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## **Adaptations to adult attachment and intimacy following spinal cord injury: A systematic review**

*Purpose:* Experiencing spinal cord injury (SCI) can be life-changing for individuals and their families. Previous reviews have focused on coping and psychological adjustment, sexual function and sexuality or factors facilitating or impeding interpersonal relationships after SCI. However, there is very little synthesis of research focusing on changes to adult attachment and emotional intimacy post-SCI. This review aims to examine the mechanisms of change in adult attachment and intimacy in romantic relationships following SCI.

*Materials and methods:* Four online databases (Psycinfo, Medline, CINAHL and Scopus) were searched for qualitative papers concerning romantic relationships, attachments and intimacy post-SCI. Sixteen of the 450 papers met inclusion criteria. These were quality assessed and analysed using meta-ethnography.

*Results:* Three main themes emerged from the analysis: a) strengthening and maintaining adult attachment; b) changes in roles; and c) changing views of intimacy.

*Conclusion:* Many couples face significant changes to adult attachment and intimacy following SCI. Systematic ethnographic analysis of their negotiations enabled the identification of underlying relational processes and adaptation strategies associated with changes to inter-dependence, communication, role revision and re-definition of intimacy. **The findings indicate that healthcare providers should assess and respond to challenges faced by couples post-SCI using evidence consistent with adult attachment theory.**

Keywords: spinal cord injury; couple relationships; adult attachment; intimacy; adjustment; qualitative research; systematic review

## **Introduction**

Spinal cord injury (SCI) whether traumatic or non-traumatic, is life changing for individuals affecting their social and community participation [1] and impacting those with whom they have family and romantic relationships [2, 3, 4]. Although each individual will experience SCI differently [5], SCI and its associated changes and challenges can be a significant cause of stress for both the individual who has sustained the injury and those close to them [6]. This has been shown to necessitate substantial adjustments for the individual with the SCI [5], their partners and families, both in the short and longer term.

DeSantos-Madeya [7] studied 20 individuals with SCI and their family caregivers and found significant changes and challenges still evident five to ten years post-injury. These included a sense of loss and a lack of independence and freedom felt by both members of the dyad especially in the early stages following injury [8]. For example, those with SCI describe feeling ‘chained to the injury’ [7, p. 279]) due to their increased reliance on others while their partners felt their own loss of independence due to the increased responsibility and caregiving burden placed on them. Despite difficulties, couples also sought to adjust to their new circumstances through finding novel, positive ways of viewing their situation and attempting to create a new sense of normality [7], for instance, by re-engaging in activities together. This is similar to Chun, Heo & Lee’s [9] paper that discusses the importance of savouring normal family time following SCI to foster a sense of belonging and normality.

Similar challenges to new and changing lives, roles and responsibilities, as well as ways of trying to adjust to these, have also been found in studies focusing

specifically on couple relationships following SCI. Past research has found an increased risk of relationship breakdown and divorce post-SCI [10], with certain factors such as social integration or health perception found to be possible indicators of relationship difficulty following injury [11]. Beauregard and Noreau [13] discussed the impact of SCI on the life of the individual with SCI and their partner, considering areas such as domestic roles and responsibilities, leisure time and sexuality. There are also individual challenges for each member of the couple. For example, Dickson et al. [13] discuss the significant psychosocial impact on those who have experienced SCI, while Barrett [14] considers the possible shame felt by many males living with SCI due to perceived differences between culturally held views of masculinity and their reality.

There may also be significant changes in roles for partners of individuals with SCI following the injury as the extent of their caregiving responsibilities becomes clear. Adaptation can be a long process that encompasses several different stages from feeling hurt and distress, to trying to re-configure roles and to eventually starting to adapt to their new life with their partner [15]. Through gradually adapting to their new situation, those who care for partners with SCI seem to begin to gain more confidence in their caregiving abilities and therefore require less external support, whilst they and their partner develop a better, mutual understanding of each other's needs [16]. Dickson et al. [13] report that spousal caregivers can adapt to the significant changes to their situation through increased flexibility and by viewing their life differently from the life they had prior to their partner's injury.

Many reviews that focus on the impact of SCI on couple relationships seem to concentrate on the sexual, physical relationship (e.g. [17]). Understandably, as SCI

can affect sexuality in numerous ways [18], this can have a notable impact on relationships for both those with SCI and their partners [19, 20]. Despite this, sex remains important for many individuals and couples following SCI [21, 22]. In their study interviewing 20 women with SCI, Fritz et al., [23] found that individuals' views of sexuality broadened following injury, encompassing more than just penetrative sex, thereby potentially aiding their adaptation process. Similar results have been found in studies focusing on males' sexuality following SCI (e.g. [24]). Furthermore, Beckwith and Yau's [25] study with seven Australian women with SCI suggested a stepwise process of adapting that may potentiate recommencing sexual relationships following injury.

The role of partner support has been found to be important in facilitating relationships post-SCI [3] and in supporting the individual with SCI to adapt to their injury [26]. In their longitudinal study of people with SCI, Holicky and Charlifue [27] found that marriage seemed to be linked with less depression and higher levels of well-being, life satisfaction and quality of life. Similarly, detrimental effects on depression and life satisfaction have been associated with a higher prevalence of self-reported loneliness amongst those living with SCI [28]. Guilcher et al. [29] found that the quality and quantity of interaction may impact positively upon feelings of loneliness. Families are systems that can adapt in response to constantly changing circumstances and environments by using coping strategies [30]. However, the impact of SCI may disrupt the natural processes of mutual support used by couples when faced with stressful situations as priority within relationships may now be re-allocated to supporting the individual with SCI [31].

Beyond identifying difficulties and facilitators there is a need for research to adopt a more relational focus on adult adjustment processes following the onset of chronic illness or disability [32] and, more specifically following SCI, as called for by Bertschi et al. [33] in their review of dyadic coping when one partner has a chronic sensory or physical impairment. The changes that happen to relationships following SCI and the related adjustments made can be thought of in relation to adult attachment, or the way in which ‘relationship processes unfold across a person’s lifespan’ [34, p.598]. Individuals’ levels of attachment anxiety and avoidance are thought to affect their sense of security and need to seek reassurance in relationships, as well as their feelings towards physical and emotional intimacy [34]. Attachment type is therefore proposed to play a role in people’s behaviour and affect in relationships [35]. Chopik et al.’s [34] longitudinal study found that attachment styles change during the lifespan, prompted by pivotal moments requiring adjustments or change [36]. It therefore seems pertinent to consider whether this is also the case following SCI.

There is a growing body of qualitative research considering the lived experience of those with SCI from different cultural perspectives [e.g. 37, 38], focusing in particular on relationships with their partner. Many of these studies look specifically at physical and emotional intimacy, but there is an emergent literature concerning the processes by which relationships adapt after one partner experiences SCI. However, very few studies synthesise the findings of these papers. A recent systematic review by Earle et al. [4] provided a summary and thematic synthesis of 27 studies focused on sex, sexuality and relationships after SCI and particularly on how people’s view of SCI had impacted their sexual identity. Although relational models have been used to consider the impact SCI may have on couple relationships (e.g. [39]), to our knowledge, there is

a lack of current systematic reviews which consider couples' adjustment to their relationship following SCI from a relational perspective. Therefore, as people with SCI adapt their expressions of intimacy and sexuality within partnered relationships, this review addresses what their experiences disclose about the process and mechanisms underlying this.

### ***Aims of the Study***

This systematic review aims to review qualitative literature regarding experiences of relationships of those living with SCI following injury. The review will consider whether adjustments to adult attachment and intimacy are evidenced following SCI and, if so, what the mechanisms of change underpinning these adaptations may be.

It is hoped that the review will inform the gap in understanding which is evident in clinical rehabilitation and re-integration practice following SCI (e.g. [40]) so that those who support individuals and their families will be better able to design interventions to promote positive adjustment for both partners.

### **Materials and Methods**

#### ***Design***

A meta-ethnography design [41] was used to synthesise the findings of the papers identified. Using this inductive and interpretative method of analysis, studies are translated into each other, revealing common analogies, metaphors and ideas between accounts [41, 42]. However, the original 'sense' of the papers is also maintained throughout the analysis [41]. Noblit and Hare's [41] seven stages for conducting meta-

ethnographic analysis were followed throughout. Table 1 provides a brief explanation of these seven stages.

table 1. Summary of Noblit and Hare's [41] seven stages for conducting meta-ethnographic research

### *Search Strategy*

Four databases were searched for relevant papers (Psycinfo, Medline, CINAHL and Scopus). These databases were chosen in consultation with the research supervisor and a librarian experienced in social science literature reviews. An original search was conducted in July 2020 with an additional search in January 2023. The search terms focused on three main concepts: SCI, relationships and couples. Key word and subject heading searches were conducted, where possible.

No similar reviews were identified by a search of the Prospero database in May 2020 or January 2023. Table 2 outlines the search strategy used.

table 2. Search strategy

### *Data Selection*

Following the search of databases all duplicates were removed. The researcher read the titles and abstracts of the remaining papers and then reviewed the full text and reference lists of the most relevant papers.

### *Inclusion and Exclusion Criteria*

The inclusion and exclusion criteria used to filter data are summarised in Table 3.



table 3. Inclusion and exclusion criteria

## **Results**

The Results section is structured to report firstly on the search outcomes together with an appraisal of the quality of these papers and secondly, to provide a synthesis of the data from those papers using meta-ethnography methods, as suggested by Noblit and Hare [41]. Table 8 will show the culmination of this process and summarise the main themes that emerge.

### ***Results of Search Strategy***

Figure 1 is a PRISMA diagram [43] summarising the process by which the final papers were selected.

figure 1. PRISMA diagram

Following the electronic database search, 692 papers were retrieved. Of the 60 papers that were assessed for eligibility, 44 were excluded for reasons such as focusing solely on physiological sexual adjustment following SCI, not using primarily qualitative methodology or only containing the perspectives of the partners of individuals with SCI. A further paper was omitted due to it being a university dissertation with uncertainty regarding whether it was peer-reviewed (as explained in Boland et al. [44]). In all, 16 journal papers were reviewed.

### *Study Characteristics*

All studies meeting the inclusion criteria used a variety of qualitative methodologies. Although no date limit was set for the papers, all relevant studies were published between 2000 and 2022. The data included in the papers was collected in community settings across several countries. Thus, it represents a diversity of cultural experiences and associated views on coupledness, gender roles within relationships and the meaning of SCI. The majority of data was collected by interview, although one study [45] also included some written correspondence.

In total the 16 papers included 223 participants (127 males) with SCI and 95 participants who chose at interview either to identify as the person with SCI's partner or caregiver. All participants identified as heterosexual and the total takes into account that two papers separately analysed the same dataset [24, 46]. Table 4 gives study characteristics including detailed information regarding the gender and partnered status of participants with SCI and notes when their data was supplemented with data from their partners (or family caregivers in one paper [47]).

table 4. Summary of the characteristics of the journal articles included in the review

### *Quality Appraisal*

The Critical Appraisal Skills Programme's (CASP) appraisal tool for qualitative research [48] was used to review the quality of the 16 papers included in the analysis. This CASP tool consists of ten questions devised to support the quality assessment of qualitative research by considering the validity, strength and value of each paper.

A reviewer independent to the study assessed a sub-set of the papers using the CASP to ensure reliability. The Kappa process was completed as an additional check on reliability. This showed a high level of inter-rater reliability.

(Cohen's kappa,  $\kappa = .754$ ,  $p < .000$ ).

Any conflicts were resolved through discussion. The ratings given to each paper after consensus was reached are noted in Table 5. A rating of 'yes' was given to a paper if it was felt that it reached all the criteria suggested on the CASP, while a rating of 'no' was given if the paper was not felt to meet any of the criteria. The papers reaching elements of the criteria suggested on the CASP were given a rating of 'unclear'.

The CASP is acknowledged to have several limitations. It lacks a scoring system, its implementation is subjective, it does not facilitate scrutiny of theory [49] and it fails to allow consideration of papers' clinical implications or broader relevance. Furthermore, the process of appraising quality using the CASP can be limited by publishing requirements which may constrain reporting of qualitative methodology and measures to ensure rigour and coherence [49], this may especially be the case in papers with shared methodology. Table 5 summarises the CASP ratings for the papers included in this review, based on Feder et al.'s [50] rating system. Here, papers could achieve a maximum of 18 points: two points for 'yes' on the CASP, one for 'unclear' and zero for 'no'. The researcher did not cross-reference CASP ratings during data extraction to avoid influencing the choice of data. Although there could be reason to exclude papers with a low score on the CASP from the review, it was decided that exclusion of these papers would reduce the veracity of the sample. Weitkamp et al. (2021) [32] argue that excluding low-quality papers may be an error as the ratings can only be thought of as providing an estimate of study quality.

table 5. Quality appraisal based on the CASP [48]

### *Synthesis*

In order to enhance transparency, Noblit and Hare's [41] seven phases for conducting meta-ethnographic research were closely followed throughout, culminating in producing a 'Line of Argument' in which the main interrelationships between themes were expressed. Although there are many different ways in which a qualitative analysis and synthesis can be presented, the researchers chose Noblit and Hare's [41] guidance as most appropriate to a meta-ethnographic review. After the papers had been read several times, each study's main ideas and metaphors were listed. Table 6 summarises each paper's main concepts.

table 6. Main concepts and metaphors of the papers reviewed

The papers' main themes seemed to be directly related and comparable to each other, allowing for 'reciprocal translation' [41]. Guidance on reciprocal translation devised and tabulated by Britten et al., [42] was followed to aid the translation process. This process yielded 16 sub-themes.

Phase six of Noblit and Hare's [41] guidance focuses on synthesising the translations to create a broader understanding of the constituent parts derived from the papers. The 16 sub-themes were placed under six super-ordinate themes classifying the possible adjustments to intimacy and adult attachments into three main areas – strengthening and maintaining adult attachment, changes in roles and changing views of intimacy. Table 7

shows how one of the six super-ordinate themes was formed, while Table 8 provides further details of these master, super-ordinate and sub-themes.

table 7. An example of how the superordinate theme 'We' and its associated sub-themes was formed.

table 8. Master, super-ordinate and sub-themes and associated papers

Noblit and Hare [41] state that each researcher will synthesise data differently based on their interests, values and position. Although it is impossible to avoid this potential bias [51], the researcher tried to maintain awareness of these possible influences by keeping a reflective diary and adhering to Ahern's [51] guidance on reflexive bracketing.

### ***Master Themes and Super-Ordinate Themes***

The themes noted above will now be discussed in more detail.

### ***Strengthening and Maintaining Adult Attachment***

Despite the vast majority of papers viewing SCI as a possible threat to adult attachment and intimacy, the first theme reflects the positive adjustments made to relationships following injury and how this strengthened and maintained adult attachment.

*Reasons for Maintenance.* For many participants, the injury allowed them to see their relationship and its strength in a new light, providing hope for the future and aiding their rehabilitation and adjustment post-SCI. The injury and its effects also strengthened some couples' attachment, thereby bringing them closer.

‘There is more time for us to stay together and we have more opportunities to communicate and express ourselves. He was always working from early in the morning and back late in mid-night in the past. We hadn’t enough time to talk to each other. Now, he has to stay at home all day. We have a lot of time to chat with each other and discuss almost everything that is happening around us’ [Partner, 6, p.769]

‘...a lot more things are open for discussion now than they were, so in a lot of ways intimacy has improved. We’ve gotten a lot closer’ [Person with SCI, 40, p. 440]

It seemed that support, love and a strong relationship prior to SCI allowed adjustment following the injury to be slightly easier and more successful.

‘We knew each other for more than 10 years before our marriage. We had a happy marriage before my accident. We respect each other and discuss things openly and regularly, including my illness. I still remember when I was in hospital I had initiated a separation but my husband turned down such an idea. He said that he would not leave me alone. My disability seems not to be a big deal to him’ [Person with SCI, 52, p. 9]

It appeared that a sense of duty or obligation, rather than ‘the power of love’ [6, p. 796] lay behind some couples’ decision to try to make adjustments following SCI in order to remain in their relationship. This especially seems to be reflected in findings from some non-Western societies [6, 52].

‘*We*’. Another theme was that of interdependency, communication and support, with couples experiencing and adjusting to SCI together. The use of the word ‘we’ in Freeman et al.’s [40] study reflected how couples saw themselves as an entity

navigating a shared experience together following SCI. Couples also referred back to their 'relationship biography' [53] to enable them to jointly work through the challenges posed by SCI.

'We both tried... We were both thinking that the injury is not going away, so we just have got to deal with it together. That is how we coped with it' [Partner, 53, p. 295]

Interdependence seems to be an important part of encountering this shared challenge. Engblom-Deglmann and Hamilton [5] propose a continuum of connection to stagnation on which to place couples adapting to SCI, with connection deemed to be the most beneficial. This interdependency seems to be in relation to both emotional support and to everyday roles, tasks and responsibilities.

'So I was always the one that he went to even after it happened on his fears about life not being the same or if people were looking at him differently. I was always the one...'  
[Partner, 5, p. 9]

'I need more help and my wife needs more emotional help and help with stuff around the house. Even though physically I can't even open the door, at least I can help her with telling my son to close the door, then she doesn't have to do it at the time. I can help her with those things...'  
[Person with SCI, 53, p. 296]

Communication – one of the dimensions of relational turbulence theory [54] - is also discussed in the papers. The communication difficulties faced by some following injury emerged as important. For example, some individuals engaged in protective behaviours,

minimising their own distress to protect their partners, but with this often leading to wider relationship difficulties [47, 55].

‘I made it look like, you know what, I’m totally okay, don’t worry about me, everything is fine. I almost never wanted to complain about anything to him [caregiver], thinking, oh my god, this is too much already, and if I even tell him that, oh my god, my hands hurt today or something, and I can’t do something, I’m just putting more pressure on a person. I usually would never...I would just kind of deal with the pain, and move on because I didn’t want to put any more burden on that person... I think he got frustrated with me a lot, not telling him what was wrong or something. I think there was a lot of frustration on his part, on knowing what to do or how to help because I wasn’t co-operating, and letting him know what kind of help I needed’ [Person with SCI, 47, p. 6]

### ***Changes in Roles***

This theme reflects the pervasive change in roles following SCI and the need to adjust to these.

*Negotiating New Roles.* Research papers explored the need to discover what works in relationships in relation to establishing new roles, finding alternate ways of fulfilling previous roles and responsibilities or, more rarely, in maintaining previously held roles. For some, this was also related to the interdependence and sharing of tasks discussed above.

‘I do a little bit of laundry, like I put the stuff in the washer and transfer it to the dryer, but she folds the clothes because I really hate folding clothes. If she has a faucet leak,



then I'll fix that, so there's stuff like that. So, we trade back and forth that way' [Person with SCI, 47, p. 8]

Engblom-Deglmann and Hamilton [5] discuss the need for couples to adapt to find a balance between dependence and independence within their relationships. This also applies to any caring roles within the relationship in order to 're-establish the boundaries of care' [53, p. 296].

'Someone in a wheelchair, even if they need help, usually want to maintain as much independence as they can without making them feel coddled or feel like a baby or that they aren't still a man. He's still a man, it just looks different now and that's been hard' [Person with SCI, 5, p.13]

For many participants, the SCI and related adaptation significantly challenged their pre-injury identity. It seemed that being cared for and being unable to fulfil traditional gender roles threatened their previous sense of masculinity or femininity, often leading to frustration and despair and challenging the sense of independence and equality in relationships.

'If I helped I'd get yelled at because I wasn't letting him 'be a man' and if I watched him and didn't help, he'd get mad too' [Partner, 5, p. 12]

'You lose all your dignity. Toileting, for instance, [you] can't go to toilet by yourself and you have to be fed, washed, teeth cleaned, and that sort of stuff. It was just that I couldn't have thought of anything worse than this' [Person with SCI, 53, p. 293]

‘He’s always got in his mind, I think, that he’s looking after me. Which is lovely at one level, but [...] it’s not ideal, in terms of an equal relationship and that’s really sad I think’ [Person with SCI, 56, p. 1089]

It appeared that adapting to external support and the particular impact this had on intimacy and its expression was an additional challenge for some with SCI and their partners.

‘It’s hard, because there’s carers in the house [...] knowing that somebody else might hear and be involved – and you can hear people walking down the corridor. And that makes, that makes it awkward’ [Person with SCI, 56, p. 1088]

*Caregiving.* This sub-theme focuses on the challenges of caregiving experienced by the partner of the individual with SCI. Many partners felt that they had lost elements of their past identity, blurring the boundaries between the partner/lover and carer role, occasionally impacting upon their mental health [57]. Jeyathevan et al. [47] discuss the notion of ‘asymmetrical dependency’ that can have significant impact on caregivers’ wellbeing.

‘When he has a bowel accident in the middle of night and I have to clean up his shit, I hate it. I hate it so much. And I get... Like I am there trying to clean it up and put all the shit through the washing machine, thinking ‘Why the hell would I stay with this person?’ ‘What am I getting out of this?’ [Partner, 53, p. 294]

‘You go from 100% being a wife and mom...then all the sudden BOOM! Okay, now I am a nurse too’ [Partner, 5, p. 12]

Despite the perceived difficulty of caregiving, Kim and Kim's [53] paper discusses how some partners saw caring for their partner as a natural role to adopt post-SCI.

'It was just a natural thing to do. It was never like 'I thought I wouldn't do it'. It was just my job and it was my life' [Partner, 53, p. 293]

### *Changing Views of Intimacy*

Adjustments to intimacy and its definitions is another important theme. This reflects the adjustments required in both how intimacy is perceived and enacted in relationships.

*Expanding Definition of Intimacy.* Several participants spoke about the need to develop a more holistic notion of intimacy, encompassing both emotional and more traditional views of physical intimacy and penetrative intercourse.

'Meaning of sexuality? I guess how one feels or expresses their intimate feelings...it's not all about sex at all. For me it's more emotional.

[Sexuality is] the intimacy between two people...it's not defined by one particular act [intercourse]. Sexuality is everything from the intimacy between two people, their interactions, the different ways that they arouse each other and the different ways that they inspire each other in those intimate moments' [Person with SCI, 58, p. 5]

...Penetrative sex isn't everything. There's lots of ways to have sex [Partner, 57, p. 3]

For men, this often challenged their definition of masculinity and preconceptions of the roles they should adopt in their relationship, often contradicting views of maleness held in their communities.

‘...before my injury [I had] very specific stereotypes in my head where the man was supposed to be the strong one and the man was supposed to be the dominant persona, especially like in a sexual sense. Now, after my injury, I really can’t be the physical, dominating [person] in a sexual relationship and it plays into the way I actually feel about sexuality. And I don’t think there is any general way to look at how a man or women should act in this situation. I think everyone enjoys [sexuality] in a bunch of different ways’ [Person with SCI, 58, p. 6]

For some, this enabled them to reach a deeper, more enjoyable level of intimacy, fulfilment and connection with their partners.

‘I think that it [SCI] brought us closer. Instead of just having sex, it’s more loving, touching, squeezing... And I think that...added more to our relationship. Rather than just hopping in bed and jumping on one another, you know, you lay around or sit in the living room chair or whatever, and just pet and talk...and that gets *me* off just as much as *doing* anything’ [Person with SCI, 45, p. 49]

*Finding New Ways of Being Intimate.* Papers evidenced how participants experimented to find new ways of being intimate and close with their partners, in line with their expanding view of intimacy. Communication, trust, openness, connection, trial and error and flexibility were all deemed important in this process. For some, this also meant a shift in focus from their own pleasure to that of their partner, commensurate with a sense of making a continued contribution to their sexual bond.

‘I think the key is you have to have really good communication, you have to explain what your needs and wants are and limitations... There is more to sex than intercourse,

even just having good communication and being able to talk to each other about your fantasies, your dreams or whatever is really, really healthy' [Person with SCI, 59, p. 20]

'[Before SCI] I was just basically thinking about myself a lot of the time. And I think after my spinal cord injury I've also learned that your partner is very, very important to think about. And you can have a positive experience from your partner's reaction as well. [Sex] definitely doesn't feel the same as what it used to feel like, so I think it's very difficult for me to only focus on myself when it's very difficult for me to get to that point [climax] so I tend to focus I think more so on my partner' [Person with SCI, 58, p. 6]

Engblom-Deglmann and Hamilton [5] explain how some couples fail to experiment and connect in developing new forms of intimacy, approaching this need to adapt with stagnation and constriction. This is clear in several papers that reflect on SCI as a threat to current and future relationships, intimacy and the view of self as a sexual being.

'I think that not having strong sensations during sexual intercourse is a big problem for me. I have to guess where my boyfriend touches and kisses me. So, it makes me feel very tense and nervous. As a result, my muscles can become stiff and tight. And the sexual activity has to be finished prematurely' [Person with SCI, 52, p. 16]

'I hated the idea of feeling that I was being, not raped, but being used, you know, just lying there and – so, over time, we tried some other positions out. And it worked'  
[Person with SCI, 56, p. 1088]

### ***Line of Argument***

The overall line of argument [41], grounded in the ethnographic synthesis above, concerns whether living with SCI requires adjustments to adult attachments and intimacy in relationships and the mechanisms underlying these.

It is clear that adaptation and adjustment are needed in several domains following SCI. Although this is achieved to different degrees, it seems that communication, mutual support, openness and relationship security prior to injury are all important mechanisms in ensuring successful adaptation, creation of ‘new meanings’ of relationships and sharing of each other’s lives post-SCI [53].

Experiencing SCI requires changes to roles within relationships and thereby to attachments, with some of these appearing significant. Changes in roles pose challenges and threats to the identity of both partners, with possible blurring of lover-carer roles. It appears that the dependence of an individual with SCI on their partner can lead to some caregivers feeling increased pressure and stress, whilst the partner living with SCI may experience frustration and lack of independence and self-worth.

For some, experiencing SCI seems to strengthen the couple’s attachment, increasing their sense of togetherness as they face shared challenges and resulting adjustments as a team. Some participants seemed aware of the strength of their attachment and relational security prior to the injury, whilst for others the injury seemed to prompt awareness.

As evidenced, SCI provides an undoubted threat to intimacy and attachment. While some individuals and couples seem to have difficulties adapting, successful

adjustment appears to be based on developing a more holistic view of intimacy. This encompasses both emotional and physical intimacy and experimenting with new ways of being intimate. For many, establishing a new, expansive sense of intimacy seemed to challenge the traditional views of physical relationships, gender and sexuality held within their culture and previously, also, by themselves. However, it seems that developing a broader mutual understanding of sexual expression led to improved satisfaction with intimacy and romantic relationships. Moreover, for some, these adaptations led to higher levels of satisfaction and connection within their intimate relationship than was the case prior to injury, consistent with ‘appreciation’ as characteristic of post-traumatic growth [60-62].

An overarching emergent theme appears to be that of challenging traditional gender roles, norms and expectations regarding both roles and intimacy within relationships following SCI. It seems that openness to question these roles is important when considering couples’ adjustment to SCI within relationships.

## **Discussion**

This systematic review aims to synthesise research exploring the lived experience of **people** with SCI and their partners in relation to different elements of their partnership. It summarises existing qualitative research that considers the adjustments that may be required to adult attachment and intimacy following SCI but places its main focus on deriving some of the mechanisms that are behind these changes.

The systematic review yields three main themes: strengthening and maintaining adult attachment, changes in roles, and changing views of intimacy. These seem to

encompass other overarching themes of creativity through open communication, both in relation to roles and intimacy; joint coping and interdependence; and adjustments to identity, roles and responsibilities. Many narratives from papers included in the review also appear to be influenced by the constant threat posed by SCI and its implications to attachment and intimacy, as well as the role of cultural expectations and understanding in this process. This could be conceptualised as a threat to participation in various elements of life, including relationships, found to be common amongst individuals with SCI [63].

The importance placed by couples on maintaining adult attachment became clear during the review. While some couples reflected on the past strength that was inherent in their relationship, others felt that experiencing the joint challenge of SCI together strengthened their attachment. This is similar to research by Hellström et al. [64], Molyneux et al. [65] and Colquhoun et al. [66] emphasising the importance dyads placed on maintaining coupledness when one partner was living with dementia and to Weitkamp et al. [32] in regard to neurological and physical disability. Furthermore, Salmon and Young [67] discuss the importance of attachment relationships with healthcare professionals in providing a sense of safety when acquiring and living with an illness or disability. This may suggest that individuals re-evaluate their sense of relational security following SCI and its associated uncertainty. Immediately following injury, attachment relationships with healthcare professionals may offer perceived safety, while maintaining attachment to a partner allows couples to jointly negotiate challenges and develop new appreciation of their coupledness post-SCI. Chun and Lee's [68] research supports the notion of post-traumatic growth and strengthening of relationships following SCI - growth that is focused on factors such as a new



appreciation of life post-injury and valuing a strong and close relationship with their partner.

Many theories of dyadic coping place an emphasis on the importance of spouses facing challenges and coping together as an entity [70], thereby suggesting a reliance on existing attachment security. These include the notion of active engagement in relationship-focused coping [70] or the idea of common dyadic coping [71]. This echoes Gilad and Lavee's [31] description of support within a relationship during stressful periods fostering a greater sense of trust between partners, leading them to become committed to the further growth of the relationship. The theme of couples sharing common aims, support and interdependence in order to adjust to SCI is echoed in Gilad et al.'s [72], description of a 'reciprocal positive intention' (p. 461) central to dyadic support, in which both partners support each other.

Another theme is related to significant changes in roles and responsibilities for both partners post-SCI, possibly leading to a sense of loss of couple [53] and individual identity [73]. It seems that these role changes require significant adjustments within the couple relationship to re-establish or maintain successful role reciprocity [74]. Changes in roles may also cause changes to intimacy and the nature of attachment as one partner may adopt the role of caregiver and the other of care recipient (e.g. [39]). This source of stress and adaptation may lead to greater trust and growth within a relationship [31]. However, many papers described this as a potential challenge for the individual with SCI and their partner, leading to re-establishing relationship boundaries. These considerations often touched upon how traditional gender roles may be challenged by

SCI and associated change in roles and responsibilities. This may have been more evident in this systematic review due to the culturally diverse set of papers used. Several papers reflected the experiences of establishing broader views of intimacy and sexuality following SCI, encompassing both emotional and physical elements. Once again, this is thought to challenge socially-constructed views and expectations of intimacy and sexual relationships. Despite this, challenging **previously held** notions of sexuality brought increased satisfaction for some. This is in line with Pascoal et al. [75] who found emotional intimacy to be the main predictor of sexual satisfaction amongst 193 participants with sexual arousal difficulty. Štulhofer et al. [76] also found emotional intimacy to be related to greater sexual desire and satisfaction amongst a group of heterosexual men.

Studies also discuss the role of experimentation and creativity when adjusting to new ways of being intimate within relationships following SCI and when establishing new roles post-injury. However, it seems that a strong relationship is needed for this to happen successfully, whilst failure to adapt following SCI may lead to relationship difficulties [77]. The necessity of communication within a strong, supportive relationship is a recurring theme in many of the studies included. This is reflected in ideas such as those of Engblom-Deglmann and Hamilton's [5] of adjustment happening in relationships on a continuum from connection and flexibility to constriction and stagnation. The importance of a strong relationship that enables open conversation is consistent with communication models of dyadic coping that highlight openness, communication and engagement within relationships [69,74,78].

The social construction of sexuality, disability and gender roles seems to impact upon many themes included in this review. Sakellariou [46] tracks how the notion of disability has moved over time from being situated in the individual to being socially- and culturally-constructed. He discusses this in light of the idea that SCI can challenge **previously held** notions of gender roles and expectations regarding both domestic and sexual roles, often leading males to feel emasculated. This **concurs with** the findings of other papers. For example, Esmail et al. [79] found that societal stigma influenced the sexual identities of individuals with SCI and their confidence to engage in sexual relationships. Similarly, Potgeiter and Khan [80] discuss differences between the ways young people with SCI in South Africa saw themselves and how society viewed their sexuality. They conclude that socially-constructed limitations were greater barriers to stopping the adolescents from expressing their sexuality than the disability itself. This resonates with the World Health Organisation's (WHO) definition of disability as a dynamic interplay of health and wider societal and environmental factors that limit participation [81].

Many of the factors described above, including couples drawing on past or newly-formed relational strength, partners viewing their injury as a joint challenge and the process of developing and experimenting with broader views of intimacy, seem to be important mechanisms of change within adult attachment and intimacy following SCI.

### ***Strengths and Limitations***

This paper provides a comprehensive review of the lived experiences of 223 individuals with SCI and 95 partners, focusing on the adjustments needed to adult attachment and

intimacy following an injury of this kind. To the best of our knowledge, this is the first systematic review on this topic that synthesises qualitative papers from across the world to provide a culturally-diverse understanding of the processes and mechanisms underlying couple adaptation to SCI.

However, this review also has limitations. All papers include heterosexual couples exclusively, omitting an LGBTQ+ perspective. Furthermore, while the culturally-diverse nature of the papers allows global comparisons, many papers are culturally specific (e.g. [6,82]). This is considered a limitation as socially-constructed concepts central to this review are likely to be deeply rooted in the society and culture in which they are formed [24] in line with the WHO's definition of disability [81]. Many of the papers also address community settings and only consider the experience of those living with SCI at one time-point. This therefore limits pursuit of causality and means that a richer understanding of the experience of relationship adjustment following SCI in different settings and across time cannot be established.

All papers were critically reviewed using the CASP prior to inclusion in the study, leading to the omission of non-peer reviewed and reflective papers. Although this is important in upholding the review's quality, it also means that some important experiences from different perspectives may not have been included. The CASP can also be criticised: it does not sufficiently enable consideration of the theoretical basis or clinical implications of papers and does not provide an opportunity to form a more nuanced evaluation of the studies [49].

Meta-ethnography was used to synthesise the papers included in the systematic review. Meta-ethnography is an effective and commonly-used way of synthesising qualitative research [44]. However, it can also place significant pressure on the researcher due to its strong interpretative focus [83]. Consequently, it may have been beneficial to involve other members of the research team in elements of the systematic review analysis, such as checking each paper's themes, in order to increase methodological rigour. Meta-ethnography has also been criticised as lacking in consistent guidance on how to conduct the analysis [84], leading to a lack of transparent, high-quality reporting of meta-ethnographic studies [85]. The focus on researcher interpretation and a lack of consistent guidance may increase the risk that the views and experiences of the researcher might significantly influence interpretation of the data.

#### *Critical Appraisal of Papers*

Although all papers were rated of moderate to high quality with a sub-set of these papers rated separately by two individuals, it must be remembered that these ratings are largely subjective. The papers were heterogeneous in terms of their focus and participants, with some only including the views of individuals with SCI whilst others also considered the experiences of partners and other family caregivers. Although this allowed a wide range of experiences to be captured, it may mean that the papers lacked a joint consistent focus which may limit their generalisability and effected the overall coherence of the data.

Many studies lacked a reflexivity disclosure, raising questions about the potential impact of this on how they were analysed, interpreted and reported, as well as

the possibility of less awareness by researchers of possible unconscious biases about disability, gender and sexuality. Furthermore, a minority of papers [45,52,83] failed to provide adequate detail of the ethics of their research, which raises questions about the safety of participants and the possibility of replicating the research in the future.

Although the included papers referred to existing research when discussing their findings, very few linked these to any theories, with the exception of Engblom-Deglmann and Hamilton [5], Jeyathevan et al. [47] and Li and Yau [52] who used the results of their studies to develop their own models. This casts doubts as to the lack of theoretical grounding for the vast majority of the papers and increases the difficulty of locating the findings within a theoretical framework, testing theories and models and replicating the studies. Furthermore, some papers failed to consider their limitations (e.g. [6,46] or the wider implications of the research (e.g. [55]).

### ***Implications for Future Research***

Despite a growing body of qualitative research that looks at the impact of SCI on relationships, a deeper understanding is still required, particularly regarding non-sexual aspects of coupledness. Further psychological research on SCI, especially longitudinal studies, informed by relevant theories such as relational turbulence [54], adult attachment (e.g.[86,87]) and post-traumatic growth [60-62] would also be beneficial, especially in developing and synthesising existing research on the factors underlying the growth and strengthening of relationships post-injury and the processes underlying successful role reciprocity and communication after SCI. A better understanding of adjustments to relationships over time following SCI would enable a richer, longitudinal view to be established.

This study has suggested some possible mechanisms for successful change and adaptation within relationships following a SCI. These include communication and openness, partners showing each other mutual support, those in relationships facing the injury together and couples having a strong sense of relationship security prior to the injury. However, these are tentative suggestions. It would therefore be beneficial for future research to further build upon the results of the systematic review by using empirical findings to identify these mechanisms and to develop these further. It is hoped that, by gaining further insight into these possible mechanisms, it would be possible to use this information to promote the processes that seem to underlie the successful change and adaptation in relationships following SCI amongst couples living with an injury of this kind, as well as the possibility of developing instruments to measure this. This seems extremely pertinent given the apparent lack of theoretical underpinnings in the papers included in this systematic review, strongly advocating the need for further research to identify the process underpinning adaptation and adjustment in relationships following SCI.

Furthermore, additional studies looking at different ages, sexualities, ethnicities and relationship statuses would enable a more inclusive understanding, addressing wider perspectives and diversity. As many of the notions included in this review seem to be deeply rooted in cultural definitions, expectations and understanding, it follows that more research exploring individuals' experiences in specific countries and communities would enable a more reliable comparison of similarities and differences between cultures and contexts. However, it is acknowledged that this would also require greater researcher reflexivity.

### ***Clinical Implications***

This review strongly identifies the need for professionals to provide support to couples following SCI for both partners to develop and maintain strategies and mutual support that might enable them to better cope and adjust to SCI and its associated stressors, as suggested by Bodenmann et al. [88]. This support should be offered both immediately after injury and during subsequent years and should encompass several aspects of life and relationships affected by SCI – physical, psychological and existential [82].

Offering support to partners as well as individuals with SCI seems important as an injury of this kind affects both, with the support and understanding of the non-injured partner helping the individual with SCI [52]. Coupledness and mutual support is an important theme in this review. It is crucial that health professionals recognise this, with both partners seen as equal members within the adjustment process [40], in line with Kayser et al.'s [89] description of a 'we-disease' that impacts upon both members of a couple.

Many studies (e.g. [45,56]) emphasise the need to provide information and support focusing on both the physical and emotional aspects of intimacy to couples following SCI. This appears pertinent as improved sexual functioning has been found to increase quality of life of those with SCI [90]. This support should be client-centred but informed by an understanding of diversity. For example, Mona et al. [91] suggest that support should be offered with consideration to the societal and cultural narratives surrounding SCI, relationships and intimacy in the context of the WHO's definition of disability [81].

### ***Conclusion***



This review reflects the lived experiences of those living with SCI and their partners, highlighting the challenges that face many couples following injury. Jointly embarking on the process of adjusting to SCI can bring many couples together and strengthen their attachment. But adapting to an injury of this kind can also bring challenges. These include significant changes in role reciprocity, as well as needing to adapt to different ways of being intimate. However, these adaptations to attachment and intimacy seem to be played out against a background of socially- and culturally-constructed notions of disability, sexuality and gender roles. Many individuals with SCI report needing to challenge these to successfully adjust to their injury and maintain attachment and intimacy within their relationships (e.g. [46]).

The systematic review highlights the need for further psychological research into coupledom following SCI informed by relational models and theories. There is also a need for further research examining the impact of SCI on relationships using more heterogeneous, diverse samples. Following SCI, it is strongly suggested that both members of a couple should be offered appropriate evidence-based support to facilitate their adjustment, both individually and as a couple.

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***Declaration of Interest***

*The authors report there are no competing interests to declare.*

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