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1 **Women’s Experiences of Sexuality After Spinal Cord**
2 **Injury: a UK Perspective**

3
4 **Women’s Experiences of Sexuality After SCI**
5

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30

31 **Abstract**

32 **Study design:** Cross sectional phenomenological qualitative study

33 **Objectives:** To investigate women's experience of sexuality after spinal cord injury
34 (SCI) with a focus on rehabilitation and manging practical impact.

35 **Setting:** Women with SCI living in the community in United Kingdom (UK).

36 **Methods:** Participants were recruited via 3 UK SCI centres, ensuring tetraplegia,
37 paraplegia and cauda equina syndrome representation. Single semi-structured
38 interviews exploring individual's experiences around sexuality following SCI were
39 recorded and transcribed for thematic analysis.

40 **Results:** Twenty seven women aged 21-72 years, sexually active since SCI were
41 interviewed, each lasting 17 - 143 minutes (mean 55 minutes). Six key themes
42 emerged: physical change, psychological impact, dependency, relationships and
43 partners, post injury sexual life, sexuality rehabilitation.

44 **Conclusion:** Sexuality remains an important, valued aspect of female identity
45 following SCI; sexual activity continues and though altered remains enjoyable and
46 rewarding. Sexuality rehabilitation should commence early, preparing women for
47 altered sexual sensation, disclosure of altered sexual function to partners, and
48 encouraging early self-exploration. Techniques optimising continence management
49 in preparation for and during sex should be taught. Participants identified a need for
50 women-only education and support groups, increased peer support, self-esteem,
51 communication and social skills training and even fashion advice and pampering
52 sessions during rehabilitation. Support and education for partners are needed. Staff
53 require support to be knowledgeable and confident in addressing women's sexuality

54 needs. Use of the Ex-PLISSIT model for psychosexual support, could help staff to
55 better meet these needs.

56

57 **Keywords**

58 Sexuality, women, spinal cord injury, cauda equina syndrome, rehabilitation.

59

60

61 **Introduction**

62 Sexuality forms an integral part of individual identity [1], encompassing how
63 individuals think, feel, identify and express themselves, and establish relationships
64 [2]. Current literature on sexuality following spinal cord injury (SCI) and cauda equina
65 syndrome (CES, included in SCI throughout this paper) focuses largely on males,
66 with little exploration of women's needs [3], attributable to the larger proportion of
67 males with traumatic SCI [4], the complexities of erectile dysfunction and male
68 fertility [5] and potentially reflecting societal perceptions around sexuality in disabled
69 individuals [6]. No qualitative studies with significant participant numbers have
70 explored women's sexuality after SCI from a UK perspective.

71 Depending on the level and density of injury, female sexual function is affected
72 directly and indirectly by SCI. Genital sensation, vaginal lubrication and orgasm may
73 be impaired [7,8,9]; reduced mobility, incontinence, pain and spasticity are common
74 [3,10,11,12]. Psychosexual consequences may limit sexual activity and adjustment
75 more than physical impairments [12,13] particularly regarding desire, subjective
76 arousal, body image, self-esteem and self-confidence [12]. Relationships are also

77 affected [12,13,14]; associations between stable relationships, sexual satisfaction
78 and self-esteem have been identified [14,15].
79 Women may not receive appropriate support around altered sexuality during
80 rehabilitation [1,12,16]. Little research has explored women's priorities and needs
81 regarding sexuality, including when after injury support for altered sexuality should
82 be provided. It has been suggested that rehabilitation should encourage individuals'
83 positive self-esteem and provide partner counselling, helping both parties adapt to
84 life after a SCI [17], but it is unclear from the literature whether such
85 recommendations are achieved in current clinical practice.

86 Most qualitative studies exploring sexuality in SCI women have small participant
87 numbers and few have explored the perspective of women themselves in detail;
88 none extensively explore the practical impact of SCI-related impairments on
89 sexuality and their management. This study aimed to explore women's lived
90 experience of sexuality and sexuality rehabilitation in the United Kingdom (UK),
91 including how women manage SCI symptoms around sexual activity, to support
92 improved female sexual rehabilitation outcomes by promoting research and practice
93 development which addresses women's needs and priorities.

94

95 **Methods**

96 An applied phenomenological study was undertaken to obtain a descriptive, realist
97 account of the lived experience of sexuality and sexual rehabilitation amongst
98 women with SCI. An interpretive phenomenological approach seeks to ascertain
99 and understand phenomena from the perspective of the individuals who experience
100 it while acknowledging the contribution of both the context in which experiences

101 occur and the researchers own experience in the interpretation of the data. While an
102 objective approach is essential, bracketing, or the setting aside of the researchers
103 experiences and perspective, is not undertaken [18]. This is appropriate in an
104 applied qualitative study where the research questions arose from the clinical
105 practice of the researchers. The chief investigator was a nurse with more than 25
106 years of experience in SCI care and the interviewer an occupational therapist with 13
107 years of experience in SCI care. Two women with SCI were included in the research
108 team. Data collection was undertaken using loosely structured interviews to explore
109 the experiences and priorities of participants; a prompt list (appendix 1 – data on
110 menstrual issues will be reported in a separate publication) was utilised to ensure
111 that issues identified from the literature and the experience of the researchers were
112 addressed.

113 Purposive sampling was undertaken to recruit a sample of up to 30 women reflecting
114 a range of ages, and the sample stratified to include varied levels and density of SCI.
115 Recruitment was continued until data saturation was achieved i.e. no new
116 information was generated from interviews [19]. Consecutive volunteers, who met
117 the inclusion criteria, were recruited from 3 SCI centres in the UK. These criteria
118 were age 18 years or older, SCI of any level and density affecting sexual function, at
119 least 1 year post initial rehabilitation and sexually active since SCI. Sexual
120 orientation was not an inclusion or exclusion criteria. Following their response to an
121 invitation letter sent to all female patients over 18 years of participating centres,
122 potential participants were contacted by telephone to assess whether inclusion
123 criteria were met and to discuss participation in the study.

124 Participants were interviewed once by a single researcher in their home or SCI
125 centre, or via tele-conferencing or telephone. Written informed consent was gained
126 prior to interviews, which were digitally recorded and professionally transcribed.
127 Access to a psychosexual therapist after interview was available for all participants, if
128 required.

129 Nvivo software supported content analysis using a thematic approach consisting of
130 coding of data, identification of concepts and themes, sorting of data by theme or
131 concept and summarising or synthesising the data to produce descriptive and
132 explanatory accounts [20]. Coding of data was undertaken by the researcher who
133 interviewed participants, and the chief investigator. Transcriptions were shared with
134 other members of the research team to identify themes.

135 We certify that all applicable institutional and governmental regulations concerning
136 the ethical use of human volunteers were followed during the course of this research.
137 Two lay women with SCI contributed to the development and conduct of this study
138 as part of the research team.

139

140 **Results**

141 A total of 937 invitations were sent to potential participants. Sixty six women were
142 contacted by telephone after responding positively to the invitation letter. Where
143 volunteers did not meet inclusion criteria or the required number in that sample
144 stratification were already met, this was explained and they were thanked for their
145 interest. One woman was referred directly to a psychosexual therapist following the
146 initial screening process.

147

148 Twenty seven of 66 responders aged 21-72 years were interviewed (duration 17 -
149 143 minutes, mean 55 minutes) before data saturation was achieved. Demographic
150 and injury details of participants are given in Table 1. Of 12 women with paraplegia
151 recruited to the study, 5 had Asia Impairment Scale (AIS) A injuries, 1 B, 2 C and 2
152 D. Of the 9 participants with tetraplegia 1 had an AIS B injury, 2 C and 6 D. Six
153 women with CES were recruited to the study. Neurological levels were taken from
154 the most recent assessment in the medical record, with consent, using the
155 International Standards for Neurological Classification of SCI. One woman was
156 referred to psychosexual services after interview but not as a direct consequence of
157 being interviewed. One woman was signposted on to fertility services and two
158 others to peer support services.

159 Six interrelated themes emerged as summarised in Figure 1. All participants
160 contributed to the themes of physical change, psychological impact, sexual life after
161 SIC and sexuality rehabilitation. All but two women contributed to the relationships
162 and partners theme. Six women contributed to the dependency theme, 3 of whom
163 were tetraplegic, 2 paraplegic and 1 diagnosed with CES.

164

165 [INSERT TABLE 1 HERE]

166

167 [INSERT FIGURE 1 HERE]

168

169 **1. Physical change**

170 Participants reported a range of physical consequences: reduced libido, arousal,
171 satisfaction and orgasm; bladder, bowel and pelvic floor dysfunction; pain, spasticity

172 and autonomic dysreflexia (AD). Altered vaginal sensation (absent, reduced,
173 fluctuating or position dependent) was prevalent. While for some sensation improved
174 over time, complete vaginal sensory loss was devastating and affected participants'
175 view of intercourse:

176 *"I told him to stop pretty soon after he penetrated me, because it was freaking me*
177 *out that I couldn't feel it. Yes, so no it wasn't a good experience"* (42 yrs, T12, C).

178 While enhanced erogenous zones above the SCI level (head, neck, back, lips,
179 earlobes, nipples) were common and stimulation of these contributed to orgasm,
180 other stimulation that was pleasurable pre-injury sometimes became hypersensitive
181 and unpleasant. Some participants reported that medications including pregabalin,
182 gabapentin and baclofen reduced their clitoral and vaginal sensation:

183 *"If somebody said to me, you know, "Your sexual dysfunction is down to the*
184 *pregabalin," I would never have believed it. But when you get off it, you think, "Oh,*
185 *okay, well it actually did make a big difference." It doesn't solve the problem but it*
186 *does make a bit of a difference, yes."* (38yrs, T4, C).

187 Lack of vaginal lubrication was effectively managed with over-the counter water-
188 soluble gel. A degree of AD was tolerated during sex but severe occurrences meant
189 stopping sexual activity. Urinary and faecal incontinence during sex was common,
190 described as 'awful', 'embarrassing', 'mortifying', 'horrible', 'gross', 'distressing'. One
191 participant ended a relationship after such an episode, while others reported partners
192 seemed understanding and accepting of the risks:

193 *"He's been messed on a few times, he's been wet more than a few times.*

194 *Fortunately, he just kind of ignores it and we deal with it at the end. [...] I guess*
195 *that's where being in an established relationship before the injury helps, because*
196 *you already know each other. And if you're going to meet a new partner and then*
197 *you go and mess all over them, that's, it's not the best start, is it? ” (45yrs, T11, B).*

198 Though less frequent, inability to control stool or flatulence were considerably more
199 difficult to endure than urinary leakage:

200 *“This is really embarrassing, but when I'm having sex, it almost feels like I need to do*
201 *a poo, like that's never happened before. And if I've got trapped wind, it will just*
202 *come out without me being able to hold it in. There's no, I have no control over it*
203 *when I'm having sex. [...]. But I just don't say anything, I just kind of ignore the fact*
204 *that it's happened. It's like, “oh my God, please don't say anything, don't notice that*
205 *that just happened”” (26yrs, T11, D)*

206 Those with lower motor neurone injury found abdominal pressure from penetration
207 expelled any stool in the rectum, intensified by certain positions (e.g knees to
208 abdomen). Digital rectal checking and evacuation of stool before sex, and avoidance
209 of eating before sex were employed to reduce the risk of faecal incontinence. A
210 regular bowel routine was also important and as bowel management skills improved
211 with time from injury, participants found that the frequency of faecal incontinence
212 reduced although the anxiety remained.

213 Strategies to reduce urinary leakage included catheterisation before sex and
214 reduction of fluid intake in the hours before planned sexual activity. To reduce their
215 risk of urinary tract infection (UTI) women washed and catheterised immediately after

216 sex, impacting negatively on their experience. UTI was a sexual “turn off” as was the
217 use of incontinence sheets, catheters and urine bags:

218 *“It is a killer and it’s only because me and him are so close that we can kind of laugh*
219 *it off. And he goes, “If it doesn’t bother you, it doesn’t bother me.” But in the back of*
220 *my mind, I tell him, “Yes it does bother me a little bit, because it’s not what I chose to*
221 *have, is it? It’s not something you’d stick on for sex.” (41yrs, C5, C)*

222 The damaging impact of bladder and bowel dysfunction and management on
223 sexuality and quality of life was clear:

224 *“Our whole life revolves around bladder and bowel. So, yes, sexual activity is no*
225 *different” (45yrs, T11, B).*

226

227 **2. Psychological impact**

228 Anxieties were common: ability to satisfy a sexual partner, when sexual activity
229 should recommence, risk of injury, what to expect, avoiding passivity. Relinquishing
230 physical control to a partner was difficult but could be achieved:

231 *“I hated the idea of feeling that I was being, not raped, but being used, you know,*
232 *just lying there and – so, over time, we tried some other positions out. And it*
233 *worked” (48yrs, T5, D).*

234 Satisfaction with body image was reduced. To look ‘sexy’ was difficult. Weight and
235 shape changes, scarring and medical devices were difficult to accept:

236 *"I certainly haven't accepted what I'm like. I don't like looking in the mirror, I don't*
237 *like having photographs taken. I've gained a lot of weight"* (38yrs, T4, C).

238 Management of incontinence, even when effective, impaired sexuality. Preparation
239 for sex could be a 'mood killer':

240 *"okay you feel like sex, let's get down to it. And then I'd be like, "Oh well hang on a*
241 *minute because I've got to go and empty my bladder, I've got to go and make sure*
242 *there's nothing in my bowel [...] okay it's gone now, don't feel like it any more"* (38yrs,
243 T4, C).

244 Emptying the bladder before sex was seen as essential but:

245 *"self-catheterising made me feel completely sexless"* (69yrs, C3, D)

246 Some women experienced feelings of detachment, and expressed a need to hide
247 from others, referring negatively to their body: *"dead from the waist down"* (42yrs,
248 T12, C) or *"I'm a wreck, I'm half a person"* (60yrs, T12, A).

249 *"I just thought, "I'm never going to have a boyfriend again. I am ugly and my body is*
250 *different, I don't like it and I don't want to show it to anybody else. That's it for me"*
251 *(37yrs, T7, A)*

252 Confidence and self-esteem were reduced after SCI but the support of significant
253 others could help with this. For one woman serial one-off sexual encounters
254 increased her confidence; others reported that with increasing time since injury
255 confidence grew.

256 *“The last three years I’ve slowly started to feel a little bit more confident, better in*
257 *myself, able to face the world a little bit better. But before that I was an absolute*
258 *recluse. I wouldn’t really go out, I wouldn’t socialise. I wouldn’t have people visit. I*
259 *was miserable company” (44yrs, CES).*

260 Some recognised the impact of their low self-esteem on others’ perceptions of them
261 and the need to address it before engaging in a relationship:

262 *“when you’re projecting that you don’t feel good about yourself, into the world, then*
263 *people treat you like you’re more of a victim” (42yrs, T12, C).*

264

265 **3. Dependency**

266 Participants with tetraplegia experienced frustration and guilt at needing their partner
267 to manage sexual activity:

268 *“I feel a bit bad for him, because I – if it was under normal circumstances, the lady*
269 *would get up and clean their self up, wouldn’t she [...] But if he wants sex with me, he*
270 *also has to clean up all the mess afterwards” (41yrs, C5, C).*

271 Knowing that carers might be aware of sexual activity was a barrier to sexual activity:

272 *“It’s hard, because there’s carers in the house [...] knowing that somebody else*
273 *might hear and be involved – and you can hear people walking down the corridor.*
274 *And that makes, that makes it awkward” (36yrs, C5, B)*

275 The partner's role was delicately balanced. Partners could help with care needs but
276 not perceive themselves as carers. Needs such as undressing produced confusion
277 between partner and carer roles.

278 *"he'll go, "Why you tell them I was your carer?" And I'll say to him, "Because you do*
279 *care for me." And he goes, "But I'm not your carer, I do it because I love you."*
280 *(41yrs, C5, C).*

281 Sometimes a caring attitude risked changing 'lovers' to carer and dependent.

282 *"he's always got in his mind, I think, that he's looking after me. Which is lovely at*
283 *one level, but [...] it's not ideal, in terms of an equal relationship and that's sad really*
284 *I think" (72yrs, L1, C).*

285

286 **4. Relationships and partners**

287 Relationship status influenced women's experiences of sexuality after SCI. For most
288 of those in a stable relationship at time of injury this eased the impact of and
289 adjustments to altered sexuality, and reinforced the emotional significance of sex:

290 *"I've always enjoyed sex and it had nothing to do with like the end result, having the*
291 *orgasm. It was all about the closeness thing. It's all about – to me, a marriage is*
292 *about being close" (38yrs, T4, C).*

293 Conversely, SCI contributed to some established relationships ending due to
294 changes in lifestyle and leisure interests, different emerging priorities and difficulty

295 with adjustment:

296 *“The accident brought us closer together emotionally, but it also created a rift*
297 *because it was so difficult to adjust. I think I’m better off now I’m with somebody who*
298 *chose me for who I am now rather than somebody who chose me for who I was.”*
299 *(42yrs, T12, C).*

300 Those single or in casual relationships at time of injury worried about future
301 relationships:

302 *“am I ever going to be able to have a husband because I mean, unless you have a*
303 *husband who’s in a wheelchair [...] it’s very difficult to understand”. (50yrs, C6, B)*

304 Some had tried internet dating though this came with risks:

305 *“I thought it was a bit creepy, wanting to know about it (her disability) and, yes,*
306 *they’d been with other wheelchair users. And he was like, “That’s not going to put*
307 *me off. I quite fancy that, somebody like that.” [...] I just ignore them and don’t do it.*
308 *[...] But I wonder whether there’s some men [...] find the chair, disabled thing better*
309 *because they like to be a little bit more controlling” (36yrs, C5, B).*

310 How and when to disclose intimate disability-related information to potential sexual
311 partners was challenging:

312 *“it’s taken me a long time being with them before I would want to have sex and have*
313 *them stay over. Longer than I would have been able-bodied, I think. [...] I have to trust*
314 *them a lot more” (36yrs, C5, B)*

315 particularly when disabilities are not obvious:

316 *“when do you tell somebody something like that? And it is quite heart-breaking when*
317 *they kind of – you don’t hear from them again once you’ve told them. So, you know,*
318 *you’ve gone on lots of dates and then you kind of bring up the conversation. It’s*
319 *almost like telling somebody you’ve got an STI (sexually transmitted infection)”*
320 *(44yrs, CES).*

321 Some women opted to be immediately and completely open with a new partner:

322 *“It’s like, “No, I’m like this, so we need to do it like that, because, you know, I don’t*
323 *move this leg. [...]” So it’s always plain. Black and white” (38yrs, T12, C).*

324 In contrast, some women never shared the extent of their disability, particularly
325 regarding bladder, bowel and orgasm dysfunction. Others felt they educated their
326 partner about their SCI, though the timing of this varied within a new relationship.

327 The acceptance and support of a partner made participants feel secure and loved
328 but the women’s altered sexuality caused difficulties for some partners. A woman’s
329 inability to orgasm could be construed as personal failure; some partners feared
330 causing harm during sex:

331 *“if we’re having a good run of sex, and then I start bypassing or getting the sweats,*
332 *then that’s, that will put him off, because he’s like, “If you’re going to be this ill*
333 *afterwards, why do I want to do something that will make you ill?”” (41yrs, C5, C)*

334

335 **5. Sexual life after SCI**

336 Some women had low expectations of sexuality after SCI;

337 *“It was just that that was going to be part of my life that wasn’t going to happen. And*
338 *it’s always been quite an important part of my life. So yes I was really devastated*
339 *that this was it” (44yrs, CES)*

340 Others feared recommencing their sex life, likened by one woman to losing her
341 virginity again, by another as *“a whole new ball game”* (45yrs, T11, B). Rarely,
342 satisfaction achieved from sexual intercourse increased post-injury; more commonly
343 loss of orgasm reduced sexual enjoyment:

344 *“not being able to orgasm [...] I’ve finally accepted that I’m not going to really get*
345 *much or any pleasure from sex. Actually, not even much, any. Like, even the thought*
346 *of it is just, it seems just like such a big chore, and it seems so pointless” (21yrs,*
347 *CES).*

348 Participants reported using masturbation to investigate their post injury body:

349 *““Don’t be afraid to touch yourself.” Because how can you tell your husband where to*
350 *touch you if you don’t know yourself?” (59yrs, CES).*

351 However it is not always a positive experience:

352 *“I had a little kind of fiddle around to see what I could feel [...] I wanted to know what I*
353 *could expect from, you know, what – and there was nothing, absolutely nothing. I was*
354 *pretty devastated actually.” (31yrs, T7, A)*

355 Sexual spontaneity was lost for some women, associated with minimising the risk of
356 incontinence and in scheduling sex when energy, spasm and pain were optimal.
357 Preparation for sex was a “military procedure” (34yrs, CES) removing ‘romance’, but
358 not preparing was too risky. Sex toys and pornography enhanced sexual experiences
359 for some women.

360 *“I did buy myself a dildo to see how I would feel, to experiment, you know. And I*
361 *found that I liked it [...] I’d see things on TV and I’d realised that I did have a sexual*
362 *desire [...] I actually bought a sex tape [...] then I bought myself a dildo.” (50yrs, C6,*
363 *B)*

364 Partners were also reported to benefit:

365 *“Vibrators definitely work for both of you. The only thing I would tell you is never ever,*
366 *to anybody, never ever be afraid to experiment” (59yrs, CES).*

367 Reduced physical flexibility and control limited sexual positions and sometimes caused
368 accidents (falls, pulled muscles, fractured pelvis). Profiling beds and pillows were
369 used by many participants to assist with positioning, balance and comfort but using
370 them also reduced spontaneity.

371 The use of humour and good communication within their relationship was important
372 for some participants. Acceptance and gratitude that some sexual life was still
373 possible were also expressed.

374 *“It’s not the same [as] pre-injury. But it’s still something. And, like I said, for me,*
375 *something is still better than nothing. And I just make do” (48yrs, T5, D).*

376 Even when unable to orgasm, most of the participants valued sex as a positive,
377 rewarding experience, with the emotional component often increasing in importance:

378 *"It was always the two went together, the physical and the emotional. But now, it's*
379 *an awful lot more emotional. It's a, it's a lot more of that side of it". (45yrs, C5, D)*

380

381 **6. Sexuality rehabilitation**

382 Experience of sexuality rehabilitation was varied; experience with printed literature
383 and group sessions covering fertility were common while some women received no
384 information; other women saw sexual rehabilitation as male orientated. A demand
385 for female orientated sexual rehabilitation was frequently voiced:

386 *"what I found is, it is all centred around men, it's all centred on their dysfunction and*
387 *obviously they can't get an erection and there's all these toys and gadgets and things*
388 *for them to do to get the erection. And Viagra and all of that. But when it comes to*
389 *women, it seems that, well okay you can have sex normally, if you've got a willing*
390 *partner to have sex with. But there is nothing out there that says how to climax [...] it*
391 *can't be just about men and their sexual dysfunction after a spinal cord injury. It has*
392 *got to be sort of a joint thing, because women like to have sex as well." (38yrs, T4,*
393 *C)*

394 Women felt their sexuality seemed unimportant to health care professionals (HCPs),
395 particularly for individuals single at injury:

396 *"By focusing on men with spinal cord injury, it's kind of saying that, well, you know, if*

397 *you're man, you will get another partner. But if you're a woman, well you might not.*
398 *And you're dealing with too much crap to have that weighing down on you. You*
399 *really are" (37yrs, T7, A).*

400 Participants felt that HCPs lack knowledge, are too embarrassed to discuss sex and
401 are unable to signpost them to sources of information and support. Women wanted
402 HCPs to be knowledgeable and approachable about sexuality; in education about
403 sexuality after SCI they wanted less emphasis on reproduction and more focus on
404 enjoyment and the emotional aspects of sex:

405 *"I think sometimes they're uncomfortable about talking about things like that. They're*
406 *sort of, 'Oh let's push it under the carpet,' sort of thing. People need to be a bit more*
407 *open about things like that. [...] if you are open, sexuality is part of everyday life, it's*
408 *about who you are and what you are" (60yrs, T12, A).*

409 Participants wanted reassurance or 'permission' from HCP's to recommence sexual
410 activity, to ensure they were not putting themselves at risk, to know what to expect
411 and what was "normal" after their SCI.

412 *"being told that [...] you're not delicate – because, after you come out of hospital, you're*
413 *treated with kid gloves and you don't know what is safe to do and what isn't safe to*
414 *do" (45yrs, T11, B)*

415 Women's experiences suggested that staff were unaware of how early some women
416 explore sexuality with a partner, achieved despite inpatient status; independent living
417 facilities or single-occupancy rooms provided private opportunities:

418 *“It wasn’t like planned, [...], it was like stealing something, you know, because I was*
419 *still in rehab, you know. And I had my own room obviously. So that was that.” (48yrs,*
420 *T5, D)*

421 However, lacking confidence and feeling sexually unattractive during rehabilitation
422 was common; support and opportunities to improve self-confidence, self-esteem,
423 body image and social skills were identified as essential:

424 *“just going socially and talking to people, how to approach that, that you’re still – I don’t*
425 *know, [...] worthy of conversation, [...] the physical practicalities, talking to somebody*
426 *in an environment where everybody else is standing up – would have been useful*
427 *before you go home. [...] yes, social relationships as well as intimate relationships,*
428 *(45yrs, T11, B).*

429 Psychosexual counselling and women-only education sessions experienced by some
430 participants were reported as beneficial. Couples counselling and greater access to
431 peer support were identified as potential ways to improve sexuality rehabilitation:

432 *“I know it was something that was worrying [husband] at least as much as me, about*
433 *whether we would ever have a sex life again, and it might well have been useful if*
434 *there was somebody who was trained that we could have spoken to as a couple, at*
435 *that time, I think” (72yrs, L1, C).*

436 Access to a specialist HCP at all stages post-injury was also identified as valuable:

437 *“Coming towards recovery and leaving (rehabilitation), you are thinking about it, and*
438 *wondering is it going to be the same, is there going to be problems? Am I going to*
439 *work properly? And, you know, that type of thing. So, I think to have somebody make*

440 *the approach [...] saying, "Look, we're here. If you'd like to discuss it with us any time*
441 *before you leave, just tell us." Or, "After you get home, if you have any problems, you*
442 *can contact us on these numbers, and talk about it." I think that would definitely be a*
443 *good idea." (59yrs, C5, D)*

444 Sexuality emerged as a highly personal issue for these women and they felt it should
445 be addressed accordingly in the rehabilitation process. Their requirement for
446 support was fluid with needs and expectations of individuals changing over time. For
447 some, sexuality was not a priority during rehabilitation and women regretted missing
448 opportunities to learn about what later seemed important. Many women suggested
449 changes to sexuality rehabilitation but appreciated that style and content would need
450 to be flexible:

451 *"It depends on individual situations. You don't want to offend people. You don't want*
452 *to scare people, you know. I think maybe sometimes a one-on-one session might work*
453 *as well, before doing the group thing, [...] because if I go ahead and say, "Okay, why*
454 *don't you introduce some sexy videos," it might be offensive to some people [...] But I*
455 *know that it would definitely help some people. Well it's better to have an idea of*
456 *people's levels of sexuality before injury and their expectation after injury, before you*
457 *can make these changes or introduce these things." (48yrs, T5, D)*

458 *"There needs to be some new way which doesn't involve the words 'sexual health',*
459 *or saying, (laughter) I don't know, a cup of tea and a cake. I don't know how you*
460 *pitch it, but I think [...] it's such a massive part of everyone's life [...] Maybe it's not to*
461 *everybody else, I don't know. But I think [...] we could really do with help on it [...]*
462 *I've said more to you than I have done to my incredibly close friends, [...] You don't*
463 *open up, so it's very difficult to share. So maybe just imparting more information to*

464 *people, and explaining how different it is [...] some people would go, "Oh, I don't*
465 *want to talk about it," and others would go, "No, actually, I really do want to talk*
466 *about it." "I need to know..." You need to be able to manage your expectations".*
467 *(45yrs C5, D)*

468

469 **Discussion**

470 Women remain sexual beings after spinal cord injury; the importance of sex in their
471 pre-injury lives was strongly expressed along with regret and longing for what was
472 lost. Loss of sexual sensation combined with impaired mobility, risk of incontinence
473 during sexual activity and impact of interventions to prevent it, resulted in loss of the
474 preinjury sexual self with reduced confidence, self-esteem, body-image and sexual
475 pleasure and satisfaction. While many participants felt that an enjoyable and
476 satisfying sexual life was possible after SCI, the nature of existing relationships was
477 altered and new relationships were more difficult to establish. Participants identified
478 that more female-focused rehabilitation has the potential to modify this narrative and
479 improve outcomes as summarised in Figure 1.

480 Loss of continence and management of incontinence had a profound impact both on
481 sexual self-image and ability to enjoy sexual activity. As in other papers [15,22],
482 participants were anxious about their ability to be attractive to or to sexually please a
483 partner and despite an increased emphasis on the emotional significance of
484 sexuality many women reported an overall reduction in sexual satisfaction,
485 particularly linked to loss of orgasm, in contrast to previous work [12]. Reflecting

486 other studies [21] physical self-exploration was beneficial to some women and built
487 their confidence, but for others was traumatic.

488 Participants identified increased interaction with more knowledgeable HCPs, a
489 broader approach to education which addresses ways of achieving a satisfying
490 sexual life after injury, and therapeutic intervention (psychosexual counselling)
491 during rehabilitation and beyond as ways of reducing the impact of SCI on
492 relationships.

493

494 Implications

495 While the physical results of SCI(1) are irreversible, other factors identified by
496 participants (psychological impact(2), relationships(4) and dependency(3)) which
497 influence and are influenced by post-injury sexuality(5) can potentially be modified
498 through a female-orientated approach to sexuality rehabilitation(6), again as
499 identified by participants. Early acknowledgement by HCPs of lost or altered sexual
500 sensation, and greater knowledge of and positive engagement with sexuality issues
501 could support a dialogue about post injury sexuality and prepare women for changes
502 in their sexual lives.. Sensitivity to the impact of continence management is
503 essential and research to explore how the impact of continence management can be
504 ameliorated is urgently required. While self-exploration can be suggested as part of
505 'permission giving' around sexuality during rehabilitation such exploration can be
506 traumatic and suitable help should be available to support women in this process.

507

508 Rehabilitation for women should be adapted to provide gender-specific educational
509 groups and rehabilitative activities, and should be broad-based, specifically
510 addressing not only altered physiology but optimal continence management around
511 sex and use of adjuncts such as pornography and sex toys, social and
512 communication skills to support relationships and support for partners. Use of
513 existing inpatient facilities could be re-imagined to promote the private environment
514 required for sexual exploration during in-patient care. Use of the Ex-PLISSIT model
515 [23] as a clinical and educational framework could support HCP's to meet women's
516 sexuality rehabilitation needs. This model places the concept of "permission" (to
517 raise and discuss sexual issues) at its core and emphasises it at every stage of the
518 framework. Use of the model could create a rehabilitation environment, involving the
519 whole multidisciplinary team, where women are aware that they can raise or discuss
520 sexuality issues without embarrassment to themselves or staff. This could normalise
521 discussions around sexuality, opening communication and enabling women to voice
522 anxieties or ask specific questions. HCPs need to be knowledgeable, comfortable to
523 initiate discussion of sexuality and empowered to refer on where appropriate. An
524 HCP role specialising in women's sexuality, available during rehabilitation and
525 beyond, would provide a clearly identifiable service, accessible when individually
526 appropriate.

527

528 Limitations

529 Study participants were recruited from 3 SCI units in the UK. While their experiences
530 may not reflect those of women rehabilitated elsewhere, transferability of these

531 findings is supported by the multicentre nature of recruitment to the study and
532 achievement of data saturation in what was a relatively large sample. As in other
533 studies of sexuality, women with complete tetraplegia did not volunteer to participate,
534 possibly because they are less likely to be sexually active [10,12], hence the findings
535 may not reflect the experiences of this group of women. Participants were self-
536 selected and women with positive sexual experiences may have been more
537 motivated to participate.

538

539 Conclusion

540 This study explored the lived experience of sexuality and sexual rehabilitation after
541 SCI amongst a group of women of varied ages and levels, densities and duration of
542 SCI. These women reported that their sexuality was significantly impaired by SCI
543 but that their perception of themselves as sexual beings remained an important and
544 valued aspect of their identity. Most of the participants were positive regarding their
545 present and future relationships and the overriding theme of the interviews was that
546 sexual activity continued after injury and though altered, could still be enjoyable and
547 rewarding. Few interventions were available to deal with the physical implications of
548 SCI for sex after injury and though they could be effective to some extent, they could
549 also have a further negative impact on sexual experiences. The perceived male
550 focus of current rehabilitation offerings may mean that the needs of women with SCI
551 around dealing with their altered sexuality were not met. The development of a
552 female focus in rehabilitation using the framework of the Ex-PLISSIT model,
553 education about altered sexuality which goes beyond fertility topics to promote an

554 enjoyable sexual life, and the inclusion of partners in sexuality rehabilitation could
555 improve this. Research is required to explore the benefits of these
556 recommendations.

557

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563

564

565 **Conflict of Interest**

566 The authors declare no conflict of interest.

567

568

569 **Authors' Contributions**

570 H Thrussell (research associate) was responsible for designing the research
571 protocol, recruitment of participants, data collection and analysis and writing up the
572 study for publication.

573 M Coggrave (chief investigator) was responsible for designing the research protocol,
574 data analysis and writing up the study for publication.

575 A Graham was responsible for assisting in the design of the study, assisting in the
576 data analysis and approving the write up of the study.

577 A Gall was responsible for assisting in the design of the study, recruitment at one
578 research site, assisting in data analysis and approving the write up of the study.

579 M Donald was responsible for assisting in the design of the study, data analysis and
580 approving the write up of the study.

581 R Kulshrestha was responsible for assisting in the design of the study, recruitment at
582 one research site, assisting in data analysis and approving the write up of the study.

583 T Geddis was responsible for assisting in the design of the study, assisting in data
584 analysis and approving the write up of the study.

585

586

587 **Supplementary Material**

588 - Appendix 1 is the prompt sheet used when interviewing participants. It includes
589 questions on menstruation, commencing sexual activity after injury, changes in
590 sexual activity and expectations, impact on libido and sexual satisfaction, barriers to
591 sexual activity and rehabilitation experiences regarding sexuality.

592

593

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665 **Titles and Legends to Figures**

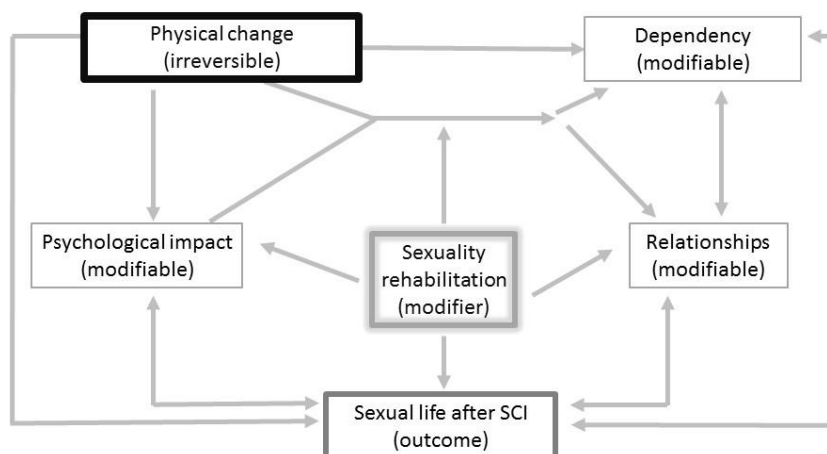
666 Table 1: Demographic and injury characteristics of participants

Part. No.	Level of SCI	Cause of Injury	Age at Injury	Age at Interview	Marital Status at Injury	Marital Status at Interview
1	CES	Non-traumatic	36	44	Single	In relationship
2	T5, AIS Grade D	Non-traumatic	45	48	Married	Single
3	T4, AIS Grade C	Non-traumatic	27	38	Married	Married
4	T11, AIS Grade D	Traumatic	25	26	Single	Dating
5	T7, AIS Grade A	Traumatic	31	37	In relationship	Co-habiting *
6	C5, AIS Grade D	Traumatic	15	50	In relationship	Married
7	T10, AIS Grade A	Traumatic	64	73	In relationship	Married
8	T12, AIS Grade C	Traumatic	15	38	Single	Married
9	CES	Non-traumatic	31	34	Co-habiting	Co-habiting
10	C6, AIS Grade B	Traumatic	34	50	In relationship	Married *
11	T4, AIS Grade A	Traumatic	19	69	In relationship	Married *
12	CES	Non-traumatic	55	56	Married	Married
13	C5, AIS Grade C	Traumatic	26	41	Co-habiting	Co-habiting *
14	CES	Traumatic	43	51	Civil partnership	Married
15	CES	Traumatic	42	52	In relationship	Co-habiting
16	CES	Non-traumatic	34	59	Married	Married
17	C4, AIS Grade D	Traumatic	50	52	Single	Single

18	T12, AIS Grade C	Traumatic	37	42	Co-habiting	In relationship *
19	T12, AIS Grade A	Non-traumatic	49	60	Married	Married
20	T9, AIS Grade A	Traumatic	41	61	Married	Married
21	C5, AIS Grade D	Non-traumatic	44	45	Married	Married
22	L1, AIS Grade C	Non-traumatic	68	72	Married	Married
23	CES	Non-traumatic	19	21	In relationship	In relationship *
24	C3, AIS Grade D	Non-traumatic	58	69	Married	Married
25	T11, AIS Grade B	Non-traumatic	30	45	Married	Married
26	C5, AIS Grade D	Traumatic	57	59	Co-habiting	Co-habiting
27	C5, AIS Grade D	Traumatic	26	36	In relationship	In relationship *

667

668 Figure 1: Model of women's sexuality after SCI



669
670
671

672 **Appendix 1: Interview Prompt Sheet**

673 Participants will be asked about their own sexuality experiences:

- 674 - Tell me about when your periods returned after your spinal cord injury, did you
675 notice any change in them?
676 - How do you manage the practicalities of menstruating since injury?
677 - What information did you gain on menstruation during rehabilitation? - Is there anything
678 you'd have liked to have known more about?
679 - How soon after injury did you engage in sexual activity?
680 - How did you feel prior to this?
681 - Did you do anything to prepare?
682 - What changes, if any, have you noticed in your sexual activity before and after your
683 injury?
684 - How does your body feel and respond compared to prior to your
685 injury?
686 - Explain to me any changes in your libido and sexual satisfaction
687 levels since injury
688 - What, if anything, stops you from engaging in sexual activity following SCI?
689 - Can you describe to me how your spinal cord injury has impacted on your
690 thoughts and expectations around sexuality
691 - What support or advice did you receive on sexuality following your SCI? From
692 who? When? When would you have like it?
693 - Is there anything regarding sexuality that you'd have liked to have been told
694 during rehabilitation? How? When?

695 At the end of the interview if the topics of bladder management, bowel management,

696 pain, spasticity and autonomic dysreflexia (for women with SCI of T6 and above) had not

697 been raised then further questions around their impact, if any, on sexuality were asked.