- 1 Moving forward on the journey - How spirituality contributes towards family resilience after
- 2 spinal cord injury

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Abstract

Purpose/Objective: The aim of this exploratory study was to consider how spirituality (encompassing meaning, hope and purpose), over time, contributed towards family resilience after SCI.

Research Method/Design: A qualitative, longitudinal study design was adopted. Semi-structured interviews were conducted with 10 family dyads (consisting of the individual with SCI and a nominated family member) on two occasions, six months apart. A thematic analysis was conducted.

Results: Participants reported drawing upon a range of different sources of spirituality, including religious faith, the natural world, inner strength, and meaningful connectedness with others. These sources of spirituality were often tested in some way after the SCI. Meaning-making responses to these tests led to three key outcomes: gratitude, hope, and deeper connectedness with others, assisting families to move forward in their journey after SCI. Over time sources of spirituality did not change significantly, however the intensity of spiritual experience lessened for some families.

Conclusions/Implications: This study indicated that spirituality after SCI plays an important role for both the injured individual and their family members. Families draw upon a range of sources of spirituality, and these sources of spirituality can assist the family to move forward together after SCI. Further investigation of how health professionals can better address spirituality during spinal rehabilitation is warranted.

Keywords: spinal cord injury, family, spirituality, resilience, hope

Impact

- This study is one of the first to consider spirituality and how it contributes towards family resilience after spinal cord injury (SCI). Perspectives from both the individuals with SCI and family members were obtained, demonstrating that the experience of spirituality is often a shared one. This finding highlighted the importance of including family members in research.
- The results of the study revealed that individuals with SCI and their family members draw upon a *range* of sources of spirituality including religious faith, the natural world, inner strength, and meaningful connectedness with others. These sources of spirituality can assist families to move forward after SCI, with gratitude, hope and deeper connectedness with others. An important question arising from the findings of this study for SCI rehabilitation is how access to sources of spirituality is facilitated for clients and their family members, and their spiritual needs addressed.
- The longitudinal data from this study revealed that spiritual experiences can be more intense earlier in the rehabilitation continuum, but for the majority of participants remain stable over time. Further research is required to confirm these findings.

1 Spinal cord injury (SCI) is an unexpected event which can affect the lives of the injured
2 individual and their family members in far-reaching ways. The physical consequences of SCI
3 may include changes to mobility, respiration, pain, continence and sexuality (Kirshblum &
4 Benevento, 2009; Palmer, Kriegsman, & Palmer, 2008). These consequences often impact
5 upon an individual's community participation and financial independence (Schonherr,
6 Groothoff, Mulder, & Eisma, 2005), relationships (Boschen, Tonack, & Gargaro, 2005;
7 Chan, 2000a), and psychological well-being (Craig, Tran, & Middleton, 2009; Gill, 1999;
8 Vocaturo, 2009). Research has outlined the challenges experienced by families after SCI,
9 including stress, anxiety and depression for the injured individual (Dryden et al., 2005;
10 Hoffman, Bombardier, Graves, Kalpakjian, & Krause, 2011; Kennedy & Rogers, 2000;
11 Williams & Murray, 2015), and distress and burden for family members (Alfano, Neilson, &
12 Fink, 1994; Boschen et al., 2005; Chan, 2000b). However, awareness of the strength and
13 positivity that some individuals with SCI and their family members draw upon is growing
14 (Kennedy, Lude, Elfstrom, & Cox, 2013; Middleton et al., 2014; Simpson & Jones, 2013).
15 This has led to interest in the area of resilience after SCI, and factors which may contribute
16 towards it such as spirituality (Kilic, Dorstyn, & Guiver, 2013; White, Driver, & Warren,
17 2010).

18 Resilience has been defined as “the process of effectively negotiating, adapting to, or
19 managing significant sources of stress or trauma” (Windle, Bennett, & Noyes, 2011, p. 163).
20 It has been depicted as a process encompassing growth, reconfiguration, and “bouncing
21 forward” (Lepore & Revenson, 2006; Richardson, Neiger, Jensen, & Kumpfer, 1990; Walsh,
22 2003). Although much resilience theory and research has focused upon the individual, there
23 is another growing body of literature which has considered resilience within the family. In
24 her framework of family resilience, Walsh suggests that family resilience ‘involves key
25 processes over time that foster the ability to “‘struggle well,’ surmount obstacles, and go on

to live and love fully” (p.1). Spirituality is included by Walsh as one of these key processes (Walsh, 2003).

Resilience has been strongly associated with other positive adjustment outcomes for individuals with SCI. Studies have reported strong associations between resilience and higher levels of life satisfaction and quality of life, and between resilience and lower levels of depression and anxiety (Bonanno, Kennedy, Galatzer-Levy, Lude, & Elfstrom, 2012; Catalano, Chan, Wilson, Chiu, & Muller, 2011; Min et al., 2014; White et al., 2010). To date, only two resilience studies have incorporated data from family members affected by SCI (Elliot, Berry, Richards, & Shewchuk, 2014; Simpson & Jones, 2013). In these studies, resilience was strongly associated with variables relating to positive adjustment such as decreased caregiver burden, greater positive affect, lower negative affect, and higher levels of social support.

Spirituality has been defined as a “unique and dynamic process” encompassing connectedness “with oneself, others, nature, or God” (1999), and “a universal and fundamental human quality involving the search for a sense of meaning, purpose, morality, well-being, and profundity in relationships with ourselves, others, and ultimate reality” (Canda & Furman, 2009, pp. 59,87). Although traditionally associated with religious faith, spirituality is a broader concept encompassing a range of meaning-making constructs such as hope, posttraumatic growth, sense of coherence, and purpose in life, as well as faith (Jones, Simpson, Briggs, & Dorsett, 2016). According to Canda and Furman (2009) spirituality is the source of religion, but not limited to it, defining religion as “an institutionalised (i.e. systematic) pattern of values, beliefs, symbols, behaviours, and experiences that are oriented toward spiritual concerns, shared by a community, and transmitted over time in traditions” (p.59).

1 Increasingly, the important role of spirituality for individuals at times of illness or
2 disability is being recognised (Cobb, Puchalski, & Rumbold, 2012; Hampton & Weinert,
3 2006; Johnstone & Yoon, 2009; Waldron-Perrine et al., 2011). Hampton and Weinert (2006)
4 identified prayer, faith, finding meaning, transcendence and family as extremely helpful after
5 chronic illness. Among adults with a traumatic brain injury, Waldron-Perrine et al (2011)
6 observed that religious well-being, namely a sense of connection to a higher power, was a
7 unique predictor for life satisfaction, distress and functional ability. A recent review of the
8 literature found that after SCI, spirituality was reported to correlate strongly with life
9 satisfaction, quality of life, and perceived health, and contribute positively to adjustment
10 (Jones et al., 2016). Most studies identified focused upon the injured individual, rather than
11 the shared experience of the family. Yet, as several studies have demonstrated, meaning-
12 making occurs within the context of relationships (Chan, 2000a; DeSanto-Madeya, 2006;
13 Feigin, 1998).

14 Few studies have considered the relationship between spirituality and resilience after
15 SCI (Monden et al., 2014; White et al., 2010). In their study of resilience and other indicators
16 of positive adjustment White et al (2010) reported that higher levels of spirituality, higher
17 levels of life satisfaction and lower levels of depression, correlated significantly with
18 resilience. Likewise, spirituality or faith was identified by Monden et al (2014) as a key
19 theme contributing to resilience. Both studies focused upon the individual with SCI rather
20 than the broader family perspective.

21 This study was part of a larger project investigating the contribution of spirituality
22 toward family resilience after SCI, incorporating both a quantitative (cross-sectional) and
23 qualitative (longitudinal) component. Here we report on the qualitative, longitudinal
24 component. The aim of this exploratory study was to consider how spirituality (encompassing
25 meaning, hope and purpose), over time, contributed towards family resilience after SCI.

Methods

Participants

Ten family dyads (10 individuals with SCI, 10 family members) were recruited from the spinal injuries unit (SIU) of a rehabilitation hospital in Sydney, Australia. The individuals with SCI were receiving inpatient rehabilitation at the time of the first interview. Two interviews were conducted with each dyad. The first was held at the SIU (time since injury ranging from two to 11 months). Due to a number of discharge barriers encountered by clients at the SIU, some patient admissions are up to 12 months long. The second interview was held six months later, when the majority of individuals with SCI had been discharged to the community. As the first one to two years post injury can be pivotal in long term coping and well-being (Bonanno et al., 2012; Middleton et al., 2014), and the period leading up to discharge from inpatient rehabilitation is identified as particularly challenging (Kennedy & Rogers, 2000). Thus the focus of this research was on this transition period.. All interviews except one were conducted in person, either at the hospital or at the participant's home. One interview was conducted by telephone, due to the distance of participant's home from the hospital.

Eligible participants met the following inclusion criteria: i) adults (aged 18 years and over), ii) individuals with traumatic or non-traumatic SCIs, and iii) able to speak English. Each individual with SCI nominated a supportive family member who was willing to participate with them in the research. Eligible family member participants were aged over 18 years, and able to speak English. Potential participants were excluded if they had been diagnosed with a mental illness (e.g. depression or anxiety) or intellectual disability, due to the increased likelihood they may find some of the interview questions distressing. Although some of the dyads also participated in quantitative component of the larger study (n=50 dyads), this was not a requirement. A purposive maximum variation sampling strategy was

adopted (Braun & Clarke, 2013; Lund Research, 2012) to ensure that a range of participants from different religious and family backgrounds were represented. Ten dyads was judged to be a feasible number (n=20 in total) to recruit within the study time frame, and appropriate within a qualitative study (Braun & Clarke, 2013; Carey, 2012).

As already indicated, a broad definition of spirituality was adopted for this study. The study's title, "The contribution of spirituality towards family resilience after SCI" was included in all information to potential participants, however it was further explained that the study would investigate 'how interactions between family members foster a sense of meaning, hope and purpose over time'. The study was approved by the Human Research Ethics Committee of Northern Sydney Local Health District.

Procedures

Data collection. Data collection employed a semi-structured interview schedule, consisting of five to six key questions (see Appendices 1 and 2 for a copy of the interview schedule). All family interviews were joint interviews, held with both the individual with SCI and a family member. The duration of each interview was approximately one hour.

This study was situated within a phenomenological framework, focused upon understanding and exploring participants' lived experiences of spirituality after SCI (Langdridge, 2007; Patton, 2015). In the first interview, participants were invited to describe their relationship and how their relationship had been affected by the SCI. Their understanding of the term 'spirituality' was then explored. Following this, a broad definition of spirituality, encompassing elements of meaning, hope and purpose, was provided, to encourage participants to reflect upon ways spirituality might be relevant in their lives. Participants were then invited to reflect upon meaning and purpose since the SCI, strengths they had noticed in one another, and hope/s they held both as individuals and as a family.

In the follow-up interviews participants were asked to again reflect upon their relationship, and any meaning or purpose they had drawn from their situation since the first interview. As with the first interview, participants were invited to reflect upon their strengths, and hopes for the future. An additional aspect of the second interview was a question aimed at exploring any strength they had drawn from their faith in God, their perspective on life, or other sources of spirituality identified in the first interview. If participants indicated ways they had found meaning they were invited to expand upon this, and discuss whether spirituality had played a role, and if so, how.

Participant consent was obtained to audio-record each interview. Interviews were then transcribed by the first author (KJ). To increase credibility and improve the rigour of the study, a copy of the interview transcript was provided to participants after the interviews for member checking (Baillie, 2015; Patton, 2015; Shenton, 2004). No corrections were suggested by participants, though one dyad provided some clarification regarding comments they had made.

Data analysis. The transcripts were subjected to thematic analysis, as outlined by Braun and Clarke (2006) using NVivo 10 qualitative analysis software. Thematic analysis is a widely-adopted method used to identify, analyse and report patterns within qualitative data. In this study, an inductive thematic analysis was adopted.

Preliminary codes were generated by the first author using line-by-line analysis (Braun & Clarke, 2006). These initial codes were considered to hold significance as they related to understanding spirituality and its relationship with family strengths (Carey, 2012). To check the credibility of the coding, peer debriefing was undertaken. A sample of the coding for 10% of the data was reviewed by an independent coder (PD) and where discrepancies arose these were discussed and adjustments made. Coding summaries were also provided at intervals to the co-authors for feedback. These processes aimed to enhance the

1 rigour of the study, and ensure the reported findings represented the participant accounts as
 2 closely as possible (Baillie, 2015; Patton, 2015; Shenton, 2004).

3 Patterns or trends among the codes were noted, and later developed into potential
 4 themes (Bazeley, 2013). Through the process of constant comparison these potential themes
 5 were then applied to relevant excerpts of the data, to test their credibility (Patton, 2015).

6 Themes were subsequently reviewed and refined, and core themes and subthemes delineated
 7 (Braun & Clarke, 2006). Finally, codes and themes generated from the initial interviews were
 8 compared with codes and themes generated from follow-up interviews. This was a critical
 9 component of the longitudinal analysis, and was conducted on a case by case basis, so that all
 10 contextual information could be taken into account. A thematic map was developed (Braun
 11 & Clarke, 2006) and then tabulated (see Table 3).

12 13 **Results**

14 **Sample Description**

15 Demographic details of the 20 participants are outlined in Table 1. Pseudonyms are adopted
 16 to protect participant confidentiality. Just over half (55%) of the participants identified as
 17 holding a religious affiliation. For most of the dyads, the same religious affiliation or spiritual
 18 outlook was held by both the injured individual and the family member. Nine of the ten
 19 families completed all interviews.

Table 1

Demographic and injury characteristics of individuals with SCI and family members

Dyad	Names*	Family Member Relationship	Sex (ISC I)	Sex (F M)	Age (ISC I)	Age (F M)	Time Since Injury (months)	SCI Level and AIS	Religious Affiliation
1	James/Hazel	Mother	M	F	19	39	11	T2 A	Christian
2	Michael/Karen	Mother	M	F	19	52	5	T10* **	None
3**	Ulrich/Momi	Father	M	M	23	41	2	C5 D	Muslim
4	Mary/Stan	Husband	F	M	63	67	4	C3 B	Catholic
5	Lena/Mike	Husband	F	M	51	55	3.5	T10* **	Christian
6	Bill/Pat	Wife	M	F	66	62	5	C5 C	None
7	Clive/Sarah	Wife	M	F	56	50	6	T4 A	None
8	Suresh/Anushka	Daughter	M	F	65	35	5	C6 D	Hindu
9	Matthew/Lucy	Mother	M	F	20	38	4	T1 A	None
10	Ted/Michelle	Wife	M	F	67	67	4	T7 A	None/Christian

Note. *Pseudonyms used, ** Only completed the initial interview, ***AIS Score missing or not recorded. SCI=Spinal Cord Injury, ISCI=Individual with Spinal Cord Injury, FM=Family Member, AIS= American Spinal Injury Association Impairment Scale (A=Complete. Complete lack of motor and sensory function below the level of injury, B= Incomplete. Some sensation below the level of the injury, C= Incomplete. Motor function is preserved below the neurological level, and more than half of key muscles below the neurological level have a muscle grade less than 3, D= Incomplete. Motor function is preserved below the neurological level, and at least half of key muscles below the neurological level have a muscle grade greater than or equal to 3). .

Themes

Four overarching themes were identified (see Table 2). These themes contributed to the formulation of the proposed Spirituality Model (see Figure 1), which outlines how spirituality may assist families to make meaning and build resilience to move forward after SCI.

Table 2

Themes and sub-themes identified in the data

Theme 1: Sources of spirituality drawn upon	
Religious Faith <ul style="list-style-type: none"> • A source of meaning and hope • Protection • Comfort (prayer, scriptures) • Guidance 	An Inner Strength <ul style="list-style-type: none"> • Inspiration from others • Determination to keep going
The Natural World <ul style="list-style-type: none"> • A sense of perspective • A source of restoration/refreshment 	Meaningful connectedness with others <ul style="list-style-type: none"> • A reason for living Long standing commitment over time
Theme 2: Response to testing of sources of spirituality	
Religious Faith <ul style="list-style-type: none"> • Why did this happen? <i>A 'second chance' at life</i> • A test of belief <i>Prayer for healing</i> • What have we done wrong? Role of karma <i>Honouring God</i> 	Inner Strength <ul style="list-style-type: none"> • Questioning whether to 'go on' <i>Positive thinking/Comparison with others</i> Meaningful connectedness with others <ul style="list-style-type: none"> • Who will 'be there'? <i>'Being there' for one another</i>
Theme 3: Key outcomes of testing process	
Gratitude <ul style="list-style-type: none"> • For life • For others • For community support • Giving back • Deepening relationships with others • Whole family change • Gratitude – couples 	Hope <ul style="list-style-type: none"> • For physical recovery <i>Prayer for healing</i> <i>Physical recovery observed</i> • For deeper and stronger relationships <i>Deepening of current relationships</i> <i>Potential relationships in the future</i> • For a meaningful life <i>A 'new normal'</i>
Theme 4: Moving forward on the Journey	
Acceptance: 'it just happened'	The Journey

Figure 1: The Spirituality Model: Moving forward on the journey – how spirituality may contribute towards family resilience after SCI

Theme 1: Sources of Spirituality. The first theme identified in the data was the source of participants' spirituality. Four sources were reported by participants including religious faith, the natural world, inner strength, and meaningful connectedness with others.

Religious faith. For several participants, a personal and close relationship with God provided them with three key benefits: a source of meaning and hope; a sense of protection; and comfort. Mike, Lena's husband, explained how his spirituality helped him find meaning:

1 *I believe in Jesus... I believe that He died, that He rose again that [pause] that there's*
 2 *something after we die... I have something, someone other than what we can see or*
 3 *touch that I can meditate, commune, pray with or to, that I derive some meaning from.*

4 A second aspect reported was the sense of protection participants felt as they reflected upon
 5 God's power and oversight of their situation. Suresh's daughter Anushka, spoke of how her
 6 Hindu beliefs led to a trust in a greater goodness and power. She explained how she had
 7 consulted a number of psychics who informed her that "*all the stars, the planets, they're*
 8 *supporting you, they're guiding you*". Lastly, many of the participants shared how their
 9 beliefs provided them with a sense of comfort and peace of mind, often through prayer or
 10 reading religious texts. For example, Ulrich commented on the importance of prayer:

11 *...you pray and after you pray you sit and maybe read some Koran and just pray to*
 12 *him (God) to say "Help me to do this help me to do that". That is the way we ask God*
 13 *to help us.*

14 ***The natural world.*** Several participants described the natural world as an important
 15 source of spirituality in their lives. Aspects of the natural world identified included observing
 16 birdlife, dragonflies, flowers, sunsets, stars, and being in the bush or on the ocean. Ted
 17 enjoyed watching birds. "*T've always loved animals and [pause] in hindsight I've always*
 18 *noticed birds but I just like nature, yeah really we're not the only beings on the planet and*
 19 *that's what it is...*". Another participant spoke of looking up at the stars, and realising that
 20 "*there's more to life than just me*". Other participants reported how they experienced the
 21 natural world as a tangible and refreshing source of restoration.

22 ***An inner strength.*** Several participants drew spiritual strength from within
 23 themselves. One participant observed that you could "*be very spiritual and have incredible*
 24 *inner spirit without being of any particular religious sect or belief*". Stories of others

surviving incredible hardship encouraged him to draw upon his own reservoirs of strength.

Determination to keep going after SCI was discussed by several participants.

Meaningful connectedness with others. Many participants spoke of how their relationships with others provided meaning and purpose, and ultimately a reason for living. Michael's mother Karen spoke of how her relationship with Michael and his brother gave meaning to her life, stating "*they are my life*". For Bill, his family provided him with a will to get up each morning and persevere through the demands of his rehabilitation program. Longstanding commitment was evident among many of the couples, four of whom had been married for more than twenty years. Mary said of her husband: "*...I believe him to be my soul mate that I'm walking through my life with*". Stan reciprocated these feelings, referring back to his marriage vows '*to death do us part*'.

Theme 2: Responses to testing of sources of spirituality. During the interviews, many of the participants communicated that their sources of spirituality had been tested in some way. This was particularly evident for three sources of spirituality; religious faith, meaningful connectedness with others, and inner strength. In most cases the meaning-making responses of participants to these tests assisted them to move forward (see Figure 1).

Religious faith tested. The religious faith of participants was tested or challenged in a number of ways after a SCI. One family member recovered from cancer shortly before his wife's SCI. "*He [God] made me recover. Then He gives me this [[his wife's SCI]. So, you do question it...*". Families also described asking the question "*What did we do?*" and wondered if they were being punished by God. Several participants responded to the test of religious faith by reframing how they perceived the situation. One participant believed God had given him a second chance at life. Another saw the SCI as a direct test of faith from God, one to be overcome. Others prayed for healing. One family member described prayer as a call to someone "*upstairs*" who might "*come down ... and help me*". Last, one family member

spoke of a belief in ‘good karma’, and her belief that, although bad karma had brought about her father’s SCI, good karma could result in recovery.

Inner strength tested. Inner strength was another source of spirituality tested. Bill’s wife Pat stated: “...you’ve got to have that [inner strength] otherwise you just fall in a heap I guess. But... it’s only when it’s tested that we decide whether or not we can go on”.

Participants spoke of two key meaning-making responses to the testing of their inner strength.

The first was adopting positive thinking, the second was to compare oneself with others deemed to be worse off. Positive thinking included looking to the future, rather than

dwelling on the past. It was the smile and optimism of his injured partner which encouraged

and surprised one family member: “...I walk in here and you’re full of smiles and optimism ‘guess what I can do today’ and ... it helps me enormously”. Optimism of family members

was also reported to raise the spirits of the injured individual: “She always comes up smiling and happy [pause, teary] turns up every day bright and cheery”. Closely associated with

positivity was the tendency of participants to make downward comparisons to those who they

considered to be worse off. One participant with paraplegia compared himself to others who

did not have use of their hands. Another compared herself with a client who had attempted

suicide. “I had this wonderful family, I had my faith, I remember lying there thinking it’s not

fair you know I have so much going for me”. She reflected on how this perspective resulted in

her feeling unexpectedly lucky.

Connectedness with others tested. Participants also spoke of a testing of their

relationship with others. Who would ‘be there’ for them? ‘Being there’ encompassed both a

physical presence and the assurance of love and support. Members of each dyad responded to

the challenge that SCI precipitated in their relationships by strengthening their commitment

to one another, and “being there”. While Michael was in a coma his mother reportedly

maintained a constant presence by his side. Reflecting upon this Michael reported: “I always

1 *could imagine, but now can see that when push comes to shove, Mum is going to be there for*
 2 *me”*. Likewise, Lucy, who moved house to provide her son with accessible accommodation,
 3 reassured him “*your family will always be there*”.

4
 5 **Theme 3: Key Outcomes of Testing Process.** Having been tested, sources of
 6 spirituality were identified to build family through contributing i) gratitude; ii) hope for the
 7 future; and, iii) deepening relationships with one another and others. These contributions
 8 spirituality made towards strengthening family relationships and family resilience were
 9 interwoven with one another, and formed part of an ongoing and evolving process (see Figure
 10 1).

11 **Gratitude.** Many of the participants spoke of feelings of thankfulness, new
 12 appreciation, or gratitude. Four sub-themes pertaining to gratitude were identified from the
 13 data: i) gratitude for life itself, ii) gratitude for others within the family, iii) gratitude for
 14 community support, and, iv) a desire to give back in some way.

15 *Gratitude for life: Life as a ‘gift’.* After sustaining such a life-threatening injury,
 16 many individuals with SCI spoke of their thankfulness to have survived. Matthew described
 17 how his perspective on life had changed since the SCI:

18 ... you know it’s kind of made me realise well you know, how do I put it, [pause] yeah
 19 just [pause] lucky to be here...I should be dead. I really should be. I don’t know how
 20 I’m alive but you know, that’s exactly why I’m grateful.

21 Lena’s husband reported that her SCI had increased his appreciation of life, and particularly
 22 family life, leaving him with a ‘thankful mindset’.

23 I think I’ve learnt there are no guarantees...I advise people to kiss their wives
 24 goodnight and go and make up with your kids ... and do it today, ... cause you really
 25 don’t know what tomorrow’s going to bring.

As Muslims, Ulrich and his father Momimi considered everything in life, including the SCI, to be a gift from God and something to give thanks for.

Gratitude for others: “We have a new appreciation of each other”. In addition to gratitude for life, participants also spoke of a greater appreciation or thankfulness for one another. Michael’s mother Karen spoke of how, nearly losing her son after a motor vehicle accident, had changed her outlook on life. “It just it makes you ... feel totally differently [pause] ...when you’ve come that close to losing one and realise what it would mean, you appreciate them a lot more”.

Gratitude for community support. In addition to gratitude for one another, participants reported a greater awareness and appreciation for others in their community. Suresh’s daughter Anushka considered support from others to be a gift from God: “Like they say God ... will put some people of his kind to help you... It’s God coming in a human form”.

A desire to give back. Feelings of gratitude encouraged participants to want to return the kindnesses they had received from others. Clive reflected: “A lot of the people were [pause] ...just always asking what can I do, what can I do to help, so I guess a bit of pay back for that, from people helping out”. In response to these offers of help Clive told how he and his wife held barbeques at the SIU, and later in the community became involved in offering peer support to others.

Hope. Another way spirituality contributed to family resilience, was by providing hope. Hope included; i) shared hope for recovery, ii) hope for relationships with others, and iii) hope for a meaningful life together.

Hope for recovery. Although several families discussed hope for recovery, only two families spoke of hope for complete recovery. Prayer was described by participants as one way they held onto hope. Praying for healing was reported by those from a range of religious

1 faiths, including Christianity, Islam, and Hinduism. One family member described feeling
 2 supported by the prayers of others, even though she did not share the same beliefs.

3 *Hope for deeper and stronger relationships with others.* Hazel spoke of her hope that
 4 the closeness between family members would continue. Just prior to the injury conflict had
 5 engulfed the family. Through subsequent forgiveness and love family relationships had been
 6 mended. “But we’re also hoping that the united stand between us all stays ... that’s
 7 something I’m really adamant about when we get home...”. Two young men spoke of their
 8 hopes for finding a future marriage partner and to be able to have children. “I want to be able
 9 to have a normal life ...get married, have kids [pause] job, you know”. A ‘normal’ life was
 10 one not defined by the wheelchair.

11 *Hope for a meaningful life together.* Drawing upon strength from within themselves,
 12 several participants spoke of a determination to return to a meaningful life. As one family
 13 member said “we’re determined it (the SCI)’s not going to mess our lives up”. Another
 14 individual with SCI declared “I want to start living again”. Many participants’ hopes were
 15 placed in being able to return to the things they enjoyed doing, even if this meant doing
 16 things a little differently.

17 *A “deepening of all of our relationships”.* A key source of spirituality identified in
 18 this study was meaningful connectedness with others. Commitment, love and togetherness
 19 characterised many of the dyadic relationships between couples, and between parents and
 20 adult children. Furthermore, when this commitment was tested by the event of a SCI, the
 21 majority of participants reported an increased desire to ‘be there’ for one another. This led to
 22 a deepening of relationships. Hazel described her relationship with James as being more like
 23 “...best friends rather than mother and son”. Like Hazel, Karen also noted a deepening of
 24 relationships between herself and her son Michael. She explained that the relationship

1 between her two sons, Michael and his brother, had always been close. After the SCI, Karen
 2 noticed how the relationship between *herself* and her sons had grown much closer.

3 **Theme 4: Moving Forward on the Journey.** The concept of spirituality is closely
 4 associated with finding meaning and purpose in life (Canda & Furman, 2009). Meaning
 5 making was identified as a key part of each of the three themes outlined above, culminating
 6 in the family ‘moving forward on the journey’ after SCI (see Figure 1). Participants referred
 7 to two aspects of this process of moving forward: i) accepting the situation by looking ahead,
 8 and ii) being on the journey.

9 When reflecting upon the physical cause of the SCI, many participants adopted the
 10 attitude that ‘it just happened’. “I just think well it’s happened let’s just move on, let’s just try
 11 and get your life back together...what’s happened, happened and you’ve just got to move on”
 12 (Lucy, family member). Bill provided an illustration to explain: “... you can’t drive down the
 13 highway of life looking in the rear-view mirror. You’ve got to look ahead to see what’s in
 14 front of you and adjust the steering accordingly...”. For these participants and others, their life
 15 now looked quite different to the one they had envisioned prior to the SCI, but this did not
 16 prevent them from looking forward.

17 Accompanying participants’ accounts of looking ahead and moving forward, was
 18 imagery associated with being on a journey. Mary shared her belief that she was “on a
 19 journey for a reason”, Hazel commented that “we know our little journey hasn’t ended”, and
 20 Mike hoped that “God will be with us in our journey”. At other times words were used to
 21 describe the process of moving forward on the journey, including phrases such as: “taking
 22 that next step”, “around the corner”, working “our way around it”, or being able to “just get
 23 on with it”. Moving forward might mean taking a “different direction” or “different road”,
 24 but moving towards a shared destination nonetheless.

1 **Changes in spiritual intensity over time**

2 Overall, many aspects of the participants' perspective and outlook remained stable between
 3 the first and second interviews. Data collected at the second interview tended to reinforce or
 4 emphasise themes identified in the first interview, rather than raising new themes. As
 5 indicated in Table 3 however, changes were observed among a small number of families. The
 6 key change identified was a decrease in spiritual intensity from the first to the second
 7 interview. Within this key change, two sub-themes were identified: i) moving from
 8 dependency upon God to a desire to honour Him, ii) changed priorities, leading to a decrease
 9 in spiritual practices such as meditation.

Table 3

11 *Longitudinal Interview Data*

Dyad	Sources of Spirituality	Spiritual themes – Interview 1	Spiritual themes – Interview 2	Challenges between Interview 1 & Interview 2	Significant changes observed between interviews 1 and 2
1	<ul style="list-style-type: none"> • Religious faith (new) • Meaningful connectedness 	<ul style="list-style-type: none"> • Prayer, faith • Gratitude, appreciation • Hope for recovery • Hope for relationships • Purpose 	<ul style="list-style-type: none"> • Prayer, faith (FM only) • Gratitude (FM) • Hope for recovery • Hope for relationships 	<ul style="list-style-type: none"> • Friend's suicide (ex-client) • Death of family member • Breakup with girlfriend • Difficulty keeping carers • Feeling overwhelmed 	<ul style="list-style-type: none"> • Diminished intensity of new religious faith (Individual with SCI only)
2	<ul style="list-style-type: none"> • Meaningful connectedness 	<ul style="list-style-type: none"> • Gratitude for relationships • Hope for new relationships 	<ul style="list-style-type: none"> • Gratitude for relationships • Hope for new relationships 	<ul style="list-style-type: none"> • Living back with mother • Brother becoming a Christian post SCI 	<ul style="list-style-type: none"> • Questioning of religious faith due to brother's conversion
4	<ul style="list-style-type: none"> • Natural world • Meaningful connectedness (FM) 	<ul style="list-style-type: none"> • Hope for recovery 	<ul style="list-style-type: none"> • Hope for recovery 	<ul style="list-style-type: none"> • Participant still an inpatient at time of second interview 	<ul style="list-style-type: none"> • Frustrations due to delayed discharge and lack of access to natural world
5	<ul style="list-style-type: none"> • Religious faith 	<ul style="list-style-type: none"> • 	<ul style="list-style-type: none"> • Honouring 	<ul style="list-style-type: none"> • Physical 	<ul style="list-style-type: none"> • Changed focus

	<ul style="list-style-type: none"> • Meaningful connectedness • Natural world 	Dependency upon God <ul style="list-style-type: none"> • Desire to give back • Journey with God • Gratitude • Hope for relationships 	God <ul style="list-style-type: none"> • Gratitude • Hope for relationships 	challenges <ul style="list-style-type: none"> • Tiredness 	from dependence upon God to honouring God
Dyad	Sources of Spirituality	Spiritual themes – Interview 1	Spiritual themes – Interview 2	Challenges between Interview 1 and Interview 2	Significant changes observed between interviews 1 and 2
6	<ul style="list-style-type: none"> • Inner strength • Natural world • Meaningful connectedness 	<ul style="list-style-type: none"> • Hope for recovery in hands • Hope for relationship and a fulfilling life 	<ul style="list-style-type: none"> • Hope for recovery in hands 	<ul style="list-style-type: none"> • Several re-admissions to hospital • Less recovery as had hoped 	<ul style="list-style-type: none"> • Feelings of disappointment regarding minimal recovery, but hopeful still of further gains • Minimal change in outlook
7	<ul style="list-style-type: none"> • Inner Strength 	<ul style="list-style-type: none"> • Meditation (FM) • Acceptance – ‘just get on with it’ 	<ul style="list-style-type: none"> • Desire to give back • Acceptance 	<ul style="list-style-type: none"> • House not ready so living in apartment in city • FM returning back to work, assisting with care 	<ul style="list-style-type: none"> • Less time to meditate
8	<ul style="list-style-type: none"> • Religious faith 	<ul style="list-style-type: none"> • Hope for recovery - walking 	<ul style="list-style-type: none"> • Hope for recovery 	<ul style="list-style-type: none"> • Living in temporary accommodation • Some recovery 	<ul style="list-style-type: none"> • No changes
9	<ul style="list-style-type: none"> • Inner strength • Meaningful connectedness 	<ul style="list-style-type: none"> • Hope for future relationships • Appreciation for life and family • Desire to meditate (FM) 	<ul style="list-style-type: none"> • Hope for future relationships • Appreciation for life and family 	<ul style="list-style-type: none"> • Moving back with family into new accessible home • No time to meditate (FM) 	<ul style="list-style-type: none"> • Less time to meditate – FM busy with house renovations
10	<ul style="list-style-type: none"> • Religious faith (FM) • Inner strength (client) 	<ul style="list-style-type: none"> • Hope for a fulfilling life 	<ul style="list-style-type: none"> • Hope for a fulfilling life 	<ul style="list-style-type: none"> • readmission to hospital for skin, bladder 	<ul style="list-style-type: none"> • No changes

1 *Note.* FM=Family Member only

At the first interview Lena described how she felt God had brought about significant healing in her body. By the second interview she explained that she felt God was asking her to be more actively involved. Similarly, in the second interview her husband Mike noted that his faith had changed from “clinging to God, just to get through” to relying upon God “to help me with my role now”. He expressed that his main desire now was to honour God in his circumstances.

Two family members reported how their priorities changed between the first and second interviews. Both expressed a desire and interest in meditation at the time of the first interview. By the second interview the time available to meditate had decreased, and become less of a priority in their lives. Their lives had become much busier, and being home the individual with SCI was more reliant upon their support and assistance. Furthermore, activities in their own lives had resumed, including caring for other children and returning to work.

Discussion

This study sought to investigate the contribution spirituality makes towards family resilience after SCI. Much of the literature pertaining to spirituality has focused upon religion and religious belief (2015; Jones et al., 2016). Yet definitions of spirituality have emphasised the construct’s breadth, and encompassed connectedness with God, others, self and nature (Meraviglia, 1999). In developing the Sources of Spirituality Scale, Davis et al (2015) argued for a “more flexible and fluid way of thinking about what spirituality is” (p.512). Consistent with Davis et al, this study identified a range of sources of spirituality. A relationship with God, alongside meaningful connectedness with others, inner strength, and

1 the natural world, were all important sources of spirituality, providing meaning, purpose and
2 perspective in participants' lives.

3 For several participants, religious faith was an important factor in their adjustment
4 and meaning-making journey. Importantly, it was a personal relationship with God rather
5 than religious traditions, which was highlighted by participants. This is consistent with other
6 research which has demonstrated the importance of a sense of connection to a higher power,
7 rather than religious traditions, in predicting life satisfaction and lower levels of distress
8 (Waldron-Perrine et al., 2011). Of particular significance was the role of prayer, reported by
9 participants to be the way they accessed help from God, and obtained comfort. It also was the
10 way many of them generated hope for healing and recovery. Although prayer has repeatedly
11 been found to be an effective coping strategy for those confronted by both chronic illness and
12 disability (Hampton & Weinert, 2006; Meraviglia, 1999) there is little research pertaining to
13 it within the field of SCI. This study suggested that further investigation into the role of
14 prayer among families from faith backgrounds may be valuable.

15 Connectedness with others is a key component of definitions of spirituality (Canda &
16 Furman, 2009; Meraviglia, 1999). Yet, as demonstrated, much of the research in the area of
17 spirituality after SCI has focused upon the individual. This trend of focusing upon individual
18 adjustment, rather than family adjustment, has also been identified within the context of
19 resilience and SCI (Jones, 2009) and generally within the area of posttraumatic growth
20 (Berger & Weiss, 2009). Within this study, meaningful connectedness with others was both a
21 source of spirituality, and, through testing and subsequent meaning-making responses, an
22 outcome. The deepening of such relationships was closely linked with the other two key
23 outcomes, gratitude and hope.

24 Gratitude has become an area of increasing interest within the field of positive
25 psychology and posttraumatic growth, with a recent study identifying it as a key component

of spiritual resilience (Manning, 2014). In this study, participants expressed gratitude for life, for others, and for community support. Gratitude encouraged them to want to give back, by helping others. However gratitude has received little attention within the areas of health and disability fields (Elosua, 2015). While its importance for individuals with SCI has been considered (Chun & Lee, 2013), the implications within the wider family has not previously been investigated.

Hope has attracted much interest in the area of SCI, however like the concept of gratitude, research has focused almost exclusively upon the individual with SCI (Dorsett, 2010; Kennedy, Evans, & Sandhu, 2009; Lohne, 2009). A key finding in this study was that hope is often shared within families. Hope after SCI often appears to be focused upon a cure or full recovery (Dorsett, 2010). As time since injury increased this study found that the focus of hope often moves to focus on quality of life, relationships with others, and the journey itself. This is consistent with other research findings on hope (Dorsett, 2010; Lohne, 2009).

This study highlights important clinical implications for health professionals in the area of SCI rehabilitation. Awareness of the important role of spirituality is growing in other areas of health (Best, Butow, & Olver, 2014; Cobb et al., 2012; Meaningful Ageing Australia, 2016). Coinciding with this awareness is acknowledgement that the spiritual needs of clients can be addressed by a range of staff, and that individuals and their family members are expectant that this should occur (Best et al., 2014; Hilbers, Haynes, & Kivikko, 2010). However, barriers have also been identified including lack of time, lack of knowledge and staff discomfort (Meredith, Murray, Wilson, Mitchell, & Hutch, 2012).

The results of this study suggest a number of implications for rehabilitation professionals such as: including family members in discussions about spirituality; acknowledging the wide range of sources of spirituality and facilitate client and family member access to these; and training for staff. This may involve increasing access to

resources which enable clients and family members to tap into their sources of spirituality. Access to the natural world may be very important to some families. For others, it may be finding time in their program to pray and meditate, or have meaningful time with their family members. It is also apparent from this study that although the term ‘spirituality’ may not be widely used, using closely associated terms such as ‘meaning’, ‘hope’, ‘gratitude’ and ‘connectedness’ may assist clinicians to discuss these spiritual matters. Addressing spiritual needs may be particularly important in the early stages after SCI, as the longitudinal findings implied. The results of this study suggest that accessing sources of spirituality may assist clients and family members to build strength and resilience, and further investigation of how it can be better addressed after SCI is warranted.

Study Limitations

Due to its exploratory nature, this study had a number of limitations. While overall the dyads were positive, and desiring to move forward, this finding may have been subject to some bias related to the interests of those families who volunteered to participate in a study on the topic of spirituality. The experience of families who were struggling or unable to move forward may have been under-represented in this study. It would be beneficial to include such cases in future studies, so that such experiences can be further examined and understood. This would aid in developing the proposed ‘Spirituality Model’ further. Furthermore, interviewing the members of the family together may have influenced what topics were or were not discussed. It is possible that the positive outlooks adopted by members of each dyad may have been exaggerated in an attempt to ‘put on a brave front’. For the purposes of this study, the benefits of having members of the dyad present in the interview outweighed such a limitation, however future studies may consider interviewing members of each dyad both together and separately. Last, in this study, the date since the injured individual’s SCI was

wide-ranging (2-11 months). This may have impacted upon the findings, especially the longitudinal findings, as a number of participants were potentially at different stages of adjustment. Future studies would benefit from recruiting participants whose injury occurred within a narrower time frame where possible.

Conclusion

Spirituality assisted families in this study to move forward on their journey together by expressing gratitude, holding onto hope, and deepening connections with others. These aspects were identified as key outcomes of the testing of sources of spirituality; specifically, religious faith, inner strength and meaningful connectedness with others, which then contributed towards family resilience. The religious beliefs of several families highlighted the important role faith played in assisting them in many of these areas, but for those without religious belief other sources of spirituality provided similar assistance. These outcomes clearly depicted what Walsh (2003) has referred to as families ‘bouncing forward’ at times of challenge and adversity, rather than merely ‘bouncing back’. Implications for health professionals include facilitating access to a range of sources of spirituality, and addressing spiritual need among clients and family members, therefore enabling families to move forward in strength and resilience. Further research to develop the findings of this exploratory study is warranted.

Acknowledgements

The authors wish to thank Catherine Simpson who provided editorial assistance with Figure 1.

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