Does spirituality facilitate adjustment and resilience among individuals and families after SCI?

Ms Kate Jones (corresponding author)

Spinal Injuries Unit, Royal Rehab

PO Box 6, Ryde

New South Wales 1680

Australia

Ph: (61 2) 9808 9269 E-mail: katefjones@yahoo.com.au

Associate Professor Grahame Simpson

Brain Injury Rehabilitation Research Group

Ingham Institute of Applied Medical Research

Liverpool, New South Wales, Australia

Associate Professor Lynne Briggs

School of Human Services and Social Work

Griffith Health Institute, Griffith University

Southport, Queensland, Australia

Dr Pat Dorsett

School of Human Services and Social Work

Griffith Health Institute, Griffith University

Southport, Queensland, Australia

Keywords: Spinal cord injury, spirituality, family, resilience

Abstract

Purpose: The purpose of this scoping review was to investigate the role of spirituality in facilitating adjustment and resilience after spinal cord injury (SCI) for the individual with SCI and their family members. *Method:* *Data Sources:* Peer reviewed journals were identified using PsychInfo, MEDLINE, CINAHL, Embase and Sociological Abstracts search engines. *Study Selection:* After duplicates were removed 434 abstracts were screened applying inclusion and exclusion criteria. *Data Extraction:* The selected 28 studies were reviewed in detail and grouped according to methodological approach. *Results:* Of the 28 studies relating to spirituality and related meaning-making constructs 26 addressed the adjustment of the individual with SCI alone. Only two included family members as participants. Quantitative studies demonstrated that spirituality was positively associated with life satisfaction, quality of life, mental health, and resilience. The utilisation of meaning-making and hope as coping strategies in the process of adjustment were highlighted within the qualitative studies. Clinical implications included recommendations that spirituality and meaning-making be incorporated in assessment and interventions during rehabilitation. The use of narratives and peer support was also suggested. *Conclusions:* Spirituality is an important factor in adjustment after SCI. Further research into the relationship between spirituality, family adjustment and resilience is needed.

- Implications for Rehab
- Higher levels of spirituality were associated with improved quality of life, life satisfaction, mental health, and resilience for individuals affected by spinal cord injury.
- Health professionals can enhance the role spirituality plays in spinal rehabilitation by incorporating the spiritual beliefs of individuals and their family members into assessment and intervention.

- By drawing upon meaning-making tools such as narrative therapy, incorporating peer support, and assisting clients who report a decline in spirituality, health professionals can provide additional support to individuals and their family members as they adjust to changes after spinal cord injury.

Introduction

Much is known about the physical, social and psychological challenges faced by individuals and their family members after spinal cord injury (SCI) [1,2]. Physically, the injured individual may experience changes to their mobility, continence, sexuality, fertility, and levels of pain. Poor physical health has also been observed among family members [3], who in some instances provide care on a daily basis. Physical changes and care requirements often lead to vocational and financial changes, which can impact upon the whole family [4,5]. In addition to physical and social challenges, and often as a direct result of them, reported psychological consequences of SCI include feelings of grief and loss, isolation, depression, anxiety and despair for all affected [2,3,5-10]. Historically, few studies have looked beyond these physical, social and psychological challenges. However more recently there has been a growing interest in factors which might facilitate adjustment and build resilience after SCI [11,12]. One such factor which may play an important role in contributing towards adjustment and resilience after SCI is spirituality [13].

A key aspect of spirituality, observed both within healthcare settings and outside, is the concept of transcendence. In their research paper investigating outcomes among rehabilitation and cancer outpatients Tate and Forchheimer [14] suggested that it is the theme of transcendence which is unique to definitions of spirituality; “the notion that spirituality is something separate from the physical, social, or psychological, and that implicit in spirituality is a capacity to rise above the circumstances of these other life realms” (p.402). Writing in the area of palliative care Millard [15] proposes that human beings “are meaning-makers and meaning-seekers with an innate desire to transcend or move beyond situations of hardship or suffering” (p.111). The idea of transcendence has spanned both religious and secular perspectives. According to Pargament [16] discerning the “transcendental design” in the midst of suffering is a key coping mechanism at times of crisis for many who hold religious

beliefs. In contrast, a more secular perspective on transcendence is provided by Viktor Frankl who wrote of transcending suffering as a prisoner in Nazi Germany [17]. In the midst of suffering Frankl was able to picture and meditate upon not only upon an image of his wife who he dearly loved, but also upon a future away from his present reality. He describes this freedom of thought as a ‘spiritual freedom’ one which could not be taken away, and a process which created meaning and purpose (p.67). Frankl’s account reveals a spirituality encompassing meaning, hope and ultimate purpose, and one not necessarily attached to religious traditions or beliefs.

Encompassing far reaching concepts such as religion, meaning, belief, hope and peace, the understanding of the importance of spirituality for individuals at times of illness or disability is growing rapidly [18-22]. In her study of rural women Hampton and Weinert found that prayer, faith, verse, finding meaning, transcendence and family were extremely helpful for many of their participants in coping with the stress of a chronic illness[19]. Johnstone and Yoon found that positive spiritual experiences and a willingness to forgive were related to better physical health among individuals with chronic disabilities (including SCI).[22] In addition to the individuals affected by illness or disability, spirituality has also been studied among family members who provide support roles. In their study of spirituality among wives of men with prostate cancer, Ka’opua et al [23] observed that spirituality facilitated adaptation in four areas: marriage preservation and couple intimacy, personal growth and continuous learning, health-related attitudes and community connections. Such findings might also apply to family members of individuals with SCI. As with many studies in the area of health, this study focused upon the adaptation of family members alone and did not encompass a systemic perspective addressing the experience of both family members *and* the individual with the condition.

Adopting a systemic perspective Walsh [24] has suggested that spirituality and other beliefs are important for the family as a whole in a range of contexts (facing various crises or chronic stresses). In her framework of family resilience she has proposed that making meaning of adversity, positive outlook, transcendence, and spirituality, are among key processes which assist a family to “rally in times of crisis, to buffer stress, reduce the risk of dysfunction, and support optimal adaptation” (p.3). Such a systemic perspective has been supported by the findings of cancer studies which have incorporated the perspective of both the affected individuals *and* their family members [21,25]. Within the area of SCI few studies on adjustment have been conducted adopting a family systems approach [26-28].

In addition to Walsh a number of authors and researchers have suggested that a significant relationship between spirituality and resilience may exist. In his metatheory of resilience research Richardson [29] proposed that three waves of resiliency inquiry have taken place over time: i) the search for resilience qualities or characteristics, ii) the understanding of resilience as a process, and most recently iii) recognition of resilience as a force or energy “within everyone that drives them to seek self- actualisation, altruism, wisdom, and harmony with a *spiritual* (italics added) source of strength” (p.319). Acknowledging the importance of such a relationship, Connor and Davidson [30] have included an item pertaining to spirituality in their measure of resilience (CDRS). Given this proposed relationship between spirituality and resilience, there may be important clinical implications regarding the role of spirituality within the context of spinal rehabilitation.

To the best of our knowledge no other reviews have been conducted investigating spirituality and spinal cord injury. Given the absence of such reviews a scoping review was conducted. The purpose of a scoping review is to determine the breadth and depth of the literature within a particular field [31]. The aim of this scoping review was to identify studies which have considered spirituality after SCI, and to examine how spirituality, and/or other

associated meaning-making constructs, might contribute to both individual and family adjustment and resilience. The first three objectives of the scoping review were to identify studies which have investigated the role of spirituality in facilitating adjustment after SCI for: 1) the individual with SCI; 2) the family members; 3) and the family system (i.e., the whole of family inclusive of the person with SCI). The fourth objective of the scoping review was to identify which if any of studies identified from objectives 1-3 considered the relationship between spirituality and resilience.

Methods

A scoping review was conducted, using the five stages outlined by Arksey and O'Malley [32] and later refined by Levac et al [31]: i) identifying the research question, ii) identifying relevant studies, iii) study selection, iv) charting the data, v) collating, summarising and reporting results.

i) Identifying the research question

To identify the research question, Levac et al [31] recommended that researchers clearly articulate the scope of enquiry by defining the concept, target population, and health outcomes of interest. The target population for this scoping review was adults affected by SCI, acquired during childhood or as an adult, and their family members. Both traumatic and non-traumatic injuries were included. Drawing upon the existing literature on indicators of psychosocial adjustment among individuals after SCI, health outcomes of interest associated with spirituality included quality of life (QOL) [14,33] life satisfaction[34], mental health and resilience [13]. QOL is a multi-dimensional construct, which according to Tate and Forchheimer encompasses physical, functional, psychological, social and spiritual domains [14]. Life satisfaction has been understood to refer to the cognitive-judgemental

(subjective) aspects of QOL [34,35]. Studies of mental health within SCI have included those pertaining to depression [9,10,13], anxiety [8], and psychological well-being [36].

Due to the range of possible frameworks and definitions pertaining to the concept of spirituality, it was necessary to adopt an inclusive approach to ensure the scoping process achieved a breadth of coverage. Spirituality is often associated with religious faith or the beliefs of a range of religious traditions, such as Christianity, Buddhism, and Islam [18]. Such an association has been emphasised by Pargament [16] who has suggested that religion and spirituality are intimately connected, and crucial coping mechanisms in the midst of suffering. However, in *Man's Search for Meaning*, Frankl explored the strong relationships connecting meaning, purpose, hope and spirituality, which may exist apart from formal religion. [17]. Drawing upon these works and others, theorists and researchers have suggested that spirituality is a key component or element of a number of associated meaning-making constructs and processes, including religious faith [16], meaning making [37,38], purpose in life [39], sense of coherence [40], posttraumatic growth [41], and hope [42]. These constructs, outlined below, were included in this scoping review due to their close relationship with spirituality.

Religious Faith

Differentiating spirituality from religion is not an easy task, particularly when the two overlap in many cultures and are even used interchangeably. Within Western culture Judeo-Christian beliefs and ideas have been particularly prominent, providing established frameworks of understanding [43]. Pargament [16] has defined religion as '*a search for significance in ways related to the sacred*'. He uses the term religion not in its broad sense but "one that includes both institutional religious expressions and personal religious expressions, such as feelings of spirituality, beliefs about the sacred, and religious practices' (p.4). Measures of religious faith

include the Spiritual Wellbeing Scale (SWBS) [44] which contrasts existential spirituality with religious spirituality, and the Brief Multidimensional Measure of Religiousness and Spirituality [22].

Meaning making

Frankl [17] wrote that when an individual's search for meaning is successful, it enables him or her to cope with suffering. After a traumatic loss it has been proposed that some individuals undergo a process to reconstruct their world, make sense of the loss, and engage in meaning finding processes [38]. What may become most important is not why a traumatic event has occurred, but the belief that one is living a purposeful life in harmony with one's individual beliefs and values [36]. The process of meaning reconstruction has been closely associated by some authors with the sharing of narratives and spiritual stories [45,46]. Global meaning-making has been measured via the Purpose-in-Life Test [47] which measures the degree to which an individual perceives himself or herself to find meaning in his or her life.

Sense of Coherence

Spirituality has been recognised as having a close relationship with sense of coherence (SOC) [21,48]. Antonovsky [40] described SOC as 'a global orientation' consisting of three intertwined components: comprehensibility, manageability and meaningfulness. Rutter [49] has suggested that a person's response "to any stressor will be influenced by his appraisal of the situation and by his capacity to process the experience, attach meaning to it, and incorporate it into his belief system" (p.608). One way SOC is measured is by the "Sense of Coherence" scale developed by Antonovsky.

Posttraumatic growth

Posttraumatic growth (PTG) has been defined by Tedeschi and Calhoun [41] as “positive psychological change experienced as a result of the struggle with highly challenging life circumstances”, described by five factors: i) greater appreciation of life and changed sense of priorities, ii) more intimate relationships with others, iii) a greater sense of personal strength, iv) recognition of new possibilities for one’s life, and v) spiritual development. Growth in spirituality or existential meaning making is seen as one way in which persons may experience positive change after stress or loss, and may not necessarily preclude experiences of vulnerability or distress. Indeed, it has been suggested that such experiences may even contribute to a sense of strength, and a deeper faith [41]. Posttraumatic growth has been measured by the posttraumatic growth inventory (PTGI) [50].

Hope

According to Dufault and Martocchio [51] hope is “a multi-dimensional dynamic life force characterised by a confident yet uncertain expectation of achieving a future good which...is realistically possible and personally significant” (p.380). Dorsett [52] has suggested that hope “provides a reason to go on living, helps maintain motivation, positive expectations, and may mediate the effect of depression” (p.89) . Measures of hope include the Herth Hope Index [53] and the Hope Scale [54].

ii) Identifying relevant studies

A number of search terms were entered to identify studies on the topic of spirituality and associated meaning-making constructs in the field of SCI. These search terms were drawn from the work of Frankl [17], Pargament [16], and others in area of spirituality and healthcare [18,55]. The search terms “spirituality”, “meaning”, “purpose in life”, “sense of coherence”, “posttraumatic growth”, “hope”, “faith”, “beliefs”, and “religion” were used to identify

studies on the topic of spirituality. All search terms were then combined with ‘spinal cord injuries’ or ‘spinal cord injury’ and were entered into the following journal databases:

Psycinfo, Medline, Cinahl, Embase and Sociological Abstracts. To address the second and third objectives, the search term ‘family’ was added to narrow the initial results from the first search to those pertaining to family members. Papers were restricted to studies reporting empirical data, published within a 20 year timeframe (between 1994 and 2013), written in English, and from peer reviewed journals. As long as a study was empirical, no limitations were placed upon the research design and could include correlational, field, experimental, case study and qualitative designs.

iii) Study selection

Studies were excluded if they focused upon a diagnosis other than SCI, centred only upon one specific aspect of SCI adjustment (e.g., research procedures, pain management, sexuality, continence, clinician experiences), or focused solely upon the beliefs or perspectives of health professionals or the research community. Studies which incorporated data from a number of diagnostic groups were accepted if specific data for SCI was reported. If a number of papers reported on the same study, only the article most pertinent to the aims of the scoping review was retained. This was sometimes the case when authors had published further papers after a study, but included analysis that had already been covered, or was not relevant to the scoping review’s aim. Editorials and commentaries were excluded.

The first author (KJ) conducted the search. After duplicates were removed, the titles and abstracts were screened to identify articles that met the the eligibility criteria. In cases where an initial decision could not be made the full text of the article was obtained. If uncertainty still existed as to whether the article should be included after review of the full text, the other authors (GS, LB, PD) were consulted and a consensus decision reached.

Reference lists of selected articles were also reviewed to identify any further studies on the topic.

iv) Charting the data

The first step in charting the data involved collecting descriptive information about the studies. The study descriptors comprised: first author, year of publication, country in which the research was conducted, study design, main construct of interest (i.e., spirituality or one of its related constructs; religious faith, meaning making, sense of coherence, posttraumatic growth, hope), sample size, injury characteristics, study setting, and outcomes/key themes.

v) Collating, summarising and reporting results

The results were grouped according to the four study objectives, and the study results tabulated. In the case of the quantitative studies, significant results from statistical analyses testing the association between spirituality and quality of life, mental health status and/or resilience were extracted. For the qualitative studies, the key themes identified by the authors were collated and grouped.

Results

Applying the search terms generated 761 citations. After duplicates were removed and titles and abstracts screened, full text versions of the remaining 140 articles were reviewed to finalise which articles met the inclusion criteria. The study flow is detailed in figure 1.

Insert figure 1 about here

A total of 28 studies relating to spirituality (or associated meaning-making constructs) met the review criteria. Papers were clustered in more recent years, with 23 of the 28 papers published from 2005 onwards. Most studies were conducted in either the United States (15) or Europe (7), with the remainder conducted in Canada (3), the Middle East (2) and Australia (1). Research design was fairly evenly balanced, with 11 of the 28 studies utilising qualitative

methodology (five longitudinal) and 17 quantitative (13 cross-sectional and four longitudinal).

In relation to the first objective, 26 studies were identified as considering the role of spirituality or other associated meaning-making constructs in facilitating individual adjustment after SCI. Three of these studies addressed individual adjustment within the context of family relationships but did not incorporate the family member perspective directly. No studies were identified to correspond with the second objective, studies which solely considered the family member perspective.

Two studies adopted a systemic approach corresponding to the third objective. Only one study met the criteria for the fourth objective, focusing upon spirituality and resilience [13]. As there were no studies identified which considered spirituality from a sample comprising family members only (objective 2), the results will focus upon those studies which investigated the relationship between spirituality and individual adjustment, systemic (whole of family) adjustment and resilience. One paper addressed the criteria of both the first and fourth objectives, and therefore the elements of the study relevant to each objective are reported respectively.

Objective 1: Spirituality and individual adjustment after SCI

Quantitative studies n=16

Sixteen quantitative studies considered the relationship between spirituality or associated meaning-making constructs and other positive outcomes after SCI related to individual adjustment. Constructs of interest investigated included spirituality, purpose in life or meaning, hope, posttraumatic growth, and sense of coherence. Sample sizes for the studies ranged from 25 to 444, with 14 studies recruiting samples of individuals with SCI alone, and the other two having mixed samples which included a sub-group of people with SCI. Injuries

encompassed both tetraplegic and paraplegic levels of injury, and incomplete and complete lesions. Injury data were inconsistently reported across studies, and sometimes not recorded at all, making comparisons difficult. As seen in table 1, six of the 16 quantitative studies focused exclusively upon newly injured people (up to two years post SCI). Participants from other studies were either a combination of new and older injuries, or those who had sustained their injuries over two years previous. Only two quantitative studies [56,57] made specific comparisons between participants who had been injured for different lengths of time.

Insert table 1 about here

Of the 16 studies, nine focused specifically upon spirituality. All of these nine studies were cross-sectional. These studies reported positive associations with other indicators of adjustment after SCI including life satisfaction [13,14,58,59], quality of life (QOL) [14,57,59-61], and perceived health [62]. White et al [13] reported significant positive correlations between spirituality and satisfaction with life, and a negative correlation between spirituality and depressive symptoms. Brillhart [60] reported a significant positive correlation between psychological/spiritual factors and life satisfaction. Such a relationship was found among adults with paediatric onset SCI. For example, Chlan et al [58] found that over half the participants with paediatric-onset SCI endorsed the importance of religion, and that spiritual coping emerged as a predictor of life satisfaction. In their study of rehabilitation outpatients Tate and Forchheimer [14] found that spirituality or spiritual coping was positively associated with QOL and life satisfaction. In a later study the same authors found that spirituality was also predictive of perceived health status, and again explained a significant amount of variance in scores on life satisfaction [57]. All studies treated spirituality as an independent variable which predicted outcomes, rather than viewing spiritual status as an outcome in and of itself.

It was apparent that how spirituality was conceptualised or defined varied among the nine papers focused upon spirituality. Tate and Forchheimer [14] identified that spirituality is seen to be a construct ‘distinct from, yet conceptually related to, religion and religiosity’, and closely aligned with transcendence. Brillhart [60] defined spirituality in terms of harmony, interconnectedness and the “ultimate Other”. Other authors relied upon measures of spirituality or religion to define the concept, such as Franklin et al [62] who used the Brief Multidimensional Measure of Religiousness and Spirituality [22], and White et al [13] who used the Intrinsic Spirituality Scale, which does not mention religion. In two papers distinctions between spirituality and religion were made using the Spiritual Wellbeing Scale (SWBS) [44] which contrasts existential spirituality with religious spirituality [59,61]. The Functional Assessment of Chronic Illness Therapies – Spiritual (FACIT-SP) [63] or the Functional Assessment of Cancer Therapies –Spiritual Well-Being (FACT-SP), were used by three studies [14,57,59]. Only two of these compared scores on the factors of these scales (meaning, faith).

Findings from those studies which considered both spirituality and religion support the assertion that such a distinction may be important. Utilising the Spiritual Well-being Scale (SWBS)[64] Matheis et al distinguished ‘religious spirituality’, a meaningful relationship with God and attendance at religious services, with ‘existential spirituality’, encompassing a worldview or perspective leading to ultimate life purpose and meaning [61]. They found that existential spirituality, rather than religious spirituality, was a predictor of global QOL, and significantly related to life satisfaction, general health, and social QOL . This, they argued, suggested that QOL was more related to an ‘active search for life purpose’ rather than ‘adherence to a predefined set of practices and values’ (p.269). Reporting less of a difference between the two, Riley et al[59] observed that participants who demonstrated either religious *or* existential spiritual well-being were more likely to report high levels of

purpose or meaning in life and self-harmony. Individuals with religious well-being found 'greater strength and comfort in their faith' believing they would be fine despite their situation [59]. The benefits of religious support were noted by Franklin et al [62]. They found that religious support was the only domain on the BMMRS to demonstrate a significant positive correlation with general mental health among persons with SCI. This domain measured the perceived help, support and comfort received from one's congregation [62]. No other studies considered this social aspect of religious experience.

Participants' religious beliefs were more evident in some studies than others. All nine quantitative studies of spirituality and individual adjustment were based in the USA, where Christianity was the dominant faith among participants. The majority of participants in these studies identified themselves to be religious or spiritual [56,58,61], and in at least one study, almost exclusively Christian [62]. Marini and Glover-Graf [56] found that 72 % of their sample believed that God or spiritual beliefs gave them meaning or purpose, and 48% believed there was a spiritual reason for their SCI.

Although the studies generally identified a positive association between spirituality and the health outcomes, this was not universal. One study found that a small proportion of participants a decrease in religious faith was experienced after SCI [56]. For these participants negative views about God or a spiritual power emerged after their SCI. Such negative views included feelings of anger towards God or a spiritual power, feeling abandoned by God or a spiritual power, or feeling that their family was being punished for having sinned. Comparing participants who had been newly injured with those injured for longer periods of time, this same study noted that while participants soon after injury focused on religion or spirituality, those injured for longer periods of time demonstrated less reliance upon God or a spiritual power. As this was a cross-sectional rather than a longitudinal study no further comparisons were made [56]. The only other study to consider the impact of time

since injury (TSI) upon spirituality found no relationship between TSI and spirituality scores [57].

In addition to the nine studies specifically considering spirituality, seven studies measured constructs closely related to spirituality, namely sense of coherence (SOC) [38,65], purpose in life (PIL) [36,39], hope [1,66] and meaning [67]. Positive outcomes associated with these constructs included psychological well-being [36,65], life satisfaction [66], perceived growth [67], and adjustment [1,38,39]. Three of these studies were longitudinal.

Two studies considered SOC. In one of the longitudinal studies Kennedy et al studied the power of SOC in predicting psychological well-being, appraisals, and coping behaviours [65] over the longer term. They found that those individuals with higher scores of SOC at six weeks post injury showed better psychological outcomes at one year post-injury, including less anxiety, less depression, and better psychological QOL. They were also more likely to use positive “acceptance” as a coping strategy. In a cross-sectional study which also considered the relationship between SOC and adjustment (as measured by the scales of the Reactions to Impairment and Disability Inventory (RIDI), Lustig [38] found that perceived strengthened SOC was associated with adaptive adjustment, whereas perceived weakened SOC was associated with nonadaptive adjustment after SCI.

Two studies investigated PIL among adults with traumatic SCI. Thompson et al [39] found that PIL mediated between most measures (neuroticism, aggression, activity, sociability, and internal health locus of control) and adjustment, as measured by the *Ladder of Adjustment* (Crewe & Krause). DeRoos-Cassini et al [36] also administered measures of PIL and found that increased global meaning making was significantly related to an increase in psychological well-being.

The relationship between hope and adjustment after SCI was considered in two quantitative studies. Kennedy et al [1] found that higher hope agency, as measured by the

State Hope Scale was associated with higher levels of acceptance after SCI. Participants with less hope perceived their injury as “more threatening”. In another longitudinal study, Kortte et al [66] observed that hope and positive affect demonstrated a significant positive relationship with life satisfaction during the initial period of acute rehabilitation after SCI and contributed to the prediction of life satisfaction at a three month follow-up.

Lastly, Davis and Novoa [67] investigated meaning-making among individuals with SCI by asking the question, “Some people who have had a traumatic injury find themselves searching to make sense or find some purpose in their injury. Have you done this since your injury?” Responses were coded and used in conjunction with quantitative data measuring posttraumatic growth, positive and negative affect, and subjective well-being. As with many of the studies [1,36,39,61,66,68] the severity of injury was not significantly associated with study variables. More frequent “searching for meaning” was associated with declines in adjustment, whereas increases in “found meaning” were associated with improved adjustment over time. Finding meaning was associated with greater perceived growth, using the post-traumatic growth inventory (PTGI).

Only five of the 16 papers in this group considered the clinical implications of their findings. Marini and Glover-Graf [56] proposed that clinicians incorporate client religious views in their assessments. They suggested that this is particularly important for the small minority of individuals who may believe they have been abandoned or punished by God. In their study of spirituality and QOL Matheis et al [61] suggested that treating professionals question individuals’ use of spirituality, and if appropriate, support such use, to assist them achieve a more satisfying life. Brillhart [60] proposed that rehabilitation nurses have a unique opportunity to promote spirituality and life satisfaction among individuals with SCI, and challenged the profession to investigate the best ways to do so. Both Lustig [38] and deRoos-Cassini et al [36] have proposed that clinical interventions around meaning-making should be

incorporated into the rehabilitation process, to aid the process of adjustment after SCI. No intervention studies were identified in this review.

Qualitative studies n=10

The 10 qualitative studies, primarily focused on individual adjustment, addressed spirituality or meaning-making after SCI as a process. Constructs of interest within this group included spirituality, meaning, hope and posttraumatic growth. Although nine of these studies did not directly focus upon spirituality, underlying themes of meaning making, new life, openness to change, and growth through suffering were identified. Authors drew upon a broad spectrum of theory and perspective, incorporating ideas from philosophy and narrative approaches. Three studies addressed the perspective of the person with SCI on spirituality or meaning making within the family context, but did not include family members as participants. Sample sizes of the studies ranged from nine to 67. Injury data were similar to the quantitative studies with most samples consisting of individuals with SCI, and one a mixed sample (SCI, TBI). Four studies were conducted with participants who had been injured in the previous two years, four with participants injured for longer than two years, and two studies with samples containing both newly injured participants and those who had been injured for a number of years.

Insert Table 2 about here

The only authors to explicitly consider spirituality as a concept within this group were McColl et al [69]. They described spirituality as “a propensity to find meaning in experience through one’s relationships with others, with a supreme power, and with one’s self” (p.817). From their interviews with individuals with brain injury or SCI, McColl et al identified five themes which they argued impact upon all aspects of spirituality: i) awareness, relating to a greater appreciation of life, others, and the world ii) closeness, encompassing increased

intimacy, particularly within the family iii) trust, involving allowing others to provide help due to new dependency and reliance, iv) vulnerability, as participants “recognised that they were not invincible or immortal”, and v) purpose, due to the purpose of life which had changed for many participants with some specifically referring to God or a Creator having a plan for them (p.821). McColl et al [69] incorporated these themes into a framework for the consideration of spiritual issues associated with disability, encompassing intra-personal issues (relationship with self), inter-personal issues (relationship with others), and trans-personal issues (relationship with nature and /or a supreme being). This study stands alone as the only one in the scoping review to specifically consider spirituality as a relational concept.

Two other qualitative studies incorporated the family as an important element regarding the meaning making process after SCI, but did not include family members as participants. In their qualitative study of posttraumatic growth after SCI, Chun and Lee [70] observed that the experience of meaningful family relationships, meaningful engagement in activities, and appreciation for life all emerged as themes. Rather than an obstacle, Chun and Lee [70] conclude that traumatic injury appears to be an opportunity to realise the importance of family and to build meaningful relationships through “emotional intimacy, gained trust, and a sense of mutuality”. Meaningful engagement is seen to be part of the process of building alternative life stories that “characterise a renewed sense of personal agency and fulfilment through active engagement in meaningful activities and meaningful relationships with others” (p.887).

Focusing upon meaning construction after SCI, Angel et al [71] identified six phases individuals with SCI passed through in the search for meaning: i) surviving physically and regaining vitality, ii) moving back to life where possibilities present themselves, iii) working with progress to pursue possibilities, iv) fading process narrow possibilities down, v) exploiting limited possibilities, and vi) living a life with qualities despite limitations.

Relatives were seen to play an important role in the first and second phases by encouraging “the patient to stay alive” and nurturing a hope and “imagination of the future” (p.47). After these early stages it was suggested that the person with SCI “took over the imagination of a future” and family input was less imperative, though some form of support may still have been required to ‘regain meaning’ (p.48). The nature of this support was not elaborated on by the authors. As the family perspective was not provided in this study it is difficult to draw further conclusions. One longitudinal study considered the process of meaning-making over time. Interviewing participants at four intervals in the first two years post-injury, Kennedy et al[72] asked, “What do you think you have gained from the experience of your spinal cord injury?” Thirteen themes were identified and included among them appreciation of life or relationships, changed personality, acceptance, new skills and spirituality. The most frequently reported positive change related to perspective/appreciation of life.

Five papers considered the process of hope for individuals after SCI [52,73-76]. The authors of these papers identified similar themes regarding different types of hope, and in three longitudinal papers, the process of hope over time. Hope was observed to often be associated with desire for recovery, or a return to life as it had been, but hope was also used to refer to hope for a life worth living, even in the absence of recovery. In two studies hope was closely associated with spirituality or religious belief.

Smith and Sparkes [75] observed three kinds of hope among men who sustained SCI through sport: concrete hope, transcendent hope, and despair (loss of hope). Drawing upon the work of Frank [45] the authors suggested that each kind of hope was shaped by a particular narrative type: restitution narrative, the quest narrative and the chaos narrative. Those influenced by a ‘restitution narrative’ focused upon walking again, being cured, and returning to their pre-injury lifestyles. The ‘quest narrative’, which Frank has suggested encompasses a spiritual dimension, was associated with embracing “uncertainty and finitude,

celebrating surprise, play, novelty, mystery, and openness to change” [75]. In contrast, the chaos narrative resulted in a loss of hope, with participants who adopted this narrative perceiving life post-SCI to be over.

In a cross-sectional report from a longitudinal study of hope among individuals with SCI, Lohne and colleagues [73,77] observed that hope was associated with suffering and longing within the first year after the SCI. Three to four years after the SCI Lohne identified three main themes from interviews with the same participants; life-related hopes, body-related hopes, and creative and expanding hopes, where hope became about enjoying life within the limits experienced. In another longitudinal study Dorsett [52] identified three foci of hope: i) hope for a complete recovery, ii) hope for a cure, and iii) hope for a satisfying quality of life. For many participants in this study hope was an important factor in coping with their SCI and a strong motivator to survive and ‘get on with life’.

In the only study to consider adjustment after SCI within a Muslim society Babamohamadi et al [76] found that hope was one of the most common coping strategies among individuals in Iran. These included hope for successful surgery, hope in God for divine healing or miracles, hope for medical progress, and hope in the future. Religious beliefs and hope were closely entwined, with participants viewing their SCI as part of divine fate or test. Many sought help through prayer.

The only other qualitative study to consider individual adjustment after SCI was by Papadimitriou and Stone [37] who drew upon interview data from individuals with SCI in both inpatient and community settings to further develop ideas regarding the role of human temporality after SCI. The authors asserted that the present is only “made meaningful” in light of both future projections and the past. A SCI brings about disconnection between the past, present and future, as future plans become no longer viable, and the past has no bearing upon either the present or the future, due to dramatically changed circumstances. The

disruption caused by a SCI is perceived as an opportunity for restructuring, which some participants in their study even described as a “second life” or being “born again” (p.2128).

A few authors amongst this group of qualitative studies drew specific clinical implications from their studies. Angel et al [71] recommended narratives as a beneficial tool in therapeutic interventions, to assist inpatients to draw meaning and hope for the future in their current circumstances. Chun and Lee [70] and Papadimitrou and Stone [37] highlighted the importance of peer support in their studies. They suggested that peers provide hope for the future, and examples of successful living after SCI. Chun and Lee also recommended that clinicians utilise meaning-focused programs in their work with clients. Similarly Dorsett [52] suggested that social workers can play an important role in hope development with clients, and a key role in the rehabilitation team by exploring meaning and appraisals.

Objective 3: Spirituality within the family after SCI

Among the 28 studies only two adopted a systemic approach [26,28]. These two studies incorporated the dual perspectives of the injured individual and a family member. One of these studies was quantitative and the other qualitative.

Quantitative study

Adopting a family systems approach Feigin [26] investigated the reciprocal relationships between sense of coherence (SOC) and adjustment for spouses two to 10 years after SCI or cerebrovascular accident (CVA) in Israel. Feigin reported a significant relationship between the SOC and adjustment to disability for individuals, and a relationship between the SOC and adjustment of both partners in a marriage. When the individual with a disability had a higher SOC than their spouse, they were less anxious and healthier than those individuals with a disability whose SOC was lower than their spouse. Likewise, when the spouse had a higher SOC than the individual with a disability, the spouse was less anxious, more accepting of the

disability, more highly engaged in work and study, and healthier compared to those spouses with a lower SOC than the individual with the disability. This study demonstrated the relational aspect of SOC and its impact upon the adjustment of both members in the marriage.

Qualitative study

The other report to incorporate the perspective of family members was a qualitative study by DeSanto-Madeya [28], who sought to explore “the everyday world” of living for families affected by SCI. In her interviews with 20 dyads (person with SCI and a family member) she identified seven themes related to the meaning of life with SCI: looking for understanding in a life that is unknown; stumbling along an unlit path; viewing self through a stained-glass window; challenging the bonds of love; being chained to the injury; moving forward in a new way of life; and reaching a new normalcy. These themes emphasised the important role family relationships play throughout the meaning making process, and revealed how dynamic this process can be. Like the study by Feigin [26] this study considered the process of meaning-making from a systemic perspective. Issues of spirituality were most apparent within the theme of ‘moving forward in a new way of life’ encompassing ‘believing the injury happened for a reason, faith in God, desire to help others’.

Objective 4: Spirituality and resilience

Only one of the 28 studies considered spirituality and its relationship with resilience. In their study of resilience and indicators of adjustment after SCI White et al [13] reported significant positive correlations between resilience, satisfaction with life, and intrinsic spirituality. The study was conducted with individuals with SCI who were undertaking inpatient rehabilitation and measures were repeated at three time-points; upon admission to the unit (T1), 3 weeks later (T2), and at discharge (T3). The authors found that although resilience did not change

over time, there were small significant changes in spirituality scores which increased from T1 to T2, then decreased from T2 to T3 close to their starting point. Further investigation of these constructs is recommended in the paper, particularly the relationship between resilience and spirituality. As this study only considered individuals with SCI undergoing initial rehabilitation, no family or systemic perspective was provided.

Discussion

The results of this scoping study support the claims that spirituality plays an important role in contributing toward individual adjustment after SCI. An important distinction arose between studies that conceptualised spirituality as a measurable construct (utilising quantitative methodology), and others which conceptualised spirituality as a process of growth and meaning making (utilising predominantly qualitative methodology). Quantitative studies revealed how spirituality and other meaning-making constructs have been positively associated with life satisfaction, quality of life, perceived health, and resilience. Qualitative studies provided invaluable information about how spirituality and related constructs have been understood as part of a process, narrative, or journey leading to growth and positive change.

Spirituality has been proposed as a key process of family resilience [24]. However of the 28 studies identified in the scoping review only five adopted an approach which addressed the wider family experience of meaning making after SCI, and only two of these included the perspective of both the individual with SCI and their family members [26,28]. The only study to specifically consider spirituality as a relational concept was that by McColl et al [69], who demonstrated that much potential exists within the field of SCI to conceptualise spirituality within the context of relationships, whether they be transpersonal, interpersonal, or intrapersonal. Given the importance placed upon spirituality in the

framework of family resilience by Walsh[24], this lack of pertinent investigation in the area of SCI is significant.

Other areas also clearly warrant further investigation. First, the definitions and understandings of spirituality within the papers of this scoping study were wide ranging and dependent upon a number of different measures. Although the relationship between religion and spirituality was explored by some, little exploration of different religious beliefs was present. Most studies it seems were conducted within a predominantly Christian context. The only contrast to this was provided by Babamohamadi et al [76], who investigated Islamic beliefs of individuals with SCI observing that individuals with Islamic beliefs viewed the SCI as a fate provided by God or a divine test interestingly this was also the only study to consider the role of prayer. Further research which considers a range of religious perspectives and activities would enhance awareness in this area. Furthermore only one study considered the role of congregational or social support [62], which is a surprising finding given the identified importance of social support after SCI [78]. Individual and family member participation in religious communities after SCI would be another area worthy of further examination. The only two studies identified to consider the impact of time since injury (TSI) upon spirituality were cross-sectional, and reported mixed findings. A greater number of longitudinal studies are required to consider changes in spirituality over time. It may be that the early stages of rehabilitation are when the role of spirituality is most important, but this is yet to be determined.

Negativity towards God or a higher power after a traumatic injury was reported by participants in some studies but not explored in depth. How such experiences by some may affect adjustment is unknown. A bi-directional relationship between spirituality and trauma has been identified by others [51] and is illustrated well by Mitchell [62] in a personal account of challenges to his own faith after SCI. Highlighting some of the complexity around

this issue was the study by Davis and Novoa [67] which found that whereas finding meaning was associated with improved adjustment, more frequent searching was actually associated with declines in adjustment after SCI. This distinction between searching for meaning and finding meaning, and how these correlate with spirituality and/or religious faith may be worthy of further investigation. Better understanding of these issues could improve interventions within a health or rehabilitation context.

Only a few studies in this scoping review made recommendations for clinical interventions in the area of spinal rehabilitation. These included suggestions that health professionals incorporate the spiritual or meaning-making resources of individuals with SCI into assessment and intervention [36,38,56,61,70], draw upon meaning-making tools such as narrative therapy[71], incorporate peer support [37,70], and assist clients who report a decline in spirituality to manage such emotions as anger or abandonment [56]. It was apparent from this review that hope and spirituality are often closely intertwined, and that for many individuals it is hope which assists them to draw meaning, move forward and to adjust to their changed circumstances [28,75]. Further investigation of clinical interventions associated with spirituality would potentially assist health professionals to better facilitate adjustment for both individuals and families affected by SCI.

A challenge for this scoping review was how to decide which meaning-making terms would be included to search for papers on the topic of spirituality. Including papers that focused upon spirituality, faith, religion, beliefs, posttraumatic growth, sense of coherence, purpose in life and hope resulted in a broad range of articles. This limited the study to some extent, due to the breadth of material and consistency required regarding the inclusion of articles. Other search terms which may have been relevant to the topic of spirituality, such as ‘forgiveness’ and ‘gratitude’ could be included in future research. It is also possible that some articles may have not been identified due to the databases which were used, and which

do not directly associate selected terms with spirituality. This review demonstrated that spirituality is a dynamic concept which is only beginning to be investigated within the area of SCI, and much potential exists to explore it further.

Conclusion

This scoping review confirmed that although spirituality is increasingly being acknowledged to play an important role regarding individual adjustment after SCI, there is a paucity of studies which have addressed spirituality and adjustment within the family. Furthermore, how spirituality may contribute toward individual or family resilience after SCI is currently unknown. Is spirituality merely an indicator of adjustment, or does it play a critical role in building resilience within the family after SCI? It would appear that an empirical investigation to consider such a question would be one of the first to do so.

Declaration of Interest

None.

Reference List

1. Kennedy P, Evans M, Sandhu N. Psychological adjustment to spinal cord injury: The contribution of coping, hope and cognitive appraisals. *Psychology, Health & Medicine* 2009;14:17-33.
2. Gill M. Psychosocial implications of spinal cord injury. *Critical Care Nursing Quarterly* 1999;22:1-7.
3. Kester B, Rothblum E, Lobato D, Milhous R. Spouse adjustment to Spinal Cord Injury: Long-term medical and psychosocial factors. *Rehabilitation Counseling Bulletin* 1988;32:4-21.
4. Alfano D, Neilson P, Fink M. Sources of stress in family members following head or spinal cord injury. *Applied Neuropsychology* 1994;1:57-62.
5. Boschen K, Tonack M, Gargaro J. The impact of being a support provider to a person living in the community with a spinal cord injury. *Rehabilitation Psychology* 2005;50:397-407.
6. Kolakowsky-Hayner SA, Kishore R. Caregiver functioning after traumatic injury. *NeuroRehabilitation* 1999;13:27-33.
7. Chan RC. Stress and coping in spouses of persons with spinal cord injuries. *Clinical Rehabilitation* 2000;14:137-144.
8. Kennedy P, Rogers BA. Anxiety and depression after spinal cord injury: A longitudinal analysis. *Archives of Physical Medicine and Rehabilitation* 2000;81:932-937
9. Dryden DM, Saunders LD, Rowe BH, May LA, Yiannakoulis N, Svenson LW, Schopflocher DP, Voaklander DC. Depression following traumatic spinal cord injury *Neuroepidemiology* 2005;25:55-61.
10. Hoffman J, Bombardier C, Graves D, Kalpakjian C, Krause J. A longitudinal study of depression 1 to 5 years after spinal cord injury. . *Archives of Physical Medicine and Rehabilitation* 2011;92:411-418.
11. White B, Driver S, Warren A. Considering resilience in the rehabilitation of people with traumatic disabilities. *Rehabilitation Psychology* 2008;53:9-17.

12. Simpson G, Jones K. How important is resilience among family members supporting relatives with traumatic brain injury or spinal cord injury? *Clinical Rehabilitation* 2013;27:367-377.
13. White B, Driver S, Warren AM. Resilience and indicators of adjustment during rehabilitation from a spinal cord injury. *Rehabilitation Psychology* 2010;55:23-32.
14. Tate DG, Forchheimer M. Quality of life, life satisfaction, and spirituality: Comparing outcomes between rehabilitation and cancer patients. *American Journal of Physical Medicine and Rehabilitation* 2002;81:400-410.
15. Millard R. Facing the situation. In: Rumbold B, editor. *Spirituality and Palliative Care: Social and Pastoral Perspectives*. Oxford: Oxford University Press; 2002. p 97-115.
16. Pargament K. *The psychology of religion and coping*. New York: The Guildford Press; 1997.
17. Frankl V. *Man's Search for Meaning*. Massachusetts: Beacon Press; 2006.
18. Cobb M, Puchalski CM, Rumbold B, editors. *Oxford Textbook of Spirituality in Healthcare*. Oxford: Oxford University Press; 2012.
19. Hampton J, Weinert C. An exploration of spirituality in rural women with chronic illness. *Holistic Nursing Practice* 2006;20:27-33.
20. Johnstone B, Glass BA, Oliver RE. Religion and disability: Clinical, research and training considerations for rehabilitation professionals. *Disability and Rehabilitation* 2007;29:1153-1163.
21. Strang S, Strang P. Spiritual thoughts, coping and 'sense of coherence' in brain tumour patients and their spouses. *Palliative Medicine* 2001;15:127-134.
22. Johnstone B, Yoon DP, Johnstone B, Yoon DP. Relationships between the Brief Multidimensional Measure of Religiousness/Spirituality and health outcomes for a heterogeneous rehabilitation population. *Rehabilitation Psychology* 2009;54:422-31.
23. Ka'opua LS, Gotay CC, Boehm PS. Spiritually Based Resources in Adaptation to Long-Term Prostate Cancer Survival: Perspectives of Elderly Wives. *Health & Social Work* 2007;32:29-39.
24. Walsh F. Family resilience: a framework for clinical practice. *Family Process* 2003;42:1-18.

25. Kim Y, Carver CS, Spillers RL, Crammer C, Zhou ES. Individual and dyadic relations between spiritual well-being and quality of life among cancer survivors and their spousal caregivers. *Psycho-Oncology*;20:762-770.
26. Feigin R. The relationship between the sense of coherence and adjustment to disability studied in the context of marital interrelations. *Marriage & Family Review* 1998;27:71-90.
27. Murray CI, Sullivan AM, Brophy DR, Mailhot M. Working with parents of spinal cord injured adolescents: A family systems perspective. *Child & Adolescent Social Work Journal* 1991;8:225-238.
28. DeSanto-Madeya S. The Meaning of Living With Spinal Cord Injury 5 to 10 Years After the Injury. *Western Journal of Nursing Research* 2006;28:265-289.
29. Richardson GE. The metatheory of resilience and resiliency. *Journal of Clinical Psychology* 2002;58:307-321.
30. Connor KM, Davidson JR. Development of a new resilience scale: The Connor-Davidson Resilience Scale (CD-RISC). *Depression and Anxiety* 2003;18:76-82.
31. Levac D, Colquhoun H, O'Brien K. Scoping studies: advancing the methodology. *Implementation Science* 2010;5.
32. Arksey H, O'Malley L. Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology* 2005;8:19-32.
33. Middleton J, Tran Y, Craig A. Relationship Between Quality of Life and Self-Efficacy in Persons With Spinal Cord Injuries. *Archives of Physical Medicine and Rehabilitation* 2007;88:1643-1648.
34. Post MW, Van Dijk AJ, Van Asbeck FW, Schrijvers AJ. Life satisfaction of persons with spinal cord injury compared to a population group. *Scandinavian Journal of Rehabilitation Medicine* 1998;30:23-30.
35. Diener E, Emmons R, Larsen J, Griffin S. The satisfaction with life scale. *Journal of Personality Assessment* 1985;49:71-75.

36. DeRoos-Cassini T, De St Aubin E, Valvano A, Hastings J, Horn P. Psychological well-being after spinal cord injury: Perception of loss and meaning making. *Rehabilitation Psychology* 2009;54:306-314.
37. Papadimitriou C, Stone DA. Addressing existential disruption in traumatic spinal cord injury: a new approach to human temporality in inpatient rehabilitation. *Disability and Rehabilitation* 2011;33:2121-2133.
38. Lustig DC. The adjustment process for individuals with spinal cord injury. *Rehabilitation Counseling Bulletin* 2005;48:146-156.
39. Thompson NJ, Coker J, Krause JS, Henry E. Purpose in life as a mediator of adjustment after spinal cord injury. *Rehabilitation Psychology* 2003;48:100-108.
40. Antonovsky A. *Unraveling the mystery of health: How people manage stress and stay well*. San Francisco: Jossey-Bass; 1987.
41. Tedeschi R, Calhoun L. Posttraumatic Growth: Conceptual Foundations and Empirical Evidence. *Psychological Inquiry* 2004;15:1-18.
42. Elliott J. Hope. In: Cobb M, Puchalski CM, Rumbold B, editors. *Oxford Textbook of Spirituality in Healthcare*. Oxford: Oxford University Press; 2012. p 119-126.
43. McColl MA. Spirituality and disability. In: McColl MA, editor. *Spirituality and Occupational therapy*. Second ed. Ottawa: Canadian Association of Occupational Therapists; 2011. p 31-39.
44. Bufford R, Paloutzian R, Ellison C. Norms for the Spiritual Well-Being Scale *Journal of Psychology and Theology* 1991;19 56-70.
45. Frank AW. *The Wounded Storyteller: Body, Illness and Ethics*. Chicago: University of Chicago Press; 1995.
46. Rumbold B. Models of spiritual care. In: Cobb M, Puchalski CM, Rumbold B, editors. *Oxford Textbook of Spirituality in Healthcare*. Oxford: Oxford University Press; 2012. p 177-183.
47. Crumbaugh J. Cross-validation of the Purpose-in-Life Test based on Frankl's concepts. *Journal of Individual Psychology* 1968;24:74-81.

48. Delgado C. Sense of coherence, spirituality, stress and quality of life in chronic illness. *Journal of Nursing Scholarship* 2007;39:229-34.
49. Rutter M. Resilience in the face of adversity. Protective factors and resistance to psychiatric disorder. *British Journal of Psychiatry* 1985;147:598-611.
50. Tedeschi R, Calhoun L. The Posttraumatic Growth Inventory: Measuring the positive legacy of trauma. *Journal of Traumatic Stress* 1996;9:455-471.
51. Dufault K, Martocchio BC. Hope: its spheres and dimensions. Symposium on compassionate care and the dying experience. *Nursing Clinics of North America* 1985;20:379-91.
52. Dorsett P. The importance of hope in coping with severe acquired disability. *Australian Social Work* 2010;63:83-102.
53. Herth K. Abbreviated instrument to measure hope: development and psychometric evaluation. *Journal of Advanced Nursing* 1992;17:1251-9.
54. Snyder CR, Harris C, Anderson JR, Holleran SA, Irving LM, Sigmon ST, Yoshinobu L, Gibb J, Langelle C, Harney P. The will and the ways: development and validation of an individual-differences measure of hope. *Journal of Personality and Social Psychology* 1991;60:570-85.
55. Rumbold B. Dying as a spiritual quest. In: Rumbold B, editor. *Spirituality and Palliative Care: Social and Pastoral Perspectives*. Oxford: Oxford University Press; 2002. p 195-218.
56. Marini I, Glover-Graf NM. Religiosity and Spirituality Among Persons With Spinal Cord Injury: Attitudes, Beliefs, and Practices. *Rehabilitation Counseling Bulletin* 2011;54:82-92.
57. Forchheimer M, Tate DG. The relationship of spirituality and depression to health among people with spinal cord injury. *Topics in Spinal Cord Injury Rehabilitation* 2007;12:23-34.
58. Chlan K, Zebracki K, Vogel L. Spirituality and life satisfaction in adults with pediatric-onset spinal cord injury. *Spinal Cord* 2011;49:371-375.
59. Riley BB, Perna R, Tate DG, Forchheimer M, Anderson C, Luera G. Types of spiritual well-being among persons with chronic illness: Their relation to various forms of quality of life. *Archives of Physical Medicine and Rehabilitation* 1998;79:258-264.
60. Brillhart B. A study of spirituality and life satisfaction among persons with spinal cord injury. *Rehabilitation Nursing* 2005;30:31-34.

61. Matheis EN, Tulskey DS, Matheis RJ. The relation between spirituality and quality of life among individuals with spinal cord injury. *Rehabilitation Psychology* 2006;51:265-271.
62. Franklin KL, Yoon DP, Acuff M, Johnstone B. Relationships among religiousness, spirituality, and health for individuals with spinal cord injury. *Topics in Spinal Cord Injury Rehabilitation* 2008;14:76-81.
63. Peterman AH, Fitchett G, Brady MJ, Hernandez L, Cella D. Measuring spiritual well-being in people with cancer: the functional assessment of chronic illness therapy-spiritual well-being scale (FACIT-SP). *Annals of Behavioral Medicine* 2002;24:49-58.
64. Ellison CW, Smith J. Toward an integrative measure of health and well-being. *Journal of Psychology and Theology* 1991;19:35-48.
65. Kennedy P, Lude P, Elfstrom ML, Smithson E. Sense of coherence and psychological outcomes in people with spinal cord injury: Appraisals and behavioural responses. *British Journal of Health Psychology* 2010;15:611-621.
66. Kortte KB, Gilbert M, Gorman P, Wegener ST. Positive psychological variables in the prediction of life satisfaction after spinal cord injury. *Rehabilitation Psychology* 2010;55:40-47.
67. Davis CG, Novoa DC. Meaning-making following spinal cord injury: Individual differences and within-person change. *Rehabilitation Psychology* 2013;58:166-177.
68. White B, Driver S, Warren A. Resilience and indicators of adjustment during rehabilitation from a spinal cord injury. *Rehabilitation Psychology* 2010;55:23-32.
69. McColl MA, Bickenbach J, Johnston J, Nishihama S, Schumaker M, Smith K, Smith M, Yealland B. Changes in spiritual beliefs after traumatic disability. *Archives of Physical Medicine and Rehabilitation* 2000;81:817-823.
70. Chun S, Lee Y. The Experience of Posttraumatic Growth for People With Spinal Cord Injury. *Qualitative Health Research* 2008;18:877-890.
71. Angel S, Kirkevold M, Pedersen BD. Getting on with life following a spinal cord injury: Regaining meaning through six phases. *International Journal of Qualitative Studies on Health and Well-Being* 2009;4:39-50.

72. Kennedy P, Lude P, Elfstrom ML, Cox A. Perceptions of gain following spinal cord injury: A qualitative analysis. *Topics in Spinal Cord Injury Rehabilitation* 2013;19:202-210.
73. Lohne V. Back to life again -- patients' experiences of hope three to four years after a spinal cord injury -- a longitudinal study. *Canadian Journal of Neuroscience Nursing* 2009;31:20-25.
74. Lohne V, Severinsson E. The power of hope: patients' experiences of hope a year after acute spinal cord injury. *Journal of Clinical Nursing* 2006;15:315-323.
75. Smith B, Sparkes A. Men, sport, spinal cord injury, and narratives of hope. *Social Science & Medicine* 2005;61:1095-1105.
76. Babamohamadi H, Negarandeh R, Dehghan-Nayeri N. Coping strategies used by people with spinal cord injury: a qualitative study. *Spinal Cord* 2011;49:832-837.
77. Lohne V, Severinsson E. Patients' experiences of hope and suffering during the first year following acute spinal cord injury. *Journal of Clinical Nursing* 2005;14:285-293.
78. Anson CA, Stanwyck DJ, Krause JS. Social support and health status in spinal cord injury. *Paraplegia* 1993;31:632-638.

Figure 1: **Database Search**

Table 1: Quantitative studies

	First Author, Year, Country	Study Design	Construct/s of interest	N, TSI	Injury Characteristics	Measure/s of Spirituality and/or Meaning	Significant outcomes
1	Brillhart [60] 2005, USA	Cross-sectional, prospective	Spirituality	230, NR	SCI only Cervical 1-4: n=41 Cervical 5-7: n=85 Thoracic 1-12: n=85 Lumbar 1-5: n=14 Not stated: n=5	QLI [79] - Factor III includes 'peace of mind' and 'faith in God'.	QLI psychological/spiritual factors correlate with SWLS (r=.60).
2	Chlan [58] 2011, USA	Cross-sectional, prospective	Spirituality	298, M 16.6, (SD 6.5), Range 6-38 yrs.	SCI only, Pediatric-onset Paraplegia 44% Tetraplegia 56% ASIA A: 70.5%	i) Brief COPE [80] (spiritual coping domain only) - 'I've been trying to find comfort in my religion or spiritual beliefs' - 'I've been praying or meditating' ii) Importance of religion scale (Likert scale 1-5)	55% of participants used spiritual coping 'a medium to a lot'. Importance of religion correlate with SWL (r=.14), spiritual coping with SWL (r=.17). Spiritual coping predictor of SWL, religious coping <i>ns</i>

	First Author, Year, Country	Study Design	Construct/s of interest	N, TSI	Injury Characteristics	Measure/s of Spirituality and/or Meaning	Significant outcomes
3	Davis [67] 2013, Canada	Mixed method, longitudinal, prospective	Meaning, PTG	67, <1 yr	SCI only Paraplegia 34.3% Tetraplegia 58.2% Other 7.5%	i) Assessment of meaning making (five questions with coded responses) ii) PTGI [50]	Having found meaning after SCI is more adaptive than searching for meaning. Depressive symptoms increased over time for people who had not found meaning but remained stable for people who reported finding meaning. Depressive symptoms increased over time for people who searched for meaning frequently, but remained stable for people not searching for meaning. Individuals finding more meaning also reported greater perceived growth through the trauma.
4	deRoos-Cassini [36] 2009, USA	Cross-sectional, prospective	PIL	79, M 17.5 mths (SD 14.7mths) Range 0.1-62 mths	SCI only Partial paraplegia: n=21 Complete paraplegia: n=20 Partial tetraplegia: n=34 Complete tetraplegia: n=4	PIL scale [47] -measures the degree to which an individual believes they are living a meaningful life	PIL correlate with psychological well-being ($r=.70$); PIL accounted for an additional 42% of the variance in psychological well-being after perceived loss of physical functioning was entered.
5	Forchheimer [57] 2007, USA	Cross-sectional, prospective	Spirituality	444, Range 10-30 yrs.	SCI only Injury details not documented	FACIT-SP [63] -spirituality total and two scales: meaning and faith	Spiritual well-being independent predictor of perceived health status, also independent predictor of global life satisfaction. No relationship found btw TSI and scores on FACT-SP

	First Author, Year, Country	Study Design	Construct/s of interest	N, TSI	Injury Characteristics	Measure/s of spirituality	Significant outcomes
6	Franklin [62] 2008, USA	Cross-sectional, prospective	Religious Beliefs	25, M 133.5 mths (SD 51.9 mths), Range 7 to 564 mths	SCI only Injury details not documented	BMMRS [81] -Scales include: meaning, values/beliefs, daily spiritual experiences, forgiveness, religious support, private religious practices, organisational religiousness, religious and spiritual coping	BMMRS religious support correlate with SF36 General Mental Health Scale ($r=.70$). Participants with SCI received significantly more religious support than healthy controls.
7	Kennedy [1] 2009, UK	Cross-sectional, prospective	Hope	54, < 1 yr	SCI only Tetraplegia: n=27 Paraplegia: n=27 Complete: n=22 Incomplete n=32	State Hope Scale [82] -measures a person's current evaluation of their goal-directed thinking. Subscales: i) agency, ii) pathways	Higher hope agency/higher challenge appraisals had positive correlation with higher levels of acceptance. Threat appraisals best predictors of anxiety and depression.
8	Kennedy [65] 2010, Europe	Longitudinal prospective	SOC	237, < 1 yr	SCI only Complete paraplegia: n=74 Incomplete paraplegia: n=52 Complete tetraplegia: n=41 Incomplete tetraplegia: n=68	SOC scale [83] -measures comprehensibility, manageability, and meaningfulness	High SOC at 6 weeks post injury predicted better psychological outcomes at 1 year post-injury. A model of SOC, appraisals, coping behaviours explained 61.8% of the variance in psychological quality of life, 66.5% of variance in depression, and 37.7% in anxiety at 1 year post-SCI.

	First Author, Year, Country	Study Design	Construct/s of interest	N, TSI	Injury Characteristics	Measure/s of spirituality	Significant outcomes
9	Kortte [66] 2010, USA	Longitudinal, prospective	Hope	87, Range 7-61 days in inpatient rehab unit	SCI only Complete paraplegia: n=18 Complete tetraplegia: n=9 Incomplete paraplegia: n=31 Incomplete tetraplegia: n=29	Hope Scale [54] Benefit Finding Scale [84]	Greater benefit finding, hope and positive affect account for an additional 20% in the variance of life satisfaction during acute rehabilitation phase after controlling for demographic and barrier variables (depression, negative coping) and an additional 9% in the variance of life satisfaction at 3 months after discharge.
10	Lustig [38] 2005, USA	Cross-sectional, prospective	SOC	48, M 106 mths (SD 99 mths), Range 1 mth-27 yrs	SCI only Injury details not documented	SOC scale [83]	Strengthened SOC group had negative correlations with anxiety ($r=-.63$), depression ($r=-.59$), shock ($r=-.58$) and internalized anger ($r=-.50$). Weakened SOC group correlation with anxiety ($r=.48$), internalized anger ($r=.48$), depression ($r=.47$), externalized anger ($r=.45$), shock ($r=.36$) and negative correlation with acknowledgement ($r=-.59$) and adjustment ($r=-.55$)

	First Author, Year, Country	Study Design	Construct/s of interest	N, TSI	Injury Characteristics	Measure/s of spirituality	Significant outcomes
11	Marini [56] 2011, USA	Cross-sectional, prospective	Spirituality	157, < 2 yrs, 2-5 yrs, > 5 yrs	SCI only T 1 or below: n=65 C5-C8: n=46 C2-C4: n=32	Spirituality and SCI survey (created for this study and based on Spirituality and Chronic Pain Survey [85]). -assesses participants' religious and spiritual beliefs.	Over 50% of participants felt connected to God or a Spiritual Power (G/SP); 72% felt G/SP gave them meaning or purpose in life; 48% believed there was a spiritual reason for their SCI. Some (10%) expressed anger with G/SP, feeling abandoned, punished, and/or that the disability made them a worse person. Some individuals more focused on religious/spirituality practices and beliefs soon after injury, but these beliefs dissipate over time.
12	Matheis [61] 2006, USA	Cross-sectional, prospective	Spirituality	75, M 7.56 yrs, Range 1-32 yrs	SCI only Low quadriplegia: n=31 High paraplegia: n=17 Low paraplegia: n=15 High quadriplegia: n=12	SWBS [64] - Measures existential spirituality (life connection and purpose) and religious spirituality (relationship with God, sense of satisfaction and positive connection with God)	98.7% of participants used some form of spiritual-based coping. Existential spirituality (as compared to religious spirituality or nonspecific spirituality) only significant predictor of global QOL, accounting for 34% of the variance in life satisfaction and 33% of the variance in perceived general health.
13	Riley [59] 1998, USA	Cross-sectional, prospective	Spirituality	216, NR	Mixed diagnostic groups SCI, n=34 Consistency	SWBS [64] FACT-SP [86] -asks about participant's spiritual well-being over the last seven days	Between-groups analyses found participants in religious or existential groups reported higher levels of purpose and meaning in life, QOL and life satisfaction compared with a nonspiritual group.

	First Author, Year, Country	Study Design	Construct/s of interest	N, TSI	Injury Characteristics	Measure/s of spirituality	Significant outcomes
14	Tate [14] 2002, USA	Cross-sectional, prospective	Spirituality	208, NR	Mixed diagnostic groups (including SCI) Injury details not reported	FACT-SP [86]	Spirituality (FACT-SP) independent predictor of life satisfaction, but not predictor of quality of life in model in which FACT emotional, FACT functional, SF-36 physical function, SF-36 social function were significant predictors.
15	Thompson [39] 2003, USA	Cross-sectional, prospective	PIL	1391, M 8.9 yrs (SD 7.3 yrs)	SCI only Paraplegia 45% Tetraplegia 55%	PIL scale [47]	PIL negative correlation with neuroticism-anxiety ($r=-.46$), aggression-hostility ($r=-.20$), chance of health locus of control ($r=-.20$), powerful others health locus of control ($r=-.12$), positive correlation with activity ($r=.34$, sociability ($r=.45$), health locus of control ($r=.22$)
16	White [13] 2010, USA	Longitudinal	Spirituality	42, Range 29-107 days in inpatient rehab	SCI only Injury details not reported.	Intrinsic Spirituality Scale [87] - measures intrinsic spiritual beliefs with six questions	No significant changes in resilience over three time points during inpatient rehabilitation (Admission, 3 weeks post-admit, discharge). Correlations were observed at each point between resilience and spirituality ($r=.35$, $.29$, $.56$).

	First Author, Year, Country	Study Design	Construct/s of interest	N, TSI	Injury Characteristics	Measure/s of spirituality	Significant outcomes
17	Feigin [26] 1998, Israel	Cross-sectional, prospective	SOC	N=80 people with disability N=72 non-disabled spouses, Range 2-12 yrs	Mixed diagnostic groups SCI =73%, Injury details not reported	SOC Scale [83]	SOC for SCI and partners combined accounted for 73% of the variance in adjustment. Non-disabled partners with higher SOC than their disabled partner had significantly higher adjustment scores in comparison to their partner; Non-disabled partners with lower SOC than their disabled partner had significantly lower adjustment scores compared to their partner.

NR= Not reported; SCI = Spinal cord injury; TSI= Time since injury; SOC = Sense of Coherence; PTG = Post traumatic growth; PTGI = Post traumatic growth inventory; PIL = Purpose in Life; QOL=Quality of Life; QLI = Quality of Life Index [88]; SWL = Satisfaction with Life; SWLS = Satisfaction with Life Scale [35]; FACIT-SP= Functional Assessment of Cancer Therapy - Spirituality [63]; BMMRS = Brief Multidimensional Measure of Religiousness/Spirituality [81]; SF36= Medical Outcomes Study Short Form[89].

Table 2: Qualitative Studies

	First Author, Year, Country	Study Design	Construct/s of interest	N, TSI	Injury Characteristics	Key Themes
1	Angel [71] 2009, Denmark	Longitudinal	Meaning	12, < 2 yrs	SCI only Incomplete lesion: n=9 (3 severe) Complete lesion: n=3	Regaining meaning via six phases: surviving physically and regaining vitality, moving back to life where possibilities present themselves, working with progress to pursue possibilities, fading progress narrow possibilities down, exploiting limited possibilities, living a life with qualities despite limitations.
2	Babamohamadi [76] 2011, Iran	Cross- sectional	Religious Beliefs, Hope	18, Range 2.5-26 yrs	SCI only Paraplegia 83.3% Quadriplegia 16.7%	Three coping strategies; seeking help from religious beliefs, hope, making efforts towards independence.
3	Chun [70] 2008, Canada	Cross- sectional	PTG	15, M 10.7 yrs	SCI only Paraplegia 100%	Experience of meaningful family relationships; experience of meaningful engagement; appreciation of life.

	First Author Year, Country	Study Design	Construct/s of interest	N, TSI	Injury Characteristics	Key Themes
4	Dorsett [52] 2010, Australia	Longitudinal	Hope	46, Range 6 mths – 10 yrs	SCI only Paraplegia: n=19 Quadriplegia: n=27 Complete: n=16 Incomplete: n=30	Hoping for complete recovery, hope for a cure, hope for a satisfying quality of life.
5	Kennedy [72] 2013, UK/Europe	Longitudinal	PTG	232, < 2 yrs	SCI only Paraplegia: 51.83% Tetraplegia: 47.71%	Thirteen themes of gains since SCI included: perspective/appreciation of life, changed personality, nothing, understanding/perspective of disability/SCI, appreciation of relationships, knowledge of SCI/body, relationships, new goals/priorities/opportunity/challenge, acceptance, appreciation of health/health care, spirituality and new skills.

	First Author Year, Country	Study Design	Construct/s of interest	N, TSI	Injury Characteristics	Key Themes
6	Lohne [77] 2005, Norway	Cross- sectional	Hope	10, < 1 yr	SCI only Incomplete lesion: n=6 Complete lesion: n=4 (range C5- L4)	‘The vicious cycle’ - suffering (loneliness, impatience, disappointment, bitterness, dependency); ‘longing’ - former experiences and source of new hope
7	Lohne [73] 2009, Norway	Cross- sectional	Hope	9, Range 3-4 yrs	SCI only Incomplete: n=5 Complete: n=4 (range C5-L4)	Life-related hopes, body-related hopes, creative and expanding hopes.
8	Smith [75] 2005, UK	Cross- sectional	Hope	14, NR	SCI only Injury details not reported.	Three kinds of hope: concrete hope, (restitution narrative), transcendent hope (quest narrative), and despair (chaos narrative).

	First Author Year, Country	Study Design	Construct/s of interest	N, TSI	Injury Characteristics	Key Themes
9	McColl [69] 2000, Canada	Cross- sectional	Spirituality	16, < 2 yrs	Mixed diagnostic groups SCI, n = 8	Changes in spirituality: greater awareness of the self; greater appreciation and closeness with others; a new understanding of trust; a sense of purpose in life that was not present before the injury; greater awareness of their own mortality and vulnerability.
10	Papadimitriou [37] 2011, USA	Cross- sectional	Meaning	10, 14, 12, NR	SCI only Injury details not reported	SCI understood as disruption in human temporality: disconnection from a future and from one's past.
11	DeSanto-Madeya [28] 2006, USA	Cross- sectional	Meaning	40, Range 5-10 yrs	SCI only T10: n=3 T8: n=2 C6-7: n=1 C5-6: n=11 C4-5: n=3	Looking for understanding to a life that is unknown, stumbling along an unlit path, viewing self through a stained glass window, challenging the bonds of love, being chained to the injury, moving forward in a new way of life, reaching normalcy.

SCI=Spinal Cord Injury; NR=Not reported, TSI= Time since injury; PTG= Post traumatic Growth