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1            **Neuropathic Pain in a Rehabilitation Setting after Spinal Cord Injury:**  
2            **An Interpretative Phenomenological Analysis of Inpatients' Experiences**

3

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19

20 **Conflict of Interest.**

21 The authors declare no conflict of interest.

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23

24            **Neuropathic Pain in a Rehabilitation Setting after Spinal Cord Injury:**  
25            **An Interpretative Phenomenological Analysis of Inpatients' Experiences**

26            *Study Design:* Qualitative, semi-structured interviews.

27            *Objectives:* Neuropathic pain (NP) can be psychologically and  
28            physically debilitating, and is present in approximately half of the spinal  
29            cord injured (SCI) population. However, under half of those with NP are  
30            adherent to pain medication. Understanding the impact of NP during  
31            rehabilitation is required to reduce long-term impact and to promote  
32            adherence to medication and psychoeducation recommendations.

33            *Setting:* United Kingdom.

34            *Methods:* Five males and three females with SCI and chronic NP, resident in  
35            rehabilitation wards at a specialist SCI Centre in the UK, took part. Semi-  
36            structured interviews were conducted with participants less than 15 months  
37            post-SCI (mean = 8.4 months). Verbatim transcripts were subject to  
38            Interpretative Phenomenological Analysis (IPA).

39            *Results:* Three super-ordinate themes were identified, mediating pain and  
40            adherence: (1) the dichotomy of safety perceptions; (2) adherence despite  
41            adversity; and (3) fighting the future. Analyses suggest that experience of the  
42            rehabilitation setting and responsiveness of care shapes early distress.  
43            Attitudes to medication and psychosocial adjustment are relevant to  
44            developing expectations about pain management.

45            *Conclusions:* Enhancing self-efficacy, feelings of safety in hospital, and  
46            encouraging the adoption of adaptive coping strategies may enhance  
47            psychosocial and pain-related outcomes, and improve adherence to  
48            medication. Encouraging adaptive responses to, and interpretation of, pain,  
49            through the use of interventions such as coping effectiveness training,  
50            targeted cognitive behavioural pain management, and acceptance-based  
51            interventions such as mindfulness, is recommended in order to reduce long-  
52            term reliance on medication.

53            Keywords: SCI/SCD; pharmacological treatment; acceptance; coping; safety

54

55

## Introduction

56 Over 60% of individuals with spinal cord injury (SCI) are affected by chronic pain<sup>1,2</sup>,  
57 a significant problem that should be addressed from its onset to facilitate early  
58 adjustment to both pain and SCI. People with neuropathic pain (NP) often report  
59 difficulty managing it, describing unique sensory qualities of pain, including burning,  
60 electric, and crushing sensations<sup>3</sup>, and these can be potentially distressing in nature.  
61 NP typically fluctuates in severity, worsening over time<sup>2</sup>, with between 34% and 41%  
62 of the SCI population with NP in the early stages of rehabilitation living with it at five  
63 years post-injury<sup>4</sup>, signifying a potential correlation and the need for early  
64 intervention/management.

65 Despite its prominence, and the limited effectiveness of medication<sup>5</sup>, common  
66 practice first line treatment for NP remains targeted pharmacological pain  
67 management<sup>6</sup>. Such approaches are essential, given the structural and biochemical  
68 changes associated with nerve damage after SCI<sup>7</sup>. However, poor adherence is  
69 common in pain populations<sup>8</sup>; fewer than half (43%) of people with NP were  
70 compliant with their drug regimes in one study<sup>9</sup>. Adherence is related directly to the  
71 participants' beliefs regarding the necessity of, and concerns regarding, medication<sup>10</sup>,  
72 indicating that psychosocial factors mediate pain-related behaviours and its  
73 persistence. Perceptions of low pain control and catastrophic thinking have been  
74 identified as factors playing a role in outpatients with SCI<sup>11</sup>. Other work has  
75 suggested that variables such as functional status, emotional status, and coping  
76 variables do not predict chronic pain<sup>1</sup>. However, the majority of research is focused  
77 on outpatients, as opposed to early rehabilitation. Given the correlation between pain  
78 during rehabilitation and its long-term presence, there may exist a critical time  
79 window for responding and mitigating the effects of pain, thus facilitating the

80 adjustment process.

81 Previous qualitative work has explored experiences of social support  
82 following SCI<sup>12</sup>, pain management<sup>13</sup>, memories of pain<sup>14</sup>, NP acceptance<sup>15</sup>, the lived  
83 experience of NP itself by people with SCI living in the community<sup>16</sup>, and the use of  
84 metaphorical language when communicating NP<sup>17</sup>. Despite evidence that 70% of  
85 patients report NP within six months of injury, and often find nothing to help alleviate  
86 pain<sup>18</sup>, no published work has considered the experiences of those in the early stages  
87 of rehabilitation from a qualitative perspective. This work will serve to highlight  
88 patient understandings during a critical time, where they are learning how to navigate  
89 life with SCI and NP, and focus future work on key aspects identified as significant  
90 by those living with NP. This can also aid healthcare staff in identifying and  
91 correcting any false understandings, and contribute towards minimizing the risk of  
92 distress caused by chronic pain as an outpatient following rehabilitation.

93 This study, therefore, presents the results of analysis of eight verbatim  
94 transcripts of interviews with inpatients with SCI and NP in rehabilitation at a  
95 specialist spinal center in the UK. The data was analyzed using Interpretative  
96 Phenomenological Analysis (IPA)<sup>19</sup> in order to enrich current understanding of NP  
97 from the perspective of those who are in the early stage of adjustment to SCI. This  
98 study aims to identify what is most important to those living with NP during  
99 rehabilitation in terms of impact and management.

100

101

## **Method**

### ***Participants***

103 Participants were recruited from The National Spinal Injuries Centre. Inclusion  
104 criteria were: inpatients NP of a duration of at least three months (adhering to the  
105 International Association for the Study of Pain<sup>20</sup> definition of chronic pain), over 18  
106 years of age; and English speaking. Participants were not recruited if they held any  
107 significant cognitive impairment, mental illness or head injury. People meeting the  
108 inclusion criteria were approached by members of the direct care team, and directed  
109 to the researchers for further information. Of the 11 patients contacted, three declined  
110 to participate and eight were interviewed. Due to the large amount of data obtained,  
111 and IPA's detailed, idiographic approach to analysis, this sample size is considered  
112 appropriate, in accordance with recommendations of a small sample size<sup>21</sup>. Five  
113 participants were male, three were female. Participants have been given pseudonyms  
114 in order to preserve confidentiality and anonymity. Demographic characteristics are  
115 presented in Table 1.

RUNNING TITLE: Neuropathic pain during rehabilitation

116 Table 1. Participant demographics.

Participant* (Gender)	Age (years)	Employment status	Marital status	Cause of injury	Time since injury (months)	Level of injury	Completeness of injury (ASIA Impairment Scale <sup>22</sup> )	Pain location(s)	Average pain intensity (NRS) <sup>***</sup>
Jimmy (M)	71	Retired	Married	Fall	12	C6	C	Left arm, hands	8
Alice (F)	23	Unemployed	Single	RTA**	14	C3	C	Whole body	10
Amir (M)	69	Retired	Married	Non-traumatic	10	C3	C	Right side & arm, feet	4
Jennifer (F)	63	Full-time	Married	Fall	9	C5	B	Shoulders, chest	10
Deb (F)	80	Retired	Widowed	Fall	10	C4	A	Whole body	3
George (M)	82	Retired	Widowed	Non-traumatic	4	T5	A	Legs	7
Mark (M)	51	Full-time	Married	RTA	4	C2	B	Shoulders, arms, hands	3
Dave (M)	40	Full-time	Married	Diving accident	4	C6	B	Neck, arms	2

117

118 \*Participant names changed to preserve anonymity.

119 \*Road traffic accident.

120 \*Numerical rating scale.

121 **Materials**

122 *Interview schedule:* In order to elicit in-depth, detailed information, an interview  
123 schedule was developed and piloted with two individuals with SCI to ensure  
124 questions were appropriate and to trial the length of the interview. This is presented in  
125 Table 2.

126 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?
    - 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?
- 

127

128 **Procedure**

129 Local ethical approval was secured for the study from The National Health Service  
130 Research Ethics Committee (ref: 13/LO/0558), the local Research and Development  
131 office (RXQ/549), and The University of Buckingham.

132 A member of the direct care team identified and approached eligible patients  
133 with information regarding the study and asked if they would consider taking part,  
134 after which patients were provided with detailed information and offered time to  
135 consider their consent. Written, informed consent was obtained, and interviews were  
136 conducted in private rooms. Interviews lasted between 40 and 60 minutes.

137 Interviews were audio-recorded and participants were given freedom to lead  
138 the interview, unrestricted by the imposition of topics, such that discussion centered  
139 on what participants felt was most important in their experience<sup>21</sup>. Participants were  
140 able to discuss what was of importance to them, and focus upon their own personal  
141 experience and the meanings of NP to them and their experience, as recommended by  
142 Smith et al.<sup>21</sup>. Any identifying information (e.g. participants, friends and families, and  
143 healthcare professionals) has been anonymised.

144

145

#### 146 *Data Analysis*

147 The systematic approach to IPA recommended by Smith, Flowers & Larkin<sup>21</sup> was  
148 followed. Interviews were transcribed verbatim and read a number of times to ensure  
149 familiarity with the data. Analytic notes and reflections (descriptive, linguistic, and  
150 conceptual) were made to aid the emergence of themes. Searching for similarities and  
151 differences across emergent themes then enabled super-ordinate themes to be  
152 developed, representing aspects of the experience considered most important from  
153 participants' perspectives. This process was completed in an idiographic manner.  
154 Following analysis of all transcripts, a cross-case analysis was conducted, establishing  
155 patterns, and identifying themes present across at least half of the sample, as well as  
156 convergences and divergences across cases. A table was generated, within which were  
157 super-ordinate and sub-ordinate themes, with illustrative quotes. Throughout this  
158 process, the data was constantly revisited (i.e. after analytical notes, emergent themes,  
159 and super-ordinate themes were developed) to ensure that themes remained grounded  
160 in the data and reflected participants' accounts<sup>21</sup>.

161           IPA is interpretative in nature, suggesting that individual researchers may  
162 interpret data differently, due to differences in personal backgrounds. Therefore, as  
163 recommended by Smith, Flowers, & Larkin<sup>21</sup>, a reflective diary was used in a  
164 determined effort to ‘bracket-off’ prejudgments and information learned from  
165 previous interviews. To achieve rigor and quality in the analysis, two independent  
166 auditors, both of whom have experience with people with SCI, or IPA, validated  
167 super-ordinate themes and corresponding quotations to ensure themes were grounded  
168 in the data. Interpretations were discussed with the first author to illuminate areas of  
169 the experience that may have been more easily identifiable to the auditors. The  
170 interpretations presented here are considered credible and meaningful, although it is  
171 acknowledged that these are not the only interpretations of the data.

172

### 173 *Ethical Considerations*

174 Confidentiality of interviews and anonymity was ensured throughout the study. The  
175 process of thinking about, and discussing pain could cause some distress, and  
176 participants were offered the opportunity for a close family member to be present  
177 during their interview, if they wished. They were informed of their right to pause the  
178 interview and take a break, and to withdraw at any point, and have their data  
179 destroyed. Participants were provided with a debriefing form containing contact  
180 details of the authors, as well as an independent SCI charity, should they wish to  
181 discuss the research, available support, or any issues arising from their interview. No  
182 participants chose to have a family member present, nor voiced distress arising from  
183 the interview, or asked to have their data withdrawn.

184 **Results**

185 Three super-ordinate themes arose from the data: (1) The Dichotomy of Safety  
 186 Perceptions; (2) Adherence Despite Adversity; and (3) Fighting the Future. Super-  
 187 ordinate themes and their corresponding sub-ordinate themes are presented below (see  
 188 Table 3).

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

<i>The Dichotomy of Safety Perceptions</i>	<i>Adherence Despite Adversity</i>	<i>Fighting the Future</i>
Confinement in 'Prison' vs. Shelter in a 'Safe Haven'	Desperation and Hopelessness	Pain is Impermanent
Positive Perceptions of Staff	Resigned and Indifferent	Pain is Persistent, and I Accept it

190

191 *The Dichotomy of Safety Perceptions*

192 Participants' descriptions suggested that the environment was an important factor in  
 193 their overall sense of safety, emotional security, and the immediate availability of care  
 194 as and when needed; during flare ups of pain, for example. This was accompanied by  
 195 positive perceptions of staff as empathetic and compassionate, which also aided  
 196 psychological wellbeing. Such perceptions could play a role in the interpretation and  
 197 experience of pain, as well as the extent of adherence to pain management.

198

199 *Confinement in 'Prison' or Shelter in a 'Safe Haven'*

200 For those who perceived hospital negatively, confinement and desires to leave  
 201 hospital as soon as possible were characteristic of their discussions. When asked if  
 202 there was anything that could help him cope with pain, Jimmy's interpretation used  
 203 powerful catastrophic imagery:

204

RUNNING TITLE: Neuropathic pain during rehabilitation

205           Getting out of this ward would be important. I mean, it's like being in a cell, 24/7. I  
206           know the staff are very good, but like [. .] how often are you going to see the staff?  
207           You know, they're busy themselves ... The nurses are running around, like all the  
208           time they're here. They don't stop [Jimmy].

209

210       Jimmy insinuates that because he perceives the rehabilitation staff as being very busy  
211       he feels he cannot rely on them to meet his needs. The imagery of being in a prison  
212       cell implies a sense of extreme restriction and isolation.

213           Yet, the rehabilitation environment comforted other participants, leading to an  
214       interpretation of hospital as a 'safe haven':

215

216           I am happy here though, I feel comfortable. Probably just knowing there are nurses  
217           around if I need them ... At home, I do worry, like if something goes wrong, there's  
218           nobody there to help me cope with the pain [Alice].

219

220       Alice is reassured that staff can meet her needs. As a result of the immediate access to  
221       knowledgeable staff, she feels able to cope with pain. The lack of direct access to  
222       such people when at home causes her to feel distressed; insecure and anxious. This  
223       also suggests that she holds an external locus of control with regard to pain  
224       management, relying on others to provide her with pain relief and suggesting she does  
225       not feel equipped to do this herself.

226           Like Alice, George also felt safe in hospital:

227

228           This hospital is great, absolutely perfect this hospital is. Yep. They've dealt with  
229           spinal injuries in the past, this is what it was made for. They understand, you come  
230           here if you're in my condition because they expect it, they've dealt with it, and they

231           can deal with it as and when you need it, any time of day [George].

232

233   George was comforted by the specialist nature of the hospital and experience of the  
234   staff working in the unit, as well as their constant availability. The factors acted as a  
235   potential stress buffer, allowing him to feel safe and as though any pain flares could  
236   be managed as necessary. Thus, he felt able to focus upon rehabilitation with few  
237   concerns.

238

239   *Positive Perceptions of Staff*

240   Participants often judged staff in a positive light, regarding them as valuable in terms  
241   of their ability to help with pain and injury coping. Alice's quote in the theme above  
242   also reflects positive perceptions of staff, in that personal characteristics of staff,  
243   particularly their knowledge and immediate availability, contributes towards feelings  
244   of security and being cared for. Jimmy also had strong relationships with his  
245   rehabilitation team, despite perceiving the hospital environment as restrictive (prison-  
246   like, see page 10):

247

248           The physio is good, at least you know the people are trying to help you, you know.  
249           They're so dedicated, the people that do it. They care, quite a lot actually, 100%.  
250           They're very good. It makes me feel better, they're supposed to be coming round  
251           today, and they can come round whenever you need them. I find them very good, and  
252           not only just the exercise they give you, it's the way they talk to you, they're very,  
253           very helpful. I've got very strong relationships with them; they're very good [Jimmy].

254

255   Jimmy suggests that, despite perceiving hospital as prison-like, his experience has  
256   been enhanced by staff who are seen as responsive, helpful, and facilitate the

257 rehabilitation process. The rapport and social relationships built between himself and  
258 the staff may be beneficial for his psychological well-being. Such positive judgments  
259 appear to be mediated by perceptions of staff knowledge and skill, empathy, and  
260 compassion. This theme highlights the importance of these qualities in staff and the  
261 surrounding environment as key to overall feelings of psychological containment,  
262 mitigating distress, and belief in the ability to cope with pain and the demands of  
263 rehabilitation.

264

#### 265 *Adherence Despite Adversity*

266 There was a spectrum of reasons for and against adherence discussed in relation to  
267 pharmacological treatment of NP, with participants identifying themselves at two  
268 opposite and extreme points. The majority voiced perceptions of medication as  
269 ineffective, expressing concerns regarding side-effects, which led to either reduced  
270 adherence, or a resignation to adherence due to perceptions of no alternative options.  
271 At the other end of the spectrum, others found satisfactory relief in their drug regime,  
272 which increased adherence. Centrally, however, participants expressed a desire for  
273 complete pain relief, despite the extent to which it was presently managed. This theme  
274 demonstrates the importance of understanding patient expectations of pain relief.

275

#### 276 *Desperation and Hopelessness*

277 Five of the eight participants felt that their pain medication was inadequate, with a  
278 high degree of focus placed on hopes for total pain relief:

279

RUNNING TITLE: Neuropathic pain during rehabilitation

280 I was on 5mg [pain medication]<sup>1</sup>, and I said it's not enough, so they put me on 10,  
281 and it's still not enough, so they put me on 15, and that still isn't enough, and I think  
282 20 is the most you can have. But like I said, I don't want to take any more. There's no  
283 more medication that can help [Alice].

284

285 Alice highlights both her ambivalence about the effectiveness of medication and her  
286 desperation for adequate pain relief. Her focus is on medication as the sole provider of  
287 pain relief, which she admits is not a helpful approach. Alice's quotes illustrate both  
288 her hopelessness towards medication to bring pain relief, reflecting a general  
289 hopelessness about how to manage her pain, and perception of a lack of alternative.

290 George voiced concerns regarding the ineffectiveness of medication and lack  
291 of alternative:

292

293 They [hospital staff] don't know what to do to stop the pain. There's just not a  
294 painkiller on the market for this sort of pain. It's not as if you can take an aspirin or,  
295 like the old days, or paracetamol. They don't work, don't touch it [George].

296

297 George's statements indicate a sense of futility about pain control on a global and  
298 personal scale, as well as his external locus of control, seeing staff as those  
299 responsible for his pain relief. Such a view emphasizes a need for psychosocial  
300 management to be further addressed during rehabilitation, which may mitigate the  
301 effect of such perceptions on adherence and other health-related behaviours.

302

303 *Resigned and Indifferent*

---

<sup>1</sup> Descriptive information provided by the authors

RUNNING TITLE: Neuropathic pain during rehabilitation

304 Two participants acknowledged the benefits of medication, but felt resigned to taking  
305 it as a last resort, or the only option. When asked how she manages her pain, and how  
306 she feels about taking medication, Jennifer responded:

307

308       Nothing I can do really. Just have to take tablets [Jennifer].

309

310       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  
311       you'd be a screaming loony. Well you would, because you couldn't take the pain  
312       [Jennifer].

313

314 Jennifer indicates that she would prefer not to rely on medication but presents a  
315 resignation that if she did not take it her pain would be unmanageable. Despite her  
316 negative perception of medication, the metaphor of losing her sanity suggests that  
317 pain acts as a threat to her emotional integrity, thus motivating her adherence.

318       In contrast, Mark was appreciative of his pain management:

319

320       I've been very lucky that the consultant has given me quite a heavy dose of long-term  
321       release medical prescription. I can also have morphine; you know liquid morphine, as  
322       and when I need that, every four hours. So, the pain relief has been good [Mark].

323

324 Mark had faith in his pain management regime, comforted by his ability to take strong  
325 medication as and when needed. He refers to being 'lucky', suggesting that he may  
326 have been aware of others without good pain control, but is happy with his own  
327 regime, despite it being a 'heavy dose'. The variance of experiences within this theme  
328 suggest that attitudes towards medication vary widely and are linked to hopelessness  
329 and hopefulness and may affect adherence to medication even during the inpatient

330 rehabilitation phase.

331

332 *Fighting the Future*

333 Participants' discussions often became future-oriented and presented uncertainty  
334 around whether pain would persist. Some participants perceived their pain as a  
335 temporary phenomenon that would not persist, whilst others did not feel that pain  
336 interfered with their rehabilitation, and acknowledged that it might not resolve.  
337 Regardless of their stance, participant narratives reflected a fight against pain to  
338 engage in forward-planning and rehabilitation.

339

340 *Pain is Impermanent*

341 Five of the eight participants considered their pain a temporary presence, and had  
342 hopes for complete pain relief, despite the potential persistence of NP:

343

344       The pain won't be there when I get home. I'm certain that it won't ... I think that by  
345       the time I leave, I'm getting better and better, and the pain will go away ... It's not an  
346       unknown thing, it will go away [Amir].

347

348       Haven't accepted it, just putting up with it ... I hope it's more temporary for me. I  
349       hope so, I hope so [Jennifer].

350

351 Amir discussed his future with optimism, a belief that did not allow for any  
352 consideration that NP might persist, and thus may have allowed him to focus upon  
353 rehabilitation. Such perceptions may also prevent the development of adaptive coping  
354 strategies, pain management, and acceptance of both injury and NP, should NP  
355 persist. Jennifer also voiced uncertainty regarding the trajectory of NP, implying that

356 there exists a sense of the unknown with regard to NP during inpatient rehabilitation,  
357 with many expressing desires for a pain-free future. However, should NP persist  
358 following discharge, such patients may be at risk of increased distress as a result of  
359 their expectations not being met. Patients may find that they are potentially  
360 unprepared to manage NP and adhere to pain medication and education provided  
361 throughout rehabilitation if their goal is for complete pain relief.

362

363 *Pain is Persistent, and I Accept it*

364 A minority of participants, David and George, expressed an understanding that NP  
365 may persist beyond rehabilitation, illustrating a need to foster improved understanding  
366 of the potential persistence of NP following SCI. Participants appeared to have  
367 accepted the likelihood that NP would persist, and had begun to prepare for a  
368 potential future with pain present:

369

370         Yeah, I've come to terms with it [pain], and I've come to terms that I'm going to go  
371         home, this same way, with pain [George].

372

373 When considering his discharge into the community, George voiced his acceptance of  
374 pain's presence, suggesting that he is not necessarily overwhelmed by the idea that  
375 pain could be permanent. He remains focused on his goal of going home, rather than  
376 letting pain disrupt his rehabilitation and emotional well-being. Such acceptance  
377 could reduce NP's interference in daily life, and improve views of the future, as well  
378 as adherence and adjustment.

379

380

381 **Discussion**

382 This study investigated the subjective meanings and experiences of chronic NP in  
383 inpatients with SCI, in order to explore its impact upon rehabilitation and  
384 management. Three themes emerged regarding the experience of NP: (1) The  
385 Dichotomy of Safety Perceptions; (2) Adherence Despite Adversity; and (3) Fighting  
386 the Future. The environment, and empathy and compassion from staff were  
387 significant factors for participants, and may play influential roles in pain-behaviours,  
388 coping, and medication adherence. Issues surrounding medication efficacy were  
389 prominent, with many participants voicing ambivalent feelings about medication and  
390 hopes for complete pain reduction. Finally, future-oriented discussion implied that  
391 there remains some uncertainty surrounding pain's persistence, with many  
392 participants discussing expectations of a pain-free future. This is a key issue to be  
393 discussed with patients early in rehabilitation; providing accurate information but  
394 maintaining hope whilst taking account of overall adjustment/readiness for  
395 information. The potential for NP to cause psychological distress in some people is  
396 also highlighted, with key influences being perceived inadequate pain relief, and the  
397 perceived restriction or limited availability of support in the hospital environment.  
398 This may interact with overall adjustment to injury and engagement in rehabilitation.  
399 The themes reflect the considerations of those with NP after SCI as they progress  
400 through rehabilitation towards discharge, and as they begin to adjust to the injury,  
401 supporting the idea that pain management approaches should be incorporated into  
402 interactions throughout the rehabilitation experience.

403 The first theme involved participant interpretation of their surrounding  
404 environment. Such interpretations may reflect overall appraisals in relation to coping  
405 with SCI, as well as their pain experience. Interpreting hospital positively appeared to

406 be related to perceptions of staff availability and responsiveness as well as optimism  
407 in the ability to cope with overall consequences of SCI. Benefits of feeling safe in  
408 hospital include increased focus on recovery<sup>23</sup>, and obtaining adequate rest<sup>24</sup>, and  
409 suggest that feelings of safety are also related to perceptions of coping with pain and  
410 rehabilitation. Those describing hospital negatively did so using powerful metaphors,  
411 accompanied by feelings of being unable to cope with their SCI and pain, which may  
412 be associated with catastrophic thinking. *Feeling* safe, therefore, may be just as  
413 important as *being* safe<sup>25</sup>. It is difficult to make inferences from the emergence of this  
414 theme, due to the lack of existing research regarding patient interpretations of hospital  
415 environments<sup>26</sup>. The emergence of such a theme, however, suggests that it is a key  
416 issue for people in rehabilitation, and indeed cases of extended inpatient care.  
417 Environmental factors, particularly around the responsiveness of care and perceived  
418 quality of relationships with staff should, therefore, be considered, with more research  
419 needed exploring perceptions of inpatient environments in order to better understand  
420 their relationship with coping and pain management.

421       Factors mediating perceptions of staff and sense of security included  
422 knowledge, trust, presence, empathy, and compassion, which may influence how  
423 people learn to manage NP. Some participants were comforted by the expert  
424 knowledge they perceived the staff to have; others remained aware that staff were not  
425 always readily available if they needed them. A recent concept analysis of patient  
426 feelings of safety identified similar themes<sup>27</sup>, highlighting their prominence among  
427 hospitalized patients. Building rapport and trust are key goals for rehabilitation staff,  
428 and can improve patient satisfaction and treatment compliance, allowing patients to  
429 achieve better outcomes from their care<sup>28</sup>. These findings suggest that such  
430 psychosocial factors are linked with how people cope with pain after SCI.

431           Empathy and compassion were identified as important to participants, both  
432 having the potential to play significant roles in encouraging health benefits such as  
433 treatment adherence<sup>29</sup>. Olsen and Hanchett<sup>30</sup> found negative relationships between  
434 nurse-expressed empathy, and distress experienced by the patient, and between  
435 patient-perceived empathy and distress experienced by the patient, thus supporting  
436 this finding. Improving staff awareness of interpersonal interactions and promoting  
437 patient-perceived empathy and compassion, as well as communication, rapport, and  
438 friendliness, should be encouraged<sup>31</sup>. These characteristics were acknowledged as  
439 beneficial to psychosocial wellbeing by those in this study, and were elicited in  
440 response to questioning about what aids pain coping.

441           Adherence Despite Adversity concerned a core belief that pain relief was the  
442 most important mechanism to cope with pain, often associated with ambivalence  
443 towards medication. Many participants saw medication as the only option to manage  
444 pain, highlighting a discrepancy between patient expectations and the goals of  
445 rehabilitation. Adherence behaviour was variable depending on such competing  
446 beliefs, suggesting that non-adherence behaviour could be presenting itself prior to  
447 discharge from hospital, and prescribers and rehabilitation staff should address pain-  
448 related motivations and what patients consider a satisfactory outcome in order to  
449 maximise adherence. Further work is required to establish whether pre-discharge  
450 adherence behaviour is a useful indicator of problematic nonadherence post-  
451 discharge.

452           Many participants voiced a dislike of medication, either refusing to adhere, or  
453 continuing to take it despite their aversion. Patients, however, often have fears of not  
454 being believed regarding pain, or burdening care staff, which may become barriers to  
455 providing complete information regarding adherence<sup>32,33</sup>, and impact the patient-staff

456 relationship. Participants in this study were provided with individualized goal-focused  
457 rehabilitation programmes by the treating center, during which a holistic pain  
458 management approach is promoted. However, this study suggests that those who are  
459 most distressed by the NP may not be as receptive to pain management messages, and  
460 it may be helpful to examine the messages that prescribing staff give to counter the  
461 perception of total pain relief as a primary goal. Fostering effective patient-clinician  
462 communication and offering patients informed choice may be of longer-term benefit.  
463 Such improvements may promote a collaborative approach in pain management<sup>34</sup>,  
464 along with improved adherence and pain management.

465         Participants discussed hopes surrounding NP post-discharge. Those who felt  
466 pain was manageable did not appear distressed, and felt able to make plans. This has  
467 been associated with patients taking a more active approach to pain management, and  
468 using less medication<sup>35</sup>. Whilst chronic pain is correlated with depressed mood,  
469 increased self-efficacy in individuals with SCI can serve to mitigate the complex  
470 interaction between chronic pain on mood<sup>36</sup>, and is positively correlated with life  
471 satisfaction<sup>37</sup>. Levels of self-efficacy, however, are reduced in those with SCI,  
472 compared to the general population<sup>38</sup>, suggesting that those distressed by NP may  
473 have lower self-efficacy and high external locus of control. Acceptance of injury is  
474 commonly addressed in rehabilitation; improving pain self-efficacy may moderate the  
475 extent to which pain interferes with their lives<sup>39</sup> and could act as a long-term stress  
476 buffer.

477         Others discussed hopes for a pain-free future, which may prevent adaptation to  
478 NP and SCI in the long-term. Coping Effectiveness Training<sup>40</sup> teaches appraisal and  
479 cognitive behavioural coping skills, such that a client is able to choose the optimum  
480 coping response in particular situations. This has been shown to improve

481 psychological adjustment to SCI<sup>41</sup>. Participants expressing this theme may have used  
482 coping strategies that may be considered maladaptive (such as delaying help-seeking),  
483 and suggests that both acceptance of pain and acceptance of injury may be associated  
484 as early as during inpatient rehabilitation. Enabling acceptance of pain and the  
485 adoption of approach-focused coping strategies in relation to pain, as well as general  
486 adjustment to injury, could be helpful for this group.

487

#### 488 **Limitations**

489         As the small sample was primarily made up of people aged over 60 (reflective  
490 of the changing demographic of an ageing SCI population), the results may not be  
491 representative of the wider SCI population. The self-selecting sample also suggests  
492 that these participants may have been more willing to talk to a stranger about their  
493 experiences than the non-volunteering population, and that those effectively  
494 managing NP were less motivated to participate. A replication study involving a  
495 sample with a wider variety of levels of injury may be useful to explore variance in  
496 experience.

497         The nature of the IPA methodology limits the degree to which conclusions can  
498 be drawn about causal links between themes. Future work should, therefore,  
499 quantitatively explore the relationship between environmental perceptions, including  
500 perceived empathy and compassion of staff in relation to perceived self-efficacy in  
501 the management of NP, and how patient perceptions about the goals of pain  
502 medication and perceived acceptable nature of the outcome influence adherence to  
503 pain medications. It may also be of benefit to interview staff who work with people  
504 with SCI, to gain a 360-degree understanding of NP in rehabilitation, and of potential  
505 barriers to care and how these might be overcome.

506

507 **Conclusion**

508         Participants resident in a rehabilitation facility expressed concerns in three  
509 broad domains in relation to NP; pain relief and ambivalence about medication,  
510 interpretations of the environment and staff empathy/compassion, and the potential  
511 transitory or persistent nature of pain in the future. The issue of how medication is  
512 used for pain relief, even in this relatively early stage of transition from acute to  
513 chronic pain, seems to be important in terms of managing distress and future chronic  
514 pain. This is a significant issue, since those living with NP following SCI are likely to  
515 continue experiencing it. Psycho-educational interventions based around the  
516 biopsychosocial model of pain should be tailored to each individual's unique needs  
517 and experience, with a clear systematic message presented early in rehabilitation that  
518 long-term medicating may not be a useful goal. Emphasis should be placed on  
519 alternative strategies and on fostering moving towards acceptance.

520

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524

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526 The authors declare that there are no conflicts of interest, and agree to the publication  
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528

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