obviously I'm having a baby ... I'm scared to, like what if I try and pick him up and I get pain? Like, I'm scared I might drop him or I can't ... do stuff with him because I'll be in so much pain.* (Daniel: page 17, lines 399-405)

Here, Daniel's description evokes the image of his body as a victim of medication. Whilst the effects of his medication have psychological consequences, Daniel appears to prioritise his physical health, such that he can live as long as possible for his child. His fears centre on the physical damage that medication can do to his body, which further fuels his fear of an early death, as well as fear for his family. Given contextual information such as his age (26 years old) and the future arrival of his first

child, further pressure may be placed on Daniel to be able to cope with his pain. If Daniel's pain was not present in his life, or managed to a better extent than currently, then perhaps his fear may have been reduced. Daniel's account continued in this way, containing very little positive speech, focussing instead upon his fears of pain.

Following discussion of the negative consequences of medication, Sharon provided insight to the benefits of medication, being the only participant of the group to recognise the need for medication for the purpose of pain management; "*If it wasn't for the medication I take I would probably not be able to function as well as I do*", "*I just, I don't see the pain going away without some kind of … medicine. You know? And it doesn't go away it just masks the pain a little bit so that you can function.*" (Sharon). Her belief of the need for medication for pain management is combined with her belief that medication is not as helpful as it should or could be, resulting in a desire for a wholly effective medication; "*I wish there was some magical pill I could take that could take the pain away, you know. Like, there just, there just doesn't seem to be.*" (Sharon).

During her interview, Sharon acknowledged some benefit of her medication, in its ability to aid her daily functioning but her desires for a "*magical pill*" may be interpreted as a wish that stems from the inadequacy of current medication. This desire may indicate the hope for a cure, and may pose a threat to her psychological well-being, should she ruminate excessively upon it. Such hopes may cause Sharon to become engaged in a negative perseverance loop, in which unrealistic hopes are reinforced by the search for an impossible cure. Sharon, however, acknowledged the fact that it was a "*wish*", which may not be possible to answer. This suggests that she remained hopeful, yet resigned in the fact that her hope may not currently be fulfilled.

Sharon's comment sums up the experiences of all of the participants, in that, whilst medication is available and may be efficacious to a small extent, an adequate biomedical treatment may currently be a long way off for those with a spinal cord injury. Participants voiced concerns indicative of their unmet expectations of what the biomedical approach should be able to provide them with. Some participants articulated a preference to protect their psychological well-being, with others preferring to protect their physical health, indicating that people with NP following SCI desire a form of pain management that combines psychosocial interventions alongside medical treatment, in order to manage their pain.

5.11.1.2 Subordinate theme two: Relationships with healthcare professionals: Losing faith. In line with the superordinate theme of a perceived gap in desires and provisions, and potentially contributing to their dissatisfaction with their drug regime, five out of eight participants also voiced multiple experiences relating to their unmet expectations of HCPs involved in their care. There appeared to be a progressive loss of faith in the healthcare profession with participants expressing disappointment and resentment towards those involved in their care. They indicated significant discrepancies between patient expectations and the abilities of HCPs to meet those expectations.

For Daniel, his lack of faith in HCPs manifested in the time he waited for a referral to a pain team, as well as his doctor's apparent lack of help and support during this time, providing him with insufficient information in order to obtain further care:

Like I've said to my doctors … it's taken this long to get an appointment sorted out. As soon as I went to [local hospital] they were like couldn't believe that I

wasn't with a pain team … they said, "Your doctor should have done it"
[referred Daniel to a pain team]. But my doctor said to ring them, when I said "I
haven't got a number", he looked at a bit of paper and said "well I haven't got
the number either". So I was like, alright well that's a load of good then.
(Daniel: page 18, lines 427-432)

Daniel expected that his doctor would provide him to access to the relevant

information and a referral to what he needed. This expectation was not met, and

consequently, the actions of his doctor may have delayed Daniel's ability to obtain

further care. His expectation for further care to be obtained with relative ease was

reinforced by the reactions of HCPs at a local hospital, who expressed shock at the time

taken to get there. It appeared as though Daniel was left to find further support by his

own means, with scant assistance from his doctor. Daniel expressed disappointment

with his doctor's lack of effort, and summed up this experience using sarcasm in

bitterness, framing it positively, but intending it to mean the opposite. This comment

allowed Daniel to express his disappointment and lack of faith in his doctor, whilst also

protecting himself from the potential negative effects of his disappointment, such as

embarrassment.

In line with Daniel's comment, Harry made a comment more obviously

reflecting his dissatisfaction with his relationships with medical staff; *"The consultants*

haven't got all the answers you know … they'll fill you up with mind-altering drugs in

the hope that it will help you but … not for me." (Harry). This discussion was heavily

loaded with negative tone and further reinforced his resentment of the medication that

HCPs seemed to rely on. He also displayed dissatisfaction with the lack of information

provided, highlighting his expectation that HCPs should be able to provide him with the

answers he desired, nor with a better alternative. However, it may be that the consultants did not have the information to share. The individual and subjective nature of SCI and subsequent NP may make such information provision difficult. His use of the second person pronoun "*you*" appeared to apply his experience to everyone, suggesting that he might believe that there exists a global HCP-reliance upon medication, and that many SCI pain patients are being filled up "*with mind-altering drugs*" with little benefit. The comment that consultants prescribe medication "*in the hope that it will help*" further implies that staff are struggling to find answers, but still acting with the patient's best interests at heart.

In contrast to this, once again, Sharon offered some insight into the opposite end of the scale of relationships with HCPs, with some positive information provision from nurses, whilst also acknowledging the discrepancies between her expectations and reality. These discrepancies occurred through the shortcomings in communications between herself and doctors:

> *The nurses were really good about the pain, really explaining the pain to me and how … the medicines helped … they were actually more informative than the doctors. Well [hospital] is a great place … but the doctors have interns with them, so a lot of times you know they talk like you're not there … because they're talking to them [interns]. And then you tell them "I can hear you, hello I'm right here I can hear you … So, watch what you say! So, and I can hear when you're in the hallway too so, something you don't want me to hear close the door!" … so that's hard.* (Sharon: page 7, lines 159-165)

Sharon discussed the beneficial information provision by nursing staff. Her comment "*they were actually more informative than the doctors*" implies that she may have expected doctors to provide information about her pain, as opposed to nurses. Her experience of doctors is of them speaking about her rather than to her, and this apparent lack of direct communication may pose a significant threat to her relationships with HCPs, by informing her expectations of future encounters with them. As well as the effects on relationships, the lack of communication may also have influenced her own psychological well-being, such as her self-esteem. Being spoken about, rather than to, by HCPs may induce feelings of distress or depersonalisation. The actions of such HCPs may have caused Sharon to feel belittled, as though doctors are not there to care for her, but to focus upon the training of future doctors. It may be that the doctors described by Sharon were prioritising the education of their students, but this has a negative bearing on Sharon's faith in their care provision and implies a need for improvement in the way HCPs provide information to patients where students are present.

Sharon continued to speak about the distinct lack of information provision and described a dispute between herself and her physiotherapists:

Nobody told me I would be so disabled because of this pain. It is not fun. The physiotherapists don't care if you hurt. They say "they give you medication so you don't hurt so you have to do this exercise" [imitating physiotherapists]. "But it hurts" [speaking as herself]. "It doesn't hurt, you just think it does" [physiotherapists]. "It does hurt!" [self] (Sharon: page 7, lines 150-153)

Here, Sharon described her physiotherapists' lack of belief of her pain experience. These members of staff fail to acknowledge it as a real experience,

appearing to dictate her pain to her rather than listening to her story. Sharon's quote conveys her physiotherapists' comments as rather condescending; *"it doesn't hurt, you just think it does"*, which may cause humiliation and resentment towards HCPs, centring on their disbelief in her pain experience, and their patronising speech.

As Emma articulates very well; *"There's an old saying in nursing. "Pain is what the patient says it is" ... why don't people hear that anymore?"* (Emma). From her own medical experience as a nurse, Emma acknowledged that her pain is subjective in nature, influenced by various factors and thus, experienced differently by everyone. This quotation supports Sharon's experience, in that it appears as though her physiotherapists do not seem to *"hear"* that *"pain is what the patient says it is"*. Emma acknowledged that the problems associated with chronic pain, such as its subjectivity, make measurement and treatment problematic, and repeated disputes with patients searching for cures, may make *"hearing"* the experience more difficult. Further, this difficulty may induce compassion fatigue, a phenomenon in which compassion gradually diminishes over time and may contribute towards the lack of *"hearing"* of the patients' pain experiences.

Both Sharon and Emma articulated experiences relating to HCPs imposing their own beliefs over their patients', as well as a lack of sympathy. Whilst the HCPs involved in such disputes may be professionals in their area of work, they may not have direct experience of neuropathic pain, and need to acknowledge that it is the patient who is the expert in their experience. Emma's account centred on her experiences of voicing her pain to HCPs who do not seem to listen to her, and as a result, she became distressed. When asked if she would like to take a break from the interview, Emma

responded; "*No, fine [crying] you just get emotional thinking oh gosh why don't they listen? Why do you have to have such a fight? Absolute fight with the books.*" (Emma). Here, Emma questioned the choices of HCPs. Her use of the metaphor, to "*fight with the books*", suggests that HCPs are following prescribed guidelines set by a senior body for code and conduct. Such guidelines (e.g. The National Formulary), however, are perceived to be ineffective in supporting HCPs in providing ample care. Her frustration manifested towards seemingly inappropriate parameters that did not meet her needs. Still, this indicates a disparity between the beliefs of HCPs and their ability to offer what the patients suggest they want and need, and this caused Emma emotional distress in her fight for her experience to be heard.

Rebecca described an experience with a particular consultant involved in her care, in which her expectations were not met:

> *The first visit to the new consultant, and the second appointment I've had just, he basically agreed "yes there is things happening, but there's nothing that can be done" were his exact words. "There is nothing that can be done". I've never had a problem with … doctors, nurses, things like that, just very rarely, and I thought … I wouldn't have a problem [with the new consultant]. I asked to have him as my consultant, thinking that he would be fine, he smiled all over the years and he's looked fine, and I thought maybe he'll have like more modern outlook or something. But um.* (Rebecca: page 12, lines 293-13; 300)

Rebecca's expectations of a particular consultant were shaped by her first impressions of him. Whilst her expectations were high as a result of this initial impression, her actual experience contrasted her expectation, leading to disappointment

and a progressive loss of faith for future consultations HCPs. Her interview ended shortly after the quote presented here, but Rebecca's final utterance "*But um*" has great impact on the result of her speech, indicating that the consultant did not meet her expectations without actually saying so explicitly. Such an utterance may be considered a gem. The unfinished sentence does not need to be completed in order to convey her disappointment and feeling of being let down. This is a theme that was echoed regularly throughout Rebecca's interview.

This theme lends further support to the superordinate theme, suggesting that discrepancies exist between the expectations that patients have of their healthcare team, as well as the services and information that the HCPs are able to provide. Patients may hold unrealistic expectations of HCPs, and that the information and services that HCPs might offer are governed by guidelines provided by a senior body. This, alongside communication issues and feelings of disbelief, contribute to the resentment, disappointment, and progressive loss of faith in HCPs involved in care. The difficulty in obtaining information may have potentially negative impact upon the individual's well-being, their future expectations, and their view of the healthcare service currently provided.

5.11.1.3 Subordinate theme three: Lack of input into own care. A third theme that contributed to 'The Chasm' was the lack of patient input into their care. In this, participants voiced frustration when refused particular services and medications they had asked for or expressed interest in. Emma articulated this theme particularly strongly:

I felt I went to my GP and I felt so frustrated that my whole life was being judged by someone else in order to say "no, well, we know better than you". As much as it's my [said with emphasis] experience, it's my pain, I'm telling you my experience, you don't seem to be listening because you're not giving me what works for me. (Emma: page 21, lines 492-496)

Emma asked her GP for a particular medication and described feeling as though her opinion does not matter to the GP. Emma's knowledge and previous experience of the medication led her to request it again, yet she felt met with resistance, and perceived that her priorities, thoughts, and feelings, were disregarded, believing that HCPs thought that they *"know better"*. Emma described the need to remain stubborn in her fight for medication she wanted. Reflected in her interview is her belief that she is the expert in her experience and she suggested that, perhaps, the traditional biomedical approach does not consider patients as experts. As such, HCPs may be prioritising the use of medication that they favour, even where patients, like Emma, report that the medication does not work for them. This may be further contributing to the chasm between Emma and her GP, causing her to feel unheard, with a lack of input into her own personal care, potentially fuelling an apparent resentment of HCP's choices. This may also inform the participants' choices to abandon or alter drug regimens unnecessarily.

Daniel's lack of input into his own care manifested itself in a particular situation where his pain was so unbearable that he called for an ambulance to take him to A&E. He had not abandoned his drug regime, but his pain drove him to extreme measures of contacting emergency services for help. The quote describes a communication between Daniel and emergency staff:

... and then they gave me drugs, but I take 20mls of the drugs that I have liquid ... that's like meant to be loads, so they'll come and they'll give me like 5 [mls]. So I'm saying like "look I take like 20, 5's not going to do anything". And they were like "well just see how it goes". I'm like "well no because I take them all the time" ... (Daniel: page 7, lines 163-167)

He stated that his usual 20ml dose is *"meant to be loads",* as in, a high dose, and yet the staff involved in his care in this situation gave him a much smaller dose, despite his expert knowledge of his condition, which suggests that the dose offered by them is insufficient. The disagreement from the HCPs described by Daniel may imply that judgement was made about his pain and the relevant dose of medication, or cynicism towards his knowledge. Daniel's attempt at obtaining his usual dose and having input into his care whilst in A&E seemed futile. Although staff may be adhering to protocol and guidelines (for example, they may not be allowed to administer high doses without knowledge of a patient's history), Daniel perceived this as a lack of belief, and a refusal to allow him to contribute to his pain relief.

Evidence from Sharon's transcript supports this theme, although in a less obvious manner:

... they had me at 200mg of Wellbutrin [brand name of bupoprion, for major depressive disorder] ... [the] rehabilitation doctor decided that I needed to take nerve medicine ... so, they decided to take me off the Wellbutrin and put me on Nortriptyline [anti-depressant also used for treatment of neuropathic pain] or something like that ... Right now I'm only at 20mg and I've tried my doctor like "can you give me 200[mg] back?" ... You know, this is going to be fun [laughter]. So I told the kids "if I'm grouchy and crying all the time and acting

> *crazy it's because they're changing my anti-depressant medication"* (Sharon: page 4, lines 87-95)

Throughout this quote, the third person pronoun *"they"* is repeatedly used when referring to the medication changes. This seems to suggest that the decisions to change medication were not as a result of her experience or input, but seemingly arising from someone else's decision. She also mentioned explicitly requesting increases in her dosage in response to her doctor's decision to dramatically reduce it. It appears as though this choice was made without Sharon's input or contribution, and her repeated use of the third person pronoun 'they' may indicate that she experiences a sense of a loss of control over her own life. The sarcasm in her comment *"this is going to be fun"* signifies a worry about her future pain, arising from her loss of control. She quotes herself speaking to her children and further blaming the negative effects of the medication on HCPs who are changing her medication.

Participants indicated that, despite the lack of opportunity, they do desire input into their care. Removing such an opportunity may have a demeaning effect upon the participants, and any feelings of being valued by their care team. Being able to contribute to their own care would grant participants opportunity for independence and autonomy, as well as feelings of significance in their own lives.

5.11.2 Superordinate Theme Two: The Battle for Ultimate Agency in Life.

The superordinate theme of 'The Battle for Ultimate Agency in Life' is presented second; the theme with second highest prevalence amongst participants. Seven out of eight participants voiced this theme, with each participant fighting either a winning or a losing battle for agency over their psychological well-being, their lives, and their pain. This theme appears to encompass the psychological aspect of the biopsychosocial model, through its depictions of the psychological consequences of the pain. The extent to which participants were 'winning' or 'losing' was seemingly closely related to their apparent levels of pain-acceptance.

In each analysis, it appeared as though an ongoing battle for agency in life was being fought between the participant and their pain. This theme is discussed in terms of a continuum, in which pain appeared to be winning at certain points in participants' lives, whilst they were winning at other points. The metaphor of a 'battle' aids in describing this apparently ongoing struggle for physical and psychological control, which appeared to swing from pain to the participant and back again continuously.

Table 4. Master Table for 'The Battle for Ultimate Agency of Life'

	James	Harry	Daniel	Rebecca	Dave	Emma	Sharon	Sean
The Battle for Ultimate Agency of Life	■	■	■	■	■	■		■

For the majority of the participants who took part, a discussion surrounding the concept of a battle was expressed, with pain described in terms of controlling their ability to live and make choices about their own lives. Metaphors were often used, likening pain to an embodied entity, relentlessly attacking. Many spoke of psychological anguish related to the uncontrollability of the pain and their futile fight against it, whilst others illustrated the fight as a malleable concept, which was ongoing. The presence of this theme manifested itself in some participants who thought of themselves as a passive 'victim' of pain's attacks. This theme also highlights the psychological impact of pain, highlighting the impact of perceptions of a lack of control of pain.

Some participants were more willing to surrender control to their pain, whilst others discussed desperate attempts to escape the pain and reduce its grasp over their lives. Such attempts often proved futile, resulting in further resentment and negative impact. For Daniel, no escape from the battle existed, and he seemed to have lost all hope of regaining any control over his life again. When asked how his pain makes him feel, he responded; "*Just like horrible and low. I feel depressed ... Because there's no*