

**Do partners of people that have acquired a spinal cord injury experience post-traumatic growth?**

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**Note to Reader**

The thesis is presented in three parts as described below, a literature review, research report and reflective paper. The literature review and research report are presented in the format required for submission to the specified peer review journals. Minor stylistic changes have been made to maintain consistency in the presentation and overall requirements of the thesis.

The literature review will be submitted to the Journal of Positive Psychology. The focus of the literature review was appropriate for the aims and scopes of the journal, hence this journal being selected for submission. The word limit for articles is 7,500 words. The submission details for this journal can be found in Appendix A.

The research report will be submitted to The Journal of Loss and Trauma. The focus of the research report was appropriate for the aims and scope of the journal; hence this journal was selected for submission. There is no predetermined word or page limit for articles submitted to the Journal of Loss and Trauma. The submission details for this journal can be found in Appendix B.

The reflective review presents a reflexive account of the research journey and discusses process issues. The review is written in the first person in order for the reader to comprehend and identify with the researcher's involvement in the research process.

Word Count: Less than 20,000 (Excluding references)



**Thesis Abstract**

Post-traumatic growth refers to the positive changes people can experience after a traumatic event, because of highly stressful life circumstances. Changes attributed to post-traumatic growth include changes in life philosophy, personal growth and more meaningful relationships. The person closest to an individual is often their partner, and whilst something is known about post-traumatic growth after a spinal cord injury, the experiences of partners of people with spinal cord injury are much less researched. This project aims to gain insight of the experience of post-traumatic growth for non-injured partners.

The literature review focuses on the experiences of post-traumatic growth when a partner has had a spinal cord injury. Published articles were identified, searched and critically appraised. The following themes emerged: burden of care, coping strategies, time for self and independence, communication, support, better relationships and leisure. The review highlighted a gap in the evidence base regarding the experiences of post-traumatic growth in partners of people who have had a spinal cord injury.

The empirical paper investigates this phenomenon. A qualitative methodology analysis, using interpretative phenomenological analysis (IPA), was conducted in order to explore the experiences of post-traumatic growth in partners of people who have experienced spinal cord injury. The themes were identified from an analysis of partner interviews. The implications for clinical practice are discussed.

Finally, the reflective review presents the researcher's experience of the research project throughout the process. The author offers a reflective account of the research journey, and discusses the issues that arose relating to ethics, confidentiality and power differentials.

The findings will be beneficial and of practical use to partners of people with spinal cord injury and health care professionals working in spinal injury settings. They will help professionals to understand this potential area of growth in order to benefit the families with whom they work.

**Literature Review**

**Do the partners of people that have acquired a spinal cord injury experience post-traumatic growth?**

**Abstract**

Spinal cord injury affects the individual and their partners (Chan, 2000b). A background examination of the quantitative literature highlighted that post-traumatic growth can occur following spinal cord injury and aid rehabilitation within the individual, these findings led to a review of the qualitative literature to investigate partner experiences of post-traumatic growth. The review revealed seven themes: burden of care, coping strategies, time for self and independence, communication, support, better relationships and leisure, and identified factors that can help facilitate and impede post-traumatic growth in partners of people with spinal cord injury. These were identified as being related through principles associated with post-traumatic growth and a process model was proposed about partner experiences. How the process of growth is experienced however, has not been fully investigated. This research has highlighted the need for further studies that will explore the process, experiences and factors that promote post-traumatic growth in individuals.

Keywords: post-traumatic growth; spinal cord injury; partners, spouses; literature review

## Introduction

### *Spinal Injury and the National Health Service (NHS)*

Within the United Kingdom (UK), spinal cord injury (SCI) affects an estimated 10–15 people per million of the population per year; there are around 40,000 individuals in the UK living with a traumatic SCI. Most injuries are in young men but the mean age of injury is increasing, including those injured over the age of 60 years (Royal College of Physicians, 2008). The National Service Framework for long-term conditions recommends an increased capacity for spinal cord injuries (Department of Health, 2005) within healthcare settings, so that more people can be offered short-term in-patient professional support, reducing the need for longer in-patient stays. People are often cared for at home by partners as an alternative to in-patient hospital care. It is therefore important to look at the wellbeing of partners in order to reduce long-term admissions to hospital.

According to the NHS spinal taskforce, to meet all of the needs of patients, spinal services need to go beyond the management of degenerative conditions and focus on trauma (Department of Health, 2010). The current UK best practice guidelines for the management of patients with SCI do not discuss the impact of SCI on partners', or their recommended involvement in after-care (British Association of SCI Specialists, 2005; British Orthopaedic Association, 2006; Spinal Injury Association, 2007; Royal College of Physicians, 2008). Given that a person's social network can have a significant impact on the way an individual adapts to their injury, there is a need to focus on significant others in an individual's rehabilitation (Kaiser & Kennedy, 2011). It is therefore important to focus on the post-traumatic experiences, not only of individuals who have experienced injury, but also the partners whose lives are also affected (Beauregard &

Noreau, 2010). So do partners of people that have acquired a spinal cord injury experience post-traumatic growth? This review will first consider alternative models to recovery and then look more closely at post-traumatic growth in partners in particular.

### *Adjustment and the recovery model*

Psychological adjustment refers to the psychological processes through which human beings manage or cope with the demands, challenges, and frustrations of everyday life (Weiten, Dunn & Hammer, 2011). Adjustment tends to be construed only in terms of affect and emotion, and key elements of adjustment have been identified as the presence of low negative affect and high positive affect (De Ridder, Keenen, Kuijer & Middendorp, 2008). In contrast, the recovery model emphasizes and supports an individual's potential for recovery. The focus is on experiencing improved quality of life and higher levels of functioning, in spite of mental health difficulties.

Anthony (1993) defines recovery as a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by the illness. It involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness. Recovery can be seen within the model as a personal journey requiring hope, a secure base, supportive relationships, empowerment, social inclusion, coping skills and ultimately finding meaning. The recovery model is holistic and embraces all aspects of life, including housing, employment, education, mental health and healthcare treatment and services. It is a model that is typically introduced in mental health services. The recovery model and adjustment described is distinctly different from post-traumatic growth. So what is post-traumatic growth?

*Definition of post-traumatic growth*

Post-traumatic growth refers to the positive changes experienced after an unforeseeable traumatic event. This growth after trauma arises from the struggle for meaning within the person themselves, through struggle with the reasons that the event occurred, and its aftermath (Tedeschi & Calhoun, 2004).

The idea that trauma and suffering can be possible sources of positive change can be seen in the ideas and writing of the early Hebrews and Greeks, as well as in teachings of all major religions (Tedeschi & Calhoun, 1996). Trauma research has traditionally focused on the negative symptoms resulting from trauma, with much of the literature detailing the severity and chronicity of symptoms and the development of psychological disorders (Joseph, Williams & Yule, 1993). In contrast, the individual's experience and the impact on the individual's identity and sense of self has been largely overlooked, which negates the impact of trauma on the very identity of the person (Wilson et al., 2001).

Core beliefs are integral to post-traumatic growth because they are the essence of how we see ourselves, others, the world, and our future (Janoff-Bulman, 1992). When core beliefs and schema are challenged, people are thrown into disarray; lives can appear inconsistent and unpredictable. This shattering of one's core beliefs and the 'self' generates a search for meaning about events which can drive the person to question, reformulate and reconstruct their very basic core beliefs (Janoff-Bulman, 1992). Following a trauma existing schema are challenged, and through cognitive processing and restructuring the trauma is incorporated into new schema that are therefore resistant to future shocks. The person experiences these challenges as growth, integrating reactions and cognitions about the past with the new schemas that emerge through this

ruminative process. This allows an acceptance of traumatic events and a renewed outlook for the future and oneself. So does post-traumatic growth involve psychological processes distinct from those seen in adjustment and recovery?

***Adjustment, the recovery model and post-traumatic growth***

Post-traumatic growth and traditional models of psychological adjustment are thought to be independent processes. Post-traumatic growth assumes that domains of growth are conceptually distinct from general emotional adjustment, and operate at a deeper schematic level than emotional adjustment, which centres on emotion and affect. Unlike adjustment and recovery, with post-traumatic growth, both growth and emotional distress may coexist.

In contrast, adjustment is about coping in the face of major life stress and is a reaction to the traumatic event itself, whereas post-traumatic growth is a reaction to the struggle for meaning of the event. Post-traumatic growth transforms the person, their core beliefs about themselves, and the world around them (Tedeschi & Kilmer, 2005). It operates at a schematic level and is not simply an increase in well-being or a decrease in distress (Tedeschi & Calhoun, 2004), and as such it is worthy of investigation in its own right. Post-traumatic growth is activated by an event so traumatic that it significantly threatens or shatters the fundamental schema of the individual (Calhoun & Tedeschi, 2004). This breakdown of schema enables the individual to question their previous assumptions of the world and to start to rebuild their lives. The greater the challenge to core beliefs about the world, the greater the positive correlation with the amount of post-traumatic growth reported (Cann et al., 2010).

In contrast, the recovery model focusses on overcoming mental health difficulties, but these concerns are not pre-requisites for post-traumatic growth. Within the recovery



model there is a need to find an overall purpose in life, such as a social or work role. Post-traumatic growth differs as it assumes a reconstruction of schema and beliefs, which influences how an individual sees one's self and their future. The term 'growth' in itself emphasises development beyond previous levels of adaptation, psychological functioning, or life awareness. It implies that there is something positively new that signifies an additional benefit compared to the pre-crisis level of functioning (Zoellner & Maercker, 2006). This defining element is key to healthcare providers being able to differentiate adjustment and recovery from post-traumatic growth.

### ***Background***

The experiences of partners of individuals with spinal cord injury have been under researched in comparison to the injured individuals. For healthcare professionals to assist these partners, it is first important that they understand their experiences. Quantitative research can provide an understanding of whether post traumatic growth and benefit finding can occur. This background examination will look at the factors that can impact on the quality of life of an injured individual and then more specifically, their partners. Non-injured partners may experience emotional stress and difficulties comparable to, or greater than, the injured partner (Chan, 2000b).

### ***Factors affecting overall quality of life of the injured individual***

Many factors can affect the overall quality of life of an injured individual. Warren, Wrigley, Yoels & Fine (1996) examined the life satisfaction of thirty-eight SCI patients, one year post-discharge. They used a life satisfaction questionnaire and found that the three most important psychosocial variables for high satisfaction were closeness to family, the level of family activities, and blaming oneself for the injury. When describing family support, the closest people are often partners; partners are clearly important for a high level of life satisfaction.

Stensman (1994) conducted a longitudinal study on seventeen SCI patients, interviewing them six times over a period of six months to five years. He used a subjective quality of life scale from 0-10 and asked about the cause of the accident. Stensman found that people who were blameless for the accident continually reported a low quality of life. It seems that being blameless may prevent a person trying to search for meaning and trying to understand why the trauma occurred, it can make it difficult to accept the trauma and move on. This is in contrast with Tedeschi & Calhoun (2004), who state that through trying to understand why the trauma occurred, growth occurs.

Crewe & Krause (1988) conducted a questionnaire study of one hundred and twenty-two individuals who got married before and after SCI. Although those married after injury reported a higher life satisfaction, all injured individuals reported benefiting emotionally and physically from having a partner. Thus it seems that there can be psychological growth for individuals following SCI.

Holicky & Charlifue (1999) conducted a study with two hundred and twenty-five British individuals with long term SCI, who sustained their injuries at least twenty-six years prior to the study. They were assessed with a range of psychosocial tests to assess life satisfaction, stress, depression and community integration. They found that spousal support is positively correlated with life satisfaction, quality of life, and reduced depression. They concluded that spouses might be the most important element in successful rehabilitation and long-term home care for married people with spinal cord injuries. Thus it is imperative that we understand the needs and experiences of non-injured spouses and partners, in order to benefit both partners in a relationship.

*Factors affecting overall quality of life of partners*

Blanes, Carmagnani & Ferreira (2007) conducted a study with sixty primary caregivers, thirty-one of whom were married. They gave structured questionnaires and interviews to assess health related quality of life. They found that compared to the general population, caregivers tended to develop psychological problems rather than physical illness, visited their general practitioner more, and reported poorer health. This study identified the existing need for caregiver support pathways from services.

Weitzenkamp, Gerhart, Charlifue, Whiteneck & Savic (1997) conducted a study with one hundred and twenty-four spouses of SCI survivors that had been injured for twenty-three years or more. Questionnaires and standardised tests were administered to assess quality of life, life satisfaction and depression. They found that caregivers have a higher incidence of fatigue, anger, resentment, and emotional and physical stress than their partners or spouses who are not the caregivers. Thus it seems that people will respond to SCI in different ways, and non-injured partners make more negative attributions than their injured partners.

Post, Bloemen & De Witte (2005) conducted a survey of two hundred and sixty-five couples where one partner had a SCI. Questionnaires were self-developed with rehabilitation centres and patient organisations. They posted the survey out and from the returns identified that care giving responsibilities most frequently fall to partners, and that the partners experience a high level of burden. They concluded that prevention of caregiver burnout should be part of the lifelong care package for people with SCI. It is imperative that services take the impact on caregivers into account in the cost of providing care to people with SCI.

### **Rationale and aims of the literature review**

Within the quantitative literature there is very little focus on the growth, experiences and needs of the partner, and indeed whether the partners of people that have acquired a spinal cord injury experience post-traumatic growth? Quantitative research lacks personal insight into how it is experienced and facilitated. Qualitative research however, provides insight into individuals' experiences of certain situations, enabling the researcher to understand the meanings attached to these experiences. This review aims to investigate partners' experiences of post-traumatic growth. Therefore, only qualitative research will be appraised. A review of the qualitative literature will give us a greater understanding of the needs, lived experiences, and growth that occurs post SCI in caregiving partners. The qualitative research evidence base will be reviewed to provide insight into partners' experiences of post-traumatic growth, and to answer the following question; do partners of people that have acquired a spinal cord injury experience post-traumatic growth?

### **Methods**

#### ***Search Strategy***

EBSCO host was used to search published articles. Health, life sciences, psychology and sociology databases were searched, which were comprised of AMED- the allied and complementary medicine database, Medline, PsycInfo, SPORTDiscus with full text, CINAHL and eBook collection (EBSCOhost). Google Scholar was also used to search articles. The search terms used for this part of the review were: spinal cord injury, spinal injury, post-traumatic growth, carer, carers, partner, partners, spouse and spouses.

The initial search delivered one hundred and fifty-two articles. All articles were then subject to inclusion and exclusion criteria with the aim to identify those relevant to the review question. Reference lists were also examined and relevant articles retrieved for review, from which a further five were identified. Many of the searches generated duplicate articles or articles that were unrelated to the study and these were discounted from the review. The initial search was conducted on December 1<sup>st</sup> 2010 and the final search conducted on October 13<sup>th</sup> 2014.

*Inclusion criteria for studies*

- Peer reviewed quantitative, qualitative or qualitative/quantitative articles written in English.
- The term post-traumatic growth was first coined in 1995 and only studies after this date have been included.
- This review will include only those studies with working age adults.
- Literature which has focused on post-traumatic growth concepts and spousal/partner in-depth experiences of living with SCI.

*Exclusion criteria for studies*

- Experiences of post-traumatic growth relating to carers that are not partners.
- The focus of the article was not on the post-traumatic growth of the partner.
- The primary difficulty of the partner was not SCI.

From the initial one hundred and fifty-two papers, one hundred and thirty-seven were omitted due to the focus of the article being on the injured individual, with no

pertinent partner details or experiences recorded. Abstracts and full text searches were scrutinised. Of the fifteen potential articles selected for review, seven were not related to overall experiences and focused solely on the sexual rehabilitation and needs of partners. These articles were excluded from the review because experiences of post-traumatic growth were not discussed.

### *Search results*

<b>Criterion Applied</b>	<b>Number of articles</b>
Number of articles regarding post-traumatic growth, spinal cord injury and partners	152
Qualitative and qualitative/quantitative articles	15
Met inclusion criteria fully	8

### *A review of the qualitative literature*

Following the application of the inclusion and exclusion criteria, one hundred and thirty-seven papers were excluded from review because they focussed on the injured individual, with no partner experiences recorded relating to growth or its processes. The eight remaining qualitative papers were reviewed using the Aveyard (2007) model of systematic review. The summary table (p.17) shows the main points, and the strengths and limitations contained within each paper. In the next stage the results and discussion sections of each paper were scrutinised, and codes applied to the main findings discussion points. Each section was coded. The next stage was to see which codes were

the most prevalent and similar across the papers, and themes were developed based on the codings. The codes and themes were compared to ensure the development of themes were robust. The final stage was to contrast the similarities and differences in the review, look at the developing themes and to consider how they all linked together. Once all of the papers were introduced in the dominant themes, they were critically appraised in accordance with Aveyard's guidelines (2007).

A summary of the papers is provided in Table. 1 (pp 17-21).

### ***Reviewing the articles***

The Critical Skills Appraisal Programme (CASP) qualitative research critical appraisal tool was used to appraise papers as recommended by Aveyard (2007). The literature review outlines the selected papers and methodological considerations of each, in line with the dominant theme found after critical appraisal. This review is presented thematically, with the most dominant themes to emerge from the literature discussed first.

Table 1

*Summary of papers for literature review*

Record	1	2	3	4
Study	Beauregard & Noreau (2010)  Spouses of persons with spinal cord injury: impact and coping	Chan (2000a)  How does spinal injury affect marital relationships?  A story from both sides of the couples	Boschen & Gregaro (2009)  Experiential outcomes of the SCI support provider role	Isaksson, Josephsson, Lexell & Skar (2008)  Male experiences of giving and taking social support after spinal cord injury to their partner
Method	Qualitative: Semi-structured phone interviews and content analysis	Qualitative: semi-structured interviews and content analysis	Qualitative and quantitative: questionnaires and focus groups	Qualitative: semi-structured interviews
Participants	24 spouses of SCI individuals	66 persons with spinal cord injury and 40 spouses	100 participants in questionnaires and 46 participants in qualitative focus groups	4 male participants
Main findings	Spouses apply several strategies to overcome the	Impact on spouses is different and most	Supporting a person with a spinal cord injury requires	Men required practical and emotional support when



	difficulties they encounter	problems were due to lack of communication	huge lifestyle changes and many people feel underprepared emotionally and cognitively	adjusting to living with their partner's spinal cord injury
Strengths	Focuses on the in depth experiences of partners	In depth experiences of spinal cord injury on marital relationships from spouses perspective	Identifies difficulties with providing support based on in depth experiences	Highlights the roles professionals can have in helping rehabilitation and how people change over time
Weaknesses	Researchers own role and biases in study not considered  Differences in British and Canadian healthcare systems	Study was based in Hong Kong which is culturally different from Britain so findings may not be generalisable	Researchers own role and biases in study not considered	Gender specific and small sample size
Relevance	Impact on spouses explored in depth	Spouses experiences compared to individuals with spinal cord injury on same topics – direct comparison	Impact on caring for individuals with SCI explored	Role of professional in providing support and in depth experiences

Record	5	6	7	8
Study	Chan (2000b) Stress and coping in spouses of persons with spinal cord injuries	Dickson, O'Brien, Ward, Allan & O'Carroll (2010) The impact of assuming the primary caregiver role following traumatic spinal cord injury: An interpretative phenomenological analysis of the spousal experience	Angel & Buus (2011) The experience of being a partner to a spinal cord injured person: A phenomenological-hermeneutic study	Dickson, O'Brien, Ward, Flowers, Allan & O'Carroll (2012) Adjustment and coping in spousal caregivers following a traumatic spinal cord injury: An interpretative phenomenological analysis
Method	Qualitative: semi-structured interviews	Qualitative: semi-structured interviews	Qualitative: semi-structured interviews	Qualitative: semi-structured interviews
Participants	5 male participants and 35 female participants	10 female participants and 1 male participant	3 female participants and 4 male participants	10 female participants and 1 male participant
Main findings	Spouses of persons with spinal cord injury suffer levels of stress comparable to those of their injured partner	Assuming a caregiver role has a negative impact on spouses and creates psychological distress.	Partners experienced much distress and felt they were left to manage the difficult process by themselves	Venting emotions, social support and focusing on the positive aspects of their situation promoted coping

Strengths	Highlights partners need services as much as their injured partner	Emphasises the non-injured partner experience of psychological distress from their perspective enabling greater understanding of their situation	Highlights non-injured partners experience distress 1 and 2 years after injury to their partner and require more support	Highlights non-injured partners require social support and positive reappraisal of their situation promotes coping
Weaknesses	Poor level of methodological detail provided. Study difficult to replicate. Ethical issues and reflexivity not discussed	Researchers own role and biases in study not considered	Sample recruitment strategy was not disclosed  Researchers own role and biases in study not considered  Differences in British and Danish healthcare systems	Researchers own role and biases in study not considered
Relevance	Stress and coping in non-injured partners explored	Non-injured partner experiences explored in depth	Highlights the burden and difficulties faced by the non-injured partner 0-12 months after their partner's injury	Highlights the need to develop and deliver interventions for non-injured partners

### Themes

The qualitative literature identified seven themes that will be presented in order of prevalence and then reviewed at the end to consider their connection.

#### *Burden of Care*

Caring for an injured partner after a SCI can be viewed as an extension of the traumatic incident, and create a burden of care for the non-injured partner. This continual reminder of the trauma that has occurred can lead to a search for meaning as to why the event occurred, a key part of post-traumatic growth (Tedeschi & Calhoun, 2004).

Assisting someone with their personal needs created a sense of additional burden for the partner and the individual involved (Chan, 2000a). Chan explored the impact of SCI on marital relationships in Hong Kong. Semi-structured interviews were undertaken with sixty-six people with SCI and forty spouses. These interviews were analysed using content analysis which demonstrated that the concept of burden arose most frequently within the interviews. Using another methodology such as interpretive phenomenological analysis with fewer spouses, could have provided richer experiential accounts of the impact of SCI on marital relationships.

Chan (2000b) used questionnaires and semi-structured interviews with forty non-injured spouses and found that professionals often ignored the impact of care giving burden on partners, because attention was focused on the person with the SCI. This study looked at the sources of stress and patterns of coping in spouses of people with spinal cord injuries in a Hong Kong Chinese population. Chan found that partners experienced stress levels comparable to the individual with the SCI, which he argues should be considered in any

rehabilitation programs. This was an important addition to the evidence base because it has highlighted the level of stress experienced by non-injured partners.

Further studies have examined men's experiences and processes of change in supporting a partner with a SCI (Isaksson, Josephsson, Lexell & Skar, 2008). Using semi-structured interviews and a narrative approach the authors demonstrated that the additional time required for tasks created a sense of burden on carers, for example, having to complete tasks in mornings and evenings along with a full time job was extremely difficult for partners. The authors gave clear examples of the care giving burden partners' experience, which was a strength of this study.

In addition, it seemed that partners experienced an increased burden through interactions with the healthcare system, which increasingly became a feature in their lives (Boschen & Gregaro, 2009). The authors explored the personal impact of providing support to somebody with a SCI in the community. They used focus groups to explore the personal experience of supporting a partner with an SCI, and found burden to be a recurring theme. This study was an important addition to the evidence base because it highlighted the negative impact healthcare systems can have on partners.

The extra tasks partners have to take on is an additional burden on carers (Beauregard & Noreau, 2010) and to get a better understanding of this, the authors conducted semi-structured interviews with twenty-four spouses. The authors used content analysis to find that partners applied several strategies to overcome their difficulties, such as engaging in activities without their partner, spending time alone and having open communication between partners. This study was important in highlighting the practical difficulties partners face; however using a more in-depth methodology such as IPA with fewer spouses may have lead to richer experiential data about these practical difficulties.

Dickson, O'Brien, Ward, Allan & O'Carroll (2010) conducted semi-structured interviews with eleven people and analysed them using IPA. They found that assuming a caregiver role could be unfulfilling and create a non-reciprocal relationship. It seemed to have a negative impact on spouses and created psychological distress. Partners described having to do two people's jobs without much help and recognition from others (Angel & Buus, 2011). Using semi-structured interviews and a narrative approach with seven people, the authors found that some relatives were so affected that they reached out for support from the non-injured partners themselves instead of offering support. This increased the caregiving burden. This study highlighted the high levels of burden and distress non-injured partners experience between one and two years after their partner's injury, and that those partners require psychological support.

The caregiving role can leave partners feeling overwhelmed by caregiver burden (Dickson et al., 2012). Using semi-structured interviews with eleven people and interpreting them using IPA methodology, the authors found that caregiver burden left partners with a lot of pent up emotions that left them feeling highly volatile at times. This study was important as it highlighted that allowing partners to vent their emotions, have social support and positively re-appraise their situation promoted coping and reduced burden.

### ***Coping Strategies***

Coping strategies are important in determining how partners react to adversity such as the SCI of a loved one, and their ability to find meaning after a traumatic event. Previous experience of life crises enabled partners to be more resilient and cope better, by previously identifying where to access the right emotional and practical support from family and friends (Isaksson, Josephsson, Lexell & Skar, 2008). Being emotionally prepared enabled better coping, and if this was not available there was a need for new coping strategies to be

developed (Boschen & Gregaro, 2009). Emotion-focused coping strategies such as venting emotions and taking time out from their situation, helped moderate burden and promote coping in non-injured partners (Dickson et al., 2012). This highlights the importance of providing psychological care to partners of people with SCI.

Another key component in coping was having a high internal locus of control which seemed to increase partners' life satisfaction, and decrease depression post injury (Chan, 2000b). This was characterised by more problem-solving, positive reappraisal and more competent coping strategies, features that resonate with post-traumatic growth principles (Joseph, Linley and Harris, 2005). Positive re-appraisal may help partners cope better with burdensome roles (Dickson et al., 2010). Having outside assistance to help cope with everyday tasks can be very beneficial to non-injured partners (Beauregard & Noreau, 2010). Assistance from family and friends can allow for a return to work (Angel & Buus, 2011). This assistance enabled partners to have more time for themselves and reclaim some independence. So what impact does time for self have on partners and how might this influence their post-traumatic growth?

### ***Time for self/independence***

Time alone enables cognitive processing with new schema emerging through this ruminative process (Janoff-Bulman, 1992). These schemata can help partners to find meaning from their new found situation. Non-injured partners were aware of the need for time to themselves away from their injured partner to maintain their sense of self (Dickson et al., 2010). Time alone provided a chance for partners to forget their problems for a while and gain a sense of normality (Angel & Buus, 2011; Dickson et al., 2012). A failure to have time alone often led to diminishing social circles, and as a result previous leisure activities were discontinued (Chan, 2000a). Encouraging injured spouses to re-engage in social activities was beneficial to non-injured partners, (Isaksson et al., 2008; Beauregard & Noreau, 2010) enabling a greater

appreciation of each other's personal space, and a better understanding of each other's need for independence. Expression of this need was facilitated through clearer communication.

### ***Communication***

Partners of people with SCI have identified how important it is to communicate feelings and thoughts with their partners, especially in difficult times such as after a SCI (Chan 2000b; Isaksson et al., 2008; Dickson et al., 2012). Critically, Isaksson et al. (2008) identified that this communication of one another's needs and feelings helped to find new meaning in their changing lives.

Relationships were stronger post-injury when there were opportunities to communicate and express feelings (Dickson et al., 2010). Chan (2000a) reported that problems of communication and interaction were common, and that this in particular created increased family and marital stress. Open and honest communication between partners was the best way to overcome relationship difficulties (Beauregard & Noreau, 2010). Having fewer difficulties enabled them to have a greater focus on pleasurable activities. This communication helped to gain an understanding of how partners can reduce insecurities, improve their wellbeing, and support one another in their daily lives (Angel & Buus, 2011), all things that would encourage growth. Developing improved communication may prevent the need for lengthy psychological support from services.

### ***Support***

Partners often had a drop in social role activities and frequently experienced a significant change in friends. They were often highly deprived of their desired social lives and unable to release frustration and burden (Chan, 2000a). Partners with more social support were more



satisfied with their life situation after their partner's injury (Chan, 2000b; Dickson et al., 2012).

Professional, practical and emotional support can lead to better understanding and feelings of competence for partners (Isaksson et al., 2008; Angel & Buus, 2011). Boschen & Gregaro (2009) found that partners experienced negative consequences from their spouse's injury and thought that they would have benefited from professional assistance, rather than being left to their own untested methods of coping. This left them feeling unprepared to support their injured partner and led to high levels of emotional stress. Boschen & Gregaro (2009) reported that many services were not fit to meet the needs of partners. Partners were often left worrying about other family members and children, as well as the injured individual. They found some partners who were unwilling to accept support for themselves because they did not see themselves as being the injured party, this could prevent growth following trauma.

A lack of support soon after the injury can lead people to resent services, and avoid contact with professionals (Dickson et al., 2012). Support can mean different things to different people (Boschen & Gregaro, 2009), and it is important for services to understand individual needs when developing support packages. Supporting non-injured partners through active involvement, or consultation in decision-making processes during rehabilitation can reduce psychological distress (Dickson et al., 2010; Angel & Buus, 2011). Providing the right support leads to better relationships, a change often attributed to post-traumatic growth (Joseph, Linley & Harris, 2005). When distress is reduced and support is available, growth can occur.

### ***Better Relationships***

Partners grew closer to each other post injury, motivating one another through identifying and rediscovering strengths such as resiliency and optimism in each other (Beauregard &

Noreau, 2010). Partners experienced personal growth and identified personal strengths such as advocacy and multitasking abilities, which they were unaware that they possessed (Boschen & Gregaro, 2009).

In the longer term, professional support for partners post injury led to better relationships with their injured partners (Isaksson et al., 2008; Dickson et al., 2010, 2012). Boschen & Gregaro (2009) found that the injury allowed some partners in their study to recharge or restart their relationships, redefine their roles and advance their relationship to a deeper level. Growth at an individual level helped their relationships too. Partners benefited from gaining a sense of control in their lives. This was achieved through actively educating themselves on community resources and treatments. This allowed for more understanding in relationships and promoted a sense of accomplishment and control, something that could also be achieved through leisure activities.

### *Leisure*

Partaking in pleasurable leisure activities allows for rumination and meaning making of situations, which are necessary parts of post-traumatic growth (Tedeschi & Calhoun, 2004). Partners found it difficult to leave their injured partners alone and resume their own social circles after their partner's injury, yet encouraging injured partners to resume previous leisure activities was often beneficial to both partners (Isaksson et al., 2008).

A lack of leisure activities can change a relationship, especially if socialising is a key part of the relationship (Boschen & Gregaro 2009), but Beauregard & Noreau (2010) found that difficulties around participating in leisure activities were principally due to obstructions to accessing venues. Careful planning and creating accessible sites for leisure could greatly improve the quality of life of couples living with SCI. Increased leisure activities for the injured partner could also increase the social circles for the non-injured partner (Chan,

2000a). This could provide an opportunity for increased social integration and more psychological support from peers instead of, or in addition to, psychological services.

***Critique – validity, reliability and transferability***

It is important that researchers demonstrate a systematic and rigorous approach to increase the validity of their research (Aveyard, 2007). Within the studies by Chan (2000a, 2000b) the reliability and validity of the studies were reduced, as in the first study the recruitment process and criteria were not explained and the methods of data collection were not provided. In the second study no details about the semi-structured interviews were provided and the methods of analysis were not described. The recruitment process was also unexplained in the study by Angel & Buus (2011), which limits the extent to which the findings can be generalised to others. Within the studies by Dickson et al. (2010, 2012) the researchers own role and biases were not considered.

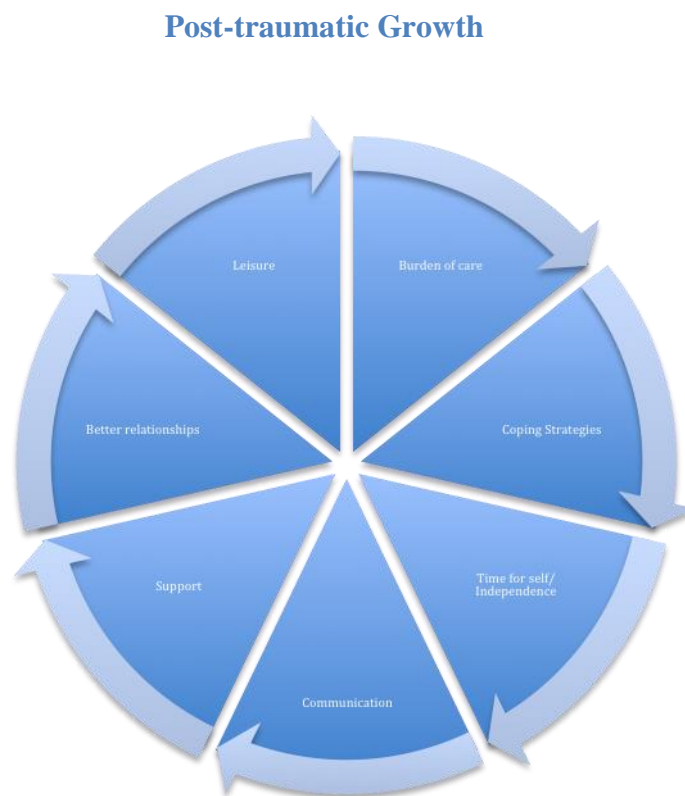
The study by Isaksson et al. (2008) only represented the experiences of men and therefore reduced the transferability of the study to women. It would be beneficial to interview women with the same methodology, to compare and contrast their experiences with men, and explore any differences linked to their processes of change and growth.

Studies by Chan (2000a; 2000b), Isaksson et al. (2008), Boschen & Gregaro (2009), Beauregard & Noreau (2010) and Angel & Buus (2011), were not undertaken in the United Kingdom (UK). While they have highlighted important considerations in relation to SCI, partners and post-traumatic growth, there are social and cultural differences in the services and resources available to partners. This would mean that differences between healthcare systems in other countries could have reduced the transferability of the studies to British partners, and the findings may not transfer to the UK context where health and social care is provided by publicly funded services.

## Discussion

Do the partners of people that have acquired a spinal cord injury experience post-traumatic growth? The findings from the review support the notion that they do. The themes are linked through their connection and resonance with post-traumatic growth principles, such as meaningful changes beyond emotion and affect (Tedeschi & Calhoun, 2004) and something positively new that signifies an additional benefit to pre-crisis level (Zoellner & Maercker, 2006). The order of themes follows a process that can be likened to experiencing post-traumatic growth. Figure 1 demonstrates the cyclical process identified.

*Figure 1.* The post-traumatic growth process model.



After the initial traumatic event, the SCI, non-injured partners feel the burden of care and the traumatic experience continues. Following the traumatic event a search for meaning

occurs (Tedeschi & Calhoun, 2004). Coping strategies are employed to manage and make sense of the events. It is this reaction to the struggle for meaning that facilitates post-traumatic growth (Tedeschi & Kilmer, 2005). Time is spent alone, which enables cognitive processing with new schema emerging through this ruminative process (Janoff-Bulman, 1992). The time away from each other enables partners to identify their needs and communicate these more clearly to each other. This enables greater support, which leads to better relationships, which Joseph, Linley & Harris (2005) identified as a change often attributed to post-traumatic growth. These new circumstances enable the non-injured partner to feel able to pursue their own pleasurable leisure activities again. The post-traumatic growth process provides additional benefits to the pre-crisis level (Zoellner & Maercker, 2006). Partners may identify with certain stages of this process model and recognise their growth, and this may also be useful for clinicians, services and researchers in raising awareness of post-traumatic growth.

### *Gaps in literature*

How partners have grown individually and learned about themselves has not been addressed in the literature. The wellbeing of a partner is crucial to a relationship (Holicky & Charlifue, 1999). It would be useful to elicit exactly which specific factors promoted growth, and at which point these were effective. Findings from Blanes, Carmagnani & Ferreira (2007) demonstrate the importance of looking at the wellbeing of partners to prevent psychological problems and poor health. This can reduce the burden on services from partners and injured individuals. How relationships have grown stronger between couples, family and friends, and what factors facilitated this should also be considered. It is also important to identify what type of support for partners would have been helpful at the time of the SCI, to promote growth.

### *Future Research*

In-depth life interviews may provide valuable personal insights, and research must investigate the specific needs of non-disabled partners (Holicky & Charlifue, 1999; Crewe & Krause, 1988). It would be beneficial to have follow-up studies, where support focusing on eliciting post-traumatic growth for partners and couples is offered immediately after an injury. The benefits to both the individual with the SCI and their partners could be invaluable in assisting future couples. Thus, the experiences of having support and no support could be reviewed. The question of what characteristics determine post-traumatic growth requires further study. Discussing partners' in-depth experiences would enable this area to be addressed and explored. Further research in the UK would help identify whether post-traumatic growth has universal similarities or whether there are cultural differences.

### **Conclusion**

This paper has looked at post-traumatic growth, SCI and the partners of people with SCI. A background to the factors that can affect personal growth and relationships was provided. A review of the literature highlighted themes that can create and maintain distress if not addressed, and themes that can assist in understanding trauma and post-traumatic growth. Gaining in-depth accounts of how people experienced post-traumatic growth and which factors facilitated this was identified as a gap in the literature, and seen as a direction for future research.

### References

- Anthony, W. A. (1993). Recovery from mental illness: The guiding vision of the mental health service system in the 1990's. *Psychosocial Rehabilitation Journal, 16*, 11-23.
- Aveyard, H. (2007). *Doing a literature review in health and social care: A practical guide*. Maidenhead: Open University Press.
- Beauregard, L., & Noreau, L. (2010). Spouses of persons with spinal cord injury: impact and coping. *British Journal of Social Work, 40*, 1945–1959.
- Blanes, L., Carmagnani, M. I., & Ferreira, L. M. (2007). Health-related quality of life of primary caregivers of persons with paraplegia. *Spinal Cord, 45*, 399–403.
- Boschen, K. A., & Gregaro, J. (2009). Experiential outcomes of the SCI support provider role. *Topics in Spinal Cord Injury Rehabilitation, 14*, 69-87.
- British Orthopaedic Association. (2006). *The initial care and transfer of patients with spinal cord injuries*. London.
- British Association of Spinal Cord Injury Specialists. (2005). *Management of individuals with spinal cord injury in general hospitals good practice guidelines*. Retrieved from <http://www.bascis.pwp.blueyonder.co.uk/philosophy.htm>.
- Calhoun, L. G., & Tedeschi, R. G. (2004). The foundations of posttraumatic growth: New considerations. *Psychological Inquiry, 15*, 93-102.
- Cann, A., Calhoun, L. G., Tedeschi, R. G., Kilmer, R. P., Gil-Rivas, V., Vishnevsky, T., & Danhauer, S. C. (2010). The Core Beliefs Inventory: A brief measure of disruption in the assumptive world. *Anxiety, Stress & Coping, 23*, 19-34.
- Chan, R. (2000a). How does spinal cord injury affect marital relationship? A story from both sides of the couple. *Disability and Rehabilitation, 22*, 764-775.

- Chan, R. (2000b). Stress and coping in spouses of persons with spinal cord injuries. *Clinical Rehabilitation, 14*, 137-144.
- Crewe, N. M., & Krause, J. S. (1988). Marital relationships and spinal cord injury. *Archives of Physical Medicine and Rehabilitation, 69*, 435-438.
- Department of Health. (2010). *Organising quality and effective spinal services for patients: a report for local health communities by the Spinal Taskforce*. London: Department of Health.
- Department of Health. (2005). *The National Service Framework for long term conditions*. London: Department of Health.
- De Ridder, D., Geenen, R., Kuijer, R., & van Middendorp, H. (2008). Psychological adjustment to chronic disease. *The Lancet, 372*, 246-255.
- Dickson, A., O'Brien, G., Ward, R., Richard, Allan, D., & O'Carroll, R. (2010) The impact of assuming the primary caregiver role following traumatic spinal cord injury: An interpretative phenomenological analysis of the spouse's experience. *Psychology and Health, 25*, 1101-1120.
- Dickson, A., O'Brien, G., Ward, R., Flowers, P., Allan, D., & O'Carroll, R. (2012). Adjustment and coping in spousal caregivers following a traumatic spinal cord injury: An interpretative phenomenological analysis. *Journal of Health Psychology, 17*, 247-57.
- Holicky, R., & Charlifue, S. (1999). Ageing with spinal cord injury: the impact of spousal support. *Disability & Rehabilitation, 21*, 250-7.



- Isaksson, G., Josephsson, S., Lexell, J., & Skar, L. (2008). Men's experiences of giving and taking social support after their wife's spinal cord injury. *Scandinavian Journal of Occupational Therapy, 15*, 236-246.
- Janoff-Bulman, R. (1992). *Shattered assumptions*. New York: Free Press.
- Joseph, S., Linley, A. P., & Harris, G. J. (2005). Understanding positive change following trauma and adversity: Structural clarification. *Journal of Loss and Trauma, 10*, 83-96.
- Joseph, S., Williams, R., & Yule, W. (1993). Changes in outlook following disaster: The preliminary development of a measure to assess positive and negative responses. *Journal of Traumatic Stress, 6*, 271-279.
- Kaiser, S., & Kennedy, P. (2011). An exploration of cognitive appraisals following spinal cord injury. *Psychology, Health and Medicine, 16*, 708-718.
- Post, M. W. M., Bloemen, J., & De Witte, L. P. (2005). Burden of support for partners of persons with spinal cord injuries. *Spinal Cord, 43*, 311-319.
- Royal College of Physicians. (2008). *Chronic spinal cord injury: management of patients in acute hospital settings: national guidelines: Concise Guidance to Good Practice series, No 9*. London: RCP.
- Spinal Injury Association. (2007). *Managing Spinal Cord Injuries: The First 48 Hours*. Milton Keynes.
- Stensman, R. (1994). Adjustment to traumatic spinal cord injury. A longitudinal study of self-reported quality of life. *Paraplegia, 32*, 416-22.
- Tedeschi, R. G., & Calhoun, L. G. (1996). The post-traumatic growth inventory: Measuring the positive legacy of trauma. *Journal of Traumatic Stress, 9*, 455-471.

- Tedeschi, R. G., & Calhoun, L. G. (2004). Post-traumatic growth: Conceptual foundations and empirical evidence. *Psychological Inquiry, 15*, 1-18.
- Tedeschi, R. G., & Kilmer, R. P. (2005). Assessing strengths, resilience, and growth to guide clinical interventions. *Professional Psychology: Research and Practice, 36*, 230-237.
- Warren, L., Wrigley, J. M., Yoels, W. C., & Fine, P. R. (1996). Factors associated with life satisfaction among a sample of persons with neurotrauma. *Journal of Rehabilitation Research and Development, 33*, 404-8.
- Weiten, W., Dunn, D., & Hammer, E. (2011). *Psychology applied to modern Life: Adjustment in the 21st century: Tenth Edition*. Belmont: Wadsworth Publishing Company.
- Weitzenkamp, D. A., Gerhart, K. A., Charlifue, S. W., Whiteneck, G. G., & Savic, G. (1997). Spouses of spinal cord injury survivors: The added impact of caregiving. *Archives of Physical Medicine and Rehabilitation, 78*, 822-827.
- Wilson, J. P., Friedman, M. J., & Lindy, J. D. (2001). An overview of clinical consideration and principles in the treatment of PTSD. In Wilson, J. P, Friedman, M. J., & Lindy, J. D. (Eds.), *Treating psychological trauma and PTSD* (pp.59-94). New York: Guilford.
- Zoellner, T., & Maercker, A. (2006). Post-traumatic growth in clinical psychology: A critical review and introduction of a two component model. *Clinical Psychology Review, 26*, 626-653.

**Research Report****Abstract**

Post-traumatic growth refers to the positive changes one can undergo after a traumatic experience. Partners of people with spinal cord injury suffer levels of emotional stress comparable to, or greater than, their injured partners. The aim of this research is to gain insight and understanding of how post-traumatic growth can be experienced by non-injured partners. Interpretative phenomenological analysis (IPA) was adopted for the methodology. Five partners were recruited. The accounts of partner experiences resonated with the conceptual ideas of post-traumatic growth. One master theme, new identity, and six sub themes arose from the findings. Implications for clinical practice are discussed.

Keywords: post-traumatic growth; spinal cord injury; partners, spouses; interpretative phenomenological analysis (IPA); interviews, semi-structured; resilience; loss of identity, strengths; research; qualitative

## Introduction

### *Spinal cord injury*

Spinal cord injury (SCI) is described as one of the most devastating traumatic types of impairment which has profound effects on both the spinal injured person and their family members (Gill, 1999; Krause, 1998). In the UK it is estimated that 10–15 people per million of the population per year are affected by SCI, equating to around 40,000 individuals. The NHS spinal taskforce (Department of Health, 2010) suggests that the provision of spinal services needs to go beyond the management of degenerative conditions and focus on trauma in order to meet all the needs of patients. It is important therefore to understand how people develop and grow through the trauma of SCI, which has a profound effect on wellbeing.

### *Post-traumatic growth*

Tedeschi & Calhoun (1995) coined the term “post-traumatic growth”, a phrase that refers to the positive changes one can experience after an unforeseeable traumatic event. The term “growth” underscores that the person has developed beyond their previous level of adaptation, psychological functioning, or life awareness. It expresses that in people's lives there is something positively new that signifies a kind of additional benefit compared to pre-crisis level (Zoellner & Maercker, 2006). Post-traumatic growth is not simply a return to baseline from a period of suffering, it is an experience of improvement that for some people is deeply meaningful and goes beyond changes in emotion and affect. Changes often attributed with post-traumatic growth are changes in life philosophy, personal growth and more meaningful relationships (Joseph, Linley & Harris, 2005).

A trauma impacts the psychic core, the very soul of the person and their identity (Wilson, Friedman & Lindy, 2001). Core beliefs are one theoretical conceptualisation of how we see

ourselves, other people, the world, and the future (Janoff-Bulman, 1992). Once these beliefs and schema are challenged, people are thrown into disarray and their lives can appear inconsistent and unpredictable. It is this challenging of one's core beliefs and thus the self, that generates a search for meaning as to why the event occurred as well as drive the person to question, reformulate and reconstruct their very basic core beliefs (Janoff-Bulman, 1992). Integrating one's reactions to, and cognitions about the past with the new schemas that emerge from this rumination process, allow for both an acceptance of traumatic events and for a renewed outlook on the future and oneself.

To understand the experiences of partners of people with SCI, we need to know whether there is any evidence of these non-injured partners experiencing post-traumatic growth.

#### ***Post-traumatic growth and partners***

The person often closest to an individual is their partner and the experiences of partners of people with SCI are much less known and researched. Kennedy et al., (2000) found acceptance of the injury was related to improved psychological wellbeing along with having good quality social support (Kennedy & Rogers, 2000), being married (Holicky & Charlifue, 1999) and being younger (Woodrich & Patterson, 1983). These findings show that having supportive partners and relatives can improve a person's wellbeing after trauma.

A particularly interesting area of research has been that of the burden of support felt by partners (Post, Bloemen & De Witte, 2005) and the stress felt by partners (Chan, 2000b). The authors found that spouses of people with SCI suffer levels of stress comparable to those of their injured partners and go through similar experiences. These findings offer a valuable insight into partners experiencing similar effects to their injured partners. They do not however, explore how this process occurs for these partners. If injured partners can

experience post-traumatic growth, then it is conceivable that their non-injured partners could do the same if they have similar stress levels and experiences.

Beauregard & Noreau (2010) looked at the personal impact of coping in spouses of people with SCI, whilst Isaksson, Josephsson, Lexell & Skar (2008) looked at men's experiences of giving and taking social support after their wife's SCI. Both studies found spouses needed both emotional and practical support to handle their new life situation, which is essential if couples are coming to services.

Kaiser & Kennedy (2011) found that others can have a significant effect in the way an individual adapts to their injury, and there is a need to focus on significant others in an individual's rehabilitation. Research has centred on quality of life (Blanes, Carmagnani & Ferreira, 2007) identifying carer needs (Chen & Boore, 2007) and wellbeing (Manigandan et al., 2000). SCI has a lasting effect not only on the individual but also on the people in the system around the individual.

### ***Research Aims***

The research aims to gain insight and understanding into the experience of post-traumatic growth in partners of people who have experienced SCI. It aims to increase understanding of the complex issues experienced by partners of people with a SCI, and to assist healthcare services in understanding and identifying how growth may be facilitated to improve wellbeing for partners.

## **Methods**

### ***Design***

IPA methodology fitted with the aims of the research; to analyse how participants experience post-traumatic growth following their partner's SCI. Semi-structured interviews were

conducted which were then transcribed, coded and analysed to identify shared and differing themes across the data.

IPA was chosen because it recognises that people attribute meaning to their experiences in their interactions with the environment around them (Smith, Jarman & Osborn, 1999). IPA was designed to gain insight into individual participant's psychological worlds (Willig, 2008). It aims to see a person's reality and the way they perceive events, and the meanings ascribed to these events through interpretation. IPA is concerned with gaining a better understanding of individual experience that is in the 'nature and quality of phenomena as they present themselves' (Willig, 2008 p.56). The phenomenon under investigation is SCI. Each person interprets phenomena in different ways, as everyone attaches different meanings and emotions to these phenomena (Willig, 2001).

This position appeared to fit most closely with the research question to understand the non-injured partner's experience of post-traumatic growth, associated with living with someone with SCI. It is a method that through the use of semi-structured interviews gathers rich accounts of how individuals deal with health related problems.

### ***Foregrounding***

IPA allows for a thorough exploration of idiographic subjective experiences and social cognitions (Biggerstaff & Thompson, 2008). The philosophical roots of IPA uphold that people construct their own meanings of events in response to experiences, and that these meanings are influenced by social constructions. This is in line with the author's epistemological position; through interpretation it becomes possible to attempt to access another person's social cognition. IPA recognises that this access is complex and biased by the researcher's own influences in the process.

The researcher is a male, able-bodied trainee clinical psychologist with a background in working with individuals who are experiencing difficulties and who are in distress. Interest in post-traumatic growth developed from lectures on the topic at university whilst an undergraduate. The researcher has no personal history of SCI, but his previous experiences include working with individuals who have had chronic pain, spinal injury and experienced trauma. Working within these settings raised his awareness of the effect of trauma and injury on both the individual, and the network around them. It was seen that this disrupts the lives and psychological wellbeing of family members. It is not always as a direct result of the trauma itself, but from changes in the individual's behavior. These experiences developed an interest in investigating whether or not people underwent any transformational changes in these relationships post SCI.

### ***Setting***

The study took place in an NHS Spinal Cord Injury service. The multi-disciplinary team provides simultaneous care and attention to people with SCI and all its effects. Full support is provided to the patient, partners and family members until discharge and sometimes even afterwards.

### ***Participants***

A purposive sampling approach was followed for recruitment. The multi-disciplinary team within the service knew all participants recruited. Information about the research study was provided to care professionals working in the SCI service, giving clear information about inclusion criteria and exclusion criteria. They then identified partners of people that had experienced SCI and met the requirements of the study.



Participants were then contacted to see if they would like further information regarding the study with a letter of invitation (Appendix C). Information that explains the background and nature of the research was then sent out. The information included an opt-in and opt-out form which participants could return to the researcher by stamped addressed envelope.

Participants were eligible if they were aged eighteen or over and they were the partner of a person who had experienced SCI, three to five years after their injury. Participants were excluded from the study if they had gross cognitive impairment that affected their ability to participate in the interview, ability to give informed consent, and if they were no longer the primary partners at the time of the interview. If they were involved in an on-going compensation case with partners they were also excluded as this could bias relationships.

### ***Confidentiality and ethics***

To protect the identity of participants they were given pseudonyms that will be used throughout the remaining report. All participants were debriefed at the end of each interview by the researcher, and also given the opportunity to be debriefed by a member of staff without the researcher being present to further ensure their wellbeing.

No form of inducement or coercion was used in recruiting participants, and it was made clear to them that they were free to choose whether or not to participate in the study. Participants were given time to consider the implications of taking part in the research. The researcher contacted participants after twenty four hours to enable reflection on whether they would like to participate in the study. Once the researcher had received the opt-in form, participants were contacted by telephone to answer any further questions about the study and to arrange to meet with the researcher. The sample consisted of five partners of people who had experienced SCI, of which there were four women and one man. All partners were employed and married.

Ethical approval for conducting the study was obtained from a local university ethics committee (Appendix D), a NHS ethics committee (Appendix E) and the NHS Spinal Cord Injury service research ethics committee (Appendix F). Participants had the opportunity to read a detailed Participant Information Sheet (Appendix G) before deciding whether or not to take part in the study. A participant partner information sheet (Appendix H) was also provided to detail how the study would affect them. The researcher obtained written informed consent prior to the interview, from both the participant and their partner (Appendix I; Appendix J). All interviews took place in a private room.

Table 1

*Participant Information Table*

Participant	Gender	Age	Severity of Partner's injury		Time in relationship since injury
1 Jill	Female	75	Paraplegic	Complete	3-5 years
2 Bob	Male	65	Tetraplegic	Incomplete	3-5 years
3 Mary	Female	50	Tetraplegic	Complete	3-5 years
4 Ann	Female	57	Paraplegic	Incomplete	3-5 years
5 Helen	Female	54	Paraplegic	Complete	3-5 years

Tetraplegia refers to paralysis of both arms and both legs. Paraplegia is paralysis of the lower half of the body including both legs. If the

injury is 'complete' there is no movement or sensation below level of injury, if incomplete there may be some sensation or movements (but

not normal) below the level of injury.

Researchers using IPA methodology typically recruit small samples enabling detailed case-by-case analyses of individual transcripts (Smith, 2008). With this approach also being utilized with case studies, IPA studies are based on an idiographic approach. Detailed understandings of a particular group in which the research occurred are discussed, as opposed to making general claims for a larger population (Smith, Flowers & Larkin, 2009). It is for this reason that IPA studies are conducted with small samples enabling the researcher to understand phenomena in particular contexts.

### ***Procedure***

Participants in the study were individually interviewed using a semi-structured interview schedule (Appendix K). This was confirmed with both clinical and academic supervisors. The researcher asked questions from the interview schedule in order to facilitate narration of their experiences. The interviews were audio-digitally recorded with their consent and later transcribed and analysed. Participants were offered the opportunity receive their transcripts.

### ***Data analysis***

The analysis followed the steps outlined in Smith's (2008) presentation of the analytic process. The stages reflect the process for the first transcript; the remainder of the transcripts followed the same process and were compared.

#### ***Stage 1: looking for themes in the first case***

Interview transcripts are analysed, read and re-read to allow the author to record any initial thoughts, reflections, or questions that are raised by the text (Appendix L).

#### ***Stage 2: emerging theme titles***

Return to the start of the transcript, a more systematic analysis of the text takes place. Emerging theme titles are identified (Appendix L & M).

*Stage 3: connecting the themes*

Emergent themes are listed and connections between them are sought. The initial list is chronological, and then theoretical ordering takes place. Some themes will cluster together; others emerge as super ordinate concepts (Appendix M).

*Stage 4: Production of a table of themes*

The final stage entails the author collating all the themes under their respective subordinate theme headings. A summary table is then generated that offers a coherent overview of the analysis (Table.2). Themes that are not rich in evidence and do not fit well in the emerging structure can be dropped. Themes that emerge in later transcripts are checked against earlier transcripts. The themes are then translated into a narrative account and verbatim extracts from the transcripts will be used to support and illustrate themes.

Table 2

Master Table of Themes

Master Theme	Sub Themes	Example quote	Jill	Bob	Mary	Ann	Helen
New Identity	Resilience and strength	“...you just do it; you’ve got to do it so get on with it. So I suppose in that way I’m strong, I mean I wouldn’t, I wouldn’t dream of not doing it, I don’t consider it.” (Jill, 437-440)	37-38, 40, 437-440, 444-446,	97-98, 267-268, 288-289, 300-303,	22-27, 217-219, 219-221, 366-374,	22-25, 30-33, 370-373, 375,	22-24, 358-363, 365-367, 380-381
		“...it makes you such a strong, a heck of a lot stronger person um, I wouldn’t have done half of what I’d do now I don’t think had I not gone through these stages” (Mary, 219-221)			378-380, 401-404,	384-385, 399-406	
	Time for self	“You don’t necessarily need to be together all the time, and like I think we’ve sort of come to understand now” (Ann, 405-407)					
		“I do appreciate my afternoon out very much [[laughs]] my garden, I go out in the garden if I get tensed up and that, I love to get out in the garden...” (Jill, 378-380)					

New Identity	Support	“well I think its helped a lot you know because er, you know, people asking how you are and popping in, you know its nice for both of us just to see people really” (Helen, 138-141)	132-33, 175-177, 228-232,	65-66, 152-155, 158, 211-212	69, 169- 172, 175-178,	69-74, 241-253,	67-71, 122-127, 131-134, 138-141,
		“well I had a lot of support, um from people here you know, if I wanted anything I just had to ask them” (Bob, 211-212)					
New identity	Lack of understanding about new role	“it’s difficult because of the type of injury it is, it’s one day it’s just so different, every day was different” (Helen, 390-392)	275-283, 302-304, 330-335,	n/a	101-104, 263-265, 233-240,	233-240, 317-320, 322-328,	390-392, 395-396, 400-403,
		“I think sometimes ignorance is bliss...the biggest thing I found upsetting here was that he had a pressure sore and, within the first week one of the sisters said yes he could be home for Christmas day...well it was January, middle of January by the time he got up and I found that very, very hard” (Jill, 275-283)					
New Identity	Love and appreciation	“Well love for him really, and my appreciation because we’ve had a very good life, we’ve had a good marriage all along” (Jill, 431-432)	42-47, 81-82, 191-195,	39-45, 47-49, 403,	125-127, 129,	263-266, 268-270,	207-211, 260-263, 266-268,

		“we are far more appreciative of it probably than you were before, you just took things before and got on with your life whereas now you’ve got time to think” (Jill, 201-204)	201-204, 263-265, 431-432	405, 407-409,	130-132	272,	280-281,
		“it’s gone stronger, stronger and stronger because he knows I’m 100% there all the time, I’m there every day” (Mary, 125-127)					
New Identity	Communication	“understanding and listening, listening a lot more and then sectioning everything off, how to deal with things, prioritising, that’s what I’ve got, it’s the understanding I think more than anything I think more than anything because it’s obviously a whole new, a whole new field to go onto but, er just, just listening, listening a lot more.” (Mary, 11-16)	211-213, 218-220	68-70, 72-74, 206-209,	11-16, 144-149, 211-214,	100-106, 166-169, 209-210,	79-83, 84, 87- 91, 100- 102,
		“but you know, you make your feelings both to him and to other people more known now, you make sure” (Jill, 211-213)					

*Quality Enhancement*

The quality of the work was enhanced using guidelines by Elliott, Fischer & Rennie (1999) as follows:

*Owning one's perspective*

The author's values and assumptions have been disclosed in the foregrounding section on page 40.

*Situating the sample*

Participants consisted of four females and one male, with an age range of 21 years, from 54-75 years. There were three partners with complete spinal injuries and two with incomplete spinal injuries. A table is provided on page 43.

*Grounding in examples*

Examples from the data have been used to demonstrate and support the analytic procedure used, as highlighted in Table 2 on page 46, and in appendix L. The themes and their discussion demonstrate the understanding the researcher has generated from the data.

*Providing credibility checks and coherence*

Examples of the transcripts were handed to the research supervisor. They read transcripts for all five interviews in accordance with guidelines by Smith (2008). Notes were compared and themes were checked for coherence and credibility.



*Accomplishing general versus specific research tasks*

Specific cases of partners have been discussed and seen by the thesis supervisors.

*Resonating with readers*

Analyses were checked by both the academic and clinical supervisors and were deemed to stimulate resonance within the reader through moving, thought provoking accounts of growth following unforeseen trauma.

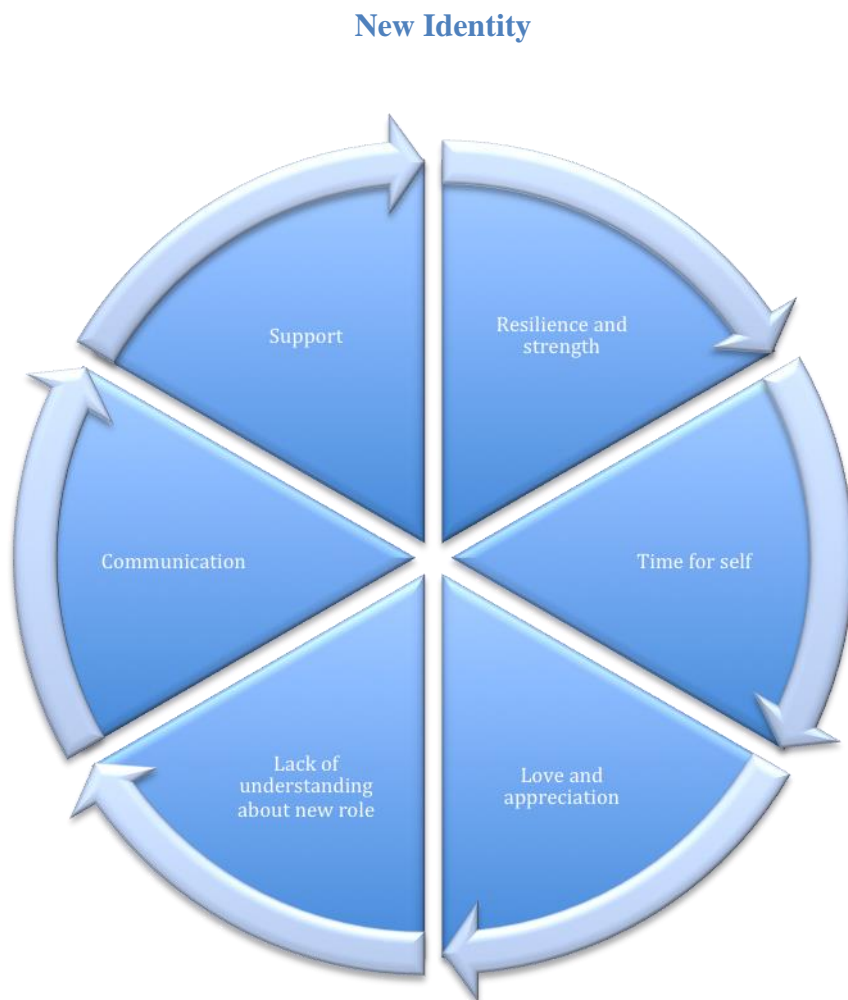
**Findings and Discussion**

This research aimed to see whether partners of people with SCI experience post-traumatic growth, and how this is achieved. A single master theme and six sub themes arose during the analysis of the data. The master theme was new identity with sub themes being; resilience and strength, time for self, support, lack of understanding about new role, love and appreciation, and communication. Themes were consistent with theoretical conceptualisations of post-traumatic growth. The sub themes promoted the search for meaning and new core beliefs, which helped partners to form new schema, a new identity and a new outlook on their lives. The master theme and sub themes identified were interlinked through their resonance with the conceptual ideas of post-traumatic growth, such as finding meaning through struggle, experiencing changes within themselves on a deeper level beyond emotion and affect, learning to adapt to new circumstances, growing stronger and more resilient as individuals, and developing stronger and more meaningful relationships (Tedeschi & Calhoun, 1995).

### *New Identity*

The master theme, new identity, encompasses the non-injured partner's new sense of self after their experiences, and their attempts to find meaning within their struggle from the aftermath of the event. A cognitive rebuilding process occurs where the traumatic experience is integrated with existing schema to form new schema. As demonstrated in Figure 1, the master theme incorporates all of the six sub themes where each one is integrated with existing schema to form a new identity.

*Figure 1.* New Identity Model.



When an unforeseen traumatic event occurs people often feel that at least some part of them, be it their views of the world, their sense of themselves or their relationships,

have been threatened or shattered. Those who try to rebuild their lives exactly as they were can remain vulnerable and struggle. Those who accept their newfound circumstances and find meaning from their experiences, can rebuild a more meaningful life and identity and become open to new ways of living:

“I can step back then, I can step back I can be me, I’m not a carer, I’m not continuously looking and seeing what can be done or whatever, I’m myself and I’m a wife and I’m my daughter’s mum and I can be that role you know which is nice”

(Mary, 200-207)

This quote highlights how the partner values being able to take on different roles besides being a carer. The partner has accepted their new role whilst acknowledging their old roles have been integrated into a new identity.

### ***Resilience and strength***

A key theme running through all the transcripts was that of resilience, supporting previous research by Bonanno (2004) which stated that resilience to trauma is common. It is a sense of innate resolve to overcome adversity and adapt to new challenges and circumstances. As one partner stated:

“...you just do it; you’ve got to do it so get on with it. So I suppose in that way I’m strong, I mean I wouldn’t, I wouldn’t dream of not doing it, I don’t consider it.”

(Jill, 437-440)

Partners expressed both a sense of being strong and getting stronger for others around them, but also for themselves. They acknowledged that they must continue to live and

move forwards with their lives. Other partners highlighted the importance of remaining resilient and maintaining a positive outlook despite adversity:

“I think you can only, you can only try and be positive, you, if you let the negatives creep in I think that’s when your nightmares start and I really do believe you’ve got to keep a positive outlook every day”

(Mary, 366-374)

Being resilient and gaining strength offers new perspectives on life and a re-evaluation of what is important to focus on. It enables people to gain more confidence in overcoming their adversity. When a challenge is overcome it can build confidence and increases the confidence to overcome subsequent future challenges. Hence being resilient in the present increases the likelihood of being resilient in the future and develops strength, as was the case for these partners.

One partner highlights how she recognised her new strength and experienced this as growth:

“...it’s learning how to get what you need, fighting authorities and God knows what else and it makes you such a strong, a heck of a lot stronger person um, I wouldn’t have done half of what I’d do now I don’t think, had I not had to go through these stages.”

(Mary, 217-221)

The partner is able to have insight into the fact that overcoming different stages of adversity has led to her experiencing growth and new found strength. She feels stronger

and more capable of overcoming any future challenges. All partners acknowledged new strength and growth within themselves.

### *Time for Self*

Having time for self, independence to do things a person enjoys, and time to reflect, were things partners valued. They identified these as coping mechanisms and as a way to release tension. This supports previous findings by Chan (2000a) who identified that partners were aware of the need for time to themselves away from their partner, even when they did not have an opportunity to do so.

“If you’ve got another interest or hobby you can go away and you can do that, I mean some days I’ll say oh I’m taking the dog out, even if it’s just a walk you’ll take the dog and it just clears your mind, and puts everything back into perspective”

(Helen, 293-297)

Partners can change into the roles of carers for long periods of time. Time away from this role can be vital to remind themselves of the other parts of their lives, and the other roles they wish to fulfil. This enables the recognition of growth, changes and greater enjoyment from life. Having time to ruminate, develop new schema, and finding meaning through an individual’s struggle with the aftermath of a traumatic event is enabled through time alone.

### *Support*

The level and type of support received by partners within their social network had a huge impact on their ability to adjust to the new changes in their lives. This supported previous research by Isaksson et al. (2008) and Boschen & Gregaro (2009), which highlighted how emotional support from family and friends was seen as crucial in

enabling partners to understand their situation and better support their injured spouses. One partner highlighted how much the support they received helped them to cope, and was a necessity to overcome challenges:

“my sister in law did stay Monday, Tuesday, Wednesday and my son was there Friday, Saturday, Sunday and I’d spend one night by myself, um, and that was a tremendous help, I don’t think I’d have got through without that”

(Jill, 228-232)

Similar to other themes this affirms how relationships have been strengthened, a conceptual component of post-traumatic growth. The partner feels that she would not have been able to overcome the challenges she faced were it not for the support of family. The importance of this cannot be understated as post-traumatic growth might not have been possible for this partner, and she may have experienced major distress without support. Practical support from services and others in a partner’s social circle was also valued:

“Well I had a lot of support, um from people here you know, if I wanted anything I just had to ask them”

(Bob, 211-212)

The above quotes highlight how practical support helped put a partner at ease and feel secure. Partners recognise a need to learn to adapt to their new situation by themselves and rely on their own strengths, yet do that with the reassurance that somebody is there if they struggle. Having support enabled partners to have the mental and physical capacity to recognise, develop and expand their strengths. Supportive partners can aid post-traumatic growth by providing a way to formulate narratives about the changes

that have occurred. They can provide new perspectives that can be integrated into schema change (Neimeyer, 2001).

*Lack of understanding about new role*

One area that prevented growth for partners was a lack of understanding and uncertainty about their new role as a carer, and a perceived lack of support from services. This supported previous research by Isaksson et al. (2008), who highlighted how partners experienced a lack of support from services:

“I think sometimes ignorance is bliss...the biggest thing I found upsetting here was that he had a pressure sore and, within the first week one of the sisters said yes he could be home for Christmas day...well it was January, middle of January by the time he got up and I found that very, very hard”

(Jill, 275-283)

The partner repeats the word ‘very’ to emphasise her difficulty. Her phrase ‘ignorance is bliss’ is a powerful example of how distressing uncertainty is for partners, and how knowing nothing of the situation would be less distressing than receiving mixed messages from professionals. This highlights how important it is that services provide partners with the right information and update any changes. Being unprepared for the reality of the situation and a lack of knowledge was a source of distress and pain for partners:

“The other thing I think they perhaps could improve on was with the toileting because that, at first that really horrified me”

(Jill, 302-304)

The partner uses powerful language here by use of the word ‘horrified’ to describe the utter shock of her new role. Having prior information from services might have prevented this reaction or prepared the partner for it. Experiencing such a shock without feeling prepared, and lacking knowledge of what to do in a new situation can create a sense of isolation and uncertainty. This highlights the importance of services sharing knowledge with partners at the outset.

Some partners found it difficult to have their needs met by services and to access the right support to increase their understanding:

“even though they’re fantastic staff they just don’t really know what, how to prepare you or advise you from day one of where you should go for this, what to do for that you know... it is a bit of a gap really because you could have had a bit of a springboard from the beginning and set things in motion from then rather than waiting.”

(Mary, 233-240)

This highlights how important it is for services to recognise the importance of a support network for partners and families in order to adjust to their new circumstances, and to intervene with the right support at the outset. Although services try their best to provide support and the correct information, partners are often unaware of what is available and how it may benefit them. Without this the chances of personal growth are greatly reduced. Support can be vital in making sense of events in the aftermath of a traumatic event and finding meaning. The right support can enable positive new schemas to be formed and post-traumatic growth to be experienced.



***Love and appreciation***

Love for their partner and identifying this as strength was also a coping strategy for many couples, they recognised this was a driving force and motivation for them to overcome all challenges:

“Well love for him really, and my appreciation because we’ve had a very good life, we’ve had a good marriage all along”

(Jill, 263-265)

It appears that if the relationship is strong then all other things can be worked on and overcome. Partners experienced stronger and closer relationships following adversity:

“It’s gone stronger, stronger and stronger because he knows I’m 100% there all the time, I’m there every day”

(Mary, 125-127)

This is important and highlights that partners can identify and build on existing strengths which is a key element of post-traumatic growth (Tedeschi & Calhoun, 1995). Having a greater sense of appreciation for partners and things in life was a consistent theme across couples:

“We are far more appreciative of it probably than you were before; you just took things before and got on with your life whereas now you’ve got time to think”

(Jill, 201-204)

Going through adversity and traumatic events enabled a greater sense of what was important in life, a greater appreciation of one’s own life and allowing more time for reflection. This reflection can facilitate growth and enable the identification of new

meanings and development of new schema. There was also a deep sense of appreciation for others within a social network, highlighting growth in relationships with others:

“...they were just as good before but er, we’re more needful of it more now aren’t we so you do notice it more. You, generally you appreciate people and you appreciate life far more than you did before, it’s a matter of not taking things for granted.”

(Jill, 191-195)

This highlights the ability to develop positive aspects of relationships and see relationships from a different perspective, and perhaps on a deeper level. This enables growth and once again is an important element of post-traumatic growth.

### *Communication*

Being able to communicate openly and honestly with one another was vital in being able to cope with the challenges and obstacles couples faced, and vital in being able to develop stronger relationships. One partner highlighted how this enabled more personal growth:

“understanding and listening, listening a lot more and then sectioning everything off, how to deal with things, prioritising, that’s what I’ve got. It’s the understanding I think more than anything I think more than anything because it’s obviously a whole new, a whole new field to go onto but, er just, just listening, listening a lot more.”

(Mary, 11-16)

The importance of listening to each other and having a shared understanding is stated here, and can lead to a greater sense of altruism whereby the partner wishes others to

understand their thoughts, feelings and experiences. Respecting their partner and their abilities is essential in maintaining a relationship and this is achieved through communication:

“you know he’s still got a mind and he’s still got you know, ability to talk and be himself and whatever so it’s like, I treat him no different to as he was before the accident. He’s just the same for me you know so I’ll tell him off or you know, have a shout or whatever and it’s exactly the same so I think that helps”

(Mary, 144-149)

This respect and understanding is vital for growth in a relationship. This supported previous research by Chan (2000b) who found that relationships tend to be stronger post-injury when there are opportunities to communicate and express feelings.

### **Summary**

The aim of this research was to gain an increased understanding of the complexity of living with people after a SCI, and what experience, if any, there is of post-traumatic growth. The findings from this study highlighted how partners of people with SCI experience post-traumatic growth, and that there is resonance with the conceptual ideas of post-traumatic growth as stated by Tedeschi & Calhoun (1995). Partners developed beyond their previous level of adaptation, psychological functioning, and life awareness. They identified something positively new that signifies a kind of additional benefit compared to pre-crisis level as highlighted in previous research by Zoellner & Maercker (2006).

The transcripts detailed a time of significant change for individuals and their relationships. Partners identified new and old strengths, became more resilient and

developed a greater sense of love and appreciation for life and people. Support was required from others to help partners come to terms with their new life situation and to cope with the situation. Time was required for self-reflection and communication was required to express thoughts and feelings to loved ones, to resolve differences and overcome challenges. Partners developed and experienced post-traumatic growth from these experiences. It was however, still an experience in which there were feelings of hopelessness, struggle and uncertainty.

### *Critique and further research*

This research focused on the experiences of post-traumatic growth in partners of people with a SCI, three to five years post injury. There were limitations in the methodology that may have had an impact on the validity of the findings. Participants were recruited using a purposive sampling approach, where potential participants were identified and contacted. Out of seven identified partners, two declined to participate. This reduced the number of males in the study and as a result there was a gender bias. This may have been pertinent as previous research by Joseph et al. (2005) found that women tend to report more growth than men. A study with an equal gender split may have shown less overall growth being reported.

Participants had access to psychological services at the recruitment site and consequently may have reported more positive experiences due to a greater understanding of their thoughts and feelings. They may have been more assertive in seeking support than individuals who did not take part in the study. It would be interesting to compare participants without access to psychology to discover whether they report fewer positive experiences.

This research focused on post-traumatic growth at a specific time of injury. A longitudinal methodology with interviews at different time points along the

relationship, greater than three to five years post injury would be useful. It would enable researchers to identify whether post-traumatic growth occurs in common stages throughout a relationship, or whether it is individual with no set pattern. It would also be interesting to see if themes changed over time and if so, in which areas.

This research did not investigate the influence of culture and how that may influence experiences and meanings of post-traumatic growth. Future research would benefit from incorporating this into the study aims. It would also be interesting to replicate the study with partners from a different service. This could be another spinal injury service or another medical setting such as a chronic pain management service for example, to see if partners have similar growth experiences.

An interesting area to investigate would be how much support and involvement injured individuals need and want from their partners, as each partner is likely to have his or her own requirements. It would also be interesting to see whether partners ever see too much support as a burden, both from families and services. Clearly this is a complex area that would benefit from further research.

### ***Clinical implications***

This research raises awareness of implications for clinical practice. The findings show that partners may experience post-traumatic growth but be unaware that it can be facilitated. Identifying contributing factors could improve wellbeing, reduce long term distress and reduce the need for interventions from services. It would be beneficial to have the concept of growth normalised and be seen as expected rather than an exception. Indeed the absence of any growth may be an indicator of distress.

Health care professionals working with these partners should be made aware of the different aspects of growth that can occur, and alert partners to how this can be facilitated and be of benefit. This could reduce distress and the need for long term psychological interventions. There should be an awareness that partners may be at different stages of the growth process. Though they may strive to be independent of services, support should always be available and reminders provided. Clinical psychologists can play a key role in their services by teaching and educating their departments, enabling others to disseminate knowledge about post-traumatic growth and its facilitation.

Healthcare professionals should ask partners whether they have attempted to make meaning of their situation and assess whether the partner is still in shock or coping adequately. The shock of having their partner seriously injured could make people forget their own needs. Services should provide practical support and offer psychological support immediately after a traumatic incident. Clinical psychologists could undertake assessments with partners directly, conduct joint consultation with other multidisciplinary team members or provide supervision to other healthcare professionals working with partners. Further support could be provided in the form of literature to take away so partners may return to it if unable to do so previously.

It would be beneficial for partner wellbeing if they were provided with time and space to process information at the time of diagnosis. Healthcare professionals should discuss factors that may be contributing to feelings of lack of control and being overwhelmed, with strategies put in place to reduce this. Awareness should be raised of how they may be feeling and questions that they may be asking themselves based on the experiences

of others. Partners should be signposted to support groups and services providing them with a source of support that normalizes their experiences.

### References

- Beauregard, L., & Noreau, L. (2010). Spouses of persons with spinal cord injury: impact and coping. *British Journal of Social Work, 40*, 1945–1959.
- Biggerstaff, D. L., & Thompson, A. R. (2008). Interpretative phenomenological analysis (IPA): A qualitative methodology of choice in healthcare research. *Qualitative Research in Psychology, 5*, 214-224.
- Blanes, L., Carmagnani, M. I. S., & Ferreira, L. M. (2007). Health-related quality of life of primary caregivers of persons with Paraplegia. *Spinal Cord, 45*, 399-403.
- Bonanno, G. A. (2004). Loss, trauma and human resilience. *American Psychologist, 59*, 20-28.
- Boschen, K. A., & Gregaro, J. (2009). Experiential outcomes of the SCI support provider role. *Topics in Spinal Cord Injury Rehabilitation, 14*, 69-87.
- Chan, R. (2000a). How does spinal cord injury affect marital relationship? A story from both sides of the couple. *Disability and Rehabilitation, 22*, 764-775.
- Chan, R. (2000b). Stress and coping in spouses of persons with spinal cord injuries. *Clinical Rehabilitation, 14*, 137-144.
- Chen, H. Y., & Boore, J. R. P. (2007). Establishing a super-link system: spinal cord injury rehabilitation nursing. *Journal of Advanced Nursing, 57*, 639–648.
- Department of Health. (2010). *Organising quality and effective spinal services for patients: a report for local health communities by the Spinal Taskforce*. London: Department of Health.



- Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology, 38*, 215-229.
- Gill, M. (1999). Psychosocial implications of spinal cord injury. *Critical Care Nursing Quarterly, 22*, 1-7.
- Holicky, R., & Charlifue, S. (1999). Ageing with spinal cord injury: The impact of spousal support. *Disability Rehabilitation 21*, 250-257.
- Isaksson, G., Josephsson, S., Lexell, J., & Skar, L. (2008). Men's experiences of giving and taking social support after their wife's spinal cord injury. *Scandinavian Journal of Occupational Therapy, 15*, 236-246.
- Janoff-Bulman, R. (1992). *Shattered assumptions*. New York: Free Press.
- Joseph, S., Linley, A. P., & Harris, G. J. (2005). Understanding positive change following trauma and adversity: Structural clarification. *Journal of Loss and Trauma, 10*, 83-96.
- Kaiser, S., & Kennedy, P. (2011). An exploration of cognitive appraisals following spinal cord injury. *Psychology, Health and Medicine, 16*, 708-718.
- Kennedy, P., Marsh, N., Lowe, R., Grey, N., Short, E., & Rogers, B. (2000). A longitudinal analysis of psychological impact and coping strategies following spinal cord injury. *British Journal of Health Psychology, 5*, 157-172.
- Kennedy, P., & Rogers, B. A. (2000). Anxiety and depression after spinal cord injury: A longitudinal analysis. *Archives Physical Rehabilitation, 81*, 932-937.

- Krause, J. S. (1998). Adjustment after spinal cord injury: A 9-year longitudinal study. *Archives of Physical Medicine and Rehabilitation*, 78, 651–657.
- Manigandan, C., Saravanan, B., Macaden, A., Gopalan, L., Tharion, G., & Bhattacharji, S. (2000). Psychological wellbeing among carers of people with spinal cord injury: a preliminary investigation from South India. *Spinal Cord*, 38, 559-562.
- Neimeyer, R. A. (2001). *Meaning reconstruction and the experience of loss*. Washington, DC: American Psychological Association.
- Post, M. W. M., Bloemen, J., & De Witte, L. P. (2005). Burden of support for partners of persons with spinal cord injuries. *Spinal Cord*, 43, 311–319.
- Smith, J. A. (2008). *Qualitative Psychology: A practical guide to research methods, second edition*. London: Sage Publications.
- Smith, J. A., Flowers, P. & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. London: Sage Publications.
- Smith, J. A., Jarman, M., & Osborn, M. (1999). Doing interpretative phenomenological analysis. In M. Murray & K. Chamberlain (Eds.), *Qualitative health psychology: Theories and methods* (pp.218–241). London: Sage publications.
- Tedeschi, R. G., & Calhoun, L. G. (1995). *Trauma and transformation: Growing in the aftermath of suffering*. Thousand Oaks, California: Sage Publications.
- Willig, C. (2001). *Introducing qualitative research in psychology: Adventures in theory and method*. Buckingham: Open University.

- Willig, C. (2008). *Introducing qualitative research in psychology: Adventures in theory and method second edition*. Maidenhead: McGraw-Hill Open University Press.
- Wilson, J. P., Friedman, M. J., & Lindy, J. D. (2001). An overview of clinical consideration and principles in the treatment of PTSD. In J. P. Wilson, M. J. Friedman & J. D. Lindy (Eds.), *Treating psychological trauma and PTSD* (pp. 59-94). New York: Guilford.
- Woodrich, F., & Patterson, J. B. (1983). Variables related to acceptance of disability in persons with spinal cord injuries. *Journal of Rehabilitation, 49*, 26-30.
- Zoellner, T., & Maercker, A. (2006). Post-traumatic growth in clinical psychology: A critical review and introduction of a two component model. *Clinical Psychology Review, 26*, 626-653.

**Reflective Review****Abstract**

This paper follows on from a qualitative piece of research that investigated the experiences of post-traumatic growth in partners of people that have experienced spinal cord injury. This paper presents a reflexive account of the researcher's positions throughout the research process. It will offer a reflective account of the research journey and discuss the process issues that arose. This thesis was affected by organisational difficulties in obtaining permission to begin research, and difficulties in recruitment and data collection. Following this there will be a reflection on the methodology, limitations of the study and learning points from the research.

## **Introduction**

This paper follows on from the research report, which explored the experiences of post-traumatic growth in partners of people that have experienced spinal cord injury (SCI). The research yielded one master theme, new identity, and six sub themes: resilience and strength, time for self, support, lack of understanding about new role, love and appreciation and communication.

This paper presents a reflective account of the research and is written in the first person in order for the reader to comprehend, and identify with the involvement of the researcher in the research process.

### **Reflexive account**

#### ***My personal position***

The decision to explore post-traumatic growth has been something I have been personally and professionally curious about for many years. I had been a student at university when I came across the term 'post-traumatic growth' in my lectures. This seemed to be a new focus in psychology and appealed to me because it was a way of looking at human strengths and characteristics that could be developed and enhanced through painful, traumatic experiences. Going through difficult times is something that everybody experiences and is part of what makes us human. Recognising how these times change us positively can reduce the distress of these events, improve well being and assist in coping. The term post-traumatic growth became increasingly familiar in my following years as an assistant psychologist as positive psychology became more popular and mainstream. I introduced the concept in my workplace through setting up and facilitating a positive psychology group as an assistant psychologist, in various

clinical settings. This made it clear to me that positive psychology and post-traumatic growth were relevant in clinical settings and could be of benefit to people.

### ***Stance as a researcher***

Interpretative phenomenological analysis (IPA) originates from two key theoretical positions namely, phenomenology and symbolic interactionism. IPA is phenomenological as it is concerned with subjective reports rather than attempting to formulate an objective account, and recognises that research is a dynamic process (Smith, 1996). Symbolic interactionism suggests that the focus of study should be how meanings are constructed by individuals in the context of their social and personal worlds (Smith & Osborn, 2003). These meanings can only be attained through an interpretive process (Smith, Flowers & Larkin, 1997).

IPA recognises the active role of the researcher in the interpretation of meanings, in that whilst the participants are trying to make sense of their world, the researcher is trying to make sense of the participant attempting to make sense of their world. Therefore a double hermeneutic process is apparent in IPA (Smith & Osborn, 2003). It is important that the researcher considers and acknowledges any potential 'subjective influences' upon the research process.

### ***Researcher Characteristics***

A male researcher who was younger than all of the participants and unmarried carried out the research interviews. It may have been that certain aspects of the relationship experience such as intimacy for example, may not have been discussed due to feeling uncomfortable talking about these issues with a male researcher. It could also have been the case that participants were over emphasising their positive relationship

experiences in order to mask any distressing issues they did not wish to disclose with the researcher.

I was aware that being a British Asian, able bodied, male twenty seven year-old clinical psychologist in my third year of training could impact on the research process. There was an awareness that my previous clinical experiences and personal assumptions may well have subdued some responses and promoted others. From my perspective I felt that participants were open and honest in their discussions around their experiences of post-traumatic growth, and most of the questions I asked whilst interviewing the participants were open-ended in nature. Most of the research that has been carried out with this population has been conducted by researchers and practitioners working within SCI settings, however this was a new area for me. A lack of clinical experience in this area may have been an advantage as participants were aware that I was not directly linked to the service and feedback was anonymous. They may have been more open and honest knowing that they were not going to potentially see me in the future as a therapist. Having not worked with this population before also meant I had less set preconceptions about what I would expect partners to say.

### **Process issues**

The completion of this research project has been one of the most difficult and stressful journeys I have been on in my life. There were organisational difficulties in waiting for signatures to get ethical approval, leading to many months of delays, difficulties in gaining ethical approval and difficulties in arranging interviews. Never have I had such a sense of uncertainty, lack of control and reliance on others for so long. Through this however, I have learned more about myself than I could have anticipated before starting and experienced my own growth.

Initially the route of traumatic head injury was considered due to an interest in the field and discussion with a clinician in the field. This raised an interesting dilemma; I was interested in the experiences of service users and hence wanted to adopt a qualitative methodology, whereas the clinician wanted a quantitative methodology to be used. After several meetings there was a lot of pressure at this point to agree with the clinician and change the project based on the wants of the clinician. The clinician had now refused to supervise my project if I adopted a qualitative methodology. Having initially approached this clinician, I felt as if withdrawing now would come across as rude and have wasted the time of both of us. At this point I sought supervision from my university supervisors and clinical placement supervisors. This highlighted the benefit of using the experience of others, and through this supervision I was able to come to a decision.

The area of post-traumatic growth was something I was very interested in and felt passionate about exploring; particularly the experiences people went through. With advice from my supervision I explained this to the initial clinician I had planned to work with. They were very understanding and actually recommended some other areas to consider. After this meeting I felt extremely relieved, the clinician had understood the situation and there were positive repercussions. Soon after I found a new supervisor who was very happy with my chosen methodology, shared similar interests and was keen to supervise me.

Conducting research can be a very lonely process and this highlighted the importance of having a supervision system in place, and not feeling as if you have to do everything by yourself. This situation created a dilemma of 'head versus heart'. There were two choices; the first was to follow the lead of the head injury clinician and their recommendations. In hindsight this may have been much more simplistic in terms of



procedure, but was a lot more removed from the topic I wanted to explore. The second choice was to follow my heart, identify a new niche area to explore post-traumatic growth in, and stay true to my interests and research aims. On reflection, making the decision to follow my heart definitely seemed like the right choice. It made me test my passion and resolve in pursuing a topic I was deeply interested in and I have learned many lessons about remaining optimistic and determined.

A particularly fascinating and totally unexpected aspect of this research process is that I feel I have experienced my own post-traumatic growth. This was achieved by going through the traumatic experiences of trying to gain signatures, overcome organisational difficulties, gain ethical approval and manage all this alongside placements and difficulties in my personal life. Through this I have found new meaning about the priorities of my career and my interests. I have developed better relationships with those close to me and have found a new love and appreciation for things outside of clinical work and academia. Perhaps the most recognisable strength has been increased resilience, a sense of being able to withstand and overcome any difficulty regardless of how many more obstacles are placed in the path to the final destination. This will assist me in my future clinical work and in all aspects of my life.

### ***Ethical considerations and reflexivity on the interview process***

Building rapport with participants in interviews is a key aspect of research interviews. In order to achieve this I followed a number of steps. Participants were spoken to before interviews were conducted to arrange suitable times to meet, discuss my role and discuss the study. In this way I was prepared to share something of myself and engage in conversations about my professional background, and personal information where relevant. This enabled participants to feel more comfortable in taking part in the

study and helped to minimise power imbalances, as I was not an expert who would judge them by their responses.

The rapport built from the initial contact helped engagement in interviews. This led to sharing of a whole range of emotions from happiness to sadness and laughter, as people recalled accounts of their experiences. It was made clear to participants that they did not have to express anything they did not wish to disclose and could stop the process at any time. The aim was to maximise benefit and minimise harm (British Psychological Society, 2010). All participants said that they found the interviews to be insightful and beneficial.

### *Presumptions*

Having gone through various ethics panel's discussing sensitive topics that participants may bring up and become distressed by, I was aware of having to put fears and concerns of these issues arising to one side and adapt my interviews should they arise. A conscious effort had to be made not to avoid these topics should they come up and enable the interviewee to discuss whatever they wished to. This may have been frustrating should the interview go off topic but it would allow insight into key concerns for participants. It was vital as a psychologist to respect the knowledge, insight and experience of clients (British Psychological Society, 2009). This is similar to work in clinical settings when reading client notes and hearing things from colleagues about a client, can create certain preconceptions about that client. It is important to be as fair and objective as possible.

Although no distressing topics came up I wondered whether I had deviated too much from my interview schedule in some of my interviews. After reading key literature I was reminded that researchers should adopt a flexible and creative approach to their

research (Smith, 2008; Willig, 2008). This approach does not claim to create a definitive account of participant transcripts; instead the results are co-constructions between the researcher and the participants. This led to ideas emerging from my first interview which resulted in new questions for my future interviews.

### *Confidentiality and consent*

A difficulty that arose frequently was the injured partner wanting to know exactly what was said during the interview of their non-injured partner. Due to the nature of the topic being discussed both partners had to consent for the interview to take place. Many injured partners expected to be present during the interview and refused to allow their relationship to be discussed without their presence, even if their non-injured partner wished to do so. Many non-injured partners who had consented to take part in the study had to be excluded because their partners refused to provide consent. Whilst this was frustrating, it is vital that the confidentiality of all involved is maintained (British Psychological Society, 2009; 2010)

### *Power*

The recruitment procedure highlighted how a power imbalance is existent for the non-injured partner and the researcher. Even if they wish to take part in the study and express their views and discuss their experiences of post-traumatic growth, they are unable to if their injured partner decides against it. This created a real sense of powerlessness for me and the non-injured partners, who very rarely have an opportunity to discuss themselves as a person and the more positive aspects of their relationships. At first I felt as if this was one-sided and biased against the non-injured partners, who were unable to talk and express their opinions. On reflection however, I realised that this powerlessness was also there for their injured partners who felt unable

to discuss their experiences and were the ones resigned to their injuries. Spinal cord injury can have a devastating effect on individuals and their families, and this real sense of powerlessness was felt for the first time at this point through conversations with partners.

Services can play a key role in empowering these service users, and taking small steps such as enabling people and their stories to be heard can be a massive step in reducing power differentials between individuals, couples and services. A dilemma that was difficult not to think about was when the non-injured partner was telling me that they wanted to discuss their experiences as they were finding things difficult, and went on to tell me their personal experiences and sensitive information. Although I was aware that the interview could not continue due to both partners not consenting, I listened to their experiences and felt I had a duty of care to that person even if I was not seeing them in a clinical role. No further input was required from services for any of the partners and there were no risk issues raised after enquiring. By doing this however, I left with information that I could not use in the research report results but may have affected my thoughts and views when undertaking interviews, and undertaking my reflective analysis.

### ***Dual consent***

A key theme was the injured partner fearing that something may be discussed which would make their partner want to leave them, and not trusting their partner to tell them what was said after the interview. This was difficult to predict as some partners were able to discuss this openly and come to a resolution. Many were not ready to discuss such issues with their partners and refused to communicate with their partner or services. One couple asked me to call back after a few days after they had a chance to

discuss things. The first time I rang I spoke to the injured partner who stated that they had massive rows over the project. They felt it would be a betrayal of trust to not let them be present at the interview. After explaining this would not be possible it was decided that the interview should not go ahead. Later that day however, I received a phone call from the non-injured partner stating that they would be happy to take part and were looking forward to the interview.

This created an uncomfortable situation where I had to explain that I had already had to cancel the interview at request of their partner. This non-injured partner then stated that they would persuade their partner to agree. Although I desperately wanted to secure an interview, ethically I knew it would be inappropriate under these circumstances if both partners were not happy and one had to persuade the other partner against their will.

This highlighted how difficult the research process can be when there is not clear communication, but particularly when dual consent is required from a couple. Within this study it was an unexpected factor that had a big impact on the number of potential participants eligible to take part in interviews.

### ***The right to withdraw***

Another situation that arose was that of partners accepting to take part in the interview but then changing their mind. Participants were made aware of their right to withdraw from the process at any time without reason. Two participants withdrew from the study, one male partner and one female partner. The potential male partner had initially agreed to take part in the interview, however when I called to arrange a time to meet for the interview they informed me that they had changed their mind. At this point I was struggling to recruit participants and I was left feeling upset and disheartened. What was particularly frustrating was not being aware of the reason, was it personal or

something to do with the research information provided? It was however their right to withdraw, and by putting myself in their position I could think of situations where I may want to withdraw and not have to explain why.

The implications for the study would have been less of a gender bias and another male perspective. The implications for both persons withdrawing were missing out on the opportunity for more opinions that could have further validated findings, and led to new themes emerging.

### ***Practical arrangements***

Another difficulty was that that of practical arrangements in getting to and from places. The interviews had to take place at a hospital where clinicians were available should an interviewee become distressed, and require debriefing and assistance from a qualified member of staff. Some partners were only available to meet in the evenings due to their work commitments and some could not drive. Hence the only time to meet was when they had scheduled appointments at the hospital for which they had prearranged transport. These times were months ahead and not suitable within the required timeframes. This automatically ruled out many potential participants. This highlights how important it is to take all factors into consideration when planning and recruiting for a research project, and will certainly be taken into account for future research projects.

### **Reflection on Methodology**

Interpretative phenomenological analysis (IPA) was selected as the methodology for this study because it emphasises personal meaning, and sense making in a particular context for people who share a similar experience (Smith, Flowers & Larkin, 2009). It

is judged to be especially appropriate for rigorous and in-depth investigations of psychological experiences and is a method widely used in clinical and health psychology (Reid, Flowers & Larkin, 2004). It aims to capture the quality and texture of individual experiences and explore the meanings of these experiences (Willig, 2001). IPA is a suitable method of enquiry for exploring the experiences of post-traumatic growth in partners of persons with a SCI, as the meanings and interpretations derived are not objective phenomena or truths but are socially constructed (Willig, 2001). Other qualitative methodologies such as grounded theory were not selected because there is less emphasis on participant experience in a particular context, and more on the structure and content of narratives and forming explanatory theoretical-level accounts (Smith, Flowers & Larkin, 2009). Smith, Jarman and Osborn (1999) highlighted that IPA cultivates creativity and interpretation during data analysis; and is therefore possibly less constrained than other qualitative methodologies. On completion of the analysis and with the sample size in this study, I felt that IPA had been an appropriate method to explore my research question.

The fact that I only managed to recruit five participants into the study may have been advantageous, as it enabled a deeper insight into the lives of five partners than perhaps a larger sample would have enabled. Smith and Osborn (2003) highlighted that studies have been published using IPA where samples of one to fifteen and more have been used. Hence there is no correct sample size figure to use with this method. When carrying out research there are sometimes factors beyond control of the researcher and the researcher has to make do with the sample size available. To allow the researcher to explore a phenomenon as a specific group shares it, sample sizes should be as homogenous as possible as IPA is not focused on generalisability. The sample in this

study was as homogenous as possible given the inclusion criteria, participant difficulties and the service their partners were in.

### *Limitations of the study*

One of the main limitations of this study was the generalisability of findings. It may have been more appropriate instead to think in terms of transferability. This basically refers to 'applying the findings of a study to context similar to the context in which they were first derived' (Henwood & Pidgeon, 1996). The findings could then be applied or compared with similar research within spinal injury services nationally and possibly internationally. Due to unforeseen circumstances and time restraints the study sample was still small in comparison to other qualitative research. This may have limited the transferability of findings. Had time limits and resources permitted, a larger sample would have added to the findings and conclusions made.

The responses examined were predominantly those of women and hence there may have been a gender bias. It would be interesting to note if the responses provided would have been different had I been a female researcher. Another possible limitation consistent with qualitative research in general was the degree to which my own beliefs, assumptions and viewpoints impacted on the interpretation of data. I was curious as to whether I neglected data that did not fit with my worldviews when analysing my results. I was of a different age and culture to all participants, and my understanding of concepts such as strength and resilience may have been different. Hence there may have been subtle differences in the way something was said, to the way it was interpreted. I attempted to minimise this effect by being as open and transparent as possible during my reflections, and applying validity checks during the data analysis stage of the study.



*Learning points**Academic*

The process of conducting the literature review has highlighted how critical it is to evaluate the evidence base prior to conducting research. There will always be gaps in research as more knowledge is gained and there are more questions to answer. Advancements in learning and theories will only be made through critiquing the available literature and conducting further research.

The process of conducting the research study highlighted how crucial it is to have a clear research question, direction and focus when beginning research. This then requires careful planning at each stage with the flexibility for setbacks. The process of using interpretative phenomenological analysis has increased my understanding of its philosophical origins and the application of a qualitative methodology to research.

*Clinical*

Conducting this research has made me more aware of the needs of partners and the factors that can lead them to come in to contact with, and avoid contact with, mental health services.

Reflecting on this enabled me to see how services can attempt to meet the needs of partners to the best of their ability, but sometimes fail to provide exactly what is required. This highlights how important it is to continually conduct research to improve theory-practice links and help services provide the best care possible for service users and their families.

It is important to reflect on how we are influenced as practitioners by our own assumptions, biases, dominant discourses in the systems we operate in and our working

environments. This enables us to truly be reflective scientist practitioners. Conducting the literature review highlighted how important it is to refer to the evidence bases available for our everyday practice. We should question, critique and justify the techniques and theories we use to ensure we are providing service users with the best possible service.

### *Personal*

It is important to acknowledge the impact I may have had on the process and results of the research, and the importance of making this transparent for others. This should also be highlighted and discussed more often in my supervision, about the effect my influences have on the people I work with as a practitioner. From the difficulties experienced with this research study, I have gone through my own growth experience and learned a lot about my own strengths and growth factors.

### **Conclusions**

This research has provided understanding of the role of post-traumatic growth experienced in partners of persons with SCI. It has provided further insight into the needs of this population, and highlighted that post-traumatic growth can be facilitated to reduce partner distress and improve their well being. It has also highlighted the need to raise awareness of partner needs amongst spinal injury services.

### References

- British Psychological Society. (2009). *Code of ethics and conduct*. Leicester: British Psychological Society.
- British Psychological Society. (2010). *Code of human research ethics*. Leicester: British Psychological Society.
- Henwood, K. L., & Pidgeon, N. F. (1992). Qualitative research and psychological theorizing. *British Journal of Psychology*, 83, 97-111.
- Reid, K., Flowers, P., & Larkin, M. (2004). Exploring lived experience: An introduction to interpretative phenomenological analysis. *The Psychologist*, 18, 20–23.
- Smith, J. A. (1996). Beyond the divide between cognition and discourse: Using interpretive phenomenological analysis in health psychology. *Psychology and Health*, 11, 261-271.
- Smith, J. A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*, 1, 39-54.
- Smith, J. A., Jarman, M., & Osborn, M. (1999). Doing interpretative phenomenological analysis. In M. Murray & K. Chamberlain (Eds.), *Qualitative health psychology: Theories and methods* (pp.218–241). London: Sage publications.

Smith, J. A., & Osborn, M. (2003) Interpretative phenomenological analysis. In

J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp.51-80). London: Sage publications.

Smith, J. A., & Osborn, M. (2008). Interpretative phenomenological analysis. In J. A.

Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp.53-80). London: Sage publications.

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological*

*analysis: Theory, method and research*. London: Sage publications.

Willig, C. (2001). *Introducing qualitative research in psychology: Adventures in theory*

*and method*. Buckingham: Open University Press.

Willig, C. (2008). *Introducing qualitative research in psychology*. Maidenhead: Open

University Press.

**Appendix A** - Author guidelines for the Journal of Positive Psychology – selected journal for literature review

Taken from:

<http://www.tandfonline.com/action/authorSubmission?journalCode=rpos&page=instructions&>

## **Manuscript preparation**

### **1. General guidelines**

- Papers are accepted in English only. American or British English spelling and punctuation is accepted provided that usage is consistent throughout the text. Please use single quotation marks, except where ‘a quotation is “within” a quotation’.
- A typical article will not exceed 7,500 words (inclusive of tables/references/figure captions/footnotes/endnotes). Papers that greatly exceed this will be critically reviewed with respect to length. Authors should include a word count with their manuscript.
- Manuscripts should be typed double spaced, with margins of at least one inch. All pages should be numbered.
- Manuscripts should be compiled in the following order: title page; abstract; keywords; main text; acknowledgments; appendixes (as appropriate); references; table(s) with caption(s) (on individual pages); figure caption(s) (as a list).
- [Abstracts](#) of no more than 150 words are required for all papers submitted.
- Each paper should have four to ten [keywords](#) .
- Search engine optimization (SEO) is a means of making your article more visible to anyone who might be looking for it. Please consult our guidance [here](#) .
- Section headings should be concise.
- All the authors of a paper should include their full names, affiliations, postal addresses, telephone numbers and email addresses on the cover page of the manuscript. One author should be identified as the corresponding author. The affiliations of all named co-authors should be the affiliation 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 the article is accepted.
- For all manuscripts non-discriminatory language is mandatory. Sexist or racist terms should not be used.
- Authors must adhere to [SI units](#) . Units are not italicised.
- When using a word which is or is asserted to be a proprietary term or trade mark, authors must use the symbol ® or TM.

### **2. Style guidelines**

- Description of the Journal’s [article style](#) and [quick guide](#)
- Description of the Journal’s [reference style](#) and [quick guide](#)
- [Guide to using mathematical symbols and equations](#)

- [Word templates](#) are available for this journal. If you are not able to use the template via the links or if you have any other template queries, please contact [authortemplate@tandf.co.uk](mailto:authortemplate@tandf.co.uk)

### 3. Figures

- It is in the author's interest to provide the highest quality figure format possible. **Please be sure that all imported scanned material is scanned at the appropriate resolution: 1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour.**
- Figures must be saved separate to text. Please do not embed figures in the paper file.
- Files should be saved as one of the following formats: TIFF (tagged image file format), PostScript or EPS (encapsulated PostScript), and should contain all the necessary font information and the source file of the application (e.g. CorelDraw/Mac, CorelDraw/PC).
- All figures must be numbered in the order in which they appear in the paper (e.g. Figure 1, Figure 2). In multi-part figures, each part should be labelled (e.g. Figure 1(a), Figure 1(b)).
- Figure captions must be saved separately, as part of the file containing the complete text of the paper, and numbered correspondingly.
- The filename for a graphic should be descriptive of the graphic, e.g. Figure1, Figure2a.

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## 6. Supplementary online material

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- [Information about supplementary online material](#)

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**Appendix B** – Author guidelines for Journal of loss and trauma – selected journal for submitting research report

Taken from :

<http://www.tandfonline.com/action/authorSubmission?journalCode=upil20&page=instructions>

### **Submission of Manuscripts**

Original manuscripts should be submitted to John Harvey, Department of Psychology, University of Iowa, Iowa City, IA 52242-1407; phone (319) 335-2473; fax (319) 335-2799; e-mail: [john-harvey@uiowa.edu](mailto:john-harvey@uiowa.edu) . Authors are strongly encouraged to submit manuscript files via email attachment. The manuscript should be prepared using MS Word or WordPerfect and should be clearly labeled with the authors' names, file name, and software program. Each manuscript must be accompanied by a statement that it has not been published elsewhere and that it has not been submitted simultaneously for publication elsewhere. Authors are responsible for obtaining permission to reproduce copyrighted material from other sources and are required to sign an agreement for the transfer of copyright to the publisher. All accepted manuscripts, artwork, and photographs become the property of the publisher.

All parts of the manuscript should be typewritten, double-spaced, with margins of at least one inch on all sides. Number manuscript pages consecutively throughout the paper. All titles should be as brief as possible, 6 to 12 words. Authors should also supply a shortened version of the title suitable for the running head, not exceeding 50 character spaces. Each article should be summarized in an abstract of not more than 100 words. Avoid abbreviations, diagrams, and reference to the text. Please consult our guidance on keywords [here](#) .

Manuscripts, including tables, figures, and references, should be prepared in accordance with the Publication Manual of the American Psychological Association (Fourth Edition, 1994). Copies of the manual can be obtained from the Publication Department, American Psychological Association, 750 First Street NE, Washington, DC 20002-4242; phone (202) 336-5500.

### **Illustrations**

Illustrations submitted (line drawings, halftones, photos, photomicrographs, etc.) should be clean originals or digital files. Digital files are recommended for highest quality reproduction and should follow these guidelines:

- 300 dpi or higher
- sized to fit on journal page
- EPS, TIFF, or PSD format only
- submitted as separate files, not embedded in text files

### **Tables and Figures**



Tables and figures should not be embedded in the text, but should be included as separate sheets or files. A short descriptive title should appear above each table with a clear legend and any footnotes suitably identified below. All units must be included. Figures should be completely labeled, taking into account necessary size reduction. Captions should be typed, double-spaced, on a separate sheet. All original figures should be clearly marked in pencil on the reverse side with the number, author's name, and top edge indicated.

### **Proofs**

One set of page proofs is sent to the designated author. Proofs should be checked and returned within 48 hours.

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**Appendix C** – Letter of Invitation to participants

The Robert Jones and Agnes Hunt   
Orthopaedic and District Hospital  
NHS Trust

**MIDLANDS CENTRE FOR SPINAL INJURIES**

Oswestry

Shropshire

SY10 7AG

Telephone 01691 404000

Minicom/text 01691 404558

Clinical Psychology

Direct line: 01691 404649

**Experiences of post-traumatic growth in spinal cord injury partners****Letter of Invitation to Participants**

Dear,

I am a trainee clinical psychologist working in Shropshire. I am writing to invite you to take part in a research study, taking place at the Midlands Centre for Spinal Injuries. I am carrying out the study as part of the Doctorate in Clinical Psychology at Staffordshire and Keele Universities.

The research I am completing is looking at the experiences of partners of people who have sustained a spinal cord injury in the last 3-5 years. There hasn't been a great deal of research which has looked specifically at how spinal cord injury impacts upon the lives of partners and so understanding more about this would help to inform services to better support couples in the future. I am particularly interested to find out about whether partners' experience any positive changes as a result of coping with the impact of spinal cord injury. This is known as 'post-traumatic growth'.

Taking part in this research would involve completing a single interview where you would be asked to talk about your personal experiences of growth since your partners injury. The main focus of the interview would be about looking for any areas of positive change in your life. Even if you do not feel that there have been any positive changes, I would still be very interested to find out more about your experiences.

The research has been approved by the Staffordshire University and NHS ethics committees.

I am enclosing the study information sheet for you to have a look at. If you think you might be interested in taking part and/or would like to find out more, please complete the slip at the bottom of this page and return it, either to the health professional who has given it to you, or in the pre paid envelope. Alternatively you may contact the Midlands Centre for Spinal Injury Psychology department to confirm your interest on 01691 404649. If I do not hear from you in two weeks I will assume you do not wish to take part in the study.

I will then make contact with you to discuss the study and see whether you would like to be involved. By returning this form you are not committing yourself to taking part. I hope that you will be interested in finding out more and look forward to hearing from you soon.

Many thanks and best wishes,

Kamaldip Kahlwan

Trainee Clinical Psychologist

Working under the supervision of Dr Sally Kaiser, Clinical Psychologist, MCSI

---

**OPT-IN SLIP**

I am considering taking part in the study investigating the experiences of post-traumatic growth in partners of people who have experienced spinal cord injury. I am happy for you to make contact with me about this.

Name:

---

Address:

---

Telephone Number:

---

OPT-OUT SLIP

I would not like to take part in the study investigating the experiences of post-traumatic growth in partners of people who have experienced spinal cord injury

Name:

---

Address:

---

---

Telephone Number:

---

Appendix D – letter of approval from Staffordshire University Peer Review



Faculty of Health/Faculty of Sciences

To whom it may concern

Application for Independent Peer Review Approval

Researcher: Kamaldip Kahlwan

Study Title: Experiences of post traumatic growth in spinal cord injury partners

I can confirm that Staffordshire University supports this research project proposal being put forward by the above research project applicant, and that the University is willing to act as sponsor of the project if it received LREC approval.

Our support for this project takes account of the outcome of an independent peer review of its scientific merit undertaking within the University.

I can also confirm that the University has generic indemnity/insurance arrangements in place as stated on the attachment to this letter, that arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed, that arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts and that the duties of sponsors set out in the NHS Research Governance Framework for Health and Social Care will be undertaken in relation to this research.

A handwritten signature in black ink, appearing to read 'Jim Radcliffe'.

Dr Jim Radcliffe  
Chair,  
University Academic Ethics Sub-Committee

**Appendix E** – Letter of approval from NHS Research Ethics Committee**Health Research Authority****NRES Committee East Midlands - Derby**

Research Ethics Office  
The Old Chapel  
Royal Standard Place  
Nottingham  
NG1 6FS

Telephone: 0115 8839436  
Facsimile: 0115 8839294

21 March 2012

Mr Kamaldip Kahlwan  
Trainee Clinical Psychologist  
Staffordshire and Shropshire Foundation Trust  
20 Park Avenue  
Goldthorn Park  
Wolverhampton  
WV4 5AL

Dear Mr Kahlwan

**Study title:** A qualitative study of the experiences of post traumatic growth, in partners of people that have experienced spinal cord injury

**REC reference:** 12/EM/0079

Thank you for your letter of 14 March 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Vice-Chair.

**Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

**Ethical review of research sites****NHS sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

**Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of approvals from host organisations*

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		
Evidence of insurance or indemnity		15 July 2011
GP/Consultant Information Sheets	2	24 January 2012
Interview Schedules/Topic Guides	2	02 February 2012
Investigator CV		02 February 2012
Letter from Sponsor		02 February 2012
Letter of invitation to participant	2	13 March 2012
Other: CV for Helen Combes		31 January 2012
Participant Consent Form: Partner	1	02 February 2012
Participant Consent Form: Participant Consent Form	2	13 March 2012
Participant Information Sheet	2	13 March 2012
Participant Information Sheet: Partner	2	13 March 2012
Protocol	1	02 February 2012
REC application		06 February 2012
Referees or other scientific critique report		21 January 2011
Response to Request for Further Information		14 March 2012

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### After ethical review

#### Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:



- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

<b>12/EM/0079</b>	<b>Please quote this number on all correspondence</b>
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With the Committee's best wishes for the success of this project

Yours sincerely



**Mr Peter Korczak**  
**Chair**

Email: [carol.marten@nottspct.nhs.uk](mailto:carol.marten@nottspct.nhs.uk)


Enclosures: "After ethical review – guidance for researchers"

Copy to: David Clark-Carter, Staffordshire University  
Mellor Building  
Stoke-on-Trent ST4 2DE

Miss Teresa Jones,  
RJAH Orthopaedic Hospital NHS Foundation Trust  
Research Office  
Oswestry SY10 7AG



**Appendix F** – Letter of approval from NHS Robert Jones and Agnes Hunt Orthopaedic Hospital NHS Foundation Trust Research and Development department

**The Robert Jones and Agnes Hunt**   
**Orthopaedic Hospital**  
NHS Foundation Trust

Research Office  
Oswestry  
Shropshire  
SY10 7AG  
Telephone 01691 404143  
Email: teresa.jones@rjah.nhs.uk

Mr Kamaldip Kahlwan  
c/o Sally Kaiser  
MCSI  
RJA Orthopaedic Hospital

13<sup>th</sup> April 2012

**Confirmation of NHS Trust Approval of Research Study**

Dear Mr Kahlwan

I can confirm that approval has been granted by the Robert Jones & Agnes Hunt Orthopaedic Hospital NHS Foundation Trust Research Management and Governance Office for the following research study, which falls under the requirements set out in the NHS Research Governance Framework.

<b>Title:</b>	A qualitative study of the experiences of post traumatic growth in partners of people that have experienced spinal cord injury.
<b>R&amp;D / CLRN Reference:</b>	RL1 465
<b>Ethics Reference:</b>	12/EM/0079
<b>Chief Investigator:</b>	Mr Kamaldip Kahlwan
<b>Principle Investigator (RJA):</b>	Sally Kaiser
<b>Sponsor:</b>	Staffordshire and Keele Universities
<b>Funder:</b>	PhD project – university funded
<b>Proposed local study end date:</b>	1 <sup>st</sup> July 2012

You may begin this research study within the Robert Jones & Agnes Hunt Orthopaedic Hospital NHS Foundation Trust.

Please read carefully the following additional information that is applicable to this confirmation of approval.

Please note that your research study may be monitored or audited by this research office or other relevant authority as part of the requirements set out



In order for us to continue to meet the requirements for Research Governance you are requested to provide us with the following documents (electronic or paper) relating to this study:

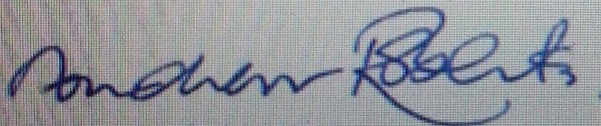
- A copy of all NRES Annual progress report(s) (if applicable)
- A copy of the NRES End of Study Declaration
- A copy of the final report no more than 6 months after completion of the study

You are also requested to notify us about any of the following that are applicable:

- Amendments to any documents that require REC approval
- Changes to the study start and end dates
- Changes in personnel / members of the research team
- Changes to details of locations of the study
- Any serious adverse events (SAE, SUSAR) within the timescale specified on the NRES website.

Wishing you every success with the study.

Yours sincerely



Mr Andrew Roberts  
Research Director.

**Appendix G – Participant Information Sheet**

The Robert Jones and Agnes Hunt   
Orthopaedic and District Hospital

NHS Trust

**MIDLANDS CENTRE FOR SPINAL INJURIES**

Oswestry

Shropshire

SY10 7AG

Telephone 01691 404000

Minicom/text 01691 404558

Clinical Psychology

Direct line: 01691 404649

**Participant Information Sheet****Experiences of post-traumatic growth in spinal cord injury partners****Information Sheet**

You are being invited to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Do not hesitate to contact me if there is anything that is not clear to you or if you would like more information. Please take time to decide whether or not you wish to take part.

Thank you for taking the time to read this.

**What is the purpose of the study?**

The aim of the study is to learn more about the experiences of post-traumatic growth in partners of people with spinal cord injury. Post-traumatic growth refers to the positive ways you change as a person after dealing with difficult events, and the new way you see yourself and the world around you. Being able to discuss experiences may be helpful in making sense of the difficulties you have gone through and to identify the ways in which you have experienced positive growth in different areas of your life. It is hoped that by increasing our understanding of the experience of partners that we may be able to think about ways to offer better support and services to meet the needs of future couples.



Why have I been chosen?

We are looking for around 10 volunteers who would be prepared to take part in this study. We are hoping to talk to people who are the partner of someone who has sustained a spinal cord injury in the last 3-5 years. You are being invited to participate as the team at the Midlands Centre for Spinal Injuries have identified you as someone who fits into these criteria. Your partner has been contacted and asked if they would be happy for us to send you information about the study.

Do I have to take part?

No. It is completely up to you to decide whether or not you wish to take part. If you do decide to take part you will be asked to sign a consent form. Even after signing this form you can still choose to withdraw from the study at any time and without giving a reason. Deciding to take part in this study or not, will not have any impact on the ongoing service received by your partner from the Midlands Centre for Spinal Injuries.

What will happen to me if I take part?

If you decide to take part, the researcher will call you to arrange a convenient time to meet together at the Midlands Centre for Spinal Injuries, in order to complete the interview. When you attend, the researcher will firstly go through all the information about the study with both you and your partner and answer any questions either of you may have. If you are both still happy to continue, you will both be asked to sign consent forms, prior to yourself completing an interview.

The interview itself will take place in a private room within the centre. Your partner will not be present for the interview. It should take approximately one hour to complete. The purpose of the interview is to find out about your experiences, so you will be able to focus on areas that you feel have been important for yourself. You do not need to talk about anything that you feel uncomfortable sharing. During the interview you can choose not to answer any question you are asked. You will also be given the opportunity to ask any questions you may have.

All interviews will be audio taped. This tape will be used to produce a typed transcript of what was said in the interview. All names and identifying information will be removed from the transcript and so whatever is said will be anonymous. After the transcription has been made, the tape will be destroyed.

You can choose to be sent a copy of your interview transcript if you request this from the researcher after your interview.

The researcher will then look at the interview transcripts for patterns and differences in how different participants have talked about their experiences. Together this information will be used to help to develop understanding about partners' experiences following spinal cord injury.

What are the possible disadvantages of taking part?

Taking part in this study will involve talking to the researcher about your experiences. This might be emotional and it is possible that you might talk about issues which you have not thought about before, or which may be upsetting for you. You may disclose information that is deeply sensitive in nature. Please think about this before agreeing to participate. You may wish to discuss this research with your partner before making a decision about participating.

The researcher is a trainee clinical psychologist and has experience of talking to individuals about emotive issues. He will therefore try to remain sensitive to the fact that what may be said may be difficult. You would be in control of the interview, and would not need to talk about anything that you prefer not to. The interview can be stopped at any time.

What are the possible advantages of taking part?

Having the opportunity to reflect on your experiences and identify areas in which you feel you have experienced growth and found new or different meaning could be a positive personal experience. You may find it helpful to have the opportunity to share your experiences and talk about your situation with an objective researcher.

The information from the study will help us help learn more about the experiences of post-traumatic growth in partners of people with spinal cord injury. We hope that this may lead to future benefits in improved support for other partners in a similar situation to you.

What will happen if I do become upset following the interview

If you were to feel upset after completing the interview, the clinical psychology team at the centre would be happy to see you to provide further support, as required.

Any further support would be undertaken with the usual boundaries of confidentiality of specialist psychological services and information shared would not be used in any way as part of the research study.

Will my taking part in this study be kept confidential?

The audio tape of your interview will be kept securely until it has been transcribed by the researcher. The tape itself will then be destroyed. Your name will not be attached to the typed interview transcript and anything which you say which may identify you (e.g. names of people or places etc.) will be removed or changed so that you cannot be recognised. Your name and address will not be used other than to write to you during the research process. All information will be kept in a locked filing cabinet or on a computer with a protected password. Anonymised interview transcripts will be read by the researcher and another psychologist involved in the analysis process. They will not be included in their entirety in any report that is written. Quotes from

the interviews will be included in reports written about this study, but you will remain anonymous. Your partner will not be given any information about the content of the interview and it will be your choice if you wish to share with them what was discussed, or not.

What will happen to the results of this research study?

This study will be written up as part of a Doctoral Thesis for the University of Staffordshire and will be retained in the University Library. You will be sent a written summary of the study results once it is completed if you request it. The results of the study may also be written for inclusion in a scientific journal. If this occurred you would be able to request a copy of any resulting publications.

Who is organising and funding the research?

The researcher is carrying out the study for a Doctorate in Clinical Psychology at Staffordshire and Keele Universities.

Who has reviewed the study?

The study has been reviewed and approved by university and NHS ethics committees,

**What happens next?**

If you have decided that you would like to participate in this study you can contact the researcher (details below), or the team at The Midlands Centre for Spinal Injuries to arrange a time to complete the interview. Both consent forms from yourself and your partner will need to be returned with the opt-in form before any interview can take place. A reminder letter will be sent to you after two weeks if no response is received.

If you are unsure and have any questions please feel free to contact the researcher to discuss any aspect of the study.

Thank you for taking the time to read this information.

Researcher:

Kamaldip Kahlwan

Trainee Clinical Psychologist,

Mellor Building  
Staffordshire University  
College Road  
Stoke-on-Trent  
Staffordshire  
ST4 2DE

kkahlwan@nhs.net

If you are unhappy about any aspect of the way you have been approached or treated during the course of the study, you may contact

Dr Sally Kaiser

Clinical Psychologist

Midlands Centre for Spinal Injuries

Robert Jones & Agnes Hunt Orthopaedic & District Hospital

Tel: 01691 404511

Email: [Sally.Kaiser@rjah.nhs.uk](mailto:Sally.Kaiser@rjah.nhs.uk)

Alternatively you can contact the Patient Advice and Liaison Service (PALS) which is a confidential service that provides support to patients, carers and relatives, representing their views and resolving local difficulties on the spot by working in partnership with Trust staff.

**The PALS Officer**

Robert Jones & Agnes Hunt Orthopaedic & District Hospital

NHS Trust,

Oswestry

Shropshire

SY10 7AG

**Tel:** 01691 404606

**Email:** [PALS.office@rjah.nhs.uk](mailto:PALS.office@rjah.nhs.uk)

Thank you for your interest in this study

**Appendix H** – Participant Partner Information Sheet

The Robert Jones and Agnes Hunt   
Orthopaedic and District Hospital  
NHS Trust

**MIDLANDS CENTRE FOR SPINAL INJURIES**

Oswestry

Shropshire

SY10 7AG

Telephone 01691 404000

Minicom/text 01691 404558

Clinical Psychology

Direct line: 01691 404649

**Participant Partner Information Sheet****Experiences of post-traumatic growth in spinal cord injury partners****Information Sheet**

Your partner is being invited to take part in a research study. This is likely to involve experiences of how their relationship with you post-injury being has helped them experience personal growth. It is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Do not hesitate to contact me if there is anything that is not clear to you or if you would like more information. Please take time to decide whether or not you would like to give consent for your partner to take part.

Thank you for taking the time to read this.

**What is the purpose of the study?**

The aim of the study is to learn more about the experiences of post-traumatic growth in partners of people with spinal cord injury. Post-traumatic growth refers to the positive ways you change as a person after dealing with difficult events, and the new way you see yourself and the world around you. Being able to discuss their experiences may be helpful in making sense of the



difficulties your partner has gone through and to identify the ways in which they have experienced positive growth in different areas of their life. It is hoped that by increasing our understanding of the experience of partners, that we may be able to think about ways to offer better support and services to meet the needs of future couples.

Why has my partner been chosen?

We are looking for around 10 volunteers who would be prepared to take part in this study. We are hoping to talk to people who are the partner of someone who has sustained a spinal cord injury in the last 3-5 years. Your partner is being invited to participate as the team at the Midlands Centre for Spinal Injuries have identified them as someone who fits into these criteria.

Do I have to take part?

No. All that is requested from yourself is that you sign a consent form which states that you are happy for your partner to take part in the study. Even after signing this form you can still choose to withdraw your consent from the study at any time and without giving a reason. Deciding to take part in this study or not, will not have any impact on the ongoing service received by you and/or your partner from the Midlands Centre for Spinal Injuries.

What will happen to the results of this research study?

This study will be written up as part of a Doctoral Thesis for the University of Staffordshire and will be retained in the University Library. The results of the study may also be written for inclusion in a scientific journal.

**What happens next?**

If you have decided that you would like to give consent for your partner to participate in this study, please sign your consent form which is provided and return it with your partners consent form. Both consent forms from yourself and your partner will need to be returned with the opt-in form before any interview can take place. A reminder letter will be sent to you after two weeks if no response is received.

If you are unsure and have any questions please feel free to contact the researcher to discuss any aspect of the study.

Thank you for taking the time to read this information.

Researcher:

Kamaldip Kahlwan

Trainee Clinical Psychologist,

Mellor Building  
Staffordshire University  
College Road

Stoke-on-Trent  
Staffordshire  
ST4 2DE

[kkahlwan@nhs.net](mailto:kkahlwan@nhs.net)

If you are unhappy about any aspect of the way you have been approached or treated during the course of the study, you may contact

Dr Sally Kaiser

Clinical Psychologist

Midlands Centre for Spinal Injuries

Robert Jones & Agnes Hunt Orthopaedic & District Hospital

Tel: 01691 404511

Email: [Sally.Kaiser@rjah.nhs.uk](mailto:Sally.Kaiser@rjah.nhs.uk)

Alternatively you can contact the Patient Advice and Liaison Service (PALS) which is a confidential service that provides support to patients, carers and relatives, representing their views and resolving local difficulties on the spot by working in partnership with Trust staff.

**The PALS Officer**

Robert Jones & Agnes Hunt Orthopaedic & District Hospital  
NHS Trust,  
Oswestry  
Shropshire  
SY10 7AG

**Tel:** 01691 404606

**Email:** [PALS.office@rjah.nhs.uk](mailto:PALS.office@rjah.nhs.uk)

Thank you for your interest in this study

**Appendix I – Participant Consent Form**



The Robert Jones and Agnes Hunt   
Orthopaedic and District Hospital  
NHS Trust

**MIDLANDS CENTRE FOR SPINAL INJURIES**

Oswestry

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Telephone 01691 404000

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Clinical Psychology

Direct line: 01691 404649

**Participant Consent Form**

**Experiences of post-traumatic growth in spinal cord injury partners**

Name of Researcher:

Kamaldip Kahlwan

Trainee Clinical Psychologist

Midlands Centre for Spinal Injuries

RJ & AH Orthopaedic Hospital

Oswestry, Shropshire, SY10 7AG

01691 404511

I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions

I understand that my participation is voluntary and that I am free to withdraw at any time without my legal or medical rights being affected

I give consent for audio taping of the interview

I give consent for direct quotes from the transcript of this interview to be used anonymously in the study write up

I give consent for direct quotes from the transcript of this interview to be used anonymously in any subsequent publications

I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the Midlands Centre for Spinal Injuries from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research.  
I give permission for these individuals to have access to my records.

I agree to take part in the above study

Name of Participant

Signature

Date

---

---

---

Name of Researcher

Signature

Date

---

---

---

**Appendix J – Participant Partner Consent Form**



The Robert Jones and Agnes Hunt   
Orthopaedic and District Hospital  
NHS Trust

**MIDLANDS CENTRE FOR SPINAL INJURIES**

Oswestry

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Clinical Psychology

Direct line: 01691 404649

**Participant Partner Consent Form**

**Experiences of post-traumatic growth in spinal cord injury partners**

Name of Researcher:

Kamaldip Kahlwan

Trainee Clinical Psychologist

Midlands Centre for Spinal Injuries

RJ & AH Orthopaedic Hospital

Oswestry, Shropshire, SY10 7AG

01691 404511

I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions

I understand that my partners participation is voluntary and that they are free to withdraw at any time without legal or medical rights being affected

I agree that the transcript of this interview can be used for the purposes of research and publication and that any anonymised quotations from this research can be used in write up and publication

I agree that I am happy for my partner to take part in the above study

I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the Midlands Centre for Spinal Injuries from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

Name of Partner

Signature

Date

---

---

---

Name of Researcher

Signature

Date

### **Appendix K – Interview Schedule**

In accordance with IPA methodology the interview schedule will be an initial guideline only. The researcher will move away from the questions on the interview schedule if the interview enters an area that is not covered by the questions but is of relevance to the study.

Questions will focus around:

#### Section A - Personal resources and changes

- How would you describe yourself as a person?
- In which areas do you feel you have grown as a person since living with your partner after the spinal cord injury (SCI)?
- What do you think facilitated this?
- What may have possibly prevented any growth in these areas and how could this be overcome?

#### Section B - Relationships

- How has your relationship with your partner grown since the SCI?
- What facilitated this?
- How have your relationships with others grown since the SCI?
- What facilitated this?
- What would have been helpful at the time of the SCI to help these changes?

#### Section C - Coping strategies

- What helps you cope with the challenges of living with someone with an SCI?
- What would have been helpful at the time of the SCI to help these changes?
- What resources do you have to deal with these?

#### Section D - closing question

- Is there anything else you would like to tell me about the experiences of post-traumatic growth, from living with someone with a spinal cord injury?

Appendix L – Example excerpt of transcript analysis

372		appreciate that.	
373	R	Yeah, but like you said a bit of training or information would	
374		have been helpful at the time?	
375	1	Yes, yeah.	
376	R	So what helps you cope with the challenges of living with	
377		someone with a spinal injury?	
378	1	[.] what helps me cope? Well I do appreciate my afternoon	
379		out very much [[laughs]] my garden, I go out in the garden if	time for self
380		I get tensed up and that, I love to get out in the garden, the	copying strategy
381		weather, you're different when the weather's nice and I	Talks about Ray again -
382		mean Ray will come out in the garden then and he's, it's	Its like identities become merged.
383		sometimes hard in the winter when you're stuck in. Yeah,	- difficult to talk about self. New identity
384		no I'm ok, um [.] er I have a nephew that comes up, he was	
385		a policeman amongst other things, he was also a PTI in the	
386		army and he comes up and does physio with Ray 3 times a	
387		week, which is excellent, you have a natter as they're doing	
388		it, that, that helps me, the amount of visitors we have does	social support
389		help me very much so, and helps Ray.	
390	R	And what would have been helpful at the time of the injury	
391		to help these changes?	
392	1	[.] couldn't have been anything more really than we had	social support.
393		which was just the general support of people around. We	
394		couldn't have really had more support [.] um, no we couldn't	
395		have.	
396	R	Ok, and	

*Handwritten notes on the left side of the transcript:*

- awareness of need for time a lone time
- laughs - needs time
- admits - difficult to admit to me!
- knows the factors that make things easier!
- Trying to convince herself she is ok!
- talking to others helps
- Is she convincing herself? she is ok - but really she is not sure?
- Could she cope without visitors?
- Support from others valued
- repeats herself to emphasise point

*Handwritten notes on the right side of the transcript:*

- social support
- social support.

*Summary notes at the bottom right:*

- Themes
- Descriptive Comments
- Linguistic Comments
- Conceptual Comments



33 R Ok. So in which areas do you think you've grown as a  
 34 person since living with your partner after the spinal cord  
 35 injury?

36 1 Um, as I say I don't panic as much. I'm probably in some  
 37 ways er, more, well you've just got to get used to it haven't  
 38 you so in one way as I say I was a contented person  
 39 anyway, but I'm more contented, you know it's, um, [.] I  
 40 mean we used to go out, we used to go on holiday, we'd  
 41 been to Norway months before but I'm quite content, so yes  
 42 I've become more contented, um, in a way you look at thing  
 43 differently, you're glad to be here, um, whereas before you  
 44 know you'd be wanting to do something and, now, I mean  
 45 now if he went out in his garage all day [[laughs]] I'd be  
 46 absolutely delighted you know, um so yes, you appreciate  
 47 life more definitely, you know you do.

*Is she identifying  
 whether things  
 were already  
 there?*  
 37  
 38  
 39 finds it  
 40 hard to talk  
 41 about  
 herself

*resilience*

*She appreciates what  
 she has a lot more  
 now*

*Greater appreciation*

48 R Ok, what do you think facilitated this  
 49 Having to, being so grateful that he was here, because I  
 50 didn't think he was going to, I never thought he would, you  
 51 know the first week I didn't think he was going to make it.  
 52 So you're just grateful that he's here, and also that he's, I'm  
 53 very grateful that he's sort of dealt with it so well, um, he's a  
 54 different person, he's lacking in confidence whereas he was

*Does she have a lack of  
 choice/control here?*  
 49  
 50  
 51  
 52 more appreciative of  
 what she has now

*Does she have a new  
 role in her life now?*  
 55  
 56

*new life role*

55 very much the one in control of the home before, he was  
 56 the breadwinner and he's you know, he was, the family  
 57 were always coming to him, 'what would you do with this'  
 58 well he doesn't now, but he's very easy to live with [.] very,  
 59 very easy, you can't complain, he never complains why  
 60 should I [[laughs]]

*She hints it hard to  
 express herself once again  
 does she feel like she  
 can't complain?*  
 58  
 59  
 60

61 R Ok, so what may have possibly prevented any growth in  
 62 these areas? And how do you think that could have been  
 63 overcome?

64 1 At first, um as I said I was a panicker and at first it it upset  
 65 me to see him so lacking in confidence, he's getting a bit  
 66 better now, um and suffering a lot because he get's, he's

67 still talks about her  
 68 father getting hurt  
 69 herself  
 70  
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 73 R  
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 79 R  
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 85 R  
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 96  
 97 R  
 98

got fluid in the spinal cord which causes a lot of pain and  
 you can see it and you'll say to him, 'are you in pain, do you  
 want...' 'no, no I'm alright, I'm alright, I think I'm alright',  
 'what do you mean you think', 'well I think I'm alright' you  
 know and that, that got very upsetting at times, still does but  
 not to the extent that he used to

Ok, so it's less?  
 Yeah, yeah, and as I say the panicking, I was a panicker  
 um but that got better because um you just realise these  
 things do happen um, different things will happen, you know  
 er and they generally work out ok, you learn how to cope  
 with them.

Ok, so you learn how to cope ok. So how has your  
 relationship with your partner grown since the injury?

Um, [...] ooh, we're, well we're more appreciative of each  
 other, he's very, very appreciative, I think he said he didn't  
 think I'd be able to cope as well as I did and he's very, very  
 appreciative of that

That's nice

And again, I'm the same with him, well you know he'll say  
 I'm useless and that well and all the work he'll cause I'll say  
 no, in many ways he causes less work than he did when he  
 was working, he used to have dirty overalls and used to  
 have machine stuff all over the place whereas you know  
 [[laughs]] you were hovering every day you don't have to  
 now, so in some ways there's less work physically, although  
 it's more mental now. So I would say we've always had a  
 good relationship, we've always been really upfront with  
 each other, um, it's got even better, we've just celebrated  
 50 years of marriage

Oh, congratulations! And what do you think facilitated this  
 growth?

*Handwritten notes:*  
 - loss of identity?  
 - new merged identity?  
 - resilience  
 - better relationship  
 - good communication  
 - better relationship  
 - open communication

**Appendix M** – Emerging themes and connecting the themes

## Emerging themes

- Difficulty recalling an emotive experience
- Difficult to talk about self
- Greater appreciation
- Lack of choice/control
- New life role
- More emotionally demanding
- Resilience
- Social support
- Open communication
- Better relationships
- Independence
- Time to stop and reflect
- Strong relationships
- Difficulty dealing with new situation
- Lack of knowledge creating distress
- Lack of support from hospital
- Hope
- New merged identity
- Loss of identity
- Time alone
- Practical support
- Resilient personality
- Improved communication
- Using own initiative for support
- Strengths
- Greater understanding
- Right people for support
- Uncertainty
- Lack of support for carer
- Trust
- Commitment
- Variety of roles
- Services not giving advice
- Love
- Appreciation
- Growth
- Respect
- Time for reflection

## Sub Themes

Resilience and strength	<ul style="list-style-type: none"> <li>• Resilience</li> <li>• Hope</li> <li>• Resilient personality</li> <li>• Strengths</li> <li>• Greater understanding</li> <li>• Growth</li> </ul>
Time for self	<ul style="list-style-type: none"> <li>• Difficult to talk about self</li> <li>• Independence</li> <li>• Time to stop and reflect</li> <li>• Time alone</li> <li>• Time for reflection</li> </ul>
Support	<ul style="list-style-type: none"> <li>• Social support</li> <li>• Practical support</li> <li>• Right people for support</li> <li>• Lack of support from hospital</li> <li>• Lack of support for carer</li> </ul>
Lack of understanding About new role	<ul style="list-style-type: none"> <li>• Lack of choice/control</li> <li>• New life role</li> <li>• Difficulty dealing with new situation</li> <li>• Lack of knowledge causing distress</li> <li>• Using own initiative for knowledge</li> <li>• Uncertainty</li> <li>• Variety of roles</li> <li>• Services not giving advice</li> </ul>
Love and appreciation	<ul style="list-style-type: none"> <li>• Greater appreciation</li> <li>• Trust</li> <li>• Commitment</li> <li>• Love</li> <li>• Appreciation</li> </ul>
Communication	<ul style="list-style-type: none"> <li>• Open communication</li> <li>• Improved communication</li> <li>• Respect</li> <li>• Better relationships</li> <li>• Strong relationships</li> </ul>

## Master theme

## Sub Themes

New Identity	<ul style="list-style-type: none"> <li>• Resilience and strength</li> <li>• Time for self</li> <li>• Support</li> <li>• Lack of understanding about new role</li> <li>• Love and appreciation</li> <li>• Communication</li> </ul>
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