

School of Psychology Ysgol Seicoleg

## **Experiences of change and adjustment**

# within couple relationships following

# spinal cord injury

Thesis submitted in partial fulfilment of the requirement for

the degree of:

**Doctorate of Clinical Psychology (DClinPsy)** 

South Wales Doctoral Programme in Clinical Psychology

Cardiff University

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25<sup>th</sup> May 2021

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## Acknowledgements

My main and most important thanks go to all the individuals with spinal cord injury who volunteered to take part in this study. I feel very privileged that you chose to share your personal experiences and stories with me with such candour. Without you the study would not have been possible.

Thank you to my supervisor, Dr Jenny Moses, who has shared her expertise and passion for this field of research with me during the past few years. I'm extremely grateful for your encouragement and guidance.

I would also like to thank those who have supported with the research and recruitment process – the spinal cord injuries and support groups, Dr Gareth Thomas, Helen Thrussell, Michelle Donald and Dr Susanna Moss.

Thank you to all those who have supported me during the past few years. To my various placement supervisors who have been so encouraging and understanding and to my fantastic cohort for their support and humour. Thank you to my friends who have tried their best to understand what I do, but have nevertheless been their brilliant, supportive selves.

Finally, a massive thank you to my parents and Dorian for putting up with my stress, listening to my moaning and for their never-ending encouragement, support and belief in me. Diolch o waelod calon.

## Preface

All relationships negotiate changes and challenges over time. However, relationships may be especially challenged where one partner has faced a significant, life-changing spinal cord injury (SCI). The two papers composing this thesis focus on the experience of individuals living with SCI and address how romantic relationships may have to change and adjust to enable their maintenance post-injury.

Perhaps because SCI commonly affects sexual functioning, there are many research papers that examine the sexual aspects of relationships following SCI as a component of disability. However, the aim of this thesis is to establish a broader, psychologically-informed perspective of how individuals' experiences of SCI may affect their relationships more broadly. It is hoped that constructing a deeper understanding will inform development of appropriate support for those with SCI and their partners, aiding them to positively adjust and maintain their relationships following injury.

#### Paper one

The first paper considers the adjustments that may be required within relationships following SCI and how this may impact upon intimacy and adult dyadic attachment. Despite a growing body of literature researching the experiences of individuals and their partners following SCI and focusing on how injury may affect their relationship, including emotional and physical intimacy, there is a lack of synthesis of their findings.

This paper looks at how individuals living with SCI, and some couples, have experienced changes and associated adaptations to their relationships post-injury. A meta-ethnographic approach was used to synthesise 15 qualitative papers. The results revealed three master themes and six related super-ordinate themes that reflected the processes and changes within relationships, adult attachments and both emotional and physical intimacy following SCI.

The review findings showed that many aspects of their relationships required adaptation from both partners. Communication was of great importance as couples negotiated new roles, determined boundaries around caregiving and experimented to discover new ways of being intimate. The SCI and associated need for adjustment meant that some couples felt that their relationships became stronger as they faced challenges deriving from the injury as an entity rather than as individuals. However, other dyads had greater difficulty adapting. For many, the SCI seemed to threaten their attachment, bringing a constant danger of relationship breakdown. It seems that the experiences of many individuals were strongly situated within the way their culture viewed and defined disability, gender and relationships. In some cases, this appeared to make the adjustment process more complex and challenging.

The clinical implications of the synthesis suggest that both partners should be offered culturallysensitive, person-centred support, both immediately after the injury and in the years that follow. It is hoped that this will aid them to develop successful, relational processes of coping that focus on both partners' experiences, needs, hopes and abilities. This support should focus on all elements of romantic relationships, not just sexual functioning and physical intimacy.

#### Paper two

The second paper also adopts a qualitative approach to gather a rich understanding of the experiences of individuals who live with SCI. This paper considers the changes couples faced when one partner is living with SCI, as well as how relationships are maintained after injury. It looks at both the processes that may have helped adaptation and relationship maintenance and those that may have made this more difficult.

This paper consists of semi-structured interviews with nine people living with SCI, all of whom had partners. Four participants were female and five male. Some had been with their current partner at the time of injury whilst others had started their relationship post-SCI. Interpretative phenomenological analysis was used to analyse the data and four super-ordinate themes emerged.

These themes included the way in which relationships continue to develop and adapt following injury and how couples have to negotiate changes to roles and boundaries within their relationships. Another theme concerned how partners, faced with sexual function changes following SCI, need to experiment and adapt in order to maintain both physical and emotional intimacy. The final theme summarised some of the factors that those interviewed felt were most important for relationship maintenance.

The clinical implications of paper two included the need for both partners to be made aware of the support that is available to them after SCI. It is suggested that the focus of this support should be on guiding couples to develop greater flexibility and understanding within their partnership to enable them to better communicate, solve difficulties and approach and adjust to new roles and ways of being intimate following injury. It is hoped that this would support the maintenance of relationships after a member of a couple has experienced SCI.

## Paper 1

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

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Abstract and keywords word count: 209 Word count for remainder of paper: 8124 following corrections (excluding tables, figures and references)

Prepared in accordance with author guidance for the Disability and Rehabilitation journal (Appendix A).

#### Abstract

*Purpose:* Experiencing a spinal cord injury (SCI) can be life-changing for individuals and their families. Previous reviews have focused on coping and psychological adjustment, factors facilitating or impeding interpersonal relationships and sexual adjustment and sexuality following SCI. However, there is very little work synthesising 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 were searched for qualitative papers focusing on romantic relationships, attachments and intimacy following SCI. After removing duplicates, 15 of the 409 papers found met inclusion criteria. These were quality assessed and analysed using meta-ethnography.

**Results:** Three main themes emerged from the analysis: a) strengthening and maintenance of 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. Some experience these as positive, whilst the process of adaptation posed great difficulty for others. It is recommended that healthcare providers and others who support couples following SCI are aware of these processes and provide couples with appropriate support to negotiate challenges.

#### Keywords

Spinal cord injury; couple relationships; adult attachment; intimacy; adjustment; qualitative research; systematic review

#### Implications for Rehabilitation

- Experiencing SCI brings relational challenges and changes for individuals and their partners.
- Adjusting to SCI may require couples to re-establish roles and to broaden their definition of intimacy.
- Individuals with SCI and their partners should receive appropriate support to enable them to adjust to these changes during rehabilitation and thereafter.

#### 1. Introduction

Spinal cord injury (SCI) is life-changing and has an estimated global incidence of 930,000 people (James et al., 2019) with a rising annual rate of traumatic SCI (Furlan, Sakakibara, Miller & Krassioukov, 2014). Although each individual will experience SCI differently (Engblom-Deglmann & Hamilton, 2020), 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 (Chan, 2000). This has been shown to necessitate substantial adjustments for the individual with the SCI (Engblom-Deglmann & Hamilton, 2020), their partners and families, both in the short and longer term.

In her qualitative study of 20 individuals with SCI and their family caregivers, DeSanto-Madeya (2006) found several challenges and changes facing the families 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. These difficulties were found to be most pronounced in the early stages following injury (Boschen, Tonack & Gargaro, 2005). However, despite difficulties, couples also sought to adjust to their new circumstances, finding novel, positive ways of viewing their situation and attempting to create a new sense of normality (DeSanto-Madeya, 2006). The need for research adopting a more relational focus on the adjustment process following SCI is clear from Bertschi, Meier and Bodenmann's (2021) interpersonal description of how couples adjust where a partner has a chronic health impairment, including SCI.

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 (DeVivo, Hawkins, Richards & Go, 1995), with certain factors such as social integration or health perception found to be possible indicators of relationship difficulty following injury (Karana-Zebari, de Leon & Kalpakjian, 2011). Beauregard and Noreau (2010) 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, Ward, O'Brien, Allan and O'Carroll (2011) discuss the significant psychosocial impact on those who have experienced SCI, while Barrett (2018) 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 (Angel & Buus, 2011). 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 (Isaksson, Josephsson, Lexell & Skär, 2008). Dickson et al. (2011) 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. Ostrander, 2009). Understandably, as SCI can affect sexuality in numerous ways (Hess & Hough, 2012), this can have a notable impact on relationships for both those with SCI and their partners (DeSanto-Madeya, 2009; Eglseder & Demchick, 2017). Despite this, sex remains important for many individuals and couples following SCI (Singh & Sharma, 2005; Massoumi, Zarei, Razavi & Khoei, 2017). In their study interviewing 20 women with SCI, Fritz, Dillaway and Lysack (2015) 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. Sakellariou & Sawada, 2006). Furthermore, Beckwith and Yau's (2013) 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 (Amsters et al., 2016) and in supporting the individual with SCI to adapt to their injury (Kreuter, 2000). In their longitudinal study of people with SCI, Holicky and Charlifue (1999) found that marriage seemed to be linked with less depression and higher levels of well-being, life satisfaction and quality of life. Similarly, despite high prevalence of self-reported loneliness amongst those living with SCI and the detrimental effect this can have on depression and life satisfaction (Robinson-Whelen, Taylor, Feltz & Whelen, 2016), Guilcher, Craven, Bassett-Gunter, Cimino and Hitzig (2021) 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 (Roy & Andrews, 1999). 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 (Gilad & Lavee, 2010).

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' (Chopik, Edelstein & Grimm, 2019, 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 (Chopik et al., 2019). Attachment type is therefore proposed to play a role in people's behaviour and affect in relationships (Cassidy & Shaver, 2008). Chopik et al.'s (2019) longitudinal study found that attachment styles change during the lifespan, prompted by pivotal moments requiring adjustments or change (Gillath, Karantzas & Fraley, 2016). 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, 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, O'Dell, Davies and Rixon (2020) 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. However, although relational models have been used to consider the impact SCI may have on couple relationships (e.g. Ledbetter, Carr & Lynn, 2020), 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.

#### 1.1 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 recovery practice following SCI (e.g. Freeman, Cassidy & Hay-Smith, 2017) so that those who support individuals and their families will be better able to design interventions to promote positive adjustment for both partners.

#### 2. Materials and Methods

#### 2.1 Design

A meta-ethnography design (Noblit & Hare, 1988) 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 (Noblit & Hare, 1988; Britten et al., 2002). However, the original 'sense' of the papers is also maintained throughout the analysis (Noblit & Hare, 1988). Noblit and Hare's (1988) seven stages for conducting metaethnographic analysis were followed throughout.

#### 2.2 Search Strategy

Four databases were searched for relevant papers (Psycinfo, Medline, CINAHL and Scopus). These databases were chosen following discussion with the research supervisor and a librarian experienced in social science literature reviews. The search was conducted in July 2020 with the search terms focusing 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 March 2021. Table 1 outlines the search strategy used.

#### Table 1. Search strategy

Database	Search strategy
PsycINFO	(spinal cord injuries/ or hemiplegia/ or paralysis/ or paraplegia/ or quadriplegia OR ((spinal cord injur* or hemiplegia or paralysis or paraplegia or quadriplegia or cauda equina or tetraplegia).mp) AND (relationship satisfaction/ or marital satisfaction/ or relationship quality/ or marital relations/ or interpersonal relationships/ or attachment behaviour/ or interpersonal interaction/ or adjustment/ or coping behavior/ or intimacy/ or sexuality/ or sexual satisfaction or marital relation* or adult attachment or adjustment or intimacy or *sex* or sexuality or marital satisfaction or sensuality or sexual satisfaction or affection or affection. mp) AND (couples/ or spouses/ or partners/ or husbands/ or wives/ or dyads/ OR ((couple\$ or spouse\$ or partner\$ or husband\$ or wives or dyad\$).mp)
Medline	(spinal cord injuries/ or hemiplegia/ or paralysis/ or paraplegia/ or quadriplegia/ or cauda equina/ OR ((spinal cord injur* or hemiplegia or paralysis or paraplegia or quadriplegia or cauda equina or tetraplegia).mp) AND (interpersonal relations/ or adaption, psychological/ or social adjustment/ or family relations/ or social adjustment/ or sexuality/ or sexual behavior/ or sex/ OR (relationship satisfaction or relationship quality or marital satisfaction or marital quality or marital relation* or interpersonal relation* or adult attachment or adjustment or intimacy or sexuality or sexual satisfaction or sexual behavior or affection or sex).mp) AND (spouses/ OR ((dyad\$ or couple\$ or spouse\$ or husband\$ or wives).mp)
CINAHL	(spinal cord injuries/ or hemiplegia/ or paralysis/ or paraplegia/ or quadriplegia/ or cauda equina/ OR cauda equina syndrome/ OR ((spinal cord injur* or hemiplegia or paralysis or paraplegia or quadriplegia or cauda equina or cauda equina syndrome or tetraplegia).tw) AND (interpersonal relations/ or marital satisfaction/ or attachment behavior/ or dyadic adjustment scale/ or coping/ or intimacy/ or sexuality/ or sexual satisfaction/ or affection/ or sex/ OR ((relationship satisfaction or relationship quality or marital satisfaction or sex/ OR ((relationship satisfaction or relationship quality or marital satisfaction or sexual relation* or adult attachment or adjustment or intimacy or sexuality or sexual expression or sensuality or affection or *sex*).tw) AND (couples/ or marriage/ OR ((dyad\$ or couple\$ or spouse\$ or husband\$ or wives or partner\$).tw)
Scopus	("spinal cord injur*" or hemiplegia or paralysis or paraplegia or quadriplegia or "cauda equina" or tetraplegia).tw) OR (relationship W/2 satisfaction or relationship W/2 quality or marital W/2 satisfaction or marital W/2 quality or marital W/2 relation* or adult W/2 attachment or adjustment or intimacy or *sex* or sexuality or "sexual expression" or sensuality or sexual W/2 satisfaction or affection).tw) AND (couple\$ or spouse\$ or partner\$ or husband\$ or wives or dyad\$).tw)

#### 2.3 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.

2.3.1 Inclusion and Exclusion Criteria

The inclusion and exclusion criteria used to filter data are summarised in Table 2.

Table 2. Inclusion an	d exclusion criteria
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	Inclusion criteria	Exclusion criteria
Patient population	<ul> <li>Adults over the age of 18 with SCI (traumatic, non-traumatic and including cauda equina)</li> <li>Experience of partners of adults with SCI, as long as the experience of the person with SCI is also included in the study</li> </ul>	<ul> <li>Those under 18 years of age</li> <li>Those without SCI</li> <li>Studies only including the viewpoint of partners of individuals living with SCI</li> </ul>
Phenomena of interest	<ul> <li>Relationship with a romantic partner following SCI</li> <li>Changes to intimacy, adult attachment or partner relationships following SCI</li> </ul>	<ul> <li>Changes to other types of relationships following SCI</li> <li>Studies focusing solely on the physiological aspects of intimate relationships and sexual functioning or its remediation following SCI</li> <li>Studies focused on fertility and the impact of fertility treatment on intimate relationships following SCI</li> </ul>
Context	<ul> <li>Individuals negotiating changes to intimacy, adult attachment or partner relationships living at home</li> <li>Individuals negotiating these changes living in inpatient rehabilitation settings</li> </ul>	<ul> <li>Individuals living in settings other than their home or rehabilitation settings</li> <li>Individuals remaining in acute hospital settings after injury onset</li> </ul>
Study design	<ul> <li>Studies using qualitative designs and methodology</li> <li>Studies which have been subject to peer review</li> <li>Papers written in English</li> </ul>	<ul> <li>Studies using quantitative design and methodology</li> <li>Studies using mixed methodology where quantitative aims and objectives are primary and qualitative methods, analyses and results are reported to annotate and illustrate the quantitative findings</li> </ul>

## 2.4 Results of Search Strategy

Figure 1 is a PRISMA diagram (Page et al., 2021) summarising the process by which the 15 final papers were selected.

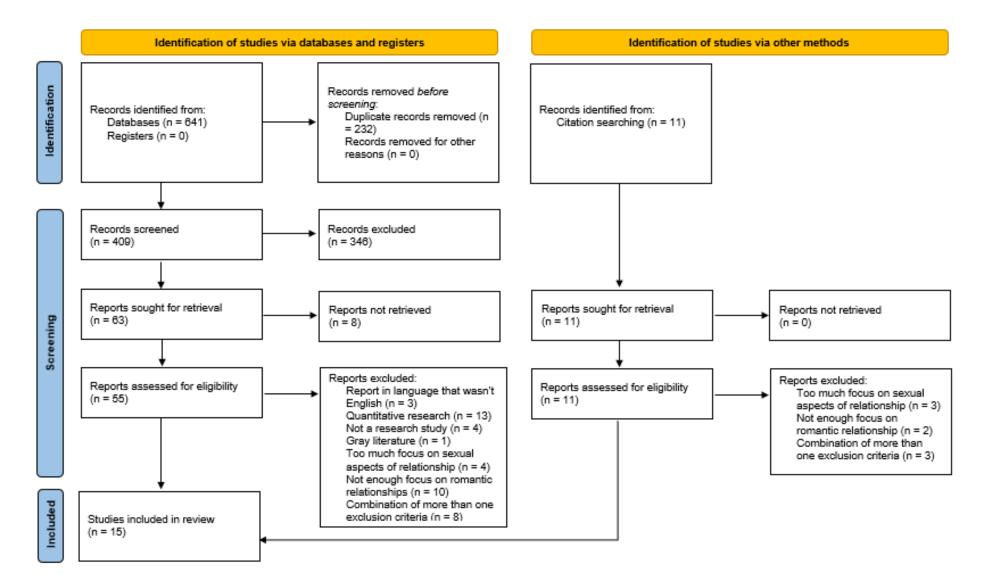


Figure 1. PRISMA Diagram

Following the electronic database search, 641 papers were retrieved. An additional 11 papers were found through searching the retrieved papers' reference lists. Of the papers found through the search of databases, the 409 papers remaining, after the removal of duplicates, were screened. Following the initial screening process, 346 articles not meeting the criteria detailed above were excluded and an attempt was made to locate 63 of the articles to read in full. Unfortunately, it was not possible to find eight of these. Of the 55 papers that were assessed for eligibility, a further 43 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 and therefore deemed to be 'grey literature' with uncertainty regarding whether or not it was peer-reviewed (as explained in Boland, Cherry & Dickson, 2017). This systematic review consists of 15 journal articles.

#### 2.5 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 2020. The data included in the papers was mainly collected in community settings across several countries. Thus, it represents a diversity of cultural experiences and associated views on couplehood, gender roles within relationships and the meaning of SCI. The vast majority of data was collected by interview, although one study (Leibowitz & Stanton, 2007) also included some written correspondence.

All papers included data clearly derived from the person with SCI, with some papers supplementing this with data provided by their partners. However, one paper also included qualitative data from other family caregivers (Jeyathevan, Cameron, Craven, Munce & Jaglal, 2019), whilst another (Li & Yau, 2006) included the experiences of both women with poliomyelitis and those with SCI. These papers have been included, as the data from those with SCI and their partners were clearly

delineated. It was therefore possible to ensure that this review only includes data from individuals with SCI or their partners. Two papers also included separate discussions of the same dataset (Sakellariou, 2006; Sakellariou & Sawada, 2006). Table 3 gives an overview of each paper's characteristics.

Paper	1. Angel, 2015	2. Angel & Kroll, 2020	3. Chan, 2000	4. Engblom-Deglmann & Hamilton, 2020	5. Freeman, Cassidy & Hay-Smith, 2017
Sample	9 married individuals with SCI	12 individuals with SCI, with additional data from 7 partners 2 years after injury	66 individuals with SCI and 40 spouses	11 couples where the male has SCI	5 married couples where the husband has SCI
Setting	Rehabilitation and community, Denmark	Community, Denmark	Community, Hong Kong	Community, USA	Rehabilitation units, New Zealand
Data collection, analysis and other additional details	<ul> <li>Narrative interviews</li> <li>Phenomenological- hermeneutic analysis</li> <li>Data collected over two years</li> </ul>	<ul> <li>Interview</li> <li>Phenomenological- hermeneutic analysis</li> <li>Secondary analysis of data collected over 10 years</li> </ul>	<ul> <li>Semi-structured</li> <li>interview</li> <li>Content analysis</li> </ul>	<ul> <li>Semi-structured</li> <li>interview</li> <li>Grounded theory</li> <li>analysis</li> </ul>	<ul> <li>Semi-structured</li> <li>interview</li> <li>Interpretative</li> <li>phenomenological</li> <li>analysis</li> </ul>
Participant details - gender, mean age and ethnicity	- 5 males, 4 females - Mean age 40-50 years	- 6 males, 6 females - Average age 40-50 at time of first interview	<ul> <li>Individuals with SCI, 13 females and 53 males, mean age 45.1 years</li> <li>Spouses 35 females, 5 males, mean age 41.2 years</li> </ul>	- 11 males and 11 females - All Caucasian	- 5 males and 5 females
Summary of overarching themes	Support of a partner aiding rehabilitation. Partner providing love, emotional and physical support and giving the injured partner hope for the future. Support can foster dependency.	Loss of sex life common following SCI. Although this can be re-established following injury, many challenges have to be overcome for this to happen.	SCI disrupts the usual, gender-based roles within a household. Inability to fulfil expected gender roles challenges males' self-esteem and masculinity. Partners need to discuss and agree on roles and responsibilities following SCI.	Constant need for adaptation following SCI. How couples adjust on a continuum from connection and flexibility to constriction and stagnation. This is the case for both actions and interactions.	The couple embarks on rehabilitation as a singular unit with mutual support for each other. This is not always acknowledged by healthcare professionals and can challenge the process of maintaining a relationship following SCI.

## **Table 3.** Summary of the characteristics of the journal articles included in the review

Paper	6. Jeyathevan, Cameron, Craven, Munce & Jaglal, 2019	7. Kathnelson, Kurtz Landy, Ditor, Tamim & Gage, 2020	8. Kim & Kim, 2020	9. Leibowitz & Stanton, 2007	10. Li & Yau, 2006
Sample	19 individuals with SCI and 15 family caregivers	6 men with SCI	9 couples where the male has SCI	24 women with SCI	10 women, 4 with polio and 6 with SCI
Setting	Community, Canada	Community, Canada	Community, Australia	Community, USA	Community, Hong Kong
Data collection and analysis	- Semi-structured interviews - Thematic analysis	<ul> <li>Telephone interview</li> <li>with standardised, open-</li> <li>ended questionnaire</li> <li>Descriptive</li> <li>phenomenology</li> </ul>	<ul> <li>Individual and joint</li> <li>interviews</li> <li>Descriptive</li> <li>phenomenology</li> </ul>	<ul> <li>- 21 structured interviews</li> <li>and 3 written responses</li> <li>- Content analysis</li> </ul>	<ul> <li>Semi-structured</li> <li>interviews</li> <li>Content analysis</li> </ul>
Participant gender, mean age and ethnicity	<ul> <li>Those with SCI, 13 male,</li> <li>6 females</li> <li>Family caregivers, 3</li> <li>males, 12 females (9</li> <li>spouses/partners)</li> </ul>	- 6 males - Mean age 41	- 9 males, 9 females - Mean age 58	- 24 females - Mean age 34.8 years	- 10 Chinese women - Mean age 40.8 years
Summary of overarching themes	Model of dyadic coping proposed illustrating how couples are on a continuum regarding their coping styles. These likely to contribute to a deterioration of the relationship or the rebuilding and maintenance of the relationship on three main areas of difficulty – adaptability, caregiver- care recipient traits and sex and intimacy.	SCI challenging commonly-held stereotypes and beliefs around sexuality, physical attractiveness and masculinity. Important to develop a more holistic and emotional sense of sexuality following SCI. Improving one's sex life following SCI thought to increase general quality of life and happiness.	SCI thought to be a 'biographical disruption' of couplehood. This leading couples to have to reconstruct and create new meanings of their partnership.	Ongoing process of developing a more holistic view of sexuality following the injury. This as part of a process of adapting to SCI.	Although sex and sexuality deemed important for women with physical disabilities, many have negative feelings regarding their sexuality and do not see themselves as sexual beings. Five-factor model proposed conceptualising the differing view of women regarding their sexuality.

Paper	11. Parker & Yau, 2012	12. Sakellariou, 2006	13. Sakelleriou & Sawada, 2006	14. Sunilkumar, Boston & Rajagopal, 2015	15. Thrussell et al., 2018
Sample	4 women with SCI	6 men with SCI	6 men with SCI	7 men with SCI	27 women with SCI
Setting	Community, Australia	Community, Greece	Community, Greece	Community, India	Community, UK
Data collection and analysis	<ul> <li>Semi-structured</li> <li>interviews</li> <li>Thematic analysis</li> </ul>	<ul> <li>Unstructured interview</li> <li>Heuristic</li> <li>phenomenological</li> <li>approach</li> </ul>	<ul> <li>Unstructured interview</li> <li>Heuristic</li> <li>phenomenological</li> <li>approach</li> </ul>	- Open-ended interview - Thematic analysis	<ul> <li>Semi-structured</li> <li>interviews</li> <li>Interpretative</li> <li>phenomenological</li> <li>analysis</li> </ul>
Participant gender, mean age and ethnicity	- 4 females - Average age 41.75 years	- 6 males - Mean age 40.3 years	- 6 males - Mean age 40.3 years	- 7 males - Mean age 41 - All Malayalam-speaking	- 27 females - Mean age 49.17
Summary of overarching themes	Reconstruction of sexual identity following SCI takes time. Those who have experienced SCI want to be recognised as sexual beings despite their disability.	Participants do not see the SCI itself as a barrier to sexual intimacy. However, cultural beliefs, social difficulties and the physical environment negatively effects the sex lives of those with SCI. Dependency at odds with the cultural expectations of independence in relation to masculinity and sexual relationships.	Most barriers to sexuality deriving from society and traditional notions of masculinity, disability and sexuality. Although participants able to fight against these views to reclaim their sexuality, some choose not to and hold on to these traditional definitions.	Although all partners wanted a healthy, satisfying sex life, this is difficult to achieve following SCI. Often there is a substantial gap between individuals' desire regarding sexual functioning and the reality of their situation. This can create emotional, social and physical isolation between partners.	Although women remained sexual beings following their injury, they felt an acute sense of loss around what had changed. Possible to have a sexual relationship following SCI, but this can be difficult as people's pre-injury relationships may have changed and difficulty forming new ones. Additional support and guidance needed during rehabilitation to support women with SCI to continue to have fulfilling sex lives.

#### 2.6 Quality Appraisal

The Critical Appraisal Skills Programme's (CASP) appraisal tool for qualitative research (Critical Appraisal Skills Programme, 2018) was used to review the quality of the 15 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.

The CASP was used prior to the final decision regarding which papers would be included in the review to ensure the exclusion of any of very poor quality (Boland et al., 2017). However, the researcher did not cross-reference CASP ratings during data extraction to avoid influencing the choice of data. The CASP was also used to gain a better understanding of the strengths, values and limitations of each paper. A reviewer independent to the study assessed a sub-set of the papers using the CASP to ensure reliability. There was 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 4.

The CASP is acknowledged to have several limitations. It lacks a scoring system, its implementation is subjective and it does not facilitate scrutiny of theory (Long, French & Brooks, 2020). It also fails to allow consideration of papers' clinical implications or broader relevance. Table 4 summarises the CASP ratings for the papers included in this review, based on Feder, Hutson, Ramsay and Taket's (2006) rating system. Here, two points are given to an answer of 'yes' on the CASP, zero points to an answer of 'no' and 1 to an answer of 'unclear'. 'Unclear' refers to a lack of or limited information to suggest whether or not the paper had reached the standards suggested by the CASP. As the tenth question on the CASP does not include a 'yes', 'no' or 'unclear' scoring system, a maximum score of 18 was given to the papers.

<b>Fable 4.</b> Quality appraisal based on the CASP (2018)			√ (yes)	X (no)	? (unclear)
Paper	1. Angel, 2015	2. Angel & Kroll, 2020	3. Chan, 2000	4. Engblom- Deglmann & Hamilton, 2020	5. Freeman et al., 2017
Was there a clear statement of the aims of the research?	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$
Is qualitative methodology appropriate?	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$
Was the research design appropriate to address the aims of the research?	$\checkmark$	?	$\checkmark$	$\checkmark$	$\checkmark$
Was the recruitment strategy appropriate to the aims of the research?	$\checkmark$	?	$\checkmark$	$\checkmark$	$\checkmark$
Was the data collected in a way that addressed the research issue?	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$
Has the relationship between researcher and participant been adequately considered?	Х	Х	Х	$\checkmark$	?
Have ethical issues been taken into consideration?	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$
Was the data analysis sufficiently rigorous?	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$
Is there a clear statement of findings?	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$
Score	16	14	16	18	17
How valuable is the research?	Relation to existing research and implications considered. Limitations and directions for future research not discussed.	Suggestions for healthcare provision, future research and limitations discussed. Existing research considered.	Implications discussed. No consideration of limitations, existing knowledge and further research.	Implications, future research and limitations discussed. Existing research considered.	Implications, future research and limitations discussed. Existing research considered.

Paper	6. Jeyathevan et al., 2019	7. Kathnelson et al., 2020	8. Kim & Kim, 2020	9. Leibowitz & Stanton, 2007	10. Li & Yau, 2006
Was there a clear statement of the aims of the research?	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$
Is qualitative methodology appropriate?	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$
Was the research design appropriate to address the aims of the research?	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$
Was the recruitment strategy appropriate to the aims of the research?	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$
Was the data collected in a way that addressed the research issue?	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$
Has the relationship between researcher and participant been adequately considered?	Х	Х	Х	?	$\checkmark$
Have ethical issues been taken into consideration?	$\checkmark$	$\checkmark$	$\checkmark$	?	?
Was the data analysis sufficiently rigorous?	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$
Is there a clear statement of findings?	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$
Score	16	16	16	16	16
How valuable is the research?	Implications, future research and limitations discussed. Existing research considered.				

Paper	11. Parker & Yau, 2012	12. Sakellariou, 2006	13. Sakellariou & Sawada, 2006	14. Sunilkumar et al., 2015	15. Thrussell et al., 2018
Was there a clear statement of the aims of the research?	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$
Is qualitative methodology appropriate?	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$
Was the research design appropriate to address the aims of the research?	?	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$
Was the recruitment strategy appropriate to the aims of the research?	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$
Was the data collected in a way that addressed the research issue?	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$
Has the relationship between researcher and participant been adequately considered?	Х	Х	$\checkmark$	Х	Х
Have ethical issues been taken into consideration?	?	$\checkmark$	$\checkmark$	?	$\checkmark$
Was the data analysis sufficiently rigorous?	?	$\checkmark$	$\checkmark$	$\checkmark$	?
Is there a clear statement of findings?	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$
Score	13	16	18	15	15
How valuable is the research?	Implications, future research and limitations discussed. Existing research considered.	Implications and links to existing research discussed and some consideration of transferability of findings. Areas of future research and limitations not mentioned.	Implications discussed. Limited consideration of areas of future research and transferability of findings.	Implications, future research and limitations discussed. Existing research considered. Some discussion around transferability.	Implications, future research and limitations discussed. Existing research considered.

#### 3. Results

#### 3.1 Synthesis

Noblit and Hare's (1988) seven phases for conducting meta-ethnographic research were followed throughout the analysis. After the papers had been read several times, each study's main ideas and metaphors were listed to allow translation between studies. Table 5 summarises each paper's main concepts. The papers' main themes seemed to be directly related and comparable to each other, allowing for 'reciprocal translation' (Noblit & Hare, 1988). The guidance and associated table described by Britten et al. (2002) was followed to sort the information and aid the translation process. This process yielded 16 sub-themes.

 Table 5. Main concepts and metaphors of the papers reviewed

Paper number and author	Main themes, concepts and metaphors
1. Angel, 2015	Partnership reinforcing past roles and values and inspiring hope; partner minimising own difficulties to support individual with SCI; partner meeting individual with SCI's needs allowing life to recommence; sharing problems and solutions; support bringing greater intimacy; support fostering dependence and vulnerability; challenges and 'lost life' for caring partner
2. Angel & Kroll, 2020	Strong relationship pre-injury predictive of strong relationship post-injury; change in roles bringing loss for both partners; exploring new ways of being intimate
3. Chan, 2000	Cultural norms influencing decision to remain in relationship; power of love in maintaining relationships; injury strengthening relationship; caregiving burden; carers not from choice; renegotiating and re-establishing roles; mutual understanding and support; sacrificing to maintain relationship; duty and responsibility of caring; dependency; loss of roles
4. Engblom-Deglmann & Hamilton, 2020	Adjusting together; emotional support and connection (or not - stagnation); negotiating and re-negotiating care needs; carer juggling roles; burden of support; challenging traditional gender roles; frustration of being cared for and threat to independence; experimenting with and developing new ways of being intimate (or not – stagnation); expanding view of intimacy and sexuality; external support to maintain role as partner, not carer; loss of roles and masculinity; experimenting to new roles; caregiving but not from choice
5. Freeman et al., 2017	Shared experience, meaning and adjustment; mutual support; finding what works; discovering new ways of being close and intimate; expanding views of intimacy; injury strengthening intimacy; health professionals not always acknowledging couple as a team
6. Jeyathevan et al., 2019	Protective buffering compared to openness; difficulty adapting and accepting; caregiver burden and asymmetric support; carers losing identity and freedom; change in roles impacting relationship; juggling different roles; negotiating roles; increased creativity when being intimate; adjusting to create a new normal
7. Kathnelson et al., 2020	Expanding views of sexuality and intimacy; changing focus of intimacy and sexual pleasure

8. Kim & Kim, 2020	SCI a shared challenge; maintaining interdependency; SCI giving new perspective on life and relationship and
	strengthening attachment; no benefits of caring role; negotiating roles and expectations and challenging traditional
	gender roles; injury threat to traditional gender roles and independence; role of external carers; caring a burden, duty
	and/or choice; caring a threat to previous roles and identity
9. Leibowitz &	Viewing intimacy and sexuality in a holistic sense and this can enrich relationship; improvising, experimenting and
Stanton, 2007	adapting to new ways of being intimate
10. Li & Yau, 2006	Obligation to remain in a relationship; injury challenging view of self and bringing loss of past identity and role; exploring
	and changing to focus of intimacy; support, openness and understanding from partner regarding limitations (or not);
	power of love in relationship maintenance; injury challenging traditional gender roles
11. Parker & Yau,	Unconditional love and support; experimentation, communication and creativity regarding intimacy
2012	
12. Sakellariou, 2006	Injury a threat to masculinity and independence; finding new ways of being intimate
13. Sakellariou &	More inclusive definition of sexuality; experimenting with intimacy and not having to conform to a traditional model of
Sawada, 2006	sexual relationships
14. Sunilkumar et al.,	Difficulty adjusting to being cared for; loss of roles; negotiating new roles and responsibilities; finding other ways of being
2015	intimate
15. Thrussell et al.,	Varying degrees of communication and honesty between couples; balancing lover-carer roles; being cared for a threat to
2018	independence and equality; greater emphasis on emotional intimacy; experimenting with intimacy; wider view of sex and
	intimacy

Phase six of Noblit and Hare's (1988) guidance focuses on synthesising the translations to create a broader understanding of the constituent parts derived from the papers. The sub-themes formed in phase five were placed under six super-ordinate themes focusing on the possible adjustments to intimacy and adult attachments within relationships following SCI in relation to three main areas – roles within the relationship, intimacy, and how adjustment can strengthen relationships. Table 6 shows how one of the super-ordinate themes and related sub-themes were formed, while Table 7 provides further details of these master, super-ordinate and sub-themes.

**Table 6.** An example of how the superordinate theme 'We' and its associated sub-themes wereformed.

Sub-theme	Paper	Theme, concept or metaphor	
	Angel, 2015	Sharing problems and	
		solutions	
	Jeyathevan et al., 2019	Protective buffering compared	
Communication		to openness	
	Thrussell et al., 2018	Varying degrees of	
		communication and honesty	
		between couples	
	Chan, 2000	Mutual understanding and	
		support	
Interdependence	Engblom-Deglmann &	Emotional support and	
	Hamilton, 2020	connection	
	Freeman et al., 2017	Mutual support	
	Kim & Kim, 2020	Maintaining interdependency	
	Engblom-Deglmann &	Adjusting together	
	Hamilton, 2020		
Shared experience	Freeman et al., 2017	Shared experience, meaning	
		and adjustment	
	Kim & Kim, 2020	SCI a shared challenge	

Master theme	Super-ordinate	Sub-theme	Relevant papers
	theme		
Strengthening and	Reasons for	<ul> <li>New strengths and</li> </ul>	1, 2, 3, 5, 8, 10, 11,
maintaining adult	maintenance	perspectives	15
attachment		- Power of love	
		<ul> <li>Duty/obligation</li> </ul>	
	'We'	- Communication	1, 3, 4, 5, 6, 8, 15
		- Interdependence	
		- Shared experience	
Changes in roles	Negotiating new roles	- Finding what works	1, 2, 3, 4, 5, 6, 8, 10,
		- Challenge to and loss	12, 13, 14, 15
		of past identity	
		- Adjusting to external	
		carers and support	
	Caregiving	- Challenges of	1, 3, 4, 6, 8, 15
		caregiving	
		- Duty	
Changing views of	Expanding definition	- More holistic view of	4, 5, 7, 9, 13, 15
intimacy	of intimacy	sexuality	
		- Focus on emotional	
		intimacy	
	Finding new ways of	- Experimenting with	2, 3, 5, 6, 7, 9, 10,
	being intimate	intimacy	11, 12, 13, 14, 15
		- Adapting to new ways	
		of being intimate	
		- Communication	

Table 7. Master, super-ordinate and sub-themes and associated papers

Noblit and Hare (1988) state that each researcher will synthesise data differently based on their interests, values and position. Although it is impossible to avoid this potential bias (Ahern, 1999), the researcher tried to make themselves aware of these possible influences by keeping a reflective diary and adhering to Ahern's (1999) guidance on reflexive bracketing.

#### 3.2 Master Themes and Super-Ordinate Themes

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

#### 3.2.1 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.

**3.2.1.1 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' (Chan, 2000, 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' (Freeman et al. 2017, p.440)

Many papers suggest 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' (Li & Yau, 2006, p. 9) Although a less common theme, it seems that a sense of duty or obligation, rather than 'the power of love' (Chan, 2000, 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 (Chan, 2000; Li & Yau, 2006).

**3.2.1.2 'We'.** A theme in seven of the papers 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 (2017) study reflected how couples saw themselves as an entity navigating a shared experience together following SCI. Couples also referred back to their 'relationship biography' (Kim & Kim, 2020) 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' (Kim & Kim, 2020, p. 295)

Interdependence seems to be an important part of encountering this shared challenge. Engblom-Deglmann and Hamilton (2020) 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...' (Engblom-Deglmann & Hamilton, 2020, 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...' (Kim & Kim, 2020, p. 296)

Three papers discuss communication, one of the dimensions of relational turbulence theory (Solomon, Knoblock, Theiss & McLaren, 2016). Although a less common theme, 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 (Angel, 2015; Jeyathevan et al., 2019).

'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' (Jeyathevan et al., 2019, p. 6)

## 3.2.2 Changes in Roles

This theme reflects the pervasive change in roles following SCI and the need to adjust to these. It was evident in 12 papers.

**3.2.2.1 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' (Jeyathevan et al., 2018, p. 8)

Engblom-Deglmann and Hamilton (2020) 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' (Kim & Kim, 2020, 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' (Engblom-Deglmann & Hamilton, 2020, p. 13)

For participants in ten papers, the SCI and related adaptation significantly challenged their pre-injury identity. For many, 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' (Engblom-Deglmann & Hamilton, 2020, 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' (Kim & Kim, 2020, 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' (Thrussell et al., 2018, p. 1089)

Although a less common theme, three papers discuss the challenge for those with SCI and their partners of adapting to external support and the particular impact this had on intimacy and its expression.

'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' (Thrussell et al., 2018, p. 1088)

**3.2.2.2.** *Caregiving.* Six papers discuss 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. Jeyathevan et al. (2019) 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?' (Kim & Kim, 2020, p. 294)

'You go from 100% being a wife and mom...then all the sudden BOOM! Okay, now I am a nurse too' (Engblom-Deglmann & Hamilton, 2020, p. 12)

Despite the perceived difficulty of caregiving, Kim and Kim's (2020) 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' (Kim & Kim, 2020, p. 293)

## 3.2.3 Changing Views of Intimacy

Adjustments to intimacy and its definitions was a theme in 13 of the papers. This reflects the adjustments required in both how intimacy is perceived and enacted in relationships how intimacy is perceived and how it is enacted in relationships.

**3.2.3.1 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.

Joe: '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.

Will: [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' (Kathnelson et al., 2020, p. 5)

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' (Kathnelson et al., 2020, 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' (Leibowitz & Stanton, 2007, p. 49)

**3.2.3.2 Finding New Ways of Being Intimate.** Twelve of the papers reflect on 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 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.

'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' (Parker & Yau, 2012, 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' (Kathnelson et al., 2020, p. 6)

Engblom-Deglmann and Hamilton (2020) 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' (Li & Yau, 2006, 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' (Thrussell et al., 2018, p. 1088).

#### 3.3 Line of Argument

The overall line of argument summarises the discussion above in considering 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 (Kim & Kim, 2020).

Experiencing SCI requires changes to roles within relationships and thereby to attachments, with some of these appearing significant. For some, 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 (Tedeschi & Calhoun, 1996; 2004; Kalpakjian et al., 2014).

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.

# 4. Discussion

This systematic review aims to synthesise research exploring the lived experience of those living 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.

The systematic review yields three main themes: strengthening and maintaining adult attachment, changes in roles, and changing views of intimacy post-SCI. 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 (Fekete, Brinkhof, Tough & Siegrist, 2017).

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, Nolan and Lundh (2007), Molyneaux, Butchard, Simpson and Murray (2011) and Colquhoun, Moses and Offord (2019) emphasising the importance dyads placed on maintaining couplehood when one partner was living with dementia. Furthermore, Salmon and Young (2009) 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 couplehood post-SCI. Chun and Lee's (2008) 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 (Regan, Lambert, Falconier, Kissane & Levesque, 2015), thereby suggesting a reliance on existing attachment security. These include the notion of active engagement in relationship-focused coping (Coyne & Smith, 1991) or the idea of common dyadic coping (Bodenmann, 2005). This echoes Gilad and Lavee's (2010) 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, Lavee and Innes-Kenig's (2009) 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 (Kim & Kim, 2020) and individual identity (Dickson, O'Brien, Ward, Allan & O'Carroll, 2010). It seems that these role changes require significant adjustments within the couple relationship to re-establish or maintain successful role reciprocity (Siegrist, Tough, Brinkhof, Fekete & SwiSCI Study Group, 2020). 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. Ledbetter et al., 2020). This source of stress and adaptation may lead to greater trust and growth within a relationship (Gilad & Lavee, 2010). However, many papers described this as a potential challenge for the individual with SCI and their partner, leading to reestablishing 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, Narciso and Pereira (2013) who found emotional intimacy to be the main predictor of sexual satisfaction amongst 193 participants with sexual arousal difficulty. Štulhofer, Ferreira and Landripet (2014) 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. 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 (2020) 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 which highlight openness, communication and engagement within relationships (Siegrist et al., 2020; Regan et al., 2015; Wadham, Simpson, Rust & Murray, 2016).

The social construction of sexuality, disability and gender roles seems to impact upon many themes included in this review. Sakellariou (2006) 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 is similar to the findings of other papers. For example, Esmail, Darry, Walter and Knupp (2010) found that societal stigma influenced the sexual identities of individuals with SCI and their confidence to engage in sexual relationships. Similarly, Potgeiter and Khan (2005) 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 (WHO, 2011).

Many of the factors described above, including couples drawing on past or newly-found 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.

#### 4.1 Strengths and Limitations

This paper provides a comprehensive review of the lived experiences of 201 individuals with SCI and 81 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. Chan, 2000; Sunilkumar et al., 2015). 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 (Sakellariou & Sawada, 2006), in line with the WHO's definition of disability (2011). 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 very low-quality or reflective papers and grey literature. 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 (Long et al., 2020).

Meta-ethnography was used to synthesise the papers included in the systematic review. Metaethnography is an effective and commonly-used way of synthesising qualitative research (Boland et al., 2017). However, it can also place significant pressure on the researcher due to its strong interpretative focus (Campbell et al., 2011). 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. Further criticism of metaethnography includes a general lack of consistent guidance on how to conduct the analysis (Cunningham et al., 2019), leading to a lack of transparent, high-quality reporting of metaethnographic studies (France et al., 2014). The focus on researcher interpretation and a lack of consistent guidance may therefore suggest there is a risk that the views and experiences of the researcher may significantly influence the interpretation of the data.

#### 4.1.2 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 (Leibowitz & Stanton, 2007; Li & Yau, 2006; Sunilkumar et al., 2015) 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 (2020), Jeyathevan et al. (2015) and Li and Yau (2006) 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. Chan, 2000; Sakellariou, 2006) or the wider implications of the research (e.g. Angel, 2015).

#### 4.2 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 couplehood. Further psychological research on SCI, especially longitudinal studies, informed by relevant theories such as relational turbulence (Solomon et al., 2016), adult attachment (e.g. Bartholomew, 1990; Brennan, Clark & Shaver, 1998) and post-traumatic growth (Tedeschi & Calhoun, 1996; 2004; Kalpakjian et al., 2014) 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 this systematic review 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 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 further identify the processes 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.

#### 4.3 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, Falconier and Randall (2017). This support should be offered both immediately after injury and during subsequent years and should encompass several aspects of life and relationships effected by SCI – physical, psychological and existential (Sunilkumar et al., 2015). 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 (Li & Yau, 2006). Coupledom 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 (Freeman et al., 2017), in line with Kayser, Watson and Andrade's (2007) description of a 'we-disease' that impacts upon both members of a couple.

Many studies (e.g. Leibowitz & Stanton, 2007; Thrussell et al., 2018) 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 (Anderson, Borisoff, Johnson, Stiens & Elliott, 2007). This support should be client-centred but informed by an understanding of diversity. For example, Mona, Cameron and Cordes (2017) 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 (WHO, 2011).

#### 4.4 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. Sakellariou, 2006).

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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# Paper 2

# '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 and keywords word count: 187 Word count for remainder of paper: 8351 following corrections (excluding tables, figures and references)

Prepared in accordance with author guidance for the Disability and Rehabilitation journal (Appendix A).

#### Abstract

**Background:** 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 studying the formation, maintenance and adjustment of couple relationships post-SCI. This study uses a qualitative approach 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 was 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.

# Keywords

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 SCI that require adjustment, creativity, openness and negotiation of roles within romantic relationships.
- Both those living with SCI and their partners should be offered specialist support to aid this adaptation process, both shortly following injury and in subsequent years.

#### 1. Introduction

Spinal cord injury (SCI) can be life-changing for the injured individual and their families. Although each experience of SCI will be different (Engblom-Deglmann & Hamilton, 2020), it can be a significant source of stress within marital relationships (Chan, 2000) and can have marked psychological impacts on both partners (Angel & Buus, 2011; Dickson, Ward, O'Brien, Allan & O'Carroll, 2011). Research has shown negative effects on individuals' levels of distress and life satisfaction post-SCI (Post & van Leeuwen, 2012), while Krause, Newman, Clarke and Dunn (2017) found decline in satisfaction with sex and social life in the years following injury. DeVivo, Hawkins, Richards and Go (1995) discovered higher risks of marriage break-down following SCI, especially among certain population sub-groups (Karana-Zebari, de Leon & Kalpakjian, 2011).

Despite the reported negative impact on couple relationships post-injury, Holicky and Charlifue (1999) 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 (2017) also found those with SCI who had a partner were more likely to be employed two years post-injury. There seems to be great value in the support individuals receive from close relationships after SCI (Pearcey, Yoshida & Renwick, 2007). Partners are also thought to play an important role in adjustment and rehabilitation post-SCI, providing hope for the future (Angel, 2015; Kreuter, 2000).

A predominant theme in many studies has been changes to sex and physical intimacy following SCI (Hess & Hough, 2012; Earle, O'Dell, Davies & Rixon, 2020). SCI can disrupt individuals' sense of sexual identity (Li & Yau, 2006), challenging culturally-constructed views of sexuality (Kathnelson, Landy, Ditor, Tamim & Gage, 2020; Sakellariou, 2006; Sakellariou & Sawada, 2006). Although possible to reestablish physical relationships and sexuality following SCI (Angel & Kroll, 2020), this can take time and may be a challenging process (Parker & Yau, 2012; Thrussell et al., 2018). Sunilkumar, Boston and Rajagopal (2015) describe how differences between sexual desires and reality following SCI can cause relationship difficulties, while Kathnelson et al. (2020) and Fritz, Dilloway and Lysack (2015) discuss the need to establish a broader view of sexuality post-injury. The review by Earle et al. (2020) summarised these changes in sexual intimacy.

Changes have also been found in role reciprocity within relationships. Kim and Kim (2020) discuss challenges faced by both partners following SCI: those without SCI providing care and those 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 (Chan, 2000). Jeyathevan, Cameron, Craven, Munce and Jaglal (2019) describe the concept of 'asymmetrical dependency', describing unequal levels of dependency within partnerships. This concurs with Engblom-Deglmann and Hamilton's (2020) description of the difficulties of trying to balance independence and dependence following injury and the importance of negotiating roles post-SCI (Chan, 2000; Jeyathevan et al., 2019). Role changes within couples may also engender intimacy and attachment adjustments (Eglseder & Demchick, 2017; Ledbetter, Carr & Lynn, 2020) by changing partners' levels of dependence on each other.

Some researchers provide evidence that couples may re-value their relationships following injury (Chan, 2000; Freeman, Cassidy & Hay-Smith, 2017), consistent with the model of post-traumatic growth (Tedeschi & Calhoun, 1996; 2004; Kalpakjian et al., 2014). Engblom-Deglmann and Hamilton (2020) theorise that couples' adaptation to SCI can be conceptualised on a continuum from connection and flexibility to constriction and stagnation. Angel and Buus (2011) describe the possible steps underlying the adjustment process following injury, culminating in individuals finally feeling able to adapt to their life post-SCI. Jeyathevan et al. (2019) 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. (2019) 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 mentioned, research tends to focus on changes to sexual relationships following SCI (Ostrander, 2009) or on the impact on wider family relationships and networks (DeSanto-Madeya, 2009; Meade, Taylor, Manwitz & Thomas, 2004). Although some studies have addressed changes to romantic relationships following SCI, many of these are highly culturally specific (Chan, 2000; Sakellariou, 2006; Sakellariou & Sawada, 2006; Sunilkumar et al., 2015) or do not adopt a longitudinal view of the adaptation process, focusing on time spent in rehabilitation units immediately after injury (Freeman et al., 2017). 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. Regan et al., 2015). 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.

# 1.1 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 adapt and adjust to maintain quality and intimacy within partnerships 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.

#### 2. Materials and Methods

## 2.1 Design

Information was gathered from individuals with SCI using semi-structured interviews and analysed using Interpretative Phenomenological Analysis (IPA; Smith, 1996). 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 (Smith & Osborn, 2015; Willig, 2008).

## 2.2 Ethics

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

## 2.3 Recruitment

Posters publicising the study were posted on the social media accounts of SCI charities and groups in the UK and Ireland (Appendix D) and information also shared at a virtual global sex and disability conference. This enabled a snowballing method of recruitment as the study's information was widely shared on social media.

Those interested in participating were asked to contact the researcher to receive further information. They were then sent participant information sheets (Appendix E) and asked to opt-in if they wished to participate, providing the researcher with their preferred contact details.

## 2.4 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 at the height of 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.

# Table 1. Participant information

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

#### 2.5 Data Collection

Consistent with IPA methodology, data was collected in detailed semi-structured interviews, offering participants the opportunity to fully represent their experiences (Willig, 2008). The interview was devised following consideration of current research and consultation with individuals with SCI or working with those with SCI. An individual living with SCI also assisted in co-construction of the semistructured interview. The questions (Appendix F) 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 (Appendix G). Those consenting also completed a brief demographic questionnaire (Appendix H). Each interview was audio recorded (35 to 90 minutes) and followed by completion of an electronic version of the Dyadic Coping Inventory (Bodenmann, 2008; Appendix I) and the Dyadic Adjustment Scale-7 (Hunsley, Best, Lefebvre & Vito, 2001; Appendix J), further contextualising the sample.

Following interview, participants were given the chance to reflect on what was discussed and provided with a debrief form (Appendix K) 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.

## 2.6 Data Analysis

Although it has been argued that there is not solely one 'correct' way of doing IPA (Smith & Osborn, 2008), Smith and Osborn (2015) and Willig's (2008) 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.

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. This step is represented in column A in Appendix L.

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 (Appendix L).

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



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

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 (Appendix M). 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 & Osborn, 2015; Willig, 2008)

The author and main researcher is 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. Individuals living with SCI and a researcher who had previously researched a similar topic provided consultation on the study. 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 views throughout the research process, from recruitment to the analysis and reporting of data. As someone with limited knowledge of SCI and its impact on individuals and their families prior to beginning this research project, she was also aware of the information she had gained from background reading that discussed ways of coping with challenges within relationships that were either deemed effective or maladaptive. The researcher was aware that 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 extremely conscious of these potential biases throughout, using the reflective diary as a way of mitigating their possible influence on the research.

Various themes were noted when analysing transcripts, which were then clustered to create subthemes. Table 2 provides an example of the creation of the theme 'Increasing Strength and Confidence'. Subsequently, the sub-themes were synthesised to create master themes (Table 3). As IPA focuses on gathering rich accounts of individual experiences (Hale, Treharne & Kitas, 2007; Saunders et al., 2018), these were used to synthesise meaning rather than attempting to pursue saturation.

Participants were sent a copy of the sub- and master themes to check their suitability in describing client experience (Appendix N), in line with Lincoln and Guba's (1985) 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.

Participant	<b>Example of sub-theme</b> 'that was really tough, but I think from a relationship point of view, that brought us much closer'				
Amy					
Blake	'We're gonna have more stress with itbut I think it's also, I don't know if 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 firstand then when y 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'				

# Table 2. Creation of the theme 'Increasing Strength and Confidence'

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

Super-ordinate themes	Secondary themes	Participant Louise, John, Sarah, Neil, Blake, Emily			
Ongoing development of relationship	Learning and adjusting				
F	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			

#### 3.1 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.

## 3.1.1 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 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)

#### 3.1.2 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)

#### 3.1.3 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 reestablish 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).

## 3.2 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.

### 3.2.1 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.

#### 3.2.2 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)

#### 3.2.3 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 (Siegrist, Tough, Brinkoff, Fekete & SwiSCI Study Group, 2020). 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 it also meant a lack of privacy with "almost like a third person in the relationship" (Amy).

## 3.3 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.

3.3.1 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.

#### 3.3.2 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)

## 3.3.3. 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)

#### 3.4 Relationship Maintenance

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

#### 3.4.1 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)

### 3.4.2 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.

## 3.4.3 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)

#### 3.4.4. 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)

## 4. Discussion

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

During interviews, several changes and associated attempts at maintaining relationships through adjustment became clear. This concurs with Solomon and Theiss' (2011) 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 (2020, p.301). Cayless, Forbat, Illingworth, Hubbard and Kearney (2010) and Little, Paul, Jordens and Sayers (2002) 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 Butera-Prinzi, Charles & Story, 2016).

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 (Carr, Freedman, Cornman & Schwartz, 2014; Chandola, Marmot & Siegrist, 2007). However, some individuals described a sense of increased dependency on partners and worries about being 'a burden'. Altschuler (2015) 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 (Manne et al., 2004a).

This notion of responsiveness seems important in wider models of communication, such as the relationship intimacy model (Manne et al., 2004b; Manne & Badr, 2008) 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 (Solomon, Knobloch, Theiss & McLaren, 2016) suggestion that differing emotions and cognitive appraisals will be associated with couples' use of more or less open and aligned communication styles.

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 (1999). 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 (Pascoal, Narciso & Pereira, 2013; Štulhofer, Ferreira & Landripet, 2014). This echoes many participants' experiences of developing a more holistic sense of intimacy following SCI, focusing more on emotional closeness and physical touch.

Participants spoke about a joint process of relationship adaptation and maintenance, reflecting findings from other qualitative research exploring relationships following SCI (e.g. Freeman et al., 2017). The collaborative coping model (Berg et al., 2008) and the relationship coping-model's notion of active engagement (Coyne & Smith, 1991) 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 (Kuijer et al., 2000).

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 (Altschuler, 2015).

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. Frontera & Mollett, 2017; Riedman et al., 2020), 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. 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 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'. The differences in experience depending on whether or not a relationship had been established prior to injury concurs with Rolland's (1987) 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 (2003) 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 (2006, 2009) in their study of family caregivers and partners of individuals with SCI, and consistent with the notion of post-traumatic growth (Tedeschi & Calhoun, 1996; 2004; Kalpakjian et al., 2014). However, for others, SCI seemed to challenge couples' resources and relational supports, leading to difficulties.

#### 4.1 Clinical Implications

Clinically, many concepts discussed during the interviews seemed to resonate with principles of the Acceptance and Commitment Therapy (ACT) model (Hayes, Strosahl & Wilson, 1999). This therapy mode has preliminary evidence of its efficacy with SCI (Torabian, Sabet & Meschi, 2019) and a large evidence base supporting its use with difficulties related to SCI, such as chronic pain (Feliu-Soler et al., 2018; Hughes, Clark, Colclough, Dale & McMillan, 2017). 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 (Harris & Hayes, 2019). 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 (Gilbert, 2010; 2014) 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 (Gilbert, 2010), 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 (Gilbert, 2014), as has also been found in studies looking at SCI (Engblom-Deglmann & Hamilton, 2020). It is therefore possible that using CFT to

increase the soothing-affiliative system for individuals with SCI and their partners may be beneficial in increasing a sense of safety and connection with others, thereby reducing the strength of the threat and drive systems (Matos & Steindl, 2020). As the use of CFT has been found effective in reducing shame (e.g. Matos & Steindl, 2020), 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 (Berg & Upchurch, 2007). 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, Meier and Bodenmann's (2021) 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. (2016) also highlight the importance of supporting both partners to gain greater awareness of behaviours that reinforce relationships following SCI. Some of this support may derive from the ACT hexaflex (described by Harris & Hayes, 2019), 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. Parker & Yau, 2012). 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. (2021) 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.

#### 4.2 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 western countries, 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. Bertschi et al., 2021), a strong sense of partnership and coworking 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 way of analysing data. Although steps were taken to minimise this, it must be acknowledged that another researcher might have interpreted the data differently (Brocki & Wearden, 2006; Smith, Flower and Larkin, 2009). Furthermore, Tuffour (2017) 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. (2019), 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 in 2020 and early 2021, following several months of 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.

## 5. Conclusions

In conclusion, this study shows that couples are faced with several changes and challenges following SCI, requiring adjustment within relationships. Following injury, communication appears key to processes 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. These processes are in line with many psychological models of adjustment and growth.

Publishing the results of the study will aid healthcare professionals providing support to those who have experienced SCI and their partners to negotiate changes and maintain relationships, immediately after injury and in the years and decades that follow.

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# Appendices

# Appendix A. Disability and Rehabilitation journal guidelines for authors

# Aims and scope of the journal

*Disability and Rehabilitation* is an international multidisciplinary journal publishing on all aspects of disability, rehabilitation, and services for those who are handicapped.

*Disability and Rehabilitation* aims to encourage a better understanding of disability and to promote rehabilitation science, practice and policy aspects of the rehabilitation process. The journal provides an important forum for the dissemination and exchange of ideas amongst global health practitioners and researchers.

Disability and Rehabilitation covers a range of topics such as:

- Rehabilitation in practice
- Rehabilitation Policy
- Assessment procedures
- Education and training

*Disability and Rehabilitation* accepts quantitative and qualitative research papers, reviews, case studies, multidisciplinary perspectives, and letters.

#### Preparing your paper

All authors submitting to medicine, biomedicine, health sciences, allied and public health journals should conform to the Uniform Requirements for Manuscripts Submitted to Biomedical Journals, prepared by the International Committee of Medical Journal Editors (ICMJE).

We also refer authors to the community standards explicit in the American Psychological Association's (APA) Ethical Principles of Psychologists and Code of Conduct.

We encourage authors to be aware of standardised reporting guidelines below when preparing their manuscripts:

- Case reports CARE
- Diagnostic accuracy STARD
- Observational studies STROBE
- Randomized controlled trial CONSORT
- Systematic reviews, meta-analyses PRISMA

Whilst the use of such guidelines is supported, due to the multi-disciplinary nature of the Journal, it is not compulsory.

# Structure

Your paper should be compiled in the following order: title page; abstract; keywords; main text, introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s); figures; figure captions (as a list).

In the main text, an introductory section should state the purpose of the paper and give a brief account of previous work. New techniques and modifications should be described concisely but in sufficient detail to permit their evaluation. Standard methods should simply be referenced. Experimental results should be presented in the most appropriate form, with sufficient explanation to assist their interpretation; their discussion should form a distinct section.

Tables and figures should be referred to in text as follows: figure 1, table 1, i.e. lower case. The place at which a table or figure is to be inserted in the printed text should be indicated clearly on a manuscript. Each table and/or figure must have a title that explains its purpose without reference to the text.

The title page should include the full names and affiliations of all authors involved in the preparation of the manuscript. The corresponding author should be clearly designated, with full contact information provided for this person.

# Word count

Please include a word count for your paper. There is no word limit for papers submitted to this journal, but succinct and well-constructed papers are preferred.

# Style guidelines

Please refer to these style guidelines when preparing your paper, rather than any published articles or a sample copy.

Please use any spelling consistently throughout your manuscript.

Please use double quotation marks, except where "a quotation is 'within' a quotation". Please note that long quotations should be indented without quotation marks.

For tables and figures, the usual statistical conventions should be used.

Drugs should be referred to by generic names. Trade names of substances, their sources, and details of manufacturers of scientific instruments should be given only if the information is important to the evaluation of the experimental data.

# Formatting and templates

Papers may be submitted in any standard format, including Word and LaTeX. Figures should be saved separately from the text. To assist you in preparing your paper, we provide formatting template(s).

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#### Checklist: what to include

- Author details. Please ensure everyone meeting the International Committee of Medical Journal Editors (ICJME) requirements for authorship is included as an author of your paper. All authors of a manuscript should include their full name and affiliation on the cover page of the manuscript. Where available, please also include ORCiDs and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the article PDF (depending on the journal) and the online article. Authors' affiliations are the affiliations where the research was conducted. If any of the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after your paper is accepted. Read more on authorship.
- 2. A structured **abstract** of no more than 200 words. A structured abstract should cover (in the following order): the *purpose* of the article, its *materials and methods* (the design and methodological procedures used), the *results* and conclusions (including their relevance to the study of disability and rehabilitation). Read tips on writing your abstract.
- 3. You can opt to include a **video abstract** with your article. Find out how these can help your work reach a wider audience, and what to think about when filming.
- 4. 5-8 **keywords**. Read making your article more discoverable, including information on choosing a title and search engine optimization.
- 5. A feature of this journal is a boxed insert on **Implications for Rehabilitation**. This should include between two to four main bullet points drawing out the implications for rehabilitation for your paper. This should be uploaded as a separate document. Below are examples:

Example 1: Leprosy

- Leprosy is a disabling disease which not only impacts physically but restricts quality of life often through stigmatisation.
- Reconstructive surgery is a technique available to this group.

• In a relatively small sample this study shows participation and social functioning improved after surgery.

# Example 2: Multiple Sclerosis

- Exercise is an effective means of improving health and well-being experienced by people with multiple sclerosis (MS).
- People with MS have complex reasons for choosing to exercise or not.
- Individual structured programmes are most likely to be successful in encouraging exercise in this cohort.
- 6. **Acknowledgement**. Please supply all details required by your funding and grant-awarding bodies as follows: *For single agency grants*: This work was supported by the under Grant . *For multiple agency grants*: This work was supported by the under Grant ; under Grant ; and under Grant .
- 7. **Declaration of Interest**. This is to acknowledge any financial interest or benefit that has arisen from the direct applications of your research. Further guidance on what is a declaration of interest and how to disclose it.
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- 9. **Data deposition.** If you choose to share or make the data underlying the study open, please deposit your data in a recognized data repository prior to or at the time of submission. You will be asked to provide the DOI, pre-reserved DOI, or other persistent identifier for the data set.
- 10. **Supplemental online material.** Supplemental material can be a video, dataset, fileset, sound file or anything which supports (and is pertinent to) your paper. We publish supplemental material online via Figshare. Find out more about supplemental material and how to submit it with your article.
- 11. **Figures.** Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour). Figures should be saved as TIFF, PostScript or EPS files.
- 12. **Tables.** Tables should present new information rather than duplicating what is in the text. Readers should be able to interpret the table without reference to the text. Please supply editable files.
- 13. **Equations**. If you are submitting your manuscript as a Word document, please ensure that equations are editable. More information about mathematical symbols and equations.
- 14. Units. Please use SI units (non-italicized).

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# Declaration of Interest Statement

Please include a declaration of interest statement, using the subheading "Declaration of interest." If you have no interests to declare, please state this (suggested wording: *The authors report no conflicts of interest*). For all NIH/Wellcome-funded papers, the grant number(s) must be included in the disclosure of interest statement. Read more on declaring conflicts of interest.

# **Clinical Trials Registry**

In order to be published in a Taylor & Francis journal, all clinical trials must have been registered in a public repository at the beginning of the research process (prior to patient enrolment). Trial registration numbers should be included in the abstract, with full details in the methods section. The registry should be publicly accessible (at no charge), open to all prospective registrants, and managed by a not-for-profit organization. For a list of registries that meet these requirements, please visit the WHO International Clinical Trials Registry Platform (ICTRP). The registration of all clinical trials facilitates the sharing of information among clinicians, researchers, and patients, enhances public confidence in research, and is in accordance with the ICMJE guidelines.

# Complying with ethics of experimentation

Please ensure that all research reported in submitted papers has been conducted in an ethical and responsible manner, and is in full compliance with all relevant codes of experimentation and legislation. All papers which report *in vivo* experiments or clinical trials on humans or animals must include a written statement in the Methods section. This should explain that all work was conducted with the formal approval of the local human subject or animal care committees (institutional and national), and that clinical trials have been registered as legislation requires. Authors who do not have formal ethics review committees should include a statement that their study follows the principles of the Declaration of Helsinki.

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Please confirm that all mandatory laboratory health and safety procedures have been complied with in the course of conducting any experimental work reported in your paper. Please ensure your paper contains all appropriate warnings on any hazards that may be involved in carrying out the experiments or procedures you have described, or that may be involved in instructions, materials, or formulae.

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This journal uses ScholarOne to manage the peer-review process. If you haven't submitted a paper to this journal before, you will need to create an account in the submission centre. Please read the guidelines above and then submit your paper in the relevant Author Centre, where you will find user guides and a helpdesk. By submitting your paper to *Disability and Rehabilitation* you are agreeing to originality checks during the peer-review and production processes.

The Editor of *Disability and Rehabilitation* will respond to appeals from authors relating to papers which have been rejected. The author(s) should email the Editor outlining their concerns and making a case for why their paper should not have been rejected. The Editor may choose to accept the appeal and secure a further review, or to not uphold the appeal. In case of the latter, the Editor of *Disability and Rehabilitation: Assistive Technology* will be consulted.

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Authors are further encouraged to cite any data sets referenced in the article and provide a Data Availability Statement.

At the point of submission, you will be asked if there is a data set associated with the paper. If you reply yes, you will be asked to provide the DOI, pre-registered DOI, hyperlink, or other persistent identifier associated with the data set(s). If you have selected to provide a pre-registered DOI, please be prepared to share the reviewer URL associated with your data deposit, upon request by reviewers.

Where one or multiple data sets are associated with a manuscript, these are not formally peer reviewed as a part of the journal submission process. It is the author's responsibility to ensure the soundness of data. Any errors in the data rest solely with the producers of the data set(s).

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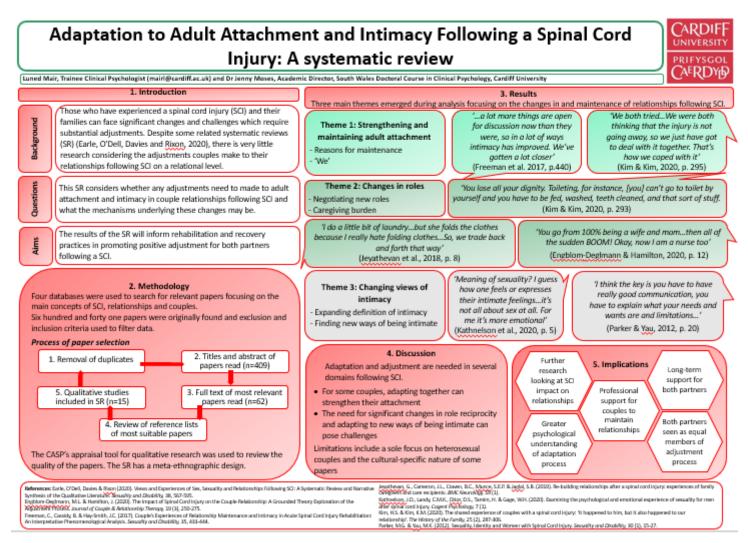
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https://www.tandfonline.com/action/authorSubmission?show=instructions&journalCode=idre20&u tm\_source=TFO&utm\_medium=cms&utm\_campaign=JPE14957 Appendix B. Poster presentation summarising the systematic review presented at the European Spinal Psychologist Association's E-Conference, 6.05.2021



#### Appendix C. Ethics Committee Approval Letter



School of Psychology Ysgol Seicoleg

17<sup>th</sup> April 2020

Cardiff University Tower Building, 70 Park Place, Cardiff, CF10 3AT, Wales, UK Tel +44(0)29 2087 4007 www.cardiff.ac.uk/psychology

Prifysgol Caerdydd

Adeilad y Twr, 70 Plas y Parc, Caerdydd, CF10 3AT, Cymru, DU Ffôn +44(0)29 2087 4007 www.cardiff.ac.uk/psychology

Dear Luned,

The Ethics Committee has considered your revised PG project proposal: How do couple relationships change and adapt following a spinal cord injury? (EC.20.01.14.5933R).

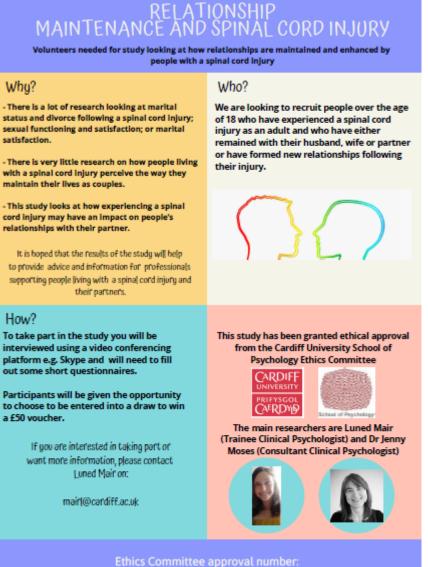
The project has been approved.

Please note that if any changes are made to the above project then you must notify the Ethics Committee.

Best wishes,

Adam Hammond School of Psychology

#### Appendix D. Recruitment Poster



EC.20.01.14.5933R

# Appendix E. Participant Information Sheet



School of Psychology Ysgol Seicoleg

South Wales Doctoral Programme in Clinical Psychology De Cymru Rhaglen Doethuriaeth mewn Seicoleg Glinigol



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#### PARTICIPANT INFORMATION SHEET

Title of project: How do couple relationships change and adapt following a spinal cord injury?

#### Introduction

I would like to invite you to take part in a research project that looks at how relationships change following a Spinal Cord Injury, and what people do to try to maintain their relationships when this happens.

Please take the time to read the information below carefully. This should help you decide whether you would like to give your consent to take part in the study. Please contact me using the details at the end of this information sheet if you have any questions.

The information below discusses why the research is being done and what participating in the study would involve.

#### Who is doing the study?

My name is Luned Mair and I am a Trainee Clinical Psychologist on the South Wales Doctoral Programme in Clinical Psychology. This study is being undertaken as a part of my course and has been ethically approved by Cardiff University.

The study is being supervised by Dr Jenny Moses, Clinical Psychologist, South Wales Programme in Clinical Psychology and Dr Susanna Moss, Clinical Psychologist, Cardiff and Vale University Health Board.

#### Why is this study being done?

I know that experiencing a spinal cord injury can have a big impact on several areas of people's lives. This study aims to focus on one of these areas – the effect of spinal cord injury on people's relationship with their husband, wife or long-term partner.

I plan to study how relationships with a partner may change following a spinal cord injury and whether this enables people to cope with the injury and its impact on their lives. I also hope to consider what couples do to maintain relationship quality after a spinal cord injury.

I will also be thinking about what works and what may not work to maintain quality and well-being in the relationships of those living with a spinal cord injury. I hope that this will help in providing advice and information for professionals supporting others living with a spinal cord injury and their partners.

# Who will be invited to take part in the study?

I am hoping to interview people over the age of 18 who have experienced a spinal cord injury and are living at home (rather than in a rehabilitation unit). Those who take part will need to have been in a romantic relationship for at least a year before they participate in the study.

I am aiming to speak to a maximum of 16 people about their experiences of living with a spinal cord injury and how this may have affected their relationship with their husband, wife or partner.

# Do I have to take part?

No. Participation is voluntary and it is entirely your choice whether you decide to take part or not. If you do decide to take part, you can change your mind and withdraw from the study at any time without giving a reason for this.

You are welcome to contact me if you have any questions about the study or taking part. Please take as much time as you need to consider whether you would like to participate in the research.

# What will happen if I decide to take part in the study?

If you decide to take part in the study, please complete the form that is enclosed with this information sheet and post it back in the stamped-addressed envelope provided. You can also e-mail it back if you prefer, using the address that's on the sheet. This will let us know that you consent to being contacted about the study. I would also be very grateful if you could complete the brief questionnaire asking questions such as your age, gender, relationship and history of spinal cord injury and return it to me with the form. This will allow me to have some basic information about the people who take part in the study.

If you return the form letting us know that you would like to be contacted, I will get in touch with you using your preferred contact method. This will be an opportunity for me to answer any questions you may have. If you choose to continue with the study, I will arrange a time for us to have a conversation over Skype or another secure video conferencing platform.

I will be contacting you to see whether you still want to take part in the study if we have not heard anything from you 3 weeks after you returned the form expressing your interest to take part. You will be able to let me know that you do not want to take part in the study at this point should you wish.

When we have a conversation over video, we will take some time re-reading this information sheet and you will have an opportunity to ask me any further questions you may have about the study. If you agree to take part, I will ask you to read and sign a consent form. This shows that you agree to take part in the study. If you consent to take part in the study, I will ask you some questions about your experience of living with a spinal cord injury, how this may have affected your relationship with your partner and what you do to cope with this. Following the interview, I will ask you to complete a brief questionnaire measuring your satisfaction with your relationship and how you and your partner cope with stress.

It is likely that the interview will last around 60-90 minutes inclusive of breaks, with an additional 30-45 minutes to complete the questionnaires and for me to answer any questions you may have, as described above.

# What will I be asked in the interview?

During the interview I will ask you questions about your experiences of living with a spinal cord injury, the impact this may have had on your relationship with your husband, wife or partner and how your relationships may have changed over time. If you have formed a relationship following your injury, I will ask about whether the injury may have affected your new relationship. I will also be interested in what you and your partner have done to try to cope with any stresses that you may have faced because of the spinal cord injury and what you think is important in creating and maintaining a good relationship following an injury of this kind.

I will be asking you questions about your relationship; however, you do not have to answer any questions that you do not want to. You will be welcome to take a break at any point during the interview, or can choose to withdraw from taking part in the research at any time.

The interview will be recorded using an audio-recorder. The audio recording will later be used to type up exactly what we spoke about during the interview. After the interview, there will be an opportunity for you to discuss any concerns you may have about taking part in the research. You can also ask me any questions you may have.

I may contact you again by e-mail or post following the interview to ask you for feedback on the themes that may have been found during the interviews. You do not have to take part in the feedback process and can choose to withdraw from the study at any time without giving a reason for this.

#### How will my information be used?

Either I or an independent transcriber will type up the interviews word-by-word. The transcriber is bound by rules of confidentiality and will not share any information heard when typing the interview.

After the interviews have been typed I will look at the interviews in more detail and will try to recognise any themes that may emerge. I plan to see whether those who have taken part in the research may have shared common themes, experiences or opinions about the topics discussed, or whether people may hold different opinions.

The themes that may be found in the interviews will be written up in a study report. Small sections of interview will be quoted in this report, but they will not be accompanied by any identifiable information. I will use made-up names (pseudonyms) next to the direct quotes used.

A full record of your interview may be included in the back of my report. Your name will not be included and I will remove any other details that could be used to identify you such as important dates and the names of people, places and services.

All audio recordings and typed up copies of the interviews will remain anonymous and the audio recordings will be deleted as soon as they have been typed. All copies of the interview will be stored securely in an electronic format. All consent forms and questionnaires will be stored in a locked filing cabinet. Your name and details will not be linked to your typed interview or your questionnaires. All written information collected during the research will be stored securely for 15 years.

As a part of my training, my supervisors will read anonymised sections of the interview to support me in writing my report. My supervisors will not see any names or identifying details.

# What if I decide I don't want to carry on with the study?

You can choose to withdraw from the study at any time, even if you have completed the interview. Please contact me at any point if you decide that you do not want to continue taking part in the study. We will then have a discussion about what you would like me to do with the information you may have provided by that point.

You have the right to ask for all information you may have provided to be destroyed. If you do so, we will no longer keep your information and this will not affect your current or future care in any way.

# What will happen to the information after the study report has been written?

I hope to publish the study report in an academic journal. I may also present the results of the study at relevant conferences. Anonymised quotes would be used in the publications and presentations and all identifiable details will be removed.

You would be welcome to read a full copy of the research report after it has been written. After the interview, you will be asked whether you would like to receive a summary of the study's findings as soon as it is ready.

#### What are the possible disadvantages of taking part?

You will be asked to give up to two-and-a-half hours of your time to participate in the interview and to complete the questionnaire.

The interview will be asking you about the experience of living with a spinal cord injury and the effect this may have had on your relationship. I am aware that these may be difficult, emotional and very personal topics to discuss.

You would be welcome to have a break at any time during the interview and do not have to answer a question if you are not comfortable in doing so. You can withdraw from the study at any time, without giving a reason for this. You are also welcome to bring someone with you to the interview if this would make you feel more comfortable.

After the interview, you will be given the opportunity to talk about the experience of being interviewed. You will also be able to talk about anything you found difficult about the interview

process and any thoughts and/or feelings you may have experienced when taking part in the research. You will be able to ask any further questions you may have about the study at this point.

# Will I get paid?

You will not receive any payment for taking part in the research. However, you will be given the choice of being entered into a prize draw for the chance of winning a £50 voucher.

# What are the potential benefits of taking part?

You may not find that taking part in the study benefits you directly. However, I hope that sharing your experience will help us to gain a better understanding of how spinal cord injury affects all aspects of people's relationships with their husband, wife or partner and what may or may not work in coping with these changes and in maintaining relationships over time.

I hope that this knowledge will be used by those working with people who have experienced a spinal cord injury to make positive changes to their clinical work and to provide useful advice and further guidance and support to people like yourself and their families.

# Will taking part in the study affect my treatment?

Your decision as to whether to take part in the study or not will have no impact on any medical treatment or on any support received from charities. It will not have any impact on access to medical care or the quality of treatment or clinical care of your health and wellbeing in living with a spinal cord injury.

# What if there is a problem?

If you have any concerns about the research, please contact me or my supervisor, Dr Jenny Moses, on the details below. You may also contact the Cardiff University Ethics Committee by e-mailing psychethics@cardiff.ac.uk or by phoning the main Cardiff School of Psychology phone number on 02920 874007 and asking for the ethics department.

# Will others find out that I am taking part in the study?

My supervisors and I will ensure that all the information you provide as a part of the study will be kept confidential. However, I will have a duty to break confidentiality if I am worried about your safety or the safety of others but I will, where possible, talk to you about this first before breaking confidentiality. In these circumstances, I would discuss any concerns I had about yours or others' safety with my research supervisors.

# Who is monitoring this study?

This study has been reviewed by a Research Ethics Committee. This is an independent group of people who ensure that your rights, safety and dignity are protected.

The study was reviewed and approved by the Cardiff University Research Ethics Committee on the 17<sup>th</sup> of April 2020, with amendments approved on the 14<sup>th</sup> of August 2020. My supervisors also regularly monitor the study.

# Thank you for taking the time to read this information!

# **Contact details**

Luned Mair (Trainee Clinical Psychologist) mairl@cardiff.ac.uk

Dr Jenny Moses (Clinical Psychologist) Academic Supervisor, South Wales Doctoral Programme in Clinical Psychology Jenny.Moses@wales.nhs.uk Telephone number: 02920 870582

# Appendix F. Semi-Structured Interview Questions

**Warm up question:** Can you tell me a little about your relationship e.g. how long have you been together? What was it that first attracted you? What do you think makes you a good team? Would you say you and your partner communicate well?

# Theme 1: How romantic relationship has been maintained and strengthened

Having lived with a spinal cord injury for a number of years, how do you think your relationship has adapted?

- Have there been any times when the SCI has got in the way/ has come between you?
- Have there been any times when you might have become closer because of it?

# Describe the role you feel you have in your relationship. Do you feel this has changed in the years since your spinal cord injury?

- What do you give to the relationship and what do you receive?
- How you think others would describe your relationship?

What do you feel has been the main strength of your relationship with your partner during the past year?

# Theme 2: Emotional intimacy

What do you and your partner do to try to maintain closeness in your relationship?

Living with an SCI, have there been changes in the way you and your partner express love and tenderness toward each other?

# Theme 3: Support

What do you and your partner do to support each other when faced with difficulties associated with living with a disability?

What are the main ways in which you and your partner have cared for each other during the past year?

• If you sometimes need physical 'hands on' care from your partner how do you keep that separate? Or how do you make it part of your romantic relationship?

# Theme 4: Post-traumatic growth

Has your view of romantic relationships changed since living with the spinal cord injury? If so, how?

Have you found that living with a disability has made you value different things in your romantic relationship? If so, how? What?

# Theme 5: Impact of living with the challenges of a spinal cord injury on the relationship

Can you tell me a little about how the spinal cord injury has affected your relationship during the past year?

Have there been times during the past year in which you feel that there has been difficulties in your relationship with your partner?

How do you and your partner cope with the challenges that you may face during your relationship?

# **Closing questions**

How do you see your relationship with your partner in the future?

What advice would you give a person who has recently sustained a spinal cord injury if they were worried about how they could maintain their relationship following the injury?

#### Appendix G. Consent Form



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# **CONSENT FORM**

Title of project: How do couple relationships change and adapt following a spinal cord injury?

Name of researcher: Luned Mair, Trainee Clinical Psychologist

E-mail: mairl@cardiff.ac.uk

**Address:** South Wales Doctoral Programme in Clinical Psychology, 11<sup>th</sup> Floor, School of Psychology, Tower Building, 70 Park Place, Cardiff, CF10 3AT.

Please initial each of the following statements if you agree:

1. I confirm that I have read and understood the information sheet dated (Version 1.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered to my satisfaction.

2. I understand that my participation is entirely voluntary and that I am free to withdraw at any time without giving reason. If I choose to withdraw from the study my medical care or legal rights will not be affected.

3. I understand that participation will involve my interview being audiorecorded, with possible use of anonymous word for word quotation in the research report. I consent for anonymous quotations of mine to be published in the research report.

4. I consent to completing two questionnaires:

a) measuring my satisfaction with my relationship









1	34

# b) measuring how my partner and I cope with stress in our relationship

5. I am aware that my data will be anonymised when my interview is typed up. This will either be done by the researcher or by a transcription service. I understand that my data will be kept in a secure location, away from any pieces of information that may identify me.

6. I consent to the interview being recorded and transcribed, either by the researcher or transcription services. I understand that the audio recording will be destroyed once they have been transcribed, but the transcriptions will be kept securely in electronic format for a period of 5 years.

7. I agree to take part in the above study.

Signed:	

Name printed: \_\_\_\_\_\_

Date: \_\_\_\_\_

For use of researcher

Researcher's name printed: \_\_\_\_\_

Date: \_\_\_\_\_







Appendix H. Demographic Questionnaire

# How do couple relationships change and adapt following a spinal cord injury?

Please complete the following questionnaire by writing your answer in the spaces provided or by ticking the appropriate box. The questionnaire asks for some basic details about you, your relationship and the spinal cord injury.

 1. Participant code

 2. Age

 18-30

 18-30

 31-40

 31-40

 41-50

 51-60

 61-65

 All the series of the series o

# 4. Length of current relationship

Female

Please give your answer in months and/or years

5. Marital status						
Married						
Civil partnership						
Unmarried						
6. Do you currently live with your partner?						

Yes

# 7. Gender of partner

Male

Female

**8. Length of time since spinal cord injury** Please give your answer in months and years, if possible

9. What is the level of your spinal cord injury?

10. Is your injury complete or incomplete?

Complete

Incomplete

# Appendix I. Dyadic Coping Inventory (Bodenmann, 2008)

# DYADIC COPING INVENTORY (DCI)

This scale is designed to measure how you and your partner cope with stress. Please indicate the first response that you feel is appropriate. Please be as honest as possible. Please response to all items by marking the appropriate case, which is fitting to your personal situation. There are no false answers.

# This section is about how you communicate your stress to your partner.

		very rarely	rarely	some- times	often	very often
1.	I let my partner know that I appreciate his/her practical support, advice, or help.					
2.	I ask my partner to do things for me when I have too much to do.					
3.	I show my partner through my behavior when I am not doing well or when I have problems.					
4.	I tell my partner openly how I feel and that I would appreciate his/her support.					

#### This section is about what your partner does when you are feeling stressed.

		very rarely	rarely	some- times	often	very often
5.	My partner shows empathy and understanding to me.					
6.	My partner expresses that he/she is on my side.					
7.	My partner blames me for not coping well enough with stress.					
8.	My partner helps me to see stressful situations in a different light.					
9.	My partner listens to me and gives me the opportunity to communicate what really bothers me.					
10	My partner does not take my stress seriously.					
11	My partner provides support, but does so unwillingly and unmotivated.					
12	. My partner takes on things that I normally do in order to help me out.					
13	My partner helps me analyze the situation so that I can better face the problem.					
14	When I am too busy, my partner helps me out.					
15	When I am stressed, my partner tends to withdraw.					

#### This section is about how your partner communicates when he/she is feeling stressed.

	very rarely	rarely	some- times	often	very often
<ol> <li>My partner lets me know that he/she appreciates my practical support, advice, or help.</li> </ol>					
<ol> <li>My partner asks me to do things for him/her when he has too much to do.</li> </ol>					
<ol> <li>My partner shows me through his/her behavior that he/she is not doing well or when he/she has problems.</li> </ol>					
<ol><li>My partner tells me openly how he/she feels and that he/she would appreciate my support.</li></ol>					

	very rarely	rarely	some- times	often	very often
20. I show empathy and understanding to my partner.					
21. I express to my partner that I am on his/her side.					
22. I blame my partner for not coping well enough with stress.					
<ol> <li>I tell my partner that his/her stress is not that bad and help him/her to see the situation in a different light.</li> </ol>					
<ol> <li>I listen to my partner and give him/her space and time to communicate what really bothers him/her.</li> </ol>					
<ol><li>I do not take my partner's stress seriously.</li></ol>					
26. When my partner is stressed I tend to withdraw.					
<ol> <li>I provide support, but do it so unwillingly and unmotivated because I think that he/she should cope with his/her problems on his/her own.</li> </ol>					
<ol> <li>I take on things that my partner would normally do in order to help him/her out.</li> </ol>					
<ol> <li>I try to analyze the situation together with my partner in an objective manner and help him/her to understand and change the problem.</li> </ol>					
<ol> <li>When my partner feels he/she has too much to do, I help him/her out</li> </ol>					

#### This section is about what you do when your partner makes know his/her stress.

# This section is about what you and your partner do when you are both feeling stressed.

	very rarely	rarely	some- times	often	very often
<ol> <li>We try to cope with the problem together and search for ascertained solutions.</li> </ol>					
<ol> <li>We engage in a serious discussion about the problem and think through what has to be done.</li> </ol>					
<ol> <li>We help one another to put the problem in perspective and see it in a new light.</li> </ol>					
34. We help each other relax with such things like massage, taking a bath together, or listening to music together.					
<ol> <li>We are affectionate to each other, make love and try that way to cope with stress.</li> </ol>					

# This section is about how you evaluate your coping as a couple.

	very rarely	rarely	some- times	often	very often
<ol> <li>I am satisfied with the support I receive from my partner and the way we deal with stress together.</li> </ol>					
37. I am satisfied with the support I receive from my partner and I find as a couple, the way we deal with stress together is effective.					

Appendix J. Dyadic Adjustment Scale-7 (Hunsley, Best, Lefebvre & Vito, 2001)

# APPENDIX. DAS-7

Most persons have disagreements in their relationships. Please indicate below the approximate extent of agreement or disagreement between you and your partner for each item on the following list.

- 1. Philosophy of life \_\_\_\_
- 2. Aims, goals, and things believed important \_\_\_\_
- Amount of time spent together \_\_\_\_

5	4	3	2	1	0
Always	Almost	Occasionally	Frequently	Almost	Always
Agree	Always	Disagree	Disagree	Always	Disagree
	Agree			Disagree	

How often would you say the following events occur between you and your mate?

- Have a stimulating exchange of ideas \_\_\_\_
- 5. Calmly discuss something together \_\_\_\_
- Work together on a project \_\_\_\_

0	1	2	3	4	5
Never	Less	Once or	Once or	Once a	More
	than once a month	twice a month	twice a week	day	often

7. The dots on the following line represent different degrees of happiness in your relationship. The middle point, "happy," represents the degree of happiness of most relationships. Please circle the dot which best describes the degree of happiness, all things considered, of your relationship.

0	1	2	3	4	5	6
•	•	•	•	•	•	•
Extremely Unhappy				Very Happy	Extremely Happy	Perfect

Note: The total score for the DAS-7 is the sum of the responses to the seven items.

# Appendix K. Debrief Form



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#### **Debrief Sheet**

Thank you very much for taking part in this study, it is very much appreciated.

The study aimed to look at how experiencing a spinal cord injury may change a person's relationship with their husband, wife or partner. I was interested in discovering how couples cope, support each other and maintain quality in their relationships following a spinal cord injury.

I hope that the results of the study will enable people supporting individuals living with a spinal cord injury to have a better idea of the types of changes that may happen in couple relationships following an injury of this kind, and the strategies people use to try to overcome these difficulties. It is hoped that the information gathered during the study will be used to further support individuals who have experienced a spinal cord injury, their partners and wider family.

#### **Further support**

It is possible that you may have found our conversation about the possible effects of spinal cord injury on your relationship with your partner a difficult one. This is understandable, and you may feel low or anxious after taking part in the interview.

Here are some suggested sources of support if you do feel low, upset or want to talk to someone:

- Talking to your friends and family may allow you to get some immediate support.
- Your GP may also be able to support you if you feel upset for a longer period of time than you feel comfortable with.
- There are also many charities that you may find useful to contact. Their details are in the resource pack given to you with this debrief sheet.

#### Contact

Please contact me on the details below if you wish to receive information about the results of the study. I will send you a summary of the results as soon as they are available. Please also contact me or my supervisor, Dr Jenny Moses, if you have any further questions about the study.

The data that you provided during the study will be held securely and anonymously. If you have any concerns regarding the research, please contact us on the details below. If you remain unhappy, you can contact Cardiff University on 02920 879131 or e-mail resgov@cardiff.ac.uk and can submit a formal complaint should you wish.

Thank you once again for taking part in this study.

Yours faithfully,

Luned Mair Trainee Clinical Psychologist Supervised by: Dr Jenny Moses Consultant Clinical Psychologist

# **Researcher:**

Name: Luned Mair Address: Doctorate in Clinical Psychology, 11<sup>th</sup> Floor, School of Psychology, Tower Building, 70 Park Place, Cardiff, CF10 3AT

Telephone number: 02920 870582 E-mail: mairl@cardiff.ac.uk

# Academic supervisor:

Name: Dr Jenny Moses Address: Doctorate in Clinical Psychology, 11<sup>th</sup> Floor, School of Psychology, Tower Building, 70 Park Place, Cardiff, CF10 3AT

Telephone number: 02920 870582 E-mail: Jenny.Moses@wales.nhs.uk **Appendix L.** Extract from analysis, including further information on the process of analysing the data (as also described in Figure 1). Information on the stages of analysis from Willig (2013).

Column A – preliminary thoughts, emergent themes and questions were noted. In some instances, this included comments on the use of language, the context of participant experience and descriptive comments. This is described in step 1 of figure 1.	Column B – original transcript	Column C – key emergent themes are noted, including the use of psychological terminology if appropriate. In this stage the experiences described in the transcript are captured. This is described in step 2 of figure 1.
	Um, yeah, I suppose it was a two-parter and if we think about intimacy first. So, did it take you a long time to sort of find out what works, I suppose, and explore what works or did it fall into place quite quickly? And, I suppose not just with intimacy but also with support and those sorts of boundaries around what you feel comfortable getting support with and what you don't.	
Enjoyment of establishing sexual relationship following injury. Use of complimentary adjectives. Casual relationship prior to injury – contrast to start of serious relationship post-injury.	Yeah, yeah, it fell into place really quickly. So, we had an intimate relationship really quickly, um, and it was gr-, it was amazing to, well, be with someone. You know, I, I was inum, like a very casual relationship, um, I was living in [country], so I was kind of seeing, um (talks to daughter), um Oh yeah, I was seeing, I was basically I wasn't really in a relationship. I was seeing a guy, kind of like a couple of guys, which sounds really	Intimacy important from the start. Enjoyment of establishing sexual relationship following injury.

Sounds outrageous – sense of self-judgement around behaviour prior to SCI.	bad, but it wasn't, it was like really, not, um, yeah, it was really casual. So, um, I wasn't really in a relationship, um, and then I broke my back and, um, and I don't like, even with both of these guys I'd only like kind of like been out on three or four dates with them or something (laughs). Sounds outrageous (laughs).	
'Weren't really relationships' – when does a casual relationship become a 'real' relationship?	Anyway! And, and then I broke my back. Tot-, like both of those relationships weren't really relationships, so it was nothing. I was, I had been, I had had a serious relationship about a year before that which I'd ended and I was, um, maybe still kind of in love with the guy. Um, but and, and kind of kept up with him I suppose.	
Starting relationship appearing to have been beneficial to overall adjustment and emotional wellbeing following injury. 'Exciting, fun, gorgeous guy' – painting positive picture. Injury happening at time when not thinking about a serious relationship, settling down etc.	Um, but, in terms of my relationship with [husband], I was in quite a low place and then I met him, and then it was all exciting and fun and, um, I'd met this gorgeous guy and all this stuff so, um, I guess I didn't really, and I was only 26, but I wasn't sort of, and at that stage of my life I wasn't thinking about particularly the future, I was just thinking about what's fun and what's, what's, what could happen now and, and Yeah,	Relationship helping with adjustment and coping following injury. Injury happening when not thinking about a serious relationship.

	and it was really sexy (laughs). So, um, that was really, really nice.	
Concerns of establishing relationship following injury and what sexual relationship would be like. Starting relationship seeming to be a relief following injury. Physical and emotional connection.	But I think that was quite important in my life and I remember thinking how am I gonna out-, am I gonna meet someone, um, and what's it going to be like, um, even what's sex going to be like, umespecially if I can't orgasm or feel stuff. Umyeah, and then I met him and it was really exciting and lovely, um, and nice and gentle and kind and everything else. Um, yeah, and I really fancied him, so that's good and it obviously worked both ways (laughs).	Concerns of establishing relationship following SCI. Physical and emotional attraction right from the start.
Knowing how much support to give. Matter of naturally knowing, without having to learn too much. Importance that understanding of SCI and what support is needed there from start?	Um, yeahand in terms of kind of support it was easy because he knew, because I met him on a, on a course, on one of these Backup courses and he, um, he knew, like he's, he's, he's just, he's just really easy to be around. So, he wasn't like	Not trying to help partner at the start – accepting SCI.
Husband having some understanding of SCI before meeting her. Not having to explain everything as a basis of understanding and knowledge there already. Off-putting to have to teach new partner about the injury and its effects?	trying to help me, he also knew about spinal cord injury, he'd spent time with, on these courses previously with other people who needed more support. So, he'd, um, like he, he knew about bowel problems, bladder and bowel problems and stuff. We didn't need to talk about any of that, which was nice. Um, yeah, I don't, in fact I'm trying to think because it was quite a long	Partner having previous understanding of SCI – not needing to explain things.

'Really positive memories about it' – starting relationship a positive, happy time. Minimising difficulties? Sense that it felt the right time to start a relationship after re-gaining own independence. Not wanting to be dependent on someone else.	memories about it. And it, and by that point I was transferring in and out of the car and quite able to do everything I needed to independently apart from putting my wheelchair in the boot, you know, it was, that was it, he just did that. Um, so, I didn't really have to ask him to do anything, and we were both living with our parents. I was living with my mum and he was livinghe'd just graduated, he was living with his parents. So, um	Establishing own independence before starting relationship. Importance of not having to ask partner for help.
Partner having to provide practical support when the environment isn't suitable for a wheelchair user. 'Wasn't really an issue' - idea that some types of care are OK and acceptable, whereas wouldn't be comfortable with others. Not a blanket rule, and this can be flexible.	Ah, at his parents I guess he had to help me. So, he had to like, when I met them, they've only got like an upstairs toilet so he had to carry me upstairs to the toilet. Still do-, still does usually. Umbut that wasn't really an issue, yeah.	Flexible care boundaries at time.

Appendix M. Example of summary table of themes from Burgess' interview

Main theme	Sub-theme	Line
Qualities	Communication	7, 40, 46, 51, 55, 271, 294, 347, 357, 378, 400, 407, 412
	Time together and apart	20, 21, 49, 78, 149, 155, 223, 275, 277, 299, 308, 318, 326, 351
	Complementary traits	36, 101
	Dealing with challenges	86, 92, 204, 219, 232, 256, 266, 354, 380, 385, 393
	Support	148, 295
	Affection	283
Roles	Flexible roles	26, 206, 209, 215, 222, 233, 239
	Learning to care	63, 111, 210
	Clear roles	141
Strength	Strength and confidence in relationship	30, 184, 370
	Couples as a team/shared life	74, 81, 175, 253, 254, 360
	Closer with adversity	159, 163, 183
Changes and challenges	Partner's concerns of establishing relationship	43, 288, 346
External support	SCI community	113, 120, 124, 129
	Family and friend support and acceptance	134, 136, 389
Intimacy	Intimacy in relationship from start	286
Normalising SCI relationship		138, 321
SCI always there	Constant part of relationship	61, 109
	SCI my normal	337
	Establishing understanding of self before relationship	70

# Appendix N. Document summarising themes sent to all participants



School of Psychology Ysgol Seicoleg

South Wales Doctoral Programme in Clinical Psychology De Cymru Rhaglen Doethuriaeth mewn Seicoleg Glinigol



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Thank you for taking part in our research project looking at how couple relationships change and adapt following a spinal cord injury. We really appreciate the time you took to participate in the interview and to complete the questionnaires.

As promised, here is some information about the study's results, how they will be shared and how we hope they may have some impact on the experience of others in the future.

#### What happened after the interview?

After I interviewed all the participants, I transcribed the interviews word-by-word and then went through each one looking for common themes, experiences and opinions. I then used a systematic research procedure to identify common themes shared by the interviews and to create overarching categories which fitted with the experiences described. This involved reading and re-reading the transcripts and thinking deeply about what they revealed.

The main themes I have derived from the data to answer the question 'How do couple relationships change and adapt following a spinal cord injury?' are summarised below. I would be grateful if you could read the themes and contact me if you feel I have totally misrepresented your experience. Although you may not feel that all themes apply to your experience of relationships following spinal cord injury, I hope I have succeeded in ensuring that the themes are appropriate and as relevant as possible.

#### Theme 1. Ongoing development of the relationship

This theme captures how relationships continue to change, adapt and adjust following an injury as couples have to deal with new challenges. These may or may not be related to the spinal cord injury itself. It also includes the idea that individuals and couples need to re-establish their identity following the injury and work to create a new version of themselves or their relationship. The increase in strength and confidence many felt in their relationship after overcoming difficult experiences is also a part of this theme.

#### Theme 2. Roles

This theme describes the loss and/or change of roles that may be felt following a spinal cord injury, meaning that the responsibilities of both partners within the relationship may change. This may also

lead to the need for couples to negotiate roles and responsibilities together, either after an injury or when starting a new relationship. It seems that the negotiation of roles can assist to establish clear boundaries e.g. who does what around the home or which elements of care and support a person with a spinal cord injury is happy for their partner to do. However, the interviews also revealed some possible difficulties and challenges commonly faced when trying to establish and negotiate new roles.

This theme also includes experiences of receiving care from a partner, as well as perspectives on how partners may feel about this. Finally, the possible benefits and difficulties that having carers may hold for a relationship is also specified.

# Theme 3. Intimacy

This theme encompasses physical, sexual and emotional intimacy. It outlines the changes that couples may experience in expressing intimacy following a spinal cord injury and the changes and challenges that this brings. It captures how couples report experimenting and making adjustments in order to maintain a sense of intimacy within their relationship. This may mean adapting to find new ways of being sexually intimate or adjusting the meaning of intimacy and how it is shown and experienced emotionally. It also includes the challenges some found in trying to maintain and/or re-establish intimacy following injury.

# Theme 4. Relationship maintenance

The final theme includes concepts that seem to be important in maintaining relationships, both in general and following a spinal cord injury. This includes communication and humour – the importance many felt in talking about and sharing difficulties and concerns, as well as the role of humour in talking about and dealing with situations that may be difficult or embarrassing. The theme of communication also thinks about what participants chose to share or not share with their partner.

Within this theme, support is also discussed. This encompasses mutual emotional support within the couple. It also includes the experience of some in using external support to help with maintaining, strengthening and adjusting either individually or as a couple following a spinal cord injury or other challenges. Negotiating time together and apart is another theme that emerged.

The idea of the couple as an entity is the final theme included here. 'We' or 'coupledom' evolved through facing and overcoming a spinal cord injury and associated challenges together. It also includes the idea of couples sharing values, hopes and focus.

# What will happen to the results of the study?

The research project is a part of a Cardiff University Doctorate in Clinical Psychology. This means that it will be submitted to be examined as a part of the course. However, we also plan to publish the study in an academic journal. We will contact the charities that have helped us with recruitment, such as the Backup Trust, to let them know what you helped us to discover.

# What are the implications of the study?

As a part of the study, we will be making some recommendations based on the data we collected. These recommendations are:

- That those who have experienced a spinal cord injury and their partners should have access to specialist support focusing on maintaining and/or establishing romantic relationships following injury should they wish.

- Support should be focused on the emotional aspects of relationships and intimacy as well as the more physiological, sexual aspects.

- Partners of those who have experienced a spinal cord injury should also be offered appropriate support following injury should they wish.

Thank you once again for participating in the study. Please do not hesitate to get in touch should you have any questions or corrections.

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# Appendix O. Summary sheet sent to spinal cord injury charities



School of Psychology Ysgol Seicoleg

South Wales Doctoral Programme in Clinical Psychology De Cymru Rhaglen Doethuriaeth mewn Seicoleg Glinigol



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Thank you for publicising our research project looking at how couple relationships change, adapt and are maintained following spinal cord injury. We really appreciate the time you took to advertise the study on your social media platforms.

Due to your support, we thought you might be interested in learning more about the study's results, how they will be shared and how we hope they may have some impact on the experience of those with spinal cord injuries and their partners in the future.

#### Main results of the study

This was a qualitative study in which nine participants took part in an interview. Each interview was transcribed and then analysed to derive common themes.

Below is some information on each of the main themes that emerged from the data to answer the question 'How do couple relationships change and adapt following a spinal cord injury?'

#### Theme 1. Ongoing development of the relationship

This theme captures how relationships continue to change, adapt and adjust following an injury as couples negotiate new challenges. These may or may not be related to the spinal cord injury itself. It also includes the finding that individuals and couples need to re-establish their identity following the injury and work to create a new version of themselves or their relationship. Many participants reported increased strength and confidence in their relationship after overcoming difficult experiences together.

#### Theme 2. Roles

This theme incorporates the loss and/or change of roles that may follow a spinal cord injury, meaning that the responsibilities of both partners within the relationship change. This may also lead to the need for couples to negotiate roles and responsibilities together, either after an injury or when starting a new relationship. It seemed that the negotiation of roles can lead to clear boundaries e.g. who does what around the home or which elements of care and support a person with a spinal cord injury is happy for their partner to do. However, some difficulties and challenges were also acknowledged when couples tried to establish and negotiate new roles.

This theme also includes participants' experiences of receiving care from a partner, as well as their perspective on their partner's views about this. Finally, the possible benefits and difficulties that having carers may hold for a relationship is also specified.

# Theme 3. Intimacy

This theme encompasses physical, sexual and emotional intimacy. It elaborates the changes that couples may experience in expression of intimacy following a spinal cord injury and the changes and challenges that this brings. It captures how couples report experimenting and making adjustments in order to maintain a sense of intimacy within their relationship. This may mean adapting to find new ways of being sexually intimate or adjusting the meaning of intimacy and how it is prioritised. It also includes the challenges some found in trying to maintain and/or re-establish intimacy following injury.

# Theme 4. Relationship maintenance

The final theme includes concepts that seem to be important in maintaining relationships, both in general and following a spinal cord injury. This includes communication and humour – the importance many felt in talking about and sharing difficulties and concerns, as well as the role of humour in talking about and dealing with situations that may be difficult or embarrassing. The theme of communication also explored what participants chose to share or not share with their partner.

Within this theme, the notion of support is also discussed. This encompasses mutual emotional support within the couple. It also includes some participants' experience of using external support to help with maintaining, strengthening and adjusting either individually or as a couple following a spinal cord injury or other challenges. Negotiating time together and apart was another component of which couples found valuable in relationship maintenance.

The idea of the couple as an entity is the final theme which emerged: 'We' as a couple facing and overcoming a spinal cord injury and associated challenges together and 'We' sharing values, hopes and focus.

# What will happen to the results of the study?

The research project is a part of a Cardiff University Doctorate in Clinical Psychology. This means that it will be written up and submitted to be examined as a part of this qualification. However, we also plan to publish the study in an academic journal. Please do not hesitate to get in touch should you require any further information about the study as relevant to your charity membership.

#### What are the implications of the study?

As a part of the study, we will be making some recommendations based on the data we collected. These recommendations are:

- That those who have experienced a spinal cord injury and their partners should have access to specialist support focusing on maintaining and/or establishing romantic relationships following injury should they so wish.

- Support should extend to the emotional aspects of relationships and intimacy as well as the more physiological, sexual aspects.

- Partners of those who have experienced a spinal cord injury should also be offered appropriate support following injury should they wish.

Thank you once again for supporting the study. Please do not hesitate to get in touch should you have questions, comments or dissemination queries.

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