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RUNNING TITLE: Neuropathic pain during rehabilitation

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

3

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20 **Conflict of Interest.**

21 The authors declare no conflict of interest.

22

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^{1,2},
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 sensations³, and these can be potentially distressing in nature.
61 NP typically fluctuates in severity, worsening over time², 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-injury⁴, signifying a potential correlation and the need for early
64 intervention/management.

65 Despite its prominence, and the limited effectiveness of medication⁵, common
66 practice first line treatment for NP remains targeted pharmacological pain
67 management⁶. Such approaches are essential, given the structural and biochemical
68 changes associated with nerve damage after SCI⁷. However, poor adherence is
69 common in pain populations⁸; fewer than half (43%) of people with NP were
70 compliant with their drug regimes in one study⁹. Adherence is related directly to the
71 participants' beliefs regarding the necessity of, and concerns regarding, medication¹⁰,
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 SCI¹¹. Other work has
75 suggested that variables such as functional status, emotional status, and coping
76 variables do not predict chronic pain¹. 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 SCI¹², pain management¹³, memories of pain¹⁴, NP acceptance¹⁵, the lived
83 experience of NP itself by people with SCI living in the community¹⁶, and the use of
84 metaphorical language when communicating NP¹⁷. Despite evidence that 70% of
85 patients report NP within six months of injury, and often find nothing to help alleviate
86 pain¹⁸, 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)¹⁹ 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 Pain²⁰ 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 size²¹. 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 ²²)	Pain location(s)	Average pain intensity (NRS) ^{***}
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 experience²¹. 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.²¹. 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 & Larkin²¹ 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' accounts²¹.

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, & Larkin²¹, 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]¹, 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*

¹ 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 recovery²³, and obtaining adequate rest²⁴, 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* safe²⁵. 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 environments²⁶. 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 themes²⁷, 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 care²⁸. 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 adherence²⁹. Olsen and Hanchett³⁰ 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 encouraged³¹. 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^{32,33}, 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 management³⁴,
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 medication³⁵. 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 mood³⁶, and is positively correlated with life
471 satisfaction³⁷. Levels of self-efficacy, however, are reduced in those with SCI,
472 compared to the general population³⁸, 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 lives³⁹ 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 Training⁴⁰ 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 SCI⁴¹. 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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