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* *little light at the end any more, it's just like a big black hole. Because it it, it's it's just like [. .] it's never going to end."* (Daniel).

Loaded with negative affect, this quote indicates how extremely damaging chronic NP can be to one's psychological well-being. The use of the idiom *"no light at the end of the tunnel any more"* suggests that Daniel used to think that his battle wound end. However, it seems as though he had relinquished the last of his hope for a life without pain and surrendered to it, allowing it to become dominant in his experience. His struggle to articulate his belief that his pain will not end, stumbling in the last sentence, suggests that the suffering induced by the pain had taken its toll on his emotional and psychological well-being, forcing him to admit and accept defeat. Daniel is an example of a participant who may be considered at the 'losing' end of the battle continuum, having apparently giving up engaging in the battle for control.

Daniel is quoted embodying his pain as a devil, which induces a powerful image that highlights his distress, and a struggle against his perception of a malevolent, evil, and torturous pain, thus reinforcing the sense of a battle against NP: ***"****It's like some little devil in the corner. Yeah, you know like that little exorcist thing in the corner ... You just think of a bad thing ... why is someone torturing me?"* The quote illustrates his psychological anguish, and his language use may be associated with catastrophic thinking; his view of pain as punishing induces distress, fear, and further physical pain. Such language demonstrates a struggle to adjust to NP.

Emma found her pain particularly distressing, and voiced this through the use of metaphors: "*What I meant by sitting in a pit of fire ... you've got every nerve ending that's just going hellfire, and you just don't know what to do with yourself.*" Emma's quote encapsulates the distress voiced by many participants, exemplifying the sheer intensity with which NP is experienced. Her use of metaphor extends from ‘pit of fire’ to ‘hellfire’ thus helping her to demonstrate her perception of pain as hellish, an inescapable torment that she is unable to fight against. Such language may also be considered catastrophic thinking.

Rebecca explained how its unpredictable nature influenced her experience of being engaged in battle with NP: “*It seems to be, it quietens down for a bit, and then it sort of rears its ugly head, and then gets, can be severe, really bad, not so bad, whatever.*” The phrase ‘rears its ugly head’ conjures the image of the undesirable pain unpredictably materialising without warning, which she then engages in battle with, but then settles. Rebecca perceives pain as something ‘ugly’ that is to be avoided. The listener may be better able to comprehend the experience thanks to Rebecca’s metaphor, which adds emotional detail to the experience. Her use of the word ‘whatever’ may be an attempt to distance herself from the emotional impact of the pain, which may be induced through her use of metaphor, or vice versa.

Rebecca’s following extracts illustrate the dynamic nature of the battle with pain, in which Rebecca is sometimes winning and sometimes losing:

> *Either you give up and die, or you get on with it. So I get on with it … and I bounce back again I’m fine. I know it’s really hard to live with and etcetera etcetera, I’m not one to moan … I just think in life you know, I’m alive and I want to enjoy as much of life as possible. And I’m not going to let anything stand in my way. I’m not selfish or anything but, to do with the pain side I’m not going to let it get in the way of it. You know what I mean, take over. If I let it take over what will I do? Scream and cry all day? Go nuts? Bang my head up against the*

> *wall? What am I going to do? You see, so I either give up or, carry on. And I carry on because I always choose the best choice.* (Rebecca: page 10, lines 224-231)

This quote illustrates Rebecca's determination to live life well and her positive self-image without letting her pain get in the way of that, and therefore 'winning' the battle. Rebecca indicated that she had chosen to fight the battle for control, and described a limited set of choices she has given herself in order to cope with her pain; to *"give up and die"* is to let the pain win, but to *"get on with it"* is to prevent the pain from winning, and here, Rebecca appears to prioritise having some sort of enjoyment in life even with pain present, without letting it *"get in the way"* of her achieving this. She asks sarcastic rhetorical questions about her options if she lets the pain *"take over"*, which suggest that letting the pain win provides no beneficial purpose, with the potential to achieve nothing but further negative consequences. As a result of this, the only way for Rebecca to enjoy her life was to *"choose the best choice"* for her own well-being and to accept that the pain is present, without letting it win the battle.

However, at other times it becomes apparent that her pain may be winning, further reinforcing the concept of the battle as a continuous experience; "*It's a living hell. Oh I wouldn't wish it on my worst enemy, put it that way."* Describing pain as *"a living hell"* suggests that, at times, pain may become overwhelming. Further instances in the interview indicate that her battle with pain is one experienced on a continuum:

> *That's life, and I don't mind being disabled. I don't mind being paralysed, because I can use my arms, and I'm thankful every day for the use of my arms ... So everything's brilliant it's just the pain and so, hard [. .] And it's just [. .] just*

> *so agonising … the burning and stinging, it's like fire [. .] and it's just, ugh. It's just like fire, it's horrible.* (Rebecca: page 6, lines 137-143)

> *… it's always been there, the worst thing in my life that's one thing when I do pass away, not looking forward to it yet though, but when I do, I know I'll be smiling in the back of my mind, I'll be thinking at least there'll be no more pain* … (Rebecca: page 8, lines 183-186)

Whilst Rebecca is not looking forward to her death, she commented on looking forward to being relieved of pain, suggesting that she saw death as her only escape from her pain. The comments presented here may be indicative of her losing the battle at certain times when the pain is overwhelming, whilst she may be winning at other times.

James discussed his engagement in an apparently futile fight, prior to surrendering:

> *… no matter what you do, go as far as you like, whatever you want to do, you can't get rid of it, you can't escape it. It's there, and no matter what you try and do, it's there now, it'll be there when you wake up. It's going to hit when you're trying to go to sleep, you can't do anything about it.* (James: page 13, lines 322-325)

James' issue arose from his lack of control over his pain. His battle has involved him attempting to free himself from his pain, an endless force that he is powerless to escape from. He suggested that he engaged in multiple futile activities in attempts to escape the pain. James chooses to state that the pain is there *"when you wake up"* and "*when you're trying to go to sleep"*, suggesting that it is present and dominating in every aspect of his life, regardless of the time of day. Additionally supporting the concept of a fight, James mentions, *"it's going to hit"*. This comment may reflect a gem, and may be a slip of the tongue that reflects a potential belief that he is a passive victim of his controlling pain.

Further, James personifies his pain; "*... the only way that I can describe it is that ... you're doing whatever you're doing ... and a little person inside flicks a switch and shuts you down. It just, literally just collapse."* The imagery elicited in being *"shut down"* suggests that the instantaneous effects cause James' mind to become enveloped in the darkness of the pain, the only phenomenon that exists at that moment in time. James adds further support to the concept of being locked in a futile battle with potentially uncontrollable pain: "*[The] pain will just be like [. .] it's just, just like someone's hitting you."* [James]. The battle for control, therefore, manifests itself in a psychological manner, bringing with it potentially negative psychological and sometimes physical consequences. Some of the participants discussed appeared to have given up hope of regaining control, after engaging in repeated searching for ways to manage pain. Such repeated searching may have predisposed these participants to difficulties in accepting pain's presence, leading them to become destined to fight a losing battle, due to the lack of definitive solution to chronic neuropathic pain after SCI.

Harry further illustrates the malleability of the battle. Similarly to James and Daniel, on particularly bad days of pain, his life was controlled by its presence:

> *On bad days I knew they were going to be bad because I'd wake up in the morning and ... you know for that day my life would revolve around pain, I wouldn't be able to do what I wanted to do.* (Harry: page 3, lines 75-77)

Harry described being unable to go about his daily life, due to a loss of control, suggesting that the pain consumed his world and became his priority, until it has passed, after which he was able to regain control and continue his normal life; "*So, I knew that when I was in a pain phase that I would have to stay indoors and life would come to a halt."* Harry stated that his pain was *"100%, it's me. It's my identity. It's who I am. It's what happens to me."* suggesting that, during these 'pain phases', the pain defines him and controls his ability to live life well.

On the other hand, however, Harry describes occurrences in which he feels able to live with the pain present, explaining that good days outweigh the bad. When the pain was at a lesser intensity, he felt able to live a happy life and consequently win the battle; "*… if you get a day of pleasure, it erases all memories of the pain, it's remarkable the way the brain works. So, you know, life isn't abject misery for me because I have pleasurable days."* Harry's battle for control seemed to be ongoing, in what appears to be a malleable concept, in which the pain and the battle change day-by-day; some days control was relinquished to pain, whereas on other days life was back in his control, refusing to let the bad days dominate the good:

> *… when I'm in a comfortable phase, it erases, it doesn't erase the memory of the pain but it erases the distress of the pain and, you know, today's a good day so great. You know just get on with life …* (Harry: page 9, lines 219-221)

Harry acknowledged the influence of his own mind and psychological strength to influence his pain experience, illustrating how he felt able to live quite comfortably in this way, finding solace in temporarily forgetting the anguish previously experienced. This suggests that Harry’s pain may be enmeshed with his self-concept, but not always interfering with it, dependent on the extent of pain’s interference in his life.

Sean further illuminates the battle, discussing pain as a phenomenon that is there, but he is not engaged in battle with. Sean discussed his view of the future with pain in it:

> *… it [pain] hasn’t held me back so far … just like carrying around another bag I suppose. Don’t think about it. It’s just another weight ... something I can deal with that I’m not too fussed about, you know, doesn’t get in the way as much as possibly other people’s responses to pain … I can’t see it holding me back at all really.* (Sean: page 13, lines 301-305)

For both Harry and Sean, it seems that pain was considered a phenomenon that has the potential to be restrictive to their ability to live their life adequately in the way they want to live, which it sometimes did. Sean appraised his pain more neutrally than negatively, describing it as *“just another bag ... just another weight”;* a burden that is present, but not too heavy for him to carry. His repeated use of the word ‘just’ emphasises that his pain was merely a non-intrusive presence that had little interference upon his life, thus allowing him to live well with the pain and injury. Whilst the pain still had the ability to interfere, Sean indicated that this was easier to cope with, with Harry acknowledging that the good days were matched with bad days, but that it is possible to live well despite NP’s presence.

This theme presents a complex, dynamic relationship between the participants and their NP. A sense of a battle is illustrated by the quotes provided, with participants discussing their negative perceptions of pain and highlighting its potential to pose negative consequences to their psychological health, whilst also describing attempts to ‘escape’ pain and manage their ability to live their lives with little disruption from NP. This battle is a complex construct and encouraging living well despite pain may be a beneficial goal for rehabilitation.

5.11.3 Superordinate Theme Three: The Coexistence of Social Cohesion and Social Alienation. The third superordinate theme was articulated in detail by five of the eight participants. Although this theme had the fewest number of supporting participants, the information provided was rich in experiential meaning and therefore considered an important aspect of the experience.

This theme examines the differences in social support available to the patients, and the restrictions that the patients put on themselves in their ability to obtain and utilise social support for their benefit. As such, the social aspect of the biopsychosocial model may be framed by this theme. Participants tended to acknowledge the importance of social support, particularly from other people with SCI, but upon discharge from hospital, they chose to exclude themselves in order to avoid becoming a burden to the able-bodied community. Despite the focus upon the feeling of unison with other SCI individuals, the participants in this study were outpatients living in the community, potentially in isolation from other people with SCI, and with little direct communication with others with SCI. As a result of this, participants voiced concerns relating to their feelings of being isolated amongst the able-bodied population who did not understand their experience. Participants felt that the able-bodied social support available in their lives was insufficient, and SCI social support was beneficial but lacking in direct availability. A frustration existed towards the able-bodied and their inability to understand owing to their lack of direct experience of SCI-specific pain. This theme is specific to family and friends, as opposed to healthcare professionals, which may suggest that participants did not consider HCPs as a part of their social support network, or that HCPs are better able to understand their experiences than lay people in the community. Table 5 indicates the presence of each theme in each participant.

Table 5. Master Table for 'The Coexistence of Social Cohesion and Social Alienation'

	James	Harry	Daniel	Rebecca	Dave	Emma	Sharon	Sean
United but Alone in The Pain Experience	🟧	🟧	🟧				🟧	
Painful Self as an Affliction on Social Relationships	🟧	🟧	🟧			🟧	🟧	

5.11.3.1 Subordinate theme one: United but alone in the pain experience. The data reveal interesting experiences with regard to the available social support. Participants who voiced this theme suggest that others with a SCI and subsequent NP understand the experience that they are going through. However, due to its low risk of occurrence there exists a lack of readily available and sufficient social support from the SCI community upon discharge. When Daniel spoke about his referral to a pain management programme at a specialised spinal unit he discusses the feeling of unity with other SCI patients:

> *I think being around people in wheelchairs more might give me [unfinished sentence] I'm looking forward to that … that's why they call [specialised spinal*

> *unit] bubble world, because everyone's the same, you don't feel like an outcast, do you know what I mean?* (Daniel: page 20, lines 480-482)

Daniel stumbled in his initial sentence, leaving it fragmented and without meaning. He intended to say that being around people in wheelchairs might give him something. Considering the statement that follows, his initial statement may be interpreted as being around similar others may have a positive impact on his psychological well-being and self-image because of their understanding, thus he may consider himself less of an *"outcast*" than he currently feels. Feeling as though "*everyone's the same"* in the specialised spinal unit suggests that in the community, Daniel may feel 'different' and therefore like a lesser equal, in comparison with other able-bodied.

In his pain management programme, Daniel may have felt able to compare his pain with others, ask questions, and obtain advice regarding the coping strategies that others use. This may be more beneficial for his pain and coping, providing him with a sense of camaraderie and belonging. In addition, whilst able-bodied individuals may be able to provide Daniel with advice, he may consider it impractical due to their lack of understanding of his specific type of pain. Referring to the spinal unit as a "*bubble world"* suggests that he considered it a safe environment in which he was protected from judgement and the lack of understanding of the 'real world'. This suggests that he may feel isolated in the community, despite the presence of his friends and family around him.

Harry discussed of his own lack of understanding of neuropathic pain in the acute time after his injury, before his own pain developed. At this point, he suddenly understood what others went through:

> *When I was first injured I … chat[ted] to the old boys … you know they would talk to me about pain and so on and I would wonder what they were talking about. And one day, I saw somebody in pain … every now and again, he would go rigid with pain, and he would tremble. And we used to look at him, he couldn't talk ... And you could see that he was in such pain that … nothing else existed, just this pain for him. Then I realised what some people are going through and I used to think poor old him … and now I know what that's like.* (Harry: page 5, lines 109-117)

After the onset of his own pain, Harry came to understand the experiences that others had previously spoken of, and was able to express empathy towards others in pain. He appeared to identify himself as united with others in the experience as a result of the onset of his pain and suggests a potential exclusion of others who do not experience it.

Whilst James was attempting to explain his pain during his interview, he commented on the difficulty in articulating pain in order for the able-bodied to understand sufficiently; "*It's very difficult to try and explain to a point where people can understand, but if you were to run it by somebody else with a spinal cord injury they'd know exactly what I was on about."* Adequately describing NP to anybody without a SCI appears difficult to achieve, whereas the direct experience of those with SCI makes this task easier. The perceived lack of able-bodied understanding may arise from the absence of direct experience of SCI-specific NP, and it may be that difficulty arises in comparing such pain to a general pain that the able-bodied may understand, due to limited available comparisons. Further, it could be that there are no words that can adequately describe pain to an extent that is understandable by the able-bodied. James went on to further support this theme:

> *No matter how much family and friends, partners etcetera, they can believe that they understand, they will never ever truly be able to grasp how painful things are, because you can't physically describe it …. When I'm trying to tell you about the rods and things … unless you experience it, you can't.* (James: page 5, lines 114-117)

This quote may be interpreted in a number of ways. First, it may be interpreted in terms of his inability to communicate the pain; the uniqueness of NP, and the lack of prior experience, caused difficulty in describing it. This may be a factor in his perception of the able-bodied inability to understand it. If he is unable to explain the pain adequately, how are the able-bodied to understand it? James used imagery to try to elicit understanding, but difficulty in achieving adequate understanding may remain. Second, James directed his speech towards the interviewer and the able-bodied in general, using the third person pronoun 'you', stating that *"unless you experience it, you can't"* understand it. This implies that those without direct experience of living with SCI, it is not possible to understand NP.

When asked to what extent he believes his family understands, James responded; "*They try and understand but they've struggled. So, nobody is ever really going to figure it out unless they actually, and I hope they never do, end up with a spinal cord injury,* *so*." His family's struggle to understand is, thus, generalised to the rest of the able-bodied population. At the same time, James indicated the unity experienced with others with SCI. His statement sums up the feelings of the participants within this theme very well; ascertaining his belief that only those with SCI can understand SCI-specific NP, and that having a SCI is the only way in which to achieve a thorough understanding.

Again, he repeats his difficulty in describing his pain; "*Trying to … explain to you how it feels really. It's quite difficult. It's more difficult than I thought it was going to be if I'm honest.*" In the moment of the interview, James reflects; "*It's just trying to help somebody understand [. . . . . .] helping them try and understand something that potentially they're never going to understand, know what I mean?*" Prior to interview he may not have planned how he would describe the pain, yet in the process of attempting to describe it, he realised just how difficult it is to help others understand. The six-second pause may have been a time during which to reflect upon how best to describe NP.

Sharon agreed that those without SCI attempted to understand but may never be fully able to. Her interview contributed evidence for feeling united with the SCI community, and isolation from the able-bodied population:

> *Unless you're in the wheelchair … I know people say "I understand how you feel", but they don't, you don't … you know? But they [users of a specialised SCI global online community] do, the website, because they're living that too … It's a great website for support, resources … if you just want to blow off steam, you can do that. It's a great place.* (Sharon: page 5, lines 118-121)

Sharon's distress lay in the fact that able-bodied do not understand, even where they say that they do, because they are not living the same experience. She generalised this lack of understanding to the interviewer, further highlighting her belief that nobody can understand her experience. Consequently, Sharon felt socially isolated and distressed in the able-bodied community context. She did, however, have instant access to an internet network of people with SCI who have a shared understanding of her experience, which helped to facilitate a sense of belonging. This network meant that others could provide her with some of the social support she desired, whilst also offering her opportunity to compare herself against others, access to specialised resources, and an outlet for her to *"blow off steam"* without judgement.

Whilst feeling a part of a specific social group may serve a beneficial purpose, feeling socially isolated from the general able-bodied population may pose significant risks upon the individual's well-being, such as an increased sense of loneliness, and symptoms of depression. This theme suggests that social support provided by similar others is desired by outpatients living with NP after SCI but is often difficult to obtain. The social support that is readily available in the form of able-bodied friends and family is seen as inadequate, arising from the absence of shared knowledge and experience. Self-imposed restrictions on social activities or discussion of pain were implemented, posing risks to physical and psychosocial well-being. Pain education for those around the outpatient, and access to specialist communities and peer support/mentoring for those with SCI could, therefore, be made more easily accessible to patients.

5.11.3.2 Subordinate theme two: Painful self as an affliction on social relationships. Participants' discussions of being socially united with other SCI patients, and feelings of alienation from the able-bodied appeared to be based around factors out of their own control. For example, the nature of NP meant that fostering understanding in others was a difficult task. Within this theme, participants voiced feelings of self-perceived burdening their friends and family. Arising from this perception, many participants discussed attempts to reduce their level of burden upon others.

Harry articulated this theme particularly strongly, focussing upon the negative consequences of his pain upon his wife's psychological and social well-being:

> *… my wife, she retreats into her shell when I'm in agony, she's seen it so many times [. . .] and because it impacts on her so much, she could even … enter a sort of phase of to get on with it you know. "For God's sakes", you know? Become irritable with me …* (Harry: page 14, lines 319-322)

> *… it makes me feel as if my pain is responsible for her emotional pain … it makes me feel uncomfortable. Very uncomfortable sometimes, particularly when the pain is prolonged, and I know that she's suffering because you can see that it's impacting on her … because she loves me she doesn't want me to be so distressed and knowing that I am distressed with all the pain and there's nothing she can do.* (Harry: page 14, lines 328-332)

Harry's concerns with burdening his wife lay in his perception of the psychological distress that it caused for her, which perpetuated his own distress. He discusses his wife's attitude towards him when he is in pain, suggesting that her irritability and distress arise as a result of his pain. The three-second pause at the start of the first quote suggests that he may have found it difficult to articulate. His perception of burdening his wife may be inevitable due to the nature of their relationship and his injury; Harry's wife did not want to see him in pain, but he felt unable to hide it from somebody he is so close to, physically and emotionally. This, therefore, may have made his wife's distress unavoidable. Harry acknowledged that his pain may be an affliction to his wife, posing risks to her psychological well-being.

He also suggested that his pain was an affliction to his wife's ability to live her own life; her social well-being:

> *… and it impacts on what she can do as well because I can't move my hands as a tetraplegic, and if I need the nifedipine [medication for high blood pressure] then she's got to be around to give it to me. So she can't just spontaneously go out and fulfil her life. So yes, it does impact greatly on the family.* (Harry: page 8, lines 183-187)

As well as the psychological effects, it is also possible to see that there are physical consequences. Harry's restricted mobility meant that he was unable to open his medication, needing his wife to be present should he need to take it. His wife's lack of ability to take a break and "*fulfil her life*", due to his personal requirements, may lead to stress, burnout, and compassion fatigue, which may pose a threat to both his and his wife's quality of life, satisfaction, and their ability to support one another.

Further to this, Harry acknowledged that his self-perceived burdening was not limited to his wife, but implicated the rest of his family:

> *I'd have to shut myself away from the family. I don't want them to see my misery. I don't want to impart my misery to them … but at the same time I'm part of the family so everybody suffers really.* (Harry: page 4, lines 84-86)

Again, Harry suggested that felt as though he was a burden to his entire family, causing them unavoidable distress because of his own distress. His belief that being around his family causes his own *"misery"* to spread to them, led to efforts to isolate himself in order to protect them from distress. However, his significant role within the family, as husband, father, and grandfather, meant that he was unable to protect them from his distress as much as he would have liked.

Daniel's concern surrounding the impact of his pain on his family is discussed earlier, but he also voiced anxieties of being an affliction upon his friends:

> *… you don't want to go from that [being in pain with his partner present], then go and see your mates and be like, carry on talking about it … You have a little moan but … you've just got to forget about it, otherwise that's going to be your whole life … You don't really want to talk to your mates about how much you feel pain … Otherwise that's all you're ever going to be talking about.* (Daniel: page 12, lines 290-295)

When broaching the topic with his friends, Daniel appeared to draw new boundaries in social etiquette, considering it unacceptable to burden them with pain-talk. Further, situations with friends may have reduced social pressure to discuss feelings. Instead, he chose to limit his pain dialogue to his partner, with whom he may feel safe discussing his experience, and who may be more understanding. Daniel took these preventative measures in order to prevent the pain from encompassing and controlling his *"whole life"* as a form of self-protection in order to maintain some sense of normality in what he may perceive as an 'abnormal' life as a spinally-injured patient. Further still, concerns regarding his friends' perceptions of him may also motivate the refusal to discuss pain in front of them, in order to protect his social image, an issue prevalent throughout Daniel's interview.

The idea of being a burden to others was also represented in Emma's interview, where her concerns centred on her children:

> *So at home, I was the queen of the grumps. I've got two young boys [ages omitted] did I want to play with them? One I was so knackered I couldn't do anything, sleeping every afternoon, over late to go and pick them up from the childminder's, needing the childminder to take them all the time and this is their six-week holiday, and you expect a little bit of time from me?* (Emma: page 13, lines 317-320)

During her interview, Emma expressed a lot of frustration towards her experience, which resonated in her discussion of her children's expectations of her. Emma's pain affected her energy, and perceived her children to be demanding attention and time that she may not want to, or be able to, provide. Self-perceived burdening ascended from her inability to meet their needs. Further to this, Emma uses the word *"you"* rather than 'they' when referring to her children, implying that, perhaps, she feels as though others in her life *"expect"* time from her.

Sharon also presented this theme within her interview, displaying a perception of burdening individuals involved in her care:

> *I was talking to my therapist about it but uh, I'm not any more very much because ... how much can you talk about pain? It's just pain. Nobody wants to hear about pain over and over and over again [laughter] so no I guess I don't really talk too much about pain.* (Sharon: page 9, lines 199-202)

Sharon outlined that she used to speak to her therapist about her pain, and then stopped due to a self-imposed restriction. Her short sentence *"It's just pain"* suggests that the nature of pain means that there is a limit on how much it should be discussed. When Sharon stated that *"nobody wants to hear about pain over and over and over again"* she laughed mid-way through the sentence as though in contempt and scorn towards her idea that people do not want to hear about her experience. It may also be that Sharon has assumed that her personal belief (that pain should not necessarily be discussed) is resonated by others. Her perception appeared to be that pain-talk may elicit negative consequences for the listener, which she would not like to burden others with her pain.

The emergence of this theme suggests that people with NP post-SCI impose restrictions on the extent to which they allow themselves to discuss their pain with others. This may be in attempts to protect others from the negative consequences of their pain, as well as to protect their own self-image. Further, a distinct preference for keeping pain to themselves was acknowledged, and this in itself may pose significant threats upon the participants' psychological well-being, such as rumination and anxiety about the future, as well as their perceptions of who can provide them with adequate social support.

5.12 Discussion

The current study aimed to explore how neuropathic pain is experienced by those with SCI after discharge from a rehabilitation unit. From the participants' accounts of their experiences of pain following SCI, three themes emerged: (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'. These themes encompass the biomedical, psychological, and social impact, thus identifying that NP is experienced in a biopsychosocial manner. The results suggest a need for pain management to target these three factors in order to aid coping and adjustment to NP after SCI. Moreover, whilst participants' accounts seemed to agree on themes, their accounts also indicate the contextual and subjective nature of the experience, identifying how each theme affects each participant on an individual level, and therefore, how pain management should be made specific to the unique needs of the individual. The results indicate that interventions encompassing the whole experience rather than one aspect could provide the most benefit by improving physical, psychological, and social functioning. Each super-ordinate theme will be discussed in relation to the literature in order of appearance within the results.

Participants felt that the biomedical approach was inadequate due to its tendency to rely on medication that offered limited efficacy, without offering patients a choice in their care, consequently leaving them feeling unheard. The discrepancies between what patients wanted, and what they were actually offered or provided with, contributed towards the creation of a 'chasm' that distanced patients from staff involved in their care. Thus, an adequate level of care and pain relief was seen as an unattainable goal, through the utilisation of the biomedical approach alone. This theme highlights the perceived inadequacy of the biomedical model in those with SCI; a perception shared by other chronic pain populations (Osborn & Smith, 1998; Waddell, 1992), and suggests the need for a more comprehensive treatment or management programme, incorporating the themes that arose in the present study via psychosocial, acceptance-based, and educational, interventions, for chronic neuropathic pain after SCI.

The participants expressed a distinct resentment of their perceived reliance on medication, which HCPs offered as the only option available. According to Cardenas & Jensen (2006), pharmacological treatments are the most widely available treatments for pain after SCI, which may explain these perceptions. Few studies have examined pharmacological treatment for those with NP after SCI (Attal, Mazaltarine, Perrouin-Verbe, & Albert, 2009). However, participant claims of inefficacy support findings that pharmacological treatments are unsuccessful in relieving pain in the majority of people with SCI (Widerstrom-Noga & Turk, 2003; Siddall, 2009), with non-pharmacological interventions such as acupuncture, exercise, and psychological treatment offering superior efficacy (Heutink, Post, Wollaars, & van Asbeck, 2011).

As a result of their perceptions of reliance and the occurrence of undesirable side effects such as cognitive interruption, many participants discussed conscious choices to alter their drug regime (reducing or increasing dosage), or abandon it completely. This has been previously identified as a problem for those with SCI (Henwood & Ellis, 2004), and is a common occurrence in pain populations (Broekmans, Dobbels, Milisen, & Morlion*,* 2009). McCracken, Hoskins, and Eccleston (2006) demonstrate that adherence is mediated by patient beliefs or concerns, whilst Rosser, McCracken, Velleman, Boichat, and Eccleston (2011) suggested that non-adherence to drug regimens is associated with side effects and fears of dependency. Alternative interventions that focus on reframing such negative cognitions, or focus on the psychological ability to cope with pain without the need for medication may offer improvements in adherence by reducing the number of concerns patients have regarding their treatment.

Many patients described a ‘trade-off’ when considering medication, with participants, willing to ‘give up’ pain relief in favour of fewer side effects and anxieties. This suggests that patients are missing out on potential pain relief due to the occurrence of side effects that may be more difficult to cope with than the pain itself. This is reflected in another study (Gregorian, Gasik, Kwong, Voeller, & Kavanagh*,* 2010), which found that, of their sample of 618 pain patients, 96% of those with chronic pain, and 92% of those with acute pain, experienced at least one side effect as a result of their medication, such as nausea and vomiting. Lansbury (2000) advances this, suggesting that the fear of side effects is also related to concerns for loss of control or independence. The negative associations discussed by participants in the present study regarding medication resulted in a refusal to take medication, in order to preserve their identity (Monsivais & Engebretson, 2012). This study suggests that side effects of medication can have some impact upon the extent to which patients feel in control of their lives and to what extent patients are able to accept their pain. Reducing or controlling for the side effects of medication, as seen in the current study, may, therefore, have some potential benefit for the psychological well-being of persons with

SCI and chronic pain, and may also offer positive influences on pain acceptance through increases in perceived control.

The results of the current study suggest that agreement exists among those with SCI regarding the lack of psychosocial treatment options available for the management of their pain. Knowledge of other available management techniques, and protocols regarding how to manage chronic NP after SCI may, therefore, be incomplete and the inclusion of non-pharmacological options should be considered. This result is reflected in work by Lofgren & Norrbrink (2012), who found evidence for a discrepancy between what SCI patients are offered from healthcare and what they actually want. In their study, patients were given pharmacological treatments as the only option offered by HCPs, but used complementary therapies, such as relaxation, for neuropathic pain self-management, therapies which they had often had to find by themselves through trial and error. This is supported by evidence indicating that interventions such as massage, physiotherapy, and psychological therapy, are used more frequently than pharmacological interventions by those with pain after SCI (Heutink, Post, Wollaars, & Van Asbeck, 2011). Participants in the current study suggested that SCI patients consider non-pharmacological treatments safer and more effective methods in managing pain, and that increasing awareness of non-pharmacological pain management techniques and interventions is a worthwhile endeavour.

The participants in this study suggested that pharmacological interventions were unsuitable for the management of NP, and that techniques such as education and relaxation may be of benefit to those with SCI and NP. Non-pharmacological interventions, such as physiotherapy and occupational therapy, are utilised in order to improve fitness, posture, independence and daily activity after SCI (Mingaila & Krisciunas, 2004; Behrman & Harkema, 2000; Popovic et al., 2006). Such interventions can also offer reductions in both musculoskeletal and neuropathic pain at the same time as improving mood, with few undesirable side effects (Norrbrink, Löfgren, Hunter, & Ellis, 2012; Martin Ginis, Jung, & Gauvin, 2003). Side-effects of medication were a common issue for participants in the present study, indicating that these interventions may be effective strategies to use in isolation from, or as an adjunct to, pharmacological treatment for NP.

Further, psychological strategies such as cognitive behavioural (CBT) pain management programmes are infrequently adopted for SCI populations (Cardenas & Jensen, 2006; Turner, Cardenas, Warms, & McClellan, 2001), despite evidence suggesting that cognitive behavioural techniques such as education, goal-planning and setting, and relaxation, offer benefits in terms of increased mood and reduced catastrophic thinking (Norrbrink, Kowalski, & Lundeberg, 2006, Byrnes, Beilby, Ray, McLennan, & Schug, 2012; Craig, Hancock, Dickson, & Chang, 1997). This treatment approach is effective in general pain populations (Morley, Eccleston, & Williams, 1999; Vlaeyen & Morley, 2005), and Nicholson Perry, Nicholas, and Middleton (2009) suggest that such approaches should be effective for those with SCI. The present study suggests that incorporating the SCI-related psychological variables discussed by participants, such as acceptance of the injury and its consequences, may offer superior outcomes in terms of pain management. There is a need, therefore, to examine the applicability of such interventions and their efficacy for those with SCI.

Participants discussed progressive losses of faith in the team involved in their care. For some, information provision was a problem, whilst others experienced difficulties in obtaining further care for their pain needs, indicating that discrepancies existed between what was offered, and what they wanted. Dissatisfaction with information provision is reflected by chronic low back pain patients (Snelgrove & Liossi, 2009), and may result in a reduced adherence to medication (Coulter & Fitzpatrick, 2003). Patient-staff relationships are important in adherence to medication, with a positive relationship more likely to lead to better health status, recall of information, and adherence to prescribed interventions (Stewart, 1995; Zolnierek & DiMatteo, 2009; Stavropoulou, 2011). This may result in a search for information from other, potentially less reliable sources such as the internet, which may further fuel unrealistic expectations of treatment and relationships with the care team (McIntosh & Shaw, 2003). This, therefore, has significant clinical implications with regard to medication adherence and suggests that HCPs should attempt to communicate verbally, and non-verbally, express empathy in order to build rapport, and engage in collaborative decision making, in order to encourage a positive patient-staff relationship. However, there exist no studies exploring medication adherence in those with SCI in order to confirm this.

The concerns of participants relating to the lack of information provision and knowledge are reflected in those of HCPs (Morley-Forster*,* Clark, Speechley, & Moulin*,* 2003), which may be fuelled by a lack of training or education on the effects and side effects of medicines. McParland, Eccleston, Osborn, and Hezseltine (2010) used IPA in their study of chronic pain, finding that patients sought fair treatment from HCPs, but blamed the same HCPs when they were not offered, or were unable to access, the fair treatment they desired, something which may be occurring for the SCI population. Rosser, McCracken, Velleman, Boichat, and Eccleston (2011) hypothesise that HCP concerns may exacerbate the concerns of the patient, which may result in greater mistrust in a prescribing doctor, and therefore general non-adherence to medication (over- and under-use). This evidence, alongside the evidence provided by participants in this study, suggests that openness and trust in the patient relationship with their care team is a key aspect of the treatment (Parsons et al*.,* 2007).

The present study suggests that psychological and social support is important to SCI outpatients, yet there appeared to be a lack of patient autonomy and preparation in terms of outpatient pain management. Dickson, Ward, O’Brien, Allan, and O’Carroll (2011) found that a lack of post-discharge care was a concern for those with SCI, who were left to deal with their SCI on their own, without any form of psychological support. Dickson, Allan & O’Carroll (2008) found that SCI patients felt physically prepared for the community, but not psychologically prepared. The lack of autonomy identified by those in the present study suggests that perhaps the focus of spinal units remains upon physical rehabilitation, rather than pain management and community reintegration. The Such focus upon physical rehabilitation may prevent the development of psychological adjustment and acceptance, despite the importance of such psychological and social preparation in terms of readjustment to the community outside of a spinal unit (Nunnerly, Hay-Smith & Dean, 2013).

Concerns surrounding relationships with staff were discussed, with many participants feeling unheard, with a lack of ability to contribute towards their own care.

Previous accounts suggest that patients with chronic pain experience feelings of being ignored or blamed for their pain (Eccleston, Williams, & Rogers*,* 1997; Lillrank, 2003). Similarly, Werner & Malterud (2005) found that chronic pain patients were often fearful of not being believed by HCPs, with doctors tending to reach for medication as the 'easy way out' of difficult consultations. HCPs involved in the care of chronic pain patients, however, may appear helpless to the patient, due to a lack of understanding of such pain (Chew-Graham, May, & Roland*,* 2004). This may be particularly true for SCI patients living with chronic neuropathic pain, due to an even narrower literature base, and the need for specialist training and knowledge of the injury. For those in the present study, the negative feelings induced by HCP responses and attitudes towards chronic NP had debilitating consequences upon not only the psychological well-being of the individual, but upon the expectations of patients for future relationships with HCPs, which may subsequently influence medication adherence, and pain-related outcomes.

A lack of information provision was also identified by participants in this study, which may cause patients to develop unrealistic hopes and desires for curing or reducing pain completely, when only symptom management may be possible. Participants may have misunderstood the goals of HCPs involved in their care, whilst HCPs may have misunderstood the needs of their patients, thus contributing to the discrepancies in the care pathway, and a misunderstanding of each person's objectives. Whilst research suggests that treatment of SCI-specific pain is difficult (Yezierski, 1996) due to an incomplete understanding of NP (Widerstrom-Noga, Finnerup, & Siddall*,* 2009), it appears as though SCI patients are not informed of the difficulty in treating their specific pain. Hansson, Fridlund, Brunt, Hansson and Rask (2011) found that HCPs tend to focus upon their areas of expertise, such as medication, potentially ignoring psychosocial difficulties; a strategy that is wholly unhelpful for any chronic pain sufferer, regardless of medical aetiology. This result suggests that collaborative approaches to care, in which information that is requested is provided in a timely manner, may, therefore, reduce discrepancies in understandings and provide realistic knowledge of NP and its management.

Participants described attempts to offer input into their own care, to little or no avail. Previous work and the evidence presented in this study highlight the importance of increasing patients' sense of self-worth and participation in their own care. This, however, does not appear to be currently offered as part of standard care. This lack of participation and autonomy in their own care induced feelings of frustration and disempowerment, as though their care team were in control of their lives. Hansson, Fridlund, Brunt, Hansson, and Rask (2011) conducted a qualitative study on the experiences of chronic pain patients' encounters with the health service, finding that, whilst the patients tended to have positive experiences, the negative ones were of particular salience, indicating areas for improvement. The distress voiced by those in this study, arising from their lack of input, suggests that such frustrations may be reduced if HCPs accredit patients with pain, loosening the restriction on pain management protocol, and allow them easier access to the treatments they desire, thus enabling patient empowerment and responsibility in their own care.

Collaborative approaches to pain management, however, may not be currently happening in practice. This may have influenced the non-adherence described by many participants in the present study, and is reflected by Osterberg and Blaschke (2005), who suggest that poor patient-staff relationships may reduce medication adherence. It may be possible to increase adherence and reduce pain, therefore, by improving patient-staff relationships, internal locus of control, communication of information, and social support. If patients feel fully informed of their condition and treatment, they may be better able to take responsibility for their lives by making informed decisions surrounding their care. This may, therefore, lead patients to feel empowered (Barrie, 2011). Clark (2000) advocates that people with SCI should drive their own rehabilitation, with HCPs providing medical knowledge, assistance, and support as and when it is required, in order to empower patients. Where patients have the opportunity to make their own decisions, engaging in collaborative efforts with their care team, positive health outcomes are more likely to occur (Stewart, 1995). This study suggests that interventions to educate HCPs working with those with SCI may improve the implementation of collaborative care.

This study implies a need for a collaborative effort between patients and staff when making decisions regarding care and treatment (Quill & Brody, 1996), and that patients would welcome the active consideration of ways to enhance the patient's sense of control. Such a collaborative ethos already exists with regard to SCI rehabilitation and goal planning (Duff, Evans, & Kennedy, 2004), yet it seems that this has not yet been translated to pain management. The lack of autonomy described by those in the present study suggests that HCPs should, therefore, prioritise patient integrity and independence, offering a collaborative approach to treatment. At the same time, building strong rapport with patients by displaying empathy and compassion, such that the relationship may be perceived as meaningful, may also be of benefit. These suggestions are made in order to increase patient confidence in treatment and information provision, medication adherence, and positive pain-related outcomes.

The concept of a battle for control was prominent, suggesting that there is a psychological aspect of the pain experience after SCI that should be treated or managed, thus rejecting the idea of the purely biomedical model of pain. The extent of pain interference in daily life was discussed, and is suggested to have a much greater impact on psychological well-being than pain intensity alone (Cuff, Fann, Bombardier, Graves, & Kalpakjian, 2014), may mediate feelings of control. This implies a need to promote a sense of control of one's life and potentially acceptance of NP among those who are newly injured in order to encourage adaptive adjustment and psychological well-being.

Many participants appeared worried and displayed feelings of helplessness and fear regarding their pain, suggesting their consideration of pain as a threat. These perceptions may play a role in the pain's disruptiveness and intensity, which may reinforce the pain's presence within the individual's consciousness (Smith & Osborn, 2007) and inform a heightened vigilance towards pain (Van Damme, Eccleston, & Roelofs*,* 2004). This correlates with previous research by Sullivan et al. (2001), who found associations between catastrophising and distraction, disruptiveness, intensity, and vigilance. Improving patient perceptions of control over their pain may, therefore, improve quality of life, community reintegration and physical and psychological outcomes (Craig, Nicholson Perry, Guest, Tran, & Middleton, 2015).

The extent to which an individual believes that 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 treatment of catastrophic thinking, as well as coping skills training in order to improve patients' sense of control, may reduce such negative outcomes (Turner, Barlow, & Ilbery, 2002). Other research has suggested that catastrophising may be perpetuated by poor communication within the patient and HCP relationship (Houben, Gijsen, Peterson, de Jong, & Vlaeyen, 2005), which may consequently give rise to the loss of the battle and decreased acceptance of pain that appears in the current study.

Some participants' experiences were also characterised by repeated searching for cures and management techniques, causing them to become 'stuck' in their unsuccessful biomedical coping strategies that they repeat, despite failure and frustration (Aldrich, Eccleston, & Crombez, 2000), as in the misdirected problem-solving model (Eccleston & Crombez, 2007). Further, their hopes for a self without pain may indicate that their self-concepts may be 'enmeshed' with their pain, thus inducing psychological distress and potentially worsening the perception of pain, in the form of a negative feedback loop (Pincus & Moreley, 2001). Further, Kortte, Gilbert, Gorman, and Wegener (2010) found that high levels of hope and positively framed experiences aided in increasing life satisfaction after discharge from a spinal unit. Osborn & Smith (2006) suggest that engagement with pain as part of acceptance therapy may, therefore, be beneficial in helping patients to come to terms with their potentially new painful identity, and improve their ability to retain life autonomy.

All participants had obtained their injuries through potentially life threatening situations, but none explicitly described searching for, or finding, meaning. Finding meaning in a SCI may lead to better adjustment to the injury, whilst more frequent searching for meaning and cures may be predictive of worse adjustment (Davis & Novoa, 2013). Finding meaning in an injury may provide a patient with a sense of control (Taylor, 1983), and personal post-traumatic growth (Davis & Morgan, 2008). However, there exists a need for further work to establish the extent to which finding meaning can influence pain perception. Simple interventions in practice that encourage patients to shift away from the focus upon pain intensity towards pursuing valued activities and achieving post-traumatic growth may have significant impact upon the psychological well-being of those with NP after SCI.

Many participants adopted the use of metaphors in order to communicate the battle. Pain catastrophising is a significant predictor of pain behaviour (Thibault, Loisel, Durand, & Sullivan, 2008), which may be reflected in the use of distress-inducing metaphors (Jamani & Clyde, 2008). Metaphors referring to the threat of pain, and perceptions of its uncontrollability indicate attribution of responsibility to pain, and away from the self. The communal coping model of pain (Sullivan, 2012) states that catastrophising is a form of interpersonal communication used to cope with pain, motivated by proximity or support-seeking, and to solicit empathic responses. The use of catastrophic metaphors may increase the risk of negative emotional states and hypervigilance (Holmes, Arntz, & Smucker, 2007; Villemure & Bushnell, 2009). Therefore, by using metaphors to attain social support, increased focus is placed upon threatening appraisals of pain, which can be seen in the participants' descriptions. Distress may be exacerbated by such rumination and perceptions of helplessness, which may contribute towards the recursive process of fearful, alarmist cognitions surrounding pain (Vlaeyen & Linton, 2000). For participants in the present study, communicating NP through the use of metaphors may have exacerbated distress. This is evidenced in participants' discussions of pain as an embodied entity, and suggests a need for further work to establish the impact of such language on psychosocial well-being.

Similarly, for thoughts that are intrusive and uncontrollable, distress may be induced or exacerbated (Philips, 2011). Pain-related images are positively associated with depression, anxiety, ratings of pain unpleasantness (Gosden, Morris, Ferreira, Grady, & Gillanders, 2014), and catastrophising (Gillanders, Potter, & Morris, 2012). This evidence suggests that metaphor use may pose risks to the psychological functioning of those with chronic pain. Further, high catastrophisers are likely to be rated as experiencing more intense pain than low catastrophisers, when evaluated by an observer (Sullivan, Martel, Tripp, Savard, & Crombez, 2006), which may suggest that the overt use of distressing metaphors serves to amplify the listener's perception of the intensity of pain. The use of metaphors that may be considered catastrophic in the present study may have aided the listener's understanding of the experience through the observation of metaphors as opposed to facial expressions or behaviours alone. This also suggests that those using metaphorical language may also have increased levels of catastrophic thinking. Future work, therefore, might explore the relationship between catastrophic thinking and metaphor use in those with NP.

This study found that there exists a simultaneous occurrence of feelings of social unison with other people with SCI, alongside feelings of social isolation from the able-bodied social support. As a result of the feelings of not being understood, participants voiced attempting to socially isolate themselves from their friends and family, in order to avoid burdening them with pain talk, or their own distress. The social context of chronic pain is considered influential in adjustment to chronic pain in general populations (Romano, Cano & Schmaling, 2011), and the emergence of this theme suggests that social context is also an influential factor contributing towards adjustment to NP after SCI.

The bond felt with others with SCI is also reflected in qualitative work by Dickson, Ward, O'Brien, Allan, and O'Carroll (2011), who explored the experience of post-discharge adjustment in SCI patients, suggesting that feelings of camaraderie are influential in multiple areas of SCI life. However, upon discharge, feelings of camaraderie are subsequently lost, potentially leading to feelings of isolation, and posing a risk to adjustment to injury, post-discharge community reintegration (Carpenter & Forman, 2004) and pain. Access to social support networks of people with SCI or to peer-mentoring schemes, and the optimisation of follow-up appointments alongside a spinal unit may promote coping.

Further, the beliefs of those in this study, and subsequent behaviours, may play a role in psychological well-being and QoL, suggesting that social and environmental aspects are central to the SCI experience, but insufficient social support may pose risks to the psychological well-being of the individual. Hammell (2007) conducted a meta-synthesis of the available qualitative literature exploring QoL in SCI individuals. The meta-synthesis included seven journal papers that met the criteria for rigour and quality, consisting of 120 participants. Every one of these papers reported some dimension of the environment influencing the participants' QoL. Duggan and Dijkers (1999) found that people with SCI experienced some level of isolation, stigma, or discrimination as outpatients. Closs, Staples, Reid, Bennett, and Briggs (2009) suggest that, whilst chronic neuropathic pain patients may have access to social support, their friends and families may be unable to understand their pain, or unable to believe it. Social support may be an important influence upon the psychological well-being of those with a SCI, and has been associated with depression, stress and self-esteem (Muller, Peter, Cieza, & Geyh, 2012). The emergence of the theme of social support in the current study supports previous work and suggests that it may play a central role in adjustment to injury and pain after SCI, a suggestion that warrant further research within SCI populations.

Participants discussed attempts made to reduce their self-perceived burden. The negative reinforcement arising from friends and family member's responses to pain may have caused participants to engage in withdrawal behaviour that may reinforce perceptions of burdening, as described in operant conditioning (Skinner, 1937). Whilst social withdrawal was done with positive intentions, this appears to be counter-intuitive, with participants actually isolating themselves from the potentially beneficial social support that is available to them. Such concerns are reflected in those with chronic back pain (Holloway, Sofaer-Bennett & Walker, 2007). Like those in this study, Holloway and colleagues' participants voiced fears of damaging their relationships, tending to suppress their true feelings in order to protect themselves and their friends and families. Feelings of shame were prominent, further reinforcing the boundaries placed upon themselves. Hammell's (2007) synthesis identified a theme of 'self-worth', occurring in all seven studies, with some participants displaying concerns for being helpless and useless, and potentially burdening family and carers. Hammell also found that many participants identified methods of obtaining a positive self-worth, such as positively reframing their identity, or developing a new one. The participants in the current study did not speak of any particular strategies used in order to increase positive self-worth, and this may suggest that pain may be an issue that is more difficult to redefine as a positive experience in the SCI population.

The attempts made by participants to reduce their self-perceived burden may have a number of psychosocial consequences on both the sufferer, and their family, consequences that may be exacerbated by the presence of NP. As a result of the injury, partners may often assume the role of caregiver, which may play a central role in the adjustment to the injury (Kennedy & Rogers, 2000). This new caregiver role may impact the caregiver’s own quality of life in ways that may be visible to the patient, leading to the perception of being a burden in those with SCI. Studies by Closs, Staples, Reid, Bennett, and Briggs (2009) and Bakitas (2007) found that feelings of burdening upon social relationships, experiencing losses of family roles, and social withdrawal, are common amongst people with chronic pain. Kowal, Wilson, McWilliams, Péloquin, and Duong (2012) found that 73% of their chronic pain patient sample displayed an increased level of self-perceived burden, which was positively correlated with pain intensity, depression, and anxiety. The theme of self-perceived burden arising in the present study suggests that such perceptions can be implicated in the experience of NP, as well as the psychological well-being of those living with it. Such perceptions, therefore, should be targeted in the management of NP, in order to encourage adaptive social support networks to develop.

According to social exchange theory (Homans, 1961), benefits and costs of what the individual is able to provide and receive in social relationships are weighed. Successful relationships are based upon equal proportions of ‘give-and-take’, whilst unsuccessful relationships occur when there is an imbalance in the costs and benefits. Osborn & Smith (1998) found that individuals with chronic pain withdrew from others due to feelings of being a burden and being unable to show their distress. The participants in this study discussed feelings of dependence, a loss of self-confidence, and felt unable to display their suffering, subsequently withdrawing from social engagements in order to reduce feelings of burdening. For those with SCI, achieving equal proportions of ‘give-and-take’ may be difficult, due to physical restrictions, which may cause distress for both the person with SCI, and their partner or primary care-giver. Involving patients and their significant others in treatment, and utilising educational approaches to teach both parties how to cope with distress, may therefore aid pain management and coping with NP.

This study suggests that perceptions of burden may have significant costs to the person with SCI, and to their family, and as such, reinforces the need for the involvement of friends and family in SCI rehabilitation and pain education. The negative impact of SCI is documented in previous work, which suggests that depression and anxiety are common amongst those with a family member with SCI (Kolakowsky-Hayner & Kishore*,* 1999; Peters et al.*,* 1992). The presence of NP after injury can also interfere with social integration, and is associated with stress, frustration, and anger within families (Smith, Torrance, Bennett, & Lee, 2007), often leading to the pain sufferer withdrawing from social activities (Breivik, Collett, Ventafridda, Cohen, & Gallacher*,* 2006). The impact of NP on friends and family described in the current study suggests that there also a need to include friends and family in SCI rehabilitation and reintegration into the community by educating both parties on how to maintain close relationships, enhance role adjustment, to communicate NP effectively, and support one another through the SCI journey, in order to prevent relationship breakdown and consequent isolation. Such intervention would contribute towards affirming a SCI individual's sense of worth, and reducing their sense of burden upon significant others (Duggan & Dijkers, 1999).

5.13 Implications for Practice

The three themes found in the present study encompass the biopsychosocial model, with each theme representing an aspect of the model. The evidence suggests that the biomedical model may be inappropriate, or too 'narrow', for the treatment of NP after SCI, failing to acknowledge the influences of the patient's social context, as well as their personal beliefs and needs (Waddell, 1992). Indeed, Heutink, Post, Wollaars, & van Asbeck (2011) report that non-pharmacological strategies for pain relief, such as acupuncture, massage, and psychological techniques, offer superior outcomes for SCI individuals, as opposed to medication alone. This study implies that those with SCI desire a dialogue with those involved in their care. Minor interventions at regular appointments could include such dialogue, thus offering HCPs extra benefit from listening to the personal stories of their patients. The identification of an individual's unique problems arising from NP would allow for pain management to be directed towards factors that would contribute towards adjustment to both NP and SCI.

Cardol, Jong, and Ward (2002) suggest that the ultimate goal of SCI rehabilitation is to obtain the highest possible autonomy, however, the current study suggests that for adjustment to chronic neuropathic pain to be successful, it should be addressed from biomedical, psychological, and sociological perspectives, as is successful rehabilitation (Cohen & Napolitano, 2007; Dorsett & Gerghty, 2008). This research is consistent with research by Summers, Rapoff, Varghese, Porter, and Palmer (1991), who found that SCI-specific pain and psychosocial factors hold much stronger associations than SCI pain and physiological factors. This suggests that psychosocial interventions should be utilised alongside pharmacological treatments in order to improve quality of life at a comprehensive level (Heutink et al*.,* 2010) and that ACT (Hayes & Smith, 2005) or mindfulness-based interventions (Kabat-Zinn, 1982) may be beneficial in improving pain-related outcomes. This study also suggests that pain management tailored by a multidisciplinary team, including specialist consultants, nurses, physiotherapists, occupational therapists, and psychologists, to the specific needs of the individual is desired by those living with NP after SCI. This would offer the most benefit in terms of pain-related outcomes by managing the impact of NP on each aspect of the patient's life, thus reducing its impact.

The results arising from the present study indicate that improving acceptance of NP, and the way the people with SCI relate to it, may improve pain-related outcomes. Past research has demonstrated the effectiveness of CBT for pain management in general chronic pain populations, effectively reducing pain experiences, and improving mood, coping, physical activity and the fulfilment of social roles (Morley, Eccleston & Williams, 1999; van Tulder et al*.,* 2001). However, recent evidence suggests mindfulness-based approaches may be more favourable, compared to other cognitive techniques (Zeidan, Gordon, Merchant, & Goolkasian*,* 2010). ACT and mindfulness, both of which have broad evidence bases for their efficacy in terms of pain management (e.g. Kabat-Zinn, 2003; Wetherell et al., 2011), may be efficacious for those with NP. ACT combines cognitive behavioural techniques (behavioural activation, exposure, skills training) with acceptance, in which thoughts are not labelled as good or bad, helpful or unhelpful. It seeks to improve psychological flexibility (behaviour that is open, centered, and engaged; Hayes, Strosahl, & Wilson, 2012), such that the patient can reduce the influence that cognitions exert over behaviour, without explicitly aiming to change thoughts. ACT has consistently demonstrated large effect sizes in its ability to reduce depression, anxiety, and disability (Vowles & McCracken, 2008; McCracken & Gutiérrez-Martínez, 2011). Such evidence, combined with the experiential evidence discussed by participants in the present study suggests that ACT may, therefore, address the concerns arising in this study.

MBIs may also target the issues discussed by those in the present study. Mindfulness involves cultivating a stable, non-judgmental awareness of the present moment (Baer, 2003) through the use of meditations. This may be useful for those wishing to reduce their medication intake, as voiced by participants in the present study, by reducing the patient's desire for medication as a means to solve a problem (Garland et al., 2014). Mindfulness has previously established efficacy for the improvement of physical and psychological well-being (Teixeira, 2008) and self-regulation (Kakigi et al., 2005), as well as interpersonal relationships (Brown, Ryan, & Creswell, 2007) for those with chronic pain, making it an intervention relevant to the themes discussed in this study. Mindfulness interventions, however, have not previously been investigated for those with SCI. Only one previous study has explored state mindfulness in those with SCI, finding that those who were more mindful used fewer avoidance techniques when coping with negative events, and demonstrated fewer symptoms of depression (Skinner, Roberton, Allison, Dunlop, & Bucks, 2010). Such interventions would also be more desirable than CBT, due to the nature of SCI and its lack of cure. Alongside this, the current study provides rationale for the examination of the efficacy of MBIs for those with SCI and NP, therefore justifying future work exploring this gap in the literature.

The role of social support and the perception of being an affliction or a burden in the chronic pain experience are also prevalent themes in the current study. Little research exists exploring how social support influences the experience of chronic neuropathic pain after SCI, yet previous work suggests that feelings of burdening may predict suicidal thoughts and self-isolation in general chronic pain groups. This finding warrants further work that might explore the relationships between burden perception and perceived social support after SCI. People with SCI may be at a greater risk of depression and suicidal ideation, whilst social support may be of benefit to the psychological well-being of this population, as well as the utilisation and perception of available social support.

The social factors that arose from the data, including relationships with HCPs, and communication about medication, were central issues to participants' experiences. Such experiences, however, are relatively underrepresented in the quantitative literature compared to study of personal, internal cognitive factors such as perceived control and catastrophising. It would be of value, therefore, for future work to explore these themes in more depth from both quantitative and qualitative perspectives, such that the importance and impact of such themes upon physical, psychological, and social well-being is better understood. The present research suggests that improving the availability and quality of social support may improve pain-related outcomes through the use of education.

5.14 Limitations and Conclusions

The nature of the IPA methodology limits the degree to which causal conclusions can be drawn. In relation to the ‘relationships with HCPs’ and ‘the coexistence of social cohesion and social alienation’ themes, the participants’ perceptions of the quality of their interpersonal relationships were not measured. This may have been beneficial in confirming the presence of the theme and illuminating each one further. The psychological theme, consisting of a battle for autonomy may have also been validated through a measure of locus of control. In relation to the theme suggesting that pain medication is inadequate, medications that participants were taking was also not recorded, unless they explicitly mentioned it during their interview. If this had been done it may have been possible to identify which medications may have been causing difficulties, and report this back to the medical professions alongside suggestions regarding patients medication preferences. Recording locus of control and autonomy, quality of relationships, and medication usage/adherence may have been achieved through the use of the demographics questionnaire. However, the purpose of IPA is to let the participants’ tell their own stories, and to allow themes to emerge from the data; therefore it may not have been possible to prepare for them. This study, however, allowed for themes to emerge that may not have previously been studied and, therefore, leaves a number of doors open for future research.

The sample within this study was self-selecting, and small. All participants were sufferers of NP, but there was variance in the demographic characteristics. It may be argued, therefore, that the sample was not representative of the SCI population, nor a subset of this population, but representative of those who are more willing to talk to a stranger about their pain, and engage with research. This may mean that the sample is not fully representative of those who may be struggling to cope with their pain, or talk about it with others. The participant accounts, however, appear to reject this notion, with many participants struggling to articulate their pain and openly discussing the daily struggles they had to contend with. However, future work might explore the experiences of various subsets of the SCI population, matched in terms of demographic characteristics such as gender, level of injury, and time since injury, for a more representative analysis that may be better generalisable.

Participants took part in only one interview, which may have posed restrictions upon the participants' abilities to talk in depth about their experiences. Value may have been added to the study if participants were interviewed on more than one occasion, such that the researcher may have built a stronger rapport, and therefore the ability to ask for more depth on subjects that were not further discussed in the first interview, and to add longitudinal depth, potentially illuminating the variance of pain over time. This longitudinal depth may have also yielded data relating to processes of change during community reintegration.

The present research placed a focus upon the experiences of outpatients. The themes that emerged, therefore, may be specific to outpatients only, and with the ability to inform pain management for outpatients alone. Inpatients have not yet had the opportunity to reintegrate into the community after their injury, and have direct access to HCPs in order to manage their pain, whilst outpatients do not. If outpatients and inpatients had been interviewed and analysed together, different results may have occurred, with the potential to offer an understanding that may be applied to all of those with SCI. Further, the experience of NP as an inpatient may differ from that of an outpatient, meaning that the possible pain management techniques for each group may differ. No previous work has yet explored the inpatient experience, nor compared the two, something that future work should explore.

The present study found that NP after SCI is experienced in a biopsychosocial manner. Key themes revolved around issues with medication inefficacy, collaborative care, life control, and its social impact. These results offer rationale for the utilisation of ACT and mindfulness-based interventions for the management of chronic neuropathic pain after SCI, due to their potential to incorporate all of the emergent superordinate themes that were identified as important factors in the experience. Both ACT and mindfulness have the ability to combat biomedical perspectives, offering patients the opportunity to listen and understand their care team's choices, as well as to have their own feelings and opinions to be heard; social issues, increasing social support through friend and family understanding; and can also combat psychological consequences of pain by improving a patient's ability to self-regulate affective reactions to pain (Kakigi et al*.,* 2005). This form of pain management, therefore, may deliver more effectiveness in improving pain-related outcomes.

5.15 Personal Reflexivity

As discussed earlier, I am engaging in personal reflexivity throughout the entire research process in order to consider how I may have influenced the process and findings. I will engage in the two types of reflexivity described by Willig (2001); personal reflexivity, and epistemological reflexivity. This section aims to provide an explanation of my personal position in relation to the research. This includes some background information as to why I chose to study spinal cord injury pain, and will attempt to outline any assumptions I held at the beginning of the research process.

Before considering this piece of research, I had spent the previous year working on an acute care ward within a specialist spinal injury unit as a healthcare assistant where I hoped to gain valuable hands-on, clinical experience that could boost my career prospects. Prior to this position I had very little knowledge of spinal cord injury and was shocked at the extent to which the injury could alter an individual's life so devastatingly. I read up on the statistics of spinal cord injury and came to the realisation that they can happen to anybody, at any time. Working at such close quarters to people who needed tracheostomies to help them to breathe, as well as meeting people my age who had sustained the injury, made the experience personal and fuelled a desire to help people with SCI. Having spent one year working with spinal injured patients, watching them recover from the acute phase of their injury, learning how to live with their injury, to leaving the hospital and rebuilding their lives, and witnessing all of the psychological ups and downs, I knew in my mind that I wanted to contribute something of value to this population, in order to improve their lives after injury.

The 2012 Olympics and Paralympics were ongoing during my time working on the ward, and I was able to spend a lot of quality time with patients whilst watching the events. I recall one particular day, sitting with one patient who began to cry whilst watching a Paralympic event. He discussed feeling inspired by what the paralympians had been able to achieve. Whilst watching some of the Paralympic games myself in my own time, I frequently noticed feeling a distinct sense of pride that I was able to work with such individuals and to help them to obtain as full a life as possible. Watching the games also provided me with a sense of commitment to develop both the public awareness of spinal cord injury and its consequences, and patient awareness of what they can still achieve after an injury.

My undergraduate degree dissertation involved pain research, which had always fascinated me, due to pain’s subjective nature. I also saw spinal patients who had persistent debilitating pain after their injury, which was also psychologically debilitating for them too. How could they have no feeling from a certain point down, and yet still feel such intense pain? Outpatients were of particular interest for me. I had not been able to work with them and had been told by a member of the Spinal Injuries Association that rehabilitation after the injury really starts after discharge. Chronic pain after a spinal cord injury is a highly prevalent problem, and this may pose more of a threat after discharge than when in hospital, surrounded by healthcare professionals able to help them to cope.

At the beginning of the research process, I had assumed that outpatients suffering with chronic pain after their injury would be more negative towards their life. Upon looking back and reflecting on this, I realise that this assumption may have been heavily influenced by my previous experiences, and reading of the generally negatively focussed literature surrounding SCI and pain; although literature suggests that positive adjustment is common, a predominant focus remains on the negative psychological consequences of, and influences on, the pain experience, such as depression and anxiety. As well as this, my work experience with acute inpatients prioritised achieving short-term, predominantly physical goals for patients with very new injuries, such as sitting up in a chair. Many were, therefore, finding difficulty in adjusting and still attempting to come to terms with losses such as motor function and career opportunities. I may have then generalised this assumption to outpatients, whom I had very little experience of working with.

A spinal cord injury can happen to anyone, at any age, at any stage in his or her life. As there remains no cure for the injury, I firmly believe in the need to make their lives as comfortable as possible, as well as to offer them the same opportunities as those without SCI, in terms of health care, career opportunities, and physical and psychosocial well-being. Outlining my previous assumptions here attempts to situate myself in relation to the research. This allows me to be as reflexive as possible, in order to engage with and be open to participants' worlds. Increased integrity and trustworthiness is hoped to be achieved by providing insights into how my subjectivity may have influenced the research, as well as how the answers to the research questions have been reached. Following this, at the end of each section of this paper will be reflexive chapters in order for readers to understand my stance and contributions at each stage of the research process.

5.15.1 Epistemological Standpoint. A variety of theoretical underpinnings enable uniqueness in the epistemological standpoint of IPA, with influences ranging from critical realism, social cognition, social constructivism, to contextual constructionism, and symbolic interactionism. Smith (2004) describes IPA as combined of multiple approaches concerned with understanding the personal lived experience, which means that IPA holds an epistemological openness. Rather, it retains an epistemological openness in which the researcher is able to make explicit their stance towards the research and how knowledge is obtained and understood.

My own particular approach to this research is drawn from social constructivism, alongside some symbolic interactionism. Social constructivism posits that experiences are shaped and influenced by historical and sociocultural processes. Social meanings are, therefore, intertwined with personal meanings, such that communication acts as a resource for meaning-making (Todorova, 2011). In symbolic interactionism, goals can be obtained through the communication of our own subjective meaning-making, which also allows our sense of self to emerge.

My epistemological stance therefore denotes that individuals are always situated within a meaningful world context (Larkin, Watts, & Clifton*,* 2006). Whilst achieving goals remains an aspect of importance within symbolic interactionism, language use, when telling life stories, represents why events may or may not hold significance for the speaker. Eatough and Smith (2008) describe how we make sense of our world and self, finding ongoing significance through our own interpretative language use and I acknowledge this within my own stance towards the research.

IPA is an experiential and phenomenological approach to qualitative research, and as such acknowledges that language reflects the meanings attached to particular experiences, but also acknowledges that researchers are only able to get experience-close through their own engagement and interpretation of the participants interpretation. I have chosen to strive to understand each participant's world, remaining focussed on each individual participant in the context of their social relationships, history, culture, and interpretations of their understandings.

5.15.2 Epistemological Reflexivity. I acknowledge the fact that I may have had some influence on the research process and that my personal and epistemological standpoints as well as interactions with participants will have influenced the data collection and analysis. It is of additional importance to accept and recognise that the results of the analysis arise from my own interpretation of each participant's interpretations. In line with recommendations from Willig (2001), and through the process of reflecting on interactions and my own assumptions throughout the research process, I have therefore remained aware of how my interpretations have constructed meaning from the data. A discussion of other potential qualitative methodologies is provided earlier in terms of their ability to answer the research question and how each methodology may have given rise to a different set of analyses and thus, a different understanding of the phenomenon of study. Further, independent auditors were enrolled during the analysis in order to ensure interpretations remained grounded in the data, and to maintain a high degree of rigour and validity.

5.15.3 Methodological and Procedural Reflexivity. After each interview, I undertook a reflexive diary. This involved taking time to reflect upon the dynamics of the interaction and attempt to capture what was thought and felt throughout it in order to maintain transparency during the research process. I noted themes that piqued my interest, other events that happened during the interview and considered the role that I may have played in the data collection process. For example, any instances of shock were noted, as these episodes may have identified where I had held preconceptions about a topic. This aided me to bracket-off these assumptions and prevent them from occurring in future interviews, thus being open to the new. This section will review reflective concerns surrounding the development of the interview schedule, participant recruitment, the data obtained at interview, and the process of data analysis.

My first reflective concern focuses upon the participant recruitment process, during which I was available for potential participants to meet prior to inviting me to their homes for interview. This was done as a precaution for both the participants, and myself, but I do acknowledge that this may have had some effect on the potential participants' decisions to take part or not. Although each potential participant was given the opportunity to meet me before agreeing to take part, some chose not to, due to their own personal circumstances such as appointments, and instead contacted me at a later date through email. I found that when patients chose to meet me their choice to take part was made in a shorter amount of time, and interviews were often arranged there and then. Those who contacted me through email however, opted to take more time to consider their participation and this may have been for comfort reasons. Through meeting me first-hand some initial positive rapport with myself may have been generated, and may have enabled the participants to feel more comfortable discussing their experiences with me. Those who did not meet me prior to interview may have chosen to withhold information as a result.

In the development of the interview schedule, my assumptions will have undoubtedly played a part. My own lack of experience of being spinal cord injured and living with chronic pain present may have created some naivety towards the experience. Although I aimed to remain objective towards the experience during interviews, my influence may have manifested itself in the material I chose to follow up with prompts and as such, influencing the participants' responses. Had I the personal experience of a SCI myself, I believe the interview questions may have been different, and as such may have elicited rather different material from participants. A further reflection on the interview schedule is the number of questions provided. I initially felt that the six questions may not be enough to base an in-depth discussion upon, but subsequently found that participants were more than willing to discuss their experiences. In fact, after the first question, I was hardly required to go back to the interview schedule, which may also reflect the participants' desires to be able to tell their stories.

It may be argued that the product of the interviews is a result of the relationships between myself and each participant, in that the phenomenon manifested itself in particular ways due to the interactions. Aside from the development of the interview schedule, I may have influenced the interview myself, in asking participants for further information on topics they may have touched upon that were of interest to myself. Further, during my first interview and throughout subsequent interviews, I noted feelings of surprise at certain comments made by participants often relating to the ineffectiveness of medication, or their refusal to take medication. This highlighted an assumption on my part, and it is not until I reflected on this feeling of surprise that I came to understand that I may have previously assumed that people with SCI and subsequent chronic NP would be taking some form of pain medication. Although knowing and understanding your assumptions plays an important role in IPA research, Finlay (2002) argues that our assumptions are the basis of our understanding, and as such we are unable to truly know and step away from them. A beneficial result of this reflexivity ensured that I became more aware of the strength of previous assumptions and their potential influence upon the data already collected, and future data.

The process of data analysis itself was long and tiring, constantly moving between part and whole, between individual and group, required greater commitment than I had previously anticipated. It was a lonely process, particularly as I had a lack of direct access to anybody with a more in-depth, practiced understanding of IPA. On reflection, it may have been possible to create a similar piece of work using fewer participants and have an analysis with more depth than breadth, as at times during the analysis I felt positively overwhelmed. Multiple times during the analysis stage I felt a need to step away from the transcripts, essentially ‘taking a breather’ of a week or so, in order to be able to go back to the analysis with renewed enthusiasm. Finding the balance between presenting fine detail as well as a comprehensive overview of the participants has been difficult, made easier by the seemingly agreeing experiences of each participant with one another.

5.15.4 Analytical Reflexivity. When it came to assessing and improving the quality of my analysis, I was faced with the option of member-checking, in which various aspects of the data may be taken back to the participants in order to validate the research. It is my belief that the consequences of member-checking outweigh any potential benefits. I therefore chose not to engage in any member-checking, for reasons I will explain here.

The first option is communicative validation, in which participants ‘validate’ the first meeting (interview) in order to confirm their speech. I chose not to engage in this due to the nature of the interviews. All participants spoke negatively of the biomedical approach in particular, and, whilst participants may have felt at ease and during their interview, when faced with their transcript they may be shocked to read what they said when in the moment. Additionally, the transcription included linguistic features such as false starts, pauses, and minor utterances, which participants may have wanted to change in order to save face and to come across in a more socially-desirable way.

Second, was the option of taking the full interpretation back to the participants in order to confirm themes. I decided against this form of validation, due to time constraints and the complexity of the procedure. Additionally, this form of validation concerns me; participants are not in the phenomenological attitude and therefore less likely to understand the concept of IPA and its interpretative nature. Participants may potentially dislike or disagree with the themes; the nature of the themes may provoke participants to ask for themes and/or their quotes to be changed or reworded. Giving participants the opportunity to bias their experience does not reflect the truth of the experience, and it may be unethical to lose such truth.

A final, and perhaps most concerning, reflection for myself is upon my interpretations of the data provided by participants. This reflection arose during the interview process, where multiple participants requested a copy of the report when it comes to publication. I believe that my interpretations, whilst remaining grounded in the data, may go beyond the understanding that the participants may have had of what they were saying at the time. Participants were recruited from the same specialist spinal injuries unit, and often chose to discuss their experiences of care with healthcare professionals from in and out of the unit. Often, these experiences were negative, and as such, interpretations may reflect negatively upon the medical profession. Whilst this study aims to improve care and pain management for people with NP post-SCI, I have remained wary of my interpretations, attempting to interpret interviews sufficiently, whilst also taking care so as not to cause offence to participants, nor to undermine medical staff, should either group disagree with me.

However, instead of member-checking, I engaged with two independent auditors to assess the rigour and validity of the results, a process that I felt was extremely helpful and beneficial to the analysis. I take comfort in the fact that the final results were agreed upon by two experts, one of whom in chronic pain, the other in spinal cord injury, and that these results therefore reflect efforts to reach a combined understanding of the experience, and reflect that understanding. I believe that these interpretations are valid and realistic, appropriately reflecting what it is like to live with NP after spinal cord injury.

5.15.5 Concluding Reflexivity. I have engaged in reflexivity throughout this project, at the stages of planning and designing the research, participant recruitment, data collection, analysis, and I will continue to reflect here upon how I have been implicated in the process. I have attempted to become as phenomenological as possible throughout the interpretation of the data and the write-up of the results in order to enable an unbiased interpretation that remains grounded in the data without being influenced by my pre-judgements or preconceptions.

Throughout the process of this research, I have become continually aware of a newfound respect and appreciation for qualitative research, and myself as a qualitative researcher. Following my undergraduate degree in psychology, and my year working in a spinal unit, a typically positivist environment, I have found this venture into qualitative work exciting and scary at the same time. Prior to setting out onto this work, I found myself unquestioningly embracing the positivist approach, preferring numbers and causal laws for human behaviour. However, using IPA in particular has shown me that this qualitative approach complements quantitative work and can open up a multitude of new avenues for further research through its engagement with the idiographic, and phenomenology. I engaged in many tasks in order to assess quality and rigour throughout the process and feel as though this research is a solid project with real-world meaning and applicability.

One reflection upon the process of analysis and writing up the results is that pain is very much a subjective experience that is also contextual, and may change daily. Whilst I had gathered data on an experience common to all participants, that data was based upon a single snapshot in time, the moment that the interview was being carried out. Indeed, participants spoke of past experiences of their pain and their beliefs about the future, but the way they framed their experience appeared to be very much dependent on the state they were in at the time of interview. One participant actually stated that he was having a good pain day and that if he was having a bad pain day his account would have been different.

Furthermore, from my own experience of the interviews and analysis, and from the themes that emerged, I know that it is not possible for me to fully understand the experience, but that those with SCI want to be understood. This tells me that the research is of value in illuminating our understanding of NP after SCI, and that the participants took part in order to aid me in reaching my goal of improving current understanding. I have been privileged to reach an extended understanding of the experience thanks to this research, and have changed the way I think about the experience as a primarily biomedical one, through immersing myself in the participant accounts. I hope that this research will illuminate the understanding of those who play significant roles in the well-being of those with, such as HCPs, friends, family, and researchers alike.

I am consciously aware that I attempted to put my assumptions to one side, subsequently after realising them. Whilst I tried to do this to the best of my ability, this was a difficult task, and I acknowledge that these assumptions may have influenced the way I interpreted the data, and that differing results may have been reached by another researcher. However, engaging in the quality checks with two independent auditors (IA), who also had previous experience with chronic pain patients and patients with SCI, enabled me to feel comfortable with the themes that have been reached, and to know that these are personally and clinically relevant to the population.

The final write up of the results took six drafts to reach, until I finally felt some sense of gestalt, or ‘good enough’ interpretation of the data. I hope that this is reflected in my write up and that the reader sees the conceptual interpretation grounded within the data. I hope that the reader can recognise the effort that I have put into continually reflecting upon the research process and to disentangle the experiences. As a result of this work, which has been undeniably rewarding, in terms of the results reached and my own personal development as a researcher, I believe I can unquestionably say that I am very much looking forward to beginning on my next journey with IPA.

Chapter 6 **Study Two: The Experience of Neuropathic Pain after Spinal Cord Injury in a Rehabilitation Setting**

With regard to neuropathic pain in the acute phase of SCI, early identification of coping strategies used, and how they impact psychological functioning, may be beneficial for successful pain management (Nicholson Perry, Nicholas, & Middleton, 2009; Wetering, Lemmens, Nieboer, Huijsman, 2010). In one study, 70% of patients reported that neuropathic pain had started within six months of injury, with 23 of 50 patients reporting no pain-alleviating factors (Celik, Erhan & Laske, 2012). However, little research exists which examines pain in the acute phase of SCI, and there is much variability with regard to the prevalence of pain, which varies from 20% to 59% of the population (Burke, 1973). Neuropathic pain also has distinct variability over time, with its incidence decreasing by discharge, but often returning to inpatient frequency at one year post-discharge (New, Lim, Hill & Brown, 1997).

In contrast to outpatients, inpatient coping strategies appear to differ. Catastrophising is one such coping strategy that has been questioned with regard to its prevalence in inpatients (Nicholson Perry, Nicholas & Middleton, 2009). Taylor et al. (2012) studied the coping strategies of inpatients up to one year post-SCI, with chronic neuropathic pain, and a 7-day pain intensity rating of three or above on a visual analogue scale. Their results suggest that pain severity, and coping strategies adopted by inpatients remained stable from two to twelve months post-SCI. Pain intensity was positively correlated with life interference, suggesting that, as inpatients came closer to discharge and better able to carry out general activities, pain may be more able to interfere with their lives. Catastrophising was not prevalent, suggesting that something about the inpatient experience of pain may differ from that of outpatients.

The results of previous studies, as well as the results of the preceding outpatient study, appear to suggest that the experiences of neuropathic pain after SCI may differ between in- and outpatients, due to the different available influences upon their experiences. For example, outpatients identified a theme of feeling socially isolated. This may differ for inpatients, who may not be surrounded by their friends and family, but spend more time with others with SCI as well as staff who may be experts in SCI. By understanding the experience of neuropathic pain of inpatients as well as outpatients, it may be possible to identify how pain differs between the two groups, which pain management strategies may be of most use to each group, and to map how pain may change over time for those with SCI. The evidence presented here suggests a need for a more complete understanding of the experience of chronic neuropathic pain as an inpatient, and how it differs from the outpatient experience, in order to develop interventions targeting the specific aspects of each stage of the injury.

6.1 Research Aims

Study two aims to fill the gap in the literature base, by offering a more complete understanding of neuropathic pain after SCI. This study will, therefore, explore the experience from the inpatient perspective, and examine convergences and divergences in these experiences, through the use of IPA. This experience may differ for inpatients who, unlike outpatients, have direct access to healthcare professionals such as doctors, psychologists, and physiotherapists, and are likely to spend more of their time with others with SCI. They also do not yet have the experience of reintegrating back into the community post-injury. Pain, therefore, may have some impact on different aspects of life as an inpatient.

6.2 Research Questions

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

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

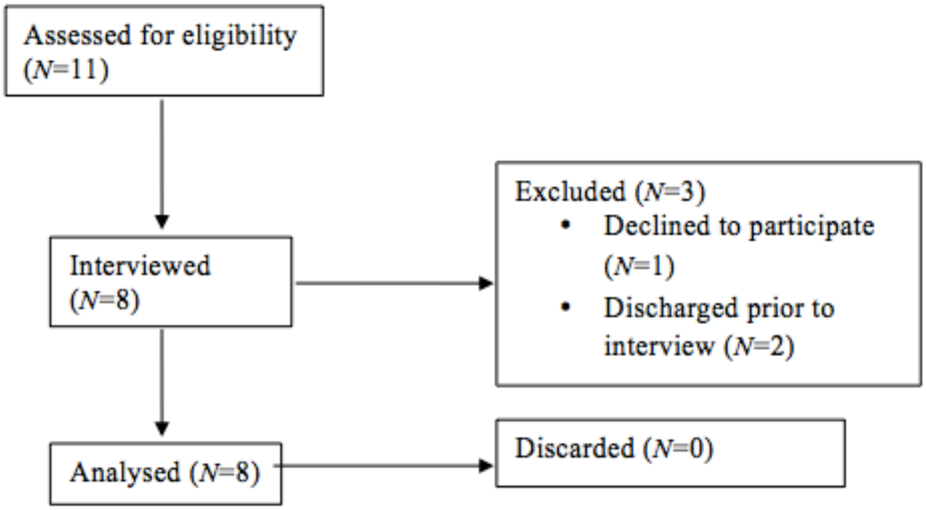
6.3 Procedure

6.3.1. Design. Exploratory, qualitative, interviews were conducted with inpatients in a rehabilitation unit with chronic NP after SCI, and analysed using IPA.

6.3.2. Participants. Participants for the inpatient study were recruited from The National Spinal Injuries Center, Stoke Mandeville Hospital, Aylesbury. Inclusion criteria were as follows: over 18 years old (no upper age limit), inpatients of The National Spinal Injuries Center, spinal cord injured for a minimum of three months, suffering with chronic NP for a period of over three months, and sufficient understanding of the English language, due to the nature of the interviews and qualitative methodology. Exclusion criteria were the same as those of the outpatients: presence of 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 inpatients were recruited, a sample size considered acceptable for this study (Smith, Flowers, & Larkin, 2009). All participants were in the spinal unit for the purpose of rehabilitation, two of whom had been transferred to the spinal unit for rehabilitation following initial care at a different, non-specialist hospital. All but two of the participants (David and George) indicated that NP interfered with their rehabilitation. The nature and timescales of the interviews allowed for abundant data generation and experiential richness, such that fewer participants needed to be recruited. A consort diagram showing the process of recruitment is shown in Figure 6.

Figure 6. Inpatient Consort Diagram.



6.3.3 Situating the Sample. Appendix A provides contextual details of each participant's individual circumstances. These are provided in order to situate each participant and illustrate how each interview was made unique by each individual's experience. Table 6 presents demographic information.

Table 6. Inpatient Demographic Characteristics.

Participant*	**Age**	**Employment status**	**Marital status**	**Cause of injury**	**Time since injury (months)**	**Level of Injury**	**Completeness of injury (ASIA Impairment level)**	**Pain location(s)**	**Average Pain Intensity (NRS)**
Jimmy	71	Retired	Married	Fall	12	C6	Incomplete (C)	Left arm, hands	8
Alice	23	Unemployed	Single	RTA**	14	C3-C4	Incomplete (C)	Whole body	10
Amir	69	Retired	Married	Non-traumatic	10	C3-C5	Incomplete (C)	Right side & arm, feet	4
Jennifer	63	Full-time	Married	Fall	9	C5-C6	Incomplete (B)	Shoulders, chest	10
Deb	80	Retired	Widowed	Fall	10	C4-C5	Complete (A)	Whole body	3
George	82	Retired	Widowed	Non-traumatic	4	T5	Complete (A)	Legs	7
Mark	51	Full-time	Married	RTA	4	C2-C4	Incomplete (B)	Shoulders, arms, hands	3
David	40	Full-time	Married	Traumatic	5	C6	Incomplete (B)	Neck, arms	2

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

6.4 Materials

Letter of invitation (Appendix B). Inpatients received the same brief, essential information letter regarding the study as outpatients. This invited those interested to request further detailed information from the researcher.

Participant information sheet (Appendix C). This provided further detail of the study specific to inpatients, including potential risks and benefits, confidentiality, dissemination plans, as well as funding and ethical review information. Inpatients were then presented with the same materials as outpatients. These included the Consent Form (Appendix D), GP Letter (Appendix E), Friend/Family Member Information Sheet and Consent Form (Appendix F), and the Demographic Questionnaire (Appendix G). The same Interview Schedule was used to maintain continuity between the in- and outpatients (Appendix H). The same Debrief Form (Appendix I) was also given to inpatients upon completion of the interview.

6.5 Procedure and Interviews

The procedure for the inpatient study was almost identical to that of the outpatient study. Staff working on the inpatient wards provided those meeting the inclusion criteria with a letter of invitation to the study to read during their inpatient stay. 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, or visited on the ward by, the principal investigator (Jasmine Hearn).

Inpatients had the same opportunities as outpatients to ask questions regarding the study, and to discuss any concerns with the researcher. The potentially distressing nature of the interview was discussed, and participants were aware that they could have a friend or family member present during their interview, should they desire. 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. The locations of interviews were in either a private office in the rehabilitation centre, or in patients' rooms if they were private.

The participants read and signed two consent forms confirming their understanding of the study. Both were counter-signed by the principal investigator. 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 read a participant information sheet specific to their role during the interview, and signed their specific consent forms in order to confirm their understanding. The participants, prior to the interview taking place, then completed a short demographic questionnaire. Those with reduced motor control were assisted in completion of the questionnaire by the researcher.

Interviews then took place following the same interview schedule used for outpatients. This was to ensure consistency, and to be able to validly explore the experience from the two time points with as few confounding questions as possible. However, the researcher did remain aware that, due to the difference in the two groups, new, unanticipated topics may have been discussed. As such, brief notes were taken throughout interviews, and unanticipated subjects probed using open questions for further elaboration. Interviews lasted between 40 minutes and 60 minutes, such that there was minimal disruption to the rehabilitation schedule.

6.6 Ethical Considerations

The study was granted full ethical approval for the inclusion of inpatients as a second participant group by The University of Buckingham Research Ethics Committee, The National Spinal Injuries Centre Research Ethics Committee, London Bloomsbury Research Ethics Committee (ref: 13/LO/0558), and the Buckinghamshire Healthcare NHS Trust Research and Development Office.

Participants were fully informed of the research prior to giving the researcher their consent. Ample time and opportunity to consider involvement in the study was offered, participants were reminded of their right to withdraw at any time, without giving a reason, and that this would not affect their standard care in and outside of the rehabilitation center. No physical risks were anticipated, and efforts were made to accommodate participants' preferences and restrictions, such that accessibility was maximised, and participants were comfortable.

All interviews were conducted in a private room in the rehabilitation unit. Participants were offered the choice of having a friend or family member present during their interview due to the sensitive nature of the interview. The effects of the interviews upon participants were continuously monitored in order to regulate any potential avenues for distress to occur. Breaks from the interview were offered regularly, as well as opportunities to offer as much or as little detail as they felt necessary. Reminders of their right to halt the interview were also provided. Verbal debriefing was provided post-interview to ensure that the participant was happy with the interview and to monitor for any adverse negative effects. The written debrief form was also provided.

Interviews were audio recorded with the consent of the participants and transcribed verbatim, at which point all patient identifiable information, place names, and other people identified by the participant, was changed to preserve anonymity and their corresponding transcribed interview data files were stored in the same manner as the outpatient data.

6.7 Analytic Strategy, Interpretation, and Quality Checks

This study utilised the same systematic analytical strategy, interpretation, and quality checks to ensure rigor as those described and used in the outpatient study (see page 94).

6.8 Inpatient Results

The key emergent themes fell under four superordinate themes: ‘The Spectrum of Medication Experience’, ‘Interpreting the Hospital Environment’, ‘Thinking About the Future’, and ‘Using Metaphors to Describe Neuropathic Pain’. Each participant voiced a minimum of three superordinate themes, each of which will be discussed in further detail here. Superordinate themes were considered prevalent if they were voiced articulately by at least half of the sample (Smith, Flowers, & Larkin, 2009). Table 7 denotes which themes each participant articulated. Participants spoke of varying aspects of the pain experience, from the impact of medication, both positive and negative, to the hospital context, including the benefits of having expert staff nearby. The data obtained contributes to a deeper understanding of the experience of inpatients, whilst also offering insight into the convergences and divergences of experience. A master table of all emergent themes arising in study two can be found in Appendix N.

Table 7. Master Table of Presence of Superordinate Themes for Inpatients

	Jimmy	Alice	Amir	David	George	Mark	Jennifer	Deb
The Spectrum of Medication Experience	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥
Interpreting the Hospital Environment	🟥	🟥		🟥	🟥	🟥	🟥	🟥
Thinking About the Future		🟥	🟥	🟥	🟥	🟥	🟥	🟥
Using Metaphors to Describe NP	🟥	🟥	🟥	🟥	🟥		🟥	🟥

This is a list of themes most prevalent, and considered most important to the sample. Themes incorporated a number of factors, reflecting the various avenues in which pain impacted upon their lives. Each super- and subordinate theme will be discussed in turn, and presented with quotes representative of the themes.

6.8.1 Superordinate Theme One: The Spectrum of Medication Experience.

The first superordinate theme presented here is one that was strongly articulated by all participants, illuminating participants' experiences by providing evidence for the failures of medication to manage their pain. Six participants felt that their medication was ineffective, with pain often worsening after taking it, but that they would continue to adhere to their drug regime despite this. On the other hand, two participants had found satisfactory pain relief in their medication, without any worries of side effects.

Inpatient participants were in the early stages of their rehabilitation and did not raise any extensive discussion of psychological pain management techniques. This superordinate theme, therefore, focuses upon the use of medication as a primary pain management technique.

Table 8. Master Table for ‘The Spectrum of Medication Experience’

	Jimmy	Alice	Amir	David	George	Mark	Jennifer	Deb
The Spectrum of Medication Experience	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦

Six of the eight participants felt that there were issues with their medication regimes, often articulating that the management of their pain was inadequate. Some participants felt that pain management was a trial and error process, and may have believed that they would obtain adequate pain management before discharge. However, for many, experiences of medication were defined by fears of side effects, and often increases in pain. Jimmy was desperate for any form of beneficial pain management, but experienced a worsening of pain: **“***But the doctors yesterday, he’s put me on extra painkillers … I had an injection about five days ago to kill the pain in my left shoulder, but it’s actually got worse!”***.** He also discussed his desperation: *I’m prepared to try anything that they give me. I’m desperate for anything that can help … It’s curable for a short amount of time but not permanently.***”**

Jimmy discussed the fact that he had been prescribed increased doses of his pain medication, as a result of a desire to reduce his pain. The extreme nature of his pain caused Jimmy to desperately seek out anything that may potentially help. The tone of shock in the quote *"it's actually got worse!"* suggests that Jimmy had, perhaps, expected the injection to be more effective than tablets alone, and thus this expectancy may reinforce a dissatisfaction with current pharmacological pain management.

Alice's concerns with medication also arose from her perception of its ineffectiveness. However, she continued to take medication, despite such ineffectiveness, as a result of having no other options:

> *One weekend they gave me my tablets to go home, they gave me some stuff, you have to take 20 mls every four hours, and, I ended up drinking a whole bottle [. .] when I was in so much pain … I was just like "give me it" and drank it all, whole bottle, which I shouldn't have but, like I say, it didn't really have much effect. I was desperate.* (Alice: page 4, lines 79-84)

Alice described a particular event that highlights her perception of her medication as ineffective, discussing a home visit during which her pain intensified. This caused her to take extreme measures, self-medicating by taking a whole bottle of medication rather than her prescribed dose, in a desperate attempt to relieve the pain. As if her perception of ineffective medication is not enough to cause her distress, Alice was also subject to side effects causing her tiredness: "*When I first took OxyContin, I was bedbound for a whole week. I had no energy. I was out of my face. Literally I was in a daze … I was sleeping all day, it was horrible."* She discussed feeling *"out of my face"*, which may be similar to feeling drunk, or unable to control her thoughts and/or actions.

Such experiences appear to have led her to believe that there is no particular medication that could help her to manage her pain, a conclusion that has also been reached by the staff involved in her care: "*There's no more medication that can help … They [staff] don't want to give me any more [laughter]. I don't want to take any more.*"

Amir articulated similar thoughts to Alice; medication did not manage his pain adequately. He also voiced concerns that medication might be an inappropriate method of managing neuropathic pain:

> *I've been given this tablet called Gabapentin, and I don't know, but the after-effect of that seems to be worse. While taking the Gabapentin, I'm still in pain, it still hurts to move my hand, and the tips of the fingers still have a burning sensation.* (Amir: page 2, lines 33-35)

> *Somebody else would take some aspirin, take this, take that … eventually it wears off, and they take another one. Maybe in a fever, things like that, I can understand medication. For chronic pain, medication is different. You think "it's only for a day", and the next and next day, you can't keep on taking it.* (Amir: page 5, lines 99-102)

Amir's first quote illustrates his expectations of medication; to reduce pain completely. However, his expectation is not met, suggesting that he finds it inadequate if it fails to reduce pain entirely. His second quote suggests that managing chronic pain is different, compared with temporary illness such as a fever, which may suggest that he perceives medication as a temporary measure. This may be due to the fact that it *"wears off"* after a period of time. He voiced that, in order to manage pain, he would need to continuously take medication, day after day, suggesting that he is in disagreement with analgesic use in the long-term, and that he sought a management technique that offered more permanence in reducing pain, without the potential side effects.

George also voiced concerns regarding his perception of ineffective medication, whilst also suggesting that he had not been prescribed pain medication specific to his NP:

> *They don't know what to do to stop the pain. There's just not a painkiller on the market for this sort of pain. It's not as if you can take an aspirin or, like the old days, or paracetamol. They don't work, don't touch it.* (George: page 4, lines 71-73)

> *When I'm in really bad pain during the day I get it, I've thought oh I really need a painkiller. The first thing they give you, or the only thing they can give you, is paracetamol. And I've gone on and on with this type of pain, till it's gone away, because the paracetamol won't touch it. I've been all night like that with pain, till the next morning.* (George: page 4, lines 77-80)

In order to manage his pain, George's care team appeared to be relying on paracetamol, rather than any other medication aimed at managing NP. George appears to think that this reliance is because paracetamol is the only available option for his pain. However, despite the current pharmacological treatment's inefficacy and his diagnosis of NP, it appeared as though George has not been offered any other form of pain management. He stated that *"they don't know what to do to stop the pain",* suggesting that he may think that there is no other option to manage the pain. This may contribute towards a perceived a shortfall in staff knowledge of appropriate pain management, and a reinforced belief that he just has to live with the pain.

In the middle of the spectrum, two participants, Jennifer and David, acknowledged both the benefits and drawbacks of medication, without placing an emphasis on reliance or ineffectiveness, as other participants had. Whilst some participants articulated feelings of negativity towards medication, Jennifer felt resigned to medication as the main, or only, source of pain relief. When asked how she manages her pain, and how she feels about taking medication, Jennifer responded: "*Nothing I can do really. Just have to take tablets."* And: "*I don't like it, I take a lot. I don't like it, but, you just have to take it. If you didn't you'd be a screaming loony. Well you would, because you couldn't take the pain."* Jennifer discussed feeling as though she has no other option but to take medication for pain relief, and if she chose not to take medication she would be unable to cope with her pain. Whilst Jennifer felt as though there was nothing else that she could do in order to manage her pain, she was resigned to taking medication as her only hope, in order to prevent her from becoming a "*screaming loony".* Such a powerful implication suggests that Jennifer may worry about how her pain and emotions may cause her to be perceived by others if she chooses not to medicate, therefore acknowledging that she was resigned to medication in order to protect her identity.

On the other hand, David felt indifferent towards medication. He felt able to manage his pain without it, but also open to the possibility of taking medication that might reduce his pain completely:

> *If someone could turn it off then it would be great but I'm reluctant to take too many drugs because I'm already taking so many here. So, a drug that had very little side effects, I'd consider it, but there's always side effects isn't there? So I*

> *think long and hard before I take medication. I don't think it's at the stage where I'd think about asking for anything. I'm not taking any medication for the pain.* (David: page 1, lines 20-24)

David's openness to medication occurred alongside a reluctance, arising from his concern regarding potential side effects. For him, an ideal compromise would encourage some adherence to analgesic if it were to reduce his pain completely, though he acknowledges that this is an unrealistic expectation. David suggested that his pain intensity may need to reach a certain point before it would justify the use of pharmacological treatment, thus he felt able to prioritise his physical and psychological well-being without having to compromise these for pain relief. This statement and the tone in which it was spoken appear to suggest that he held an impartial or resistant view of medication. However, such a view may have implications for his pain management and the impact of NP on his daily life.

For Mark and Jennifer, however, taking medication appeared to be a beneficial means of pain management, allowing them to triumph in their pain management:

> *I've been very lucky that the consultant has given me quite a heavy dose of long-term release medical prescription. I can also have morphine, you know liquid morphine, as and when I need that, every four hours. So the pain relief has been good.* (Mark: page 1, lines 2-5)

Mark was comforted in his own drug regime, and the ability to take strong medication as and when he needed it. He voiced faith in medication for pain relief, and was thankful to his consultant, who provided him with the ability to manage his pain when he needed to by prescribing morphine.

Overlap occurred within the spectrum, which allowed for Jennifer's experience to acknowledge the benefits of medication, whilst also feeling resigned to taking it. In the quote presented in the previous theme (page 197), she stated that medication prevents her from becoming a "*screaming loony*", emphasising that, despite her dislike of medication, it does offer some value. Jennifer and Mark, however, were the only participants to acknowledge the benefit of taking medication, and their views were outnumbered by those who thought negatively of medication, and whose ability to cope was unaided by it.

This theme highlights that, whilst there are varied experiences, and that pharmacological treatment may be beneficial for some people with NP, there is apparent agreement in the perceived lack of efficacy of such treatments. Unmet expectations and side effects were common issues contributing towards the aversion of medication as a pain management tool. This consequently emphasises the continued need for pain management approaches that do not necessarily rely on medication, and embrace the biopsychosocial approach.

6.8.2 Superordinate Theme Two: Interpreting the Hospital Environment. The second superordinate theme that arose concerned participants' interpretations of the hospital environment and the people within it. Making sense of the hospital environment appeared to be of meaning to participants, potentially facilitating, or hindering adjustment. Some participants interpreted their surroundings negatively, feeling trapped, whilst others perceived it positively. Further, there were differences in participants' perceptions of staff and their purpose within the hospital context. These interpretations may have affected the extent to which participants were able to cope with their pain and SCI.

Table 9. Master Table for 'Interpreting the Hospital Environment'

	Jimmy	Alice	Amir	David	George	Mark	Jennifer	Deb
Confinement in Prison vs. Shelter in a Safe Haven	■	■			■	■	■	■
Primarily Positive Perceptions of Staff	■	■		■	■	■	■	

6.8.2.1 Subordinate theme one: Confinement in prison vs. Shelter in a safe haven. Those who perceived hospital negatively, felt confined within the four walls of their rooms or wards, holding a desire to escape or to leave as soon as possible. Those who considered hospital a safe haven, felt safe and comforted by the presence of other inpatients and knowledgeable staff. Jimmy was negatively affected by his interpretation and experience of hospital:

> *Getting out of this ward would be important. I mean, it's like being in a cell, 24/7. I know the staff are very good, but like [. .] how often are you going to see the staff? You know, they're busy themselves ... The nurses are running around, like all the time they're here. They don't stop.* (Jimmy: page 6, lines 131-134)

Jimmy likened hospital to a prison cell, indicating feelings of being trapped, almost as if against his own will. He acknowledged that staff were helpful but also that they are under their own work pressure. Such constraints upon staff may mean that they were unable to offer the adequate support for Jimmy needs, thus leaving him feeling alone. This may have left him feeling unable to burden staff further, which may have reinforced his negative perception of hospital. He emphasised this image further, when discussing heaven and hell:

> *And you do wonder if there is a heaven, or a hell, or a purgatory. So you go to purgatory to pay for your sins, before you go to heaven. So I do wonder if this is my purgatory sometimes, the pain, and being trapped here. But.* (Jimmy: page 8, lines 177-180)

Once again, Jimmy discussed feelings of being trapped, likening his pain, and these feelings of entrapment in his hospital cell to purgatory, as though the combination of neuropathic pain, and being in hospital was a form of temporary punishment. This quote provides evidence for the potentially damaging effects of pain upon religious beliefs (and vice versa). Consequently, pain may compromise both psychological well-being and ability to cope with pain and SCI. Jimmy felt as though his SCI, pain, and inpatient stay were punishment that he is required to suffer in order to pay for his sins. He ends his quote with the word *"but",* which suggests that there is more to be said that Jimmy chose not to vocalise. This may imply that he felt resigned to his entrapment, but may have not wanted to discuss the issue further.

Deb was another participant who interpreted hospital negatively, and articulated physical and psychological consequences:

> *The last couple of weeks I've been very depressed. With being stuck in hospital, lying in bed all the time. It just depresses you being stuck in hospital. You can't do anything. Just lying in bed [. . .] and with the pain too, it just cripples me.* (Deb: page 4, lines 84-87)

Deb discussed feelings of depression occurring as a result of being *"stuck in hospital"*, as though she was physically trapped, unable to get out of bed, be active, and change her situation. The physical restrictions, combined with the occurrence of pain, caused her to feel as though she is crippled, weakened, or impaired in her ability to live life fully and independently, as she did before she sustained her SCI. Further, feelings of being crippled may have had a negative impact upon her identity. Despite the fact that rehabilitation aims to allow those with SCI to remain active despite the mobility issues associated with the injury, Deb appeared to appraise the hospital environment negatively, perceiving it to restrict such mobility, which consequently negatively impacted upon Deb's perception of her ability to be active and her psychological well-being.

On the other hand, however, some participants interpreted hospital as a safe haven, comforted by the idea that they were in hospital for a positive reason. For Alice, being in hospital was better than being at home, due to the immediate access to staff as and when she needed them. During the home visit described in the previous theme, Alice was provided with her regular medication, but when at home, experienced a particularly intense period of pain. Her desperation for pain relief resulted in self-medicating and risking her health, an event that may not have occurred had she been in hospital surrounded by expert staff. Here, she is quoted discussing why she preferred to be in hospital, and interpreted it as a positive place:

> *I am happy here though, I feel comfortable. Probably just knowing there are nurses around if I need them … at home, I do worry, like if something goes wrong, there's nobody there to help me cope with the pain.* (Alice: page 8, lines 165-167)

As a result of the event described, Alice felt more comfortable in hospital, in the presence of staff who were able to help her should she need it, a comfort that diminished her worry about being unable to cope with the pain. This quote suggests that Alice had a real fear of being alone and unable to cope with her pain.

Like Alice, Jennifer also felt safe in the hospital environment due to specialist knowledge:

> *I feel safe here. It's not like the other hospital. I didn't like the other one; they didn't know what to do for the pain. I like this one, they know what they're doing … They know about the pain.* (Jennifer: page 1, lines 4-6)

Prior to moving to her current hospital, Jennifer was in a general hospital, without specialist staff or facilities specifically for caring for those with SCI and with SCI-specific pain. Consequently, they may have been unable to sufficiently cater to her needs. Once moved to the specialist unit, where staff were knowledgeable and able to offer the care and management she required, feelings of safety were facilitated.

Another participant who felt that being in hospital was a positive experience was George:

> *This hospital is great, absolutely perfect this hospital is. Yep. They've dealt with spinal injuries in the past, this is what it was made for. They understand, you come here if you're in my condition because they expect it, they've dealt with it, and they can deal with it as and when you need it, any time of day.* (George: page 3, lines 64-67)

Despite not directly discussing the impact of the specialist unit environment upon his pain, George was comforted by the specialist nature of the hospital, and its reputation. The previous experience of the staff working in the unit was also a comfort, allowing him to feel safe. Further, being able to obtain help as and when needed *"any time of day"*, when it may not be possible to obtain such help outside of hospital, was another comfort to George, reinforcing his positive perception of the hospital environment. This is especially important due to the nature of SCI, and the immediacy with which help may often be required.

This theme illustrates that patients in inpatient settings not only interpret their care, but interpret the environment within which they are being cared for. Further, the nature of the patient's perceptions of the environment may pose risks to their well-being, particularly if such perceptions challenge their sense of identity and autonomy. However, many participants spoke positively of the rehabilitation environment, thus fostering a sense of safety and comfort. Such perceptions, however, may also be disadvantageous when it comes to discharge and community reintegration.

6.8.2.2 Subordinate theme two: Primarily positive perceptions of staff. The second theme regarding interpretations of the hospital environment involved participants making judgements about the staff, as to whether they were beneficial in facilitating coping with pain and injury, and the extent to which they held positive or negative relationships with them. This appeared to be mediated by perceptions of staff knowledge, empathy, and compassion. All participants who voiced this theme viewed staff in a positive light, although there were some differences in experiences and opinions. Jimmy was one such participant who held strong relationships with his care team:

> *The physio is good, at least you know the people are trying to help you, you know. They're so dedicated, the people that do it. They care, quite a lot actually, 100%. They're very good. It makes me feel better, they're supposed to be coming round today, and they can come round whenever you need them. I find them very*

> *good, and not only just the exercise they give you, it's the way they talk to you, they're very, very helpful. I've got very strong relationships with them; they're very good.* (Jimmy: page 4, lines 93-97)

The quote presented here is in stark contrast to his thoughts about being in hospital itself (page 201), suggesting that being in hospital may be made easier to cope with, providing that relationships with staff are supportive and facilitate the rehabilitation process and coping of those in hospital. His repetition of staff being *"very good"* serves to reinforce his appreciation of staff. Jimmy praised the staff for their compassion and dedication to patients, not only in providing physical care, but speaking to him like a person, despite his injury. By getting to know Jimmy personally, the staff were be better able to offer Jimmy the psychosocial support he requires, and therefore provide support that may not otherwise be directly available. This may further contribute towards reducing Jimmy's feelings of entrapment, and may aid in developing more positive perceptions of the hospital environment.

Jennifer further highlights that positive relationships with staff can facilitate coping with SCI and NP:

> *They're quite understanding about the pain. If I yell she [physiotherapist] stops straight away and eases me off. She knows how far to take it anyway so. She understands me and my body. The staff, they're all friendly. It's like being in a holiday camp really. If the nurses weren't very nice you wouldn't want to be here would you? You'd want to go home straight away. I mean I want to go home but, not 'til I'm better, it helps being here with the nurses being so nice, you know? But I can't say, I haven't got a bad word to say against any of them.*

> *Mm. And the doctors are good so, good experiences.* (Jennifer: page 3, lines 59-64)

Here, Jennifer discussed how her relationships with staff were beneficial in helping her to cope with her stay in hospital. Despite her desire to return home, positive relationships with staff helped her cope with her inpatient status, coping that may have been aided by the empathy and compassion offered by staff. Further, she found comfort in the personal knowledge that the staff have regarding her physical needs. Her comparison of hospital to a holiday camp emphasises an image of a happy, positive place, and her acknowledgement of her inability to criticise the staff in any way serves to reinforce the positive impact of strong relationships between staff and patients that may even venture into friendships.

Mark agreed that the staff were beneficial, but in terms of their specialist knowledge, rather than their relationships with patients:

> *When the doctor gives you pain relief, they're the experts. I don't go looking on the internet and muck about with what they're doing. There are a lot of young people in here who are challenging the doctors about pain relief, because they've been on the internet. And I'm thinking, "this is the best hospital in the UK, these are the best doctors in spinal" you know, why challenge them? They're there when you need them, and doing their best.* (Mark: page 9, lines 195-199)

Mark described how many younger patients researched their injury and methods of pain relief, leading them to question their healthcare professionals' choices, a practice that he disagrees with. He commented on the reputation of the hospital, and of the staff, who were, in his eyes, *"the best doctors in spinal"*. Thus, staff were perceived as experts, making informed decisions based upon their own knowledge and experience, and should not be questioned, not least by recommendations found online. Further, the fact that the staff are *"doing their best"* serves to strengthen Mark's belief that they should not be questioned, and that doing so would undermine both their authority, and their efforts. This evidence supports the value of patient-centred care.

Lastly, David suggested that there are some members of staff who are of great help to him due to their specialist knowledge, but also that there are some who are not as knowledgeable, and do not make effort to be a social support:

> *Some of the nurses and some of the HCAs [healthcare assistants] are fantastic. Some of them, I think they just don't know, they're the sort of staff that don't ask patients questions on a regular basis, so they don't build up a knowledge base, whereas some of them do, you can tell. They're supportive, and they come and do what they can when you need them.* (David: page 5, lines 98-102)

David's perception of what makes a good, helpful member of staff, is that they should have a strong knowledge base that enables them to provide adequate support to patients. On the other hand, an unhelpful member of staff does not have the specialist knowledge required to facilitate his rehabilitation. However, despite experiences with unhelpful staff who appear not to have the specialist knowledge required, his world-view of staff in general was not necessarily tainted, and he still observed them as sources of support. Despite David's perception of knowledge and experience as important for his care, social interaction, empathy, and compassion also appear to be offered by staff, and may still contribute towards empowering him and fostering adaptive psychosocial coping.

The importance of patient's perceptions of staff knowledge, empathy, and compassion, are highlighted by the emergence of this theme. Participants discussed the impact that such characteristics may have on their psychological well-being, and on their progress through rehabilitation, with positive relationships facilitating adjustment to injury, and ability to cope with pain, and with long periods of inpatient stay. The majority of those who discussed relationships with, and perceptions of, staff, articulated positive experiences. This highlight the beneficial influence of social interactions within inpatient stay. Such positive experiences may aid in the facilitation of adaptive coping and adjustment to both SCI and subsequent NP.

6.8.3 Superordinate Theme Three: Thinking About the Future. When thinking about their future, participants appraised their pain in a number of ways, each of which will be discussed here. Table 10 indicates which participants voiced which theme.

Table 10. Master Table for ‘Thinking About the Future’

	Jimmy	Alice	Amir	David	George	Mark	Jennifer	Deb
Thinking About the Future		🟫	🟫	🟫	🟫	🟫	🟫	🟫

Participants appraised their pain in a variety of ways. Some indicated a perception of uncertainty regarding the future of their pain and SCI, whilst others were more clear about their hopes. For Alice, pain had a number of consequences upon her well-being and identity: “*It’s not me; I’m not the same any more. I don’t like it. No.*” This then fuelled a desire for a cure: “*I’d love the pain to be cured, don’t want this for the rest of my life. I’d rather die. I don’t like to be reminded of this [indicating SCI].*” Alice also discussed experiencing a lack of choice in her experience:

> *I’ll have to live with the pain, don’t have a choice, but [. .] if it was on a four to five [on a VAS of pain intensity], then yeah, but a six is still strong. You can’t get rid of it, I couldn’t manage it any more than that, I’d be in bed.* (Alice: page 10, lines 220-222)

Initially, Alice discussed how the pain appeared to have changed her identity, with a perception of her pain state as undesirable and unacceptable, potentially fuelling unrealistic hopes for a cure for pain. She also suggested that the pain acts as a double-edged sword, serving as a reminder of her SCI. Feelings of hopelessness for the future are also evidenced in the quotes provided, in which Alice suggests that she has no choice but to live with the pain, followed by discussion of imposed conditions within which she would be willing to live with pain. Lower levels of pain intensity are deemed acceptable to live with, but pain rated at six on the VAS was suggested to be too high a level of intensity to cope with.

Like Alice, Deb felt forced to accept pain's current presence: "*Well you have no choice. You have to accept it. You've got it, and, other than the tablets, you've got no other way of getting rid of it. At the moment it's a permanent fixture."* She also discussed her hopes for the future:

> *But I just accept life one day at a time, and hope it improves, and if it doesn't [. .] well then I'm lumbered with it [laughter]. If you live day by day, accept what you've got, and make the most of what you've got.* (Deb: page 4, lines 87-89)

For Deb, the lack of pain management options lead to a consideration of living life *"one day at a time",* suggesting that she may feel able to live with NP in the future if she makes the most of what she has. Alongside this recognition of the potential for NP to persist, she remains hopeful for a pain-free future. Her use of the phrase *"well then I'm lumbered with it"* was framed as a joke, and appeared to be an attempt to make light of the situation, implying a dissatisfaction with pain's presence, but also highlights her uncertainty surrounding the trajectory of her pain.

Amir's articulation of this theme arose in a number of quotes that indicate his optimism regarding the trajectory of NP and SCI:

> *I just cut it out of my mind, ignore it. It still hurts, it still throbs, the impulses are going to make the body do something, I don't know what. But, there's nothing I can do, I just accept it, as part of, you know, getting back together again, getting the muscles working.* (Amir: page 3, lines 60-62)

His discussion suggests that he perceives the pain as an indicator of recovery, rather than something that might persist: "*I can't think of it being permanent, I'm quite positive about it … I guess I just accept it as a natural, healing process.*" Amir's quotes show repetition of his belief in pain as a form of healing, in that his pain is signalling physical recovery from the SCI, as well as complete reduction in pain. His use of comparisons and his inability to see pain as permanent suggests that Amir believes that pain is a temporary phenomenon, ceasing when the person has recovered from the injury: "*It's got to equalise somewhere, there's got to be a solution to get away from it. If you hit your hand, it will get better. If you uh, fall over, there will be pain but it gets better.*" This belief serves to reinforce his certainty that pain will not be present when he leaves hospital:

> *The pain won't be there when I get home. I'm certain that it won't … I think that by the time I leave, I'm getting better and better, and the pain will go away … It's not an unknown thing, it will go away.* (Amir: page 7, lines 143-145)

From Amir's perspective, there was no known reason that his pain should persist. Such determination and positivity regarding his pain-free future did not allow for any consideration of the potential for pain to persist, and thus may have allowed him to focus on rehabilitation, and preparations for the future. The confidence with which Amir spoke regarding this issue ascertained his confidence in his perception of pain as a sign of healing.

Jennifer also conceptualised her pain as a temporary presence, voicing uncertainty regarding its trajectory and coping with it in the future: "*And as long as it is a process to get better, I'm ok with it. If I've got to put up with it for the rest of my life I don't know what I'll do.*" Further discussion indicated her hope for pain to be temporary, but a recognition that it may persist: "*Haven't accepted it, just putting up with it … I hope it's more temporary for me. I hope so, I hope so.*" Jennifer felt able to accept the unpleasant experience of pain, as long as it was part of rehabilitation and a signal to recovery, and reiterated her hopes for it to remain temporary. Her chosen coping strategy is to *"put up with it"* but she also states that, currently, she does not know how she will cope in the future, should her NP continue.

Of the eight participants, two, George and David were open to the idea that their pain may persist beyond rehabilitation into community reintegration. This is illustrated by George: "*Yeah I've come to terms with it [pain], and I've come to terms that I'm going to go home, this same way, with pain.*" When asked how he thought pain would affect his future, if at all, he responded:

> *I don't know actually, well that's a thought isn't it? I've never, no never thought about it. I've been too happy in my mind and emotionally, to be going back home again, to my home, to even think about it. I really don't know. It's the unknown isn't it? I'm looking forward to it, but haven't thought about the pain side of it.* (George: page 5, lines 103-106)

When considering his discharge into the community, George voiced that, whilst he knew that he would be leaving the spinal unit with pain, its impact had not actually entered his mind when thinking about the future. George's quote indicates that his pain was not necessarily disruptive to his emotional well-being, and that focus on post-discharge adjustment may have overwhelmed any consideration of NP and his future. Although feeling unsure with regard to pain and his future, he remained positive, without using any fearful or worried language.

David discussed the impact of his own resilience on his perception of the future:

> *Because I'm quite a resilient person, you know? It's there, so what? It's not stopping me from moving on with my life, rehab is going well, I'm getting closer and closer to getting out of here and the pain has never stopped any of that ... Yeah, I'm resilient, it's part and parcel with living with SCI.* (David: page 3, lines 47-50)

> *I've accepted it, and I'm having to accept lots of things with an SCI. I realise it's not always possible to cure things. Just part and parcel ... Nothing's making me feel that this is going to really [. . .] affect my quality of life, you know? Beyond what is no longer physically possible, but I'm ok with that. It's not holding me back.* (David: page 4, lines 79-86)

David highlighted his own resilience as a factor that enabled him to move forward with his life, despite his uncertainty regarding NP and its persistence. He felt able to live his life well, despite the pain’s presence, acknowledging that cures are not available for every ailment, but that this is not necessarily a bad thing. He also acknowledged that NP may persist, but its non-disruptive nature meant that he remained able to engage with rehabilitation. He also indicated an acknowledgment that SCI may come with a variety of secondary consequences that he may now have to cope with; NP being one of them. Further, the lack of impact of pain and SCI upon his quality of life reaffirmed his uncertainty regarding NP and his future.

A variety of perceptions of SCI, NP, and the future are presented in this theme. The extent of interference of NP appeared to influence the perceptions of some participants, with many participants discussing hopes for a pain-free future, and others expressing uncertainty regarding their future. The fact that these participants were in the early stages of rehabilitation may have influenced their discussion of their future, and indicates that inpatients newly injured with NP have hopes and fears that may need to be considered in rehabilitation via educational intervention.

6.8.4 Superordinate Theme Four: Using Metaphors to Describe Neuropathic Pain. Six participants chose to describe how the pain felt, in an attempt to be understood by others. However, it appeared as though they struggled with this task, and all participants reverted to using metaphors, often likening their pain to something that might be understood by the interviewer, to demonstrate the intensity of their pain, or elicit a response from the listener. This suggests that NP may be particularly difficult to convey to others, and for both the sufferer and listener to understand, due to its subjective nature.

Table 11. Master Table for 'Using Metaphors to Describe Neuropathic Pain'

	Jimmy	Alice	Amir	David	George	Mark	Jennifer	Deb
Using Metaphors to Describe Neuropathic Pain	■	■	■	■	■		■	■

Alice illustrated her difficulty in describing NP: "*Never experienced anything like it in my life.*" She then resorted to listing a number of descriptions: "*I get fuzzing, burning, tingling … it stings … it changes all the time, it's never the same. Feels like something's crawling inside you, horrible.*" Describing her pain involved listing a number of adjectives and metaphors illustrating her difficulty in finding the descriptor most appropriate for describing NP, but also highlighting the multiple ways in which NP might be described. Describing her pain was a task made difficult by the fact that she had never experienced anything like NP before, and its fluctuating nature, therefore having nothing to compare it to: "*You can only explain so much of it, and there's a lot more to it than that, which I can't really explain."* It appears as though it is possible to describe the experience to a certain extent, with the descriptions provided sufficient to allow the listener to better empathise with Alice. The use of metaphors in this instance may help those without SCI to understand NP due to the likelihood of their own previous experience of being burnt or stung.

Jimmy felt that he was trapped by pain: "*I do wonder if this is my purgatory sometimes, the pain."* This suggests that Jimmy associates his pain with feelings of being trapped, causing him to question NP's purpose, and concluding that it acts as a form of punishment for personal sins. The quote illustrates the threat that NP poses to psychological well-being, and the potential suffering that may be induced. Further, it may be suggested that the comparison of pain to purgatory is a form of catastrophic thinking that may implicate itself upon his spiritual beliefs and fuel maladaptive cognitions.

Amir described pain using more metaphorical language, comparing it to previous pain he had suffered:

> *I mean, the pain is very difficult to explain. It could be discomfort, it could be an annoyance. It's like … you put your hand in snow and there's a burning sensation near to frostbite, like a needle, like somebody giving you an injection.* (Amir: page 7, lines 136-138)

Amir also articulated difficulty in describing his pain, suggesting that it may be a changing experience that requires different descriptions. Rather than attempt to describe NP in its own terms, he likens his pain to frostbite and injections, which he himself may have previously experienced. These may be used to compare NP with as the best way to illustrate the experience. Both metaphors are likely to have been experienced by the able-bodied, or are familiar clinical concepts that may be understood if the listener has not experienced the descriptors used.

Also using metaphor to describe the pain was George, whose quote elicits a more violent and intense image of NP:

> *Well it's like a pins and needles but like a more, harder, do you know what I mean? A bit more intense, more intensive pins and needles. And then you get like an odd thunder strike, as if lightning's taken your leg. You know, and they're the worst, but they go pretty quickly. There's [. .] it's a mixture, it's a mixture you know, pins and needles, lightning strikes, hot, hot knives, mm.* (George: page 1, lines 3-6)

This quote presents George's attempts to describe multiple facets of NP, with his struggle made clearer by his difficulty in articulating words, and his two-second pause, which may have been used to take a break and consider how best to explain his pain. His description began with pins and needles, subsequently graduating to include words such as *"intense"* and *"harder"* in order to illustrate that NP is much worse than pins and needles alone. NP was then compared to thunder and lightning in order to illustrate its intensity and sudden onset. This suggests that there may not be an adequate adjective for the purpose of describing NP, only graduated comparisons. Sean also used pins and needles: "*… pins and needles uh, is the best sort of comparison really.*" His use of pins and needles as a description also included acknowledgement of the need for comparison. The fact that Sean acknowledges this suggests that, again, there are no adequate descriptions, only comparisons.

Another instance in his interview involved George using metaphor to personify his pain as an attacker: "*It's like somebody's stabbing you all over, horrible.*" This description of an embodied pain 'stabbing' him further supports the notion of being a victim to pain. This also emphasises the sudden, forceful, and violent nature of his experience, and the severity and intensity with which NP is experienced. Further, the language used implies that NP may be perceived as an external, violent, and uncontrollable force that is likened to an attack upon the George's physical and psychological well-being.

Like Sean and George, Deb also described her pain as pins and needle like:

> *I don't call them pains really, it's all like pins and needles and, uh, a bit stronger than pins and needles, it almost feels like nails … In my body that pain is a bit different; it feels like an iron belt squashing me in, an inch around my tummy like an iron girder.* (Deb: page 1, lines 5-8)

Deb used the same example as George, and also graduated her description, going on to say that the pain is actually more like nails, which are thicker than pins and needles, and may potentially be perceived by the speaker as more painful, and therefore a better description. This illustrates that her pain may be more intense than what those without SCI experience as pins and needles. She also discussed feeling *"squashed"* in by her pain, as though a metal girder was squeezing her. This metaphor highlights how psychological distress may be induced by pain, and just how uncomfortable Deb may be in her body as a result of such pain, with the metal girder inducing feelings of tightness and inescapability. The purpose of such graduations in description may be to emphasise that pain can be even worse than his original descriptor alone. Such descriptions may be the best available to those with NP, even if they do not encapsulate the experience wholly and sufficiently.

The experience of NP was also likened to toothache: "*But uh, it's like having a continuous toothache that just will not go away until you go and get it fixed. But it's worse pain than a toothache, yeah.*" [Jennifer]. The comparison of toothache may be the best form of descriptor available to Jennifer. However, Jennifer states that it is worse than a toothache, but fails to offer further detail, making it difficult to understand the real extent of the intensity of her pain, and how it feels. Describing this experience, therefore, may be achieved to some extent, but a complete description may not always be possible. All of the quotes presented above indicate that NP is particularly difficult to describe, and that no adequate adjective exists for its communication.

6.9 Discussion

This second study aimed to explore the experience of NP from the perspective of inpatients in a rehabilitation unit. As a result of the analysis, four key super-ordinate themes emerged: (1) 'The Spectrum of Medication Experience', (2) 'Interpreting the Hospital Environment', (3) 'Thinking About the Future', and (4) 'Using Metaphors to Describe Neuropathic Pain'. A vast body of data was obtained, with results converging with, and diverging from, the experiences of outpatients. Each of the emerging themes concerns an aspect of the biopsychosocial model (Engel, 1977), with each one encompassing a biomedical, psychological, or social issue. Each participant articulated each theme from their own subjective context, implying that each individual's story should be acknowledged prior to embarking upon pain management, in order to gain some understanding of the unique needs of the individual.

The strongest theme, which was articulated by all participants, was in relation to the experience of medication. This theme resonates with the outpatients' experiences, and with Lofgren and Norrbrink's (2012) qualitative study, which found that pharmacological treatments were the only interventions for NP offered by HCPs. Their participants described being left to find their own pain management techniques, with little guidance. The perceived reliance upon ineffective medication discussed in the present study suggests that those with SCI-specific NP may welcome a collaborative approach with staff involved in their care.

Participants spoke of their active decisions to overuse medication in response to pain, even after acknowledging that it caused side-effects, and often did not work for them. The literature surrounding medication adherence in pain populations is scarce (Nicklas, Dunbar, & Wild, 2010), making it difficult to draw conclusions regarding outcomes and variables that influence levels of adherence. However, literature does suggest that non-adherence to medication, including over- and underuse, is common. A meta-analysis of 569 studies of adherence in patients with chronic conditions such as HIV, cancer, arthritis, sleep disorders, and pulmonary diseases, indicated an average non-adherence rated of 24.8% (DiMatteo, 2004). Pain populations, in particular, are less likely to adhere to medication (Broekmans, Dobbels, Milisen, Morlion, & Vanderschueren, 2009), with 92% of chronic pain patients reporting at least one side effect as a result of medication (Gregorian, Gwasik, Kwong, Voeller, & Kavanagh, 2010). Little is known about the adherence patterns of those with SCI-specific neuropathic pain. However, Gharibian, Plozin, and Roh (2013) explored adherence rates of non-SCI patients with NP, taking either antidepressants or anticonvulsants for pain relief. In each group less than half of the sample was considered compliant; 42.9%, and 43.7%, respectively, with 21.2% of the antidepressant group, and 21.4% of the anticonvulsant group considered to be persistent with their drug regime.

Participants in the present study engaged in intentional non-adherence to their pain medication, making comments suggesting that their personal beliefs regarding the need for medication, and the consequences of taking such medication, influenced their decision. One potential explanation for the variation in adherence is patient beliefs about the necessity of, and concerns regarding, medication. The Necessity-Concerns Framework (Horne & Weinman, 1999) quantifies patient beliefs about the need for treatment, and their concerns about potential consequences. Within this model, necessity beliefs and concerns are weighed against one another, with the chosen behaviour (adherence or non-adherence) resulting from the conclusions drawn. Increased adherence, therefore, would be aided by fewer concerns regarding consequences of medication, and a stronger belief in the necessity of treatment. Horne and Weinman's research found that demographic variables such as gender, level of education, and number of prescribed medications did not predict adherence. Instead, adherence was most strongly predicted by patient beliefs. Horne et al. (2013) conducted a meta-analysis of 94 articles of adherence and patient beliefs, finding significant relationships between both necessity beliefs and adherence, and concerns and adherence. This may help to explain why participants in this study chose to over- or under-use medication, and reinforces the need to take the patient's attitudes and values into consideration when discussing pain management options.

Some indifference towards taking medication was discussed in this study, as well as perceptions of medication as the only option. Such appraisals of pain may have contributed towards reduced adherence (Horne & Weinman, 2002). Further, over-use of medication appeared common, perhaps due to the increased perceived need for medication (Rosser, McCracken, Velleman, Boichat, & Eccleston, 2011). Such issues with adherence were also discussed alongside emotional responses to pain, which are associated with poorer adherence (Ross, Walker, & McLeod, 2004), suggesting that, for those with NP, there may exist complex interactions that determine medication adherence, and that each individual's beliefs and concerns should be appreciated when prescribing medication in order to maximise adherence.

With many of the participants voicing a dislike of medication and refusal to adhere, the issue of enabling patients to discuss this with their care teams then emerges. Fear of not being believed, or not wanting to burden care staff, and a lack of knowledge about treatment options, may be barriers to providing healthcare providers with complete information (Gagliese, 2009; Weiner & Rudy, 2002; Leavitt, Van Schepen, Kroustos, & Hartzler, 2012). The refusal to adhere to pain medication as directed due to such concerns may lead to serious consequences such as increased emotional distress and disability (McCracken, Hoskins, & Eccleston, 2006), lost opportunities for health, increased hospital admissions, as well as increased costs to healthcare providers via wasted resources (Horne, Weinman, Barber, Elliott, & Morgan, 2006). For those voicing a resistance to medication in this study, such barriers were commonly discussed, which may have played a role in adherence behaviours.

Whatever the reason, the emergence of this result suggests that such concerns may add to the burden of chronic pain to the patient and healthcare systems. Further, differences across experiences illustrate a need for improvements to be made in communication between patients and staff in order to facilitate a collaborative approach to pain management (Osterberg & Blaschke, 2005; Stavropoulou, 2011). This would offer patients informed choice, and improve the understanding of patient beliefs regarding medication. By listening to patient beliefs, it may be possible to address any issues or concerns, avoid the prescription of unwanted treatments, and enhance medication adherence.

Interpretations of the environment and staff appeared to be of importance in the pain experience, with positive interpretations apparently contributing towards positive mood and adjustment. Empathy and compassion from staff was an important theme here, but there exists little research surrounding patient interpretations of hospital environments (Lasiter, 2011), and thus it becomes difficult to make inferences from the data. However, there is some literature available to discuss this theme, which will be discussed here (see Burfitt, Greiner, Miers, Kinney, & Branyon, 1993; Fogarty, Curbow, Wingard, McDonnell, & Somerfield, 1999; Mollon, 2014; Olsen & Hanchett, 1997; Squier, 1990).

One interpretation participants made of the hospital environment was of the staff involved in their care, who they perceived as empathic and compassionate. These characteristics appear to play a significant role in encouraging a number of health benefits, such as treatment adherence (Squier, 1990), and reductions in anxiety (Fogarty, Curbow, Wingard, McDonnell, & Somerfield, 1999). The positive relationships with, and perceptions of, staff, described by those in the present study may contribute to feelings of being understood, which may subsequently reduce feelings of anxiety, depression, and anger. A questionnaire study by Olsen and Hanchett (1997) found negative associations between nurse-expressed empathy and patient distress, and between patient-perceived empathy and patient distress. This work is resonated by the present study, identifying empathy and compassion as important characteristics in staff. This suggests that the more empathy is offered and perceived, the better the outcomes for patients, and potentially staff.

Participants discussed feelings of being safe as important to their inpatient stay in hospital, which may be associated with coping strategies subsequently adopted. Feelings of safety in hospital may offer benefits in terms of improving patients' abilities to focus on recovery (Burfitt, Greiner, Miers, Kinney, & Branyon, 1993), and to obtain adequate rest (Granberg, Engberg, & Lundberg, 1999). Lasiter (2011) interviewed older patients and used Grounded Theory in order to explore what increased feelings of safety. Predictability was a core emerging theme that included nurse characteristics such as confidence, high education, the ability to recognise problems, quick reactions, and the necessary knowledge in case of emergency. Mollon (2014) found that factors such as trust, presence, and knowledge contribute towards a heightened sense of security in hospital. Such perceived expertise may motivate patient satisfaction and treatment adherence, allowing patients to achieve better outcomes from their care (Kim, Kaplowitz, & Johnston, 2004). Mollon (2014) also identified these themes in a recent concept analysis of patient feelings of safety, suggesting that they are prominent issues among those hospitalized, and that developing positive environments where patients receive high-quality care, whilst being made to feel safe, is of importance. The present study demonstrated that feeling comforted by immediate access to staff with expert knowledge is an important factor for inpatients after SCI. Thus, improving or maintaining high levels of staff empathy and knowledge may improve patient perceptions of safety, and their health-related outcomes. Further, it would be important to transfer feelings of safety to patients' homes following discharge, potentially through the adoption of peer-support programmes.

Participants in the present study indicated that the environment is important for physical and psychological well-being. The emergence of this theme, alongside previous work, suggests that *feeling* safe may be just as important as *being* safe (Lasiter, 2011). However, patient satisfaction during inpatient stay is rarely measured (Boev, 2012), despite its importance to patients such as those in this study. To this end, staff should attempt to improve their awareness of factors that promote patients' perceptions of safety, empathy, and compassion, particularly during an inpatient stay (Wassanaar, Schouten, & Schoonhoven, 2014), such as communication and rapport (DiMatteo & Hays, 1980), interpersonal manner, accommodation, quality of food (Shoenfelder, Schaal, Klewer, & Kugler, 2014), and friendliness (Boev, 2012), all of which are associated with positive outcomes and patient satisfaction. Feelings of safety should also be encouraged, as this can contribute to earlier recovery and positive health benefits (Lasiter & Duffy, 2013). The emergence of a theme surrounding the interpretation of the environment suggests that it is a key issue for sufferers of NP, influencing perceptions of their ability to cope, and of the care being provided. However, more research is necessary in order to improve the literature base.

A variety of perceptions of the future were discussed. Many participants discussed hopes for a future without NP, and discussed seeking cures, indicating potential self-pain enmeshment (Pincus & Morley, 2001). Others placed less emphasis on searching for a cure, and indicated self-efficacy in terms of their perceived ability to engage with rehabilitation and make plans for a future that may potentially include pain. Such future planning may be considered an adaptive coping strategy, and is associated with reduced pain, disability, depression, and anxiety, whilst the use of maladaptive coping strategies such as catastrophising is associated with negative pain-related outcomes (McCracken & Eccleston, 2003). Those who indicated perceptions of their ability to live well with their pain present, to stay active, and pay less attention to their pain may be considered to be more accepting of their situation (McCracken, 1998; McCracken & Eccleston, 2005). A willingness to have pain, and the prioritization of other aspects of life such as post-discharge care and physical rehabilitation, may contribute towards an enhanced acceptance, thus enabling better adjustment in all measures of functioning to be reached (McCracken, 1998). Beliefs regarding abilities to continue living with pain present may also mediate pain intensity, and the extent to which pain interferes (Peter, Muller, Cieza, & Geyh, 2012). The current study suggests that improving pain self-efficacy may encourage those with SCI and NP to engage with their pain, and become more open to the concept that meaningful lives can be led despite difficulties.

A further coping strategy adopted by those in the present study was that of optimism, with resilience identified as an aide to coping. Such optimism is related to better health habits, physical and psychological health, and increased recovery (Carver, Scheier, & Segerstrom, 2010). Resilience is defined as the ability to adapt to stress and adversity (Bonanno, 2004), and is associated with increased self-esteem, optimism, and perceived personal control (Major, Richards, Cooper, Cozzarelli, & Zubek, 1998). Resilience serves to moderate reactivity to stress, assists stress recovery, and mediates the ability to find meaning in experiences (Ong, Bergeman, Bisconti, & Wallace, 2006), all of which are reflected in the accounts of those in this study who felt able to make plans and were not worried about NP, suggesting that resilience and optimism may foster adaptive coping.

In conjunction with this, desires for a cure or an escape from pain, concerns regarding altered identities, and difficulties in managing NP, were common topics of discussion. Such avoidance-based thoughts and concerns are associated with health-damaging behaviours (Carver, Scheier, & Segerstrom, 2010), as evidenced in the present study by the frequent discussion of medication overuse. Those who display heightened levels of pessimism are also more likely to use maladaptive coping strategies such as avoidance and catastrophising (Goodin et al., 2013), suggesting that improving optimism may improve health and pain-related outcomes such as intensity (Vlaeyen et al., 2009; Keefe, Rumble, Scipio, Giordano, & Perri, 2004). Unrealistic optimism may also be maladaptive for coping with pain, and detrimental to health and well-being in the long-term (Hurt et al., 2014). However, the direction of the relationship between optimism and pain perception remains unclear, and it is possible that lower pain intensity or less pain may lead to increased optimism (Hanssen, Peters, Vlaeyen, Meevissen, & Vancleef, 2013). The development of positive cognitive appraisals and adaptive coping responses to SCI and pain should be targeted early on in rehabilitation in order to prevent the development of potentially health-damaging behaviours. Indeed, targeting unrealistic optimism and pessimism during comprehensive pain management has been recently recommended (Reid, Eccleston, & Pillemer, 2015).

The final theme to emerge from the analysis concerned verbal expression of NP. Multiple attempts were made to communicate how NP felt, often through the use of metaphors and imagery to describe it. This may have been a particular issue for inpatients, who are new to both the injury and pain, and may not yet have found a way to explain it appropriately or accurately. Such communication strategies further emphasise that NP is experienced in a social context, and those with SCI have a desire to be understood. Pain is an intrinsically private and subjective experience that may not be adequately described by items on pain questionnaires such as the McGill Pain Questionnaire (Melzack, 1975), especially if it is, at least partly, neuropathic (Scarry, 1985). These may not capture the experience of NP satisfactorily, and therefore personalized descriptors or metaphors may be more appropriate in achieving understanding (Tait, 2010). This suggests that the metaphors adopted in this study were considered more accurate representations of the sensory experience, and as such, allowing a deeper understanding to be reached.

Metaphors used encompassed feelings of electricity and heat, each of which may summon an emotional response from the listener, as well as increased understandings. Semino (2010) argues that metaphor use may be the only option in order to facilitate embodied simulation for the listener, and that this may provide a basis for an empathic response. Embodied simulation is the ability of the listener to relate to metaphors of pain, and is often elicited through the use of words referring to potential causes of bodily harm, due to the likelihood of the listener to have previously experience (Wilson & Gibbs, 2007), knowledge (Matlock, Ramscar, & Boroditsky, 2005), or prediction (Barsalou, 2008) of the experience described. Indeed, imagining the pain of others activates some of the neural areas activated by actual pain, and may evoke similar sensations, potentially underpinning empathy (Ochsner et al., 2008; Osborn & Derbyshire, 2010). Those opting to use metaphor in this study, therefore, may have done so in order to facilitate such perspective taking and imaginative simulation to the events indicated by the metaphor (Gibbs & Matlock, 2008).

The use of metaphor may also be considered a form of catastrophising (Jamani & Clyde, 2008), particularly if the images people hold about their pain are intrusive, uncontrollable, and enduring, potentially mediating further distress (Philips, 2011). Paying attention to pain through the use of metaphors and imagery is also associated with negative emotional states, hypervigilance, and the maintenance of persistent pain (Villemure & Bushnell, 2009; Asmundson, Wright, & Hadjistavropoulos, 2005). In a study by Gillanders, Potter, and Morris (2012), those who stated seeing visual images relating to their pain were significantly more likely to suffer with anxiety, depression, and higher self-reported levels of pain unpleasantness and catastrophising, suggesting that the use of metaphors and imagery associated with pain may mediate distress. The metaphors used by those in this study may be considered catastrophic, and may induce or exacerbate distress. Evaluating pain-related metaphor use in consultations, therefore, could deliver benefits to psychosocial well-being.

Image rescripting (Holmes, Arntz, & Smucker, 2007) offers a potential pain management technique for those using metaphors and presenting with high levels of distress, depression, anxiety, or pain intensity. This aims to transform the contents of one’s thoughts and images to less distressing imaginings (Holmes, Arntz, & Smucker, 2007). Gosden, Morris, Ferreira, Grady, Gilanders (2014) summarise that the experience of images associated with pain, and the use of metaphor, can be very distressing for the sufferer, and that the use of pain-related imagery in assessment and intervention could deliver benefits, when used supplementary to standard treatment. However, the present study indicates that the unique needs of the individual, such as their adopted coping strategies and pain-related language use, may influence how pain is managed, and it is, therefore, necessary to understand such individual requirements in order to provide adequate pain management.

6.10 Implications for Practice

The themes emerging from the present work encompass what may be considered the inpatient experience of chronic neuropathic pain. The data that emerged from participant interviews suggest that current pharmacological pain management does not adequately treat NP, with many participants articulating dissatisfaction with medication.

Perceptions of the hospital environment and staff were implicated in the experience of pain, with positive perceptions aiding coping. Concerns regarding a future with pain were a recurring issue, with spirituality, and the belief about the ability to live well with pain potentially moderating the extent of the hopes for a pain-free future. Finally, describing a pain that the able-bodied may not understand, due to lack of experience, appeared a difficult but important task. As a result of this, metaphors were adopted in attempts to elicit a more comprehensive understanding as well as empathy, despite the potentially negative consequences of using such metaphors. The results of this research suggest that NP after SCI may be more strongly related to psychosocial factors than physiological factors.

Successful physical rehabilitation post-SCI focuses on biomedical, psychological, and social properties (Cohen & Napolitano, 2007; Dorsett & Geraghty, 2008). Pain, however, is perceived by participants in this study to be managed primarily from the biomedical perspective, a perspective that fails to acknowledge the impact of psychological and social influences. The results presented here, therefore, support the implementation of psychological strategies for NP management, tailored to the individual needs and beliefs of the individual, which may be identified during assessment. Interventions such as image rescripting may be of benefit to those who are particularly distressed by images associated with their pain. Further, Coping Effectiveness Training, which is shown to improve psychological adjustment to SCI (Kennedy, Duff, Evans, & Beedie, 2003), teaches appraisal skills to allow participants to make a guided choice of the optimum coping response to stress. The appraisals of those in the present study suggest that such an intervention may be effectively utilized for those with NP, particularly if their perception of their ideal self is enmeshed with pain, by encouraging the development of adaptive appraisals and coping strategies. The present study also identifies a need for staff training and education on specific pain management techniques, and the maintenance of rapport, empathy, and compassion, despite career demands.

It may also be argued that pain management for inpatients with NP should attempt to target the themes identified in this study in order to improve coping and adjustment. The results suggest that even minor changes to standard practice, such as the cultivation of thorough understandings of NP and SCI, such that any misunderstandings and unrealistic optimism are corrected, may be of benefit, even before referral to pain management programmes. This study highlights the importance of empathy and compassion in the work of multidisciplinary staff for facilitating coping and adjustment.

The themes emerging from the present study surrounding issues of resistance towards pharmacological treatment suggest that psychological interventions such as CBT, ACT and MBIs may be of benefit to those living with SCI-specific NP. Both ACT and MBIs have well-documented evidence bases for improving pain tolerance whilst reducing distress in general chronic pain populations (Kabat-Zinn, 2003) and improving interpersonal relationships (Brown, Ryan, & Creswell, 2007; McCracken & Vowles, 2014). Further, only one study exploring mindfulness in those with SCI suggested that mood is associated with trait mindfulness, which encourages the adoption of approach coping techniques (Skinner, Roberton, Allison, Dunlop, & Bucks, 2010). Future work might, therefore, examine the efficacy of mindfulness-training interventions for those with SCI, and subsequent NP.

6.11 Limitations and Conclusions

The interpretative nature of IPA means that causality cannot be determined. For example, the relationship between acceptance and the coping strategies adopted in response to NP can be interpreted from the data, discussed, and applied to previous literature, but the utilisation of measures of cognitive coping strategies would provide quantitative validation of the presence of such strategies. However, the themes emerged from the data, and so preparing quantitative measures would not have been possible. Further, the results of the current study have identified numerous areas in which there is a dearth of literature, and thus potential avenues for future research to explore have been recognised and may offer meaning for the management of NP after SCI.

Inpatient stay meant that limited time could be spent with participants, so as to avoid disrupting their busy timetables. Further, at times, interviews had to be paused in order for standard care to continue. For example, some interviews were conducted at the same time as drug rounds, meaning that interviews had to be paused so that participants could take their medication at the appropriate time. Such interruptions often meant that participants forgot what they were saying, and lost the flow of conversation. However, efforts were made to ensure that participants were reminded of the discussion prior to the disturbance, such that the discussion could continue. Time restrictions may mean that further experiential detail was not obtained, despite the best efforts to ensure that interviews were conducted at times when appointments were scarce and interruptions could be minimised. Conducting a second interview in order to obtain further depth may have been of particular value for the inpatient study. Further, longitudinal depth that could have been obtained may have provided insight into the changing experience during rehabilitation. Assessing changes over time during inpatient stay in acceptance, perceptions of medication, and the ability to describe NP adequately, for example, would have provided for interesting discussion.

The small sample was self-selecting, suggesting that those who took part may have had experiences that motivated them to take part in the study. This study, therefore, may not be fully representative of those who did not take part. For example, people whose NP is adequately managed by pharmacological treatment, without issues such as side effects, are not represented in the present study. However, the purposive sample meant that, whilst a variety of participants were recruited, many experiences overlapped, whilst divergences offered some insight into the diversity in experiences.

The present study shows how NP poses physical and psychosocial challenges for those with SCI. Multidisciplinary pain management addressing shared understanding of pain, and fostering acceptance-based strategies, may be of benefit to the psychosocial well-being of those with NP. Despite the prevalence of the themes that emerged from the data, they are relatively under-represented within the quantitative literature. These themes, therefore, warrant further research in order to attempt to understand the inpatient experience of NP as fully as possible. The present study indicates that people with SCI desire dialogue with those working with them, and healthcare professionals would benefit from listening to each individual’s personal story.

6.12 Personal Reflexivity

As discussed in the outpatient phase of this thesis, I am engaging in personal reflexivity throughout my IPA projects. This section will focus on some background information as to why I chose to carry out another IPA study, and will attempt to outline any assumptions I may have held at the beginning of this study.

Before considering this inpatient phase of the study, I spent the previous year carrying out an IPA study focusing on the outpatient experience of chronic neuropathic pain. The results of the work suggested a number of issues that may need to be targeted in future pain management programmes for outpatients with chronic NP as a result of their SCI. As a result of this study, I wondered whether these issues were specific to the needs of outpatients, and whether the experience of inpatients with chronic neuropathic pain was different. The decision to continue with another IPA study was aided by my enjoyment of the previous study, and the interesting results that it yielded.

Before beginning this study, I made sure that all of the outpatient study was written up and completed, such that the inpatient phase would not be tainted by the outpatient results, and I could essential ‘close the book’ and begin the inpatient phase with a fresh view. Throughout the process of planning the study, I have attempted to distance myself from my experience of carrying out the outpatient study, as well as from the results that I had found. Whilst this has been a difficult process, I believe I have managed to keep a reasonable distance between the outpatient and inpatient studies, by remaining aware that the inpatient experience is unique in its own right and deserving of an analysis that engages with, and is open to, each participant’s world.

6.12.1 Methodological and Procedural Reflexivity. As in the outpatient study, I kept a reflective diary. In an attempt to capture thoughts and feelings that occurred throughout each interview, I took time to reflect on the interactions between each of the participants and myself. This also helped me to maintain transparency towards the experience and consider how I may have implicated the data obtained.

My first reflective comment arises from the recruitment process. Potential participants were initially approached by a member of staff, and then given the opportunity to meet me. All potential participants met with me having received the information sheet, after which an interview date and time was arranged. However, most patients were due to be discharged back into the community, and this can be an unpredictable process. Patients receive discharge dates, which may then be subject to change depending on the patient's health status, their preparedness, community dwelling, as well as a number of other factors. In two cases, interviews were arranged, and prior to the interview date, those participants were discharged. This meant that experiential evidence was not recorded for these participants as further contact could not be made and I did not want to disrupt the reintegration process. Thus, more participant recruitment had to be done.

When interviewing inpatients, I used the same interview schedule that I did with outpatients. As a result of my outpatient practice, I feel very familiar with the interview schedule, and consequently only used it as a guide to refer to. I rarely needed to refer to the schedule, as most participants were very articulate in discussing their experiences. However, it is still likely that I influenced the direction of interviews by prompting participants further on topics they raised spontaneously. Despite this, as a result of my previous IPA experience, I feel confident that I allowed the participants to drive the interview to whatever topic they wanted to, in order to discuss with me what was most important to them. Further, I took brief notes so that topics raised spontaneously that could be discussed further, and feel confident that I asked participants to provide further information on all spontaneously raised issues.

Another reflective concern was that of ward life. Whilst I took every measure possible to avoid interrupting the participants' daily lives in hospital, such as arranging interviews when they had no appointments and outside of meal times, there was some potential to interrupt their daily lives. All interviews were conducted in a private room, yet sometimes staff needed to interrupt interviews to speak with patients regarding a number of issues, such as medication rounds, and scheduling further appointments. These interruptions disrupted the flow of the participant's discussions, and may have resulted in forgetting what they were previously saying, and as such, the loss of experiential data.

6.12.2 Analytical Reflexivity. After I had analysed three interviews, I began to notice that some of the emergent themes and clusters appeared to be similar to those of the outpatients. This brought me to the realisation that, whilst I had strived to remain aware that the inpatient themes may differ from those of outpatients due to different surroundings, I may not have considered that the themes may be similar to those of outpatients. Upon reflecting on this, I considered that such similarities might arise from the fact that outpatients were inpatients once, and as such, I made sure to remain aware that inpatients and outpatients may have similar and different experiences, rather than completely opposing experiences. This was another example of my attempt to bracket off my pre-judgement, before realising what my pre-judgement actually was.

Constantly moving between part and whole during the data analysis did not feel as overwhelming as it did during the outpatient study. Thanks to my previous experience, the commitment required to engage in the analysis was expected, and I was able to focus much better, having previously carried it out, and familiarised myself with the process. However, I did, at times, still feel a need to step away from the analysis in order to refuel my enthusiasm. It is a very engulfing process that requires time and dedication. I feel that being aware of the commitment required to conduct an IPA study is conducive to the work.

Once again, as with the outpatient results, a final concern regards the interpretations of the data. Like outpatients, inpatients discussed sensitive, personal experiences regarding staff and the hospital environment. Whilst many comments are positive, some are negative and require care to be taken when publishing the data so as not to offend patients, but also to remain true to their accounts. Further, care is also required so as not to undermine staff at specialist spinal units, the work that they do, and the environment surrounding them. I feel confident that the results are grounded in the data, and evidenced sufficiently. This study aims to offer evidence that may help to improve care offered to those living with SCI and subsequent NP, and as such, I feel that the interpretations are adequate in achieving their goal in understanding the experience.

For the same reasons as with the outpatient study, and to remain consistent, I decided against member checking. It is my belief that the enrollment of two independent auditors for the analysis of the data was enough to improve the validity and rigor of the results. Working alongside the independent auditors permitted strong interpretations relevant to the population of study. Like the outpatient study, the final write up of the results took a number of drafts and reinterpretations before I finally felt the analysis was presented in a coherent manner. Continued efforts were made to analyse the data to reflect the participants' worlds and to reflect upon the whole research process.

6.12.3 Concluding Reflexivity. Throughout the second phase of this project, I attempted to become engaged in the phenomenological attitude, remaining open and non-judgmental, in order to achieve unbiased results that remain grounded in the data. This second IPA study has only served to reaffirm my appreciation and enjoyment of qualitative methodologies.

It was a privilege to be allowed into the personal lives of the participants who took part, and to understand the experience further. The results suggest that conducting this research was of value for researchers, healthcare professionals, and people with SCI alike, and the work has opened up further avenues for future research that may not have necessarily been open before. I hope this work will continue to be used to support future research and to contribute towards the development of clinical practice in the management of NP following SCI.

Chapter 7 **General Discussion**

The subjective meanings and experiences of in- and outpatients with chronic neuropathic pain following SCI were explored using IPA. For outpatients, results indicated that a gap existed between the care that they received and the care that they desired, with a perception of the medical profession as reliant upon medication to manage pain, which induced perceptions of non-collaborative care. Participants also voiced feelings of being trapped in a battle against their pain, fighting for life control against a pain that was described through the use of metaphors. Concerns for social well-being were articulated, and participants often felt fearful or ashamed of discussing the impact of pain with friends and family, potentially isolating themselves from significant others. Many chose to avoid discussing pain with people without SCI, in order to avoid burdening others and reduce negative judgements.

For those in the acute rehabilitation setting, four themes emerged, which helped to illuminate similarities and differences across the two samples studied. The most prominent theme was the struggle to describe pain adequately, and the use of metaphor to guide description. The use of medication was another prevalent theme, with many inpatients voicing negative experiences, but, unlike outpatients, some acknowledged the positives of medication. The hospital environment, and empathic and compassionate relationships with staff were also key themes to feeling able to manage pain. Concerns regarding the uncertainty of the future were discussed. Many discussions surrounded hopes for a future self without NP, implying potential self-pain enmeshment (Pincus &

Morley, 2001), and the need for education and acceptance-based interventions to counter potentially unrealistic beliefs.

All themes emerging from the in- and outpatient analyses encompass a biopsychosocial experience of chronic NP following SCI, highlighting the similarities between NP and chronic pain in general, as well as the potential NP has to cause psychological distress. Both in- and outpatients highlighted their perceptions of medication's dominant role in pain management, and identified a desire for a collaborative approach to pain management, with reduced reliance upon medication. Fearful thoughts in relation to pain were also common across both samples, each of whom often considered NP in terms of threatening language, which may contribute to its disruptiveness and intensity (Walsh & Radcliffe, 2002).

Metaphor use was wide-ranging across both in- and outpatients, and emphasised the threat of pain to participant's self-concept, influencing their perceptions of their identity and the extent of their control of NP. Emotional responses, empathy, and understanding may have been facilitated through the use of metaphor (Semino, 2010). Semino argues that the use of metaphor can provide the basis for empathic responses and enriched understanding. This is due to its ability to elicit embodied simulation in the listener, in which the experiences of others are understood in terms of their own previous experiences and memories. This is reflected in the current study, in that participants used words referring to potentially shared experiences such as burns and toothache. Metaphors referring to potential causes of bodily harm may be particularly useful in facilitating embodied simulation, due to previous experience of the action or activity (Wilson & Gibbs, 2007), knowledge and understanding of the domain (Matlock, Ramscar, & Boroditsky, 2005), or prediction, in which introspection of one's cognitions and emotions allows conclusions to be drawn (Barsalou, 2008). Each of these three factors may have played a role in the adoption of metaphorical language by participants in this study. Prediction and knowledge may have been particularly useful for those in this study, thus motivating their metaphor use, in order to enhance the understanding of the listener and those without SCI.

The results of these studies indicate that those living with SCI have a desire for dialogue with those working with them, and that HCPs would benefit from listening to each individual's personal story, and in turn, patients would benefit from this. This echoes results found in a Grounded Theory analysis of acceptance of NP following SCI (Henwood, Ellis, Logan, Dubouloz, & D'Eon, 2012), which suggests that the ability to live with pain without trying to reduce or cure it, may reduce suffering. Such a desire for dialogue with HCPs, as voiced by participants in this study, therefore, suggests that minor interventions in routine clinical care, such as collaborative efforts between patient and consultant, during which patients can offer input into their own care, may offer benefits in terms of distress and improved likelihood of collaborative, patient-centred care.

The present study suggests that those with SCI would benefit from acceptance- and mindfulness-based interventions, which have the potential to target each of the themes articulated throughout the two studies. Such interventions aim to foster a sense of control and acceptance of situations, whilst improving sense of identity, and the ability to pursue valued activities despite pain's presence (Hayes, 1994). MBIs hold the potential to foster adjustment to both pain and injury, whilst teaching individuals that it may be more realistic to live with pain, with a well-documented evidence base for increasing pain tolerance and reducing distress in non-SCI chronic pain populations (Kabat-Zinn, 2003), whilst improving interpersonal relationships (Brown, Ryan, & Creswell, 2007). As such, engagement in MBIs may have greater impact on psychological well-being than taking medication alone for those with chronic NP following SCI. This may also be a particularly beneficial intervention for those wishing to reduce or avoid the use of medication as a pain management strategy, as evidenced by those in both study one and study two. Only one study, conducted in Australia, has examined state mindfulness in those with SCI, finding that reduced use of avoidance techniques in response to negative events correlated with being more mindful, and resulted in improved mood (Skinner, Roberton, Allison, Dunlop, & Bucks, 2010). No previous work could be found that explored the effects of mindfulness training on psychological and physical outcomes for those with NP following SCI. The present study, therefore, provides rationale for such exploratory work.

Differences also emerged between the two groups, including their perceptions of their social relationships, with respect to their context. Outpatients felt unable to disclose or discuss their pain with the friends and family that they were most often surrounded by, due to negative reinforcement in the form of responses of others (Skinner, 1937), whilst inpatients tended to feel comforted by the expertise of the staff who most often surrounded them, despite some perceptions of being ‘trapped’ in hospital. This difference may have arisen as a result of inpatients feeling better able to communicate their pain with staff, who may be able to help or understand them better. A sense of community within a spinal unit may also encourage positive perceptions of staff and facilitate psychosocial adjustment. Outpatients may lose this sense of community spirit following discharge (Dickson, Ward, O'Brien, Allen, and O'Carroll, 2011), which may induce worries of burdening friends and family members, who also may be less able to understand their experiences. Offering outpatients continued social support through means of peer and family mentoring has been evidenced to improve life satisfaction (Sherman, DeVinney, & Sperling, 2004), self-efficacy (Ljungberg, Kroll, Libin, & Gordon, 2011), and may help to reduce feelings of burden upon families and friends, whilst facilitating improved pain communication. This difference suggests that knowledge, trust, presence, empathy, and compassion may all play a role in the likelihood of communication of pain.

A lack of qualitative literature on the phenomenological experience has led to a largely quantitative body of research that already exists. The themes arising from the present studies, therefore, may have been neglected by the aspects of chronic pain after a SCI that arose as a result of this research. It may be argued, therefore, that the results of the present study pose advantages in providing a detailed picture about the experience of NP after a SCI, which reflects the complexity of the experience in the context of the individual. The results of these studies have the ability to inform and complement the existing quantitative literature.

Quantitative research depicts that able-bodied researchers are able to understand the subjective lives of those with SCI through the use of validated quantitative measures and questionnaires. Qualitative research, however, has the ability to contribute to the quantitative literature base by illuminating experience from the fusion between patient's and expert's perspectives, rather than attempting to be objectively descriptive. This research, and IPA research in general, has been designed to stimulate further questions and investigation into the experiences of pain after a SCI and to aid in developing potential pain management techniques.

The research suggests that, whilst medication appears to be the most widely used method for the management for chronic pain after SCI, with recommendations for combined drug therapy (Hama & Sagen, 2012), there is also a need to educate healthcare professionals and patients of the potential side effects of such medication (Labianca, Sarzi-Puttini, Zuccaro, Vellucci, & Fornasari*,* 2012). Further, both HCPs and patients with SCI should be educated on the availability of complementary treatments for the pain, such as CBT, ACT, and mindfulness, each of which may deliver more pain relief than medication alone, by increasing autonomy, acceptance, the quality of social relationships, and reducing reliance upon medication.

Individual experiences may vary due to varying personal competing values. Some patients may place more focus upon pain elimination than others. Healthcare professionals should, therefore, remain aware of the potential psychological and social consequences of unmanaged pain, and attempt to tackle these together with adequate medication prescription. This could be done through a form of ‘matching’ of the patient to the most suitable treatment, dependent on the context and characteristics of the individual (Vlaeyen, Crombez, & Goubert, 2007). Healthcare professionals should remain aware of the unique religious and spiritual beliefs that patients may hold, and the effects of such beliefs on the pain experience, taking these into account when discussing pain management options.

Further, social support appeared to be a major theme that emerged from the data, with patients expressing a desire for their pain to be understood by the able-bodied, and a need to reduce feelings of burdening upon their loved ones. Chronic neuropathic pain management should focus upon managing pain from the global perspective, including friends, family, and hospital staff in management and education, such that they are better able to understand the problem and offer beneficial social support that will not increase pain behaviours, but aid coping and acceptance. Training in offering empathy and compassion to patients who desire it may also be implemented in order to improve the experience of inpatient care, and pain-related outcomes.

The results of these studies combined, suggest that the integration of imagery-based techniques with interventions such as ACT and MBIs may improve the development of psychological flexibility (Hayes, Strosahl, & Wilson, 1999), thus addressing each of the themes identified in each of the studies. Rescripting has been successfully integrated into CBT methods for those with depression and anxiety (Brewin et al., 2009; Hackman et al., 2011), demonstrating efficacy in reducing negative emotional states, and suggesting that such intervention may be suitable for those with NP post-SCI. The integration of these methods may offer superior benefit by encouraging acceptance of distressing pain-related metaphors, therefore reducing their threatening nature (Hackmann, Bennett-Levy, & Holmes, 2011), and improving their ability to cope with pain.

These studies suggest that a greater emphasis is placed upon treating patients from a multidisciplinary perspective, recognising patients' social needs for support and enhancing family preparedness, increasing staff awareness and knowledge, training staff in communication skills, reducing side effects of medication, tailoring consultations and treatments to the individual, and inform, motivate and involve the patient in their personal care and decision-making. By understanding the individual's experience from a biopsychosocial perspective, it might be possible to identify which management techniques might be most beneficial to each person.

Living with chronic neuropathic pain after spinal cord injury is a biopsychosocial experience that may not be as simple as the relationships identified by quantitative work alone may suggest. The individual accounts presented throughout this research support some quantitative work, but also provide evidence for divergences from the norm; medication is perceived as ineffective yet relied upon, collaborative care is desired, self-perceived burden results in attempts to isolate oneself, and language use may play a role in the experience, and persistence, of NP. Such evidence provides confirmation of the need to individualise treatment and management. As opposed to general chronic pain, the literature base for chronic pain after SCI is much more limited, such that the present research is intended to illuminate the experience, providing potentially new areas for future work to be carried out; CBT, ACT, MBIs, Coping Effectiveness Training, peer-support programmes, and image-based interventions should be assessed in terms of their efficacy for those with NP post- SCI, self-perceived burden and its impact upon both the sufferer and their carers, friends, and family may be investigated, and the influence of language use on pain experience may be explored further.

Chapter 8 **Conclusions**

The primary aim of this thesis was to contribute towards the current understanding of NP following SCI, by exploring the perspectives of individuals living with the phenomenon from a qualitative standpoint. In light of this aim, the complexity and individual variety in the experience of chronic NP following SCI is highlighted by each of the participant accounts studied and discussed. Despite the struggle to articulate pain, vivid descriptions were obtained, and emergent themes stressed the disruptive and threatening psychological and social impact, enriching the current understanding of NP following SCI. The themes and conclusions arising from each study highlight the complex, multi-dimensional, psychosocial and interpersonal context of pain. Self-concepts and beliefs about how friends and family may react to pain, as well as the lack of shared understanding within that social network, influenced interpersonal interactions and communication strategies in ways that made pain and disability more complex. The experience of neuropathic pain has been illuminated through the use of IPA as a multi-dimensional construct encompassing biopsychosocial elements, in which meaning-making is a core facet.

Interestingly, although not unexpected, there were some differences between inpatients and outpatients. For both in- and outpatients, NP was a biopsychosocial issue; preoccupations with the treatment of NP as a purely biomedical one were dominant, leaving participants feeling powerless and dissatisfied. This suggests that non-pharmacological interventions may be of benefit for those with SCI, particularly those that allow self-management. Such interventions have shown higher efficacy than pharmacological interventions (Heutink, Post, Wollaars, & Van Asbeck*,* 2011). Enhancing openness and trust in the doctor-patient relationship should be made a key aspect of pain management (Parsons et al*.,* 2007), and people with NP following SCI should be informed of the difficulty in managing it.

Outpatients discussed their perception of themselves as a burden to others, and their consequent disengagement from social activities, isolating themselves from potential avenues of social support. Such perceptions pose a risk to adjustment to injury, as well as community reintegration post-discharge (Carpenter & Forman, 2004). Further, the results suggest that friends and family should be more meaningfully integrated into rehabilitation, as well as the management of NP through means such as education (Dickson, Ward, O'Brien, Allan, & O'Carroll*,* 2010). The inpatient environment, which surrounded patients with empathic and compassionate staff, contributed towards feelings of safety, comfort, and perceived empathy and compassion from others. This suggests that the receipt of compassionate and empathic care is important to those with SCI, which may improve pain-related outcomes through enhanced patient satisfaction and treatment adherence (Kim, Kaplowitz, & Johnston, 2004). Issues regarding the social network were common, and emphasised the influential role of the social context of pain (Romano, Cano & Schmaling, 2011).

All participants acknowledged the difficulty in articulating the experience adequately for the understanding of the listener. Engagement in metaphor use served multiple purposes; attempts to elicit shared understanding via embodied simulation and empathy (Semino, 2010), as well as the communication of distress (Sullivan et al., 2001; Sullivan, 2012). Time since onset of NP does not necessarily equate to clarity regarding available pain management options, nor the ability to communicate it in a wholly comprehensible and meaningful way. This suggests that the experience extends beyond simply physical sensation, reflected in the perceptions of pain as a threatening, torturous, and uncontrollable experience. The use of catastrophic and distressing metaphors may promote an intensified vigilance and rumination towards pain (Gillanders, Potter, & Morris, 2012; Gosden, Morris, Ferreira, Grady, & Gillanders, 2014), reinforcing its threatening nature within the sufferer's consciousness. This highlights the importance of considering the language used by those with NP, which may represent underlying assumptions, and perceptions, and therefore, may influence intervention recommendation.

Previous qualitative work surrounding pain after SCI has explored pain acceptance (Henwood, Ellis, Logan, Dubouloz, & D'Eon, 2012), memories of pain (Sparkes & Smith, 2008), experiences of pain management (Lofgren & Norrbrink, 2012), and the questions that those with SCI have regarding pain (Norman et al., 2010). However, experiential stories of individuals with NP following SCI have not previously been explored. The studies in this thesis are, therefore, valuable to the literature. The evidence presented supports previous work and highlights the value of individual stories in providing the ability to understand the phenomena at a deeper level. NP is, therefore, considered a biopsychosocial experience in which patient-centred, collaborative care that integrates acceptance-based interventions, self-management, friend and family education, as well as language and cognition, is warranted.

8.1 Clinical Implications for the Management of Chronic Neuropathic Pain after Spinal Cord Injury

This thesis highlights the dual nature of pain, the impact of the physical experience of NP, as well as the psychosocial issues that may be induced or exacerbated. Each of the themes emerging from the data could be attended to in clinical environments by utilising relevant strategies in a manner complementary to current, standard pain management interventions. This thesis could improve the practice of healthcare professionals, by evidencing the need to remain aware of the unique experience of the patient, whilst also remaining conscious and empathetic of the influence of patients' beliefs on their experiences. However, the efficacy of strategies and techniques that may be useful for targeting each of the themes identified in this thesis (e.g. mindfulness-based interventions, image rescripting) have not yet been established. This study, therefore, opens up a range of options for future work to examine in terms of managing NP after SCI.

Issues regarding reliance upon, and side effects of, pharmacological treatment were prevalent. Many participants voiced a dislike of the perceived reliance, and the lack of efficacy of prescriptions. Such a lack of efficacy has been demonstrated in studies of the antidepressants amitriptyline and trazadone, which are found no better than placebo in randomized controlled trials, except in instances where patients have high levels of depression (Davidoff, Guarracini, Sliwa, & Yarkony, 1987; Cardenas et al., 2002). Further, pharmacological treatments are not recommended for long-term management (Wrigley & Siddall, 2002). The participants in this thesis expressed a desire for collaborative care, suggesting that psychosocial self-management systems and techniques may be of benefit. This has been previously recognised by those with SCI (Munce et al., 2014), and would ideally involve pain management techniques, communication with HCPs, promotion of acceptance, and problem solving training.

The findings of this thesis suggest that psychological interventions may prove most beneficial for those with chronic NP post-SCI. According to a recent systematic review and meta-analysis (Kamper et al*.,* 2015), multidisciplinary pain management techniques are more successful for the management of chronic pain, and disability arising from pain, than usual care interventions. From a cognitive-behavioural perspective, modifying thoughts, behaviours, emotion, communication, and coping strategies through the use of psychoeducation, offers benefit to general chronic pain populations (Turner & Clancy, 1988). However, few studies of cognitive therapy for people with SCI have been conducted, demonstrating significant improvements in pain intensity and distress (Ehde & Jenson, 2004), anxiety and participation in activities (Heutink et al., 2012; Heutink et al., 2013), whilst Norrbrink Budh, Kowalski, and Lundeberg (2006) found reductions in anxiety and depression, and improvements in quality of sleep, but not in neuropathic pain intensity, at 12-month follow-up. Further, skills taught during CBT in order to manage mood, attention, and thoughts, have been found unrelated to outcome measures at follow-up for chronic pain samples, suggesting that skills training is not a necessity for managing chronic pain (Vowles & McCracken, 2010).

The findings of this thesis, and the studies above suggest that cognitive-behavioural techniques may promote optimum psychosocial and pain-related outcomes when combined with acceptance-based interventions. The focus on psychological flexibility is reflected in acceptance-based approaches such as ACT and MBIs, in which there is an increasing interest. There is, however, a need to enhance the available literature, in order to assess the efficacy of such approaches for those with chronic pain, and those with NP after SCI. ACT does not aim to change, or 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, such that psychosocial consequences are minimised. In this thesis, participants voiced issues surrounding difficulties in accepting NP, and displayed unrealistic hopes and optimism. Facilitating acceptance in those with SCI and NP may be a particularly useful goal for this population due to the lack of cure. Thus, encouraging the ability to live well, despite the presence of pain, and to allow the pursuit of meaningful goals as opposed to searching for a cure may provide those with NP after SCI with an adaptive coping strategy (Kranz, Bollinger, & Nilges, 2010), making acceptance-based interventions ideal for this population.

The evidence provided by participants in this thesis also suggests that MBIs may be of benefit. In relation to the themes articulated in the studies presented within this thesis, previous work has established that mindfulness can improve pain and functioning (Zeidan et al*.,* 2011), whilst reducing physical and psychosocial disability, analgesic use, and GP visits (McCracken, Vowles, & Eccleston*,* 2005). The results presented in this thesis also identified that participants felt isolated as a result of their experiences and perceptions of not being understood. Mindfulness is evidenced to reduce such feelings of isolation, whilst increasing feelings of being understood by others (Mathias, Parry-Jones, & Huws, 2013). Such evidence suggests that MBIs may play a beneficial role in improving the psychological and social well-being of those with chronic pain. The participants in this study articulated a range of intrapersonal and interpersonal issues, including pain acceptance, and the importance of social networks and pain communication, each of which may be improved through engagement in MBIs, yet no experimental studies of MBIs with people with SCI could be found. The results of the thesis suggest that trialling a mindfulness-training intervention for those with neuropathic pain following SCI may benefit the literature base and provide evidence for mindfulness as a viable intervention for those with SCI and NP. Therefore, a randomized controlled trial is currently being run, so as to explore the efficacy of an eight-week, online MBI for those with SCI and NP (see Appendix O for protocol).

Integrating imagery-based techniques with psychological interventions such as ACT and MBIs may offer the most benefit to those using metaphors by developing psychological flexibility (Hayes, Strosahl, & Wilson, 1999). At the same time, themes discussed in each of the studies in this thesis can also be addressed by ACT, which can aid in the development of acceptance, reducing feelings of isolation, improving the understanding of others, and providing the patient with non-pharmacological self-management techniques. Such interventions may also be adapted to the individual requirements of patients, their communicative goals, and psychological states, thus appreciating the unique needs of the individual.

8.2 Strengths and Weaknesses of the Thesis

Strengths and weaknesses particular to each individual study are examined in the respective discussion sections, whilst those relevant to the whole thesis are reviewed here.

First, IPA’s idiographic commitment to ‘hearing’ each individual’s personal story provided a richer picture of the experience and previously established psychosocial concepts. Understanding the goals and meanings behind those words, as opposed to simply categorising them in terms of description, appearance, or in supporting or rejecting quantitative work, encouraged the emergence of themes that had not previously been identified within the literature. The themes were discussed in relation to a wide range of research approaches and reinforced the value of the IPA approach and the need for its integration in the study of NP after SCI.

Whilst the findings of the studies cannot be generalised to wider chronic pain populations, due to the phenomenological and interpretative nature of the methodology, they can be applied to those with SCI and NP. It is also notable that the results may not necessarily be limited to patients with neuropathic pain. The emergence of themes encompassing the experience from a biopsychosocial perspective may extend to those with pain arising from a variety of illnesses and diseases. It is likely that those with chronic pain without SCI experience pain in similar ways, in terms of issues with acceptance of pain, and the psychosocial impact of pain. Investigating the similarities and differences in the pain experience across a variety of pain groups may, therefore, be warranted.

This thesis attempted to ‘map’ the experience of NP over time by utilizing two samples at two different stages of SCI rehabilitation. This was achieved to some extent, highlighting the similarities and differences in experiences in a cross-sectional snapshot. However, this approach may also be considered too ‘narrow’ because only one interview was conducted with each participant, rather than multiple interviews, which may have encapsulated how the experience changes over time. A longitudinal focus, using multiple interviews with the same participants from inpatient stay through to community reintegration would have provided a clearer picture of NP over time. Further, using multiple data sources, such as psychological measures of pain catastrophising, depression, anxiety, and acceptance, could have further strengthened the work, by providing robust, quantitative evidence to support interpretations. However, this would be not possible in an IPA study, in which themes arise from the data rather than being predicted and imposed.

The themes emerging from this study have begun to be addressed in the literature (for example; Dickson, Ward, O’Brien, Allan, & O’Carroll*,* 2010; Mathias, Parry-Jones, & Huws, 2013; Moseley, Nicholas, & Hodges, 2004), which allows for the evidence provided to complement the current knowledge, and deliver further strength to the rationale for the use of multidisciplinary pain management approaches that incorporate the biopsychosocial model. However, the thesis is constituted of primarily qualitative data and analysis. Whilst this means that a vast body of rich, meaningful data was obtained, the quantitative measures taken were in relation to metaphor use, rather than the experience of pain itself. This means that, whilst every attempt was made to remain open, non-judgmental, and reflective, there is no quantitative evidence to support the interpretations made. Despite this, validations of interpretations were made by independent auditors, and the results are considered credible and meaningful interpretations. Future work, however, might consider using the IPA methodology along with the completion of quantitative measures (analysed after the IPA) so as to corroborate interpretations.

It is important to note that none of the weaknesses invalidate the thesis, but represent areas in which issues could have been addressed, had time and resources allowed. Further, this work has enabled a more comprehensive understanding of the experience to be reached, opening up new avenues for future research to explore, and for clinical interventions that have not yet been investigated to begin to be examined. Appendix O provides the rationale and methods for the examination of the efficacy of an online mindfulness-based intervention for those with NP following SCI. This study arose from the results of the thesis, and recruitment is ongoing.

8.3 Personal Reflexivity

This study cannot claim to be representative of all of those with SCI and subsequent NP, as it is not possible to hold a comprehensive understanding of any experience based on reports from a single moment in time (Thorne & Paterson, 2000). However, this cross-sectional study may become a useful foundation for a prospective study, in which the same participants are interviewed a number of times during the rehabilitation process, from inpatient status, to outpatient discharge and community reintegration. This would permit a better ‘mapping’ of the experience of NP, as well as its incidence and presentation over time. However, the narrow focus of this study, upon the experience of

NP following SCI, has allowed for revealing and clinically relevant results to be acquired.

My short time (one year) working in an acute rehabilitation ward may have enhanced and limited this work. My short-term experience may have left me naïve to certain aspects of the experience, whilst such naivety may have also allowed me to 'bracket off' assumptions, and prevent previous experience from leaking in. It is acknowledged that the results presented are not definitive interpretations, which could not be reached after a single interview, but I hope that I 'heard' what I was told by the participants by immersing myself within interviews and the data analysis process, and that the results have been conveyed accurately and meaningfully, offering readers more clarity than confusion.

It is important to me that the quality of the studies presented in this thesis remains high, and that interpretations are presented with enough verbatim evidence to justify them, and allow the reader to interrogate the analysis personally. Throughout the two studies, I have made consistent efforts to remain sensitive to the context in which the research was conducted, through the recognition of the social context of the interview, and my commitment to each individual participant's story in a serious attempt to enrich the knowledge base. This is also reflected in the introduction, in which my personal commitment to the subject, along with the methodological approach and epistemological stance, is discussed. I also believe that the depth of the description of the process of IPA conveys my dedication to, and engagement in, the study. Further, the results of each study are discussed in relation to a number of research approaches to pain management in an attempt to cover numerous bases that might aid the management of NP, rather than favouring one.

The step-by-step process of analysis developed by Smith, Flowers, and Larkin (2009) was adhered to throughout both studies, ensuring that themes remained grounded in the data. The processes of checking the analysis described in the methodology section was an attempt to make the process as transparent as possible. Independent auditors (supervisors and colleagues) were recruited for each study following the same triangulation process each time, such that the results are formed from numerous discussions and interpretations to ensure quality and rigour. It is my hope that the research within this thesis reflects the attempts made to ensure high quality results were obtained, and that the discussion of themes within the wider range of pain-related research will demonstrate both clinical and research relevance of the findings, and the IPA approach. I hope this work will have impact upon the beliefs and actions of those working and/or living with SCI.

Finally, arising from the time dedicated to the research and emersion in the qualitative approach, I have come to realise that my ability and confidence in the IPA methodology has grown consistently over time. As opposed to statistical analyses, in which the same results will occur each time a researcher carries out the same test, IPA challenged my working knowledge, ability, and confidence in developing high quality, coherent themes. This, I feel, has enabled me to strengthen my personal confidence as a researcher, something which may not have occurred had I done quantitative research alone.

My originally positivist stance has flourished and opened up to qualitative methods. I am extremely fond of the methodology and its flexibility, my reanalysis evidencing this, and have been privileged to have been allowed into the personal lives of the participants, and to obtain a rich understanding of an experience that could not be obtained through the literature base. Indeed, at the start of this venture, I did not expect to focus upon acceptance-based therapies (studies one and two), nor the environmental impact on psychological well-being (study two), and least not the use and impact of metaphorical language (studies one and two).

As a person, I feel I have absolutely grown throughout this highly enjoyable and rewarding process. I am undoubtedly looking forward to my next venture in research, whether it be using qualitative or quantitative methods. I feel a huge sense of commitment to contributing towards the literature and the enhanced quality of care that may be achieved through the publication of research. Further, I feel that my writing and critiquing skills have developed recognisably during the past three years. My published papers (Hearn, 2015; Hearn, Cotter, Fine, & Finlay, 2015; Appendix P), along with my participation in a number of conferences surrounding health psychology, and SCI, reflect this. Such participation in academic activities, and the responses of those present during conference talks suggest that the qualitative approach, and my own work are strong and worthy of recognition.

References

Akhtar, M., Kennedy, P., Webster, G., & Graham, A. (2012). What about us? Children's experiences of living with a sibling with spinal cord injury. *Journal of Paediatric Rehabilitation Medicine*, *5*(4), 301–313. http://doi.org/10.3233/PRM-2012-00226

Aldrich, S., Eccleston, C., & Crombez, G. (2000). Worrying about chronic pain: vigilance to threat and misdirected problem solving. *Behaviour Research and Therapy*, *38*, 457–470.

American Spinal Injuries Association. (2015). http://www.asia-spinalinjury.org.

Anand, K. J., & Craig, K. D. (1996). New perspectives on the definition of pain. *Pain*, *67*(1), 3–6; discussion 209–211.

Anders, K., & Simon, H. A. (1980). Verbal reports as data. *Psychological Review*, *87*(3), 215–251. http://doi.org/10.1037/0033-295X.87.3.215

Antonovsky, A. (1987). *Unraveling the mystery of health: How people manage stress and stay well* (Vol. xx). San Francisco, CA, US: Jossey-Bass.

Asmundson, G. J. G., Wright, K. D., & Hadjistavropoulos, H. D. (2005). Hypervigilance and Attentional Fixedness in Chronic Musculoskeletal Pain: Consistency of Findings Across Modified Stroop and Dot-probe Tasks. *The Journal of Pain*, *6*(8), 497–506. http://doi.org/10.1016/j.jpain.2005.02.012

Ataoğlu, E., Tiftik, T., Kara, M., Tunç, H., Ersöz, M., & Akkuş, S. (2013). Effects of chronic pain on quality of life and depression in patients with spinal cord injury. *Spinal Cord*, *51*(1), 23–26. http://doi.org/10.1038/sc.2012.51

Attal, N., Mazaltarine, G., Perrouin-Verbe, B., & Albert, T. (2009). Chronic neuropathic pain management in spinal cord injury patients. What is the efficacy of pharmacological treatments with a general mode of administration? (oral, transdermal, intravenous). *Annals of Physical and Rehabilitation Medicine*, *52*(2), 124–141.

Apparelyzed. (2013). http://www.apparelyzed.com.

Bach, C. A., & McDaniel, R. W. (1993). Quality of life in quadriplegic adults: a focus group study. *Rehabilitation Nursing*, *18*, 364–367.

Baer, R. A. (2003). Mindfulness Training as a Clinical Intervention: A Conceptual and Empirical Review. *Clinical Psychology: Science and Practice*, *10*(2), 125–143. http://doi.org/10.1093/clipsy.bpg015

Bailey, K. M., Carleton, R. N., Vlaeyen, J. W. S., & Asmundson, G. J. G. (2010). Treatments addressing pain-related fear and anxiety in patients with chronic musculoskeletal pain: a preliminary review. *Cognitive Behaviour Therapy*, *39*(1), 46–63. http://doi.org/10.1080/16506070902980711

Bakitas, M. A. (2007). Background noise. The experience of chemotherapy-induced peripheral neuropathy. *Nursing Research*, *56*(5), 323–331.

Baliki, M. N., Chialvo, D. R., Geha, P. Y., Levy, R. M., Harden, R. N., Parrish, T. B., & Apkarian, A. V. (2006). Chronic Pain and the Emotional Brain: Specific Brain Activity Associated with Spontaneous Fluctuations of Intensity of Chronic Back Pain. *The Journal of Neuroscience*, *26*(47), 12165–12173. http://doi.org/10.1523/JNEUROSCI.3576-06.2006

Banks, S. M., & Kerns, R. D. (1996). Explaining high rates of depression in chronic pain: A diathesis-stress framework. *Psychological Bulletin*, *119*(1), 95–110. http://doi.org/10.1037/0033-2909.119.1.95

Barrie, J. (2011). Patient empowerment and choice in chronic pain management. *Nursing Standard*, *25*(31), 38–41.

Barsalou, L. W. (2008). Grounded cognition. *Annual Review of Psychology*, *59*, 617–645. http://doi.org/10.1146/annurev.psych.59.103006.093639

Bassett, D. S., & Bullmore, E. T. (2009). Human brain networks in health and disease. *Current Opinion in Neurology*, *22*(4), 340–347. http://doi.org/10.1097/WCO.0b013e32832d93dd

Baxter, D. W., & Olszewski, J. (1960). Congenital universal insensitivity to pain. *Brain*, *83*, 381–393.

Becker, A. H. (1997). Emergent and Common Features Influence Metaphor Interpretation. *Metaphor and Symbol*, *12*(4), 243–259. http://doi.org/10.1207/s15327868ms1204_3

Beedie, A., & Kennedy, P. (2002). Quality of Social Support Predicts Hopelessness and Depression Post Spinal Cord Injury. *Journal of Clinical Psychology in Medical Settings*, *9*(3), 227–234. http://doi.org/10.1023/A:1016003428370

Behrman, A. L., & Harkema, S. J. (2000). Locomotor training after human spinal cord injury: a series of case studies. *Physical Therapy*, *80*(7), 688–700.

Belousov, A. B. (2012). Novel model for the mechanisms of glutamate-dependent excitotoxicity: Role of neuronal gap junctions. *Brain Research*, *1487*, 123–130. http://doi.org/10.1016/j.brainres.2012.05.063

Bennett, M. (2001). The LANSS Pain Scale: the Leeds assessment of neuropathic symptoms and signs. *PAIN*, *92*, 147–157.

Berelson, B. (1952). *Content analysis in communication research*. Free Press.

Beric, A. (1990). Altered sensation and pain in spinal cord injury. In: Dimitrijevic MR, Wall PD (eds). In *Altered sensation and pain. Recent achievements in restorative neurology.* (Vol. 3, pp. 27–36). Basel: Karger.

Bernardes, S. F., Keogh, E., & Lima, M. L. (2008). Bridging the gap between pain and gender research: a selective literature review. *European Journal of Pain (London, England)*, *12*(4), 427–440. http://doi.org/10.1016/j.ejpain.2007.08.007

Boev, C. (2012). The Relationship Between Nurses' Perception of Work Environment and Patient Satisfaction in Adult Critical Care. *Journal of Nursing Scholarship*, *44*(4), 368–375. http://doi.org/10.1111/j.1547-5069.2012.01466.x

Bohlmeijer, E., Prenger, R., Taal, E., & Cuijpers, P. (2010). The effects of mindfulness-based stress reduction therapy on mental health of adults with a chronic medical disease: a meta-analysis. *Journal of Psychosomatic Research*, *68*(6), 539–544. http://doi.org/10.1016/j.jpsychores.2009.10.005

Bombardier, C. H., Richards, J. S., Krause, J. S., Tulsky, D., & Tate, D. G. (2004). Symptoms of major depression in people with spinal cord injury: implications for screening. *Archives of Physical Medicine and Rehabilitation*, *85*(11), 1749–1756.

Bonanno, G. A. (2004). Loss, trauma, and human resilience: have we underestimated the human capacity to thrive after extremely aversive events? *The American Psychologist*, *59*(1), 20–28. http://doi.org/10.1037/0003-066X.59.1.20

Boothby, J. L., Thorn, B. E., Overduin, L. Y., & Ward, L. C. (2004). Catastrophizing and perceived partner responses to pain. *Pain*, *109*(3), 500–506. http://doi.org/10.1016/j.pain.2004.02.030

Börsbo, B., Peolsson, M., & Gerdle, B. (2009). The complex interplay between pain intensity, depression, anxiety and catastrophising with respect to quality of life and disability. *Disability and Rehabilitation*, *31*(19), 1605–1613.

Boschen, K. A., Tonack, M., & Gargaro, J. (2003). Long-term adjustment and community reintegration following spinal cord injury. *International Journal of Rehabilitation Research. Internationale Zeitschrift Für Rehabilitationsforschung. Revue Internationale De Recherches De Réadaptation*, *26*(3), 157–164. http://doi.org/10.1097/01.mrr.0000088440.78481.1f

Botvinick, M. M., Cohen, J. D., & Carter, C. S. (2004). Conflict monitoring and anterior cingulate cortex: an update. *Trends in Cognitive Sciences*, *8*(12), 539–546. http://doi.org/10.1016/j.tics.2004.10.003

Bracken, M. B., Shepard, M. J., Collins, W. F., Holford, T. R., Young, W., Baskin, D. S., … Maroon, J. (1990). A randomized, controlled trial of methylprednisolone or naloxone in the treatment of acute spinal-cord injury. Results of the Second National Acute Spinal Cord Injury Study. *The New England Journal of Medicine*, *322*(20), 1405–1411. http://doi.org/10.1056/NEJM199005173222001

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101.

Breivik, H., Collett, B., Ventafridda, V., Cohen, R., & Gallacher, D. (2006). Survey of chronic pain in Europe: prevalence, impact on daily life and treatment. *European Journal Of Pain*, *10*(4), 287–333.

Brocki, J. M., & Wearden, A. J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology & Health*, *21*(1), 87–108. http://doi.org/10.1080/14768320500230185

Broekmans, S., Dobbels, F., Milisen, K., Morlion, B., & Vanderschueren, S. (2009). Medication adherence in patients with chronic non-malignant pain: is there a problem? *European Journal Of Pain*, *13*, 115–123.

Brown, K. W., Ryan, R. M., & Creswell, J. D. (2007). Mindfulness: Theoretical Foundations and Evidence for its Salutary Effects. *Psychological Inquiry*, *18*(4), 211–237. http://doi.org/10.1080/10478400701598298

Bryant, A., & Charmaz, K. (2007). Feminist Qualitative Research and Grounded Theory: Complexities, Criticisms, and Opportunities. In *The SAGE Handbook of Grounded Theory.* (pp. 417–436). London: SAGE Publications Ltd.

Burfitt, S. N., Greiner, D. S., Miers, L. J., Kinney, M. R., & Branyon, M. E. (1993). Professional nurse caring as perceived by critically ill patients: a phenomenologic study. *American Journal of Critical Care: An Official Publication, American Association of Critical-Care Nurses*, *2*(6), 489–499.

Burke, D. C. (1973). Pain in paraplegia. *Paraplegia*, *10*, 297–313.

Byrnes, M., Beilby, J., Ray, P., McLennan, R., & Schug, S. (2012). Patient-focused goal planning process and outcome after spinal cord injury rehabilitation: quantitative and qualitative audit. *Clinical Rehabilitation*, *26*(2), 1141–1149.

Campbell, L. C., Clauw, D. J., & Keefe, F. J. (2003). Persistent pain and depression: a biopsychosocial perspective. *Biological Psychiatry*, *54*(3), 399–409.

Cardenas, D. D., & Jensen, M. P. (2006). Treatments for Chronic Pain in Persons With Spinal Cord Injury: A Survey Study. *The Journal of Spinal Cord Medicine*, *29*(2), 109–117.

Cardenas, D. D., Nieshoff, E. C., Suda, K., Goto, S.-I., Sanin, L., Kaneko, T., … Knapp, L. E. (2013). A randomized trial of pregabalin in patients with neuropathic pain due to spinal cord injury. *Neurology*, *80*(6), 533–539. http://doi.org/10.1212/WNL.0b013e318281546b

Cardenas, D. D., Warms, C. A., Turner, J. A., Marshall, H., Brooke, M. M., & Loeser, J. D. (2002). Efficacy of amitriptyline for relief of pain in spinal cord injury: results of a randomized controlled trial. *Pain*, *96*(3), 365–373.

Cardol, M., Jong, B. A., & Ward, C. D. (2002). On autonomy and participantion in rehabilitation. *Disability & Rehabilitation*, *24*, 970–974.

Carpenter, C., & Forman, B. (2004). Provision of community programs for clients with spinal cord injury: use of qualitative research to evaluate the role of the British Columbia Paraplegic Association. *Topics in Spinal Cord Injury Rehabilitation*, *9*(4), 57–72.

Carstensen, L. L., Fung, H. H., & Charles, S. T. (2003). Socioemotional Selectivity Theory and the Regulation of Emotion in the Second Half of Life. *Motivation and Emotion*, *27*(2), 103–123. http://doi.org/10.1023/A:1024569803230

Carstensen, L. L., Pasupathi, M., Mayr, U., & Nesselroade, J. R. (2000). Emotional experience in everyday life across the adult life span. *Journal of Personality and Social Psychology*, *79*(4), 644–655. http://doi.org/10.1037/0022-3514.79.4.644

Carver, C. S., Scheier, M. F., & Segerstrom, S. C. (2010). Optimism. *Clinical Psychology Review*, *30*(7), 879–889. http://doi.org/10.1016/j.cpr.2010.01.006

Cassidy, E. L., Atherton, R. J., Robertson, N., Walsh, D. A., & Gillett, R. (2012). Mindfulness, functioning and catastrophizing after multidisciplinary pain management for chronic low back pain. *Pain*, *153*(3), 644–650. http://doi.org/10.1016/j.pain.2011.11.027

Catania, J. A., & Binson, D. (1996). Effects of interviewer gender, interviewer choice, and item wording on responses to questions concerning sexual behavior. *Public Opinion Quarterly*, *60*(3), 345.

Celik, E. C., Erhan, B., & Lakse, E. (2012). The clinical characteristics of neuropathic pain in patients with spinal cord injury. *Spinal Cord*, *50*, 585–589.

Chambers, C. T., & Mogil, J. S. (2015). Ontogeny and phylogeny of facial expression of pain: *PAIN*, *156*(5), 798–799. http://doi.org/10.1097/j.pain.0000000000000133

Chapman, E., Parameshwar, J., Jenkins, D., Large, S., & Tsui, S. (2007). Psychosocial issues for patients with ventricular assist devices: a qualitative pilot study. *American Journal of Critical Care: An Official Publication, American Association of Critical-Care Nurses*, *16*(1), 72–81.

Charlifue, S. W., & Gerhart, K. A. (1991). Behavioral and demographic predictors of suicide after traumatic spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, *72*(7), 488–492.

Chew-Graham, C. A., May, C. R., & Roland, M. O. (2004). The harmful consequences of elevating the doctor-patient relationship to be a primary goal of the general practice consultation. *Family Practice*, *21*, 229–231.

Clarke, A. M. (2000). In *First National Conference of the Spinal Network*. Christchurch, New Zealand.

Cleland, J. A., Childs, J. D., & Whitman, J. M. (2008). Psychometric properties of the Neck Disability Index and numeric pain rating scale in patients with mechanical neck pain. *Archives Of Physical Medicine And Rehabilitation*, *89*, 69–74.

Closs, S. J., Staples, V., Reid, I., Bennett, M. I., & Briggs, M. (2009). The impact of neuropathic pain on relationships. *Journal of Advanced Nursing*, *65*(2), 402–411.

Cohen, C. B., & Napolitano, D. (2007). Adjustment to disability. *Journal of Social Work in Disability and Rehabilitation*, *6*, 135–155.

Cole, F., Ashworth, P., Coote, L., Toomer, E., Jenner, E., & Lewin, R. (2012). The Pain Management Plan. *Pain News*, *10*(2), 96–103.

Coulter, A., & Fitzpatrick, R. (2003). The patients' perspective regarding appropriate health care. In G. Albreccht, R. Fitzpatrick, & S. C. Scrimshaw (Eds.), *The Handbook of social studies in health and medicine.* (pp. 454–464). London: Sage Publications.

Cowan, P., Kelly, N., Pasero, C., Covington, E., & Lidz, C. (1998). *Family manual. A manual for families of person with pain.* Rocklin, CA: American Chronic Pain Association.

Craig, K. D. (1999). Emotions and psychobiology. In P. D. Wall and R. Melzack (Eds.). In *Textbook of pain* (4th edition, pp. 331–343). Edinburgh, UK: Churchill Livingstone.

Craig, A. D. (Bud). (2003). PAIN MECHANISMS: Labeled Lines Versus Convergence in Central Processing. *Annual Review of Neuroscience*, *26*(1), 1–30. http://doi.org/10.1146/annurev.neuro.26.041002.131022

Craig, A., Nicholson Perry, K., Guest, R., Tran, Y., & Middleton, J. (2015). Adjustment following chronic spinal cord injury: Determining factors that contribute to social participation. *British Journal of Health Psychology*, n/a–n/a. http://doi.org/10.1111/bjhp.12143

Craig, A. R., Hancock, K., Dickson, H., & Chang, E. (1997). Long-term psychological outcomes in spinal cord injured persons: results of a controlled trial using cognitive behavior therapy. *Archives of Physical Medicine and Rehabilitation*, *78*(1), 33–38.

Craig, A., Tran, Y., Siddall, P., Wijesuriya, N., Lovas, J., Bartrop, R., & Middleton, J. (2013). Developing a model of associations between chronic pain, depressive mood, chronic fatigue, and self-efficacy in people with spinal cord injury. *The Journal of Pain: Official Journal of the American Pain Society*, *14*(9), 911–920. http://doi.org/10.1016/j.jpain.2013.03.002

Crombez, G., Vlaeyen, J. W., Heuts, P. H., & Lysens, R. (1999). Pain-related fear is more disabling than pain itself: evidence on the role of pain-related fear in chronic back pain disability. *Pain*, *80*(1-2), 329–339.

Cuff, L., Fann, J., Bombardier, C., Graves, D., & Kalpakjian, C. (2014). Depression, Pain Intensity, and Interference in Acute Spinal Cord Injury. *Topics in Spinal Cord Injury Rehabilitation*, *20*(1), 32–39.

Davidoff, G., Guarracini, M., Roth, E., Sliwa, J., & Yarkony, G. (1987). Trazodone hydrochloride in the treatment of dysesthetic pain in traumatic myelopathy: a randomized, double-blind, placebo-controlled study. *Pain*, *29*(2), 151–161.

Davis, C. G., & Morgan, M. S. (2008). Finding meaning, perceiving growth, and acceptance of tinnitus. *Rehabilitation Psychology*, *53*(2), 128–138. http://doi.org/10.1037/0090-5550.53.2.128

Davis, C. G., & Novoa, D. C. (2013). Meaning-Making Following Spinal Cord Injury: Individual Differences and Within-Person Change. *Rehabilitation Psychology*, 1–12. http://doi.org/10.1037/a0031554

Defrin, R., Ohry, A., Blumen, N., & Urca, G. (2001). Characterization of chronic pain and somatosensory function in spinal cord injury subjects. *Pain*, *89*(2-3), 253–263.

Den Hollander, M., de Jong, J. R., Volders, S., Goossens, M. E. J. B., Smeets, R. J. E. M., & Vlaeyen, J. W. S. (2010). Fear reduction in patients with chronic pain: a learning theory perspective. *Expert Review of Neurotherapeutics*, *10*(11), 1733–1745. http://doi.org/10.1586/ern.10.115

Dickson, A., Allan, D., & O'Carroll, R. (2008). Biographical disruption and the experience of loss following a spinal cord injury: An interpretative phenomenological analysis. *Psychology & Health*, *23*(4), 407–425.

Dickson, A., Ward, R., O'Brien, G., Allan, D., & O'Carroll, R. (2011). Difficulties adjusting to post-discharge life following a spinal cord injury: An interpretative phenomenological analysis. *Psychology, Health & Medicine*, *16*(4), 463–474. http://doi.org/10.1080/13548506.2011.555769

Dijkers, M., Bryce, T., & Zanca, J. (2009). Prevalence of chronic pain after traumatic spinal cord injury: A systematic review. *Journal of Rehabilitation Research & Development*, *46*(1), 13–29.

DiMatteo, M. R. (2004). Variations in patients' adherence to medical recommendations: a quantitative review of 50 years of research. *Medical Care*, *42*(3), 200–209.

DiMatteo, M. R., & Hays, R. (1980). The significance of patients' perceptions of physician conduct. *Journal of Community Health*, *6*(1), 18–34. http://doi.org/10.1007/BF01324054

Ditor, D. S., Latimer, A. E., Ginis, K. A. M., Arbour, K. P., McCartney, N., & Hicks, A. L. (2003). Maintenance of exercise participation in individuals with spinal cord injury:

effects on quality of life, stress and pain. *Spinal Cord*, *41*(8), 446–450. http://doi.org/10.1038/sj.sc.3101487

Donnelly, C., & Eng, J. J. (2005). Pain following spinal cord injury: the impact on community reintegration. *Spinal Cord*, *43*(5), 278–282.

Donovan, W. H. (2007). Spinal Cord Injury—Past, Present, and Future. *The Journal of Spinal Cord Medicine*, *30*(2), 85–100.

Dorsett, P., & Geraghty, T. (2008). Health-related outcomes of people with spinal cord injury - a 10 year longitudinal study. *Spinal Cord*, *46*, 386–391.

Downar, J., Crawley, A. P., Mikulis, D. J., & Davis, K. D. (2002). A cortical network sensitive to stimulus salience in a neutral behavioral context across multiple sensory modalities. *Journal of Neurophysiology*, *87*(1), 615–620.

Dubner, R., Sessle, B., & Storey, A. T. (1978). *The Neural Basis of Oral and Facial Function.* New York: Plenum Press.

Duff, J., Evans, M. J., & Kennedy, P. (2004). Goal planning: a retrospective audit of rehabilitation process and outcome. *Clinical Rehabilitation*, *18*(3), 275–286. http://doi.org/10.1191/0269215504cr720oa

Duggan, C. H., & Dijkers, M. (1999). Quality of life - peaks and valleys: a qualitative analysis of the narratives of persons with spinal cord injuries. *Canadian Journal of Rehabilitation*, *12*, 181–191.

Dunne, E. A., & Quayle, E. (2001). The Impact of Iatrogenically Acquired Hepatitis C Infection on the Well-being and Relationships of a Group of Irish Women. *Journal of Health Psychology*, *6*(6), 679–692. http://doi.org/10.1177/135910530100600606

Edwards, D., & Potter, J. (1992). *Discursive psychology.* London: SAGE Publications Ltd.

Eatough, V., & Smith, J. A. (2006). I was like a wild wild person: Understanding feelings of anger using interpretative phenomenological analysis. *British Journal of Psychology*, *97*, 483–498.

Eccleston, C. (1995). Chronic pain and distraction: An experimental investigation into the role of sustained and shifting attention in the processing of chronic persistent pain. *Behaviour Research and Therapy*, *33*(4), 391–405. http://doi.org/10.1016/0005-7967(94)00057-Q

Eccleston, C. (2001). Role of psychology in pain management. *British Journal of Anaesthesia*, *87*(1), 144–152.

Eccleston, C., & Crombez, G. (1999). Pain demands attention: a cognitive-affective model of the interruptive function of pain. *Psychological Bulletin*, *125*(3), 356–366.

Eccleston, C., & Crombez, G. (2007). Worry and chronic pain: A misdirected problem solving model. *Pain*, *132*(3), 233–236. http://doi.org/10.1016/j.pain.2007.09.014

Eccleston, C., Crombez, G., Scotford, A., Clinch, J., & Connell, H. (2004). Adolescent chronic pain: patterns and predictors of emotional distress in adolescents with chronic pain and their parents. *Pain*, *108*(3), 221–229. http://doi.org/10.1016/j.pain.2003.11.008

Eccleston, C., Williams, A. C., & Rogers, W. S. (1997). Patients' and professionals' understandings of the causes of chronic pain: Blame, responsibility and identity protection. *Social Science & Medicine*, *45*, 699–709.

Ehde, D., & Jensen, M. (2004). Feasibility of a cognitive restructuring intervention for treatment of chronic pain in persons with disabilities. *Rehabilitation Psychology*, *49*(3), 254–258.

Ekman, P., Freisen, W. V., & Ancoli, S. (1980). Facial signs of emotional experience. *Journal of Personality and Social Psychology*, *39*(6), 1125–1134. http://doi.org/10.1037/h0077722

Engel, G. L. (1977). The need for a new medical model: a challenge for biomedicine. *Science*, *196*(4286), 129–136. http://doi.org/10.1126/science.847460

Ethics Committee of the British Psychological Society. (2009). BPS Code of Ethics and Conduct. *The British Psychological Society*.

Fainsilber, L., & Ortony, A. (1987). Metaphor production in the description of emotional states. *Metaphor and Symbolic Activity*, *2*, 239–250.

Fairclough, N. (1992). *Discourse and social change*. Cambridge: PolityPress.

Feinauer, L. L., & Steele, W. R. (1992). Caretaker marriages: The impact of chronic pain syndrome on marital adjustment. *The American Journal of Family Therapy*, *20*(3), 218–226. http://doi.org/10.1080/01926189208250891

Finlay, L. (2002). Negotiating the swamp: the opportunity and challenge of reflexivity in research practice. *Qualitative Research*, *2*(2), 209–230. http://doi.org/10.1177/146879410200200205

Finnerup, N. B., Grydehøj, J., Bing, J., Johannesen, I. L., Biering-Sørensen, F., Sindrup, S. H., & Jensen, T. S. (2009). Levetiracetam in spinal cord injury pain: a randomized controlled trial. *Spinal Cord*, *47*(12), 861–867. http://doi.org/10.1038/sc.2009.55

Finnerup, N. B., Johannesen, I. L., Sindrup, S. H., Bach, F. W., & Jensen, T. S. (2001). Pain and dysesthesia in patients with spinal cord injury: A postal survey. *Spinal Cord*, *39*(5), 256–262. http://doi.org/10.1038/sj.sc.3101161

Fisher, R. J. (1993). Social Desirability Bias and the Validity of Indirect Questioning. *Jounal of Consumer Research*, *20*, 303–315.

Fletcher, L., & Hayes, S. C. (2005). Relational frame theory, acceptance and commitment therapy, and a functional analytic definition of mindfulness. *Journal of Rational-Emotive and Cognitive-Behavior Therapy*, *23*(4), 315–336. http://doi.org/10.1007/s10942-005-0017-7

Fogarty, L. A., Curbow, B. A., Wingard, J. R., McDonnell, K., & Somerfield, M. R. (1999). Can 40 Seconds of Compassion Reduce Patient Anxiety? *Journal of Clinical Oncology*, *17*(1), 371–371.

Fortner, B. V., Demarco, G., Irving, G., Ashley, J., Keppler, G., Chavez, J., & Munk, J. (2003). Description and predictors of direct and indirect costs of pain reported by cancer patients. *Journal of Pain and Symptom Management*, *25*(1), 9–18.

French, D., Maissi, E., & Marteau, T. M. (2005). The purpose of attributing cause: beliefs about the causes of myocardial infarction. *Social Science & Medicine (1982)*, *60*(7), 1411–1421. http://doi.org/10.1016/j.socscimed.2004.08.008

Fritz, J. M., George, S. Z., & Delitto, A. (2001). The role of fear-avoidance beliefs in acute low back pain: relationships with current and future disability and work status. *Pain*, *94*, 7–15.

Gadamer, H. G. (1975). *Truth and Method*. Seabury Press.

Gagliese, L. (2009). Pain and Aging: The Emergence of a New Subfield of Pain Research. *The Journal of Pain*, *10*(4), 343–353. http://doi.org/10.1016/j.jpain.2008.10.013

Gamsa, A. (1994). The role of psychological factors in chronic pain. II. A critical appraisal. *Pain*, *57*(1), 17–29.

Garfinkel, H. (1967). *Studies in ethnomethodology*. Cambridge: PolityPress.

Garland, E. L., Manusov, E. G., Froeliger, B., Kelly, A., Williams, J. M., & Howard, M. O. (2014). Mindfulness-oriented recovery enhancement for chronic pain and prescription opioid misuse: Results from an early-stage randomized controlled trial. *Journal of Consulting and Clinical Psychology*, *82*(3), 448–459. http://doi.org/10.1037/a0035798

Gauthier, L. R., Rodin, G., Zimmermann, C., Warr, D., Moore, M., Shepherd, F., & Gagliese, L. (2009). Acceptance of pain: a study in patients with advanced cancer. *Pain*, *143*(1-2), 147–154. http://doi.org/10.1016/j.pain.2009.02.009

Gharibian, D., Polzin, J. K., & Rho, J. P. (2013). Compliance and persistence of antidepressants versus anticonvulsants in patients with neuropathic pain during the first year of therapy. *The Clinical Journal of Pain*, *29*(5), 377–381.

Gibbs, R. W., & Matlock, T. (2008). Metaphor, imagination, and simulation: Psycholinguistic evidence. In *The Cambridge handbook of metaphor and thought* (pp. 161–176).

Gibson, S. J., & Helme, R. D. (2001). Age-related differences in pain perception and report. *Clinics in Geriatric Medicine*, *17*(3), 433–456. http://doi.org/10.1016/S0749-0690(05)70079-3

Gijsbers, K., & Nicholson, F. (2005). Experimental Pain Thresholds Influenced by Sex of Experimenter. *Perceptual & Motor Skills*, *101*(3), 803–807.

Gillanders, D., Potter, L., & Morris, P. G. (2012). Pain related-visual imagery is associated with distress in chronic pain sufferers. *Behavioural and Cognitive Psychotherapy*, *40*(5), 577–589. http://doi.org/10.1017/S1352465812000045

Giorgi, A., & Giorgi, B. (2003). The descriptive phenomenological psychological method. In P. M. Camic, J. E. Rhodes, & L. Yardley (Eds.). In *Qualitative research in psychology:*

Expanding perspectives in methodology and design (pp. 243–273). Washington, DC: American Psychological Association.

Glaser, B. G., & Strauss, A. L. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Transaction Publishers.

Goldschneider. (1920). Pattern Theory.

Goodin, B. R., Glover, T. L., Sotolongo, A., King, C. D., Sibille, K. T., Herbert, M. S., … Fillingim, R. B. (2013). The association of greater dispositional optimism with less endogenous pain facilitation is indirectly transmitted through lower levels of pain catastrophizing. *The Journal of Pain: Official Journal of the American Pain Society*, *14*(2), 126–135. http://doi.org/10.1016/j.jpain.2012.10.007

Gosden, T., Morris, P. G., Ferreira, N. B., Grady, C., & Gillanders, D. T. (2014). Mental imagery in chronic pain: prevalence and characteristics. *European Journal of Pain (London, England)*, *18*(5), 721–728. http://doi.org/10.1002/j.1532-2149.2013.00409.x

Goubert, L., Craig, K. D., & Buysse, A. (2011). Perceiving Others in Pain: Experimental and Clinical Evidence on the Role of Empathy. In *The Social Neuroscience of Empathy* (pp. 153–165). MIT Press.

Granberg, A., Engberg, I. B., & Lundberg, D. (1999). Acute confusion and unreal experiences in intensive care patients in relation to the ICU syndrome. Part II. *Intensive & Critical Care Nursing: The Official Journal of the British Association of Critical Care Nurses*, *15*(1), 19–33.

Gregorian, R. S., Gasik, A., Kwong, W. J., Voeller, S., & Kavanagh, S. (2010). Importance of Side Effects in Opioid Treatment: A Trade-Off Analysis With Patients and Physicians. *Journal of Pain*, *11*(11), 1095–1108.

Hackmann, A., Bennett-Levy, J., & Holmes, E. A. (2011). *Oxford Guide to Imagery in Cognitive Therapy*. Oxford: Open University Press.

Hama, A., & Sagen, J. (2012). Combination Drug Therapy for Pain following Chronic Spinal Cord Injury. *Pain Research & Treatment*, 1–13.

Hammell, K. W. (2004). Quality of life among people with high spinal cord injury living in the community. *Spinal Cord*, *42*, 607–620.

Hammell, K. W. (2007). Quality of life after spinal cord injury: a meta-synthesis of qualitative findings. *Spinal Cord*, *45*, 124–139.

Hanson, S., Buckelew, S. P., Hewett, J., & O'Neal, G. (1993). The relationship between coping and adjustment after spinal cord injury: A 5-year follow-up study. *Rehabilitation Psychology*, *38*(1), 41–52. http://doi.org/10.1037/h0080289

Hanssen, M. M., Peters, M. L., Vlaeyen, J. W. S., Meevissen, Y. M. C., & Vancleef, L. M. G. (2013). Optimism lowers pain: Evidence of the causal status and underlying mechanisms. *PAIN®*, *154*(1), 53–58. http://doi.org/10.1016/j.pain.2012.08.006

Hansson, K. S., Fridlund, B., Brunt, D., Hansson, B., & Rask, M. (2011). The meaning of the experiences of persons with chronic pain in their encounters with the health service. *Scandinvaian Journal of Caring Sciences*, *25*, 444–450.

Hart, R. P., Martelli, M. F., & Zasler, N. D. (2000). Chronic pain and neuropsychological functioning. *Neuropsychology Review*, *10*(3), 131–149.

Hayes, S. C. (1994). Content, context, and the types of psychological acceptance. In S. C. Hayes, N. S. Jacobson, V. M. Folette, & M. J. Dougher (Eds.), *Acceptance and change: Content and context in psychotherapy* (pp. 13–32). Reno, NV: Context Press.

Hayes, S. C. (2004). Acceptance and commitment therapy, relational frame theory, and the third wave of behavioral and cognitive therapies. *Behavior Therapy*, *35*(4), 639–665. http://doi.org/10.1016/S0005-7894(04)80013-3

Hayes, S. C., Barnes-Holmes, D., & Roche, B. (2001). *Relational frame theory: A post-Skinnerian account of human language and cognition.* New York, NY: Kluwer Academic/Plenum.

Hayes, S. C., Strosahl, K., & Wilson K. G. (1999). *Acceptance and commitment therapy: An experiential approach to behavior change.* New York, NY: Guilford Press.

Hayes, S. C., Pistorello, J., & Levin, M. E. (2012). Acceptance and Commitment Therapy as a Unified Model of Behavior Change. *The Counseling Psychologist*, *40*(7), 976–1002. http://doi.org/10.1177/0011000012460836

Hearn, J. H. (2015). Reflecting upon qualitative research with spinal cord injured patients: A personal experience. *PsyPAG Quarterly*, (94), 25–27.

Hearn, J. H., Cotter, I., Fine, P., & A. Finlay, K. (2015). Living with chronic neuropathic pain after spinal cord injury: an interpretative phenomenological analysis of community experience. *Disability and Rehabilitation*, 1–9. http://doi.org/10.3109/09638288.2014.1002579

Heidegger, M. (1962). *Being and Time* (New Ed edition). Malden: Wiley-Blackwell.

Henwood, P., & Ellis, J. A. (2004). Chronic neuropathic pain in spinal cord injury: the patient's perspective. *Pain Research & Management*, *9*(1), 34–49.

Henwood, P., Ellis, J., Logan, J., Dubouloz, C.-J., & D'Eon, J. (2012). Acceptance of chronic neuropathic pain in spinal cord injured persons: a qualitative approach. *Pain*

Management Nursing: Official Journal of the American Society of Pain Management Nurses, *13*(4), 215–222. http://doi.org/10.1016/j.pmn.2010.05.005

Heutink, M., Post, M. W. M., Bongers-Janssen, H. M. H., Dijkstra, C. A., Snoek, G. J., Spijkerman, D. C. M., & Lindeman, E. (2012). The CONECSI trial: Results of a randomised controlled trial of a multidisciplinary cognitive behavioral program for coping with chronic neruropathic pain after spinal cord injury. *Pain*, *153*, 120–128. http://doi.org/10.1016/j.pain.2011.09.029

Heutink, M., Post, M. W. M., Luthart, P., Pfennings, L. E. M. A., Dijkstra, C. A., & Lindeman, E. (2010). A multidisciplinary cognitive behavioural programme for coping with chronic neuropathic pain following spinal cord injury: The protocol of the CONECSI trial. *BMC Neurology*, *10*.

Heutink, M., Post, M. W. M., Overdulve, C. W., Pfennings, L. E. M. A., van de Vis, W., Vrijens, N. L. H., & Lindeman, E. (2013). Which pain coping strategies and cognitions are associated with outcomes of a cognitive behavioral intervention for neuropathic pain after spinal cord injury? *Topics in Spinal Cord Injury Rehabilitation*, *19*(4), 330–340. http://doi.org/10.1310/sci1904-330

Heutink, M., Post, M. W. M., Wollaars, M. M., & van Asbeck, F. W. A. (2011). Chronic spinal cord injury pain: pharmacological and non-pharmacological treatments and treatment effectiveness. *Disability And Rehabilitation*, *33*(5), 433–440.

Heyneman, N. E., Fremouw, W. J., Gano, D., Kirkland, F., & Heiden, L. (1990). Individual differences and the effectiveness of different coping strategies for pain. *Cognitive Therapy and Research*, *14*, 63–77.

Hicks, A. L., Martin, K. A., Ditor, D. S., Latimer, A. E., Craven, C., Bugaresti, J., & McCartney, N. (2003). Long-term exercise training in persons with spinal cord injury: effects on strength, arm ergometry performance and psychological well-being. *Spinal Cord*, *41*(1), 34–43. http://doi.org/10.1038/sj.sc.3101389

Higgins, T. E. (1987). Self-discrepancy: A theory relating self and affect. *Psychological Review*, *94*(3), 319–340. http://doi.org/10.1037/0033-295X.94.3.319

Hoffman, J. M., Bombardier, C. H., Graves, D. E., Kalpakjian, C. Z., & Krause, J. S. (2011). A longitudinal study of depression from 1 to 5 years after spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, *92*(3), 411–418. http://doi.org/10.1016/j.apmr.2010.10.036

Holloway, I., Sofaer-Bennett, B., & Walker, J. (2007). The stigmatisation of people with chronic back pain. *Disability & Rehabilitation*, *29*(18), 1456–1464.

Holmes, E. A., Arntz, A., & Smucker, M. R. (2007). Imagery rescripting in cognitive behaviour therapy: Images, treatment techniques and outcomes. *Journal of Behavior Therapy and Experimental Psychiatry*, *38*(4), 297–305. http://doi.org/10.1016/j.jbtep.2007.10.007

Holzman, A. D., & Turk, D. C. (1986). *Pain Management: A Handbook of Psychological Treatment Approaches*. Pergamon Press.

Homans, G. C. (1961). *Social behavior: its elementary forms.* New York: Harcourt.

Horne, R., Chapman, S. C. E., Parham, R., Freemantle, N., Forbes, A., & Cooper, V. (2013). Understanding Patients' Adherence-Related Beliefs about Medicines Prescribed for Long-Term Conditions: A Meta-Analytic Review of the Necessity-Concerns Framework. *PLoS ONE*, *8*(12), e80633. http://doi.org/10.1371/journal.pone.0080633

Horne, R., & Weinman, J. (1999). Patients' beliefs about prescribed medicines and their role in adherence to treatment in chronic physical illness. *Journal of Psychosomatic Research*, *47*(6), 555–567.

Horne, R., & Weinman, J. (2002). Self-regulation and Self-management in Asthma: Exploring The Role of Illness Perceptions and Treatment Beliefs in Explaining Non-adherence to Preventer Medication. *Psychology & Health*, *17*(1), 17–32. http://doi.org/10.1080/08870440290001502

Horne, R., Weinman, J., Barber, N., Elliott, R., & Morgan, M. (2005). *Concordance, Adherence and Compliance in Medicine Taking: A conceptual map and research priorities.* (Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO).

Houben, R. M., Gijsen, A., Peterson, J., de Jong, P. J., & Vlaeyen, J. W. S. (2005). Do health care providers' attitudes towards back pain predict their treatment recomendations? Differential predictive validity of implicit and explicit attitude measures. *Pain*, *114*, 491–498.

Howe, D. (2008). *The Emotionally Intelligent Social Worker*. Palgrave Macmillan.

Howitt, D., & Cramer, D. (2011). *Introduction to research methods in psychology* (3rd editiom). Essex: Pearson Education Limiited.

Hsieh, H.-F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, *15*(9), 1277–1288. http://doi.org/10.1177/1049732305276687

Hughes, B., & Paterson, K. (1997). The Social Model of Disability and the Disappearing Body: Towards a sociology of impairment. *Disability & Society*, *12*(3), 325–340. http://doi.org/10.1080/09687599727209

Hurt, C. S., Burn, D. J., Hindle, J., Samuel, M., Wilson, K., & Brown, R. G. (2014). Thinking positively about chronic illness: An exploration of optimism, illness perceptions and well-being in patients with Parkinson’s disease. *British Journal of Health Psychology*, *19*(2), 363–379. http://doi.org/10.1111/bjhp.12043

Husserl, E. (1931). *Ideas: General Introduction to Pure Phenomenology (trans. W.R. Boyce Gibson).* New York: Collier.

IASP. (1994). *Classification of chronic pain: descriptions of chronic pain syndromes and definitions of pain terms. International Association for the Study of Pain: Task Force on Taxonomy.* (2nd edition). Seattle, WA: IASP Press.

Jamani, N., & Clyde, Z. (2008). Treatment of pain-related fear in chronic (persistent) pain: the role of safety-seeking behaviour and imagery. *The Cognitive Behaviour Therapist*, *1*(01), 3–15. http://doi.org/10.1017/S1754470X08000032

Jefferson, G. (2004). Glossary of transcript symbols with an introduction. In G. H. Lerner (Ed). In *Conversation Analysis: Studies from the First Generation* (pp. 13–31). Amsterdam: John Benjamins.

Jellema, P., van der Windt, D. A. W. M., van der Horst, H. E., Twisk, J. W. R., Stalman, W. A. B., & Bouter, L. M. (2005). Should treatment of (sub)acute low back pain be aimed at psychosocial prognostic factors? Cluster randomised clinical trial in general practice. *BMJ (Clinical Research Ed.)*, *331*(7508), 84. http://doi.org/10.1136/bmj.38495.686736.E0

Jensen, M. P., Hoffman, A. J., & Cardenas, D. D. (2005). Chronic pain in individuals with spinal cord injury: a survey and longitudinal study. *Spinal Cord*, *43*(12), 704–712. http://doi.org/10.1038/sj.sc.3101777

Jensen, M. P., Turner, J. A., Romano, J. M., & Karoly, P. (1991). Coping with chronic pain: a critical review of the literature. *Pain*, *47*(3), 249–283.

Jensen, M. P., Widerström-Noga, E., Richards, J. S., Finnerup, N. B., Biering-Sørensen, F., & Cardenas, D. D. (2010). Reliability and validity of the International Spinal Cord Injury Basic Pain Data Set items as self-report measures. *Spinal Cord*, *48*(3), 230–238. http://doi.org/10.1038/sc.2009.112

Kabat-Zinn, J. (1982). An outpatient program in behavioral medicine for chronic pain patients based on the practice of mindfulness meditation: Theoretical considerations and preliminary results. *General Hospital Psychiatry*, *4*(1), 33–47. http://doi.org/10.1016/0163-8343(82)90026-3

Kabat-Zinn, J. (2003). Mindfulness-Based Interventions in Context: Past, Present, and Future. *Clinical Psychology: Science and Practice*, *10*(2), 144–156. http://doi.org/10.1093/clipsy.bpg016

Kabat-Zinn, J., Lipworth, L., & Burney, R. (1985). The clinical use of mindfulness meditation for the self-regulation of chronic pain. *Journal of Behavioral Medicine*, *8*(2), 163–190.

Kaiser, S., & Kennedy, P. (2011). An exploration of cognitive appraisals following spinal cord injury. *Psychology, Health & Medicine*, *16*(6), 708–718.

Kakigi, R., Nakata, H., Inui, K., Hiroe, N., Nagata, O., Honda, M., … Kawakimi, M. (2005). Intracerebral pain processing in a yoga master who claims not to feel pain during meditation. *European Journal Of Pain*, *9*, 581–589.

Kállai, I., Barke, A., & Voss, U. (2004). The effects of experimenter characteristics on pain reports in women and men. *Pain*, *112*(1-2), 142–147. http://doi.org/10.1016/j.pain.2004.08.008

Kamper, S. J., Apeldoorn, A. T., Chiarotto, A., Smeets, R. J. E. M., Ostelo, R. W. J. G., Guzman, J., & Tulder, M. W. van. (2015). Multidisciplinary biopsychosocial rehabilitation for chronic low back pain: Cochrane systematic review and meta-analysis. *BMJ*, *350*, h444. http://doi.org/10.1136/bmj.h444

Keefe, F. J., Rumble, M. E., Scipio, C. D., Giordano, L. A., & Perri, L. M. (2004). Psychological aspects of persistent pain: current state of the science. *The Journal of Pain: Official Journal of the American Pain Society*, *5*(4), 195–211. http://doi.org/10.1016/j.jpain.2004.02.576

Kemler, M. A., & Furnée, C. A. (2002). The impact of chronic pain on life in the household. *Journal of Pain and Symptom Management*, *23*(5), 433–441.

Kennedy, P., Duff, J., Evans, M., & Beedie, A. (2003). Coping effectiveness training reduces depression and anxiety following traumatic spinal cord injuries. *The British Journal of Clinical Psychology / the British Psychological Society*, *42*(Pt 1), 41–52. http://doi.org/10.1348/014466503762842002

Kennedy, P., Frankel, H., Gardner, B., & Nuseibeh, I. (1997). Factors associated with acute and chronic pain following traumatic spinal cord injuries. *Spinal Cord*, *35*(12), 814–817.

Kennedy, P., Lude, P., Elfstrom, M. L., & Smithson, E. (2010a). Sense of coherence and psychological outcomes in people with spinal cord injury: Appraisals and behavioural responses. *British Journal of Health Psychology*, *15*(3), 611–621. http://doi.org/10.1348/135910709X478222

Kennedy, P., Marsh, N., Lowe, R., Grey, N., Short, E., & Rogers, B. (2000). A longitudinal analysis of psychological impact and coping strategies following spinal cord injury. *British Journal of Health Psychology*, *5*(2), 157–172. http://doi.org/10.1348/135910700168838

Kennedy, P., & Rogers, B. A. (2000). Anxiety and depression after spinal cord injury: a longitudinal analysis. *Archives of Physical Medicine and Rehabilitation*, *81*(7), 932–937. http://doi.org/10.1053/apmr.2000.5580

Keogh, E. (2006). Sex and gender differences in pain: A selective review of biological and psychosocial factors. *Journal of Men's Health & Gender*, *3*(3), 236–243. http://doi.org/10.1016/j.jmhg.2006.03.006

Keogh, E., & Asmundson, G. J. G. (2004). Negative affectivity, catastrophizing and anxiety sensitivity. In: Asmundson, G. J. G., Vlaeyen, J. and Crombez, G., eds. Understanding and treating fear of pain. Oxford: Oxford University Press. In *Understanding and treating fear of pain.* Oxford: Oxford University Press.

Kerns, R. D., & Otis, J. D. (2003). Family therapy for persons experiencing pain: evidence for its effectiveness. *Seminars in Pain Medicine*, *1*(2), 79–89. http://doi.org/10.1016/S1537-5897(03)00007-7

Kerns, R. D., Otis, J. D., & Wise, E. A. (2002). Treating families of chronic pain patients: Application of a cognitive-behavioral transactional model. In D. C. Turk & R. J. Gatchel (Eds.). In *Psychological approaches to pain management* (pp. 256–275). New York: The Guilford Press.

Kerstin, W., Gabriele, B., & Richard, L. (2006). What promotes physical activity after spinal cord injury? An interview study from a patient perspective. *Disability and Rehabilitation*, *28*(8), 481–488. http://doi.org/10.1080/09638280500211932

Kidder, L. H., & Fine, M. (1987). Qualitative and quantitative methods: When stories converge. *New Directions for Program Evaluation*, *1987*(35), 57–75. http://doi.org/10.1002/ev.1459

Kim, S. S., Kaplowitz, S., & Johnston, M. V. (2004). The Effects of Physician Empathy on Patient Satisfaction and Compliance. *Evaluation & the Health Professions*, *27*(3), 237–251. http://doi.org/10.1177/0163278704267037

Kingston, J., Chadwick, P., Meron, D., & Skinner, T. C. (2007). A pilot randomized control trial investigating the effect of mindfulness practice on pain tolerance, psychological well-being, and physiological activity. *Journal of Psychosomatic Research*, *62*(3), 297–300. http://doi.org/10.1016/j.jpsychores.2006.10.007

Kirmayer, L. J. (1992). The Body’s Insistence on Meaning: Metaphor as Presentation and Representation in Illness Experience. *Medical Anthropology Quarterly*, *6*(4), 323–346. http://doi.org/10.1525/maq.1992.6.4.02a00020

Kolakowsky-Hayner, S. A., & Kishore, R. (1999). Caregiver functioning after traumatic injury. *NeuroRehabilitation*, *13*, 27–33.

Kortte, K. B., Veiel, L., Batten, S. V., & Wegener, S. T. (2009). Measuring avoidance in medical rehabilitation. *Rehabilitation Psychology*, *54*(1), 91–98.

Kowal, J., Wilson, K. G., McWilliams, L. A., Péloquin, K., & Duong, D. (2012). Self-perceived burden in chronic pain: Relevance, prevalence, and predictors. *PAIN®*, *153*(8), 1735–1741. http://doi.org/10.1016/j.pain.2012.05.009

Kranz, D., Bollinger, A., & Nilges, P. (2010). Chronic pain acceptance and affective well-being: a coping perspective. *European Journal of Pain (London, England)*, *14*(10), 1021–1025. http://doi.org/10.1016/j.ejpain.2010.03.010

Kratz, A. L., Hirsh, A. T., Ehde, D. M., & Jensen, M. P. (2013). Acceptance of Pain in Neurological Disorders: Associations With Functioning and Psychosocial Well-Being. *Rehabilitation Psychology*, *58*(1), 1–9. http://doi.org/10.1037/a0031727

Krause, J. S. (1998). Skin sores after spinal cord injury: relationship to life adjustment. *Spinal Cord*, *36*(1), 51–56.

Labianca, R., Sarzi-Puttini, P., Zuccaro, S., Vellucci, R., & Fornasari, D. (2012). Adverse Effects Associated with Non-Opioid and Opioid Treatment in Patients with Chronic Pain. *Clinical Drug Investigation*, *32*(1), 53–63.

Lakoff, G., & Johnson, M. (1980). *Metaphors We Live By.* University of Chicago Press.

Lansbury, G. (2000). Chronic pain management: a qualitative study of elderly people's preferred coping strategies and barriers to management. *Disability & Rehabilitation*, *22*, 2–14.

Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology*, *3*(2), 102–120. http://doi.org/10.1191/1478088706qp062oa

Lasiter, S. (2011). Older adults' perceptions of feeling safe in an intensive care unit. *Journal of Advanced Nursing*, *67*(12), 2649–2657. http://doi.org/10.1111/j.1365-2648.2011.05714.x

Lasiter, S., & Duffy, J. (2013). Older Adults' Perceptions of Feeling Safe in Urban and Rural Acute Care. *Journal of Nursing Administration*, *43*(1), 30–36.

Lauwerier, E., Van Damme, S., Goubert, L., Paemeleire, K., Devulder, J., & Crombez, G. (2012). To control or not? A motivational perspective on coping with pain. *Acta Neurologica Belgica*, *112*(1), 3–7. http://doi.org/10.1007/s13760-012-0020-6

Lavie, N., & Fockert, J. de. (2006). Frontal control of attentional capture in visual search. *Visual Cognition*, *14*(4-8), 863–876. http://doi.org/10.1080/13506280500195953

Lazarus, R. S. (1991). *Emotion and adaptation.* Oxford: Oxford University Press.

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping.* New York: Springer.

Leavitt, A., Van Schepen, W., Kroustos, K. R., & Hartzler, M. (2012). Perceptions of pain medication in the elderly. *The Consultant Pharmacist: The Journal of the American Society of Consultant Pharmacists*, *27*(10), 738–740. http://doi.org/10.4140/TCP.n.2012.738

Legrain, V., Van Damme, S., Eccleston, C., Davis, K. D., Seminowicz, D. A., & Crombez, G. (2009). A neurocognitive model of attention to pain: Behavioural and neuroimaging evidence. *Pain*, (144), 230–232.

Levine, F. M., & de Simone, L. L. (1991). The effects of experimenter gender on pain report in male and female subjects. *Pain*, *44*(1), 69–72. http://doi.org/10.1016/0304-3959(91)90149-R

Levin, M. E., Hildebrandt, M. J., Lillis, J., & Hayes, S. C. (2012). The impact of treatment components suggested by the psychological flexibility model: A meta-analysis of laboratory-based component studies. *Behavior Therapy*, *43*, 741–756.

Levitt, H., Korman, Y., & Angus, L. (2000). A metaphor analysis in treatments of depression: Metaphor as a marker of change. *Counselling Psychology Quarterly*, *13*(1), 23–35. http://doi.org/10.1080/09515070050011042

Lewandowski, W. (2004). Psychological factors in chronic pain: a worthwhile undertaking for nursing? *Archives of Psychiatric Nursing*, *18*(3), 97–105.

Lewandowski, W., Morris, R., Draucker, C. B., & Risko, J. (2007). Chronic Pain and the Family: Theory-Driven Treatment Approaches. *Issues in Mental Health Nursing*, *28*, 1019–1044. http://doi.org/10.1080/01612840701522200

Lillrank, A. (2003). Back pain and the resolution of diagnositc uncertainty in illness narratives. *Social Science & Medicine*, *57*, 1045–1054.

Linton, S. J., & Shaw, W. S. (2011). Impact of Psychological Factors in the Experience of Pain. *Physical Therapy*, *91*(5), 700–711.

Ljungberg, I., Kroll, T., Libin, A., & Gordon, S. (2011). Using peer mentoring for people with spinal cord injury to enhance self-efficacy beliefs and prevent medical complications. *Journal of Clinical Nursing*, *20*(3-4), 351–358. http://doi.org/10.1111/j.1365-2702.2010.03432.x

Lofgren, M., & Norrbrink, C. (2012). “But I know what works” - patients’ experience of spinal cord injury neuropathic pain management. *Disability & Rehabilitation*, *34*(25), 2139–2141. http://doi.org/10.3109/09638288.2012.676146

Lyddon, W. J., Clay, A. L., & Sparks, C. L. (2001). Metaphor and Change in Counseling. *Journal of Counseling & Development*, *79*(3), 269–274. http://doi.org/10.1002/j.1556-6676.2001.tb01971.x

Mackay, J., Charles, S. T., Kemp, B., & Heckhausen, J. (2011). Goal Striving and Maladaptive Coping in Adults Living With Spinal Cord Injury: Associations With Affective Well-Being. *Journal of Aging and Health*, *23*(1), 158–176. http://doi.org/10.1177/0898264310382039

Major, B., Richards, C., Cooper, M. L., Cozzarelli, C., & Zubek, J. (1998). Personal resilience, cognitive appraisals, and coping: an integrative model of adjustment to abortion. *Journal of Personality and Social Psychology*, *74*(3), 735–752.

Manns, P. J., & Chad, K. E. (1999). Determining the relation between quality of life, handicap, fitness, and physical activity for persons with spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, *80*(12), 1566–1571.

Marriott, C., & Thompson, A. R. (2008). Managing threats to femininity: Personal and interpersonal experience of living with vulval pain. *Psychology & Health*, *23*(2), 243–258. http://doi.org/10.1080/14768320601168185

Mathias, B., Parry-Jones, B., & Huws, J. C. (2014). Individual experiences of an acceptance-based pain management programme: An interpretative phenomenological analysis. *Psychology & Health*, *29*(3), 279–296. http://doi.org/10.1080/08870446.2013.845667

Martin Ginis, K. A., Jung, M. E., & Gauvin, L. (2003). To see or not to see: effects of exercising in mirrored environments on sedentary women’s feeling states and self-efficacy. *Health Psychology: Official Journal of the Division of Health Psychology, American Psychological Association*, *22*(4), 354–361.

Matlock, T., Ramscar, M., & Boroditsky, L. (2005). On the Experiential Link Between Spatial and Temporal Language. *Cognitive Science*, *29*(4), 655–664. http://doi.org/10.1207/s15516709cog0000_17

McBeth, J., Macfarlane, G. J., & Silman, A. J. (2002). Does chronic pain predict future psychological distress? *Pain*, *96*(3), 239–245.

McCaffery, M. (1968). *Nursing Practice Theories Related to Cognition, Bodily Pain, and Man-Environment Interactions.* Los Angeles: University of California at LA Students Store.

McCaffrey, R., & Locsin, R. C. (2002). Music listening as a nursing intervention: a symphony of practice. *Holistic Nursing Practice*, *16*(3), 70–77.

McCracken, L. M. (1998). Learning to live with the pain: acceptance of pain predicts adjustment in persons with chronic pain. *Pain*, *74*, 21–27.

McCracken, L. M., & Eccleston, C. (2003). Coping or acceptance: What to do about chronic pain? *Pain*, *105*, 197–204.

McCracken, L. M., & Eccleston, C. (2005). A prospective study of pain and patient functioning with chronic pain. *Pain*, *116*, 164–169

McCracken, L. M., & Gutiérrez-Martínez, O. (2011). Processes of change in psychological flexibility in an interdisciplinary group-based treatment for chronic pain based on Acceptance and Commitment Therapy. *Behaviour Research & Therapy*, *49*(4), 267–274. http://doi.org/10.1016/j.brat.2011.02.004

McCracken, L. M., Hoskins, J., & Eccleston, C. (2006). Concerns about medication and medication use in chronic pain. *Journal of Pain*, *7*, 726–734.

McCracken, L. M., MacKichan, F., & Eccleston, C. (2007). Contextual cognitive-behavioral therapy for severely disabled chronic pain sufferers: effectiveness and clinically significant change. *European Journal of Pain (London, England)*, *11*(3), 314–322. http://doi.org/10.1016/j.ejpain.2006.05.004

McCracken, L. M., & Vowles, K. E. (2014). Acceptance and Commitment Therapy and Mindfulness for Chronic Pain: Model, Process, and Progress. *American Psychologist*, *69*(2), 178–187.

McCracken, L. M., Vowles, K. E., & Eccleston, C. (2005). Acceptance-based treatment for persons with complex, long standing chronic pain: a preliminary analysis of treatment outcome in comparison to a waiting phase. *Behaviour Research and Therapy*, *43*(10), 1335–1346. http://doi.org/10.1016/j.brat.2004.10.003

McCracken, L. M., & Zhao-O'Brien, J. (2010). General psychological acceptance and chronic pain: there is more to accept than the pain itself. *European Journal of Pain (London, England)*, *14*(2), 170–175. http://doi.org/10.1016/j.ejpain.2009.03.004

McIntosh, A., & Shaw, C. (2003). Barriers to patient information provision in primary care: patients' and general practitioners' experiences and expectations of information for low back pain. *Health Expectations*, *6*, 19–29.

McKinley, W. O., Jackson, A. B., Cardenas, D. D., & DeVivo, M. J. (1999). Long-term medical complications after traumatic spinal cord injury: a regional model systems analysis. *Archives of Physical Medicine and Rehabilitation*, *80*(11), 1402–1410.

McKinley, W. O., Seel, R. T., & Hardman, J. T. (1999). Nontraumatic spinal cord injury: incidence, epidemiology, and functional outcome. *Archives of Physical Medicine and Rehabilitation*, *80*(6), 619–623.

McMahon, S. S., Albermann, S., Rooney, G. E., Moran, C., Hynes, J., Garcia, Y., … Barry, F. P. (2009). Effect of cyclosporin A on functional recovery in the spinal cord following contusion injury. *Journal of Anatomy*, *215*(3), 267–279. http://doi.org/10.1111/j.1469-7580.2009.01107.x

McMurray, G. A. (1975). Theories of pain and congenital universal insensitivity to pain. *Canadian Journal of Psychology*, *29*, 302–315.

Murray, C. D., & Rhodes, K. (2005). “Nobody likes damaged goods”: the experience of adult visible acne. *British Journal of Health Psychology*, *10*(Pt 2), 183–202. http://doi.org/10.1348/135910705X26128

McParland, J. L., Eccleston, C., Osborn, M., & Hezseltine, L. (2010). It’s not fair: An Interpretative Phenomenological Analysis of discourse of justice and fairness in chronic pain. *Health*, *15*(5), 459–474. http://doi.org/10.1177/1363459310383593

Melzack, R. (1999). From the gate to the neuromatrix. *Pain*, *Suppl 6*, S121–126.

Melzack, R., & Casey, K. L. (1968). Sensory, motivational, and central control determinants of pain: A new conceptual model. In *The Skin Senses* (pp. 423–443).

Melzack, R., & Katz, J. (2013). Pain. *Wiley Interdisciplinary Reviews: Cognitive Science*, *4*(1), 1–15. http://doi.org/10.1002/wcs.1201

Melzack, R., & Wall, P. D. (1965). Pain mechanisms: a new theory. *Science (New York, N.Y.)*, *150*(3699), 971–979.

Melzack, R., & Wall, P. D. (1988). *The Challenge of pain.* (2nd edition). London: Penguin Books.

Merskey, H. (1979). Pain terms: a list with definitions and notes on usage. Recommended by the IASP Subcommittee on Taxonomy. *Pain*, *6*(3), 249.

Middleton, J. W., Dayton, A., Walsh, J., Rutkowski, S. B., Leong, G., & Duong, S. (2012). Life expectancy after spinal cord injury: a 50-year study. *Spinal Cord*, *50*(11), 803–811. http://doi.org/10.1038/sc.2012.55

Mineka, S., & Kihlstrom, J. F. (1978). Unpredictable and uncontrollable events: a new perspective on experimental neurosis. *Journal of Abnormal Psychology*, *87*(2), 256–271.

Mingaila, S., & Krisciunas, A. (2005). Occupational therapy for patients with spinal cord injury in early rehabilitation. *Medicina (Kauna)*, *41*, 649–654.

Modirian, E., Pirouzi, P., Soroush, M., Karbalaei-Esmaeili, S., Shojaei, H., & Zamani, H. (2010). Chronic pain after spinal cord injury: results of a long-term study. *Pain Medicine (Malden, Mass.)*, *11*(7), 1037–1043.

Mollon, D. (2014). Feeling safe during an inpatient hospitalization: a concept analysis. *Journal of Advanced Nursing*, *70*(8), 1727–1737. http://doi.org/10.1111/jan.12348

Molton, I. R., Stoelb, B. L., Jensen, M. P., Ehde, D. M., Raichle, K. A., & Cardenas, D. D. (2009). Psychosocial factors and adjustment to chronic pain in spinal cord injury: Replication and cross-validation. *Journal of Rehabilitation Research & Development*, *46*(1), 31–42.

Monsivais, D., & Engebretson, J. (2012). “I’m Just Not That Sick.” *Journal of Holistic Nursing*, *30*(3), 188–194.

Morley-Forster, P. K., Clark, A. J., Speechley, M., & Moulin, D. E. (2003). Attitudes towards opioid use for chronic pain: a Canadian physician survey. *Pain Research & Management*, *8*, 189–194.

Morley, S., Davies, C., & Barton, S. (2005). Possible selves in chronic pain: self-pain enmeshment, adjustment and acceptance. *Pain*, *115*(1-2), 84–94. http://doi.org/10.1016/j.pain.2005.02.021

Morley, S., & Eccleston, C. (2004). The object of fear in chronic pain. In: Asmundsen, G., Vlaeyen, J. and Crombez, G. (eds.). In *Understanding and treating fear of pain.* Oxford: Oxford University Press.

Morley, S., Eccleston, C., & Williams, A. C. (1999). Systematic review and meta-analysis of randomized controlled trials of cognitive behaviour therapy and behaviour therapy for chronic pain in adults, excluding headache. *Pain*, *80*, 1–13.

Moseley, G. L., Nicholas, M. K., & Hodges, P. W. (2004). A randomized controlled trial of intensive neurophysiology education in chronic low back pain. *The Clinical Journal of Pain*, *20*(5), 324–330.

Muller, R., Peter, C., Cieza, A., & Geyh, S. (2012). The role of social support and social skills in people with spinal cord injury-A systematic review of the literature. *Spinal Cord*, *50*, 94–106.

Munce, S. E. P., Webster, F., Fehlings, M. G., Straus, S. E., Jang, E., & Jaglal, S. B. (2014). Perceived facilitators and barriers to self-management in individuals with traumatic spinal cord injury: a qualitative descriptive study. *BMC Neurology*, *14*, 48. http://doi.org/10.1186/1471-2377-14-48

New, P. W., Lim, T. C., Hill, S. T., & Brown, D. J. (1997). A survey of pain during rehabilitation after acute spinal cord injury. *Spinal Cord*, *35*(10), 658–663.

New, P. W., Rawicki, H. B., & Bailey, M. J. (2002). Nontraumatic spinal cord injury: Demographic characteristics and complications. *Archives of Physical Medicine and Rehabilitation*, *83*(7), 996–1001. http://doi.org/10.1053/apmr.2002.33100

Newton-John, T. (2002). Solicitousness and chronic pain: a critical review. *Pain Reviews*, *9*(1), 7–27.

Newton, E. K., Larkin, M., Melhuish, R., & Wykes, T. (2007). More than just a place to talk: young people's experiences of group psychological therapy as an early intervention for auditory hallucinations. *Psychology and Psychotherapy: Theory, Research, Practice*, *80*, 127–149.

Nicholson Perry, K., Nicholas, M. K., & Middleton, J. (2009). Spinal cord injury-related pain in rehabilitation: A cross-sectional study of relationships with cognitions, mood and physical function. *European Journal Of Pain*, *13*(5), 511–517. http://doi.org/10.1016/j.ejpain.2008.06.003

Nicholson Perry, K., Nicholas, M. K., & Middleton, J. (2011). Multidisciplinary cognitive behavioural pain management programmes for people with a spinal cord injury: Design and implementation. *Disability and Rehabilitation: An International, Multidisciplinary Journal*, *33*(13-14), 1272–1280. http://doi.org/10.3109/09638288.2010.524276

Nicklas, L. B., Dunbar, M., & Wild, M. (2010). Adherence to pharmacological treatment of non-malignant chronic pain: The role of illness perceptions and medication beliefs. *Psychology & Health*, *25*(5), 601–615. http://doi.org/10.1080/08870440902783610

Nieto, R., Miró, J., Huguet, A., & Saldaña, C. (2011). Are coping and catastrophising independently related to disability and depression in patients with whiplash associated disorders? *Disability and Rehabilitation*, *33*(5), 389–398. http://doi.org/10.3109/09638288.2010.491576

Norman, C., Bender, J. L., Macdonald, J., Dunn, M., Dunne, S., Siu, B., … Hunter, J. (2010). Questions that individuals with spinal cord injury have regarding their chronic pain: a qualitative study. *Disability and Rehabilitation*, *32*(2), 114–124. http://doi.org/10.3109/09638280903033248

Norman, D. A., & Shallice, T. (1986). Attention to action: Willed and automatic control of behaviour. In Davidson, R. J., Schwartz, G. E., and Shapiro, D. (eds). In *Consciousness and Self-Regulation: Advances in Research and Theory.* Plenum Press.

Norrbrink Budh, C., Löfgren, M., Hunter, J. P., & Ellis, J. (2012). Patients' perspectives on pain. *Topics in Spinal Cord Injury Rehabilitation*, *18*(1), 50–56. http://doi.org/10.1310/sci1801-50

Norrbrink, C., Kowalski, J., & Lundeberg, T. (2006). A comprehensive pain management programme comprising educational, cognitive and behavioural interventions for neuropathic pain following spinal cord injury. *Journal of Rehabilitation Medicine*, *38*(3), 172–180. http://doi.org/10.1080/16501970500476258

Nunnerly, J. L., Hay-Smith, E. J. C., & Dean, S. G. (2013). Leaving a spinal unit and returning to the wider community: an interpretative phenomenological analysis. *Disability & Rehabilitation*, *35*(14), 1164–1173.

O'Connor, P. (2002). Incidence and patterns of spinal cord injury in Australia. *Accident; Analysis and Prevention*, *34*(4), 405–415.

Ochsner, K. N., Zaki, J., Hanelin, J., Ludlow, D. H., Knierim, K., Ramachandran, T., … Mackey, S. C. (2008). Your pain or mine? Common and distinct neural systems supporting the perception of pain in self and other. *Social Cognitive and Affective Neuroscience*, *3*(2), 144–160. http://doi.org/10.1093/scan/nsn006

Olsen, J., & Hanchett, E. (1997). Nurse-expressed empathy, patient outcomes, and development of a middle-range theory. *Journal of Nursing Scholarship*, *29*(1), 71–76.

Ong, A. D., Bergeman, C. S., Bisconti, T. L., & Wallace, K. A. (2006). Psychological resilience, positive emotions, and successful adaptation to stress in later life. *Journal of*

Personality and Social Psychology, *91*(4), 730–749. http://doi.org/10.1037/0022-3514.91.4.730

Osaka, N., Osaka, M., Morishita, M., Kondo, H., & Fukuyama, H. (2004). A word expressing affective pain activates the anterior cingulate cortex in the human brain: an fMRI study. *Behavioural Brain Research*, *153*(1), 123–127. http://doi.org/10.1016/j.bbr.2003.11.013

Osborne, T. L., Jensen, M. P., Ehde, D. M., Hanley, M. A., & Kraft, G. (2007). Psychosocial factors associated with pain intensity, pain-related interference, and psychological functioning in persons with multiple sclerosis and pain. *Pain*, *127*(1-2), 52–62. http://doi.org/10.1016/j.pain.2006.07.017

Osborn, J., & Derbyshire, S. W. G. (2010). Pain sensation evoked by observing injury in others. *PAINÂ®*, *148*(2), 268–274. http://doi.org/10.1016/j.pain.2009.11.007

Osborn, M., & Smith, J. A. (1998). The experience of chronic benign lower back pain: An interpretative phenomenological anslysis. *British Journal of Health Psychology*, *3*, 65–83.

Osborn, M., & Smith, J. A. (2006). Living with a body separate from the self. The experience of the body in chronic benign low back pain: an interpretative phenomenological analysis. *Scandinvaian Journal of Caring Sciences*, *20*, 216–222.

Osterberg, L., & Blaschke, T. (2005). Adherence to Medication. *New England Journal of Medicine*, *353*(5), 487–497. http://doi.org/10.1056/NEJMra050100

Palmer, M., Larkin, M., de Visser, R., & Fadden, G. (2010). Developing an interpretative phenomenological approach to focus group data. *Qualitative Research in Psychology*, *7*(2), 99–121. http://doi.org/10.1080/14780880802513194

Parsons, S., Harding, G., Breen, A., Foster, N., Pincus, T., Vogel, S., & Underwood, M. (2007). The influence of patients' and primary care practitioners' beliefs and expectations about chronic musculoskeletal pain on the process of care: a systematic review of qualitative studies. *Clinical Journal of Pain*, *23*, 91–98.

Pavlov, I. P. (1927). Conditioned reflexes: An investigation of the physiological activity of the cerebral cortex.

Peter, C., Müller, R., Cieza, A., & Geyh, S. (2012). Psychological resources in spinal cord injury: a systematic literature review. *Spinal Cord*, *50*(3), 188–201. http://doi.org/10.1038/sc.2011.125

Peters, L. C., Stambrook, M., Moore, A. D., Zubek, E., Dubo, H., & Blumenschein, S. (1992). Diferential effects of spinal cord injury and head injury on marital adjustment. *Brain Injury*, *6*, 461–467.

Philips, H. C. (2011). Imagery and Pain: The Prevalence, Characteristics, and Potency of Imagery Associated with Pain. *Behavioural and Cognitive Psychotherapy*, *39*(05), 523–540. http://doi.org/10.1017/S1352465811000282

Pincus, T., & Morley, S. (2001). Cognitive-processing bias in chronic pain: A review and integration. *Psychological Bulletin*, *127*(5), 599–617. http://doi.org/10.1037/0033-2909.127.5.599

Pincus, T., Vogel, S., Burton, A. K., Santos, R., & Field, A. P. (2006). Fear avoidance and prognosis in back pain: a systematic review and synthesis of current evidence. *Arthritis and Rheumatism*, *54*(12), 3999–4010. http://doi.org/10.1002/art.22273

Pollard, C., & Kennedy, P. (2007). A longitudinal analysis of emotional impact, coping strategies and post-traumatic psychological growth following spinal cord injury: A 10-

year review. *British Journal of Health Psychology*, *12*, 347–362. http://doi.org/10.1348/135910707X197046

Popovic, M. R., Thrasher, T. A., Adams, M. E., Takes, V., Zivanovic, V., & Tonack, M. I. (2006). Functional electrical therapy: retraining grasping in spinal cord injury. *Spinal Cord*, *44*(3), 143–151. http://doi.org/10.1038/sj.sc.3101822

Putzke, J. D., Richards, J. S., Hicken, B. L., Ness, T. J., Kezar, L., & DeVivo, M. (2002). Pain classification following spinal cord injury: The utility of verbal descriptors. *Spinal Cord*, *40*(3), 118.

Quill, T. E., & Brody, H. (1996). Physician recommendations and patient autonomy: finding a balance between physician power and patient choice. *Annals of Internal Medicine*, *125*(9), 763–769.

Radley, A., & Chamberlain, K. (2001). Health psychology and the study of the case: from method to analytic concern. *Social Science & Medicine*, *53*(3), 321–332. http://doi.org/10.1016/S0277-9536(00)00320-8

Raichle, K. A., Hanley, M., Jensen, M. P., & Cardenas, D. D. (2007). Cognitions, coping, and social environment predict adjustment to pain in spinal cord injury. *The Journal of Pain: Official Journal of the American Pain Society*, *8*(9), 718–729. http://doi.org/10.1016/j.jpain.2007.05.006

Reid, M. C., Eccleston, C., & Pillemer, K. (2015). Management of chronic pain in older adults. *The BMJ*, *350*, h532. http://doi.org/10.1136/bmj.h532

Reynolds, F., & Lim, K. H. (2007). Contribution of visual art-making to the subjective well-being of women living with cancer: A qualitative study. *The Arts in Psychotherapy*, *34*(1), 1–10. http://doi.org/10.1016/j.aip.2006.09.005

Rintala, D. H., Loubser, P. G., Castro, J., Hart, K. A., & Fuhrer, M. J. (1998). Chronic pain in a community-based sample of men with spinal cord injury: prevalence, severity, and relationship with impairment, disability, handicap, and subjective well-being. *Archives of Physical Medicine and Rehabilitation*, *79*(6), 604–614.

Rintala, D. H., Hart, K. A., & Priebe, M. M. (2004). Predicting consistency of pain over a 10-year period in persons with spinal cord injury. *Journal of Rehabilitation Research and Development*, *41*(1), 75–88.

Robinson, M. E., Riley III, J. L., Myers, C. D., Papas, R. K., Wise, E. A., Waxenberg, L. B., & Fillingim, R. B. (2001). Gender role expectations of pain: Relationship to sex differences in pain. *The Journal of Pain*, *2*(5), 251–257. http://doi.org/10.1054/jpai.2001.24551

Rodham, K., McCabe, C., & Blake, D. (2009). Seeking support: An interpretative phenomenological analysis of an Internet message board for people with Complex Regional Pain Syndrome. *Psychology & Health*, *24*(6), 619–634. http://doi.org/10.1080/08870440802563245

Romano, J., Cano, A., & Schmaling, K. (2011). Assessment of couples and families with chronic pain. In D. C. Turk & R. Melzack, *Handbook of pain assessment.* (3rd ed., pp. 98–116). New York, NY: Guildford Press.

Romano, J. M., & Schmaling, K. B. (2001). Assessment of couples and families with chronic pain. In D. C. Turk & R. Melzack (Eds.),. In *Handbook of pain assessment.* (pp. 346–361). New York: The Guilford Press.

Romano, J. M., Turner, J. A., Jensen, M. P., Friedman, L. S., Bulcroft, R. A., Hops, H., & Wright, S. F. (1995). Chronic pain patient-spouse behavioral interactions predict patient disability. *Pain*, *63*(3), 353–360.

Rosser, B. A., McCracken, L. M., Velleman, S. C., Boichat, C., & Eccleston, C. (2011). Concerns about medication and medication adherence in patients with chronic pain recruited from general practice. *PAINÂ®*, *152*(5), 1201–1205. http://doi.org/10.1016/j.pain.2011.01.053

Ross, S., Walker, A., & MacLeod, M. J. (2004). Patient compliance in hypertension: role of illness perceptions and treatment beliefs. *Journal of Human Hypertension*, *18*(9), 607–613. http://doi.org/10.1038/sj.jhh.1001721

Ruiz-Párraga, G. T., & López-Martínez, A. E. (2015). The role of experiential avoidance, resilience and pain acceptance in the adjustment of chronic back pain patients who have experienced a traumatic event: a path analysis. *Annals of Behavioral Medicine: A Publication of the Society of Behavioral Medicine*, *49*(2), 247–257. http://doi.org/10.1007/s12160-014-9654-3

Russell, J. A. (1994). Is there universal recognition of emotion from facial expression? A review of the cross-cultural studies. *Psychological Bulletin*, *115*(1), 102–141.

Sacks, H., Schegloff, E. A., & Jefferson, G. (1974). A Simplest Systematics for the Organisation of Turn-Taking for Conversation. *Language*, *50*(4i), 696–735.

Sartre, J. (1943). *Being and Nothingness: An Essay on Phenomenological Ontology*. Paris: Routledge.

Scarry, E. (1985). *The Body in Pain: The Making and Unmaking of the World*. Oxford University Press.

Scascighini, L., Toma, V., Dober-Spielmann, S., & Sprott, H. (2008). Multidisciplinary treatment for chronic pain: a systematic review of interventions and outcomes. *Rheumatology (Oxford, England)*, *47*(5), 670–678. http://doi.org/10.1093/rheumatology/ken021

Schiffrin, D. (1994). *Approaches to Discourse.* Oxford and Massachusettes: Blackwell Publishers.

Schleiermacher, F. (1998). *Schleiermacher: Hermeneutics and Criticism: And Other Writings*. Cambridge University Press.

Schrooten, M. G. S., & Vlaeyen, J. W. S. (2010). Becoming active again? Further thoughts on goal pursuit in chronic pain [A commentary on Christiansen et al.]. *Pain*, *149*, 422–423.

Semino, E. (2010). Descriptions of Pain, Metaphor, and Embodied Simulation. *Metaphor & Symbol*, *25*(4), 205–226. http://doi.org/10.1080/10926488.2010.510926

Severeijns, R., Vlaeyen, J. W., van den Hout, M. A., & Weber, W. E. (2001). Pain catastrophizing predicts pain intensity, disability, and psychological distress independent of the level of physical impairment. *The Clinical Journal of Pain*, *17*(2), 165–172.

Shaw, R. L. (2010). Embedding reflexivity within experiential qualitative psychology. *Qualitative Research in Psychology*, *7*(3), 233–243.

Schoenfelder, T., Schaal, T., Klewer, J., & Kugler, J. (2014). Patient satisfaction and willingness to return to the provider among women undergoing gynecological surgery. *Archives of Gynecology and Obstetrics*, *290*(4), 683–690. http://doi.org/10.1007/s00404-014-3248-y

Sherman, J. E., DeVinney, D. J., & Sperling, K. B. (2004). Social Support and Adjustment After Spinal Cord Injury: Influence of Past Peer-Mentoring Experiences and Current

Live-In Partner. *Rehabilitation Psychology*, *49*(2), 140–149. http://doi.org/10.1037/0090-5550.49.2.140

Shinebourne, P., & Smith, J. A. (2010). The communicative power of metaphors: An analysis and interpretation of metaphors in accounts of the experience of addiction. *Psychology and Psychotherapy: Theory, Research and Practice*, *83*(1), 59–73. http://doi.org/10.1348/147608309X468077

Siddall, P. J. (2009). Management of neuropathic pain following spinal cord injury: now and in the future. *Spinal Cord*, *47*, 352–359.

Siddall, P. J., McClelland, J. M., Rutkowski, S. B., & Cousins, M. J. (2003). A longitudinal study of the prevalence and characteristics of pain in the first 5 years following spinal cord injury. *Pain*, *103*(3), 249–257.

Siddall, P. J., & Middleton, J. W. (2006). A proposed algorithm for the management of pain following spinal cord injury. *Spinal Cord*, *44*(2), 67–77. http://doi.org/10.1038/sj.sc.3101824

Skinner, B. F. (1937). Two types of conditioned reflex: A reply to Konorski and Millier. *Journal of General Psychology*, *16*, 272–279.

Silverman, D. (2010). *Doing qualitative research* (3rd edition). London: SAGE Publications Ltd.

Skinner, T. C., Roberton, T., Allison, G. T., Dunlop, S., & Bucks, R. S. (2010). Experiential Avoidance, Mindfulness and Depression in Spinal Cord Injuries: A Preliminary Study. *Australian Journal of Rehabilitation Counselling, The*, *16*(1), 27–35.

Slade, P. D., Troup, J. D., Lethem, J., & Bentley, G. (1983). The Fear-Avoidance Model of exaggerated pain perception--II. *Behaviour Research and Therapy*, *21*(4), 409–416.

Smith, B., & Sparkes, A. (2004). Men, sport, and spinal cord injury: An analysis of metaphors and narrative types. *Disability & Society*, *19*(6), 613–626. http://doi.org/10.1080/0968759042000252533

Smith, B., & Sparkes, A. C. (2005). Men, sport, spinal cord injury, and narratives of hope. *Social Science & Medicine (1982)*, *61*(5), 1095–1105. http://doi.org/10.1016/j.socscimed.2005.01.011

Smith, B. H., Torrance, N., Bennett, M. I., & Lee, A. J. (2007). Health and quality of life associated with chronic pain of predominantly neuropathic origin in the community. *Clinical Journal of Pain*, *23*(2), 143–149.

Smith, J. A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology & Health*, *11*(2), 261–271. http://doi.org/10.1080/08870449608400256

Smith, J. A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative psychology. *Qualitative Research in Psychology*, *1*, 39–54.

Smith, J. A. (2011a). Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review*, *5*(1), 9–27. http://doi.org/10.180/17437199.2010.510659

Smith, J. A. (2011b). “We could be diving for pearls”: The value of the gem in experiential qualitative psychology. *QMiP Bulletin*, (12), 6–15.

Smith, J. A., & Dunworth, F. (2003). Qualitative Methodology. In: Valsiner, J., Ed., Handbook of Development Psychology. In *Handbook of Development Psychology*. London: SAGE Publications Ltd.

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretive Phenomenological Analysis: Theory, Method and Research*. London: SAGE Publications Ltd.

Smith, J. A., Jarman, M., & Osborn, M. (1999). Doing interpretative phenomenological analysis in M. Murray and K. Chamberlain (Eds.). In *Qualitative health psychology*. London: SAGE Publications Ltd.

Smith, J., & Osborn, M. (2003). Interpretive phenomenological analysis. In J.A. Smith (Ed.). In *Qualitative psychology: a practical guide to research methods* (pp. 51–80). London: SAGE Publications Ltd.

Smith, J. A., & Osborn, M. (2007). Pain as an assault on the self: An interpretative phenomenological analysis of the psychological impact of chronic benign low back pain. *Psychology & Health*, *22*(5), 517–534. http://doi.org/10.1080/14768320600941756

Snelgrove, S., & Liossi, C. (2009). An interpretative phenomenological analysis of living with chronic low back pain. *British Journal of Health Psychology*, *14*(4), 735–749. http://doi.org/10.1348/135910709X402612

Sparkes, A. C., & Smith, B. (2008). Men, spinal cord injury, memories and the narrative performance of pain. *Disability & Society*, *23*(7), 679–690. http://doi.org/10.1080/09687590802469172

Söderlund, A., Olerud, C., & Lindberg, P. (2000). Acute whiplash-associated disorders (WAD): the effects of early mobilization and prognostic factors in long-term symptomatology. *Clinical Rehabilitation*, *14*(5), 457–467. http://doi.org/10.1191/0269215500cr348oa

Squier, R. W. (1990). A model of empathic understanding and adherence to treatment regimens in practitioner-patient relationships. *Social Science & Medicine*, *30*(3), 325–339. http://doi.org/10.1016/0277-9536(90)90188-X

Stavropoulou, C. (2011). Non-adherence to medication and doctor-patient relationship: Evidence from a European survey. *Patient Education and Counseling*, *83*(1), 7–13. http://doi.org/10.1016/j.pec.2010.04.039

Sterling, M., Jull, G., & Kenardy, J. (2006). Physical and psychological factors maintain long-term predictive capacity post-whiplash injury. *Pain*, *122*(1-2), 102–108. http://doi.org/10.1016/j.pain.2006.01.014

Stewart, M. A. (1995). Effective physician-patient communication and health outcomes: a review. *CMAJ: Canadian Medical Association Journal*, *152*(9), 1423–1433.

Strauss, D. J., Devivo, M. J., Paculdo, D. R., & Shavelle, R. M. (2006). Trends in life expectancy after spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, *87*(8), 1079–1085. http://doi.org/10.1016/j.apmr.2006.04.022

Strong, J., Mathews, T., Sussex, R., New, F., Hoey, S., & Mitchell, G. (2009). Pain language and gender differences when describing a past pain event. *Pain*, *5*(1-2), 86–95.

Sullivan, M. J. L. (2012). The Communal Coping Model of Pain Catastrophising: Clinical and Research Implications. *Canadian Psychology*, *53*(1), 32–41. http://doi.org/10.1037/a0026726

Sullivan, M. J. L., Bishop, S. R., & Pivik, J. (1995). The Pain Catastrophizing Scale: Development and validation. *Psychological Assessment*, *7*(4), 524–532. http://doi.org/10.1037/1040-3590.7.4.524

Sullivan, M. J. L., & D'Eon, J. (1990). The catastrophizing and depression in chronic pain patients. *Journal of Abnormal Psychology*, *99*, 260–263.

Sullivan, M. J. L., Martel, M. O., Tripp, D., Savard, A., & Crombez, G. (2006). The relation between catastrophizing and the communication of pain experience. *Pain*, *122*(3), 282–288. http://doi.org/10.1016/j.pain.2006.02.001

Sullivan, M. J., Thorn, B., Haythornthwaite, J. A., Keefe, F., Martin, M., Bradley, L. A., & Lefebvre, J. C. (2001). Theoretical perspectives on the relation between catastrophizing and pain. *The Clinical Journal of Pain*, *17*(1), 52–64.

Summers, J. D., Rapoff, M. A., Varghese, G., Porter, K., & Palmer, R. E. (1991). Psychosocial factors in chronic spinal cord injury pain. *Pain*, *47*(2), 183–189.

Sutherland, R., & Morley, S. (2008). Self-pain enmeshment: Future possible selves, sociotropy, autonomy and adjustment to chronic pain. *Pain*, *137*(2), 366–377.

Tait, R. C. (2010). Metaphor and meaning in the experience of pain. *PsycCRITIQUES*, *55*(33).

Tawashy, A. E., Eng, J. J., Lin, K. H., Tang, P. F., & Hung, C. (2009). Physical activity is related to lower levels of pain, fatigue and depression in individuals with spinal-cord injury: a correlational study. *Spinal Cord*, *47*(4), 301–306. http://doi.org/10.1038/sc.2008.120

Taylor, S. E. (1983). Adjustment to threatening events: A theory of cognitive adaptation. *American Psychologist*, *38*, 1161–1173.

Taylor, J., Huelbes, S., Albu, S., Gomez-Soriano, J., Penacoba, C., & Poole, H. M. (2012). Neuropathic Pain Intensity, Unpleasantness, Coping Strategies, and Psychosocial Factors after Spinal Cord Injury: An Exploratory Longitudinal Study During the First Year. *Pain Medicine*, *13*, 1457–1468.

Tebbet, M., & Kennedy, P. (2011). The experience of childbirth for women with spinal cord injuries: an interpretative phenomenology analysis study. *Disability & Rehabilitation*, *34*(9), 762–769. http://doi.org/10.3109/09638288.2011.619619

Teixeira, M. E. (2008). Meditation as an Intervention for Chronic Pain: An Integrative Review. *Holistic Nursing Practice*, *22*(4), 225–234. http://doi.org/10.1097/01.HNP.0000326006.65310.a7

Thibault, P., Loisel, P., Durand, M. J., & Sullivan, M. J. L. (2008). Psychological predictors of pain expression and activity intolerance in chronic pain patients. *Pain*, *139*, 47–54.

Thorne, S. E., & Paterson, B. L. (2000). Two decades of insider research: what we know and don't know about chronic illness experience. *Annual Review of Nursing Research*, *18*, 3–25.

Todd, Z., & Harrison, S. J. (2010). Metaphor Analysis. In S. N. Hesse-Biber, & P. Leavy. In *Handbook of Emergent Methods*. Guilford Press.

Treede, R.-D., Jensen, T. S., Campbell, J. N., Cruccu, G., Dostrovsky, J. O., Griffin, J. W., … Serra, J. (2008). Neuropathic pain: redefinition and a grading system for clinical and research purposes. *Neurology*, *70*(18), 1630–1635. http://doi.org/10.1212/01.wnl.0000282763.29778.59

Tremblay, I., & Sullivan, M. J. L. (2010). Attachment and pain outcomes in adolescents: The mediating role of pain catastrophizing and anxiety. *Journal of Pain*, *11*(2), 160–171.

Turk, D. C., & Flor, H. (1999). Chronic Pain: a behavioural perspective. In Gatchel, RJ. & Turk, DC. (Eds). In *Psychosocial Factors in Pain: Critical Perspective* (pp. 18–34). New York: Guildford Press.

Turk, D. C., Kerns, R. D., & Rosenberg, R. (1992). Effects of Marital Interaction on Chronic Pain and Disability: Examining the Down Side of Social Support. *Rehabilitation Psychology*, *37*(4), 259–274.

Turk, D. C., & Okifuji, A. (2002). Psychological factors in chronic pain: evolution and revolution. *Journal of Consulting and Clinical Psychology*, *70*(3), 678–690.

Turk, D. C., & Rudy, T. E. (1986). Assessment of cognitive factors in chronic pain: A worthwhile enterprise? *Journal of Consulting and Clinical Psychology*, *54*(6), 760–768. http://doi.org/10.1037/0022-006X.54.6.760

Turk, D. C., Swanson, K. S., & Tunks, E. R. (2008). Psychological approaches in the treatment of chronic pain patients--when pills, scalpels, and needles are not enough. *Canadian Journal of Psychiatry. Revue Canadienne De Psychiatrie*, *53*(4), 213–223.

Turner, A., Barlow, J., & Ilbery, B. (2002). Play hurt, live hurt: Living with and managing osteoarthritis from the perspective of ex- professional footballers. *Journal of Health Psychology*, *7*, 285–301.

Turner, J. A., Cardenas, D. D., Warms, C. A., & McClellan, C. B. (2001). Chronic pain associated with spinal cord injuries: A community survey. *Archives of Physical Medicine and Rehabilitation*, *82*(4), 501–508. http://doi.org/10.1053/apmr.2001.21855

Turner, J. A., & Clancy, S. (1986). Strategies for coping with chronic low back pain: relationship to pain and disability. *Pain*, *24*(3), 355–364.

Ullrich, P. M., Lincoln, R. K., Tackett, M. J., Miskevics, S., Smith, B. M., & Weaver, F. M. (2013). Pain, depression, and health care utilization over time after spinal cord injury. *Rehabilitation Psychology*, *58*(2), 158–165. http://doi.org/10.1037/a0032047

Ullrich, P. M., Spungen, A. M., Atkinson, D., Bombardier, C. H., Chen, Y., Erosa, N. A., … Tulsky, D. S. (2012). Activity and participation after spinal cord injury: State-of-the-art report. *JRRD*, *49*(1), 155–174.

Unruh, A. M. (1996). Gender variations in clinical pain experience. *Pain*, *65*(2–3), 123–167. http://doi.org/10.1016/0304-3959(95)00214-6

Van Damme, S., Eccleston, C., & Roelofs, J. (2004). The role of hypervigilance in the experiencce of pain. In G. J. G. Asmundsen, J. W. S. Vlaeyen, & G. Crombez (Eds.), *Understanding and treating fear of pain.* (pp. 71–90). Oxford: OUP.

Van De Ven, L., Post, M., De Witte, L., & Van Den Heuvel, W. (2008). Strategies for autonomy used by people with cervical spinal cord injury: A qualitative study. *Disability and Rehabilitation*, *30*(4), 249–260. http://doi.org/10.1080/09638280701265687

Van Leeuwen, C. M. C., Post, M. W. M., van der Woude, L. H. V., de Groot, S., Smit, C., van Kuppevelt, D., & Lindeman, E. (2012). Changes in life satisfaction in persons with spinal cord injury during and after inpatient rehabilitation: adaptation or measurement bias? *Quality of Life Research*, *21*(9), 1499–1508. http://doi.org/10.1007/s11136-011-0073-7

Van Manen, M. (1990). *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy*. New York: SUNY Press.

Van Tulder, M. W., Ostelo, R., Vlaeyen, J. W. S., Linton, S. J., Morley, S., & Assendelft, W. J. (2001). Behavioral treatment for chronic low back pain: a systematic review within the framework of the Cochrane Back Review Group. *Spine*, *26*, 270–281.

Vassend, O., Quale, A. J., Røise, O., & Schanke, A.-K. (2011). Predicting the long-term impact of acquired severe injuries on functional health status: the role of optimism, emotional distress and pain. *Spinal Cord*, *49*(12), 1193–1197. http://doi.org/10.1038/sc.2011.70

Verhoeven, K., Crombez, G., Eccleston, C., Van Ryckeghem, D. M. L., Morley, S., & Van Damme, S. (2010). The role of motivation in distracting attention away from pain: An experimental study. *Pain*, (149), 229–234.

Villemure, C., & Bushnell, M. C. (2009). Mood Influences Supraspinal Pain Processing Separately from Attention. *The Journal of Neuroscience*, *29*(3), 705–715. http://doi.org/10.1523/JNEUROSCI.3822-08.2009

Vlaeyen, J. W. S., Crombez, G., & Goubert, L. (2007). The Psychology of Chronic Pain and its Management. *Physical Therapy Reviews*, *12*, 179–188.

Vlaeyen, J. W. S., Hanssen, M., Goubert, L., Vervoort, T., Peters, M., van Breukelen, G., … Morley, S. (2009). Threat of pain influences social context effects on verbal pain report and facial expression. *Behaviour Research and Therapy*, *47*(9), 774–782. http://doi.org/10.1016/j.brat.2009.05.008

Vlaeyen, J. W. S., Kole-Snijders, A. M. J., Boeren, R. G. B., & van Eek, H. (1995). Fear of movement/(re)injury in chronic low back pain and its relation to behavioral performance. *Pain*, *62*(3), 363–372. http://doi.org/10.1016/0304-3959(94)00279-N

Vlaeyen, J. W. S., & Linton, S. J. (2000). Fear-avoidance and its consequences in chronic musculoskeletal pain: a state of the art. *Pain*, *85*(3), 317–332. http://doi.org/10.1016/S0304-3959(99)00242-0

Vlaeyen, J. W. S., & Linton, S. J. (2012). Fear-avoidance model of chronic musculoskeletal pain: 12 years on. *Pain*, *153*, 1144–1147. http://doi.org/10.1016/j.pain.2011.12.009

Vlaeyen, J. W. S., & Morley, S. (2005). Cognitive-behavioral treatments for chronic pain: what works for whom? *The Clinical Journal of Pain*, *21*(1), 1–8.

Vowles, K. E., & McCracken, L. M. (2008). Acceptance and values-based action in chronic pain: a study of treatment effectiveness and process. *Journal of Consulting and Clinical Psychology*, *76*(3), 397–407. http://doi.org/10.1037/0022-006X.76.3.397

Vowles, K. E., & McCracken, L. M. (2010). Comparing the role of psychological flexibility and traditional pain management coping strategies in chronic pain treatment outcomes. *Behaviour Research and Therapy*, *48*(2), 141–146. http://doi.org/10.1016/j.brat.2009.09.011

Vowles, K. E., McCracken, L. M., & Eccleston, C. (2008). Patient functioning and catastrophizing in chronic pain: the mediating effects of acceptance. *Health Psychology: Official Journal of the Division of Health Psychology, American Psychological Association*, *27*(2 Suppl), S136–143. http://doi.org/10.1037/0278-6133.27.2(Suppl.).S136

Waddell, G. (1992). Biopsychosocial analysis of low back pain. *Baillière's Clinical Rheumatology*, *5*(3), 523–557.

Waddell, G., Newton, M., Henderson, I., Somerville, D., & Main, C. J. (1993). A Fear-Avoidance Beliefs Questionnaire (FABQ) and the role of fear-avoidance beliefs in chronic low back pain and disability. *Pain*, *52*(2), 157–168.

Wagnild, G. M., & Young, H. M. (1993). Development and psychometric evaluation of the Resilience Scale. *Journal of Nursing Measurement*, *1*, 165–178.

Wagstaff, G. F., & Rowledge, A. M. (1995). Stoicism: Its Relation to Gender, Attitudes Toward Poverty, and Reactions to Emotive Material. *The Journal of Social Psychology*, *135*(2), 181–184. http://doi.org/10.1080/00224545.1995.9711421

Waldron, B., Benson, C., O'Connell, A., Byrne, P., Dooley, B., & Burke, T. (2010). Health locus of control and attributions of cause and blame in adjustment to spinal cord injury. *Spinal Cord*, *48*(8), 598–602.

Walsh, D. A., & Radcliffe, J. C. (2002). Pain beliefs and perceived physical disability of patients with chronic low back pain. *Pain*, *97*(1-2), 23–31.

Warms, C. A., Marshall, H. M., Hoffman, A. J., & Tyler, E. J. (2005). There are a few things you did not ask about my pain: writing on the margins of a survey questionnaire. *Rehabilitation Nursing: The Official Journal of the Association of Rehabilitation Nurses*, *30*(6), 248–256.

Warms, C. A., Turner, J. A., Marshall, H. M., & Cardenas, D. D. (2002). Treatments for chronic pain associated with spinal cord injuries: many are tried, few are helpful. *The Clinical Journal of Pain*, *18*(3), 154–163.

Wassenaar, A., Schouten, J., & Schoonhoven, L. (2014). Factors promoting intensive care patients' perception of feeling safe: A systematic review. *International Journal of Nursing Studies*, *51*(2), 261–273.

Waters, S. J., Keefe, F. J., & Strauman, T. J. (2004). Self-discrepancy in chronic low back pain: relation to pain, depression, and psychological distress. *Journal of Pain and Symptom Management*, *27*(3), 251–259. http://doi.org/10.1016/j.jpainsymman.2003.07.001

Weiner, D. K., & Rudy, T. E. (2002). Attitudinal barriers to effective treatment of persistent pain in nursing home residents. *Journal of the American Geriatrics Society*, *50*(12), 2035–2040.

Weisse, C. S., Foster, K. K., & Fisher, E. A. (2005). The Influence of Experimenter Gender and Race on Pain Reporting: Does Racial or Gender Concordance Matter? *Pain Medicine*, *6*(1), 80–87. http://doi.org/10.1111/j.1526-4637.2005.05004.x

Wendell, S. (1996). *The Rejected Body: Feminist Philosophical Reflections on Disability*. Psychology Press.

Wetering, E. J., Lemmens, K. M., Nieboer, A. P., & Huijsman, R. (2010). Cognitive and behavioral interventions for the management of chronic neuropathic pain in adults - a systematic review. *European Journal Of Pain*, *14*, 670–681.

Wetherell, J. L., Afari, N., Rutledge, T., Sorrell, J. T., Stoddard, J. A., Petkus, A. J., … Atkinson, J. H. (2011). A randomized, controlled trial of acceptance and commitment therapy and cognitive-behavioral therapy for chronic pain. *Pain*, *152*(9), 2098–2107. http://doi.org/10.1016/j.pain.2011.05.016

Werneke, M. W., Hart, D. L., George, S. Z., Stratford, P. W., Matheson, J. W., & Reyes, A. (2009). Clinical outcomes for patients classified by fear-avoidance beliefs and centralization phenomenon. *Archives of Physical Medicine and Rehabilitation*, *90*(5), 768–777. http://doi.org/10.1016/j.apmr.2008.11.008

Werner, A., & Materud, K. (2005). “The pain isn’t as disabling as it used to be”: How can the patient experience empowerment instead of vulnerability in the consultation? *Scandinvaian Journal of Public Heatlh*, *33*(66), 41–46.

Wenzlaff, R. M., & Wegner, D. M. (2000). Thought suppression. *Annual Review of Paychology*, *51*, 59–91.

Widerström-Noga, E. G., Cruz-Almeida, Y., Felix, E. R., & Adcock, J. P. (2009). Relationship between pain characteristics and pain adaptation type in persons with SCI. *Journal of Rehabilitation Research & Development*, *46*(1), 43–56.

Widerström-Noga, E. G., Duncan, R., Felipe-Cuervo, E., & Turk, D. C. (2002). Assessment of the impact of pain and impairments associated with spinal cord injuries. *Archives of Physical Medicine and Rehabilitation*, *83*(3), 395–404. http://doi.org/10.1053/apmr.2002.28028

Widerström-Noga, E. G., Felipe-Cuervo, E., & Yezierski, R. P. (2001). Relationships among clinical characteristics of chronic pain after spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, *82*(9), 1191–1197.

Widerstrom-Noga, E. G., & Turk, D. C. (2003). Types and effectiveness of treatments used by people with chronic pain associaated with spinal cord injuries: influence of pain and psychosocial characteristics. *Spinal Cord*, *41*, 600–609.

Willig, C. (2001). *Introducing Qualitative Research in Psychology: Adventures in Theory and Method*. Buckingham, Philiadelphia: Open University Press.

Willig, C. (2008). *Introducing Qualitative Research in Psychology* (2 edition). Maidenhead: Open University Press.

Wilson, J. R., Hashimoto, R. E., Dettori, J. R., & Fehlings, M. G. (2011). Spinal cord injury and quality of life: a systematic review of outcome measures. *Evidence-Based Spine-Care Journal*, *2*(1), 37–44. http://doi.org/10.1055/s-0030-1267085

Wilson, N. L., & Gibbs, R. W. (2007). Real and Imagined Body Movement Primes Metaphor Comprehension. *Cognitive Science*, *31*(4), 721–731. http://doi.org/10.1080/15326900701399962

Wrigley, P. J., & Siddall, P. J. (2007). Pharmacological Interventions for Neuropathic Pain Following Spinal Cord Injury: An Update. *Topics in Spinal Cord Injury Rehabilitation*, *13*(2), 58–71.

Yardley, L. (2008). Demonstrating validity in qualitative research. In J. A. Smith (Ed.). In *Qualitative psychology: a practical guide to research methods* (pp. 232–251). London: SAGE Publications Ltd.

Yezierski, R. P. (2009). Spinal cord injury pain: spinal and supraspinal mechanisms. *Journal Of Rehabilitation Research And Development*, *46*(1), 95–107.

Yong, H.-H. (2006). Can attitudes of stoicism and cautiousness explain observed age-related variation in levels of self-rated pain, mood disturbance and functional interference in chronic pain patients? *European Journal of Pain*, *10*(5), 399–407. http://doi.org/10.1016/j.ejpain.2005.05.004

Zahavi, D. (2003). *Husserl's Phenomenology*. Standford, CA: Stanford University Press.

Zeidan, F., Gordon, N. S., Merchant, J., & Goolkasian, P. (2010). The Effects of Breif Mindfulness Meditation Training on Experimentally Induced Pain. *The Journal of Pain*, *11*(3), 199–209.

Zeidan, F., Martucci, K. T., Kraft, R. A., Gordon, N. S., McHaffie, J. G., & Coghill, R. C. (2011). Brain Mechanisms Supporting the Modulation of Pain by Mindfulness Meditation. *The Journal of Neuroscience*, *31*(14), 5540–5548. http://doi.org/10.1523/JNEUROSCI.5791-10.2011

Zolnierek, K. B., & DiMatteo, M. R. (2009). Physician Communication and Patient Adherence to Treatment: A Meta-analysis. *Medical Care*, *47*(8), 826–834. http://doi.org/10.1097/MLR.0b013e31819a5acc

Footnotes

[1] Descriptive information provided by researcher.

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

[3] Indicates long pause in which each full stop represents one second.

Appendix A

Contextual Information on Participants

Outpatients

James

James is a 38 year old, married, white British male, working part-time. He sustained a T3 to T4 level spinal cord injury as a result of a road traffic accident, leaving him with incomplete paraplegia with sensory but no motor function below his level of injury (ASIA B). His time since injury is two years. James has chronic spasm pain in his abdomen, musculoskeletal pain in his right shoulder, and neuropathic pain in his left leg. When asked how intense his pain is on a day to day basis, James indicated on a numerical rating scale that his pain scored an eight out of ten. Prior to his accident James worked as a Territorial Army sergeant in the field, in charge of organising and leading large groups of men and women. He remains a TA sergeant, working within the recruitment and training department instead of out in the field.

Daniel

Daniel is a 26 year old working full time. He is white British, and cohabits with his partner. Daniels L1 to L2 level injury occurred three years ago as a result of a gunshot to his lower back, leaving him with incomplete paraplegia with some preserved motor function below the level of injury but no sensory function (ASIA C). Daniel has diagnosed neuropathic pain that occurs mainly in his whole right leg and is rated as nine out of ten on the pain intensity visual analogue scale. Prior to his injury, Daniel worked within the army. At the time of interview, Daniel was expecting his first child.

Harry

Harry is a 65 year old retired and married, white British man who has been spinal cord injured for 32 years. A road traffic accident caused Harry to sustain a C5 to C6 level injury, with complete tetraplegia and some sensory but no motor function preserved (ASIA B). Harry has diagnosed spasms and neuropathic pain in his right hip and the whole of his abdomen and chest. He rates his pain intensity on a daily basis as eight out of ten, but goes on to say that it is a ten on the scale when his pain particularly flares up. Before his injury, Harry worked repairing and customising musical instruments but his injury prevented any further employment. Instead, Harry took up painting at home and does voluntary work.

Rebecca

Rebecca is 44 years old and unemployed. She is white British, single, and has been spinal cord injured for a period of 21 years. Rebecca was involved in a road traffic accident causing her spinal cord injury at C4 to C5 level, meaning she is a complete tetraplegic with some sensory and motor preservation in her arms but not her hands. Rebecca has diagnosed neuropathic pain that she feels all over her body from her neck down; she rates this pain as a ten on the pain intensity numerical rating scale.

Emma

Emma is a 42 year old white British nurse practitioner, working part time in a burns unit. She is married and lives at home with her husband and two children. Emma is one of two participants who sustained their spinal cord injury through a non-traumatic condition. Longitudinal extensive transverse myelitis caused Emma’s injury, which ranges from C4 to T9. As a result of her injury, Emma has incomplete tetraplegia and is able to walk as she has preserved motor function below her injury level (ASIA D). She rates her pain between three and four.

Dave

Dave is 77 years old, retired, and widowed, but with a large, close-knit family. He is the only participant to have sustained his injury as a result of a fall, which occurred 15 years prior to the interview. He is a T12 paraplegic, indicating the presence of neuropathic pain in his legs, which he rates as five out of ten on a pain intensity numerical rating scale. Dave enjoys music, reading, and attending church.

Sharon

Sharon is a white female, who remains unemployed as a result of her injury, which occurred one year ago as a result of a non-traumatic condition (spinal tumour). Her injury level is C4, incomplete paraplegic. She states that she feels pain all over her body, particularly on the right hand side, which she rates as a six out of ten on the pain intensity numerical rating scale.

Sean

Sean is a 31-year-old single male working part-time as a counsellor in a care home. His injury (level C5-C6, incomplete paraplegic) was sustained as a result of a traumatic diving accident ten years prior to the interview. Sean has a part-time carer, but likes to maintain his independence. He indicated that his pain is located in his abdomen and legs, and he rates it as four out of ten in intensity.

<u>Inpatients</u>

Jimmy

Jimmy is a retired, 71 year-old male. He is married and has three adult children, although he does not allow them to visit him in hospital. He is 6 months post-injury, at the C6 level, with incomplete paraplegia and sensory, but not motor function, below his level of injury (ASIA C). His injury occurred as a result of a fall, and his pain is located in his left arm and shoulder, and both hands. He rates it at an eight on the numerical rating scale of pain intensity.

Alice

Alice is a 23 year-old, full-time single mum of two. Her C3 to C4 level SCI, and incomplete tetraplegia (ASIA C) occurred as a result of a road traffic accident nine months prior to her interview. She has neuropathic pain all through her body from her shoulders down, which she rates between a seven and a ten on the numerical rating scale of pain intensity on a day-to-day basis. Alice enjoys her occasional home visits to be with her family.

Amir

Amir is 69 years old, married, retired, and of Pakistani origin. He is five months post-injury, at a C3 to C5 level, as a result of a slipped disk (non-traumatic). He has incomplete paraplegia (ASIA C) and feels neuropathic pain rated at four on the visual analogue scale. His pain is located in his right arm and side, and in his toes on both feet.

George

George is a widowed, retired 82 year-old. As a result of a non-traumatic cause four months prior to interview, his SCI occurred at the T9 level with complete paraplegia (ASIA A). When asked how intense his pain is, he rates it as seven out of ten, and states that it is located in both of his legs from the knee down.

Jennifer

Jennifer, a married, 63-year-old white British female, also sustained her injury as a result of a fall nine months before she took part in the interview. Prior to her accident, she worked full-time. As a result of her C5-C6 injury, she has incomplete tetraplegia (ASIA B) and neuropathic pain radiating over her chest and shoulders. She rates this pain at ten out of ten.

Deb

Deb is retired and widowed. She is 80 years of age, and the third of the inpatient participants to sustain their SCI as a result of a fall, which happened 10 months prior to interview. Her C4-C5 injury means that she has complete tetraplegia (ASIA A), and she describes her pain being all over her entire body. However, though her pain is present everywhere, she rates the intensity as three out of ten on the numerical rating scale.

Mark

51-year-old Mark is married and works full-time. He sustained his injury as a result of a road traffic accident 4 months before being interviewed. His C2-C4 injury left him with incomplete tetraplegia (ASIA B), and neuropathic pain in his shoulders, arms, and hands. He rated this as three out of ten in intensity.

David

David is 40 years old, married, and runs his own business full-time. His C6 injury was sustained as a result of a traumatic event 5 months prior to interview, leaving him with incomplete paraplegia (ASIA B), and neuropathic pain in his neck and arms. He rated this pain as two out of ten on the numerical rating scale, and he felt very positive about being discharged and going back to his family and work.

Appendix B

Letter of Invitation

THE UNIVERSITY OF BUCKINGHAM

Dear Sir/Madam,
The University of Buckingham is currently carrying out a research project investigating the experience of chronic pain in outpatients with a spinal cord injury and would like you to consider taking part. The aim of this research is to study how individuals with a spinal cord injury experience pain and to understand this experience from the patient perspective.

Am I eligible to take part?
If you have experienced pain for a period of six months or more as a result of your spinal cord injury and have no other known health condition that may affect your pain, then you are eligible to take part. You must have a good understanding of English and no cognitive impairment. All participation is voluntary and your standard care will not be affected by taking part in this research.

What will happen?
The research will involve taking part in semi-structured interviews in which you will be allowed to tell your own story. Questions will ask you to describe your pain, what it is like to live with chronic pain as a result of a spinal cord injury, coping strategies you may use and how you feel about your identity. Interviews will be audio-recorded, transcribed and then analysed using qualitative methodology at The University of Buckingham. This is expected to identify themes that highlight the most important aspects of the experience of chronic pain for individuals with a spinal cord injury.

How long will it take?
Interviews are expected to last approximately one hour.

How will this research help others?
This research has important clinical relevance as it will aid in informing the development of pain management programmes that are specific to individuals with a spinal cord injury and to confirm that the correct aspects of pain are being studied and treated. This is particularly important as pain management programmes aimed at the general population are less effective for those with a spinal cord injury.

Is there anything else I should know?
Should you state your interest; a nurse will give you a detailed participant information sheet of frequently asked questions about the study. Please read this. If you have any questions, please feel free to contact any of the researchers.

How do I get involved?

Should you consent to taking part, please approach Jasmine Hearn in the outpatients department or any of the researchers by phone or email to organise a time, date and location for your interview to take place. These details are available overleaf and on the participant information sheet.

With kind regards,

Jasmine Hearn – Principal Investigator
The Psychology Department
The University of Buckingham
Hunter Street
Buckingham
MK18 1EG

Tel: 01280 828 322 Email: jasmine.hearn@buckingham.ac.uk

Dr. Katherine Finlay – Chief Investigator
The Psychology Department
The University of Buckingham
Hunter Street
Buckingham
MK18 1EG

Tel: 01280 828322 Email: katherine.finlay@buckingham.ac.uk

Dr. Imogen Cotter – Clinical Supervisor
Department of Clinical Psychology
National Spinal Injuries Centre
Stoke Mandeville Hospital, Bucks Healthcare NHS Trust
Aylesbury
Buckinghamshire
HP21 8AL

Tel: 01296 153823 Email: imogen.cotter@buckshealthcare.nhs.uk

Independent contact point for general advice about taking part in research
The Spinal Injuries Association
SIA House

2 Trueman Place
Oldbrook
Milton Keynes
MK6 2HH

Freephone advice line: 0800 980 0501 Open 9.30am to 4.30pm Monday to Friday

Email: sia@spinal.co.uk

Appendix C

Participant Information Sheet

Participant Information Sheet

An interpretative phenomenological analysis of the experience of chronic pain in patients with a spinal cord injury.

You have stated your interest in this research. Please take some time to read through the following information in order to make an informed decision to take part. A nurse will signpost you to the principal investigator, Jasmine Hearn, who is available in the outpatients department, in order to sign your consent form together and to arrange the time, date and location for your interview to take place. This is also an opportunity for you to meet the researcher, who will be carrying out your interview, and for you to raise any questions or concerns you may have regarding the research. Please feel free to contact any of the researchers if you have any more questions after this time. Contact details are provided at the end of this document.

What is the purpose of this study?

This research is interested in exploring the experience of pain as a result of a spinal injury. You will be asked about your views and experiences of having spinal cord injury-related pain. Investigating the information provided by you and other people will aid the development of pain management programmes specific to spinal cord injured individuals.

Do I have to take part?

Your participation is voluntary; if you do take part you will be asked to sign a consent form confirming your understanding of the study, and your standard care will remain unaffected. If you are unable to sign the consent form yourself, a friend or family member may do so for you. You are free to withdraw at any time, without giving a reason, and your standard care will not be affected. Should you choose to withdraw, any information you provide will be kept for analysis, unless you state otherwise.

What will happen to me if I take part?

If you agree, you will be asked to take part in one interview that will last approximately one hour. This interview will be carried out face to face at a time and place convenient for you. This may be at your own home or at The National Spinal Injuries Center. Any travel expenses you incur will be reimbursed. The interview will be audio-taped so that it can be transcribed accurately. You will be asked questions about your experiences of spinal cord injury and pain, you do not have to answer every question and you may give the investigator as much or as little information as you like.

What are the potential risks of taking part?

It is understood that talking about pain may make some people feel uncomfortable or distressed; if you feel you may become distressed a friend or family member may be present during your interview. Additionally to this, you will have the option to take a break or halt the interview at any point. If you feel particularly distressed after your interview, the researcher can remain present with you until you feel better, and you may be put in contact with Dr Imogen Cotter, who will be able to signpost you to your local help services. If you choose not to have anybody present during your interview, you will be asked to provide contact details in case of emergency.

What are the potential benefits of taking part?

By taking part in this research, you will be contributing to an enhanced understanding of the experience of pain from the point of view of spinal cord injury patients. This research will inform the development of pain management programmes specific to spinal cord injury, ensuring that the most important aspects of pain are being treated. This is expected to enhance in and outpatient support. You may also find it therapeutic to talk about your experiences.

Confidentiality.

Audio recorded interviews will be erased after transcription. Your data will be kept completely confidential and will only be seen by the research team (see end of document); however quotes you provide will be made anonymous and used within the final report in order to give examples of what was said. Your identity, and that of anybody you may identify, will be kept anonymous and all names will be replaced with pseudonyms. Your results will be analysed for the purpose of this research, and will aid future research within this area. Your data will be stored in a password-protected computer database. All audio tapes will be kept in locked filing cabinets and will be erased after transcription. All of your data will be destroyed securely at the end of this study. Your GP will be informed of the nature of, and your participation within this study, but no data will be shared with them. However, should you disclose any particularly distressing information that may risk the safety of yourself or others, part of the researcher's duty of care may be to report this to Dr Imogen Cotter, Clinical Psychologist, and your GP.

What will happen to the results of the study?

This research will form an MSc thesis and the anonymised results will be published in academic journals. It will also be disseminated at research seminars and relevant meetings and conferences. This study will be used to help staff to learn more about pain in spinally injured patients. The National Spinal Injuries Centre may use results to devise spinal cord injury-specific pain management programmes. If you would like a copy of the report, please let the researcher know.

Am I eligible?

If you experience pain as a result of your spinal cord injury, have experienced this pain for a period of six months or more, and have no other known condition that may affect your pain, you are eligible to take part. You must have a good understanding of English and no cognitive impairment.

Who is organising and funding this study?

This research is funded by an MSc studentship from The University of Buckingham.

Who has reviewed this study?

The study has been approved by The University of Buckingham, The National Spinal Injuries Centre Research Board. All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by London Bloomsbury Research Ethics Committee.

Contacts for further information:

Jasmine Hearn – Principal Investigator
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The Psychology Department
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Dr. Imogen Cotter – Clinical Supervisor
Department of Clinical Psychology
National Spinal Injuries Centre
Stoke Mandeville Hospital, Bucks Healthcare NHS Trust
Aylesbury
Buckinghamshire
HP21 8AL
Tel: 01296 153823 Email: imogen.cotter@buckshealthcare.nhs.uk

Appendix D

Consent Form

LIVING WITH NEUROPATHIC PAIN AFTER SPINAL CORD INJURY

Jasmine Hearn
Department of Psychology
The University of Buckingham
Buckingham
MK18 1EG
01280 828 322
jasmine.hearn@buckingham.ac.uk

Consent form

Title of Project:
An interpretative phenomenological analysis of the experience of chronic pain in patients with a spinal cord injury.

Please initial each box to show your consent.

1. I confirm that I have read and understood the information sheet (version 2, dated 13th April, 2013) for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw my consent at any time, without giving reason, and that my standard care will not be affected. ☐

3. I consent for my GP to be informed of my participation within this research. ☐

4. I confirm that I do not suffer any known chronic health problems that might affect my experience of pain. ☐

5. I consent for any quotes provided by me to be used anonymously in the research report. ☐

6. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from The University of Buckingham, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

7. I agree to take part in the above study. ☐

....
Name of participant Date Signature

....
Name of researcher Date Signature

Appendix E

Letter to GP

Jasmine Hearn
The Psychology Department
The University of Buckingham
Hunter Street
Buckingham
MK18 1EG

Tel: 01280 828 322
Email: jasmine.hearn@buckingham.ac.uk

Dear Dr

Re: [Patient name]
Date of birth: [date of birth]

The National Spinal Injuries Center, in conjunction with The University of Buckingham, is currently taking part in a research study involving interviewing participants with a spinal cord injury about their experiences of pain. This involves being involved in a single, non-directive interview for a maximum of two hours, after which their participation in the study will end. During the interview participant will take the lead, talking about their pain experiences as a result of their spinal cord injury.

Your patient, [patient name], agreed to take part in this study, and took part in the interview on [date of interview]. Routine care and treatment will remain unaffected.

The interview consists of questions regarding the patient’s experiences of pain, and coping strategies they may employ.

If you would like any further information about this project, please contact me using the details above.

Yours sincerely,

Jasmine Hearn
Principal Investigator

Appendix F

Friend/Family Member Consent Form and Information Sheet

Friend & Family Member Information Sheet

An interpretative phenomenological analysis of the experience of chronic pain in patients with a spinal cord injury.

You have been invited by your friend or family member to sit with them whilst they take part in this research. Please take some time to read through the following information in order to make an informed decision to take part. Please feel free to contact any of the researchers if you have any questions or concerns about this study. Contact details are provided at the end of this document.

What is the purpose of this study?

This research is interested in exploring the experience of pain as a result of a spinal injury. Your friend or family member will be asked about their views and experiences of having spinal cord injury-related pain. Investigating the information provided by them and other people will aid the development of pain management programmes specific to spinal cord injured individuals.

Do I have to take part?

Your participation is voluntary; if you do take part you will be asked to sign a consent form confirming your understanding of the study. You are free to withdraw at any time, without giving a reason.

What will happen to me if I take part?

If you agree, you will be asked to be present during one interview with your friend or family member that will last between one and two hours. This interview will be carried out face to face at a time and place convenient for the participant. This may be at their own home or at The National Spinal Injuries Center. Any travel expenses you incur will be reimbursed. The interview will be audio-taped so that it can be transcribed accurately. Whilst we value your presence during the interview, it is important that focus remains on what the participant has to say about their experiences and that their answers are not influenced by others.

What are the potential risks of taking part?

It is understood that talking about pain as a result of spinal cord injury may make some people feel uncomfortable or distressed; your friend or family member has chosen to invite you to be present in order to manage any distress that may occur, and in any case of emergency. Additionally to this, they will have the option to take a break or halt the interview at any point. If the participant feels particularly distressed after the interview, the researcher, as well as yourself, can remain present until the participant feels better, and the participant may be put in contact with Dr Imogen Cotter, who will be able to signpost them to local help services.

What are the potential benefits of taking part?
By taking part in this research, you will be contributing to a calm environment in which the participant can remain comfortable and less distressed during their interview. They may feel they can provide more information in the presence of somebody who knows them well, and this is beneficial for the research. Their contributions can lead to an enhanced understanding of the experience of pain from the point of view of spinal cord injury patients. This research will inform the development of pain management programmes specific to spinal cord injury, ensuring that the most important aspects of pain are being treated. This is expected to enhance in and outpatient support. They may also find it therapeutic to talk about your experiences.

What will happen to the results of the study?
This research will form an MSc thesis and the anonymised results will be published in academic journals. It will also be disseminated at research seminars and relevant meetings and conferences. This study will be used to help staff to learn more about pain in spinally injured patients. The National Spinal Injuries Centre may use results to devise spinal cord injury-specific pain management programmes. If you would like a copy of the report, please let the researcher know.

Who is organising and funding this study?
This research is funded by an MSc studentship from The University of Buckingham.

Who has reviewed this study?

The study has been approved by The University of Buckingham, The National Spinal Injuries Centre Research Board. All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by London Bloomsbury Research Ethics Committee.

Contacts for further information:
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Dr. Imogen Cotter – Clinical Supervisor
Department of Clinical Psychology
National Spinal Injuries Centre
Stoke Mandeville Hospital, Bucks Healthcare NHS Trust
Aylesbury
Buckinghamshire
HP21 8AL
Tel: 01296 153823 Email: imogen.cotter@buckshealthcare.nhs.uk

Jasmine Hearn
Department of Psychology
The University of Buckingham
Buckingham
MK18 1EG

01280 828 322
jasmine.hearn@buckingham.ac.uk

Consent form

Title of Project:
An interpretative phenomenological analysis of the experience of chronic pain in outpatients with a spinal cord injury.

Please initial each box to show your consent.

1. I confirm that I have read and understood the information sheet (version 1, dated 13th April, 2013) for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw my consent at any time, without giving reason. ☐

3. I agree to take part in the above study. ☐

....	....	....
Name of participant (please print)	Date	Signature
....	....	....
Name of researcher	Date	Signature

Chapter 9

Appendix G

Demographic Questionnaire

THE UNIVERSITY OF BUCKINGHAM

Demographics Questionnaire

Personal Details:

Name: ....

Email: ....

Number: ....

Gender M F

Occupation: ....

Emergency Contact Details:

Emergency name: ....

Emergency number: ....

Age: .... Years

Employment Status: ☐ Full Time ☐ Part Time ☐ Volunteer

☐ Retired ☐ Unemployed looking for work

☐ Unemployed not looking for work/Unable to work

☐ Student

Ethnicity:

White:		**Mixed:**	
British		White and Black Caribbean	
Irish		White and Black African	
White European		White and Asian	
Any other White background		Any other mixed background	
Asian/Asian British:		**Black/Black British:**	
Indian		Black Caribbean	
Pakistani		Black African	
Bangladeshi		Other Black	
Chinese			
Other Asian			
Others:			
Any other ethnic group (please state)			

LIVING WITH NEUROPATHIC PAIN AFTER SPINAL CORD INJURY

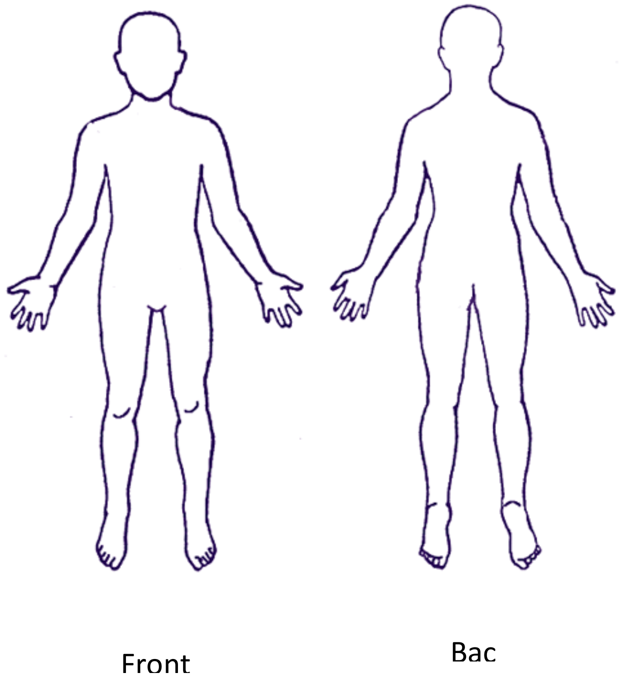
Marital Status: ☐ Single ☐ Cohabiting ☐ Married

☐ Divorced ☐ Widowed ☐ Separated

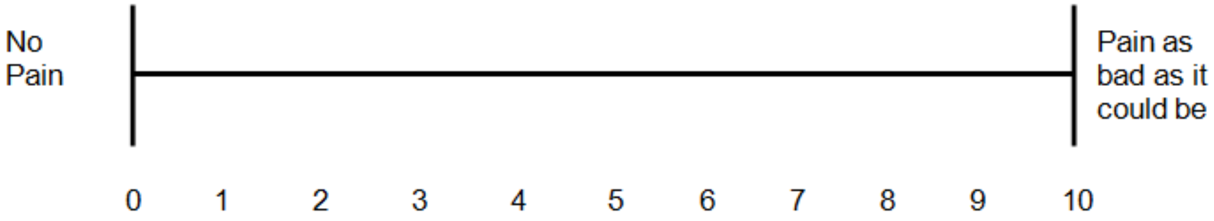
☐ Would rather not say

Time since injury: ....

Please shade where your pain is located:



On a day to day basis, how intense is your pain? (Please circle one)



Level of Injury (circle all that apply):

C1 C2 C3 C4 C5 C6
C7 C8 T1 T2 T3 T4
T5 T6 T7 T8 T9 T10
T11 T12 L1 L2 L3 L4
L5 S1 S2 S3 S4 S5

Cause of Injury: ☐ Road traffic accident ☐ Fall ☐ Sporting Injury

☐ Non-traumatic condition ☐ Prefer not to say

☐ Other (please state): ....

I have: ☐ Complete tetraplegia ☐ Incomplete tetraplegia

☐ Complete paraplegia ☐ Incomplete paraplegia

Impairment of Injury (refer to ASIA Impairment Scale below if necessary):

☐ ASIA A ☐ ASIA B ☐ ASIA C ☐ ASIA D

ASIA Impairment Scale:

A = Complete: No motor (movement) or sensory (feeling) function is preserved in the sacral segments S4-S5.
B = Incomplete: Sensory but not motor function is preserved below the injury level and includes the sacral segments S4-S5.
C = Incomplete: Motor function is preserved below the injury level, and more than half of key muscles below injury level have no muscle movement, or some movement without the help of gravity.
D = Incomplete: Motor function is preserved below the injury level, and at least half of key muscles below the injury level have a muscle movement against gravity and/or some added resistance.

Appendix H

Interview Schedule

THE UNIVERSITY OF BUCKINGHAM

Thank you for agreeing to take part in this interview. I would just like to reiterate that everything you say will be treated with complete anonymity. However, if you choose to disclose anything to me that might risk the safety of yourself or others, I have a duty of care to report this information to your GP and the Clinical Psychologist involved in this research. If at any point you feel uncomfortable or distressed please feel free to take a break.

I will be taking notes in my diary purely for my memory if you mention something interesting and I want you to tell me more about it later during the interview.

1. Tell me about your experience of pain since your spinal cord injury.
    - Where is it located?
    - How does it feel at best/at worst?
    - How often does it present itself?
2. How have you been informed about your pain?
    - How helpful was this?
3. What techniques do you use to cope with your pain, if any?
    - What is the most effective strategy, and why?
4. What is your life like since experiencing neuropathic pain?
    - How does it affect your everyday life?
    - How have others reacted to it?
    - Are there any activities you do differently now as a result of your pain?
5. How do you think neuropathic pain will affect your future, if at all?
6. Is there anything you would like to add to the discussion?

Appendix I

THE UNIVERSITY OF
BUCKINGHAM

Debriefing Form

Debriefing Form

Thank you for participating in the present study looking at the lived experience of chronic pain in individuals with a spinal cord injury. Your cooperation is greatly appreciated. This research aims to enrich the understanding of the experience of chronic pain in spinal cord injured patients. By understanding this experience from the point of view of the population, it is possible to gain insight into how this pain may be treated from a psychological perspective. The results of this research will aid the development of a pain management programme specific to the needs of the spinal cord injured patient.

We would like to reassert that all of your personal details and information you have provided will be kept confidential and anonymous. If you would like a copy of the final report please let the Principal or the Chief Investigator know.

In the event that you feel particularly distressed by what you have discussed during this study, have any questions regarding the study or would like any further advice, please do not hesitate to contact any of the researchers below and the Spinal Injuries Association:

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Hunter Street
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MK18 1EG

Tel: 01280 828 322 Email: jasmine.hearn@buckingham.ac.uk

Dr. Katherine Finlay – Chief Investigator
The Psychology Department
The University of Buckingham
Hunter Street
Buckingham
MK18 1EG

Tel: 01280 828322 Email: katherine.finlay@buckingham.ac.uk

Dr. Imogen Cotter – Clinical Supervisor
Department of Clinical Psychology
National Spinal Injuries Centre
Stoke Mandeville Hospital, Bucks Healthcare NHS Trust
Aylesbury
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HP21 8AL

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The Spinal Injuries Association
SIA House
2 Trueman Place
Oldbrook
Milton Keynes
MK6 2HH

Freephone advice line: 0800 980 0501 Open 9.30am to 4.30pm Monday to Friday

Email: sia@spinal.co.uk

Appendix J

Ethical Approval Forms

SCHOOL OF SCIENCE AND MEDICINE ETHICAL APPROVAL FORM

Tick one box: ☐ STAFF project ■ POSTGRADUATE project ☐ UNDERGRADUATE project

Title of project: An Interpretative Phenomenological Analysis of the Experience of Chronic Pain in Spinal Cord Injury

Name of researcher: Jasmine Hearn

Name of supervisor (if student project): Katherine Finlay

Section A – Ethical Questionnaire

		YES	NO	N/A
1	**Does the study involve asking people to test a computer system? If so, then please read the notes on page 4 and go to Question 13.**		X	
1a	**Does the study involve human participants? If not, please refer to Questions 13 & 14 and then go on to Section B.**	X		

		YES	NO	N/A
2	Will you describe the main experimental procedures to participants in advance, so that they are informed about what to expect?	X		
3	Will you tell participants that their participation is voluntary?	X		
4	Will you obtain informed consent (either written or by clicking a button for online surveys) for participation?	X		
5	If the research is observational, will you ask participants for their consent to being observed?	X		
6	Will you tell participants that they may withdraw from the research at any time and for any reason?	X		
7	With questionnaires, will you give participants the option of omitting questions they do not want to answer?			X
8	Will you tell participants that their data will be treated with full confidentiality and that, if published, it will not be identifiable as theirs?	X		
9	Will you debrief participants at the end of their participation (i.e. give them a brief explanation of the study)?	X		

If you have ticked **NO** to any of the above questions 2-9, **tick box B** overleaf and give a clear explanation in your proposal as to how these issues will be addressed.

			YES	NO	N/A
10	Will your project involve deliberately misleading the participants in any way?			X	
11	Is there any realistic risk of participants experiencing either physical or psychological distress or discomfort?		X		
12	Do participants fall into any of the following special groups?	Schoolchildren (under 18 years of age)		X	
		People with learning or communication difficulties		X	
		Patients	X		
		People in custody		X	
		People engaged in illegal activities (e.g. drug-taking)		X	

If you are working with any of the participants listed in question 12, you may need to obtain CRB clearance. It is your responsibility to find out, and if this is the case, then you will need to do so before starting data collection. It is to be understood that any ethical approval given by the SSMEC is subject to CRB checks being carried out if necessary.

If you have ticked **YES** to any of the above questions 10-12, **tick box B** and give a full explanation with your proposal, including what you will tell participants to do if they experience any problems (e.g. who they can contact for help) if you have ticked **YES** for question 11.

		YES	NO
13	Does the study involve the taking, keeping or use of human tissues?		X
14	Are there any safety or security issues involved in the study?		X

If you have ticked **YES** to either of the above questions, **tick box B** and give a full explanation with your proposal.

Note: there is an obligation on the lead researcher or supervisor to bring to the attention of the SSMEC any ethical implications of your research not clearly covered by the above checklist.

Section B – the proposal

PLEASE TICK **EITHER** BOX A OR BOX B BELOW AND **PROVIDE THE DETAILS REQUIRED** IN SUPPORT OF YOUR APPLICATION IN THE BOX PROVIDED ON PAGE 3. THEN SIGN THE FORM.

A. I consider that this project has **no** significant ethical implications to be brought before the SSMEC.	
B. I consider that this project **may** have ethical implications that should be brought before the SSMEC, and/or it will be carried out with children or other vulnerable populations.	X

Your proposal should contain a **brief** description of your project in **up to 250** words in the space provided on Page 3, under the given headings. **If you have ticked box B your proposal must also include a clear and concise statement of the ethical considerations raised by the project and how you intend to deal with them – this can extend beyond 250 words in length.**

Please include your proposal here under these headings. (Continue to next page if needed.)

Rationale (why you are doing what you are doing, but only very briefly):
Interpretative Phenomenological Analysis (IPA) is a relatively new qualitative methodology that explores the lived experience of phenomena through the interpretation of an individual's personal account. Thus far, research on chronic pain after spinal cord injury (SCI) has only been studied quantitatively. By using IPA to explore the experience of chronic pain in people with a SCI, it is possible to gain an insight into their life, and to find themes in their accounts that may be of use to developing SCI-specific pain management programmes. This is important for individuals with a SCI as general pain management programmes are less effective in this population and they may be susceptible to further psychological distress as a result of their pain.

Participants (how many, where from, including computer system testers):
A blanket technique will be used to sample participants. A maximum of 30 spinal cord injured outpatients of The National Spinal Injuries Center (NSIC), Stoke Mandeville Hospital will be interviewed. All participants will experience chronic pain and have no other chronic health condition that might contribute to the pain. Participants without a coherent understanding of English or with any cognitive deficits will be excluded from the research.

Methods & Measurements (data collection method etc.):
Semi-structured, non-directive interviews will be carried out. The participants will be allowed to take the lead and tell their own story. These interviews will be audio-recorded and transcribed. IPA will be used to analyse this data, with the generation of themes representing the most important aspects of chronic pain in individuals with a SCI.

Data (how and where it will be stored securely, whether it will be used for future research, etc.):
Audio tapes and printed transcripts will be kept in a locked filing cabinet at The University of Buckingham. All electronic information will be saved on a password protected computer in The Psychology Department at The University of Buckingham. All names in interviews will be changed and given pseudonyms, no participants will be identifiable from the transcripts. Participant identifiable information will be kept separate from transcripts in a password protected computer. This data will be accessible by the principle investigator (Jasmine Hearn) and the chief investigator (Katherine Finlay). The data will be kept for a period of time until the research is complete. Results of this research may inform the research of PhD student Margaret Tilley, who will be piloting a SCI-specific pain management programme.

Ethics:
Prior to interviews taking place, participants will be informed on the research, given the opportunity to ask questions. A consent form will then be signed in the presence of the researcher. Participants will be allowed a friend or family member present during the interview. If they do not want anybody present they will be asked to provide emergency contact details. Participants will be allowed to choose the location of their interview (at home or at the NSIC) for their own convenience. Prior to and at the end of interviews, the researcher will check in and out with a time schedule and location so that the supervisor is aware of the whereabouts of the researcher at all times. In talking about their experiences of pain, it is possible that some participants may become distressed or overwhelmed by the interview. In order to combat this, participants will be made aware that they can choose how much information they wish to give in answer to questions, and whether to answer questions at all. In addition, they will be made aware that they can take a break from the interview at any point, and can terminate the interview should they wish to do so. In the analysis and presentation of data, participant quotes will be used. These quotes will be made anonymous, and all participants will be given pseudonyms.

Notes for computer system testers: If your study involves asking people to test a computer system you are developing, then you should say how many you expect to test it in the Participants section above, and also who they will be ('appropriate sample' is a perfectly acceptable term). You do NOT have to complete questions 2-12. Finally, any testers should sign the disclaimer paragraph below, adapted for your specific project.

'I have been asked to user test and evaluate the **'xxx'** system. I understand that my data will be anonymous and confidential, and that it cannot be traced back to me individually. I also understand that I may withdraw from the testing at any point for any reason. I give my informed consent for my data to be used in the development of this software system and dissemination activities associated with the project.'

Signed ____________________

Date ____________________

I am familiar with the SSMEC ethical guidelines (and have discussed them with the other researchers involved in the project).

Signed J.H Print Name JASMINE HEARN Date 17/4/2013
(UG or PG Researcher(s), if applicable)

Signed Print Name KATHERINE FINLAY Date 3/5/2013
(Lead Research or Supervisor)

STATEMENT OF ETHICAL APPROVAL

This project has been considered using agreed SSMEC procedures and is now approved.

Signed Print Name LINDA LUCKHURST Date 17-04-13
(Chairman, SSMEC)

Buckinghamshire Healthcare NHS
NHS Trust

Please reply to: Research & Development Office
Stoke Mandeville Hospital
Mandeville Road
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Telephone: 01296 316259
Fax:
E-mail: denise.watson@buckshealthcare.nhs.uk

Miss Jasmine Hearn
The University of Buckingham
44 Adams Close
Buckingham
MK18 1WB

18 June 2013

Dear Miss Hearn

ID: RXQ/549 Spinal Cord Injury: An Interpretative Phenomenological Analysis.

I am pleased to confirm that all local governance checks are now complete for the above study which meets Trust requirements for full Trust Registration and indemnity. Please let us know the actual start and end dates of the project and of any changes to the research team

The Research Office will require you to provide recruitment numbers on a monthly basis.

Should you have any queries please contact the R&D office quoting the Trust ID number. May we wish you well with your project.

Yours sincerely

Denise Watson
Research Management & Governance Manager

NHS
Health Research Authority

National Research Ethics Service

NRES Committee London - Bloomsbury
HRA NRES Centre Manchester
Barlow House 3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 625 7815
Facsimile: 0161 625 7299

14 May 2013

Miss Jasmine Hearn
44 Adams Close
Buckingham
Hunter Street
Buckingham
MK18 1WB

Dear Miss Hearn

Study title:	**An Interpretative Phenomenological Analysis of the Experience of Chronic Pain in Outpatients with a Spinal Cord Injury**
REC reference:	**13/LO/0558**
Protocol number:	**1.0**
IRAS project ID:	**127935**

Thank you for your email of 14 May 2013. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 08 May 2013.

Documents received

The documents received were as follows:

Document	*Version*	*Date*
GP/Consultant Information Sheets	1.0	13 May 2013
Letter of invitation to participant	2.0	13 May 2013
Participant Consent Form: Participant	2.0	13 May 2013
Participant Consent Form: Friend & Family Member	1.0	13 May 2013
Participant Information Sheet: Participant	2.0	13 May 2013
Participant Information Sheet: Friend & Family Member	1.0	13 May 2013

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	*Version*	*Date*
Covering Letter		26 March 2013
Evidence of insurance or indemnity	Zurich Municipal	25 June 2012
GP/Consultant Information Sheets	1.0	13 May 2013
Interview Schedules/Topic Guides	1.0	06 March 2013
Investigator CV	Katherine Finlay	26 March 2013
Investigator CV	Jasmine Hearn	26 March 2013
Investigator CV	Imogen Cotter	26 March 2013
Investigator CV	Philip Fine	26 March 2013
Letter of invitation to participant	2.0	13 May 2013
Other: Debriefing Form	1.0	06 March 2013
Participant Consent Form: Participant	2.0	13 May 2013
Participant Consent Form: Friend & Family Member	1.0	13 May 2013
Participant Information Sheet: Participant	2.0	13 May 2013
Participant Information Sheet: Friend & Family Member	1.0	13 May 2013
Protocol	1.0	06 March 2013
Questionnaire: Demographic Questionnaire	1.0	06 March 2013
REC application	3.5	03 April 2013
Referees or other scientific critique report	University of Buckingham	25 March 2013
Summary/Synopsis	1.0	06 March 2013

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

13/LO/0558	**Please quote this number on all correspondence**

Yours sincerely

A. Totenhofer

Dr Ashley Totenhofer
Committee Co-ordinator

E-mail: nrescommittee.london-bloomsbury@nhs.net

Copy to: Dr Philip Fine – The University of Buckingham

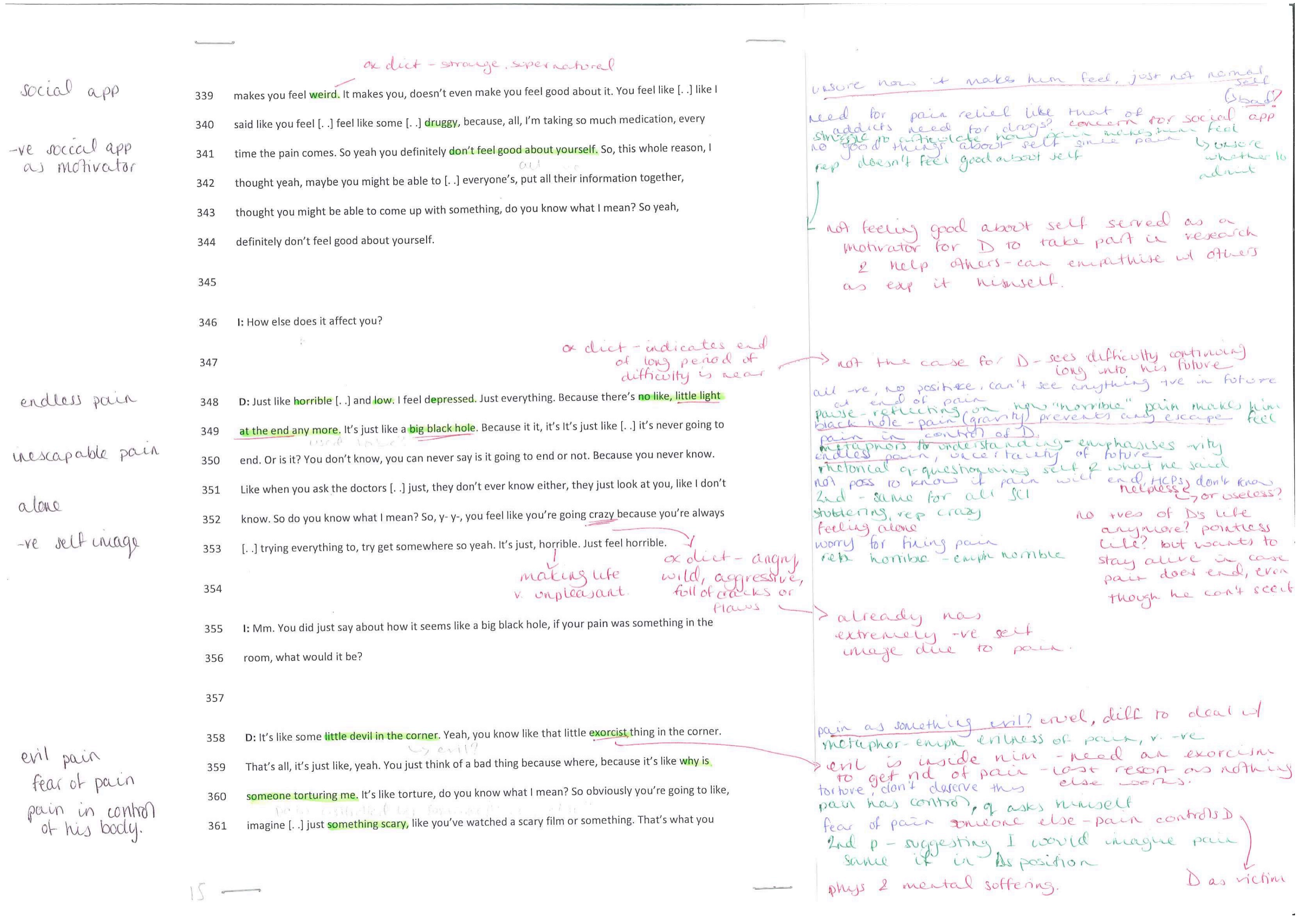
Dr Alan Martin - The University of Buckingham

Denise Watson – Buckinghamshire Healthcare NHS Trust

Dr Katherine Finlay - The University of Buckingham

Appendix K

Sample Transcript with Analysis Carried Out



ox dict - strange, supernatural

makes you feel weird. It makes you, doesn't even make you feel good about it. You feel like [. .] like I said like you feel [. .] feel like some [. .] druggy, because, all, I'm taking so much medication, every time the pain comes. So yeah you definitely don't feel good about yourself. So, this whole reason, I thought yeah, maybe you might be able to [. .] everyone's, put all their information together, thought you might be able to come up with something, do you know what I mean? So yeah, definitely don't feel good about yourself.

I: How else does it affect you?

ox dict - indicates end of long period of difficulty is near

D: Just like horrible [. .] and low. I feel depressed. Just everything. Because there's no like, little light at the end any more. It's just like a big black hole. Because it it, it's It's just like [. .] it's never going to end. Or is it? You don't know, you can never say is it going to end or not. Because you never know. Like when you ask the doctors [. .] just, they don't ever know either, they just look at you, like I don't know. So do you know what I mean? So, y- y-, you feel like you're going crazy because you're always [. .] trying everything to, try get somewhere so yeah. It's just, horrible. Just feel horrible.

making life v. unpleasant.

ox dict - angry, wild, aggressive, full of cracks or flaws

I: Mm. You did just say about how it seems like a big black hole, if your pain was something in the room, what would it be?

D: It's like some little devil in the corner. Yeah, you know like that little exorcist thing in the corner. That's all, it's just like, yeah. You just think of a bad thing because where, because it's like why is someone torturing me. It's like torture, do you know what I mean? So obviously you're going to like, imagine [. .] just something scary, like you've watched a scary film or something. That's what you

evil?

social app

-ve social app as motivator

endless pain

inescapable pain

alone

-ve self image

evil pain
fear of pain
pain in control of his body.

unsure how it makes him feel, just not normal self
bad?

need for pain relief like that of addicts need for drugs? concern for social app
struggle to articulate how pain makes him feel
no good things about self since pain
unsure whether to admit
rep doesn't feel good about self

not feeling good about self served as a motivator for D to take part in research 2 help others - can empathise w/ others as exp it himself.

not the case for D - sees difficulty continuing long into his future

all -ve, no positive, can't see anything +ve in future at end of pain
pause - reflecting on how "horrible" pain makes him feel
black hole - pain (gravity) prevents any escape
pain in control of D.
metaphors for understanding - emphasises -vity
endless pain, uncertainty of future
rhetorical q - questioning self & what he said
not poss to know if pain will end, HCPs don't know
helpless? or useless?
2nd - same for all SCI
stuttering, rep crazy
feeling alone
worry for fixing pain
rep horrible - emph horrible

no +ves of D's life anymore? pointless life? but wants to stay alive in case pain does end, even though he can't see it

already has extremely -ve self image due to pain.

pain as something evil? cruel, diff to deal w/
metaphor - emph evilness of pain, v. -ve
evil is inside him - need an exorcism to get rid of pain - last resort as nothing else works.
torture, don't deserve this
pain has control, q asks himself
fear of pain
someone else - pain controls D
D as victim
2nd p - suggesting I would imagine pain same if in D's position
phys & mental suffering.

15

protection of family from conseqs of pain

burdening family

H: I just say I'm in agony [. . .] yeah and they know what it's all about, from their experience of knowing me over the years. If I was in agony and I was able to use the phone [. .] um [. . .] there is one person, female, that I could pick up the phone and speak to. Very [. .] candidly, um [. .] and she will understand, she will try to offer a bit of help. We used to do a lot of writing together, um, used to write, for the BBC at one time, you know collaboratively. Um [. . . .] it's difficult, because [. .] um, you know, as a married man, you don't, feel that it's right to be picking up the phone, bleating to somebody else, when you could be bleating to your wife, but [. .] um my wife, bless her cotton socks, she retreats into her shell when I'm in agony, she's seen it so many times [. . .] and because it impacts on her so much, she could even um [. .] you know enter a sort of um, phase of [. .] to get on with it you know. For God's sakes, you know. Become irritable with me, so it's very important to have friends outside the family, that you can, confide in and perhaps get a bit of sympathy when you need it.

– making light of -ve beh of wife

concern for protecting wife's self identity & feelings.

family can't always be supportive - too close to situation?

I: How does your wife's reaction to your pain affect you and your pain experience?

guilt

-ve impact on ♀ well-being of self & family

circle of pain for self & wife

H: [*sigh*] [. .] it makes me feel as if [. .] my pain is responsible for her emotional pain. So that doesn't, it, it makes me feel uncomfortable. Very uncomfortable sometimes, particularly when the pain is prolonged, and I know that she's suffering because, um, you can see that it's impacting on her, and because she loves me she doesn't want me to be so distressed [. .] and knowing that I am distressed with all the pain and she's nothing she can do. Um, you know she she, she kind of retreats a little bit, trying to get away from the situation. As if it's not there [. .] and it's understandable. You know I completely understand it but it doesn't make me feel any better [. .] I just wish that she could, she could be alright as well. You know as well as me being in pain I can see that she's in pain, different sort of pain, emotional pain, but emotional pain can be horrible can't it.

pain affects wellbeing of family

em pain due to helplessness

dislike

14

friends can understand through exp of knowing H
social support beneficial in giving sympathy.
present tense - friend always available to help

one person can speak to openly about pain

understand - try to help - but H not looking for help? just some sympathy

difficult to talk to friend
pause - reflecting on just said ē
guilt for talking to someone else about problems
3rd p - disoc ~~from~~ activities he feels aren't right?
concern for → from hurting wife protecting wife's em & well-being
1st p to justify undesirable activity?
justifying talking to someone else
protection of wife who already suffers ♀ conseqs due to H pain (self & identity)

wife can't listen, sympathise

wife's ~~bt~~ reaction to pain - due to seeing it all the time - feel like H is a burden? too much reliance, responsibility?

3rd p again - suggesting how others may use strategies to cope - not as effective for himself?

→ H pain push family away? response is to react -vely towards H?

1st p - own experience
blaming self for pain effects on family
guilt - phys pain causes wife em pain
sigh & pauses to think - not think about reactions of others?
discomfort at causing disruption & -ve impact on well-being.
stumbling - trying to voice exp.
wife suffering obvious & visible
due to care for H
cycle of pain for self & wife - each inf other
wife em pain due to helplessness
rep 'you know' - vali seeking? assuming I understands?
looking for escape to protect herself? leaving H to cope alone
incomp sentence - does he know what he was going to say?
wife withrawal impacts H - circular process
wish - can't do anything else to ease wife's pain? helpless?
wish for wife's well-being

rational - like others understand effects of em pain

H → guilt for em pain → W
H ← wish for well-being ← W
H ← distress @ helplessness ← W

Appendix L

Sample Table of Clusters and Themes

Daniel

Themes & subthemes	**Page/Line no.**	**Key Words and Phrases**
Fear of future		
- Fear of increasing physical and psychological damage	15/360	Why is someone torturing me? ... something scary
	15/358	It's like some little devil in the corner
	17/399	I'm scared, really scared.
- Expectation of pain	11/256	You're always waiting for it.
- Pain controls future for self and family	17/402	I'm just scared like obviously I'm having a baby.
	18/420	It will just ruin his life.
- Medication will cause an early death	17/399	I always say that I'm not going to live long ... because of the amount of medication I take.
Biomedical approach is inadequate		
- HCPs lack of knowledge	4/79	My GP, he's never, dealt with anyone with a spinal cord injury.
	9/220	They say it's like, such a specialist subject.
	15/351	Like when you ask the doctors ... they don't ever know either
	18/431	He said well I haven't got the number either
- Diagnosis and treatment of NP are problematic	2/51	It's nerve pain as well and so hard, to detect, like what actual, what's happened to your nerves.
	10/239	It is actually an illness.
- Search for a cure	11/247	You should be able to try and cure it.
	15/342	Everyone's, put all their information together, thought you might be able to come up with something.

	17/407	I just don't think it's going to go well. It's just going to get worse.
- Resentment at biomedical approach risking health	7/165	They'll give me like 5. So I'm saying like look I take 20 ... and they were like well just see how it goes.
	17/408	They'll just give me more medication, that's just going to damage your body more
Undesirable new trapped self		
- Damaged new self	8/186	Makes you feel like you're some [. .] druggy
	14/323	You're like a write off
- Self as a victim of pain	6/147	Just like someone's hitting you.
	10/240	It ruins your life
	8/195	It just makes you feel dirty.
- Unwanted social attention (embarrassment)	14/326	Everyone's like oh you ok like getting around ... so yeah that's like embarrassing
- Excessive thinking (rumination)	11/261	You're always thinking ... it's going to be pain, and you're waiting ... and then you just over think.
	15/352	You're going crazy because you're always, trying everything to, try get somewhere
	2/69	The pain starts hitting me.
	13/314	I still don't accept it.
- Pain is not a part of the self	14/318	Yeah like, it is a part of your life, but I still wouldn't have it ... I don't want it.
	20/467	You've got other things to think about.
SCI population are united but alone	19/451	I want to spend more time with people in

- Importance of social support		chairs ... I don't know anyone in a wheelchair ... well I'm hoping they might have ideas too
	20/480	I think being around people in wheelchairs more might give me ... I'm looking forward to that ... everyone's the same, you don't feel like an outcast
- Able-bodied and own insufficient understanding	5/108	There's nothing you can do. Or obviously when people try and tell you to do stuff and you're like I'm trying but you can't.
- Helpless self and others	12/290	You don't want to go from that, then go and see your mates and be like, carry on talking about it.
- Burdening others	13/293	You don't really want to talk to your mates about how much you feel pain.
Pain is a constant struggle		
- Uncontrollable pain	1/21	They were al- always trying to get my pain, trying, it was always up and down up and down
	2/49	And now today, it's like uncontrollable.
	10/228	You don't know what's going to happen from one day to the next.
- Inescapable pain	15/348	There's no like, little light at the end any more. It's just like a big black hole
	15/349	It's never going to end
- Indescribable pain	16/362	It's not a good feeling. It's a really really bad feeling

Appendix M

Outpatient Master Table of all Emergent Themes

JAMES

Biomedical approach is inadequate

- Lack of education from HCPs
- Excessive reliance on medication
- Lack of choice and availability of pain management
- Need to create an alternative physical treatment/coping
- Current strategies and emotional reactions cause embarrassment and loss of masculinity

Pain is in control

- Pain controls the future, emotions, reactions
- Pain is not discriminatory in its occurrence
- Pain is not yet manageable
- Pain is not enmeshed with the self

Positive restructuring and appraisal of negatives

- Pain has a purpose
- Acceptance of injury
- Self motivation and perspective
- Use of humour and sarcasm to cope

Protecting the past self

- Protecting masculinity
- Adaptation of past coping strategies
- Deflecting blame onto others

Social cohesion vs. alienation

- Exclusion of able-bodied from SCI world
- Helplessness of others
- Effect of pain on social relationships

DANIEL

Fear of future

- Fear of increasing physical and psychological damage
- Expectation of pain
- Pain controls future for self and family
- Medication will cause an early death

Biomedical approach is inadequate

- HCPs lack of knowledge
- Diagnosis and treatment of NP are problematic
- Search for a cure
- Resentment at biomedical approach risking health
- Inability to challenge medical professionals

Undesirable new trapped self

- Damaged new self
- Self as a victim of pain
- Unwanted social attention (embarrassment)
- Excessive thinking (rumination)
- Pain is not a part of the self

SCI population are united but alone

- Importance of social support
- Able-bodied and own insufficient understanding
- Helpless self and others
- Burdening others

Pain is a constant struggle

- Uncontrollable pain
- Inescapable pain
- Indescribable pain

HARRY

Life control

- Pain in control of world
- Unpredictable pain
- Life secondary to pain
- Psychological states influence pain experience

Acceptance of actual self

- Retention of positive self image
- Acceptance of pain
- Self-pain enmeshment
- Positively appraising life
- Strength of own mind

Reliance on insufficient biomedical approach

- Biomedical approach is counterproductive
- New painful self as result of mistakes of HCPs
- Lack of HCP knowledge and understanding
- Excessive reliance on medication
- Psychological consequences of medication
- Lack of knowledge and availability of non-biomedical interventions

Fear-inducing pain

- Continuous pain into future
- Fear-avoidance
- Lack of preventative preparation
- Fear of pain consequences outweigh fear of pain itself

Social cohesion vs. alienation

- SCI united but alone
- Social exacerbation of pain
- Burdening to family
- Protecting self and family from psychological pain
- Need for social presence for pain management

REBECCA

Brutal unsupportive biomedical approach

- Negative responses to pain from HCPs
- Resentment of medication reliance
- Search for answers

Suspended reality lived in purgatory

- Pain exceeds expectations
- Pain is worse than injury itself
- Pain is a punishment nobody deserves

Ultimate agency is mine

- Reliance on strong self
- Pain is not in control of her
- Crying shows weakness

EMMA

Excessive reliance on inadequate biomedical approach

- Inadequacy of pain medication
- Desperation for pain control results in excessive medication use
- HCPs are in control of patient lives

Acceptance is a battle between pain and ability to live

- Pain acceptance is conditional
- Accepting pain is necessary for a good quality of life

Need for care and social support that includes family

- Lack of sufficient support from HCPs
- Negative impact of pain on family and relationships

DAVE

Inadequate available treatment options - Negative impact of pain on treatment engagement - Lack of physical treatment efficacy - No single extensively beneficial treatment
Acceptance of pain mediates identity - Use of perspective aids 'growing up' - Denial/acceptance of new, pain induced identity
Life must go on/Acceptance is necessary - Pain is out of own control - Pain relief is a magical rarity - Focus on positives - Life changes regardless of pain presence - Ability to live normal life with pain present

SHARON

Excessive reliance of insufficient biomedical approach

- Lack of HCP empathy and understanding
- HCP and patient incomprehension of pain
- Lack of patient input into own care
- Desperation induced unrealistic biomedical hopes

Development of new ‘broken’ identity

- Pain is a consequence of the ‘broken’ body
- Interplay of negative physical and psychological impact
- Unpredictability of pain is psychologically distressing
- New negative identity as result of pain

- Children as motivators for coping
- Positive refocusing of loss
- Ability to remain positive regardless of pain presence
- Positive refocusing of negative through social comparison

Self imposed social cohesion vs. social alienation

- SCI as united supportive community vs. unsupportive able-bodied
- Self imposed limit on ability to talk about pain
- Able-bodied cannot fully understand SCI pain experience

SEAN

Pain is not in control of life

- ‘Pain doesn’t hold me back’
- Pain will not make me fearful of the future
- SCI as a second chance – life is a priority over pain

Biomedical treatments are inadequate

- Negative consequences of pain medication worse than pain itself
- Lack of beneficial biomedical treatments
- Biomedical approach has unnecessary urgency for cure/treatment

Mind over medication

- Pain medication is not a necessity
- Maintenance of independence without the need for medication
- Self-strength is more beneficial than medication reliance
- Distraction is the most important coping strategy

Multifaceted conditional acceptance

- Novelty as a mediator of acceptance
- Humour and positive reframing are aids to reaching acceptance
- Social comparison as an aid to acceptance
- Acceptance is conditional on independence and ability to achieve
- Learning to live with pain is a natural progression

Appendix N

Inpatient Master Table of all Emergent Themes

JIMMY

Perpetual pain

- Pain is a permanent presence
- Unchangeable pain
- Hopeless future

The search for a cure through trial & error

- Medication failure
- Desperation for a cure
- Beneficial patient-staff relationships
- Pain management is a collaborative effort
- Pain is a burden to staff

Prisoner to pain

- Hospital is prison
- Pain is purgatory
- Negative psychological/ emotional impact

Protecting family from burden

- Faking good to protect family
- Pain expression leakage

ALICE

Nothing can be done

- Permanent, unmanageable pain
- Multiple pains
- Last minute life

- Ineffective medication is the only option
- Negative consequences
- Disbelief in psychological coping strategies
- Nobody can help me/Get on with it

To experience is to understand

Describing adequately

- Difficulty describing pain for able-bodied understanding
- SCI understanding
- Able-bodied isolation
- Embarrassment of painful self

Social context of pain

- Safety in the hands of HCPs
- Hospital is home

AMIR

Accepting pain as part of life - Pain is a double edged sword - Denial - Positive perception of temporary pain - Acceptance of pain that has a purpose - All pain gets better - Pain is part of life
Medication failure - Medication failure - Medication hinders pain's purpose - Ineffective medication is only a short-term solution
The benefits of physiotherapy - Physiotherapy is more beneficial - Increasing physical strength is only way to reduce pain
Pain is a healing process with an end in sight

GEORGE

Putting pain into words

Pain is an invisible disability

- Attempting to describe pain adequately
- AB cannot understand SCI-specific pain
- Specialist spinal unit understanding is important for physical and psychological well-being

Medication is ineffective for pain management

- Pain medication failure
- Past negative psychological effects of medication
- Unmet expectations of medication

Trial and error pain management

- Pain management as a trial and error process

Remaining positive despite unknown future

- Acceptance aided by positive support and view of future
- Positivity served as a distraction from future with pain
- Preparedness to leave hospital with pain present
- Future is unknown

Cognitive mediators of pain

- Distraction prevents pain
- Rumination causes pain
- Prevention of rumination prevents pain

JENNIFER

At home in hospital

- Safety/comfort in specialist knowledge

- Hospital is a ‘holiday camp’

Necessity for ineffective medication

- Misunderstanding of medication
- Reliance on medication
- Excessive medication
- Medication is necessary

Coping with consequences

- Physical and psychological consequences of pain
- Social & Psychological causes
- Physical/psychological methods to aid coping

Attempting to describe continuous pain

- Attempting to describe pain

- *Conditional Acceptance (MAJOR ISSUE)*
- Negative emotional response to pain and loss of independence
- Hopeful for pain-free future
- Refusal to accept permanent pain

DEB

Need to describe pain adequately - Metaphor use to describe - Pain is an annoyance rather than a major issue
Learning to live with pain is necessary - Pain has no cure/must live with pain - Acceptance is compulsory due to lack of a cure - Psychological consequences of NP suggest need for a cure
Mediators and exacerbations of pain - Relaxation as a beneficial coping strategy - Physical rehab can induce increased susceptibility to pain through a loss of control - Tiredness decreases control of pain - Medication masks pain - Distraction beneficial - Pain can interrupt life, despite distractions - Sleep solves pain problem - Faith aids coping but not acceptance
Faking acceptance - Conditional/temporary acceptance - Accepting pain and remaining strong despite not wanting to - Hoping for better
Lack of understanding of NP plants seed of doubt - HCPs label NP without explanation - Lack of explanation/understanding causes doubt of ‘realness’ of NP - Psychological interventions only benefit ‘non-real’ pain
Issue of social support - Problems like pain are magnified for the elderly due to isolation - Refusal to burden helpless family - Carers better able to provide social support than family

DAVID

Pain is present, but not a problem - Pain care is not urgent/priority - Pain won't affect QoL - Pain will not hold me back
Refusal of unnecessary medication - Reluctance to take med due to side effects - Conditions of taking medication
Resilience and acceptance as psychological protectors - Accepting pain - Acceptance of permanence - Resilience as a psychological predictor of acceptance
Knowledge is power (to cope) - To understand is to manage/cope
Desire for social connections with staff - Variable staff knowledge - Unsympathetic staff - Need for social interaction with staff
Shared experience with other patients/not alone - Unison with SCI patients

MARK

Possible to communicate pain without burdening - Desire to communicate pain to wife without burdening - Protecting family from own distress
Positive social support - Positive social support - Understanding family
Faith in pain management, staff, and specialist unit - Faith in pain management - Positive experience of medication & staff - Faith in reputation of spinal unit and staff - Unmotivated staff - Reliance on non-understanding staff for pain management
Physical health is priority over pain - Pain is not a priority - Motivated to prioritise physical health
Denial of negative impact - Denial of negative impact, focus on the positive - Pain as threat to masculinity - Imagery as a form of escapism

Appendix O

Rationale and Methods of Mindfulness Study

Exploring the Efficacy of an Online Mindfulness-Training Intervention for those with Spinal Cord Injury and Neuropathic Pain

Rationale

Pain is a significant side effect of spinal cord injury (SCI), particularly after discharge where patients do not have direct access to medicines, doctors or physiotherapy (Donnelly & Eng, 2005). Thus far, pain after SCI has been studied widely, bur from a quantitative perspective. Mindfulness is an acceptance-based therapy (Kabat Zinn, 1990), and a form of mental training based upon Buddhist meditations. It asks the individual to focus upon the breath in the body, teaching individuals to live life in the present, rather than focussing upon the past or the future. It aims to teach acceptance and a kindly awareness of the mind and body, rather than attempting to change thoughts and behaviours, as is the goal in Cognitive-Behaviour Therapy. The mindfulness-training course used in this research is provided by Breathworks.

Mindfulness was chosen as an intervention for this study, as it has not yet been piloted with the spinal cord injured population. Mindfulness training aims to modulate emotional reactions to pain by increasing attention, and has the ability to improve physical and psychological outcomes (Teixeira et al., 2008). It has been shown to improve psychological and physical health in a number of populations including cancer, arthritis, chronic back pain, and chronic headache patients (Kabat-Zinn, 1985; Brown, Ryan, & Creswell, 2007; Kabat-Zinn, 2003; Carlson, Speca, Patel, & Goodey, 2003; 2004; Kingston, Chadwick, Meron, & Skinner, 2007). Mindfulness has been successfully implemented in the treatment of depression (Ma & Teasdale, 2004; Mason & Hargreaves, 2001; Rohan, 2003).

There is no previous research examining the efficacy of mindfulness for those with SCI. This pilot research will provide evidence for or against the use of mindfulness for those with SCI, and SCI-specific pain. Should positive results occur, the mindfulness intervention may be studied with larger sample sizes, and may provide a new avenue of research for pain management. This research may aid the development of pain management programmes specific to the needs of individuals with a spinal cord injury. This is of particular importance as previous literature suggests that pain management programmes for the general population are less effective for those with a SCI. This study may also enhance the level of outpatient support and knowledge of healthcare professionals.

This study is expected to last one year.

Objective

The objective of this research is to assess the efficacy of an online mindfulness-training course on quality of life, social relationships, pain-related outcomes, and psychological outcomes for outpatients with spinal cord injury.

Design

This is a between-subjects, longitudinal, intervention study, with an intervention group, and a control group undergoing their treatment as usual. The inclusion criteria are as follows:

- All participants must have a spinal cord injury.
- All participants must be over 18 years of age and sufferers of chronic pain for three months or longer. There is no upper age limit.
- All participants must have a partner or primary caregiver willing to take part alongside them. The patient and partner/caregiver must have internet access for the entire duration of the study.
- Sufficient understanding of English must be held by all participants.

The exclusion criteria are as follows:

- Participants will not be recruited if they hold any significant cognitive impairment, mental illness or head injury.
- Participants with articulation difficulties and an insufficient understanding of English will be excluded from this study.
- Any respondents with any other long term health condition that may affect the experience of pain, or the cause of chronic pain (as opposed to the spinal injury) will be excluded.

Method

Dr Imogen Cotter, a member of the care team sat The National Spinal Injuries Centre, Stoke Mandeville Hospital, UK, will assess the database of outpatients for those meeting the inclusion criteria. With the help of the chief investigator, Jasmine Hearn, letters of invitation will be sent to all of those meeting the inclusion criteria. Adverts for participants will be placed on The Spinal Injuries Association website.

Dr Rozmin Mukhi, a member of the care team at Sheffield Teaching Hospitals, will be involved in giving invitation letters to patients eligible to take part. The invitation letter directs patients to the Chief Investigator (Jasmine Hearn).

If a patient states their interest in the study, they will be randomised into either the control group or mindfulness group, and provided with a participant information sheet specific to that group. Contact information of all researchers is provided on both the letter of invitation, and participant information sheets, and participants will be able to contact any of the researchers, should they have any questions or concerns regarding the study. Upon agreeing to take part, consent will obtained via a tick box on survey monkey. Should the participant be unable to use a computer due to reduced motor control as a result of the SCI, a friend or family member may tick the box for them, with consent from the chief investigator.

Of those who respond, 12 SCI outpatients and their partners or primary caregivers will be randomised into the mindfulness intervention group, and 12 SCI outpatients and their partners or primary caregivers will be randomised into the control group. Following obtaining consent, participants will be asked to complete a number of questionnaires online via survey monkey, after which those randomised into the mindfulness intervention group will be registered onto the training course and provided with their login details and the Mindfulness for Health book.

The SCI patients and their partner/caregivers in the mindfulness intervention group will undergo their mindfulness training independently of one another at times and locations convenient to them. After four weeks of training there is a catch up week, during which participants will be asked to complete the same questionnaires again, online, and independently of one another. After this week, there are four more weeks of training, and upon completion of the course, participants will be asked to complete the questionnaires again. Three months post-intervention, questionnaires will be completed again, to assess for longer lasting effects of the training.

The control group will receive no intervention, but SCI patients and their partners/caregivers will be required to complete the same questionnaires as the intervention group at baseline, four weeks, eight weeks, and 20 weeks, independently of one another. After the final questionnaires have been completed, participants will receive the debrief letter, and their participation in the study will end.

Outcome

Data will be analysed using SPSS, in order to assess the efficacy of the mindfulness intervention on social relationships, quality of life, psychological outcomes, and pain-related outcomes, such as catastrophising. Discussions will explain relationships between variables and how this work contributes to research into SCI. The work may also aid in the development of SCI-specific pain management programmes. The deeper understanding of management techniques for SCI-specific pain may aid in improving the provision of outpatient care and improving community reintegration following hospital discharge.

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Appendix P

Published Papers Arising from this Thesis

Discussion paper:

Reflecting upon qualitative research with spinal cord injured patients: A personal experience

Jasmine Hearn

VITAL to the qualitative paradigm, reflexivity rejects the idea that a researcher can become completely objective towards a phenomenon. Instead, researchers should reflect upon their position in relation to the research, continually questioning how and why decisions were made and results occurred. This is an ongoing process that begins at research subject choice and continues through to the write up of an analysis. Throughout my qualitative research, I have engaged in personal reflexivity in order to consider how I may have influenced the process and findings. Reflexivity involves examining the researchers preconceptions regarding the research questions and situating their contextual background by acknowledging reasons for engaging in the research, as well as how results may have emerged from the data. I will provide some of my personal reflexivity from an Interpretative Phenomenological Analysis (IPA) study of pain following spinal cord injury (SCI), in the hope that readers can understand why I chose to research this topic and how I came to make sense of the sensitive data I obtained.

Preparing for my research journey

Before considering what I would research, I spent a year working on an acute care ward within a specialist spinal injury unit. Prior to this position, I had little knowledge of SCI and was shocked at the extent to which the injury could alter an individual's life so devastatingly. At the same time, the 2012 Olympics and Paralympics were ongoing, and I repeatedly noticed that I held a sense of commitment to increasing the awareness of SCI and its consequences, but also to increasing patient awareness of what they can still achieve after an injury. It was then I knew that I wanted to research something of value to this population, in order to improve their lives after injury.

I also saw spinal patients who had persistent debilitating pain after their injury, which was also psychologically debilitating for them. I often encountered patients questioning how could they have no feeling from a certain point down, and yet still feel such intense pain. Embarking upon my research journey then, I chose to research pain management for those with SCI in the hope of contributing to improving the psychological well-being of the population in future. I began by looking into the literature, noticing that the majority of research surrounding pain following SCI was quantitative, with a rather fractured understanding of SCI-specific pain and its management. After noticing this, I began to question the literature. How could researchers understand SCI-specific pain without having an SCI? How could they possibly attempt to manage a pain that they could not experience without having an SCI? These questions enabled me to choose to research the lived experience of pain following SCI, using the IPA methodology. This approach places particular emphasis on understanding what is important to the individual in the experience (Smith, Flowers & Larkin, 2009), something that had previously been neglected in the available SCI literature.

One of my key reflections, enabling me to keep an open mind, was my early assumption that patients with pain would reflect upon life negatively. Upon looking back and reflecting on this, I came to realise that I may have been heavily influenced by my previous reading of literature that focused on psychological consequences of pain following SCI, such as depression and anxiety, despite literature also suggesting that positive adjustment following injury is common.

Maintaining a non-judgmental attitude

During the data collection process, I undertook a reflexive diary before and after interviews I conducted with patients. I took time to reflect upon the dynamics of the interaction, attempting to capture thoughts and feelings in order to maintain transparency during the research process. I noted themes that piqued my interest, and other events that occurred during the interview, considering the effects that these may have had on the interview.

It may be argued that the outcome of an interview is the product of the complex interactions between each patient and myself. For example, I asked patients to give me more information on topics that they mentioned that I had not previously anticipated. Further, during my first interview I noted feelings of surprise at the comment 'I don't take medication for my pain'. This highlighted a fore-assumption that I held, believing that all SCI patients with pain would be taking medication as a method of managing it. A beneficial result of this reflexivity ensured that I became more aware of the strength of previous assumptions and their potential influence upon the data, allowing myself to strengthen my ability to step away from such previous assumptions.

One of my most concerning reflections was upon my interpretations of the data provided. Patients often chose to discuss their negative experiences of encounters with healthcare professionals, and as such, my interpretations may reflect negatively upon the medical profession. However, I believe that by remaining true to the patients' data without undermining medical staff, and allowing others to read and understand their experiences, more benefits can be gained through the improvement of pain management and rehabilitation for the SCI population.

Furthermore, I also chose not to take the data or interpretations back to the patients who took part. It is my belief that the consequences of member checking outweigh any potential benefits. All patients spoke negatively of the biomedical approach, perhaps due to feeling at ease during their interview. If I were to take the data back to participants, this may give them the opportunity to remove or edit comments in a socially desirable manner. Consequently, this would not reflect the truth of the experience, and it may be unethical to lose such truth.

Development as a researcher

Prior to commencing my qualitative research I found myself unquestioningly embracing the positivist approach, preferring numbers and causal laws to human behaviour. Throughout the process of this research, however, I became continually aware of a newfound respect, enjoyment and appreciation for qualitative research, and myself as a qualitative researcher, with the ability to open up new avenues for research as a result of qualitative work.

Furthermore, from my own experience of the interviews and analysis, and the themes that emerged, I know that it is not possible for me to fully understand the experience, but that the SCI population does want to be understood. This makes clear to me the value of my research in illuminating our understanding of pain after SCI.

Because data can be repeatedly analysed and interpreted, it took five drafts to reach my final write up of the results, when I finally felt some sense of gestalt or 'good enough' interpretation of the data. A number of discussions with my supervisors regarding themes occurred, during which interpretations were discussed, such that the supervisors understood the themes adequately. I hope that this is reflected in future articles that I aim to publish, and in my thesis, and that the reader is able to recognise the effort that I have put into continually reflecting upon the research process and to disentangle the various experiences. I hope that this research will continue to illuminate the understanding of those who play significant roles in the well-being of the SCI population, such as healthcare professionals, friends, family and researchers.

I have been privileged to reach a deeper understanding of the experience, thanks to the patients that took part, through immersing myself in the participant accounts. Patients shared their personal and meaningful experiences with me, for which I am very grateful. As a result of this work I believe I can unquestionably say that I am very much looking forward to embarking upon my next journey with IPA, and developing my skills as an academic and a researcher.

The full version of this article is currently under review: Hearn, J.H., Cotter, I., Fine, P. & Finlay, K.A. (in submission). *Disability and rehabilitation.*

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References

Smith, J. A., Flowers, P. & Larkin, M. (2009). Interpretative Phenomenological Analysis: Theory, Method and Research. London: SAGE Publications Ltd.