Sexual function and sexual satisfaction following spinal cord injury: an interpretative phenomenological analysis of partner experiences

Barrett, O. E. C. ORCID: https://orcid.org/0000-0002-8128-9664, Ho, A. K. ORCID: https://orcid.org/0000-0002-2581-126X and Finlay, K. A. ORCID: https://orcid.org/0000-0002-8997-2652 (2024) Sexual function and sexual satisfaction following spinal cord injury: an interpretative phenomenological analysis of partner experiences. Disability and Rehabilitation, 46 (1). pp. 86-95. ISSN 1464-5165 doi: 10.1080/09638288.2022.2159073 Available at https://centaur.reading.ac.uk/109648/

To link to this article DOI: http://dx.doi.org/10.1080/09638288.2022.2159073

Publisher: Informa UK Limited

Taylor & Francis
Taylor & Francis Group

Disability and Rehabilitation

ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/idre20

Sexual function and sexual satisfaction following spinal cord injury: an interpretative phenomenological analysis of partner experiences

Olivia E. C. Barrett, Aileen K. Ho & Katherine A. Finlay

To cite this article: Olivia E. C. Barrett, Aileen K. Ho & Katherine A. Finlay (2022): Sexual function and sexual satisfaction following spinal cord injury: an interpretative phenomenological analysis of partner experiences, Disability and Rehabilitation, DOI: 10.1080/09638288.2022.2159073

To link to this article: https://doi.org/10.1080/09638288.2022.2159073

DISABILITY AND REHABILITATION
https://doi.org/10.1080/09638288.2022.2159073

Taylor & Francis
Taylor & Francis Group

ORIGINAL ARTICLE

OPEN ACCESS Check for updates

Sexual function and sexual satisfaction following spinal cord injury: an interpretative phenomenological analysis of partner experiences

Olivia E. C. Barrett, Aileen K. Ho and Katherine A. Finlay

School of Psychology and Clinical Language Sciences, University of Reading, Reading, UK

ABSTRACT

Purpose: This study explored how partners/spouses of people with Spinal Cord Injury (SCI) experienced intimacy, sexual function, and sexual satisfaction post-SCI.

Materials and methods: Qualitative, semi-structured interviews were conducted with the partners/spouses of people with SCI living in the community in the United Kingdom. Twelve participants (7 females; 5 males) were recruited using purposive sampling. A nine-item semi-structured interview design was used. Interviews were transcribed verbatim and analysed *via* Interpretative Phenomenological Analysis (IPA).

Results: Three superordinate themes were demonstrated: (1) Stolen sex through unpreparedness; (2) Redefining sex; and (3) Compromised commitment. Partners struggled to come to terms with the shock of radically altered post-SCI sexual relationships, questioning how their changed sexual relationship and sexual identity conflicted with caring requirements. To minimise post-SCI relationship changes, some partners engaged in strategies to protect against, distract from and avoid sexual intimacy, whereas others were able to retain adapted pre-injury patterns of intimate behaviour.

Conclusion: Compromised sexual function and satisfaction significantly disrupt relationship dynamics post-SCI, initiate voluntary celibacy, and limit the perceived viability of continued sexual intimacy. Specialist partner-support provisions are urgently needed, recognising that partner support needs are *not* restricted to the inpatient rehabilitation phase but importantly extend long past discharge into the community.

➤ IMPLICATIONS FOR REHABILITATION

- Sexual function and satisfaction are highly challenging areas for partners post-spinal cord injury (SCI).
- Support and education for the partner must be incorporated into SCI rehabilitation to help with both adjustment and acceptance to changes in sexual functioning post-SCI.
- Partner contributions to and experiences of sexual function and satisfaction should be given more value, as these aid in the sustainability of healthy sexual relationships and psychological wellbeing following SCI.

ARTICLE HISTORY
Received 1 May 2022
Revised 24 November 2022
Accepted 25 November 2022

KEYWORDS
Spinal cord injury; partner; spouse; rehabilitation; sexuality; sexual health; sexual partner relationships; barriers; facilitators; qualitative; interviews

Introduction

The World Health Organisation identified sexual health as a fundamental human right for all individuals [1]. A spinal cord injury (SCI) is a traumatic and life-changing event, usually associated with loss or change in sexual function [2]. Given the magnitude of such an injury, it not only impacts the person with spinal cord damage, but also significantly alters the sexual relationship for the partner of the person with SCI [3]. Thus, in addition to the person with SCI, there is a further need to focus on supporting the partner following SCI.

To date, most of the literature concerning sexuality after SCI has largely focused on physical functioning [4] and relationship sustainability [5]. Such research has tended to adopt quantitative methods in examining, long-term marital survival and relationship status, prioritising the injured person's perspective [6]. Research focusing on partner perspectives typically assesses adjustment of the partner/spouse to their new role as a partner carer [7] or primary caregiver [6]. Evidence continues to emphasise the difficulties communicating feelings and remaining socially active as a couple post-SCI [8], however, much evidence specifically focuses on the injured person's perspective.

What is known, however, is that longer-term relational stability increases the sexual satisfaction of those injured [5, 9], with both males and females living with SCI reporting better overall sexual satisfaction when in an enduring relationship [10]. Indeed, higher levels of sexual dissatisfaction are reported among individuals living with SCI without a long-term partner [5]. Given intimacy and sexual function are a joint responsibility, the impact on sexual relationships can only be adequately addressed when involving the partner [11]. Whilst partner inclusion in SCI rehabilitation is deemed critical [12], partners report receiving little or no teaching/education about the consequences of SCI on sexual activity and satisfaction [13]. Further, the ongoing need to increase both inpatient and community-based education provision for partners

CONTACT Katherine A. Finlay katherine.finlay@reading.ac.uk School of Psychology and Clinical Language Sciences, University of Reading, Reading, UK

living with a partner/spousel with SCI has been advocated [8]. There is a particular weakness in terms of study in the outpatient/community context, with no qualitative-based research currently available, directly, and singularly examining, partner experiences of sexual function/satisfaction post-SCI. It is important, therefore, to establish which changes and challenges are faced by partners post-SCI. This will enable adequately tailored education provisions and sexuality-focused services to be implemented for the partner/spouse across the full timeline of life after SCI. This qualitative study aimed to explore SCI partner/spouse experiences of sexual function and sexual satisfaction post-SCI, in a community setting.

By using Interpretative Phenomenological Analysis (IPA) to explore partner experiences of sexual function and sexual satisfaction when living with a spouse/partner with spinal cord injury, this provides a unique insight into the lived experience of sexual intimacy post-SCI rehabilitation. In contrast with other qualitative methodologies, IPA's idiographic approach aims to engage with each individual's reflections of major experiences in their lives [14], recognising that every individual may perceive the same phenomenon differently. Thus, IPA attempts to gain access to participants' 'lived' and 'personal' experiences, prioritising what is unique to them [14]. Such rich and detailed understanding [15] has the potential to enhance rehabilitative support after SCI, ensuring partners of people with SCI are appropriately recognised, supported, and acknowledged.

Methods

Design

A qualitative semi-structured interview design was undertaken using Interpretative Phenomenological Analysis (IPA) [16]. IPA is a qualitative approach aiming to provide detailed examination of personal lived experiences, producing an account of such experiences in their own terms, as opposed to delineating pre-existing theoretical preconceptions [15].

Participants

Participants for this study were recruited through Spinal Injury Case Management Ltd, a private case management company specialist in SCI care in the United Kingdom. In the UK, community-based SCI care is often devolved to private case management companies where health and rehabilitation support is offered nationwide. The private case management company engaged for recruitment offers case management services for persons and families after SCI, across the whole of England. Inclusion criteria included people who were: (i) currently a partner/spouse of someone with spinal cord injury; (ii) the spouse/partner of people with SCI who were outpatients and living in the community following inpatient rehabilitation in a designated UK spinal unit/centre; iii) not in inpatient rehabilitation; (iv) over 18+ years of age; (v) not currently undergoing treatment for a clinically diagnosed mental health condition; and (v) verbally fluent in English. Participants who experienced any condition impacting on sexual function prior to their partner's SCI or those with partners still within the inpatient phase of post-SCI rehabilitation, were excluded.

Thirty-two partners of those living with a SCI spouse were invited to take part in the study; twelve participants (7 females; 5 males) responded and were recruited for interviews. Length of time since their partner's SCI ranged from between 1.5 and 40 years ($M = 20.12$ SD $= 13.26$). Ten participants were in pre-SCI, existing relationships and two had developed new relationships post-SCI. This sample size is considered appropriate due to the large amount of data obtained for analysis and the depth involved in IPA's idiographic approach [16]. Demographic characteristics are presented in Table 1. All identifiable information has been changed and participants were given pseudonyms to preserve confidentiality [17]. No incentive was offered for participation in the study.

Table 1. Participant characteristics.

Name	Gender	Sexual orientation	Age	Partners SCI diagnosis	Years since SCI injury	Relationship status pre-injury	Relationship status post-injury	Length of relationship	Sex pre-injury	Sex post-injury
Rosie	F	Heterosexual	53	T10 incomplete	4 years	Married	Married	33 years	Yes	No
Mark	M	Heterosexual	51	T12 incomplete	2 years	Cohabiting	Married	15 years	Yes	Yes
Jenny	F	Heterosexual	56	C3/4 incomplete	5 years	Married	Married	37 years	Yes	No
Lucy	F	Heterosexual	39	T4 complete	6 years	Single	Cohabiting	1.5 years	Yes	No
Beth	F	Heterosexual	53	T6 complete	3 years	Married	Married	24 years	Yes	No
Toby	M	Heterosexual	38	T7/8 incomplete	2 years	Married	Married	10 years	Yes	Yes
Jessica	F	Heterosexual	59	T12/L1 incomplete	36 years	Single	Married	33 years	Yes	Yes
Katie	F	Heterosexual	64	T10/11 incomplete	8 years	Married	Married	40 years	Yes	No
Noah	M	Heterosexual	30	T6 incomplete	6 years	Cohabiting	Married	9 years	Yes	Yes
William	M	Heterosexual	29	L4 incomplete	3 years	Cohabiting	Cohabiting	3 years	Yes	Yes
Mohammed	M	Heterosexual	42	T10 complete	5 years	Married	Married	16 years	Yes	No
Elsie	F	Heterosexual	52	C7 complete	3 years	Married	Married	20 years	Yes	No

SCI: Spinal Cord Injury.

Table 2. Interview schedule.

1. Currently, how important would you say sex and intimacy are in your life?
2. Can you tell me about how sex and intimacy may compare to before your partner was injured?
3. What do you think the main factors or biggest challenges are for you in terms of sex and intimacy?
4. Can you tell me about how have your levels of sexual satisfaction and sexual desire may have been impacted following your partner's injury?
5. Some individuals are comfortable and open communicating about sex and intimacy with their partner and healthcare professionals, whereas others can find this quite difficult. How do you find communicating about sex with your partner? How do you find communicating about sex with healthcare professionals?
6. When thinking about the support around sex and intimacy for you and your partner, how do you think sexual health management could be better addressed?
7. If you could design a support system for improving sexual function, satisfaction, and intimacy for people with spinal cord injury and their partners, what would it be like and how would it work?
8. For you, at what point within the rehabilitation journey do you think education and support on sex and intimacy are best placed?
9. When thinking about the impact a spinal cord injury can have on sexual function for the partner, is there anything else you wish to add to our conversation today which we perhaps haven't discussed during our interview?

Materials

To explore in-depth partner experiences of sexual function and sexual satisfaction post-SCI, a 9-item semi-structured interview schedule was developed (see Table 2). Key areas for consideration were identified through qualitative elicitation interviews with: (i) people with SCI and (ii) healthcare professionals, specialist in SCI (e.g. nurses, physiotherapists, occupational therapists, psychologists, and psychosexual therapists) [18,19]. In addition, the consultation of existing psychosexual literature aided the development of the interview schedule; inclusive of relationship dynamics [20], partner wellbeing [21], training and resources [22], and communication and clinician competency [23].

Procedure

Participants identified through the case management company were invited to participate in this study *via* email and sent the study information sheet and consent form. Those expressing an interest in participating in the study returned their consent forms and a demographics questionnaire electronically in advance of interview. Semi-structured interviews were conducted face-to-face ($n = 2$) or online using a virtual platform, Zoom ($n = 8$) or Microsoft Teams ($n = 2$). Interviews were audio-recorded and varied between 45 and 96 min ($M = 47.16$ SD $=$ 11.32) in length, in line with guidelines for IPA interview depth [24].

Pre-registration

This study was pre-registered with Research Registry as part of a series of qualitative research studies investigating SCI and sexual function/satisfaction following SCI (Registration no. 6979).

Data analysis

This study followed the systematic approach to IPA as recommended by Smith et al. [16]. An open-ended, semi-structured interview design was adopted, and interviews were transcribed verbatim. To ensure familiarity with the data, transcripts were repeatedly re-read and notes relating to descriptive, linguistic, and conceptual content were made to aid development of themes during analysis.

Superordinate themes were established by way of searching idiographically in transcripts for similarities and differences across developing themes, capturing the features deemed most important from participant accounts of the experience. Following analysis of all transcripts, a cross-case analysis was conducted, determining identifying themes, commonalities and patterns present across participants. The transcripts were frequently revisited throughout this process to ensure themes reflected participant accounts and were grounded in the data [16].

IPA is interpretative in its approach, recognizing the role of the researcher, accepting that analytical accounts are jointly produced by both participant and researcher; thus they employ a 'double hermeneutic' [14] and researchers may interpret data differently. As recommended by Smith et al. [16], a reflective log was created in an effort to 'bracket-off' or strip away any pre-existing assumptions and attitudes, a key component of IPA research [16]. To enhance quality and achieve rigour throughout the analysis, the second and third authors, who have significant experience in IPA and SCI, validated the thematic representativeness and the interpretations of the corresponding quotations. The second and third authors each, independently analysed a small sample of the transcripts. Full credibility checks, verifying the interpretations and analysis by the first author were then undertaken for all remaining transcripts. All authors were closely involved in the generation of the superordinate and subordinate themes to ensure these were grounded in the data. Any discrepancies were resolved by way of further discussion and revising of themes. The interpretations presented are considered both meaningful and credible, however authors acknowledge that such findings are not the only interpretations of the data [16].

Ethical considerations

The University of Reading School of Psychology and Clinical Language Sciences Ethics committee approved the research study (approval number: 2021-114-KF). Informed, written consent was obtained prior to interviews and participants were informed about their right to pause the interview, take a break or withdraw at any time. Participants were provided with an information sheet containing contact details for the authors, in addition to SCI charities, should they wish to seek further support or to discuss any issues following their interview. The research adhered to The British Psychological Society's (2021) Code of Ethics and Conduct.

Statement of ethics

We certify that all applicable and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research.

Results

The analysis of transcripts led to the development of three superordinate themes: (1) *Stolen sex through unpreparedness;* (2) *Redefining sex;* and (3) *Compromised commitment*. Superordinate and subordinate themes are presented in Table 3. They identify, from partner perspectives, the lived experiences central to navigating sexual function and sexual satisfaction after SCI.

Stolen sex through unpreparedness

The first superordinate theme depicted the initial shock experienced by most partners upon recognition of the physical changes their partners faced in their sexual function post-SCI. Physical interferences such as spasms impeded on sexual connectedness, consequently restricting levels of sexual arousal. Attempting to sustain or regain sexual intimacy post-injury proved challenging, which, for some, resulted in needing to accept the absence of intimate sexual engagement after a partner's SCI.

Blindsided by shock

For some participants who had supported their injured spouse upon discharge home from hospital, feelings of shock and disbelief were evident upon realising the impact and changes brought about in relation to their partner's capacity for sexual function and response.

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

Superordinate themes	Subordinate themes
Stolen sex through unpreparedness	Blindsided by shock Capturing fleeting arousal Resigning from sex
Redefining sex	Relearning sex Retaining pre-injury intimacy
Compromised commitment	Selfless self-censoring Shielding from the truth The carer intrusion

For Jenny, she assumed their sex life would be 'ok' and admitted to not having given this much thought ahead of arriving home:

> You assume things will be ok, yet that is a different story when you get home and realise that the function sexually has been impacted too … me and my partner were discharged home 'blind' where this is concerned. How things went sort of left me in disbelief. I remember thinking, "as if enough hasn't been taken, his legs, his hand function, his ability to go to the toilet on his own and now this". I was just in shock [pause], complete shock. I remember feeling quite numb and quite fuzzy and not really knowing what to do, how to take it, what to say or who to talk to. At the time, talking to him wasn't an option because he was just as shocked as me. [Jenny]

Jenny vividly describes the shock she faced and suggests she had an absolute lack of psychological preparedness for managing changed sexual function. Jenny's intense feelings imply an overwhelming sense of devastation resulting from this early recognition of the enormity of the change in their sexual relationship. She verbalises feelings of shocked isolation from sources of support and a lack of preparation for the sexual implications ahead of his discharge home. Such lack of support contributed towards Jenny's uncertainties and elevated levels of anxiety for her.

Like Jenny, Mark and his partner were excited about getting home and had not given the sexual side of their relationship much thought:

> I will never forget us getting home [pause]. Home, finally, after months on the unit. I don't think we even thought about it before then, there was so much else going on, but then when we realised that this is actually an issue. It did come as a shock. I remember her being completely freaked out and asking why she couldn't respond to [pause] you know, usual arousal-type stuff. I have to be honest; I didn't know where to put myself or what to do either. In the room we were in at the other property, we had this giant clock on the wall, and I remember lying there, staring at the clock just staring, lost for words [pause], trying to concentrate on the sound of the ticking. She just lay silent at the side of me [pause]. I didn't know what to say to her and I didn't know what to think. I just laid there and stared. [Mark]

Mark's evocative quote encapsulates the distress resulting from this memorable early experience of sexual arousal after his partner's discharge from inpatient care. In this quote, Mark refers to concentrating on the clock ticking, the clock becoming a symbol of the significance of the moment, marking the time passing as he processed the shock. He recalls being *"lost for words"*, thus unable to articulate or speak due to the intensity of the experience, thus indicating the unexpected emotional impact of this first effort to re-engage with sex after his partner's SCI.

For Elsie, she too explains that the sexual side of their relationship was not something they had thought about ahead of discharge home, until beginning to explore this together:

> That's something we didn't know [about] until we started to explore it. It wasn't a very nice feeling, [a] nasty shock to our systems actually. After all we had already gone through and then that [laugh]. I can laugh about it now, but at the time, it was like getting smacked in the face with yet another problem. [Elsie]

Elsie words suggest the suddenness, unpredictable and unpleasantness of the experience for both she and her husband. Over time, Elsie seems to have partially accepted this, but when reflecting back, she uses the physical language of getting *"smacked in the face"* to highlight the unexpected shock of sexual adjustment in addition to the overload of other practical issues she and her husband had already been confronted with following his injury.

Capturing fleeting arousal

The array of physical changes associated with the nature of SCI presented challenges in relation to intimacy and sex and these were found to impede on sexual connectedness and the ability to maintain levels of arousal. For many participants, the physical challenges associated with SCI reduced opportunities to maintain, sustain, or re-build their sexual relationships with their spouse/partner, as the arousal required for such intimacy was fleeting and interrupted.

Though partners wished to fully immerse themselves in the 'moment', this proved difficult due to feelings around having to prepare oneself for physical disruption, thus resulting in a loss of sexual enjoyment and engagement.

> His spasms can be so bad, and they are really unpredictable, so it isn't as if you can prepare yourself for these coming. It sort of, you know, takes away that enjoyment. You tend to be on edge and just can't fully get into the moment. [Elsie]

Due to having to prepare for the likelihood of a spasm occurring, Elsie felt restricted in her ability and opportunity to fully engage, relax and enjoy the moment with her husband. Evidence from Jenny's transcript also supports this theme: *"You tend to be thinking about these things [spasm occurring] in the back of your head rather than actually engaging in the act itself"* [Jenny].

Similar, to Elsie, Jenny refers to mulling over her issues and concerns, indicating a loss of connectedness, and diverted attention from the sexual act itself, due to the spasms disrupting her sexual engagement. Naturally partners wanted to support their spouse where possible, however they admitted that often this resulted in their sexual attention being diverted away from the moment. This was particularly evident in the statements of male participants, as they found their attention was side-tracked, impacting on levels of erectile arousal and engagement:

> When I am aroused and ready for that sort of thing to happen in bedroom, if a violent spasm occurs, my attention turns to trying to settle this for her, like hold her legs or straighten her foot and obviously my attention is diverted. So, I slip out of the mood a bit physically. This obviously impacts on things too as the arousal and everything goes as man. [It] just slips away. [Toby]

Here, Toby voiced his struggles on being able to stay in the sexual moment once the flow has been interrupted due to physical interferences on his partner's part. Although he is keen to support her, he cannot ignore or avoid the spasms, therefore he finds it difficult (physically and psychologically) to retain his levels of sexual arousal once they have been disrupted.

Similarly, Mohammed had given this some thought when thinking about their future: *"I don't know if I could sustain things from my end if we were to try. I think it would just zone me out and I don't think I would be able to perform"*. [Mohammed]

Mohammed anticipates challenges on his part in terms of being able to perform and sustain sexual activity. His use of the future tense demonstrates introspection as he projects his worries forwards to any future sexual engagement: he is unsure whether he could successfully perform sexually as a result of his heightened awareness of his partner's SCI causing distraction and 'zoning him out' from the given moment.

Resigning from sex

The theme of resigning from sex was described by participants who were acknowledging that their sexual circumstances were not improving over time. For some, this meant sexual activity and satisfaction no longer formed a part of their relationship:

> The sex side of things is something we don't think about anymore. We have just accepted that the sex isn't there anymore and that's just how it is I suppose, you gotta just make the best from what you do have left. [Rosie]

Though Rosie clearly acknowledges sex is no longer part of their relationship following her husband's injury, she adopts a positive outlook, *"making the best"* from their situation, suggesting her willingness to make her relationship work, irrespective of sexual celibacy.

Similarly, Katie also reveals a sense of strength after acknowledging the impossibility of sustaining a sexual relationship with her husband:

> It [a sexual relationship] is all impossible to be honest, so I accepted this years ago, and just cracked on with stuff. Like some things are possible and others aren't, and the sex part isn't, so you have to just get on with it. There really isn't another option. [Katie]

Katie has accepted the loss of a sexual relationship with her husband. She describes the impossibility of now having a sexual relationship yet insinuates she does not have a choice in this matter due to her partner's injury terminating sexual opportunity.

For Jenny, this resignation from sexuality was extremely difficult and she described a loss of her husband's identity since his SCI:

> When you are put in a position such as mine, when life really has been turned upside down overnight and you sort of lose a part of that person whom my partner once was to the disability, and knowing somethings are no longer possible, it is hard to accept. In fact, it is quite unbearable at times [pause], I try not to dwell on it much. [Jenny]

Jenny's quote implies a loss of control, lack of preparedness and a situation which has forced the end of their sexual activity. She describes how *"hard"* it is to accept this, before further adding *"in fact it is quite unbearable"*. Such language and her mid-sentence pause suggest high emotional pain and a sense of intense distress which she minimises by *"trying not to dwell on it"*, implying her attempt to distance herself from the reality and emotional pain of her situation.

> Thinking about the future, it [a sexual relationship] is important for me, but I don't know if it is important any more to him and that's a sort of awkward situation to be in, because if one is feeling it and other isn't so much after everything that has now happened, I suppose I have no other option and choice but to just accept that. A bitter pill to swallow. [Beth]

For Beth, she discussed her future, reflecting on her wishes to pursue a sexual relationship with her husband, yet acknowledged that he may not share comparable sexual desire. There is a sadness expressed by her quote, as she feels forced to accept a potential sexually absent relationship in her future with her husband. Beth's use of metaphor *"a bitter pill to swallow"* at the end of this quote suggests the difficulty and hurt involved in the struggle to reach such acceptance.

Redefining sex

The second superordinate theme was frequently expressed by all participants, underlining the importance of having to adjust to changes associated with intimacy and sexual functioning following injury. For some, there was a need to apply different strategies and intervene to better support and understand SCI-related functional and physical changes. Participants who had re-engaged sexually following SCI often referred to both the past and the present. Emphasis was placed on the importance of maintaining normality where possible, positively influencing sexual and intimate relationship sustainability longer-term.

Relearning sex

Eight of the twelve participants acknowledged their apprehension and anxiety when firstly becoming sexually active with their spouse/partner, following SCI:

> I have to admit I was nervous the first time we did try to have sex because her body, everything involved, the catheter everything really was just so different, and I felt well out of my comfort zone because I didn't know what to do or how to assist her with it and she was nervous and unsure too. It was hard, I am not going to lie. I was more anxious about doing something wrong and putting her at any risk, but as they say [laughs] life begins at the end of your comfort zone. [Toby]

Toby felt overwhelmed with how different things presented and the changes involved. He was unsure how to assist or adequately support his partner due to lack of SCI bladder management knowledge, which elevated his feelings of anxiety and nervousness. He stated, *"life begins at the end of your comfort zone"*, reaffirming his dedication to work through these obstacles, and thus shows that he remains keen make the sexual element of his relationship work with his partner, albeit differently.

> I have learnt as I have gone on, but at first, I did try to stay away from the sex side of stuff with her because I didn't really know, and a lot of the stuff freaked me out a bit. This doesn't now because its different now and I have learnt about it, but like her legs, holding them or pulling them, even though she can't feel 'em, it was just that thought of hurting her. She would make a joke [laugh] and say she is broken anyway. [Noah]

For Noah, the prevalence of anxiety and apprehension around sexual engagement *"freaked"* him out. Noah's quote suggests he was ruminating about the injury, and this reflected his anxiety around putting his partner at potential harm or risk. Noah feels that over time his confidence has developed, and he now better understands how to manage things, though initially such fears led him to avoiding the initiation of intimate and sexual time with his partner.

Retaining pre-injury intimacy

Seven of twelve participants acknowledged the benefits of retaining, where possible, elements of pre-injury life and intimacy following their partner's injury. For the majority, staying close to the routine and way of life that they knew pre-injury featured as an important consideration in sustaining a healthy sexual and intimate relationship:

> For lots of people, it doesn't work out after the injury, does it? I just think to keep doing what we are doing. We have always stayed motivated and keen to make it work and I would advise others to do the same. I think the issue for other people is that they start to take on a brand-new life. and I think if it worked for you before, stay as close to that as you can. We weren't together long before her accident, but what we did worked and it worked well for us sex wise, so we just kept it the same. I think it helped her too 'cause she just thought it is pretty much the same as before, paralysis or no paralysis. [William]

William highlights both his determination and motivation to sustain normality within his relationship following his partner's injury. He refers to others adopting a different way of life, when this may not be required, expressing this is an *"issue"*, suggesting a potential awareness of others who have experienced failures within relationships following SCI. William's confidence is apparent, as he advises others to stay close to the pre-injury norm, reporting from his own personal experiences that this has worked out for her and his partner.

Contributing to this, Noah describes the changes he and his partner have had to make, yet expresses his overall enthusiasm on retaining their pre-injury situation:

> I think you gotta try keep things the same as they were before. Like we always enjoyed a Netflix and chill night and before her injury that was a time when we would get a little sexual [laughs]. So yeah, I thought when she got home, to try keep that same thing going, like it shouldn't change should it really? There isn't no reason why we cannot do that [long pause], just that little routine we had has helped us to try keep it as close to what it was before. Yeah, some things you have to change, like just giving her a hand into bed, but

> as much as you can keep the same, I think has been a massive help for us. [Noah]

For Noah, it has remained important to keep the same routine he and his partner had pre- injury. Noah refers to a "*Netflix and chill night*" as inviting intimacy and sexual opportunity. He questioned why things should change, though takes a long pause after confirming that things do not need to change, potentially suggesting a sense of uncertainty around sexual changes and associated impact. Noah points to keeping things the same being "*a massive help*" as this meant expectations can remain the same, thus keeping equilibrium.

Similarly, Elsie also highlights her "*aim*" in keeping things normal and associated to pre-injury routine:

> I have made it my aim to keep on going with what we used to be and how we were with each other. I wouldn't leave the house before his injury without giving him a peck first and I have always stuck to that since too. I will always give him a kiss and say see you soon. It is more important than what people probably think isn't it, but some things you don't quite have to change, and it is good to hold onto those. [Elsie]

Here Elsie describes elements of the pre-injury routine which she has remained keen to "*hold onto*". Elsie expresses recognition on how important these smaller parts of intimacy and maintaining routine where possible are since continuing life with her husband following his injury.

Compromised commitment

The third superordinate theme was expressed by ten of twelve participants and explored the increased pressure and change in feelings of commitment and relationship dynamics. Avoiding putting pressure on the injured partner/spouse resulted in a perceived sense of isolation, by which partners felt they needed to deal with their own concerns and issues independently without involving their partner.

Selfless self-censoring

Participants revealed how their own feelings, emotions and needs were often neglected or overlooked, due to attention being primarily focused on the needs of their injured partner/spouse.

Beth doubted how her partner would react if she were to initiate a discussion around the topic of sex and so, had learnt over time that it was safer for her to remain silent:

> I think it would be a case of him snapping back "I'm paralysed, and you think about sodding sex", or something down those lines. You learn to keep a lot in and just not say much. It is like taking a bottle of coke and shaking it so much that all of that fizz builds up, which is all of the things you want to talk about and discuss, yet you can never take the lid off. So, a lot of what I worry about stays in and just manifests inside. It does impact on your health physically and psychologically, believe me, but no one has ever given me the answers on how you can approach certain things. Even if they did, they are not the ones approaching it and having to deal with the consequences of where that discussion may lead. [Beth]

Beth's descriptive quote captures the consistent build-up of emotions, thoughts, and feelings over time. Her language suggests the overload of pressure suppressing such thoughts and feelings causes for her, yet she implies there is no opportunity for escape.

Multiple participants spoke about having to accept this changed sense of commitment when considering the broader dynamics of their relationship, indicating they had no other option but to just accept the changed consequences, should they wish to sustain their relationship with their spouse:

> I don't have a choice in the matter, so even if I wanted to say something, complain [pause], have a moan, all that sort of stuff, it wouldn't change anything, so you sort of put up and shut up. There is a lot that goes on which I guess … well [pause], I suppose people do not think about or recognise. It has been hard, it will continue to be hard, but love is love, isn't it? You don't give up on someone you love because it doesn't suit all your requirements. To keep it going, you do have to eliminate some of your own needs sometimes, like the whole intimate and sex stuff. But I don't make a fuss. [Rosie]

Rosie indicates a sense of being forced to live with and accept a terminated sex life, without being able to have the freedom to self-express her own thoughts and feelings. Rosie expresses feelings of a lack of recognition and understanding from others which exacerbate her frustration. Her determination and strength on continuing to work through such obstacles is apparent. Her language implies a degree of selflessness which she maintains to hold onto to continue her marriage without sexuality.

Toby feels similarly:

> It [long pause] may sound a bit daft and I don't want this to sound selfish at all, but it absolutely is her that this injury has impacted and affected, I have had to put whatever impacts this has brought about for me onto the back burner … you tend to be a little forgotten about I suppose. [Toby]

Similarly, to Rosie, Toby's quote clearly evidences his wish to avoid being perceived as selfish. Toby is in position whereby he feels his needs are now secondary matters or indeed dismissed altogether.

Shielding from the truth

For many participants, following their partner's injury, feelings around having to safeguard the truth of their personal, private thoughts and feelings associated about their sexual and intimate relationships with their partner/spouse were revealed:

> [Long pause] In all honesty and something I would never to say to him [partner] but I think some things I do cover up and there is this pretence that all is ok and that all is fine, but I think you naturally do that to protect the person you love. [Jenny]

Jenny not only expresses the need to "*cover up*", thus shield her thoughts and feelings from her husband, but further, refers to pretending all is ok, implying an element of muting her own viewpoints to protect her partner's feelings. The long pause taken by Jenny at the beginning of this quote may imply initial reluctance or hesitation around opening-up and honestly verbalising her perspective.

Similarly, Beth felt she had to withhold the truth about how her partner's personal care regime affected her from a sexual perspective. Reduced levels of hygiene impacted on her levels of sexual attraction:

> I will be brutally honest here, hygiene wise, he gets a bed bath and not a shower very often and I am aware of that and yes, certainly, it is certainly a put off, but something I would never want him to know. But like for anyone, without a proper bath or shower, you can get a bit smelly and sweaty and then there is all the messing about for his catheter and putting gloves on, taking gloves off, draining into the leg bag, checking how much urine [pause] … um … you become the wife, carer, nurse, counsellor, a bit of everyone. I think you start to see each other differently. I change his colostomy and complete catheterisation for him … it is hardly a 'let's jump in bed after that for sex' moment. It is really difficult to understand if you haven't lived it. [Beth]

This also remained the case for Jessica who also felt such issues had a consequential impact on her sexual desire:

> Then there is his bowel regime which I help with, and I cannot, after assisting with [that], even think about getting into bed with him. It might be hard for him to understand that, and I wouldn't ever admit it, but I cannot say we have had sex on a bowel day, it sounds awful, like

> I have a heart of stone [pause] I know, because he cannot help it, but that is just a bit off-putting. [Jessica]

Jessica held her own 'private' thoughts in relation to feeling *"put off"* sexually due to her involvement in personal care and partner levels of hygiene. This initiated an avoidance around wishing to sexual engage with her partner.

Both Beth and Jessica's quotes clearly illustrate the profound impact of personal care and hygiene-related issues on sexual engagement. Both refer to shielding/hiding this from their partners. Beth feels she has adopted the role of many people – *"a bit of everyone"* – suggesting a blurring in her sense of identity as a wife and also a carer, thus obscuring and inhibiting their sexual relationship.

Further, Beth refers to being *"brutally honest"* at the beginning of her quote suggesting a wariness around her comment being perceived as unpalatable or harsh. Jessica's use of metaphor *"like I have heart of stone"* also implies an awareness of the difficulty navigating the boundary between socially (un)acceptable perspectives about sexual relationships, bladder and bowel care, after SCI. Though such issues had a profound impact on sexual desire and satisfaction, this was evidently a very difficult area to openly discuss. Therefore, partners continued to conceal their truths.

The carer intrusion

Participants often viewed the provision of care for their spouse negatively, due to the intrusiveness and the interference which carers posed within the home environment. Accepting and adjusting to the provision of care within the home meant partners felt their privacy was compromised, impacting on familial freedom and opportunity for communication and intimate time with their partner. Jenny experienced apprehension and anxiety at times, fearing care staff would disturb them or walk in unexpectedly. This meant she could never fully relax*:*

> We might be in the middle of a really important conversation and then a carer walks in, and it is just cut off. If we are having a bad day, the atmosphere is hard because you are trying to pretend everything is ok for everyone else when sometimes it isn't. I suppose the only way I can describe it is like you lose your own freedom in doing what you want to do and just being me, acting how I want to, saying what I want to … because you're always having to think ahead. I am always thinking, what time is the next carer due in. Some knock, some don't, even though we have asked that they knock. There is always that little niggle in the back of my mind, you know, I wouldn't want them walking in on anything. I long for a little beach hut with everything we need, just me and him and no carers, no professionals, no appointments. [Jenny]

For Jenny, the constant intrusion of having care staff in the home caused feelings of edginess and tension, diminishing opportunity for both effective communication and intimate time with her husband. She experienced a loss of privacy in her own home and worried about carers disturbing them, causing a sense of insecurity and identity erosion. Jenny harbours desires for escapism and yearns for absolute privacy with her husband but such a longing feels unattainable. This was also the case for Jessica:

> I stress all of the time that our home is now shared with his care staff, therapists and everyone else who has come on board after his accident. That bit of it is hard and I don't think you ever really get used to it. [Jessica]

Jessica finds sharing her home with multiple care staff and the therapy team hard to accept. She refers to her struggles around both accepting and adjusting to now having to share her home with other people. This is not something she feels she can ever accept.

Katie and Beth also discussed the invasion of privacy resulting from care provision directly impacting on opportunity for intimate and sexual time with their spouse: *"We have no privacy with carers coming and going. It* [opportunity for intimacy] *is all just impossible to be honest"* [Katie].

Here, Katie's language implies a sense of hopelessness about intimate sexual opportunity in the future. Similarly, Beth is negative about any potential future opportunities for intimate time with her husband:

> Even the intimacy for us, we still have carers around who come in and out as they need to, checking obs [observations], managing his medication. I really don't think we would even get an hour to start anything without getting disturbed. We would have enough to think about without having to worry about carer waltzing in, I just don't think, realistically, it will ever be a possibility for us. [Beth]

Beth anticipates the difficulties both she and her husband would encounter ahead of doing so. The use of the phrase "*waltzing in"* suggests Beth perceives the carers act in a causal and care-free manner, lacking awareness about any (inter)personal needs which she and her husband have in their own home. Further, Beth's quote expresses feelings of impossibility for the future as she refers to thinking "*realistically"* about their situation and does not hold out much hope for the situation or circumstances improving.

Discussion

The current study aimed to explore the perspectives of partners of people who had a spinal cord injury, considering their thoughts on sexual function and sexual satisfaction. Results demonstrate the emergence of three superordinate themes, *Stolen sex through unpreparedness, Redefining sex, and Compromised commitment.* The importance of intimacy and sex prior to injury was collectively highlighted by partners as fundamentally impacting their perceived quality of life. Sexual satisfaction represented a highly challenging area for their relationship(s), consistent with wider findings [9]. Changes in their relationship dynamics, communication barriers about sexual satisfaction, initiation of protective behaviours which guarded their injured spouse/partner, the intrusion of care provisions, and difficulties adjusting to and accepting a changed sex life, collectively impacted on continued sexual intimacy.

After a long period of separation due to inpatient rehabilitation, and upon arrival home, the changes in their partner's sexual function post-SCI left many participants feeling overwhelmed and out of control [25]. Partners' lack of knowledge and education around sexual function post-discharge meant they were faced with significant physical, psychological, and psychosocial challenges. This restricted renewed sexual engagement, provoked fear, confusion, and sexual anxiety. Consistent with wider research, partner involvement in SCI rehabilitation is critical [12], yet in terms of sexual activity, the current research showed that partner involvement and education is inadequate. In this study, it was felt that the injured individual was discharged home to their partner, and both had a significant lack of knowledge, preparation and awareness in relation to sexual function as also demonstrated by Dickson et al. [6]. This therefore underlines the importance of embedding patient-partner sexual support and education into the SCI inpatient rehabilitation regime, as promoting awareness of functional changes and sexual activity management may effectively reduce partner anxiety. Ensuring partners receive sufficient support may also positively promote their confidence, enabling them to prepare ahead for a changed sex life which could better support their partner/spouse.

The physical outcomes of SCI were also found in this study to hinder partner capacity to become fully immersed in the sexual moment. Feelings of having to pre-prepare to manage physical disturbances (for example, spasms during sexual engagement) and support with (for example, bladder management issues) proved difficult, limiting the ability of spouses/partners to enjoy and remain fully engaged during the intercourse or intimacy. This found to reduce levels of satisfaction, rapidly diminishing participants' reported levels of arousal. Thus, a person-centred approach offered by the treating multidisciplinary team, delivering joint patient-partner support around self-management and care techniques may be useful in exploring such a multitude of complexities found to impact on sexual function [26]. In turn, this may help to promote independence and feelings of empowerment and control. Pharmaceutical options [27] and positioning [28] for example to help manage and reduce spasm activity. Further, the provision of information on associated effects of spasmolytics on erectile function for males with SCI could be discussed with the treating consultant and occupational therapist. In addition, psychological support offered for partner around sustaining sexual attention and focus.

For some partners, resuming a sexual relationship post-injury was no longer possible. Mirroring findings from our study, research continues to identify the difficulties in re-establishing life, communicating feelings and remaining socially active as a couple [25]. Such findings indicate the need for joint partner/spouse support to establish ways to effectively adapt to and accept the circumstances around sexuality post-injury.

In the current findings, partners/spouses felt that their needs in association to intimacy and sex post-injury were perceived as secondary matters and of less importance. Clinical attention and support provision tended to be primarily focused on other components of rehabilitation, thus, making the subject of sex even more difficult to approach. The apprehension around initiating discussions around sex and intimacy mirrors wider findings where apprehensiveness has been found to interfere with abilities around bonding and building intimacy [21]. Such apprehension also created communicational barriers, with partners feeling that they needed to conceal their thoughts. Coping with such challenges in isolation without partner support created a sense of loss for the partner [21]. Given feelings of emotional closeness and willingness to engage in sexual activities have found to be more important factors for sexual fulfilment of sexuality [11], promoting communication within relationships post-injury is an important indicator to enhance sexual fulfilment.

Coping with the new realities and changes in relation to intimacy and sexual functioning post-SCI proved challenging for the partner. Apprehension and anxiety were key features upon initially beginning to explore sexuality with the partner/spouse. The lack of support and understanding around the physical and functional changes now associated with sexual activity meant the partner/spouse lacked basic knowledge, subsequently causing fear around risk and potential harm. Partner/spouse participation during the inpatient rehabilitation period is key [8] and better efforts are required in establishing the importance of altered changes post-discharge for the partner/spouse [29]. Despite the ongoing need and request for sexual wellbeing programmes by people living with SCI in the community [26], healthcare providers continue to minimally address and/or implement support for sexual wellbeing within inpatient and longer-term settings [26]. Part of the reason for this may be due to the continued challenges in terms of inadequate training, knowledge, and education for healthcare professionals [23], resulting in feelings of awkwardness and hesitation broaching such discussions with patients/partners [23]. Further, lack of facilities and resources potentially contribute toward the lack of sexual wellbeing support within spinal rehabilitation [2]. Thus, such issues may play a large contributory factor impacting on the limited support and service provision for patients/partners. Therefore, increasing sexual-focused training for professionals and increasing facilities and resources may help overcome such barriers potentially posed. Given the partner/spouse situation can be alleviated by professional support [8], it is imperative for all are provided with the opportunity for support and education around sexual functioning after SCI throughout both the inpatient setting and longer-term phase of rehabilitation.

Participants strongly identified benefits in retaining pre-injury intimacy where possible, positively enhancing opportunity for intimate and sexual connectedness through familiarity of existing routines. Establishing a 'new normal' and adding creativity into sexual activity routines has found to help maintain and re-build on relationship sustainability following SCI [21]. Consistent with findings from our study, retaining elements from previous life as a coping strategy to adapt to the injury felt to be helpful [8]. Research has found for SCI partners, is it essential to maintain some of the old routines to regenerate energy and not allow the SCI to take over completely [8]. Therefore, including support for the spouse/partner and person with SCI in being able to discuss with the treating rehabilitation team pre-injury life circumstances may be helpful. By doing this, aspects of rehabilitation and care could be navigated to best mirror and focus on ways to retain pre-injury intimacy and promote independence to retain this where possible.

Partners felt compelled to disregard their own feelings and sexual needs leading to self-internalising such concerns. Participants' selflessness meant they chose to continuously place the needs of their spouse above their own. However, longer-term it is likely that this could become problematic as prolonged expressions of compassion following injury have found to deactivate partner sense of self-awareness, resulting in compassion fatigue [30] and severely affecting their own wellbeing [31]. Therefore, encouraging partners to acknowledge and seek support regarding their own personal and sexual needs is important to ensure health and wellbeing of the relationship longer-term.

Further, partners were challenged by 'off putting' elements in relation to supporting with personal care routines, hindering sexual desire, and resulting in a loss of sexual interest. Recognition of the injured spouse being in a less fortunate position when compared with oneself invited feelings of guilt which spiralled protective tendencies. Partners wished to avoid putting any pressure on their spouse, resulting in side-stepping matters around sexual function. Consistent with the current findings, the prevalence of intimate relationships changing to become 'protective' in nature has found to common feature following SCI [32]. Coinciding with our findings, signs of frustration and withdrawal have found to be linked with the burden of over-dependency and involvement in personal care, leading to reduced intimate connection and emotional detachment [21]. Wider research has identified that supporting with bodily tasks (e.g., helping to clean up after episodes of incontinence or changing of colostomy bags) has a negative impact on the sexual relationship following SCI [6]. A similar pattern followed when considering the provision of care inside the home.

The intrusion of care also hampered opportunity for sex and intimacy. Recognition around the need for care was highlighted, yet such intrusion was difficult to adjust to and accept within the home. This created feelings of entrapment and a loss of privacy. Such findings are consistent with our study, whereby partners expressed a loss of sexual relationship and personal desires to engage sexually with their spouse due to involvement in specific areas of care. This also impacted on levels of attraction towards their spouse, similar to other studies noting the importance of minimizing care involvement to enhance attraction status for longer-term relationship sustainability [33]. Partners questioned their role and felt their partner/spouse identity often became blurred with "carer", complicating relational dynamics and negatively affecting intimacy and sex [21]. Dependence on the partner for care requirements has found to impede on blurred identity and loss of identity associated with change in relational dynamics [6]. Existing research highlights the need to limit family responsibility for carrying out specific care tasks by enhancing formal, external care-support provision (e.g.,- support workers, personal assistants) in performing certain aspects of care to help with longer-term intimate and relational sustainability [21]. Thus, this prompts the question of how involved partners should be in supporting with personal care regimes. Spousal caregiving duties following SCI have found to cause greater emotional stress and role confusion for the partner [6], with transitional community-based services required to support and early detect distress associated with caregiving responsibilities [6]. There is a need to limit expectations and assumptions around the spouse/partner automatically fulfilling caregiving duties following injury [6]. To ensure the sustainability of intimate and sexual relationships, reducing care provision delivered by the spouse is a key factor for consideration.

In conclusion, the nature of a SCI affects both the individual and the partner. To date, existing literature has tended to focus on the negative impact of relationships following SCI [34]. Further, limited research has explored the sexual experiences of the partner living with a spouse following SCI. Therefore, this is the first study within the SCI population to identify the experiences, associated challenges and coping strategies used by the partner in relation to sexual function and satisfaction. If healthcare professionals work with the individual, in a holistic manner, they will need to include the partner [35]. Indeed, evidenced-based interventions are required to help the partners of those living with a spouse after SCI.

The study acknowledges its possible limitations. Participants recruited for the study were all in active relationships with and/or or married to their injured partner/spouse at the time of interview. This may have impacted on freedom of speech and restricted true expression. Future research may therefore be directed towards recruiting partners/spouses of those who have experienced unsuccessful or failed relationships with the injured spouse post-SCI. Moreover, ten participants were in pre-SCI existing relationships, whereas two participants had developed new relationships post-SCI. The authors recognise that sexual experiences may therefore differ between pre-post-injury relationships. Participants also varied in length of relationship duration and time since partners sustained SCI and authors recognise that this may impact on rehabilitative input and support offered at the time of injury, though most injuries were sustained less than 10 years ago.

Further all participants were recruited in the UK, and it is recognised that such experiences may therefore not represent the experiences of those in other countries. Future research exploring partner/spouse experiences in other countries and/or on a multinational level may therefore be of benefit. All participants were heterosexual in sexual orientation and so, further research may benefit from exploring other sexual orientations for full inclusivity.

Ethical approval

Authors certify that all applicable and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research.

Authors contributions

OB/KF/AH assisted with the study design and conceiving of the research idea. OB assisted with all data collection. OB/KF/AH completed coding of data and interpretation of results. OB completed the drafting of the manuscript. KF/AH assisted with critical revision of manuscript.

Disclosure statement

No potential conflict of interest was reported by the authors.

Funding

No financial assistance was received in support of the study.

ORCID

Olivia E. C. Barrett http://orcid.org/0000-0002-8128-9664
Aileen K. Ho http://orcid.org/0000-0002-2581-126X
Katherine A. Finlay http://orcid.org/0000-0002-8997-2652

Data availability statement

The data sets generated and/or analysed during the current study are available from the corresponding author on reasonable request under institutional restrictions.

References

[1] World Health Organization. World health statistics 2018: monitoring health for the SDGs. 2018. [Online]. http://apps.who.int/iris/bitstream/handle/10665/272596/9789241565585-eng.pdf?ua=1

[2] Hess J, Hough S. Impact of spinal cord injury on sexuality: broad-based clinical practice intervention and practical application. J Spinal Cord Med. 2012;35(4):211–218.

[3] Chan RC, Lee PW, Lieh-Mak F. Coping with spinal cord injury: personal and marital adjustment in the Hong Kong chinese setting. Spinal Cord. 2000;38(11):687–696.

[4] Earle S, O'Dell L, Davies A, et al. Views and experiences of sex, sexuality and relationships following spinal cord injury: a systematic review and narrative synthesis of the qualitative literature. Sex Disabil. 2020;38(4):567–595.

[5] Fritz HA, Dillaway H, Lysack CL. Don't think paralysis takes away your womanhood: sexual intimacy after spinal cord injury. Am. J. Occup. Ther. 2015;69(2):10.

[6] Dickson A, O'Brien G, Ward R, et al. The impact of assuming the primary caregiver role following traumatic spinal cord injury: an interpretative phenomenological analysis of the spouse's experience. Psychol Health. 2010;25(9):1101–1120.

[7] Ledbetter AM, Carr K, Lynn G. When a romantic partner has a spinal cord injury: caregiving tasks and resilience as moderators of support quality on psychosocial distress and relational closeness. J. Soc. Pers. Relatsh. 2020;37(8-9):2551–2577.

[8] Angel S, Buus N. The experience of being a partner to a spinal cord injured person: a phenomenological-hermeneutic study. Int J Qual Stud Health Well-Being. 2011;6(4).

[9] Reitz A, Tobe V, Knapp PA, et al. Impact of spinal cord injury on sexual health and quality of life. Int J Impot Res. 2004;16(2):167–174.

[10] Phelps J, Albo M, Dunn K, et al. Spinal cord injury and sexuality in married or partnered men: activities, function, needs, and predictors of sexual adjustment. Arch Sex Behav. 2001;30(6):591–602.

[11] Kreuter M, Sullivan M, Siösteen A. Sexual adjustment after spinal cord injury (SCI) focusing on partner experiences. Spinal Cord. 1994;32(4):225–235.

[12] Fisher TL, Laud PW, Byfield MG, et al. Sexual health after spinal cord injury: a longitudinal study. Arch Phys Med Rehabil. 2002;83(8):1043–1051.

[13] New PW, Seddon M, Redpath C, et al. Recommendations for spinal rehabilitation professionals regarding sexual education needs and preferences of people with spinal cord dysfunction: a mixed-methods study. Spinal Cord. 2016; 54(12):1203–1209.

[14] Smith JA. Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. Qual Res Psychol. 2004;1(1):39–54.

[15] Smith JA, Osborn M. Interpretative phenomenological analysis as a useful methodology for research on the lived experience of pain. Br J Pain. 2015;9(1):41–42.

[16] Smith JA, Flowers P, Larkin M. Interpretative phenomenological analysis: theory, method and research. 2nd ed. London: Thousand Oaks: SAGE Publications Ltd; 2021.

[17] Allen R, Wiles J. A rose by any other name: participants choosing research pseudonyms. Qual Res Psychol. 2015;13: 1–17.

[18] Barrett OEC, Mattacola E, Finlay KA. "You feel a bit unsexy sometimes": the psychosocial impact of a spinal cord injury on sexual function and sexual satisfaction. Spinal Cord. 2022;10:1–6.

[19] Barrett OEC, Ho AK, Finlay KA. Supporting sexual functioning and satisfaction during rehabilitation after spinal cord injury: barriers and facilitators identified by healthcare professionals. JRM. 2022;54:jrm00298.

[20] Meier A, Allen G. Intimate relationship development during the transition to adulthood: differences by social class. N Directions Child Adolescent Devel. 2008;2008(119):25–39.

[21] Jeyathevan G, Cameron JI, Craven BC, et al. Re-building relationships after a spinal cord injury: experiences of family caregivers and care recipients. BMC Neurol. 2019;19(1):117.

[22] Elliott S, Jeyathevan G, Hocaloski S, et al. Conception and development of sexual health indicators to advance the quality of spinal cord injury rehabilitation: SCI-High project. J Spinal Cord Med. 2019;42(sup1):68–84.

[23] Alexander MS, Aisen CM, Alexander SM, et al. Sexual concerns after spinal cord injury: an update on management. Neuro Rehabilitation. 2017;41(2):343–357.

[24] Pietkiewicz I, Smith J. A practical guide to using interpretative phenomenological analysis in qualitative research psychology. CPPJ. 2014;20:7–14.

[25] Hammell KW. Spinal cord injury rehabilitation. Dordrecht (Netherlands): Springer; 2013.

[26] Elliott S, Hocaloski S, Carlson M. A multidisciplinary approach to sexual and fertility rehabilitation: the sexual rehabilitation framework. Top Spinal Cord Inj Rehabil. 2017; 23(1):49–56.

[27] Rabchevsky AG, Kitzman PH. Latest approaches for the treatment of spasticity and autonomic dysreflexia in chronic spinal cord injury. Neurotherapeutics. 2011;8(2): 274–282.

[28] Nas K, Yazmalar L, Şah V, et al. Rehabilitation of spinal cord injuries. World J Orthop. 2015;6(1):8–16.

[29] Isaksson G, Josephsson S, Lexell J, et al. Men's experiences of giving and taking social support after their wife's spinal cord injury. Scand J Occup Ther. 2008;15(4):236–246.

[30] Mattioli D, Walters L, Cannon EJ. Focusing on the caregiver: compassion fatigue awareness and understanding. MedSurg Nursing. 2018;27(5):323–329.

[31] Karp D. The burden of sympathy: how families cope with mental illness. Oxford (UK): Oxford University Press; 2000.

[32] Kraft R, Dorstyn D. Psychosocial correlates of depression following spinal injury: a systematic review. J Spinal Cord Med. 2015;38(5):571–583.

[33] Milligan MS, Neufeldt AH. Postinjury marriage to men with spinal cord injuries: women's perspectives on making a commitment. Sex Disability. 1998;16(2):117–132.

[34] DeSanto-Madeya S. Adaptation to spinal cord injury for families post-injury. Nurs Sci Q. 2009;22(1):57–66.

[35] Esmail S, Esmail Y, Munro B. Sexuality and disability: the role of health care professionals in providing options and alternatives for couples. Sex Disability. 2001;19(4):267–282.