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RESEARCH ARTICLE

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"He's my legs, I'm his rock": experiences of adaptation and change in couple relationships following spinal cord injury

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ABSTRACT

Purpose: Experiencing spinal cord injury (SCI) can cause several challenges and changes within romantic relationships immediately after injury and in the long-term. However, there is a lack of research concerning the formation, maintenance and adjustment of couple relationships post-SCI. This study uses qualitative methods to explore how SCI may impact on couple relationships.

Methods: Four females and five males with SCI participated in a semi-structured interview. Some were with their current partner at the time of injury; others established their relationship following SCI. The data were analysed using interpretative phenomenological analysis.

Results: Analysis produced themes showing that communication, negotiating and maintaining clearly defined roles, mutual support and changing definitions of intimacy were important processes for adjustment and maintenance of romantic relationships following SCI.

Discussion: The study's results provide further insight into factors that are important for couples when maintaining and adjusting their relationship post-SCI. They have implications for healthcare providers, charities and other agencies supporting couples following SCI and for dyads learning to negotiate intimacy and relational challenges post-injury.

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Spinal cord injury; couple relationships; qualitative research; interpretative phenomenological analysis; relationship changes; relationship maintenance; adjustment

IMPLICATIONS FOR REHABILITATION

- Individuals are faced with several challenges following Spinal Cord Injury that require adjustment, creativity, openness and negotiation of roles within romantic relationships.
- Challenges included a change in identity and roles and the need to develop new ways of maintaining intimacy.
- Both those living with Spinal Cord Injury and their partners should be offered specialist support to aid this adaptation process, both shortly following injury and in subsequent years.
- Many of the points discussed in the study seem to resonate with Acceptance and Commitment Therapy, which may be a useful model to use during couples therapy following Spinal Cord Injury.

Introduction

Spinal cord injury (SCI) can be life-changing for the injured individual and their families. Although each experience of SCI will be different [1], it can be a significant source of stress within marital relationships [2] and can have marked psychological impacts on both partners [3,4]. Research has shown negative effects on individuals' levels of distress and life satisfaction post-SCI [5], while Krause, Newman, Clarke and Dunn [6] found decline in satisfaction with sex and social life in the years following injury. DeVivo, Hawkins, Richards and Go [7] highlighted higher risks of marriage break-down following SCI, especially among certain population sub-groups [8].

Despite the reported negative impact on couple relationships post-injury, Holicky and Charlifue [9] found that having a partner appeared to be a protective factor following SCI, linked with lower depression and higher life satisfaction, quality of life and well-being levels. Hilton, Unsworth, Murphy, Browne and Olver [10] also found those with SCI who had a partner were more likely to be employed two years post-injury. Arguably there seems to be unique value in the support individuals receive from close relationships after SCI [11]. Partners are also thought to play an important role in adjustment and rehabilitation post-SCI, providing hope for the future [12,13].

A predominant theme in many studies has been changes to sex and physical intimacy following SCI [14,15]. SCI can disrupt individuals' sense of sexual and gender identity [16,17], challenging culturally-constructed views of sexuality [18–20]. Although possible to re-establish physical relationships and sexuality following SCI [21], this can take time and be a challenging process [22,23]. Sunilkumar et al. [24] describe how differences between sexual desires and reality following SCI can cause relationship difficulties, while Kathnelson et al. [18], Fritz et al. [25] and Morozowski and Roughley [26] discuss the need to establish a broader view of sexuality post-injury. The review by Earle et al. [14] summarised these changes in sexual intimacy. Despite the challenges, it seems that re-establishing intimacy is one of the key determinants in whether a relationship survives following SCI [27].

Changes have also been found in role reciprocity within relationships. Kim and Kim [28] discuss challenges faced by both partners following SCI: those without SCI providing care and those

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with SCI adjusting to receiving higher levels of practical support, possibly leading to a biographical disruption of couplehood. SCI can also disrupt culturally-constructed gender roles and expectations, thereby impacting upon individuals' sense of self and self-esteem [2]. Jeyathevan et al. [29] describe the concept of "asymmetrical dependency," describing unequal levels of dependency within partnerships. This concurs with Engblom-Deglmann and Hamilton's [1] description of the difficulties of trying to balance independence and dependence following injury and the importance of negotiating roles post-SCI [2,29]. Role changes may also engender intimacy and attachment adjustments [30,31] by changing partners' levels of dependence on each other.

Some researchers provide evidence that couples may re-value their relationships following injury [2,32], consistent with the model of post-traumatic growth [33–35]. Engblom-Deglmann and Hamilton [1] theorise that couples' adaptation to SCI can be conceptualised on a continuum from connection and flexibility to constriction and stagnation. Angel and Buus [3] describe the possible steps underlying the adjustment process following injury, culminating in individuals feeling able to adapt to their life post-SCI. Jeyathevan et al. [29] also propose a model of adaptation on a continuum from deterioration to re-building and maintaining the relationship. This continuum is relevant to what Jeyathevan et al. [29] describe as the three main categories of adapting to a caregiver-care-recipient relationship – adaptability, caregiver-care-recipient traits and sex and intimacy.

Despite the importance of couple relationships in adjustment following SCI and the challenges couples face in adapting and maintaining relationships, there is very little research on adjustment processes and couplehood post-injury. As outlined, research tends to focus on changes to sexual relationships following SCI [36] or on the impact on wider family relationships and networks [37,38]. Although some studies have addressed changes to romantic relationships following SCI, many of these are highly culturally specific [2,19,20,24] or do not adopt a longitudinal view of the adaptation process, focusing on time spent in rehabilitation units immediately after injury [32]. Furthermore, there is little research linking the changes and adaptations needed following SCI to dyadic models of adjustment describing adaptation following other life-changing conditions, such as cancer (e.g., [39]). It therefore seems that there is a lack of psychologically-informed qualitative research addressing the experience of individuals living with SCI with reference to the adaptations they have had to make to their relationship post-injury.

Aims of the study

This study aims to collect and analyse qualitative data to examine individuals' experience of change and adjustment within relationships following SCI from a relational perspective. Firstly, it considers whether romantic relationships change following SCI. Secondly, it focuses on the processes couples use to enable them to address challenges, adapt and adjust and to maintain intimacy in the years following injury. It is hoped that this study will contribute towards a body of evidence-based psychologically-informed support for individuals and couples in the months and years after SCI, aiding individual and joint adaptation, well-being and coping.

Materials and methods

Design

Information was gathered from individuals with SCI using semi-structured interviews and analysed using Interpretative Phenomenological Analysis (IPA; [40]). IPA is an idiographic approach chosen due to its focus on how participants make sense of their world, the rich meanings they attribute to experiences and how they try to unpick these [41–43].

Ethics

Ethical approval from the Cardiff University School of Psychology Ethics Committee (EC.20.01.14.5933R) was granted prior to commencing the study.

Recruitment

Posters publicising the study were posted on the social media accounts of SCI charities and groups in the UK and Ireland and information also shared at a virtual global sex and disability conference. This enabled a snowballing method of recruitment.

Those self-selecting to participate were asked to contact the researcher to receive further information. They were then sent participant information sheets and asked to opt-in if they wished to participate, providing the researcher with their preferred contact details.

Participants

People 18-years-old or older with SCI who had been in a romantic relationship for at least 12 months prior to interview and lived at home rather than in rehabilitation facilities or hospitals, were eligible for inclusion. All participants also had to be able to provide informed consent and communicate in English.

Sixteen individuals expressed interest in participating. Of these, nine were interviewed, two did not meet eligibility criteria and five did not make further contact after initially expressing interest, for reasons such as ill-health. Recruitment took place during the COVID-19 pandemic, potentially influencing participation rates. Information situating the participant sample can be found in Table 1. Pseudonyms and categorical ranges have been used to ensure confidentiality.

Data collection

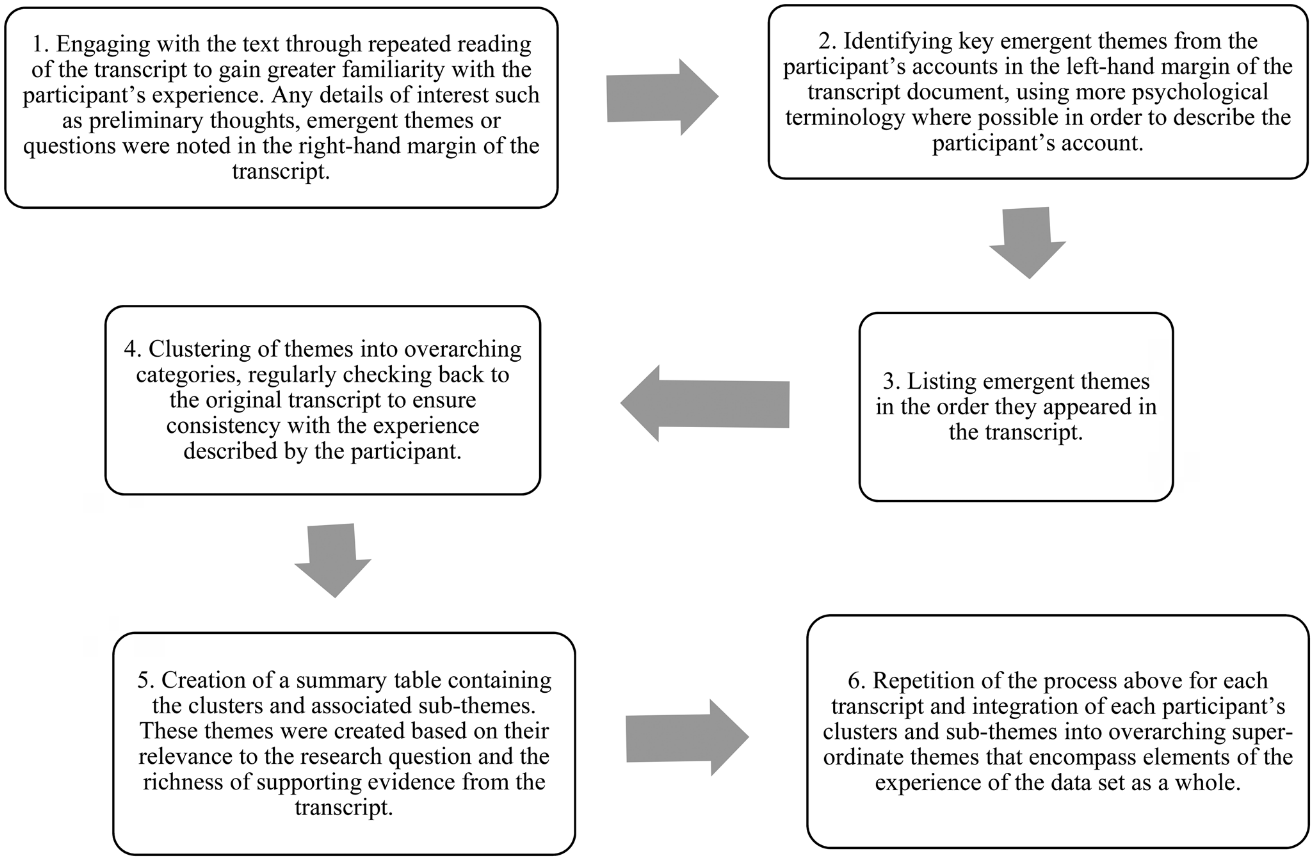
Consistent with IPA methodology, data were collected in detailed semi-structured interviews, offering participants the opportunity to fully represent their experiences [42]. The interview schedule was co-constructed with an individual living with SCI and informed by extant research and professionals working in the specialty. The questions focused on how participants coped with challenges in their relationship, its relative strengths and their views on intimacy and couplehood after SCI. Participants were asked to mainly consider their experiences during the past year, providing a clear time-frame for the data.

Pragmatically and due to the COVID-19 pandemic, all interviews were conducted using a video conferencing platform. Prior to interview, individuals were given the opportunity to ask any questions they may have about participating before electronically signing a consent form. Those consenting also completed a brief demographic questionnaire. Each interview was audio recorded (35 to 90 min) and followed by completion of an electronic version of the Dyadic Coping Inventory (DCI) [44] and the Dyadic Adjustment Scale-7 (DAS-7) [45], further contextualising the sample.

Table 1. Participant information.

Name	Location	Biological sex	Age category	Injury level	Time since injury	Biological sex of partner	Length of relationship	DCI[a] range	Category of score on DAS-7[b]
Amy	UK	Female	31–40	C5 complete	11–15 years	Male	2–5 years	Above average	30–35
Blake	USA	Male	41–50	C5/6 incomplete	26–30 years	Female	2–5 years	Average	25–29
Burgess	UK	Male	31–40	C4 complete	16–20 years	Female	2–5 years	Above average	25–29
Chris	UK	Male	41–50	C4/5 complete	11–15 years	Female	16–20 years	Above average	25–29
Emily	UK	Female	41–50	T11 incomplete	11–15 years	Male	11–15 years	Average	20–24
John	Ireland	Male	61–65	T10 complete	35–40 years	Female	21–25 years	Average	20–24
Louise	UK	Female	41–50	L5/S1 incomplete	6–10 years	Male	16–20 years	Above average	30–35
Neil	UK	Male	41–50	T12 complete	2–5 years	Female	16–20 years	–	–
Sarah	UK	Female	41–50	T8 complete	21–25 years	Male	6–10 years	Average	20–24

[a] Dyadic Coping Inventory (Bodenmann [44]).
[b] Dyadic Adjustment Scale-7 (Hunsley et al. [45]).



1. Engaging with the text through repeated reading of the transcript to gain greater familiarity with the participant's experience. Any details of interest such as preliminary thoughts, emergent themes or questions were noted in the right-hand margin of the transcript.

2. Identifying key emergent themes from the participant's accounts in the left-hand margin of the transcript document, using more psychological terminology where possible in order to describe the participant's account.

3. Listing emergent themes in the order they appeared in the transcript.

4. Clustering of themes into overarching categories, regularly checking back to the original transcript to ensure consistency with the experience described by the participant.

5. Creation of a summary table containing the clusters and associated sub-themes. These themes were created based on their relevance to the research question and the richness of supporting evidence from the transcript.

6. Repetition of the process above for each transcript and integration of each participant's clusters and sub-themes into overarching super-ordinate themes that encompass elements of the experience of the data set as a whole.

Figure 1. Steps followed during IPA (based on Smith and Osborn [76] and Willig [88,89]).

Following interview, participants were given the chance to reflect on what was discussed and provided with a debrief form which linked to relevant information and sources of support. All participants were given the opportunity to be entered into a prize draw to win a £50 Amazon voucher.

The interviewer transcribed, anonymised and stored each interview in secure electronic files.

Data analysis

Although it has been argued that there is not solely one "correct" way of doing IPA [46], Smith and Osborn [41] and Willig's [42,43] guidelines for conducting IPA were followed. Figure 1 summarises the main steps followed during the analysis process.

Prior to and during the steps noted in Figure 1, the researcher immersed themselves in the voice of the participant through listening to the recordings of the interviews and transcribing the data. This enabled the researcher to become familiar with and analyse the tone, emphasis and cadence of the participants' speech. This process was beneficial when noting comments on the use of language in the transcripts during step 1 of the analysis described in Figure 1

The author and main researcher was a trainee clinical psychologist with limited experience of working with people with SCI. However, she was supervised by a clinical psychologist with over 25 years' experience in this specialty and consultation was provided by a researcher in coupledom and by individuals living with SCI. The researcher kept a research diary throughout the research process to log her main thoughts and reflections. These included the researcher's reflections on her own views of SCI and disability and how this may influence her perspective throughout the research process, from recruitment to the analysis and reporting of data. As someone with limited fore knowledge of SCI and its impact on individuals and their families, she was also aware of how the extant literature discussed ways of coping with challenges within relationships that were either deemed effective or maladaptive. This knowledge may have influenced her views of the participants who took part in the study and the experiences they shared. The researcher therefore had to be vigilant to potential biases throughout, using the reflective diary as a way of mitigating their possible influence on the research and to assure its rigour. The researchers anticipated eliciting painful and challenging material during the research process, but followed the methods stated above as safeguards.

Various themes were noted when analysing transcripts, which were then clustered to create sub-themes. The IPA methodology is interpretative so the emergent quotes cannot be understood simply as "data" from the interviews. Table 2's purpose was not to show the reader how the theme "Increasing Strength and Confidence" was derived. Rather, its generation from the interview data involved applying IPA coding processes to the whole set of transcripts, identifying a number of quotes from participants then using cross-comparison and synthesis to elaborate their meaning and for this theme to emerge. In generation of themes and sub-themes each participant might provide one or a number of relevant quotes. Table 2 offers a simplified exemplar of the outcome of the complex analytic IPA process and was included for transparency purposes. Subsequently, the sub-themes were synthesised to create super-ordinate themes (Table 3). Table 3 expands on the process described above to list the participants whose quotes and their meaning ensured richness and contributed to the rigour of the method. As IPA focuses on gathering rich accounts of individual experiences [47,48], these were used to synthesise meaning rather than attempting to pursue saturation.

Participants were sent a copy of the sub- and super-ordinate themes to check their resonance with client experience, in line with Lincoln and Guba's [49] emphasis on the importance of respondent validation to ensure rigour in qualitative research. An individual living with SCI who consulted on the study was also asked to consider the final themes and comment on their resonance.

Results

Four overarching themes were identified during analysis. These, and their related sub-themes, are presented in Table 3, along with the names of participants whose interviews included these themes.

Table 2. Construction of the theme "increasing strength and confidence."

Participant	Example of sub-theme
Amy	"…that was really tough, but I think from a relationship point of view, that brought us much closer"
Blake	"We're gonna have more stress with it…but I think it's also, I don't know if she feels it, but maybe it is making us a little closer"
Burgess	"…it was a real nice moment to realise that once we've come through that we could kind of achieve anything"
Chris	"It's [the injury] made us more of a team"
John	"I think you might have love that brings you together first… and then when you get down to the nitty-gritty and start chasing out those issues, em, if you do resolve them you're on the right road…"
Louise	"… I think we definitely rely on each other much more now, kind of emotionally, um, than beforehand"
Sarah	"I think that the, the, just the sorts of challenges that we have to overcome means that we're closer"

Ongoing development of relationship

This theme encompasses the fluid nature of relationships and the constant need for adaptation, learning and reflection when faced with challenges.

Learning and adjusting

Several participants discussed the way in which they felt their relationship naturally changed and progressed over time due to factors such as raising a family, health challenges and growing older. This often led to relationships needing to adjust and develop.

> He's a very practical person and very, sort of, matter-of-fact about things, and so it's just never been an issue and he's adjusted as I have, I suppose I've needed to adjust to a change as I'm getting older and my injury's getting older. Things have changed and been different and he's been able to sort of accommodate and go with that. He's very flexible. (Sarah)

The need for joint adaptation when faced with challenges related to SCI and its development over time also led to the need to consider and make decisions around "future care and what we need" (Sarah).

Others discussed how they and their partner had "learnt to understand each other" (Emily) over time, realising what worked for their relationship and adapting accordingly to ensure that both partners' needs were met.

> That's something I've learnt over the years and so I have to sort of remember that if she is close or if there is an issue putting my hand out and engaging my hand around her shoulder or her waist or whatever she's standing nearby. That's reassuring and keeps closeness. (John)

Some participants accessed external support, such as counselling, to aid the process of developing a joint understanding, to "give [the couple] something to work on" and to "help [their] relationship" (Blake). Others viewed the ongoing process of

Table 3. Super-ordinate and sub-themes.

Super-ordinate themes	Sub-themes	Participant
Ongoing development of relationship	Learning and adjusting	Louise, John, Sarah, Neil, Blake, Emily
	Increasing strength and confidence	Louise, John, Sarah, Burgess, Chris, Amy, Blake
	Re-establishing identity	Louise, John, Sarah, Chris, Neil
Roles	Loss and change of roles	Louise, John, Neil, Amy
	Negotiating roles	Louise, John, Sarah, Burgess, Chris, Neil, Amy, Blake, Emily
	Giving and receiving care	Louise, Sarah, Burgess, Chris, Amy, Blake, Emily
Intimacy	Changes to intimacy	Louise, John, Sarah, Chris, Neil, Amy, Emily
	Holistic view	Louise, John, Sarah, Neil, Emily
	Experimenting and adjusting	Louise, John, Chris, Neil, Amy, Emily
Relationship maintenance	Communication and humour	Louise, John, Sarah, Burgess, Chris, Neil, Amy, Blake, Emily
	Couple as an entity	Louise, John, Sarah, Burgess, Chris, Neil, Amy, Blake, Emily
	Support	Louise, John, Sarah, Burgess, Chris, Neil, Amy, Blake, Emily
	Negotiating time	Louise, John, Sarah, Burgess, Chris, Neil, Amy, Blake, Emily

developing and learning within a relationship as a potentially challenging one that may benefit from external support to facilitate the process.

> I see us, um, having had to learnt to adapt…I see us having to learn to, um, be more open, be more honest, um, needs more support, you know as far as we're both open to having more… So, sometimes we come together like yesterday at loggerheads and it's like we could do with having someone to sort of facilitate this and help us to get past, um, some of the, some of the things that, some of the obstacles that we sort of face. (Neil)

The SCI had always been a part of the experience of some couples from the beginning of their relationship. However, for those who had started their relationship prior to the SCI, the injury appeared to significantly disrupt their sense of couplehood, causing individuals and their partners to establish new ways of maintaining their relationship. The uncertainty and threat the SCI brought to relationship that existed prior to the injury was echoed in some participants' concerns that the SCI and accompanying challenges was not what their partners "signed up for" (Sarah).

Increasing strength and confidence

Many participants spoke of facing several challenges that opened opportunities to gain strength as a couple. Whilst some were related to SCI, others included the COVID-19 pandemic, difficulties within the relationship, mental health difficulties and losses and illness within their families. Louise spoke of the need for her and her partner to "pull together" following SCI, leading to increased mutual reliance. Others described an increased understanding between partners: "She knows me, I know her" (Chris).

For many, successfully coping with adversity or threats to their relationship led to them viewing their relationship in a new, positive light or to an increased confidence in their partnership and its ability to overcome challenges in the future, based on a "strong foundation" (Louise and Burgess).

> And the fact that we've had to overcome challenges and adversity and things that have been difficult, I think it means that it's sort of tried and tested. We're very confident in each other and in our…in the strength of our relationship and I do, you know, I've seen friends that have been, you know, couples for ages and then something really difficult happens and the relationship falls apart because it's never been sort of tested in that way. Whereas I think right from the beginning, our relationship has been and, you know, we've had to be strong as a couple and so that sort of… Yeah…I think we both would say that we're pretty confident we can weather challenges together. (Sarah)

Re-establishing identity

Participants spoke about how experiencing SCI led to changes to their sense of self, and that of their partner and the relationship. Chris explained how:

> I suspect we, we're very different people because of my injury and because of coping with my injury and how we manage it between us. (Chris)

For some, change in identity following injury led to a need to grieve for the "old" self and to re-establish a sense of themselves and their abilities as they "say goodbye to the old you and…have to welcome in the new you" (Louise).

John discussed how being in a relationship led him to reflect on and gain better understanding of himself, thereby benefitting the relationship.

> …but it, uh, meant changing yourself along the way. Yeah, you change yourself. And when you change yourself and feel the better for it, and your relationship is better for it, and everything else around you goes better for it, you know. (John)

Neil described how the changes both partners had to make following injury had negative consequences for the relationship. He also spoke of the difficulties of acknowledging how both he and his wife had changed.

> I think that…if anything, the damage that's been done over the years, over the time of me being different and being more irritable, being less fun, being less physical, less being spontaneous and all the things maybe that, you know, some of the, some of the traits that she fell in love with me, you know, she sort of sees them as, things being more different than I see myself as being. So, I think that she sees me as being more different than I do. (Neil)

He spoke about adapting from one version of a partner to another over time, from the "old husband" prior to SCI, to a "new husband that came back after the accident" to a "much more… thoughtful possibly and supportive husband" (Neil).

Roles

The importance of establishing roles following SCI or when starting new relationships was evident in all interviews. This refers to negotiating roles and responsibilities within a relationship, as well as establishing caregiving boundaries.

Loss and change of roles

Many of those in their current relationship at the time of SCI spoke about role changes within their relationship post-injury. For some, this meant that their partner had to take on new responsibilities, disrupting previously clear roles. Louise described changes to her and her partner's roles since her injury.

> I would say, yeah my husband still does maybe 90% of the household stuff. Umm, you know, he does the laundry, he does the cooking, he does the cleaning, you know, he does everything. So yeah, the roles have definitely changed quite considerably. (Louise)

Neil explained how his partner had to take on additional responsibilities since his injury, leading to resentment.

> The roles have changed. She was at work doing a job and, you know, running a business that she didn't want to do, creating a lot of resentment for her against me. I wasn't helping as much as I… She was going out to work and I was staying at home. Where she wanted to be was at home. She wanted to be the, you know, the home maker. (Neil)

Some participants described a perceived loss of traditional gender-based roles, such as that of the family's protector, whilst others discussed their frustration at failing to carry out particular tasks. However, some explained how new roles had developed within the household that focused on their skills and abilities, "making up" (John) for tasks they may no longer be able to do.

Negotiating roles

All participants spoke about the process of negotiating roles within their relationships. For some, this happened organically, whilst others reached these decisions through formal discussion. Several participants spoke of both partners having clearly defined roles based on their strengths and personalities.

> He's definitely kind of my legs, umm… but I would say, umm… Yeah, as I said before, I would say I'm his rock, really. (Louise)

Others described the importance of maintaining equality and independence within post-SCI relationships.

> We both have an equal role and there's a balance about that, and that's really important because I think it can be very easy… I suspect it can be very easy if you are disabled and your partner isn't for there not to be that balance, um, where you can feel that they do everything for you and you don't do much for them and I, I don't think that's true with us. (Sarah)

> However, Sarah also questioned the implications of couples having strong practical and financial dependence on each other, suggesting that she and her husband "almost couldn't separate."

Chris discussed the importance of maintaining the husband-wife role he and his partner had prior to SCI, ensuring that his wife did not become his carer.

> I think it's about, it's about boundaries isn't it. It's setting boundaries. Um…what she's willing to do and what she doesn't want to do. Um, and then what keeps us in a husband-and-wife relationship. (Chris)

For him, this was important in maintaining their relationship and ensuring that his partner did not feel resentment for being "taken away from whatever [she] wanted to do" (Chris). Others, whose partners provided some practical care and support, also had clear caregiving boundaries.

> So, like, I don't know, like if we're out together, I'm quite happy for him to empty my leg bag but I don't particularly want him doing my bowel care. (Amy)

For others, caregiving roles were more flexible and could change depending on factors such as wanting time alone without carers, occasional health needs or having to adapt due to the COVID-19 pandemic.

> Even when we're not in lockdown, like when we go away on holiday, she still has to do them kind of aspects of [caregiving], because if we want to go away on our own for any more than two or three days then she kind of, she had to do that kind of aspect, and she was fine with that, she accepted that. It was just a small price to pay for us to enjoy our longer holidays just on, just the two of us. (Burgess)

Some participants described how both partners held a flexible caregiving role, providing practical support to the other when needed.

> When the flag went up and you were needed, you responded. (John)

Giving and receiving care

As previously mentioned, participants spoke of their partner adopting a caregiving role, either permanently or occasionally and potentially leading to the need to establish successful role reciprocity [50]. Although many viewed this as a positive in increasing closeness and trust in relationships and reducing reliance on external carers, participants also spoke about the emotional impact of giving and receiving care on both partners. Participants described feeling "worthless" (Louise) and "a burden" (Sarah and Blake) when having to depend on their partners for care. Despite many participants expressing gratitude and appreciation, a few also spoke of their concerns regarding the possible practical and emotional challenges faced by their partners in adopting a caregiving role.

> I think sometimes it, it affects me. So, I worry about the effect on him. I worry as I become more disabled that that's not what he signed up for. Um, but he would say it is what he signed up for and it's fully what he expected and that actually we're both getting older and at some point, he may be less physically able than *he* is now. (Sarah)

Burgess discussed the process of "teaching" his partner about his support needs when establishing their relationship so that she could provide occasional care. Louise and Sarah spoke about the unpredictability of their pain and fatigue and how this impacted on their partners' caregiving responsibilities.

> It would be really quite easy for someone to get frustrated and angry at the fact that some days I can do things and the next day I can't do things, or I can actually be quite well physically in the morning and then nothing particular happens but my pain will kick in and I have to then do nothing, having agreed that I would do the laundry, or something like that. (Louise)

Two participants, Chris and Amy, had live-in carers, bringing additional challenges and need for adaptation. For Chris, having live-in carers ensured that "my wife is not my carer, she's my wife." However for Amy it also meant a lack of privacy with "almost like a third person in the relationship."

Intimacy

This theme reflects the changes in intimacy following SCI and the ways in which couples experiment and adapt to maintain physical and emotional intimacy.

Changes to intimacy

Some participants described having a healthy sexual relationship with their partner, however many spoke of changes to intimacy post-SCI. Some discussed lack of sensation following injury, causing sexual intimacy to be "much of a give and not much take" (Louise) and the difficulty of this for both partners. Chris talked about the risks of having sex due to autonomic dysreflexia.

> When I ejaculate it's the same, um, because my blood pressure shoots up, um, it's quite dangerous for me, um, so that's a concern for my wife as well. So, she worries that, um, if something happens or she gets me too excited then that, that I could essentially have a stroke. (Chris)

Many participants described their frustrations at being unable to spontaneously show affection towards their partner.

> I don't always have to ask but I quite often will say, "I need a hug" or "Can I have a kiss" or whatever, um, whereas if I was an able-bodied person, I guess I'd just go and initiate it myself. (Amy)

Although physical touch and intimacy remained important for many, Neil described how hugging or holding hands with his partner "doesn't feel natural" post-SCI.

Holistic view

Participants described the importance of closeness, affection and emotional intimacy in their relationships following SCI, with intimacy moving from being "sexually-based to much more… affection-based" (Sarah).

> We can be totally intimate with each other, um, without having sex. Um, and, you know, I, because I don't get much feeling from sex, I absolutely love the intimacy part of it. You know, I have sex, I don't mind it, you know, not that I'm suffering, but that's all for him really. But the intimacy is what I really, what I really enjoy. (Louise)

After placing great importance on his ability to have penetrative sex following discharge from hospital, Neil talked about the gradual process of widening his definitions of intimacy and developing an understanding of his partner's desire to establish strong emotional intimacy before regaining physical intimacy.

> But, uh, it's not about penetration. It's about feeling and sensation. Uh, and you know, I've been really, you know, keen to explore that, uh, as well and…[wife] hasn't…I understand why she just doesn't want to embark on the physical side until she really feels that we're being really kind and loving and caring with each other, uh, which, which, I sort of, I get. I absolutely get. (Neil)

Experimenting and adjusting

Many participants spoke about their experiences of regaining both physical and emotional intimacy following SCI. Trust, communication and understanding seemed central to this process.

> So, I think the trust thing is that, um, you, I need to trust that it's comfortable and pleasurable even if I can't feel anything, you know. (Emily)

Some participants discussed how elements of sexual intimacy could be incorporated into caregiving tasks through "play showers" (Chris) or appreciating a partner's body when checking skin integrity.

The perspective of the partner was also discussed, with some participants talking about the importance of respecting a partner's wishes not to engage in sexual contact, despite this being frustrating. Neil spoke of the harm he felt he caused to his relationship by wanting to experiment and regain a sexual relationship very soon after his injury when his wife was not ready.

> Uh, when I was in hospital and, uh, I was exploring getting an erection again with, you know, I think I sort of pushed too much too soon. Um…we actually probably did a lot of damage to my relationship with [wife], um, on numerous levels but she wasn't really ready, and I think that sort of put her off and set her back, set us back. So, I think when I came back, she really wasn't ready then to explore as much as I was, which probably made me feel, it made me feel rejected hurt and, you know, um…frustrated. (Neil)

Relationship maintenance

This theme incorporates the elements participants felt were important in maintaining relationships post-SCI. These sub-themes were present in all interviews.

Communication and humour

Communication was listed by the majority of participants as the most important factor for relationship maintenance. Louise spoke about the need to talk post-SCI, allowing both partners to share grief and difficult emotions. Other participants discussed the potential difficulties of not communicating and of letting tensions and concerns "fester" (Chris).

> So, by staying strong, um, I probably delayed some of the, you know, inevitable feelings and, uh, challenges that that brought to my relationship. So, I probably would talk about, you know, being open and honest with your partner, showing vulnerability, um, sharing more, um, with them earlier on. (Neil)

Many participants described how they felt that coping with SCI and the challenges it brought increased their communication, "having to be completely honest…about everything" (Amy).

> If I'm cross with him, I still need him to help me off the sofa if I'm sat on the sofa or, and so I'm, I might really, really not want to talk to him but I have to. And he is the same that you know, he might actually feel like he wants to leave me on the blooming sofa but, you know, he would never do that so we have to kind of make up and we have to be physically close and I actually think that's a really good thing cos it forces us to deal with our issues in a head-on way, in a way I guess other couples might be able to not do. (Sarah)

Participants spoke of the importance of "not being scared to talk about anything" (Chris) and using humour to discuss potentially awkward or embarrassing situations. However, Emily reflected on how "some people with spinal cord injuries are constantly telling you about their bladder and bowels," possibly reflecting normalisation of reporting on bladder and bowel function within rehabilitation settings. Emily felt that this increased openness posed risks of over-sharing with one's partner without communication boundaries.

> It's become so normal I think for spinally cord injured people to talk about that stuff but actually…it's not normal for non-spinally injured so you've got to bear that in mind if you're going out with someone who's not spinally injured…or even someone who is! Do you still really want to talk about, you know, whatever, all that stuff? (Emily)

Couple as an entity

'We' was used consistently throughout interviews by participants to refer to both partners as a couple, or team, in dealing with everyday challenges. Sarah referred to herself and her partner several times as a team when managing some of the physical challenges following SCI.

> Over the years we have worked our way out of doing things and so if he helps me physically we have a way of doing it that just works and, you know, we don't really have to talk about it much… (Sarah)

Some also conceptualised the SCI itself as a shared experience for both partners. Chris described how his partner had "lived with the injury as long as I have," leading participants to ask for and trust their partner's opinion when concerned about their injury or its consequences.

Many participants spoke about a sense of shared commitment, focus, values and not wanting to "give up…on each other" (Blake). However, for Neil, there was a sense of sadness in realising that he and his partner were "not on the same page at the minute" and did not seem to share the same future goals and hopes for their relationship.

Support

Some participants described how external support from friends, mental health professionals, family members or the wider SCI community had benefitted their relationship and its maintenance. However, most discussed the sense of mutual emotional support within their relationship.

John spoke of a "total dependability on each other," whilst Blake described him and his partner "just being there for each other." Despite the relational challenges both partners faced, Neil acknowledged that his partner "is there if I need her to be," whilst Louise described her relationship using powerful metaphor.

> I'm really glad that he felt I was a rock that he could just cling to and I treat him the same way. He really is my rock and if something is going on I can just, yeah, we can have a cwtch [cuddle] and talk about it, um, and everything just feels so much better. (Louise)

Sarah discussed her partner's understanding and acceptance of her SCI and related challenges.

> Like everyone I get, you know, I've had skin issues sometimes or I've had bladder issues or bowel problems or, you know, stuff that goes

> with, along with a spinal injury. And [husband] is very able to just deal with that stuff. Um, he doesn't have a…his attitude to it has always just been that it's me and it's part of me and that's fine and he doesn't have an issue with that. (Sarah)

Negotiating time together

Many participants discussed the importance of spending time together as a couple, either during formal "date-nights" or holidays or when "making time for each other" at home (Louise). Those interviewed described their relationship as a friendship as well as a romantic relationship and "enjoyed each other's company" (Burgess). Some spoke about being creative in finding ways to spend time together as a couple, while Blake described how he and his partner "just [go] for a drive sometimes just to have that…closeness."

However, for other participants, spending time apart was crucial for the health of their relationship, allowing them to participate in hobbies, maintain independence and self-reflect. The negotiation and organisation of time together and apart also seemed important.

> I think that in any relationship, let alone one with spinal injury it's important to compromise and work out what each of you like to enjoy doing and what you like doing together and what you like doing apart. (Burgess)

Discussion

This study explores the possible changes within partnerships following SCI and the adjustments couples made to maintain their relationships. Data were collected using semi-structured interviews and analysed using IPA, yielding four super-ordinate themes: ongoing development of relationship; roles; intimacy and relationship maintenance.

Roles

During interviews, several changes and associated attempts at maintaining relationships through adjustment became clear. This concurs with Solomon and Theiss' [51] description of partners needing to adapt to several changes during periods of transition within relationships, prompted by perceived mismatches between previous and newly-established roles and routines. Several participants described how SCI disrupted their sense of individual and couple identity, consistent with "biographical disruption of couplehood" described by Kim and Kim [28, p.301]. Cayless et al. [52] and Little et al. [53] also describe how life-limiting conditions may challenge the sense of familiarity and predictability within people's lives. For many, this disruption led to the development of new relationship identities, often following a trajectory of grieving, role-restructuring, re-defining identity and growing as a couple or family, as discussed in the family tasks model (described by [54]).

As with the family tasks model, the process of re-defining and negotiating roles and responsibilities seemed key in many relationships. Despite SCI disrupting some participants' abilities to engage in certain tasks, there was an emphasis on the need to maintain a role and sense of equality within the household based on both partners' strengths, abilities and personalities. Research on role reciprocity strongly suggests the importance of the quality of exchange and a balanced sense of "give and take" within relationships for individuals' mental health and wellbeing [55,56]. However, some individuals described a sense of increased dependency on partners and worries about being "a burden." Altschuler [57] discusses how difficult feelings arising from changes to the balance of dependency and power between couples faced with illness can cause difficulties within romantic relationships. However, as some participants disclosed, it seems that these changes do not necessarily pose significant disruptions to notions of couplehood if both partners are responsive to, and communicate about, them and their possible impact [58].

Relationship maintenance

This notion of responsiveness seems important in wider models of communication, such as the relationship intimacy model [59,60] used in relation to couples affected by cancer diagnoses. This model proposes four types of behaviour that enhance the sense of intimacy within relationships. It includes the way couples discuss the stresses they face and share thoughts and feelings; the extent to which an individual feels understood by their partner; and individual and joint appraisals of the illness and its consequences. This sense of openness, honesty, mutual understanding, acceptance and support seemed to be notable themes emerging from the interviews, with all participants emphasising the importance of communication for adjustment and relationship maintenance. Despite this, some participants discussed the difficulties brought by their initial reluctance to be fully open with their partners post-SCI. The differences in participants' experiences of communication in the transition following SCI may be partly explained by the relationship turbulence theory's [61] suggestion that differing emotions and cognitive appraisals will be associated with couples' use of more or less open and aligned communication styles.

Intimacy

Many participants described experimentation and creativity within elements of their relationship following injury, including the experience of adapting and maintaining physical and emotional intimacy. Communication also seemed crucial to this element of adjustment, as suggested by Westgren and Levi [62]. Some participants emphasised the importance of both partners committing to this adjustment, as well as the need for emotional intimacy to enable successful physical intimacy [63,64]. This echoes many participants' experiences of developing a more holistic sense of intimacy following SCI, focusing more on emotional closeness and physical touch. This is a common theme in many other studies exploring sex and intimacy following SCI (e.g., [17,26,65]).

Ongoing development of relationship

Participants spoke about a joint process of relationship adaptation and maintenance, reflecting findings from other qualitative research exploring relationships following SCI (e.g., [32]). The collaborative coping model [66] and the relationship coping-model's notion of active engagement [67] describe the importance of couples combining their resources to engage in joint emotion sharing and problem-solving. Higher levels of active engagement within relationships facing cancer have been found to be associated with lower levels of psychological distress and greater sense of self-efficacy within relationships [68]. Several studies looking at different conditions emphasise how couples, when conceptualising their experience as a shared one, contribute to their relationship's health, aiding potential adjustments [57].

Not all participants and their partners seemed to experience SCI and associated changes in the same way. In light of research on ageing and SCI (e.g., [69,70]), it may be expected that time since injury would be an important factor in influencing participants' different experiences and the challenges they may face when maintaining relationships. Furthermore, the level of the SCI may also be expected to impact on sexual satisfaction [71]. However interestingly, it seems that the main differences in participants' experiences depended on whether or not they were in their current relationship at the time of injury.

The differences in experience depending on whether or not a relationship had been established prior to injury concurs with Rolland's [72] family-systems illness model which conceptualises how the intersectionality of illness, family and individual life cycles and family functioning influence how the illness is experienced and the related tasks families need to undertake.

Joint problem-solving is a thread that runs throughout the transcripts and reflects the cognitive processes and appraisal factors discussed in many models of dyadic coping. This idea of shared problem-solving, support and dependence is also consistent with the notion of secure adult attachment. Davila and Sargent [73] discuss individual variations in how attachment strength may change when faced with certain situations, consistent with the findings of this study. For some participants, the difficulties SCI brought, other unrelated challenges and associated adaptations led to a sense of strengthening partnership and a couple's confidence in it. This is similar to the findings of DeSanto-Madeya [37,74] in their study of family caregivers and partners of individuals with SCI, and consistent with the notion of post-traumatic growth [33–35]. However, for others, SCI seemed to challenge couples' resources and relational supports, leading to difficulties.

Clinical implications

Clinically, many concepts discussed during the interviews seemed to resonate with principles of the Acceptance and Commitment Therapy (ACT) model [75]. This therapy mode has preliminary evidence of its efficacy with SCI [76] and a large evidence base supporting its use with difficulties related to SCI, such as chronic pain [77,78]. One of the main elements of ACT is psychological flexibility, allowing individuals to be psychologically present but also to respond successfully when faced with difficulties [79]. Interestingly, this chimes with this study's findings, as couples maintained relationships through adaptation, experimentation and creativity. ACT also advocates living a values-based life, consistent with the focus many participants placed on shared values, goals and aims within relationships. Acceptance is another aspect of the ACT model emphasised in interviews, with participants discussing how partners accepted them and their injury, allowing their dyad to work together and adjust to challenges in a non-judgemental way.

Furthermore, it is possible that the Compassion Focused Therapy (CFT) model [80,81] could also be appropriate for use in therapeutic settings for individuals with SCI and their partners. In line with the three affect-regulation systems described within the CFT model [80], it is possible that those living with SCI and their partners may have a dominant threat system, and may also feel a strong sense of drive to quickly adapt to the injury. It is possible that this may leave couples with a strong sense of shame or failure [81], as has also been found in studies looking at SCI [1]. There is therefore potential for using CFT to increase the soothing-affiliative system for individuals with SCI and their partners. This may be beneficial in increasing a sense of safety and connection with others, thereby reducing the strength of the threat and drive systems [82]. As the use of CFT has been found effective in reducing shame (e.g., [82]), it is also possible that using this model would also be beneficial in reducing the sense of shame and self-criticism individuals may feel following SCI and when facing the challenges that the injury may bring to their relationship.

Research has shown how close couple relationships can act as a buffer when individuals are faced with stress and challenges [83]. Consequently, it seems essential that those who have experienced SCI and their partners are offered ongoing individual and couple support to aid the management of psychological and practical challenges and associated adjustment processes. This is consistent with Bertschi et al.'s [84] systematic review advocating that adjustment within partnerships, where there is chronic health impairment, should be seen as an interpersonal process where joint coping benefits adjustment, leading to the need for a focus on "strengthening the 'we'" (p. 18). Amsters et al. [85] also highlight the importance of supporting both partners to gain greater awareness of behaviours that reinforce relationships following SCI. This seems crucial in light of studies such as Barrett, Ho and Finlay [86] that draws attention to the emotional and adaptation difficulties also faced by the partners of those living with SCI. Some of this support may derive from the ACT hexaflex (described by Harris and Hayes [79]), including flexibility, living a values-based life and accepting difficult situations. Many of the participants in the study described experiences of either receiving or being offered therapeutic intervention post-injury. While many found this useful, Chris discussed the importance of support being offered at the right time, by a therapist with either lived or professional experience of SCI. It therefore seems important that offers of psychological support are person-centred and individualised.

Negotiating roles and responsibilities within relationships to maintain equality and independence seemed to be an important theme in the study. As couples appeared to view themselves as facing challenges as an entity, it is important they have opportunities to access joint support. This is also pertinent when considering the importance of mutual coping and role reciprocity. Several studies have suggested that support be offered for couples to regain a sense of intimacy following injury (e.g., [22]). However, existing support may need to change and focus on increasing partners' understanding and flexibility in their thinking, communication and approach to intimacy following SCI. This concurs with Balzarini et al.'s [87] paper discussing the benefits of high sexual communal strength for relationship satisfaction in partnerships with unmet sexual ideals. Participants described the ongoing adjustment and learning that is needed following injury as individuals age, start new relationships or face other challenges. It therefore seems important that specialist support is offered throughout the lifespan, rather than solely in the weeks and months following injury, encouraging couples to recognise challenges as opportunities for new learning and communication.

Limitations and further research

This study provides a qualitative perspective on individuals' experiences of adjusting and maintaining relationships following SCI. It is acknowledged that all participants were heterosexual, had self-reported scores on the DCI that were in the clinically average range and came from the UK, Ireland and the USA, possibly impacting upon the generalisability of the findings. However, this may also ensure a more in-depth understanding of the experience of a homogeneous group of participants. Further research addressing the topic from both a heterosexual and a LGBTQ+ perspective would be beneficial, as would increasing ethnic diversity. Several similarities became apparent among participants, regardless of whether they were in their current relationships at the time of SCI or had established their relationship post-injury. However, it would be useful to gain further insight into the experience of both categories of participants and partners to develop a better understanding of any unique mechanisms of maintenance and adjustment underlying the experience of particular groups. Further research interviewing dyads together would also be valuable in exploring their co-constructed cognitive and emotional experience of adaptation.

As found in this study and others (e.g., [84]), a strong sense of partnership and co-working when facing challenges and problem-solving following injury seems important for successful adjustment. Future research could therefore consider ways in which this can be fostered within relationships and in the support given to partners post-SCI.

IPA is a largely subjective and epistemological way of analysing data. Although steps were taken to ensure rigour, including the researcher keeping a reflective diary, owning their perspective and consultation with individuals living with and specialising in SCI, it must be acknowledged that another researcher might have interpreted the data differently [88,89]. Furthermore, Tuffour [90] summarises several other critiques of IPA, including the view that it lacks interpretation and is largely descriptive in nature. The vast majority of participants appeared to have largely positive experiences of their relationship following SCI, as confirmed by their DCI and DAS-7 scores. This suggests self-selection bias: those with strong romantic relationships following SCI were more likely to participate in the research, with the study possibly not including the views of those with less positive experiences. Due to the inclusion criteria, participants had to be in a relationship at time of interview, thus excluding the experiences of those who may have been less successful in maintaining their relationships post-SCI. Further research addressing the process of the disintegration of relationships following SCI, in line with research such as that of Jeyathevan et al. [29], would be beneficial given the dearth of such research. Furthermore, it is possible that those with less access to, or lower levels of confidence in, technology failed to participate due to the recruitment and research methods.

Data collection occurred during the COVID-19 pandemic when there were stay-at-home restrictions. While this provides a unique account of the experiences of those with SCI during the pandemic and the relational challenges it may have brought, the information is firmly located in this time-frame. Similar research employing psychological perspectives post-COVID would therefore be useful and may yield different themes. It should also be remembered that this study provides a snapshot of individuals' experiences in the years following SCI. Relationships and the process of adapting to living with an SCI are ever-evolving. It is therefore possible that these participants' experiences would have been different if interviewed at a different time.

Conclusions

In conclusion, this phenomelogical study explored the couple relationship experiences of nine people with SCI in heterosexual relationships. Key experiences shared by the participants included the importance of communication in the process of negotiating, adapting and providing mutual support, with couples maintaining a sense of shared values, tasks and identity. Couples also seem to face challenges as an entity, experimenting, adjusting and often gaining a greater sense of strength and confidence in their partnerships. Experiences differed depending on factors such as whether the relationships had been established prior to or after SCI and the willingness and readiness of both partners to adapt and experiment. These processes are in line with many psychological models of adjustment and growth and echo the structures of ACT.

We extrapolate that clinical approaches to couples therapy after SCI may align well with ACT. Further work is required to explore the experiences of those living with SCI and in non-heterosexual relationships, as well as those from other ethnic groups other than white. It would also be beneficial to further stud the possible unique processes of adaptation that couples may adopt depending on whether or not they were in their relationship at the time of the SCI.

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