



Living with chronic neuropathic pain after spinal cord injury: An Interpretative Phenomenological Analysis of community experience

Journal:	<i>Disability and Rehabilitation</i>
Manuscript ID:	TIDS-08-2014-022.R1
Manuscript Type:	Research Paper
Keywords:	biopsychosocial, acceptance, pharmacological treatment, spinal cord injury, social isolation, pain

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This is an Accepted Manuscript of an article published by Taylor & Francis in Journal of Disability and Rehabilitation on 20/01/2015, available online: <http://www.tandfonline.com/10.3109/09638288.2014.1002579>

Implications for Rehabilitation

- Chronic NP after SCI is often described as worse than the injury itself, often impacting upon the sufferers physical and psychological health.
- The experiences of persons with SCI-specific NP highlight the impact of pain on their physical, psychological and social health. This indicates that healthcare professionals should incorporate a biopsychosocial approach for managing pain post-SCI.
- Routine clinical follow-up of SCI patients with chronic NP, as well as comprehensive pain management treatment programmes, could address the three themes evidenced in the current study, by moving routine intervention with NP away from pain relief, towards pain management.
- Continued education for patients, friends, family members, and healthcare professionals may be beneficial in promoting understanding and awareness of NP and its consequences following SCI.

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3 **Living with chronic neuropathic pain after spinal cord injury: An**
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5 **Interpretative Phenomenological Analysis of community experience**
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12 *Purpose:* This paper presents an in-depth, idiographic study examining the lived
13 experience of chronic pain following spinal cord injury (SCI). Neuropathic pain
14 (NP) occurs in a large majority of the SCI population and is particularly
15 intractable to treatment. It can be both psychologically and physically
16 debilitating. This study examines how the experience of NP is mediated by its
17 meaning to the sufferer.
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21 *Method:* Semi-structured interviews were conducted with eight people with SCI
22 and chronic NP, attending outpatient clinics at a specialist SCI Centre in the
23 UK. Verbatim transcripts were subjected to interpretative phenomenological
24 analysis in order to further understand the experience.
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28 *Results:* Analysis suggested that NP has powerful consequences upon the
29 sufferer's physical, psychological, and social well-being, in line with a
30 biopsychosocial understanding of pain. Three super-ordinate themes were
31 identified: a perceived gap between treatments received and participants' views
32 of what they wanted and needed; a fight for life control and acceptance; and
33 feeling understood by others with SCI, but isolated from the non-understanding
34 able-bodied.
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38 *Conclusions:* The results are discussed in terms of the possible application of
39 acceptance-based therapy to NP and the potential for the alleviation of the
40 debilitating consequences of NP.
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Introduction

A large body of evidence suggests that over 60% of spinal cord injured (SCI) individuals experience chronic pain [1, 2]. Approximately half of the SCI population suffers with neuropathic pain (NP); pain resulting from central nerve damage [3]. NP is often described as severe or excruciating [4], and has specific consistent self-reported sensory qualities, including burning, electric, and crushing, that can be intrusive and distressing [5]. NP is persistent and can be continuous or intermittent, often fluctuating in severity and worsening over time [2, 6]. Siddall, McClelland and Rutkowski [7] found that NP had increased in intensity, and was present in between 34% and 41% of the SCI population, at five years post-injury.

Described by some of those with SCI as worse than the injury itself, chronic pain may be the most difficult aspect of SCI to manage [8]. NP can negatively affect an individual's physical function [9], such as their ability to return to work and daily activities [8], and quality of life [10]. Chronic NP may also serve as a risk factor to psychological well-being and adjustment to injury [1, 11].

Neuropathic pain places SCI patients at increased risk of depression [12, 13] as well as lower self-ratings of mood and quality of life [14]. Additionally, depression and pain are rated as more severe when coinciding [15] with diagnosis and treatment of one being adversely affected by the other [16]. Ullrich, Lincoln, Tackett, Miskevics, Smith, and Weaver [17] argue that pain and depression amplify one another, and that consistent pain and depression after SCI suggests treatment-resistant problems. As such, increased understanding of neuropathic pain, in particular, after SCI is important in order to develop interventions that may prevent the potentially debilitating consequences [18].

The accepted view of pain comes from the biopsychosocial model [19]. This incorporates biological factors such as physiological mechanisms, psychological factors

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2
3 including cognitive appraisals, mood, and behavioural responses, and social factors such
4
5 as relationships and the environment. Despite this, however, in routine clinical practice,
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7 pharmacological treatments currently dominate the available treatments for SCI-related
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9 pain [20]. As well as, for some, limited effectiveness in pain relief, a number of
10
11 unwanted side effects may also occur [21]. The current literature base for NP suggests
12
13 that its pathological mechanisms are complex and not fully understood [22] and so
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15 absolute pain relief may not necessarily be a realistic goal. There remains a dearth of
16
17 evidence relating to psychological and social aspects of pain management techniques
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19 specific to the needs of the SCI population.
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23 Currently, quantitative SCI-specific pain research appears to dominate the
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25 literature. This has offered valuable explanations for the persistence of chronic NP after
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27 SCI, including catastrophising [23], and solicitous responses from available social
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29 support [24, 25]. However, limited qualitative work has been conducted, focussing upon
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31 social support after injury [26], memories of pain [27], experiences of pain management
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33 [28], pain acceptance [29], and questions that those with SCI have regarding their pain
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35 [30], rather than the experience of pain itself. Other studies [31;32] have explored
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37 patients' perspectives of chronic NP through the use of focus groups, identifying
38
39 medication failure, and the need to learn to live with pain as key issues. The
40
41 understanding that can be obtained from personal experiential stories of individuals,
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43 particularly of chronic NP, can benefit the literature by improving understanding of
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45 factors that maintain distress and disability associated with pain. These personal stories,
46
47 however, appear to have been neglected [33].
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52 An effective method for achieving an in-depth understanding of the lived
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54 experience of chronic NP post-SCI is phenomenology. Phenomenology is the study of
55
56 lived experience, in which the researcher allows the participant to discuss their
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3 experience in their own terms and context, whilst remaining aware and open to
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5 previously unanticipated issues. Interpretative Phenomenological Analysis (IPA) [34]
6
7 utilises phenomenology, and was conducted on eight interviews with SCI outpatients
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9 with chronic NP, in order to gain an in depth understanding of the experience of chronic
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11 neuropathic pain and its meaning to those who live with it. IPA uses interpretation to
12
13 understand ‘what personal and social experiences mean to the people who experience
14
15 them’ [35, p. 178]. IPA has the ability to illuminate existing quantitative literature by
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17 understanding experiences through analysing accounts from those living with the
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19 phenomenon of study.
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23 This study aims to achieve a rich understanding of the experience of chronic NP
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25 post-SCI in order to explore what those living with it consider important in their
26
27 experience. This may offer an enhanced ability for friends, families, and healthcare
28
29 professionals (HCPs) to understand NP and to provide support to those living with it.
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31 Pain management techniques may also be utilised or developed as a result of the
32
33 specific needs identified by those living with SCI-specific NP.
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37 **Method**

38 *Participants*

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42 Participants were recruited from outpatient clinics at The National Spinal Injuries
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44 Centre, Stoke Mandeville Hospital. Clinic staff contacted 19 patients meeting the
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46 inclusion criteria: one year post-discharge, in order to allow for adjustment to injury and
47
48 community reintegration; NP present for a minimum period of three months, in order to
49
50 meet the International Association for the Study of Pain [36] definition of chronic pain;
51
52 no significant cognitive impairment; 18 years or over; and English speaking, due to the
53
54 nature of the qualitative methodology. Of the 19 patients contacted, eight declined to
55
56 participate and 11 were interviewed, after which three were discarded due to insufficient
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3 data, characterised by interviews that were cut short due to interruptions and time
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5 constraints. The participants represent a self-selecting sample, such that they had
6
7 experiential knowledge of the specific phenomenon of study [37], and the impact of the
8
9 pain was sufficiently motivating for them to agree to participate. The final sample thus
10
11 consisted of eight participants, in accordance with recommendations of a small sample
12
13 size [38], five of which were male, three of which were female. Participants have been
14
15 given pseudonyms in order to preserve confidentiality and anonymity. Their
16
17 characteristics are listed in Table 1.
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23 Insert Table 1 here
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26 *Procedure*

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29 Local ethical approval was secured for the study from The National Health Service
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31 Research Ethics Committee and other relevant local committees.
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33
34 Nurses preparing patients for a clinic with a medical consultant approached
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36 patients with information regarding the study and asked if they would consider taking
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38 part, after which they were provided with detailed information and offered time to
39
40 consider their consent. Written consent was obtained prior to interviews, which were
41
42 conducted in participants' homes. Interviews were conducted by the first author, and
43
44 lasted between 40 and 120 minutes.
45

46
47 Data were collected from audio-recorded, semi-structured interviews. The
48
49 interview schedule, composed of largely open-ended questions, was composed in
50
51 conjunction with the second and last authors, who work with SCI and chronic pain
52
53 patients. Each interview started with the question, 'Tell me about your experience of
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55 pain since your spinal cord injury'. Participants were given freedom to lead the
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57 interview. Unrestricted by the imposition of topics, they were able to discuss their
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3 experience in terms of their own personal context, focussing on what was most
4 important to them. This allowed for themes to emerge from participants, rather than
5 from the interviewer. An interview schedule was developed in order to elicit further
6 information from participants where necessary. This is presented in Table 2. Any
7 identifying information was changed at the stage of transcription to protect the identities
8 of participants, their friends and families, and HCPs.
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18 Insert Table 2 here
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23 *Data Analysis*

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25 Interviews were transcribed verbatim and read a number of times prior to
26 conducting IPA, as recommended by Smith, Flowers & Larkin [37]. Emergent themes
27 were developed, aided by analytic (descriptive, linguistic, and conceptual) notes and
28 reflections. Super-ordinate themes were abstracted through interrogation of emergent
29 themes to make connections. This resulted in a table of super-ordinate themes, within
30 which were sub-ordinate themes with quotes illustrating each theme.
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39 Analysis followed an idiographic, ‘bottom-up’ approach, studying one account
40 fully before moving on to the next, in order to appreciate each individual experience in
41 its own light, and consistently checking that themes were grounded in the data and
42 representative of the participant’s experience. After each participant’s interview was
43 analysed, patterns were established across cases, identifying convergences and
44 divergences across experiences. The researcher analysed iteratively, constantly moving
45 between part and whole and revisiting data in order to ensure that analysis remained
46 grounded in the data. Super-ordinate themes present across at least half of the sample
47 were then identified through cross case analysis.
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3 The interpretative nature of IPA suggests that individual researchers are likely to
4 interpret data differently, according to personal contextual backgrounds. Determined
5 efforts to ‘bracket off’ prejudgements and information learned from previous interviews
6 were made through the use of a reflective diary and focussing on the participants’
7 accounts so as to remain true to their experiences. In order to ensure rigour and quality
8 in the analysis, the second and fifth authors were enrolled as independent auditors, both
9 of whom have experience with chronic pain or SCI patients. After analysis of each
10 account, the auditors checked the super-ordinate themes and corresponding quotations
11 to ensure themes were grounded in the data. The auditors discussed thoughts and
12 interpretations in order to illuminate areas of the experience that may have been more
13 easily identifiable to them. The interpretations presented here are therefore considered
14 credible and meaningful, although it is acknowledged that these are not the only
15 interpretations of the data [37]. Sufficient data are included in order to validate themes
16 and interpretations.
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37 **Results**

38 Three super-ordinate themes illuminated the experiences of chronic pain. All patients
39 described their primary pain problem as NP. Super-ordinate themes and their
40 corresponding sub-ordinate themes are presented in Table 3. The quotes that are
41 provided are those that best illustrate the theme.
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51 Insert Table 3 here.
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55 *The Chasm Between Biomedical Perspectives and Patient Beliefs and Needs*

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3 The first super-ordinate theme of the chasm was the most prevalent theme, voiced by all
4 participants, and playing a central role in their experiences of pain. The participants felt
5 that the biomedical approach offered inadequate pain relief, non-collaborative patient-
6 staff relationships, and feelings of disempowerment.
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11 12 13 *Excessive Reliance on Insufficient Medication*

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15 Participants placed a central focus upon the inadequacies of medication, with a shared
16 sense of resentment of relying on medication, despite such inadequacies, and side-
17 effects that were often considered to be worse than the pain itself. Consequently, some
18 participants chose not to adhere to their drug regimes, either self-medicating, or
19 abandoning their drug regime completely. Harry voiced concerns about the dramatic
20 effect of medication upon his psychological well-being:
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29 (...)¹ it makes no difference whether I have them and I'm not prepared to take high
30 doses constantly, and be a zombie, and I'd rather put up with a bit of pain than take
31 those drugs and have a blank mind (...) It's like your thoughts are trying to fight their
32 way through a thick lump of fog (...) And once you are on a high dose of course it's
33 very difficult to get off them [Harry].
34
35

36 Harry outlines the negative consequences of his medication, which appeared to
37 outweigh the potential benefits, with his choosing to prioritise his psychological well-
38 being and clarity. This is reflected in Harry's desire to not 'be a zombie', implying that
39 he is unable to think clearly due to his medication, which creates a battle for conscious
40 awareness in which Harry's thoughts have to 'fight their way through a thick lump of
41 fog'. Harry is one participant who had chosen to abandon his prescribed drug regime in
42 order to preserve psychological function, and who also touches upon the potential for
43 dependency, illuminating a further worry regarding the medication reliance.
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¹ (...) represents removed text
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3 For Emma, the ineffectiveness of her drug regime, even at its highest dose,
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5 appeared to induce significant distress, and frustration towards her care team:
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7 I would say eight, nine, ten [on a visual analogue scale of pain intensity]² where I'm
8 crying and I feel like I'm in a pit of fire, actually I'm shouting at you because I want
9 you to try and help me with my drugs, and I'm on the phone to my GP saying, "what
10 can I do now? I'm in pain" (...) I'm on 1,200 [mg], I'm on top dose Gabapentin generic,
11 and it's not helping, what do I do now? [Emma].
12
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14 Emma described great difficulty in achieving satisfactory pain relief, even at the highest
15 dose of pain medication. She comments on repeatedly asking her GP 'what do I do
16 now?' in the hope of obtaining different management advice. The metaphor 'a pit of
17 fire' in Emma's quote provides evidence for psychological and sensory distress.
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24 *Losing Faith in Healthcare Professionals*

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26 Five of the eight participants voiced concerns relating to a progressive loss of faith in
27 the healthcare system due to unmet expectations. Participants expressed disappointment
28 and sometimes resentment towards those involved in their care. Harry was one who
29 reflected on his dissatisfaction with medical staff:
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36 The consultants haven't got all the answers; you know (...) they'll fill you up with
37 mind-altering drugs in the hope that it will help you but (...) not for me [Harry].
38

39 Harry's quote relates to his resentment of 'mind-altering' medication, whilst also
40 exhibiting a displeasure towards staff who are unable to provide a better alternative.
41
42

43 Instead, Harry sees his care team relying on medication without knowing if it will
44 benefit him. He sees these attempts as well meaning, but inadequate. Medical staff are
45 perceived as struggling to find answers and behaving with possibly misplaced certainty.
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49 The problematic measurement and treatment of chronic pain in general, and repeated
50 failures to 'solve the problem', with patients desperately searching for cures, may make
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57 ² [text in square brackets] represents descriptive information provided by the author
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3 it more difficult for care teams to ‘hear’ the experience. Sharon described a dispute that
4
5 supports the theme of losing faith in HCPs:
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8 Nobody told me I would be so disabled because of this pain. It is not fun. The
9 [community] physiotherapists don’t care if you hurt. They say “they give you
10 medication so you don’t hurt so you have to do this exercise” [imitating
11 physiotherapists]. “But it hurts” [speaking as herself]. “It doesn’t hurt, you just think it
12 does” [imitating physiotherapists]. It does hurt! [Sharon].
13

14 Sharon described her community physiotherapists’ inability to acknowledge her pain as
15 real experience. Sharon feels that her physiotherapists do not believe in her pain, as
16 though they know better. Sharon’s tone was resentful and suggested she finds her
17 physiotherapists’ choice of language condescending. Sharon described an inadequate,
18 almost dictatorial, patient-staff relationship that left her void of hope that the
19 physiotherapists could help.
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28 29 *Lack of Input into own Care*

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31 A third theme contributing to the chasm was the participants’ sense of a lack of input
32 into their own care. Participants stated that they had asked for particular treatments or
33 medications, but were often refused, leading to feelings of disempowerment and a loss
34 of control over their lives. Emma articulated this particularly strongly:
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41 I went to my GP and I felt so frustrated that my whole life was being judged by
42 someone else in order to say “no, well, we know better than you”. As much as it’s my
43 [said with emphasis] experience, it’s my pain, I’m telling you my experience, you don’t
44 seem to be listening because you’re not giving me what works for me [Emma].
45

46 Emma discussed encounters with her care team where she was refused medication that
47 she had requested. It may be that, perhaps, Emma feels as though her life is being
48 controlled by the decisions of her care team, who may wish to prioritise medication that
49 they favour. This loss of control may be distressing, particularly as she has also lost
50 control of some of her body as a result of the SCI.
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The Battle for Ultimate Agency in Life

The second super-ordinate theme, voiced by seven of the eight participants, was the sense of being engaged in an ongoing battle against their pain for life control, with an adversarial relationship with the pain. This theme is also closely tied with pain-acceptance, with those reporting an increased sense of acceptance winning their battle by choosing to stop fighting, and those reporting lower acceptance levels losing control to the pain.

Pain is Winning

Five of the participants appeared to feel that they were mostly losing against their pain. When pain was winning, participants described an inability to live and make choices about their own lives. Some were more willing to surrender control to their pain, whilst others desperately attempted to escape the pain in order to reduce its grasp on their lives. These attempts were futile, often resulting in further resentment of pain and an increase in pain intensity. Daniel appeared to have lost all hope of regaining control over his life again. When asked how his pain made 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].

This quote illustrates the damaging psychological consequences Daniel associated with his chronic NP. He uses imagery associated with emptiness and lack of control 'like a big black hole'. Daniel suggests that he may have relinquished his hope for a life without pain and has given up hope of winning his battle, illustrated through his use of the idiom 'no light at the end of the tunnel any more'. This catastrophic thinking appears to be associated with Daniel's distress, and average pain intensity of nine on the VAS.

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3 Rebecca also articulated this theme particularly strongly and appeared to be
4
5 struggling to function adequately with her pain present. The effect of this passage is
6
7 cumulative, and it is therefore essential to present a number of quotations together in
8
9 order to provide rich support the theme:
10

11
12 That's life, and I don't mind being disabled. I don't mind being paralysed, because I can
13 use my arms, and I'm thankful every day for the use of my arms (...) So everything's
14 brilliant it's just the pain and so, hard. And it's just, just so agonising (...) the burning
15 and stinging, it's like fire, and it's just, ugh. It's just like fire, it's horrible. [Rebecca].
16

17
18 It's always been there, the worst thing in my life that's one thing when I do pass away,
19 not looking forward to it yet though, but when I do, I know I'll be smiling in the back of
20 my mind, I'll be thinking at least there'll be no more pain. [Rebecca].
21

22 Rebecca made comments surrounding her dislike of the pain throughout her interview;
23
24 coping with her pain was a struggle that appeared to dominate her sense of recovery and
25
26 adjustment to the changes brought by the SCI. She articulated acceptance of her injury,
27
28 but appeared not to accept her pain. Although Rebecca did not have any plans to end her
29
30 life, she commented on her death, suggesting that death may be her only escape from
31
32 her pain. The comments presented here may be indicative of her struggle to live with
33
34 pain present, suggesting that pain is winning. Her average pain intensity was a
35
36 maximum of ten on the VAS.
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41 *I am Winning*

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43 In contrast to those who appeared to be losing the battle, two participants appeared to be
44
45 winning, and were able to live their lives with little disruption, despite the presence of
46
47 pain. These participants placed less focus on the fight to defeat pain, describing it as
48
49 something that was present but they were able to live with. Harry is an example of a
50
51 participant accepting his pain as a part of his identity, and able to live with it present:
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55 100%, it's me. It's my identity. It's who I am. It's what happens to me. [Harry].
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3 If you get a day of pleasure, it erases all memories of the pain, it's remarkable the way
4 the brain works. So, you know, life isn't abject misery for me because I have
5 pleasurable days. [Harry].
6

7 Harry's quote implies that he knows pain is sometimes in control but also that pain can
8 be 'trumped' by his other experiences, including pleasure. He suggests an ebb and flow
9 to experience rather than an outright fight. Harry seemed to be well adjusted to his pain,
10 accepting its presence without letting it completely dominate his life and control or
11 impact upon his good days. For Harry, the battle may be a malleable concept, in which
12 the pain may be in control some days, but he seems to be ultimately winning his
13 ongoing battle for control of his life, if not control of pain.
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23 Sean is another participant who did not feel that he had to fight against the pain:

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25 It [pain] hasn't held me back so far (...) just like carrying around another bag I suppose.
26 Don't think about it. It's just another weight ... something I can deal with that I'm not
27 too fussed about, you know, doesn't get in the way as much as possibly other people's
28 responses to pain ...³ I can't see it holding me back at all really. [Sean].
29
30

31 Sean appraised his pain more positively, which may have been associated with an
32 average daily pain rating of four, one of the lowest pain ratings given by the group.
33 Here, Sean suggests that you have to carry the bag, but you can manage the weight of it.
34 Those who were winning the battle acknowledged that the presence of pain had the
35 potential to restrict their ability to live life they way they wanted, but not totally. The
36 acceptance of NP as part of their lives and identities may benefit their overall coping.
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46 ***The Coexistence of Social Cohesion and Social Alienation***

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48 The third emerging super-ordinate theme was that of the simultaneous sense of
49 belonging and isolation. In this, participants felt supported by the understanding SCI
50 community, but also reported feeling alienated from the non-understanding able-bodied
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³ . . . represents a pause in speech
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3 community. The importance of social support, particularly from other SCI patients, was
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5 acknowledged by five of the participants. Despite the acknowledgement of the
6
7 usefulness of social support, participants purposely chose to exclude themselves from
8
9 the able-bodied community and create boundaries in order to avoid becoming a burden.
10

11 12 13 *SCI Population are United but Alone in their Experience*

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15 Participants agreed that they felt understood by other SCI individuals with chronic NP,
16
17 due to their direct experience of it, and that this was beneficial for their psychological
18
19 well-being. An essence of resentment towards the non-understanding able-bodied
20
21 community existed, however, due to the difficulty in describing NP and the able-bodied
22
23 lack of experience of it. As such, participants reported feelings of isolation from the
24
25 ‘real world’. James is one such participant who commented on the difficulty in
26
27 articulating pain adequately for able-bodied understanding. He then compared their
28
29 understanding to that of those with a SCI:
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31

32
33 No matter how much family and friends, partners etc., they can believe that they
34
35 understand, they will never ever truly be able to grasp how painful things are, because
36
37 you can’t physically describe it (...) unless you experience it, you can’t. [James].

38
39 James’ quote suggests that anyone not experiencing chronic pain will struggle to
40
41 understand it. Further, it suggests that perhaps James also sees it as part of the
42
43 uniqueness of SCI-specific pain. He also blames himself for not being able to explain
44
45 the pain adequately. This statement sums up the feelings of the participants within this
46
47 theme effectively; reflecting his belief that only the SCI population can understand the
48
49 pain, and that having a SCI is the only way in which to achieve a thorough
50
51 understanding.
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54 Sharon agreed, contributing evidence for both feelings of unison and isolation:

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56 Unless you’re in the wheelchair I know people say “I understand how you feel”, but
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58 they [able-bodied] don’t, you [interviewer] don’t [crying] but they do on the website
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3 [specialised global online SCI community] because they're living that too. It's a great
4 website for support, resources, if you just want to blow off steam, you can do that. It's a
5 great place. [Sharon].
6

7 Sharon's distress lay in the fact that the able-bodied do not understand, even where they
8 believe and say that they do, because they are not living the same experience. However,
9
10 Sharon had instant, direct access to an online network of SCI individuals. She perceived
11
12 this SCI community as able to provide her with some of the understanding and support
13
14 she desired. In contrast to her presentation of her experiences with HCPs, she felt that,
15
16 in the online community, she could discuss her pain and her injury without judgement.
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20 21 22 *Painful Self as an Affliction on Social Relationships* 23

24 Participants felt that their pain had a negative impact on loved ones, and struggled with
25
26 a sense themselves as a potential burden. Protective strategies included self-imposed
27
28 social withdrawal and refusal to talk about pain, despite acknowledging the potential
29
30 benefits of discussing pain with others. When discussing the effect of his pain upon his
31
32 wife, Harry stated:
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35
36 It makes me feel as if my pain is responsible for her emotional pain (...) it makes me
37 feel uncomfortable, very uncomfortable sometimes. Particularly when the pain is
38 prolonged, and I know that she's suffering because you can see that it's impacting on
39 her (...) because she loves me she doesn't want me to be so distressed and knowing that
40 I am distressed with all the pain and there's nothing she can do. [Harry]
41
42

43 Harry's concerns with burdening his wife lay in the impact upon her well-being and the
44
45 psychological distress that it caused for her, with a degree of guilt and responsibility
46
47 voiced.
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50 The theme of possibly choosing social isolation over the sense of being a burden
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52 also arose in Sharon's interview, about her relationships with a therapist:
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54 I was talking to my therapist about it but uh, I'm not any more very much because ...
55 how much can you talk about pain? It's just pain. Nobody wants to hear about pain over
56 and over and over again [laughter] so no I guess I don't really talk too much about pain.
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58 [Sharon]
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4 Sharon discussed a boundary she placed upon her decisions to talk to others about her
5 pain, restricting opportunities to discuss it order to protect her therapist, or possibly to
6 protect herself from anticipated judgement. Sharon implied that talking about pain was
7 likely to elicit negative social consequences, such as boredom, for the listener.
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14 **Discussion**

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17 This study set out to investigate the subjective meanings and experiences of chronic
18 pain in SCI patients. All participants identified NP as the most troublesome pain
19 experience, although some experienced several sources of pain. Participants felt that
20 there was a gap between the care that they received and the care that they desired; this
21 caused feelings of being unheard, and resentment of the apparent reliance upon
22 medication that was unsuitable. Participants also felt that they were locked in battle with
23 their pain, struggling for life control, with acceptance apparently mediating this
24 relationship. They also voiced concerns for their social well-being and implied feared,
25 or even shameful, consequences of talking about the impact of pain to people without
26 SCI. Many chose to avoid discussing pain with people without SCI, with the potential
27 to increase isolation. Non-disclosure appeared to avoid other unwanted social or
28 emotional consequences such as fear of burden, or potential negative judgement.
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44 Each of these themes draws attention to the potential for NP to cause
45 psychological distress in some people, including anxiety and depression, with
46 hopelessness and lack of personal agency key themes among those most distressed.
47 These participants visualised their pain as an endless experience in which they were
48 entrapped, with little hope for regaining a positive outlook or social presence in the
49 future, using catastrophic language and imagery. Other participants voiced that they
50 had found ways to live despite the presence of pain. These participants focused
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3 predominantly on the futility of trying to beat pain. Although level and quality of
4 articulation differed amongst participants, they raised the themes spontaneously,
5 reinforcing their prominence and pervasiveness within each individual's experience.
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10 The first sub-ordinate theme voiced by participants was the apparent reliance
11 upon medication, which participants felt was ineffective and unhelpful. As a result of
12 the perceived reliance, fears of dependency, and the occurrence of undesirable side-
13 effects such as sedation and interrupted cognitive performance, some participants made
14 conscious decisions not to adhere to their drug regimes, choosing to reduce their dose or
15 to abandon them completely. This appears to be a common occurrence in chronic pain
16 populations [39], and has been previously identified as a problem for those with SCI
17 [31]. This suggests that SCI patients with NP are engaged in a 'trade-off', willing to
18 give up pain relief in favour of fewer side-effects and freedom from anxieties, in the
19 same way as non-SCI chronic pain patients [40].
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32 The second sub-ordinate theme that participants voiced was related to patients'
33 negative relationships with HCPs, who continued to offer treatment that they found
34 inadequate. This mirrors findings in the general chronic pain literature. Eccleston,
35 Williams, and Rogers [41] suggested that relationships with HCPs could mediate
36 distress in chronic pain patients, whilst Coulter & Fitzpatrick [42] suggest that patient
37 dissatisfaction may result in reduced adherence to medication. Hansson, Fridlund,
38 Brunt, Hansson, and Rask [43] studied chronic pain patients' experiences of the
39 healthcare system, finding that staff tended to focus upon their areas of expertise, such
40 as medication, potentially ignoring psychosocial difficulties. This theme would suggest
41 that continuing with this strategy is unhelpful for any chronic pain sufferer, regardless
42 of the possible medical aetiology of the pain.
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3 The third sub-ordinate theme arising within the chasm reflects this, suggesting
4 that patients would welcome HCPs accepting pain as the patient describes it, and
5 actively considering other ways of enhancing patient control. Pain-related distress and
6 frustration may be reduced if HCPs accredit patients, and offer them empowerment and
7 responsibility. Collaborative efforts between patients and staff, in which HCPs can
8 provide medical knowledge and support as and when it is required [44], such that
9 patients can make informed decisions and drive their own rehabilitation [45]. It would
10 be interesting to explore why the collaborative ethos so embedded in SCI rehabilitation
11 and goal planning [46] appears to be absent from communication about NP, at least
12 from the perspective of participants. This theme echoes research regarding a link
13 between the quality of the HCP-patient relationship and medication adherence [47].
14 This theme suggests that, currently, a discrepancy exists between what sort of response
15 SCI patients want from HCP's in relation to their experience of NP and what they are
16 offered. This discrepancy was also identified by Lofgren & Norrbrink [28], who
17 explored the experiences of people with SCI when offered specific, collaborative pain
18 management interventions based on evidence from general chronic pain population.
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38 The concept of the battle for control was another prominent super-ordinate
39 theme, dictating an internal struggle for ultimate life control between the individual and
40 their pain, suggesting that there is a psychological aspect of the pain experience after
41 SCI that may be managed. More pain acceptance, and beliefs that the pain is not always
42 in control, was associated with less expressed distress and pain related disruption.
43 Where individuals feel that pain is in their control, quality of life, community
44 reintegration, and physical and psychological outcomes are improved [12]. Lower
45 acceptance appeared alongside struggles to obtain life control and potential
46 catastrophising, with those 'losing the battle to pain' tending to be associated with tortuous
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3 metaphors and imagery. This polarisation of language may have resulted from an
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5 attempt to convey the extent of their distress to others.
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8 These fearful thoughts may be considered as taking the form of catastrophic
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10 thinking, a well documented phenomena in research on non-NP populations. This
11
12 appraisal style considers pain as a threat, which Walsh and Radcliffe [48] suggest may
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14 contribute to its disruptiveness and intensity, and may increase physical and
15
16 psychological disability in chronic low back pain. The emotive nature of images in this
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18 theme may have informed a heightened vigilance towards pain, thus causing increased
19
20 pain intensity and disruption, as documented in the general chronic pain literature [49].
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24 This theme echoes results of a Grounded Theory analysis of acceptance in those
25
26 with SCI-specific NP [29], finding that acknowledging the permanence of pain, and the
27
28 ability to live with pain present, reduced suffering. This also indicates that the already
29
30 established relationship between acceptance and adjustment to pain [50] exists in the
31
32 SCI population, and such pain acceptance may be associated with reduced pain
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34 perception and reduced distress [51]. This suggests that a simple target for interventions
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36 with SCI patients might be fostering a sense of control, shifting focus away from the
37
38 emphasis on reducing pain intensity to responses to distress, and the issue of focussing
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40 on pursuing valued activities, and identity. Indeed, outpatient engagement in
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42 acceptance-based therapies in order to reduce catastrophic thoughts may have a much
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44 greater impact on psychological well-being than pain intensity alone [52]. The need for
45
46 acknowledgment of distress and life restriction was a key theme in participants' wishes
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48 for treatment.
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52 The third super-ordinate theme arising from the analysis identified that there
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54 exists a simultaneous occurrence of social unison with other SCI individuals, and social
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56 isolation from the available able-bodied social support. The social context of chronic
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3 pain is influential in adjustment [53], and this result may contribute to this idea. In line
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5 with results found by Dickson, Ward, O'Brien, Allen, and O'Carroll [54], outpatients
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7 articulated experiencing a connection with other SCI patients, bonded by their shared
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9 experiences, but felt that they lost this camaraderie and community spirit upon
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11 discharge. This loss of camaraderie may serve as a barrier to community reintegration,
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13 adjustment and pain acceptance following discharge from a spinal unit for those whose
14
15 distress remains heightened by the presence of pain.
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18 Participants in this study voiced their attempts at social withdrawal in order to
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20 prevent their pain from burdening their friends and families. Further, participants who
21
22 chose to only talk to those who understood their pain may have contributed to their own
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24 isolation. Closs, Staples, Reid, Bennett, and Briggs [55], found comparable results in
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26 chronic pain patients, who also engaged in social withdrawal as a result of concern for
27
28 the impact of their pain on social relationships, and increased self-perceived burden
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30 (SPB). This SPB may have a negative impact upon psychological wellbeing and is
31
32 predictive of suicidal ideation [56]. Feelings of SPB are important to target in pain
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34 management, particularly due to its positive correlation with pain intensity, depression
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36 and anxiety [57, 58], and its impact on the well-being of patient friends and families,
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38 who are at increased risk of suffering depression and anxiety [59]. Outpatient social
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40 support through the use of peer and family mentoring discussions may therefore be
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42 informed by staff knowledge of ongoing pain, in order to improve such social support.
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48 The experience of chronic NP shares a number of similarities with non-SCI
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50 chronic pain, framed within the biopsychosocial model [19, 60]. Multidisciplinary pain
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52 management programmes (PMPs) have shown general effectiveness for non-SCI
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54 chronic pain, yet SCI-specific pain has remained resistant to these [18], suggesting the
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56 need to tailor PMPs to the specific needs of the SCI population. However, this data
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3 suggests that even interventions in routine clinical follow-up of SCI patients, rather than
4
5 in specific PMPs, may have a potential impact on distress. Both the present study, and
6
7 previous content analysis of questionnaires completed by SCI patients [61], indicate that
8
9 those living with SCI have a desire for dialogue with those working with them, and that
10
11 HCPs would benefit from listening to each individual's personal story. Focus upon
12
13 improving the sense of life control, acceptance, living well despite pain, and addressing
14
15 social isolation may also be of benefit to SCI patients' well-being.
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19 A particularly useful intervention for this population may be that of mindfulness,
20
21 which has a well-documented evidence base for increasing pain tolerance and reducing
22
23 distress in non-SCI chronic pain populations [62]. Mindfulness may be useful for those
24
25 wishing to reduce or avoid medication use, such as participants in this study, due to its
26
27 ability to shift the focus to experience and reduce the desire for pain medication as a
28
29 means to solve a problem [63]. Further research has found benefits of mindfulness in
30
31 terms of physical and psychological well-being [64], and interpersonal relationships
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33 [65]. Comparable to these findings, the only study examining state mindfulness in those
34
35 with SCI suggested that being more mindful reduced the use of avoidance techniques in
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37 response to negative events, and depressive symptoms, resulting in increased positive
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39 mood [66].
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44 **Limitations & Future Research**

45
46 The nature of the IPA methodology limits the degree to which conclusions can
47
48 be drawn about any causal links between themes. It may be beneficial for future
49
50 research to explore quantitative perceptions of the quality of patients' interpersonal
51
52 relationships with family, friends, the SCI community, and HCPs, as well as
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54 quantitative measures of catastrophising, adjustment to SCI, and perceived life control,
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56 in order to validate the themes presented here. It may also be of benefit to interview
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3 HCP's who work with SCI patients, in order to understand what barriers to
4 implementing a biopsychosocial care pathway for NP exist, and how these might be
5 overcome.
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10 It may be argued that the small sample may not have been a good representation
11 of the general SCI population. It was also a self-selecting sample, suggesting that the
12 participants may have been more willing to talk to a stranger about their pain than the
13 rest of the non-volunteering population. Data from another outpatient sample may be
14 useful to explore if the themes are replicable. Previous qualitative research, including
15 content analysis and Grounded Theory, has been conducted with the SCI population.
16
17 IPA has not previously been utilised to enhance our understanding of SCI-specific NP,
18 and this study allowed for a deeper level of understanding of the experience to be
19 reached by listening to the stories of those living with it, and allowing them to articulate
20 the most important issues to them. There was also value in linking lived experience with
21 some of the published quantitative and qualitative literature. Social factors, including
22 relationships with HCP's, and communication about medication, were central issues to
23 participants' experiences but are relatively under-represented in the quantitative
24 literature compared to study of personal, internal cognitive factors such as perceived
25 control and catastrophising.
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45 **Acknowledgements**

46
47 We would like to thank all of the participants and staff at The National Spinal Injuries
48 Centre, Stoke Mandeville Hospital, for their time and co-operation.
49

50 **Declaration of Interests**

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52 None.
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Table 1. Participant characteristics ($n=8$)

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

*All names changed to preserve anonymity.

** Road Traffic Accident

*** Visual Analogue Scale of pain intensity, ranging from 0 (no pain) to 10 (pain as bad as it could be)

Table 2. Interview Schedule.

-
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?
 - Was this helpful?
 3. What techniques do you use to cope with your pain, if any?
 - What is the most effective strategy for managing your pain?
 4. What is your life like since experiencing SCI-specific pain?
 - How does pain affect your everyday life?
 - How have other reacted to your pain?
 - Are there any activities you do differently now as a result of your pain?
 5. How do you think your pain will affect your future, if at all?
 6. Is there anything else you would like to add to the discussion?
-

Table 3. Super-ordinate themes and corresponding sub-ordinate themes.

<i>The Chasm Between Biomedical Perspectives and Patient Beliefs and Needs</i>	<i>The Battle for Ultimate Agency in Life</i>	<i>The Coexistence of Social Cohesion and Social Alienation</i>
Excessive Reliance on Insufficient Medication	I am Winning	SCI Population are United but Alone in their Experience
Losing Faith in Healthcare Professionals	Pain is Winning	Painful Self as an Affliction on Social Relationships
Lack of Input into own Care		

For Peer Review

Disability and Rehabilitation - Decision on Manuscript ID TIDS-08-2014-022.R1

onbehalfof+davemuller+suffolk.ac.uk@manuscriptcen...

To: JASMINE HEARN

Monday, December 22, 2014 11:31 AM

22-Dec-2014

Dear Miss Hearn:

Ref: Living with chronic neuropathic pain after spinal cord injury: An Interpretative Phenomenological Analysis of community experience

Our referees have now considered your paper and have recommended publication in Disability and Rehabilitation. We are pleased to accept your paper in its current form which will now be forwarded to the publisher for copy editing and typesetting.

You will receive proofs for checking, and instructions for transfer of copyright in due course.

The publisher also requests that proofs are checked and returned within 48 hours of receipt.

Thank you for your contribution to Disability and Rehabilitation and we look forward to receiving further submissions from you.

Sincerely,
Professor Muller
Editor in Chief, Disability and Rehabilitation
davemuller@suffolk.ac.uk