The Contribution of Spirituality towards Family Resilience after Spinal Cord Injury: A Mixed Methods Study

Katherine Fiona Jones
BA/BSW, MSW (Advanced Practice)

School of Human Services and Social Work
Griffith Health
Griffith University

Submitted in fulfilment of the requirements of the degree of Doctor of Philosophy

February 2017
Abstract

Background

Spinal cord injury (SCI) is a catastrophic injury which can change the lives of an individual and their family in an instant. Much research in the field of SCI has focused upon the burden and distress brought about by SCI, however recent studies have considered individuals and families who have adjusted well to SCI, demonstrating strength and resilience. At the same time, within the wider areas of health and disability interest is growing regarding the role of spirituality in building resilience. Spirituality has been identified as a key process contributing toward family resilience, but few studies have investigated this relationship empirically. Studies of the role of spirituality after SCI are growing in number, but have tended to focus upon the injured individual, rather than the wider family context. Many questions remain unanswered regarding the role of spirituality within the family after SCI, and over time. Furthermore, very little research has considered staff perceptions or clinical implications regarding the role of spirituality after SCI.

Aim

This study aimed to investigate the contribution that spirituality makes towards family resilience after SCI. To fully investigate this topic, the research gathered a range of perspectives, recruiting individuals with SCI, their family members, and health professionals working in the area of SCI.

Method

A mixed methods approach was adopted to investigate the topic, incorporating three separate components:

i) a quantitative, cross-sectional component involving the administration of surveys to 50 individuals with SCI and their family members. Participants with
SCI had been diagnosed with either paraplegia (n=23) or quadriplegia (n=27). Family members were spouses (n=32), parents (n=10), adult children (n=5) or siblings (n=3). Measures on spirituality, resilience, depression, stress, anxiety, life satisfaction, and positive affect, were administered to both the individual with SCI and their family member. Both correlational and regression analyses were conducted.

ii) a qualitative, longitudinal component consisting of family interviews with 10 individuals with SCI and a nominated family member. A second follow-up interview was held with each dyad six months later. Participants with SCI had a diagnosis of either paraplegia (n=6) or quadriplegia (n=4). Family members were spouses (n=5), parents (n=4) or adult children (n=1). Religious affiliations included Hinduism, Islam, and Christianity, with some participants describing themselves as non-religious. Semi-structured interviews were conducted with each dyad and were audio recorded, transcribed, and coded. Codes were analysed using a thematic analysis.

iii) a qualitative cross-sectional component which consisted of two staff focus groups (n=12) held at the Spinal Injuries Unit. As with the family interviews, a semi-structured interview protocol was used, and a thematic analysis was conducted.

For all three components, participants were recruited from the spinal injury services at Royal Rehab, NSW.

Results

The study identified that spirituality makes an important contribution to resilience and other positive outcomes after SCI, but its role is currently not well incorporated in spinal injury rehabilitation. Results from the first component of the
study demonstrated that spirituality was strongly associated with resilience, life satisfaction, positive affect and lower levels of depression, stress and anxiety, among both individuals with SCI and their family members. Furthermore, it was observed that among individuals with SCI, spirituality made a unique and significant contribution to positive affect, and among family members towards decreasing levels of depression. The second component of the study, which consisted of family interviews, identified four sources of spirituality which individuals with SCI and their family members drew upon. These were: religious faith, the natural world, inner strength and meaningful connectedness with others. These sources of spirituality were observed to undergo a period of testing, which resulted in various meaning-making responses by participants leading to gratitude, hope and deepening relationships with others. These outcomes were identified to assist families to move forward together on the journey after SCI. The third component of the study, the staff focus groups, revealed that spirituality was perceived by health professionals to be both a help and a hindrance during spinal rehabilitation. Furthermore, it was identified that spirituality is currently not well addressed or incorporated during rehabilitation processes, and that a review of these processes and perceived barriers would be beneficial.

**Conclusions**

This study is one of the first to consider spirituality with the family after SCI, incorporating the perspectives of individuals with SCI, family members and staff. The findings demonstrated that spirituality plays an important role within the family after SCI, and can be much better addressed in spinal rehabilitation. Further investigation regarding how the spiritual needs of both individuals with SCI and their family members can be addressed and enhanced during spinal rehabilitation is warranted.
Statement of Originality

This work has not previously been submitted for a degree or diploma in any university. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made in the thesis itself.
Table of Contents

Abstract .................................................................................................................................................. i
Statement of Originality ....................................................................................................................... iv
Table of Contents ................................................................................................................................... v
List of Tables ........................................................................................................................................ vii
List of Figures ....................................................................................................................................... viii
Abbreviations ......................................................................................................................................... ix
Acknowledgements .............................................................................................................................. x

Chapter One: Introduction .................................................................................................................... 1
  1.1 Introduction .................................................................................................................................. 1
  1.2 Background to Spinal Cord Injury (SCI) ................................................................................... 2
  1.3 Spirituality ..................................................................................................................................... 9
  1.4 Resilience ..................................................................................................................................... 20
  1.5 Summary of Chapter .................................................................................................................. 29
  1.6 Project Aims and Research Questions ....................................................................................... 29

Chapter Two: Scoping review ................................................................................................................ 31
  2.1 Scoping Review Methods ............................................................................................................ 32
  2.2 Scoping Review Results ............................................................................................................... 34
  2.3 Quality Appraisal ....................................................................................................................... 63
  2.4 Scoping Review Discussion ........................................................................................................ 68
  2.5 Summary of Chapter .................................................................................................................. 72

Chapter Three: Methods ...................................................................................................................... 74
  3.1 Introduction ................................................................................................................................... 74
  3.2 Methodological Approaches ....................................................................................................... 74
  3.3 Research Design ........................................................................................................................... 80
  3.4 Research Context .......................................................................................................................... 83
  3.5 Ethical Considerations ................................................................................................................ 84
  3.6 Research Methods for Component 1 (C1): Administered Surveys ............................................. 87
  3.7 Research Methods for Component 2 (C2): Family Interviews ....................................................... 96
  3.8 Research Methods for Component 3 (C3): Staff Focus Groups .................................................. 101
  3.9 Triangulation of Data Across All Study Components .................................................................. 103
  3.10 Summary of Chapter .................................................................................................................. 103

Chapter Four: Results – Quantitative Component (C1) Administered surveys .................................. 105
  4.1 Introduction ................................................................................................................................... 105
  4.2 Sample ........................................................................................................................................ 105
  4.3 Descriptive Statistics .................................................................................................................. 106
  4.4 The Relationship Between Individual FACIT-Sp-Ex Items and Resilience ................................. 110
  4.5 Correlation analysis ..................................................................................................................... 111
  4.6 Multiple Regression Analysis .................................................................................................... 122
<table>
<thead>
<tr>
<th>Section</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.7</td>
<td>Summary of Chapter</td>
<td>128</td>
</tr>
<tr>
<td>5.1</td>
<td>Introduction</td>
<td>130</td>
</tr>
<tr>
<td>5.2</td>
<td>Sample Description</td>
<td>131</td>
</tr>
<tr>
<td>5.3</td>
<td>Themes</td>
<td>132</td>
</tr>
<tr>
<td>5.4</td>
<td>Sources of Spirituality Drawn Upon</td>
<td>135</td>
</tr>
<tr>
<td>5.5</td>
<td>Sources of Spirituality Tested/Meaning-making Responses</td>
<td>144</td>
</tr>
<tr>
<td>5.6</td>
<td>Key Outcomes of Testing Process</td>
<td>157</td>
</tr>
<tr>
<td>5.7</td>
<td>Moving Forward on the Journey</td>
<td>174</td>
</tr>
<tr>
<td>5.8</td>
<td>Summary of Chapter</td>
<td>178</td>
</tr>
<tr>
<td>6.1</td>
<td>Introduction</td>
<td>181</td>
</tr>
<tr>
<td>6.2</td>
<td>Longitudinal Themes Arising From the Data</td>
<td>183</td>
</tr>
<tr>
<td>6.3</td>
<td>Case Study on Longitudinal Changes – James and Hazel</td>
<td>187</td>
</tr>
<tr>
<td>7.1</td>
<td>Introduction</td>
<td>193</td>
</tr>
<tr>
<td>7.2</td>
<td>Sample</td>
<td>193</td>
</tr>
<tr>
<td>7.3</td>
<td>The Focus Group Interview</td>
<td>194</td>
</tr>
<tr>
<td>7.4</td>
<td>Identified Themes</td>
<td>194</td>
</tr>
<tr>
<td>7.5</td>
<td>Summary of Focus Group Component</td>
<td>208</td>
</tr>
<tr>
<td>8.1</td>
<td>Introduction</td>
<td>210</td>
</tr>
<tr>
<td>8.2</td>
<td>Spirituality and its relationship with religion</td>
<td>212</td>
</tr>
<tr>
<td>8.3</td>
<td>Positive Adjustment and Moving Forward</td>
<td>224</td>
</tr>
<tr>
<td>8.4</td>
<td>Barriers Encountered by HPs Incorporating Spirituality into Rehabilitation Practice</td>
<td>240</td>
</tr>
<tr>
<td>8.5</td>
<td>Implications for Practice</td>
<td>241</td>
</tr>
<tr>
<td>8.6</td>
<td>Limitations</td>
<td>247</td>
</tr>
<tr>
<td>9.1</td>
<td>Summary of Focus Group Component</td>
<td>250</td>
</tr>
<tr>
<td>A</td>
<td>Bibliography</td>
<td>252</td>
</tr>
<tr>
<td>B</td>
<td>Appendix A: Published Article (Scoping Review)</td>
<td>275</td>
</tr>
<tr>
<td>C</td>
<td>Appendix B: Letter of Invitation, Information and Consent Forms, and Survey Pack for Component 1 (C1)</td>
<td>291</td>
</tr>
<tr>
<td>D</td>
<td>Appendix C: Letter of Invitation, Information and Consent Form, and Interview Protocols for Component 2 (C2)</td>
<td>311</td>
</tr>
<tr>
<td>E</td>
<td>Appendix D: Letter of Invitation, Consent Form, Demographic Protocol and Focus Group Interview Protocol for Component 3 (C3)</td>
<td>319</td>
</tr>
</tbody>
</table>
# List of Tables

| Table 1 | Quantitative studies ......................................................... | 39 |
| Table 2 | Qualitative Studies .............................................................. | 56 |
| Table 3 | Quality appraisal checklist – quantitative studies (NICE) (n=19 studies) | 65 |
| Table 4 | Quality appraisal checklist – qualitative studies (NICE) (n=13 studies) | 67 |
| Table 5 | Demographic, injury and psychosocial characteristics of individuals with SCI and family members | 107 |
| Table 6 | Ratings on resilience, spirituality, positive and negative affect, depression, and life satisfaction | 109 |
| Table 7 | FACIT-Sp-Ex items – Individual with SCI and family member scores | 112 |
| Table 8 | FACIT-Sp-Ex items – High vs low resilience group | 113 |
| Table 9 | Correlations - Individual with SCI | 117 |
| Table 10 | Correlations - Family member | 121 |
| Table 11 | Results from the regression model predicting depression scores (Individual with SCI) | 123 |
| Table 12 | Results from the regression model predicting positive affect scores (Individual with SCI) | 123 |
| Table 13 | Results from the regression model predicting life satisfaction scores (Individual with SCI) | 124 |
| Table 14 | Results from the regression model predicting depression scores (Family member) | 125 |
| Table 15 | Results from the regression model predicting anxiety scores (Family member) | 125 |
| Table 16 | Results from the regression model predicting stress scores (Family member) | 126 |
| Table 17 | Results from the regression model predicting positive affect scores (Family member) | 127 |
| Table 18 | Results from the regression model predicting negative affect scores (Family member) | 127 |
| Table 19 | Results from the regression model predicting life satisfaction scores (Family member) | 128 |
| Table 20 | Demographic and injury characteristics of individuals with SCI and family members | 133 |
| Table 21 | Themes and sub-themes identified in the data | 134 |
| Table 22 | Longitudinal Interview Data | 184 |
| Table 23 | Themes identified from the focus group data | 195 |
| Table 24 | Comparisons between the Hero’s Journey (Campbell, 2008) and the Spirituality Model | 240 |
List of Figures

Figure 1: Database Search ........................................................................................................ 36
Figure 2: The Spirituality Model: Moving forward on the journey – how spirituality contributes towards family resilience after SCI ...................................................... 180
Figure 3: The Resiliency Model (Richardson, 2002, p. 311) ................................................... 236
Abbreviations

ASIA    American Spinal Injury Association Impairment Scale
DASS-21 Depression Anxiety and Stress Scales, 21 item version
DASS-21-D Depression Anxiety and Stress Scales – Depression Scale
DASS-21 A Depression Anxiety and Stress Scales – Anxiety Scale
DASS-21 S Depression Anxiety and Stress Scales – Stress Scale
FACIT-Sp Functional Assessment of Chronic Illness Therapy - Spirituality
FACIT-Sp-Ex Functional Assessment of Chronic Illness Therapy – Spirituality – Extended Version
FM     Family Member
HP     Health Professional
PANAS Positive and Negative Affect Scales
PANAS-Pos Positive and Negative Affect Scale (Positive)
PANAS-Neg Positive and Negative Affect Scale (Negative)
SCI     Spinal Cord Injury
SIU     Spinal Injury Unit
SOS     Spinal Outreach Service
SWLS    Satisfaction with Life Scale
I would like to sincerely thank a number of people who have helped me in this PhD journey. First, I would like to thank Associate Professor Grahame Simpson who was responsible for first suggesting such an undertaking might be possible, and who has encouraged me to think and work hard right to the very end. Much thanks also go to my other supervisors, Dr. Pat Dorsett and Associate Professor Lynne Briggs, who supported me, cheered me on, and provided wonderful direction and guidance. I have been very fortunate to have such an experienced, caring and wise team of supervisors. I would like to thank my colleagues and the clients of the Spinal Injuries Unit and Spinal Outreach Team, without whose support and participation the research would never have been possible. Thanks also go to Catherine Simpson, who provided assistance with the presentation of the diagrams. And lastly, a huge thank you to my friends, family, and to my husband Jason. Jason, your love, patience, care, and support (both emotional and practical) has been amazing throughout this marathon. I believe God has directed, sustained, and carried me from the beginning, and for that I am also thankful.
Chapter One: Introduction

1.1 Introduction

Since ancient times humans have sought meaning in their existence. The notion that we are part of something bigger, a “larger current in the universe”, has captivated individuals, communities and whole civilisations (Confoy, 2002, p. 28). For some people, formal religious beliefs and practices represent the outcome of this search, providing answers to life’s big questions. For others, the search for meaning and significance has taken place internally, via meditation, philosophy or reflection. Then again, some have found meaning by looking outwards towards nature and discovering that in the midst of a thunderstorm, mountain or waterfall, there is something significant that brings insight or perspective.

Spirituality is a term used to refer to such an existential search for meaning. It has been defined as 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, p. 59). As this definition suggests, although spirituality may often be assumed to relate to an “interior journey” encompassing self-reflection and meditation, for many it is expressed in relationship with others (Simmons, 2000).

The role of spirituality in adjustment to disability is of increasing interest to theorists, researchers and practitioners within the area of health (Cobb, Puchalski, & Rumbold, 2012). In her framework of family resilience, Walsh (2003) has identified spirituality as one of several key processes which assist families to thrive in the midst of adversity and move forward. Despite the increasing acknowledgement of the importance of the wider family context, the majority of research on the topic of
spirituality in health has tended to focus on individual adjustment rather than upon the adjustment of the family as a whole (Walsh, 2009a).

This project investigated the contribution of spirituality towards family resilience after spinal cord injury (SCI). SCI is a devastating condition which, in an instant, can change everything for the affected individual and their family. In this, the first chapter, background information is provided regarding SCI, including its epidemiology, causes, and economic impact within Australia. The physical and psychological impact of SCI upon individuals and their family members is also discussed. This is followed by a discussion of the concepts of spirituality and resilience, and their relevance within the fields of health and disability is highlighted. This chapter concludes with an outline of the aims and objectives of the study.

1.2 Background to Spinal Cord Injury (SCI)

“Spinal cord injury strikes like a lightning bolt. In a flash, the ground seems to be pulled from beneath you, your body no longer works the way it should, your life is turned upside down” (Palmer, Kriegsman, & Palmer, 2008, p. 1).

1.2.1 SCI, a global issue. A spinal cord injury (SCI) is an unexpected and often devastating event which abruptly interrupts the lives of an individual and their family, changing almost everything in a moment. Described as one of the most devastating conditions to occur in both developed and developing countries, global incidence of traumatic SCI range from 3.6 to 195.4 per million across the world (Jazayeri, Beygi, Shokranch, Hagen, & Rahimi-Movaghar, 2015). According to the World Health Organisation (2013), 250 000 and 500 000 people sustain a SCI every year and most are due to preventable causes. Furthermore, those with SCI are more likely to die prematurely, experience lower rates of economic participation and contribute to increased societal costs.
1.2.2 **A profile of SCI in Australia.** It has been estimated there are over 10,000 people with a SCI living in Australia (Australasian Spinal Cord Injury Network, 2016). According to the most recent data on SCI in Australia, available from the Australian Institute of Health and Welfare (AIHW) (Norton, 2010), there were a total of 362 new cases of SCI between 1 July 2007 to 30 June 2008. Within this time period the most common causes of traumatic spinal cord injuries were those related to transport (46%) or falls (28%). Other causes of injury included water-related injuries and being struck by, or collision with, a person or object. Injuries were most common among the 15-24 years of age group and were much more likely among males, with the ratio of males to females calculated as 5.3:1. Overall, the median length of stay in hospital was 133 days (Norton, 2010).

The economic cost of SCI to Australia has also been calculated (Access Economics, 2009). The total cost of SCI to Australia in 2008 alone was estimated to be $2 billion, with paraplegic injuries costing the country $689.7 million and quadriplegic injuries, $1.3 billion. These estimated costs incorporated health care costs, equipment and modifications, long term care, productivity losses, and carer costs.

1.2.3 **The hospital experience after SCI.** After a SCI, an individual and their family members undertake a journey through a number of treatment stages. The clinical pathway outlined below is typical for individuals who have sustained their SCI in NSW, Australia. For most individuals who have experienced a SCI, there is some initial surgery to stabilise the spinal cord, followed by a period of care in the intensive care unit (ICU). Following ICU, they are then transferred to one of two acute spinal units in Sydney (Royal North Shore Hospital or Prince of Wales Hospital) for several weeks. The focus of this acute period of treatment is medical care. Those who receive acute treatment at Prince of Wales Hospital stay on at that facility to undertake their
rehabilitation program, and for those admitted to Royal North Shore Hospital, the rehabilitation service is conducted at another site, Royal Rehab. Royal Rehab is a freestanding rehabilitation hospital, approximately 10 kilometres away from Royal North Shore Hospital. The focus of the rehabilitation phase is for the individual to maximise their physical function and prepare for living with their SCI in the community. Once discharged from the rehabilitation unit, individuals are reviewed by a multidisciplinary team based in the community. In NSW, the Spinal Outreach Service (SOS) monitors clients for a period of 12 months.

The period of hospitalisation can be overwhelming for both the injured individual and their family members (Vocaturo, 2009). After an individual has sustained a SCI, they embark upon a clinical pathway. The initial focus is usually placed upon issues of survival. Later, questions may arise regarding the long-term consequences of the injury. During their stay in rehabilitation, individuals with SCI are often inundated with large amounts of information regarding diagnosis and prognosis, bladder and bowel routines, medication, care requirements and equipment needs. As they become more aware of the ramifications of the SCI, both the injured individual and their family members may experience emotional responses including grief, denial, anger and depression (Vocaturo, 2009). Functional ability is monitored closely, and decisions are made regarding levels of care and support in the community. Life changes occur for both the injured individual and their family members, who are often expected to provide emotional and practical support while managing their own feelings of grief and loss (Jaworski & Richards, 1998). While some families notice significant recovery, others do not. Confronted with many unanswered questions, individuals with SCI and their families often have to make choices about how they respond to the information they receive and assess how this information applies to their own individual circumstances.
Issues also arise in this context for the rehabilitation health professionals who are often expected to address the range of hopes and fears experienced by their clients (Van Lit & Kayes, 2014).

Along each stage of the clinical pathway the physical and emotional needs of an individual affected by SCI are addressed by multidisciplinary teams, consisting of medical specialists, physiotherapists, Occupational Therapists, Recreational Therapists, Psychologists and Social Workers. In most cases these teams will meet regularly with the individual and their family members, to assist with the provision of education and the setting of goals (Byrnes et al., 2012). In the rehabilitation units, the multidisciplinary team’s focus is upon preparing the client and their family members for discharge into the community. The period just prior to discharge from hospital, and the subsequent transition into the community has been identified as a heightened time of stress for both the individual with SCI (Kennedy & Rogers, 2000) and their family members (Middleton et al., 2014)

1.2.4 Physical and emotional consequences of SCI. The impact a SCI has upon an individual’s functioning is dependent upon several variables, which include: the level of injury, the severity or completeness of the injury, the time lapse between the injury and medical treatment, the individual’s age, and other medical conditions they may have (Harvey, 2008; Kirshblum & Benevento, 2009; Palmer et al., 2008). The level of the injury itself, ranging from the base of the spinal cord, the sacrum (S1), through the lumbar (L1-5), thoracic segments (T1-12) and up to the cervical segments (C1-7), will affect how much of an individual’s body is affected (Kirshblum & Benevento, 2009). A higher injury indicates that a greater area of the body is affected. An individual who injures their spinal cord in the lumbar or thoracic sections of the spinal cord has sustained a paraplegic level of injury, and is usually able to move their upper limbs
without any impairment. An injury to the cervical segments of the spinal cord results in a quadriplegic (also known as tetraplegic) level of injury. An individual with quadriplegia is affected in both the upper and lower limbs (Harvey, 2008).

As Harvey (2008) has noted, in addition to the level of the SCI another factor which has important ramifications for the individual’s prognosis and the management of their condition is the severity of the injury. The severity, or completeness, of the SCI is assessed using the American Spinal Injury Association (ASIA) scale (Kirshblum et al., 2011). A complete injury to the spinal cord (assessed by ASIA as A) usually results in permanent impairment of the individual’s functioning below the level of injury. In contrast, after an incomplete injury (ASIA score of B, C, or D) some function or sensation below the level of injury is preserved. Such individuals may have a greater chance of recovery, and potentially return to walking. However, very few individuals make a full and complete recovery. How much an individual may recover is usually unknown for some time, possibly years, and this results in many individuals remaining hopeful for further recovery (Dorsett, 2010; Palmer et al., 2008).

Damage to the spinal cord may affect an individual’s physical functioning in a number of ways, impacting upon mobility, continence, respiration and sexual and reproductive health (Kirshblum & Benevento, 2009; Palmer et al., 2008). Neurological pain may be an additional issue to adjust to (Craig, Tran, & Middleton, 2009; Harvey, 2008). These physical consequences bear upon an individual’s community participation and financial independence (Schonherr, Groothoff, Mulder, & Eisma, 2005), relationships (Boschen, Tonack, & Gargaro, 2005; Chan, 2000a), and psychological well-being (Craig et al., 2009; Gill, 1999; Vocaturo, 2009). Schonherr et al (2005) found that among individuals with SCI, total participation in vocational and leisure activities was reduced by 40%. Decrease in economic status and decrease in sexual
ability were cited as reasons leading to divorce among individuals with SCI in Hong Kong (Chan, 2000a). Due to the physical consequences of SCI, for many individuals with SCI lifelong dependence upon equipment, government payments, attendant care, and support from family and friends becomes an unavoidable reality.

The psychological impact of SCI upon the injured individual has been extensively documented. Longitudinal studies have identified that levels of anxiety and depression are highest in acute stages of treatment and just prior to discharge from hospital (Kennedy & Rogers, 2000). In a meta-analysis of the literature pertaining to depression after SCI, Williams and Murray (2015) reported the mean prevalence of depression after SCI to be 22.2%, compared with 16% within the general U.S. medical population. One study has shown that five years after injury increased pain, worsening health status, and unsafe use of alcohol were risk factors for depression (Hoffman, Bombardier, Graves, Kalpakjian, & Krause, 2011). Life satisfaction has also been reported to be affected by SCI, and significantly determined by level of injury, pain, and secondary impairments (Van Koppenhagen et al., 2008).

In addition to the existing research focusing on how SCI affects the individual with SCI, there is a growing body of knowledge pertaining to the effect SCI has upon family members (Alfano, Neilson, & Fink, 1994; Chan, 2000b; Elliot, Berry, Richards, & Shewchuk, 2014; Kolakowsky-Hayner & Kishore, 1999; Middleton et al., 2014; Simpson & Jones, 2013b). Reported challenges for family members of an individual with SCI have included; mental weariness, isolation, (Kolakowsky-Hayner & Kishore, 1999), financial stress (Boschen et al., 2005), poor health (Kester, Rothblum, Lobato, & Milhous, 1988) and a lack of social support (Chan, 2000b). In a longitudinal study Weitzenkamp et al (1997) found that caregiving spouses of individuals with SCI
experienced greater depressive affect, physical and emotional stress, burnout, fatigue, and anger and resentment, than spouses who were not caregivers.

Very few studies have considered both the individual with SCI and their family members together (Chan, 2000a; DeSanto-Madeya, 2006; Feigin, 1998). These studies have observed that the experience after SCI is a shared one, and that there is value in incorporating both perspectives (Chan, 2000a). Furthermore, exploration of the interactions between the adjustment of the individual with SCI and their family member provide greater insight into this shared experience.

Despite the challenges faced by individuals and their families after SCI, it has been observed that many manage very well and demonstrate adaptation, strength and resilience (Bonanno, Kennedy, Galatzer-Levy, Lude, & Elfstrom, 2012; Middleton et al., 2014; Simpson & Jones, 2013b; B. White, Driver, & Warren, 2010). Research has demonstrated that some individuals and family members have even been able to identify positive gains, benefits, and areas of growth after SCI (McMillen & Cook, 2003; Pollard & Kennedy, 2007). These findings reflect a shift in focus towards a positive psychology framework (Seligman & Csikszentmihalyi, 2000). A challenge for health professionals working in the area of SCI is how to respond to this recent evidence pertaining to positive psychology, and how to incorporate these findings into rehabilitation practice.

So far, this chapter has outlined the epidemiology and economic impact of SCI within Australia, and the far reaching physical and emotional consequences of SCI for individuals and their family members. While it has been seen that those affected by SCI face many challenges, it has also been suggested that many adjust well by drawing upon sources of strength and resilience. The next section will provide background to the concept of spirituality, which is often identified as a component or characteristic
associated with resilience. Following this, and to conclude this introductory chapter, the relationship between spirituality and resilience will be considered in further depth.

1.3 Spirituality

1.3.1 Defining spirituality. Spirituality has been deemed a complex concept, defined in a number of ways and dependent upon context and culture. Definitions have tended to be expansive, incorporating both existential and religious aspects. The broad scope of these definitions is helpful in that they encompass a number of aspects of spirituality. This is evident in the following definitions and descriptions of the concept. Meraviglia has defined spirituality as the

…experiences and expressions of one’s spirit in a unique and dynamic process reflecting faith in God or a supreme being; it is connectedness with oneself, others, nature, or God; and an integration of the dimensions of mind, body, and spirit (Meraviglia, 1999, p. 24).

In a comprehensive review of the literature Canda and Furman have defined spirituality as “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, however understood”. Moreover they suggested that spirituality is an aspect of a person which orients them to connectedness, transcendence, meaning and purpose (Canda & Furman, 2009, pp. 59,87). Drawing upon similar ideas, Crisp has suggested that spirituality

…involves an awareness of the other, which may be God or other human or divine beings or something else, which provides the basis for us to establish our needs and desires for, understand our experiences of, and ask questions about, meaning, identity, connectedness, transformation and transcendence (Crisp, 2010, p. 5).
An earlier definition of spirituality provided by Hungelmann, Kenkel-Rossi, Klassen and Stollenwerk (1985) also focused upon connectedness. They described spiritual well-being as “a sense of harmonious interconnectedness between self, others/nature, and Ultimate Other which exists throughout and beyond time and space” and “achieved through a dynamic and integrative growth process which leads to a realisation of the ultimate purpose and meaning of life”. Due to its ability to succinctly encompass the various dimensions of spirituality, and use of the term ‘Ultimate Other’ rather than ‘God’, it is this last definition of spirituality which was primarily adopted for this study.

The breadth of the above definitions of spirituality raises questions regarding the specific nature of the relationship between spirituality and other closely related constructs. This in turn leads to some debate regarding how spirituality can be measured. These two points are addressed next.

1.3.2 Related constructs. It has been suggested that a number of constructs are closely related to spirituality (Cobb et al., 2012). Due to the breadth and complexity of definitions of spirituality, these were deemed important to explore further in this study. Theorists and researchers within the area of health and disability have suggested that spirituality is closely associated or overlaps with the constructs of: i) religious faith (Pargament, 1997), ii) meaning making (Lustig, 2005; Papadimitriou & Stone, 2011), iii) sense of coherence (Antonovsky, 1987), iv) posttraumatic growth (Tedeschi & Calhoun, 2004), and v) hope (Eliott, 2012). These constructs and their relationships with spirituality are briefly discussed below.

Religious faith. The nature of the relationship between spirituality and religion has generated much debate. Pargament (1997) has suggested the two concepts are intimately connected. Defining religion as “a search for significance in ways related to the sacred” he has used the term ‘religion’ in a broad sense “one that includes both
institutional religious expressions and personal religious expressions, such as feelings of spirituality, beliefs about the sacred, and religious practices” (Pargament, 1997, p. 4). Canda and Furman (2009) however, in contrast, suggest religion is a distinct concept to spirituality and refers solely to “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). These authors argued that spirituality “is the source of religion” but “not limited to it” (p.77).

Many individuals confronted with an illness (or acquired disability) may ask the question “Why?” Pargament (1997) has suggested religious traditions may provide some answers to this question. For instance, suffering may be perceived as a spiritual opportunity, the result of human sinfulness, the result of a previous life now affecting this one, a process of finding atonement or forgiveness, the action of a punishing God, or conversely, something to be blamed on “the devil”. Alternatively, religious faith may bring one to the realisation that suffering “has nothing to do with you” but is part of the natural course of being human (Wolin et al., 2009).

Another response to suffering by those who hold religious beliefs, in particular those with belief in a sovereign God or Gods, may be to surrender to the circumstances. In Arabic the word Islam means “submission to God’s will” (Sachedina, 2012). Pargament suggests that within the Jewish and Christian religions, surrender to God brings about companionship. Whereas a psychological approach to coping might suggest we “are not as powerless as we imagine”, in contrast the religious viewpoint accepts that we are powerless in significant ways and “must look past ourselves alone for answers to important questions” (Pargament, 1997, p. 8). Such believers discover God “working his will”, and find ‘a spiritual companion who makes the trauma more
manageable”. Pargament proposed that this coping strategy provides both “opportunities and challenges for spiritual growth” (Pargament, 1997, p. 223).

Often associated with religious belief and spirituality is the notion of transcendence (Canda & Furman, 2009; Crisp, 2010). Millard (2002, p. 111) described human beings as “meaning-makers and meaning-seekers with an innate desire to transcend or move beyond situations of hardship or suffering”. Tate and Forchheimer (2002, p. 402) have 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”. This idea of transcendence, while not limited to religious belief, is evident within most religious perspectives. According to Pargament (1997), transcendence provides an individual with a reason for being, a mission or calling in life. In the midst of suffering the task of the individual becomes one of discerning the “transcendental design” (p.237). In whatever way the relationship between spirituality and religion is perceived, it is generally acknowledged that religious belief plays a very important role for many, leading to meaning making and purpose in the midst of crisis.

**Meaning making.** As mentioned above, transcendence is a concept often related with religious belief. However, it is a concept which can be experienced apart from religion and in relation to other sources which provide ultimate meaning and purpose in life. Transcending suffering is clearly demonstrated in the story of Viktor Frankl, who wrote of his experience as a prisoner in Nazi Germany. In the midst of suffering Frankl was able to picture and meditate not only upon an image of his wife who he dearly loved, but also upon a future, away from his present reality. Such thoughts enabled him to ‘transcend’ his physical circumstances.
In a last violent protest against the hopelessness of imminent death, I sensed my spirit piercing through the enveloping gloom. I felt it transcend that hopeless, meaningless world, and from somewhere I heard a victorious ‘Yes’ in answer to my question of the existence of an ultimate purpose (Frankl, 2006, p. 40).

Frankl described this freedom of thought as a “spiritual freedom” which could not be taken away, and which created meaning and purpose (p.67).

Meaning making has been identified as playing an important role at times of illness or disability (Cobb et al., 2012). After a traumatic loss, such as SCI, some individuals undergo a process to reconstruct their world, make sense of the loss, and engage in meaning finding processes (Lustig, 2005). Awareness of one’s finite nature may lead to attempts to explain “what lies beyond the limits of the known world-what happens when we die, where we come from, who controls what happens to us” (McColl, 2011, p. 22). What may become most important is the belief that one is living a purposeful life in harmony with one’s individual beliefs and values (DeRoon-Cassini, De St Aubin, Valvano, Hastings, & Horn, 2009, p. 308), than why the injury occurred. Frankl stated that if “there is meaning in life at all, then there must be a meaning in suffering. Suffering is an ineradicable part of life, even as fate and death. Without suffering and death human life cannot be complete” (Frankl, 2006, p. 67).

The process of meaning reconstruction has been closely associated by some authors with the sharing of narratives and spiritual stories (Cobb et al., 2012; Frank, 1995). Meaning-making is a key component of most definitions and measures of spirituality, and the two are closely intertwined. Walsh (2003) has proposed that alongside spirituality, “making meaning of adversity” is a key process of family resilience.
**Sense of Coherence.** Spirituality has been found to have a close relationship with sense of coherence (SOC), a construct also related to meaning-making. Antonovsky (1987, p. 19) described SOC as “a global orientation” consisting of three intertwined components: comprehensibility, manageability and meaningfulness. Rutter (1985, p. 608) 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).

The relationship between spirituality and SOC has been explored within the area of health and disability. Investigating the two concepts among patients with brain tumours and their spouses, Strang and Strang (2001) identified that the meaningfulness component of SOC was closely related to spirituality, which was perceived to encompass trust in God or a general belief in “power beyond oneself, a life after death, destiny, the goodness of life or the grandness of nature” (p.132). Among patients with chronic illness, Delgado (2007) reported that both high SOC and spirituality were correlated with low stress and quality of life.

**Posttraumatic growth.** Another construct closely associated with spirituality is posttraumatic growth (PTG). PTG has been defined by Tedeschi and Calhoun (2004, p. 6) as “positive psychological change experienced as a result of the struggle with highly challenging life circumstances” and 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. Thus, growth in spirituality or existential meaning making has been seen as one way in which individuals may experience positive change after stress or loss. Tedeschi and Calhoun have emphasised that such growth may not necessarily preclude experiences of vulnerability or distress. Indeed, they have suggested that such
experiences may even contribute to a sense of strength, and a deeper faith (Tedeschi & Calhoun, 2004, p. 6).

In a systematic review of the literature pertaining to posttraumatic growth and spirituality, Shaw, Joseph and Linley (2005) found that spirituality and religion were often, though not always, beneficial after trauma, could be deepened by trauma, and were positively associated with posttraumatic growth. They also identified that positive religious coping, religious openness, readiness to face existential questions, religious participation, and intrinsic religiousness had all been associated with posttraumatic growth.

Some authors have advised caution for those investigating the perceived association between spirituality and posttraumatic growth. According to Pargament, Desai and McConnell (2006), although spirituality, and religious belief in particular, may have an important role to play in growth after trauma, the relationship is a complex one, and spirituality may also at times contribute to posttraumatic struggle or decline. These authors have suggested that such a decline may come about due to perceived abandonment by God, anger at God, or belief that one is being punished. In this study, therefore, it was deemed important to explore both positive and negative effects of spirituality upon growth after SCI.

**Hope.** According to Dufault and Martocchio (1985), hope is “a multidimensional 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 (2010, pp. 85,86) 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). Hope has been closely associated with many religious traditions, including Christianity and Islam (Eliott, 2012). It also features as a component of
measures of spirituality (Peterman, Fitchett, Brady, Hernandez, & Cella, 2002).

Empirical studies have shown hope to be closely associated with spirituality in a number of contexts, including within the areas of mental health, physical disability and chronic illness (Bassett, Lloyd, & Tse, 2008; Harrison, 1997; Lohne & Severinsson, 2006; Ottaviani et al., 2014).

1.3.3 Measurement of spirituality and the FACIT-SP. The close association between spirituality and other meaning making constructs as outlined above has led many to the conclusion that the concept of spirituality itself is a multifaceted one. This has led to a range of different conceptualisations and measurement tools focusing upon different facets or aspects of spirituality. The authors of the Spiritual Wellbeing Scale for instance have clearly focused upon distinguishing religious well-being from spiritual well-being (Ellison & Smith, 1991). Similarly, other scales have aimed to encompass both religious and non-religious perspectives of spirituality, such as the Intrinsic Spirituality Scale (Hodge, 2003). Others again have focused upon one dominant religious tradition, such as Brief Multidimensional Measure of Religiousness/Spirituality (BMMRS) which distinguishes spiritual experiences, from religious practices and congregational support (Fetzer Institute & National Institute on Aging Working Group, 1999). This wide range of measures has led to a range of interpretations and conclusions regarding the concept of spirituality and its relationship with other constructs, raising some challenges.

The measure selected for this study was the Functional Assessment of Chronic Illness Therapy – Spiritual Well-being (FACIT-SP), which incorporates scales related to both meaning and purpose, and faith (Peterman et al., 2002). An extended version has also incorporated items relating to gratitude, connections with others, and hope. This measure does not specifically refer to religious practices, however a belief in a ‘God or
higher power’ is mentioned. This broad measure seemed to best encapsulate the complexity of the construct of spirituality, and was therefore chosen for this study.

1.3.4 **Spirituality and disability.** Despite the complexity surrounding the concept of spirituality, there is an increasing awareness and acknowledgement of the importance of spirituality for individuals at times of illness or disability (Cobb et al., 2012; Glicken, 2006; J. Hampton & Weinert, 2006; Johnstone, Glass, & Oliver, 2007; Johnstone & Yoon, 2009; Waldron-Perrine et al., 2011). This is evident within a number of international studies. In their study of rural women with a chronic illness, Hampton and Weinert (2006) found that prayer, faith, finding meaning, transcendence and family were extremely helpful for many of their participants as they coped with their situation. Johnstone and Yoon (2009) reported that positive spiritual experiences and a willingness to forgive were related to better physical health among individuals with chronic disabilities (including SCI). Among adults with a traumatic brain injury, Waldron-Perrine et al (2011) observed that religious well-being, namely a sense of connection to a higher power, was a unique predictor for life satisfaction, distress and functional ability.

Within Australia, awareness of the relevance of spirituality within health contexts is also growing, and new findings are gradually being incorporated into policy and service delivery. For instance, new guidelines in the ageing sector have focused upon the spiritual needs of older people in residential care (Meaningful Ageing Australia, 2016). In the area of palliative care, work has been conducted into the spiritual needs of individuals with cancer and how these are met by medical practitioners in a Sydney hospital (Best, Butow, & Olver, 2014). Furthermore, research has been recently published by practitioners working in the area of pain and SCI (Siddall, McIndoe, Austin, & Wrigley, 2016). Highlighting the value of spirituality for
Australians, Hilbers, Haynes and Kivikko (2010) found that at a public hospital in Sydney 74% participants surveyed held spiritual or religious beliefs of some kind, 43% belonged to a community with shared beliefs, a place of worship or spiritual group, and over 70% thought it would be helpful for hospital staff to ask about their beliefs. These studies are congruent with the conclusions of Kaldor, Hughes and Black (2010) who argued from an Australian standpoint that meaning and making sense of life has a significant impact upon wellbeing, life satisfaction, physical and mental health.

The research findings outlined above demonstrate some of the challenges arising for health professionals as they address the spiritual needs of their clients. Hilbers, Haynes and Kivikko (2010) found that beliefs and practices even within the same faith group or denomination could be diverse, and emphasised that “understanding the meaning of spirituality/religion from the patient’s perspective” was paramount (p.7). These authors proposed that spiritual beliefs and practices should be incorporated as a dimension in patient-centred health care, but how this could be implemented was not explored. A program aimed at increasing spiritual knowledge and confidence of health professionals has been introduced within the area of palliative care (Meredith, Murray, Wilson, Mitchell, & Hutch, 2012). As the next chapter demonstrates, there is no evidence of such an approach to staff training within the area of SCI.

1.3.5 Spirituality within the family. In addition to the growing body of international and Australian literature which has focused upon the importance of spirituality for individuals confronted with disability or illness, spirituality has also been studied among family members who provide a support role to such individuals. Some such studies have chosen to focus upon the family members alone. In their study of spirituality among wives of men with prostate cancer, Ka’opua, Gotay and Boehm (2007) observed that spirituality facilitated adaptation in four areas: marriage
preservation and couple intimacy, personal growth and continuous learning, health-related attitudes and community connections.

Other studies, like this study, have considered the experience of both the individual affected and their family members (Kim, Carver, Spillers, Crammer, & Zhou, 2011; Strang & Strang, 2001). These studies suggest that spirituality (and related meaning making constructs) may have an important bearing upon family relationships, though research in this area is limited. In a study of individuals with cancer and their spouses Kim et al (2011) found that the spiritual well-being of one member of the couple correlated strongly with their own mental health and the physical health of the partner. Strang and Strang (2001) identified that sense of coherence (SOC) was a pivotal concept which integrated stress, coping and spirituality among individuals with a brain tumour and their spouses. For any future studies of spirituality within the area of SCI, the research above emphasises the value of addressing family relationships, rather than focusing only upon the injured individual.

At the heart of family relationships is connectedness. Canda and Furman (2009) have suggested that it is connectedness which highlights the relational nature of spirituality. They argue that the “thrust of spirituality is toward connectedness with oneself, other people, other nonhuman beings, the universe, and (for many) the sacred or divine” (p.66). In Spiritual Resources in Family Therapy, Walsh (2009b) pointed out how the “caring bonds” between family members and close bonds “nourish spiritual well-being”, and in turn “spirituality deepens and expands our connections with others” (p.60). Surprisingly, given the above, it has also been observed that the “influence of family members’ spiritual and religious beliefs on their illness experience has been one of the most neglected areas of family work” (Wright, 2009).
Due to their significant role providing support to both individuals and their family members in the process of adjustment to disability, Social Workers have a unique opportunity to progress understanding and awareness of spirituality within the field of SCI. It has been argued that spiritual and religious beliefs cannot be ignored, when a holistic perspective of an individual and their family is adopted (Crisp, 2010). Canda and Furman (2009) and others (Crisp, 2010; Rice, 2002) agree that the area of spirituality is a fundamental aspect of Social Work practice, and holds much potential which is yet to be fully realised.

This section has considered the role of spirituality in the area of health and disability, provided definitions of spirituality which incorporate key aspects of connectedness, transcendence, meaning and purpose, and considered a number of constructs closely associated with spirituality. Research investigating the role of spirituality within the areas of health and disability, for both the affected individuals and family members, has been outlined. Furthermore, the important role of health professionals, and particularly Social Workers, in this area has been highlighted. The next and final section of this introductory chapter will provide a background to the concept of resilience, and delineate some of the ways it has been associated with spirituality.

1.4 Resilience

Investigation into resilience has accompanied a paradigm shift within health, from an emphasis on pathology and problems to health promotion and the nurturing of strengths (Connor & Davidson, 2003; Richardson, 2002). While most resilience research has focused upon the individual, the focus has also been extended to resilience within families (McCubbin & McCubbin, 1996; Walsh, 2003) and communities (Buikstra et al., 2010). Traditional theories of adjustment within the area of traumatic
injury have tended to be deficit or problem-focused approaches, which have placed
greater emphasis upon the weakness of individuals and families rather than strengths (B.
White, Driver, & Warren, 2008). This trend was evident among studies identified by
Perlesz, Kinsella and Crowe (1999) in their review of the literature pertaining to family
adjustment to traumatic brain injury (TBI). The authors found that the majority of
studies within the area of family adjustment to TBI focused upon the stress and burden
of family members. They argued for research which instead considered the strength and
resilience of families after TBI, and the abilities of families to work towards positive
outcomes.

1.4.1 Resilience after SCI. As outlined earlier in the chapter, like the studies
identified by Perlesz and colleagues (1999), much research in the area of SCI has also
focused upon the stress and negativity associated with the injury. Studies have
emphasised the distress and burden experienced by family members (Alfano et al.,
1994; Boschen et al., 2005; Chan, 2000b), as well as the stress, anxiety and depression
experienced by the injured individual (Dryden et al., 2005; Hoffman et al., 2011;
Kennedy & Rogers, 2000; Williams & Murray, 2015). However in recent years, when
investigating anticipated burden and stress among those affect by SCI, researchers have
found that many individuals with SCI and family caregivers have coped and adjusted
very well after SCI, and have even been able to identify positive gains or benefits
(Kennedy, Lude, Elfstrom, & Cox, 2013; Middleton et al., 2014; Simpson & Jones,
2013b).

Resilience studies in the area of SCI are few (Bonanno et al., 2012; Catalano,
Chan, Wilson, Chiu, & Muller, 2011; Elliot et al., 2014; Guest et al., 2015; Monden et
al., 2014; Simpson & Jones, 2013b; B. White et al., 2010). Significantly, the majority of
these studies have focused upon the individual. In two of these studies of resilience
among individuals with SCI, spirituality was identified to be either closely associated or contributing towards resilience (Monden et al., 2014; B. White et al., 2010).

Simpson and Jones (2013b) and Elliot et al (2014) have been the only authors considering resilience among family members of those affected by SCI. In the first study to directly measure resilience among family members after SCI and TBI, and highlighting the importance of a strength based approach in the area of traumatic injury, Simpson and Jones (2013b) observed a significant positive association between resilience scores and positive affect, and a significant negative association between resilience scores, negative affect and carer burden. When the sample was divided into higher and lower resilience score groups, those with high resilience scores were significantly more likely to use particular carer management strategies demonstrating positive adaptation to their circumstances. These findings and others (B. White et al., 2010) suggest that there may be much to learn from those individuals and family members who demonstrate strength and resilience after a traumatic injury.

1.4.2 Conceptualising resilience. Similar to spirituality, resilience is a broad construct. In her systematic and extensive review of the literature pertaining to resilience, Windle (2011) defined resilience as “the process of effectively negotiating, adapting to, or managing significant sources of stress or trauma. Assets and resources within the individual, their life, and environment, facilitate this capacity for adaptation and ‘bouncing back’ in the face of adversity” (p.163). Much of the early research into resilience sought to identify these assets and resources, or characteristics of the individual, which facilitated resilience.

In charting the evolution of resilience research, Richardson (2002) observed that a focus upon the characteristics or components of resilience shifted towards the conceptualisation of resilience as a growth process. This shift is evident among
definitions of resilience. Luthar et al (2000) have defined resilience as “a dynamic process encompassing positive adaptation within the context of significant adversity” (Luthar et al., 2000, p. 543). Richardson, Neiger, Jensen and Kumpfer (1990, p. 34) have described resilience as “a process of coping with disruptive, stressful, or challenging life events in a way that provides the individual with additional protective and coping skills than prior to the disruption”. Resilience has also been proposed as a “process of effectively negotiating, adapting to, or managing significant sources of stress or trauma” (Windle, 2011, p. 163). This process oriented view of resilience has subsequently led to clinical implications, generating an interest in building the resilience of individuals and/or families among health professionals. White et al (2008, p. 10) have maintained that resilience is a “skill which can be learned” and involves “behaviours, thoughts, and actions that can be learned and developed in anyone”.

Further work in the area of resilience theory has raised the question, does this dynamic process of resilience refer only to ‘bouncing back’, or does it encompass growth, reconfiguration, and ‘bouncing forward’? (Frank, 1995; Lepore & Revenson, 2006; Richardson et al., 1990; Walsh, 2003). In the Resiliency Model, put forward by Richardson, Neiger, Jensen, and Kumpfer (1990), the notion that resilience encompasses growth is strongly advocated. The authors define resiliency as “the process of coping with disruptive, stressful, or challenging life events in a way that provides the individual with additional protective and coping skills than prior to the disruption that results from the event” (italics added). From this perspective, times of adversity are opportunities for “growth, development, and skill building” (p.34). According to the Resiliency Model, to arrive at a point of resilient reintegration an individual must pass through challenges, become disorganised, reorganise themselves and learn from the experience, and emerge stronger with greater coping skills than before (p.35). This process can
apply to individuals, couples, families and communities, and entails more than simply recovering of bouncing back, but growth or adaptation through disruption (Richardson, 2002, p. 313).

Such a conceptualisation of resilience as a growth process is also indicated by Lepore and Revenson (2006) who have suggested that resilience consists of three co-existing facets or forms; recovery, resistance and reconfiguration. The analogy of a tree in a storm is utilised to explain the three different forms. A tree that is still and unmoving in the wind is used to describe form of resilience the authors label ‘resistance’. A tree’s branches being moved but then returning to the same position depicts ‘recovery’, a return to homeostasis or bouncing back. Reconfiguration, however, is different again and is considered by the authors to be strongly associated with posttraumatic growth. Lepore and Revenson have suggested that reconfiguration involves “transformations that go beyond simply maintaining or returning to normal functioning” (p.27). Posttraumatic growth, they claim, may be one outcome of resilience that involves a process of reconfiguration (Lepore & Revenson, 2006).

There is some debate regarding the nature of the relationship between resilience and posttraumatic growth. Unlike Richardson and his colleagues (Richardson et al., 1990) and Lepore and Revenson (2006), Tedeschi and Calhoun (2004) have viewed resilience and posttraumatic growth as distinct concepts. To these authors and others (McGrath, 2011; Windle, 2011) the concept of resilience entails “bouncing back” to the same location, rather than change and transformation beyond pre-trauma levels of adaptation. However, Richardson et al (1990) clearly suggest such growth is an essential component of resilience, and others support this assertion (Lepore & Revenson, 2006; Walsh, 2003).
1.4.3 **Spirituality and individual resilience.** According to Richardson, there is a strong connection between spirituality and resilience. Richardson has suggested recent understandings of resilience have highlighted this relationship by depicting resilience as a force or energy that drives individuals “to seek self-actualisation, altruism, wisdom, and harmony with a spiritual source of strength” (2002, p. 319). To understand the concept of resilience better, he has called for an approach to resilience which encompasses a number of disciplines, including philosophy, psychology, physics, anthropology, sociology and theology (Richardson, 2002, p. 313).

Spiritual faith has been listed among many characteristics associated with individual resilience, which also include assertiveness, locus of control, flexibility, adaptability, a sense of humour, commitment, being able to engage support, self-efficacy, and a sense of coherence (Connor & Davidson, 2003; Earvolino-Ramirez, 2007; Windle, 2011). Like resilience, spirituality has also been described as a “dynamic process” (Hungelmann et al., 1985; Meraviglia, 1999), one that incorporates a search for a sense of meaning and purpose (Canda & Furman, 2009). Encompassing the idea of growth, and spanning the concepts of both spirituality and resilience, is the quest narrative proposed by Frank (1995). In *The Wounded Storyteller*, Frank has outlined three different narratives which he has suggested can be adopted by those affected by chronic illness; the ‘restitution narrative’, the ‘chaos narrative’, and the ‘quest narrative’.

According to Frank the *restitution* storyline goes "Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again" (p.77). Such a narrative views the body as something needing to be ‘fixed’, like a television set or other piece of equipment. The *chaos* narrative however is the opposite of the restitution narrative. The plot of the chaos narrative is that life will never get better and the story is one of
‘vulnerability, futility, and impotence’ (p.97). The *quest* story is different again to both the restitution narrative and the chaos narrative. In the quest narrative, the interruption to an individual’s life is reframed as a challenge. Illness or injury becomes a journey, and the teller has a story to tell. According to Frank quest stories meet

…suffering head on; they accept illness (or injury) and seek to use it. Illness (or injury) is the occasion of a journey that becomes a quest. What is quested for may never be wholly clear, but the quest is defined by the ill person’s belief that something is to be gained through the experience (Frank, 1995, p. 115).

Rather than loss, the emphasis moves to gains.

Frank has suggested that the idea of ‘a journey’ or ‘quest’ has much to contribute to the area of chronic illness. In *The Wounded Storyteller* he draws upon the work of Joseph Campbell (2008). Campbell proposed that a ‘hero’ on a journey is at the heart of much of the world’s mythology and religion. The first stage of Campbell’s hero’s journey is the initial departure, encompassing a call to adventure, resistance to the call, the assistance of supernatural aid, the crossing of a threshold, and a period of submission or surrender. The hero then undertakes a process of initiation which involves trials, suffering, and an eventual ‘boon’. He or she returns from the journey with something to offer the rest of humanity. The “thread of the hero-path” Campbell suggested, is there for all to follow, an indication of a “universal adventure” (p.18, 28).

It is this sense of adventure, Frank (1995) proposes, which is at the heart of the quest narrative. An individual learning of their chronic illness, subsequently struggling with this diagnosis, and then seeking assistance, he suggested, fits with the *departure* of the hero on their journey. The various challenges of chronic illness which eventually lead to some insight is well aligned with the *initiation* part of the journey, encompassing the ‘road of trials’ and ending with an ‘ultimate boon’. Lastly, an individual desiring to
give back in some way after their experience of chronic illness, could be likened to the return of Campbell’s hero, who returns with something which will aid or contribute to humanity. Such a depiction brings together the two constructs of spirituality and resilience and suggests the two may be closely related.

Whether as a component of resilience, an aspect of the resilience process, or a source of strength contributing to growth, spirituality appears to have an important role to play in resilience research (Connor & Davidson, 2003; Richardson, 2002; Walsh, 2003). What remains unknown is how spirituality contributes towards resilience, how the two constructs co-relate, and how, if at all, they might be predictors of outcome variables such as life satisfaction and emotional well-being after SCI. The most recent literature pertaining to spirituality and resilience within the field of SCI has been correlational only (B. White et al., 2010), suggesting potential exists for further exploration of this relationship.

1.4.4 Spirituality and family resilience. Although much of the resilience theory and research outlined so far has focused upon the individual, there is another growing body of literature which has considered resilience within the family. Spirituality and meaning-making have been identified as key components of family resilience (Brody & Simmons, 2007; Heiman, 2002; B. L. Jones, 2007; Patterson, 1991; Ross, Holliman, & Dixon, 2003; E. A. Thompson, 1999; N. White, Richter, Koeckeritz, Munch, & Walter, 2004). One of the significant contributors to the understanding of family resilience is Froma Walsh. Like others, Walsh (2003) has focused upon the notion of resilient growth, but applied it to the area of the family. She explains that it is resilience which suggests why some families “emerge strengthened and more resourceful” from crisis or chronic stress (p.1). According to Walsh, resilience ‘involves key processes over time that foster the ability to “struggle well,” surmount obstacles, and go on to live and love
fully” (p.1). Rather than ‘bouncing back’, Walsh has suggested that resilient families ‘bounce forward’.

In her framework of family resilience Walsh has proposed three domains of family functioning: family belief systems, family organisational patterns, and communication/problem-solving processes (Walsh, 2003). The first domain of family functioning is shared, facilitative family beliefs, which assist members to “make meaning of crisis situations; facilitate a hopeful, positive outlook; and offer transcendent or spiritual moorings” (p.6). According to Walsh, spirituality is a key process contributing to family resilience.

Supporting the premise of Walsh’s framework, empirical studies in other fields of illness or disability have suggested that spirituality and religion contribute positively to resilient growth within families (Bayat, 2007; Brody & Simmons, 2007). Brody and Simmons (2007) observed that support from the church and religious faith contributed to the resilience of fathers of children with cancer, and Bayat (2007) identified that parents of children with autism experienced ‘spiritual awakening or strengthening’ as part of their caring role. As with studies of spirituality, these research studies focused upon specific family members (in these examples, parents) rather than on the whole family.

This section has outlined how resilience has been defined and conceptualised over time, leading to current understandings of resilience as a process, one incorporating growth in the midst of adversity. As suggested in the previous section, spirituality, encompassing connectedness, transcendence, meaning and purpose (Canda & Furman, 2009), has also been closely associated with growth, and a contributor towards resilience. The journey metaphor proposed by Campbell (2008), and the quest narrative by Frank (1995) bring these two constructs together. Importantly, spirituality has also
been identified as a key aspect of family resilience by Walsh (2003), where she suggests that family resilience is the process of families ‘bouncing forward’, rather than merely ‘bouncing back’. Although some resilience research has been conducted in the field of SCI, the majority of it has focused upon the individual, and not the family unit as a whole. Family resilience after SCI is an area worthy of much further investigation.

1.5 **Summary of Chapter**

This Introduction chapter has provided a background to spinal cord injury (SCI) and the concepts of spirituality and resilience. It has been outlined how SCI is an injury which has a devastating impact upon both the individuals affected and their family members. Yet there is a growing awareness that many individuals and family members adjust very well after SCI, and demonstrate strength and resilience. Positive psychology has played an important part in highlighting the value of constructs such as hope, optimism, spirituality and resilience, and these are of increasing interest within the field of SCI. Specifically, the role of spirituality within the area of health, and its contribution to the area of family adjustment, is attracting much interest both theoretically and empirically. It’s relationship with resilience has been considered, but so far there appears to be little research examining the two constructs together within the field of SCI (Monden et al., 2014; B. White et al., 2010). Although spirituality has been proposed as one of several key processes in building family resilience (Walsh, 2003), the main focus of this field of research so far has remained on the injured individual alone.

1.6 **Project Aims and Research Questions**

The aim of this research was to investigate how spirituality contributes to family resilience after SCI. Current understandings of family resilience, such as depicted by Walsh (2003), conceptualise spirituality as a contributor toward resilience, rather than
vice versa. This was an important point for this study, as it provided some indication regarding the proposed ordering of variables within the quantitative analysis.

Drawing upon current understandings of the relationship between spirituality and resilience, the specific research questions of this project were:

i) To test whether spirituality was associated with increased resilience among families affected by SCI (both the individual with SCI and their family members), and to examine the contribution spirituality and resilience made towards other outcome variables related to adjustment after SCI,

ii) To explore how interactions between the injured individual and their family members fostered spirituality within the family over time, encompassing a sense of meaning, hope and purpose,

iii) To consider how the rehabilitation team could enhance the role of spirituality for both spinal clients and their family members after SCI.

The following chapters address these research questions and summarise the results of this study. In Chapter Two the results of a literature review that was conducted to identify studies that have investigated spirituality and other meaning-making constructs within the field of SCI are discussed. The literature review has been published (see Appendix A). Chapter Three summarises the methodology employed for this study. In doing so, a rationale for using a mixed methods approach is provided. The results of the study, pertaining to the quantitative and two qualitative components of the study, are presented in Chapters Four, Five, Six and Seven and discussed in Chapter Eight. The conclusions and recommendations for future research are summarised in Chapter Nine.
Chapter Two: Scoping review

A scoping review was conducted to identify research undertaken in the area of spirituality and spinal cord injury (SCI). The purpose of a scoping review is to determine the breadth and depth of the literature within a particular field (Levac, Colquhoun, & O'Brien, 2010). A scoping review was deemed an important first step for this study because of the wide range of definitions, broad extent of literature, and closely associated constructs, pertaining to spirituality.

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 the studies identified from objectives 1-3 considered the relationship between spirituality and resilience.

Forming the basis of this chapter are the results of a scoping review, published in 2016 (K. Jones, Simpson, Briggs, & Dorsett, 2016) (see appendix for copy of article). For the purposes of this thesis, the timeframe of the original review has been extended and a quality appraisal of the papers has been added. Although not usually an aspect of a standard scoping review (Levac et al., 2010), this appraisal section provides important additional information on the quality of the papers that were used to inform this research study.
2.1 Scoping Review Methods

A scoping review was conducted using the five stages outlined by Arksey and O’Malley (2005) and later refined by Levac et al (2010): i) identifying the research question, ii) identifying relevant studies, iii) study selection, iv) charting the data, v) collating, summarising and reporting results.

2.1.1 Identifying the research question. To identify the research question, Levac et al (2010) recommended that researchers clearly articulate the scope of enquiry by defining the concept, target population, and health outcomes of interest. As described in Chapter One, this study adopted a broad definition of spirituality and included other closely related meaning-making constructs. 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) (Middleton, Tran, & Craig, 2007; Tate & Forchheimer, 2002), life satisfaction (Post, Van Dijk, Van Asbeck, & Schrijvers, 1998), mental health, and resilience (B. White et al., 2010). QOL is a multi-dimensional construct, which according to Tate and Forchheimer (2002) encompasses physical, functional, psychological, social and spiritual domains. Life satisfaction has been understood to refer to the cognitive-judgmental (subjective) aspects of QOL (Diener et al., 1985; Post et al., 1998). Studies of mental health within SCI have included those pertaining to depression (Dryden et al., 2005; Hoffman et al., 2011; B. White et al., 2010), anxiety (Kennedy & Rogers, 2000), and psychological well-being (DeRoon-Cassini et al., 2009). Key studies in the area of resilience and SCI were outlined in Chapter One.
2.1.2 **Identifying relevant studies.** 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. Drawing upon the closely associated constructs discussed in the previous chapter, 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: Psychinfo, 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 including family members. Papers were restricted to research reporting empirical data, published within the 22-year timeframe (between 1994 and 2015), written in English, and from peer reviewed journals. As long as a study was empirical, no limitations were placed upon the research design which could include correlational, field, experimental, case study and qualitative designs.

2.1.3 **Study selection.** Included studies comprised of those focused upon spirituality (or associated meaning-making constructs) and SCI. Those 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. 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. Editorials and commentaries were excluded.

After duplicates were removed, the titles and abstracts were screened to identify articles that met 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, supervisors (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.

2.1.4 Charting the data. The first step in charting the data involved collecting descriptive information about the studies. All studies were observational (rather than experimental). 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.

2.1.5 Collating, summarising and reporting results. The results were grouped according to the four study objectives, and within each objective further grouped into quantitative and qualitative studies. The study results were 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.

2.2 Scoping Review Results

Applying the search terms generated 903 citations. After duplicates were removed and titles and abstracts screened, full text versions of the remaining 160
articles were reviewed to determine which articles met the inclusion criteria. The study flow is detailed in Figure 1.

A total of 32 articles relating to spirituality (or associated meaning-making constructs) met the review criteria, four more than the original scoping review. Papers were clustered in more recent years, with 27 of the 32 papers published since 2005. Most studies were conducted in either the United States (15) or Europe (7), with the remainder conducted in Canada (4), the Middle East (4), India (1) and Australia (1). Research design was fairly evenly balanced, with 19 of the 32 studies utilising quantitative methodology (15 cross-sectional and four longitudinal) and 13 qualitative (six longitudinal).

In relation to the first objective, 30 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, those which solely considered the family member perspective. Two studies adopted a systemic (whole of family) approach corresponding to the third objective. Only one study met the criteria for the fourth objective, focusing upon spirituality and resilience (B. White et al., 2010). As there were no research studies identified which considered spirituality from a sample comprising family members only (Objective 2), the results of the scoping review focused upon those studies which investigated the relationship between spirituality and individual adjustment, family adjustment, and resilience. One paper addressed the criteria of both the first and fourth objectives, and therefore the elements of this study relevant to each objective are reported respectively.
2.2.1 Objective 1: Spirituality and individual adjustment after SCI

Quantitative studies. Eighteen quantitative studies considered the relationship between spirituality or associated meaning-making constructs and other positive outcomes after SCI related to individual adjustment (see Table 1). 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 16 studies recruiting samples of individuals with SCI alone, and the other two consisting of mixed samples which included a sub-group of people with SCI. Participants within the studies had been diagnosed with 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 18 quantitative studies focused exclusively upon newly injured people (up to two years post SCI). Samples from other studies consisted of either a combination of participants with new and older injuries, or those who had sustained their injuries greater than two years previous. Only two quantitative studies (Forchheimer & Tate, 2007; Marini & Glover-Graf, 2011) made specific comparisons between participants who had been injured for different lengths of time. Those studies focusing specifically upon the construct of spirituality will be considered first, followed by those investigating constructs closely related to spirituality. The clinical implications drawn from the quantitative studies will then be considered.

Studies investigating spirituality. Of the 18 studies, 10 focused specifically upon spirituality. All of these 10 studies were cross-sectional, rather than longitudinal. The majority of these studies reported positive associations with other indicators of adjustment after SCI including life satisfaction (Chlan, Zebracki, & Vogel, 2011; Riley et al., 1998; Tate & Forchheimer, 2002; B. White et al., 2010), quality of life (QOL) (Brillhart, 2005; Forchheimer & Tate, 2007; Matheis, Tulsky, & Matheis, 2006; Riley et al., 1998; Tate & Forchheimer, 2002), and perceived health (Franklin, Yoon, Acuff, & Johnstone, 2008). Furthermore, one study (Rahnama et al., 2015) observed that lower
levels of spirituality, and negative spirituality, contributed towards anxiety and depression.

White et al (2010) reported significant positive correlations between spirituality and life satisfaction, and a negative correlation between spirituality and depressive symptoms. Brillhart (2005) reported a significant positive correlation between psychological/spiritual factors and life satisfaction. Such a relationship was also found among adults with paediatric onset SCI. For example, Chlan et al (2011) 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 (2002) 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 (Forchheimer & Tate, 2007). A common feature among the studies above was that they were conducted within Western countries, such as the USA and Canada. Last, and in contrast, in a study of individuals with SCI in Iran, Rahnama et al (2015) reported that lower scores in the existential dimension of spiritual well-being, and negative religious coping, contributed toward greater levels of anxiety and depression. All studies treated spirituality as an independent variable which predicted outcomes, rather than viewing spiritual status as an outcome in and of itself. The only study to consider spirituality and resilience (B. White et al., 2010) considered them both to be indicators of adjustment, however the relationship between the two was not explored. This study is discussed further under Objective Four.
<table>
<thead>
<tr>
<th>First Author (Year), Country</th>
<th>Study Design</th>
<th>Construct/s of interest</th>
<th>N, TSI</th>
<th>Injury Characteristics</th>
<th>Measure/s of Spirituality and/or Meaning</th>
<th>Significant outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arkbarpour (2015), Iran</td>
<td>Cross-sectional, prospective</td>
<td>PTG, QOL</td>
<td>95, &gt;6 months</td>
<td>SCI only Paraplegia, n=85 Tetraplegia, n = 7 Hemiplegia, n=3</td>
<td>QLI (Ferrans &amp; Powers, 1992) QLI correlate with PTGI (r=.54), including the spiritual changes dimension (r=.35).</td>
<td></td>
</tr>
<tr>
<td>Chlan (2011) 2011, USA</td>
<td>Cross-sectional, prospective</td>
<td>Spirituality</td>
<td>298, M 16.6, (SD 6.5), Range 6-38 yrs.</td>
<td>SCI only, Pediatric-onset Paraplegia 44% Tetraplegia 56% ASIA A: 70.5%</td>
<td>i) Brief COPE (Walsh, 2009b) (spiritual coping domain only) -‘I’ve been trying to find comfort in my religion or spiritual beliefs’ -‘I’ve been praying or meditating’ i) 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 ns</td>
<td></td>
</tr>
<tr>
<td>First Author, Year, Country</td>
<td>Study Design</td>
<td>Construct/s of interest</td>
<td>N, TSI</td>
<td>Injury Characteristics</td>
<td>Measure/s of Spirituality and/or Meaning</td>
<td>Significant outcomes</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>--------------</td>
<td>-------------------------</td>
<td>-------</td>
<td>-----------------------</td>
<td>----------------------------------------</td>
<td>---------------------</td>
</tr>
<tr>
<td>4  Davis (2013), Canada</td>
<td>Mixed method, longitudinal, prospective</td>
<td>Meaning, PTG</td>
<td>67, &lt;1 yr</td>
<td>SCI only Paraplegia 34.3% Tetraplegia 58.2% Other 7.5%</td>
<td>i) Assessment of meaning making (five questions with coded responses) ii) PTGI (Tedeschi &amp; Calhoun, 1996)</td>
<td>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.</td>
</tr>
<tr>
<td>5  deRoon-Cassini (2009), USA</td>
<td>Cross-sectional, prospective</td>
<td>PIL</td>
<td>79, M 17.5 mths (SD 14.7mths) Range 0.1-62 mths</td>
<td>SCI only Partial paraplegia: n=21 Complete paraplegia: n=20 Partial tetraplegia: n=34 Complete tetraplegia:n=4</td>
<td>PIL scale (Crumbaugh, 1968) -measures the degree to which an individual believes they are living a meaningful life</td>
<td>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.</td>
</tr>
<tr>
<td>6  Forchheimer (2007), USA</td>
<td>Cross-sectional, prospective</td>
<td>Spirituality</td>
<td>444, Range 10-30 yrs.</td>
<td>SCI only Injury details not documented</td>
<td>FACTT-Sp (Peterman et al., 2002) -spirituality total and two scales: meaning and faith</td>
<td>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</td>
</tr>
<tr>
<td></td>
<td>First Author, Year, Country</td>
<td>Study Design</td>
<td>Construct/s of interest</td>
<td>N, TSI</td>
<td>Injury Characteristics</td>
<td>Measure/s of spirituality</td>
</tr>
<tr>
<td>---</td>
<td>-----------------------------</td>
<td>------------------</td>
<td>--------------------------</td>
<td>--------</td>
<td>------------------------</td>
<td>--------------------------</td>
</tr>
<tr>
<td>7</td>
<td>Franklin (2008), USA</td>
<td>Cross-sectional, prospective</td>
<td>Religious Beliefs</td>
<td>25, M 133.5 mths (SD 51.9 mths), Range 7 to 564 mths</td>
<td>SCI only Injury details not documented</td>
<td>BMMRS - Scales include: meaning, values/beliefs, daily spiritual experiences, forgiveness, religious support, private religious practices, organisational religiousness, religious and spiritual coping</td>
</tr>
<tr>
<td>8</td>
<td>Kennedy (2009), UK</td>
<td>Cross-sectional, prospective</td>
<td>Hope</td>
<td>54, &lt; 1 yr</td>
<td>SCI only Tetraplegia: n=27 Paraplegia: n=27 Complete: n=22 Incomplete n=32</td>
<td>State Hope Scale - measures a person’s current evaluation of their goal-directed thinking. Subscales: i) agency, ii) pathways</td>
</tr>
<tr>
<td>9</td>
<td>Kennedy (2010), Europe</td>
<td>Longitudinal prospective</td>
<td>SOC</td>
<td>237, &lt; 1 yr</td>
<td>SCI only Complete paraplegia: n=74 Incomplete paraplegia: n=52 Complete tetraplegia: n=41 Incomplete tetraplegia: n=68</td>
<td>SOC scale (Antonovsky, 1993) - measures comprehensibility, manageability, and meaningfulness</td>
</tr>
<tr>
<td>First Author, Year, Country</td>
<td>Study Design</td>
<td>Construct/s of interest</td>
<td>N, TSI</td>
<td>Injury Characteristics</td>
<td>Measure/s of spirituality</td>
<td>Significant outcomes</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>--------------</td>
<td>-------------------------</td>
<td>--------</td>
<td>-----------------------</td>
<td>--------------------------</td>
<td>---------------------</td>
</tr>
<tr>
<td>Kortte (2010), USA</td>
<td>Longitudinal, prospective</td>
<td>Hope</td>
<td>87, Range 7-61 days in inpatient rehab unit</td>
<td>SCI only Complete paraplegia: n=18 Complete tetraplegia: n=9 Incomplete paraplegia: n=31 Incomplete tetraplegia: n=29</td>
<td>Hope Scale (Snyder et al., 1991) Benefit Finding Scale (Wolin et al., 2009)</td>
<td>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.</td>
</tr>
<tr>
<td>Lustig (2005), USA</td>
<td>Cross-sectional, prospective</td>
<td>SOC</td>
<td>48, M 106 mths (SD 99 mths), Range 1 mth-27 yrs</td>
<td>SCI only Injury details not documented</td>
<td>SOC scale (Antonovsky, 1993)</td>
<td>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)</td>
</tr>
<tr>
<td>Marini (2011), USA</td>
<td>Cross-sectional, prospective</td>
<td>Spirituality</td>
<td>157, &lt; 2 yrs, 2-5 yrs, &gt; 5 yrs</td>
<td>SCI only T 1 or below: n=65 C5-C8: n=46 C2-C4: n=32</td>
<td>Spirituality and SCI survey (created for this study and based on Spirituality and Chronic Pain Survey (Wright, 2009)). -assesses participants’ religious and spiritual beliefs.</td>
<td>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.</td>
</tr>
<tr>
<td></td>
<td>First Author, Year, Country</td>
<td>Study Design</td>
<td>Construct/s of interest</td>
<td>N, TSI</td>
<td>Injury Characteristics</td>
<td>Measure/s of spirituality</td>
</tr>
<tr>
<td>---</td>
<td>-----------------------------</td>
<td>-----------------------</td>
<td>--------------------------</td>
<td>--------</td>
<td>------------------------</td>
<td>---------------------------</td>
</tr>
<tr>
<td>13</td>
<td>Matheis (2006), 2006, USA</td>
<td>Cross-sectional, prospective</td>
<td>Spirituality</td>
<td>75, M 7.56 yrs, Range 1-32 yrs</td>
<td>SCI only Low quadriplegia: n=31 High paraplegia: n=17 Low paraplegia: n=15 High quadriplegia: n=12</td>
<td>SWBS - Measures existential spirituality (life connection and purpose) and religious spirituality (relationship with God, sense of satisfaction and positive connection with God)</td>
</tr>
<tr>
<td>14</td>
<td>Rahnama (2015), Iran</td>
<td>Cross-sectional, prospective</td>
<td>Spirituality</td>
<td>213, M 4.05 yrs Range 0.08-33.0 yrs</td>
<td>SCI Only Incomplete: n=99 Complete: n=114</td>
<td>SWBS RCOPE -Measures religious coping, using two subscales positive and negative religious coping.</td>
</tr>
<tr>
<td>15</td>
<td>Riley (1998), USA</td>
<td>Cross-sectional, prospective</td>
<td>Spirituality</td>
<td>216, NR</td>
<td>Mixed diagnostic groups SCI, n=34 Consistency</td>
<td>SWBS FACT-SP -asks about participant’s spiritual well-being over the last seven days</td>
</tr>
<tr>
<td>16</td>
<td>Tate (2002), USA</td>
<td>Cross-sectional, prospective</td>
<td>Spirituality</td>
<td>208, NR</td>
<td>Mixed diagnostic groups (including SCI) Injury details not reported</td>
<td>FACT-SP</td>
</tr>
<tr>
<td>First Author, Year, Country</td>
<td>Study Design</td>
<td>Construct/s of interest</td>
<td>N, TSI</td>
<td>Injury Characteristics</td>
<td>Measure/s of spirituality</td>
<td>Significant outcomes</td>
</tr>
<tr>
<td>----------------------------</td>
<td>-------------</td>
<td>-------------------------</td>
<td>--------</td>
<td>------------------------</td>
<td>--------------------------</td>
<td>----------------------</td>
</tr>
<tr>
<td>17 Thompson (2003), USA</td>
<td>Cross-sectional, prospective</td>
<td>PIL</td>
<td>1391, M 8.9 yrs (SD 7.3 yrs)</td>
<td>SCI only Paraplegia 45% Tetraplegia 55%</td>
<td>PIL scale (Crumbaugh, 1968)</td>
<td>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)</td>
</tr>
<tr>
<td>18 White (2010), USA</td>
<td>Longitudinal</td>
<td>Spirituality</td>
<td>42, Range 29-107 days in inpatient rehab</td>
<td>SCI only Injury details not reported.</td>
<td>ISS - measures intrinsic spiritual beliefs with six questions</td>
<td>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).</td>
</tr>
<tr>
<td>19 *Feigin (1998), Israel</td>
<td>Cross-sectional, prospective</td>
<td>SOC</td>
<td>N=80 people with disability N=72 non-disabled spouses, Range 2-12 yrs</td>
<td>Mixed diagnostic groups SCI =73%, Injury details not reported</td>
<td>SOC Scale (Antonovsky, 1993)</td>
<td>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.</td>
</tr>
</tbody>
</table>

Note: *Included injured individual and spouse. NR= Not reported; SCI = Spinal cord injury; TSI= Time since injury; QOL = Quality of Life; SOC = Sense of Coherence (Antonovsky, 1993); SWBS = Spiritual Well-being Scale (Ellison & Smith, 1991); PTG = Post traumatic growth; PTGI = Post traumatic growth inventory; PIL = Purpose in Life; QOL=Quality of Life; QLI = Quality of Life Index (Ferrans & Powers, 1992) ; SWL = Satisfaction with Life; SWLS = Satisfaction with Life Scale (Diener et al., 1985); FACIT-Sp= Functional Assessment of Cancer Therapy - Spirituality (Peterman et al., 2002); BMMRS = Brief Multidimensional Measure of Religiousness/Spirituality ; SF36= Medical Outcomes Study Short Form (Taylor, 2008)
How spirituality was conceptualised or defined varied among the 10 papers. Tate and Forchheimer (2002) identified spirituality as a construct ‘distinct from, yet conceptually related to, religion and religiosity’, and closely aligned with transcendence. In contrast Brillhart (2005) 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 (2008) who used the Brief Multidimensional Measure of Religiousness and Spirituality (BMMRS) (Johnstone & Yoon, 2009), and White et al (2010) who used the Intrinsic Spirituality Scale, which does not include reference to religious belief. In three papers distinctions between spirituality and religion were made using the Spiritual Wellbeing Scale (SWBS) (Ellison & Smith, 1991) which contrasts existential spirituality with religious spirituality (Matheis et al., 2006; Rahnama et al., 2015; Riley et al., 1998). The Functional Assessment of Chronic Illness Therapies – Spiritual (FACIT-Sp) (Peterman et al., 2002) or the Functional Assessment of Cancer Therapies –Spiritual Well-Being (FACT-SP), were used by three studies (Forchheimer & Tate, 2007; Riley et al., 1998; Tate & Forchheimer, 2002). Only two of these compared scores on the factors of these scales (meaning, faith).

Findings from those studies which considered both spirituality and religion provided evidence that such a distinction may be important. Utilising the SWBS (Ellison & Smith, 1991), Matheis et al (2006, p. 265) 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. 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). However, not all studies supported this distinction. Reporting less of a difference between the two, Riley et al (1998) 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 (Riley et al., 1998, p. 261). Rahnama et al (2015) utilised the SWBS and the Brief Religious Coping Questionnaire (RCOPE) (Rohani, Khanjeri, Abedi, Oskouie, & Langius-Eklof, 2010) to investigate both existential spiritual well-being and the impact of positive and negative religious coping.

The only study to consider the social aspect of religious experience was that by Franklin et al (2008), who found that among individuals with SCI, the domain of religious support was the only domain on the BMMRS to demonstrate a significant positive correlation with general mental health. This domain measured the perceived help, support and comfort received from one’s congregation (Franklin et al., 2008, p. 78).

The religious beliefs of participants were noted by most authors, even if demographic data on this item had not been specifically collected. Nine quantitative studies of spirituality and individual adjustment were conducted 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 (Chlan et al., 2011; Marini & Glover-Graf, 2011; Matheis et al., 2006), and in at least one study, almost exclusively Christian (Franklin et al., 2008). Marini and Glover-Graf (2011) 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.
The only quantitative study to consider spirituality and individual adjustment which was not based in the USA, was the study by Rahnama et al (2015), conducted in Iran. As highlighted by that study's authors, the majority of the population in Iran adhere to the Muslim faith. As noted by Sachedina (2012), a Muslim perspective towards injury or illness, and specifically suffering, will be different to many other faith approaches. These differences are explored further later in this thesis.

Although the studies reviewed generally identified a positive association between spirituality and the health outcomes, this was not universal. As already indicated, Rahnama et al (2015) considered the impact of negative religious coping upon anxiety and depression using the RCOPE (which includes items such as feeling abandoned by God, or anger at God). Another study observed that a small proportion of participants experienced a decrease in religious faith following their SCI (Marini & Glover-Graf, 2011). 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.

Two studies considered different experiences of spirituality over time. Comparing participants who had been newly injured with those injured for longer periods of time, Marini and Glover-Graf (2011) 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 (Marini & Glover-Graf, 2011). The only other study to consider the impact of time since injury (TSI) upon spirituality found no relationship between TSI and spirituality scores (Forchheimer & Tate, 2007).
One study published subsequent to this scoping review’s timeframe is worthy of mention here. As the only other Australian study to consider spirituality after SCI, Siddall, McIndoe, Austin and Wrigley (2016) investigated the impact of pain upon spiritual well-being. Comparing individuals with SCI and those without SCI, and using the FACIT-SP-Ex (Peterman et al., 2002), they found that levels of spiritual well-being among individuals with SCI were significantly lower than those without. They also reported a significant negative correlation between spiritual well-being and pain intensity among those with SCI.

In addition to the 10 studies specifically considering spirituality, eight studies measured constructs closely related to spirituality, namely sense of coherence (SOC) (Kennedy et al., 2010; Lustig, 2005), purpose in life (PIL) (DeRoon-Cassini et al., 2009; N. J. Thompson et al., 2003), hope (Kennedy et al., 2009; Kortte et al., 2010), posttraumatic growth (Akbarpour et al., 2015) and meaning (C. G. Davis & Novoa, 2013). Positive outcomes associated with these constructs included psychological well-being (DeRoon-Cassini et al., 2009; Kennedy et al., 2010), life satisfaction and quality of life (Akbarpour et al., 2015; Kortte et al., 2010), perceived growth (C. G. Davis & Novoa, 2013), and adjustment (Kennedy et al., 2009; Lustig, 2005; N. J. Thompson et al., 2003). Three of these studies were longitudinal.

*Studies investigating sense of coherence (SOC).* Two studies considered SOC. In one of the longitudinal studies Kennedy et al (2010) studied the power of SOC in predicting psychological well-being, appraisals, and coping behaviours 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), Lustig (2005) found that perceived strengthened SOC was associated with adaptive adjustment, whereas perceived weakened SOC was associated with nonadaptive adjustment after SCI.

*Studies investigating purpose in life (PIL).* Two studies investigated PIL among adults with traumatic SCI. Thompson et al (2003) 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, 1990). DeRoon-Cassini et al (2009) also administered measures of PIL and found that increased global meaning making was significantly related to an increase in psychological well-being.

*Studies investigating hope.* The relationship between hope and adjustment after SCI was considered in two quantitative studies. Kennedy et al (2009, p. 28) 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 (2010) 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.

*Studies investigating posttraumatic growth.* Akbarpour et al (2015) was one of only two quantitative studies to consider posttraumatic growth after SCI. This study, based in Iran, found a significant and positive correlation between posttraumatic growth and quality of life after SCI. The dimension of ‘spiritual change’ scored most highly as an area of change for participants.
Lastly, Davis and Novoa (2013) investigated posttraumatic growth and 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 (DeRoon-Cassini et al., 2009; Kennedy et al., 2009; Kortte et al., 2010; Matheis et al., 2006; N. J. Thompson et al., 2003; B. White et al., 2010) 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).

Clinical implications drawn from the quantitative studies. Surprisingly, only five of the 18 papers in this group considered the clinical implications of their findings. Marini and Glover-Graf (2011) 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 (2006) suggested that treating professionals explore individuals’ use of spirituality, and if appropriate, support such use, to assist them achieve a more satisfying life. Brillhart (2005) 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 (2005) and deRoon-Cassini et al (2009) 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. Such a finding demonstrates how much further work is required within the area of spirituality and SCI. Incorporating the findings of the above studies into clinical practice would be a key step towards addressing the role of spirituality within SCI practice.

**Qualitative studies.** The scoping review identified 12 qualitative studies which met the criteria for the first objective. These studies, which primarily focused on individual adjustment, addressed spirituality or meaning-making after SCI as a process. As seen in Table 2 constructs of interest within this group included spirituality, meaning, hope and posttraumatic growth. Although ten 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 perspectives, 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 one (a case study) 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). Six 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. As with the quantitative studies, those studies investigating the construct of spirituality will be considered first, followed by those investigating closely related constructs. Clinical implications drawn from the qualitative studies will then be reported.

**Studies investigating the construct of spirituality.** Only two of the qualitative studies explicitly considered the concept of spirituality (McColl et al., 2000; Mundle,
The quest narrative, introduced by Frank (1995), featured in the most recent of these two. In this case study, Mundle (2015) identified the restitution, chaos and quest narratives, during a series of semi-structured interviews with a woman identifying with the Catholic faith. Mundle suggested that the participant moved from one narrative type to another, eventually arriving at a narrative of ‘testimony’, where others observed her to be an “actor in her own healing drama who, in turn, could offer healing and spiritual guidance to others” (p.41).

The second qualitative study to consider spirituality stands alone as the only one in the scoping review to specifically consider the concept of spirituality as a relational construct. This is a surprising finding, particularly given the focus of definitions of spirituality upon connectedness with others (Canda & Furman, 2009; Meraviglia, 1999). McColl et al (2000) 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 (2000) 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).
Other qualitative studies considered constructs closely related to spirituality. Such constructs included posttraumatic growth, meaning and hope. These are discussed below.

**Studies investigating posttraumatic growth.** Two other qualitative studies incorporated the family as an important element regarding the meaning-making process after SCI, but like McColl (2000) did not include family members as participants. In their qualitative study of posttraumatic growth after SCI, Chun and Lee (2008) 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 (2008, p. 886) concluded 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 was 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).

**Studies investigating meaning construction.** One of the studies investigating meaning construction after SCI, recognised the important role of family members in encouraging “the patient to stay alive” and nurturing a hope and “imagination of the future” (Angel, Kirkevold, & Pedersen, 2009, p. 47). Individuals with SCI were identified to pass through six phases in their search for meaning, including: surviving physically and regaining vitality; moving back to life where possibilities present themselves; working with progress to pursue possibilities; fading process narrow possibilities down; exploiting limited possibilities, and; living a life with qualities despite limitations. Relatives however, were only perceived to play a role in the first and second phases. 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 (2013) 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.

The only other qualitative study to consider meaning reconstruction was by Papadimitriou and Stone (2011), who drew upon interview data from individuals with SCI in both inpatient and community settings. This data was used 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. It was suggested in this study that 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).

Studies investigating hope. Six papers considered the process of hope for individuals after SCI (Babamohamadi, Negarandeh, & Dehghan-Nayeri, 2011; Dorsett, 2010; Lohne, 2009; Lohne & Severinsson, 2005; Parashar, 2015; Smith & Sparkes, 2005). The authors of these papers identified similar themes regarding different types of
hope, and in the four 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. However, hope was also expressed for a life worth living, or for greater self-reliance, even in the absence of recovery. In two studies hope was closely associated with spirituality or religious belief (Babamohamadi et al., 2011; Parashar, 2015).

Smith and Sparkes (2005) 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 (1995) 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 ‘restitition 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” (Smith & Sparkes, 2005, p. 1099). In contrast, the chaos narrative resulted in a loss of hope, with participants who adopted this narrative perceiving life post-SCI to be over.

Babamohamadi et al (2011) found that hope was one of the most common coping strategies among Muslim believers in Iran. This 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.
<table>
<thead>
<tr>
<th>First Author, Year, Country</th>
<th>Study Design</th>
<th>Construct/ s of interest</th>
<th>N, TSI</th>
<th>Injury Characteristics</th>
<th>Key Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Angel, (2009), Denmark</td>
<td>Longitudinal</td>
<td>Meaning</td>
<td>12, &lt; 2 yrs</td>
<td>SCI only Incomplete lesion: n=9 (3 severe) Complete lesion: n=3</td>
<td>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.</td>
</tr>
<tr>
<td>2 Babamohamadi, (2011), Iran</td>
<td>Cross-sectional</td>
<td>Religious Beliefs, Hope</td>
<td>18, Range 2.5-26 yrs</td>
<td>SCI only Paraplegia 83.3% Quadriplegia 16.7%</td>
<td>Three coping strategies; seeking help from religious beliefs, hope, making efforts towards independence.</td>
</tr>
<tr>
<td>3 Chun (2008), Canada</td>
<td>Cross-sectional</td>
<td>PTG</td>
<td>15, M 10.7 yrs</td>
<td>SCI only Paraplegia 100%</td>
<td>Experience of meaningful family relationships; experience of meaningful engagement; appreciation of life.</td>
</tr>
<tr>
<td>4 Dorsett (2010), Australia</td>
<td>Longitudinal</td>
<td>Hope</td>
<td>46, Range 6 mths – 10 yrs</td>
<td>SCI only Paraplegia: n=19 Quadriplegia: n=27 Complete: n=16 Incomplete: n=30</td>
<td>Hoping for complete recovery, hope for a cure, hope for a satisfying quality of life.</td>
</tr>
<tr>
<td>First Author Year, Country</td>
<td>Study Design</td>
<td>Construct/ s of interest</td>
<td>N, TSI</td>
<td>Injury Characteristics</td>
<td>Key Themes</td>
</tr>
<tr>
<td>----------------------------</td>
<td>--------------</td>
<td>--------------------------</td>
<td>--------</td>
<td>------------------------</td>
<td>------------</td>
</tr>
<tr>
<td>5  Kennedy (2013), UK/Europe</td>
<td>Longitudinal</td>
<td>PTG</td>
<td>232, &lt; 2 yrs</td>
<td>SCI only Paraplegia: 51.83% Tetraplegia: 47.71%</td>
<td>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.</td>
</tr>
<tr>
<td>6  Lohne (2005), Norway</td>
<td>Cross-sectional</td>
<td>Hope</td>
<td>10, &lt; 1 yr</td>
<td>SCI only Incomplete lesion: n=6 Complete lesion: n=4 (range C5-L4)</td>
<td>‘The vicious cycle’- suffering (loneliness, impatience, disappointment, bitterness, dependency); ‘longing’- former experiences and source of new hope</td>
</tr>
<tr>
<td>7  Lohne (2009), Norway</td>
<td>Cross-sectional</td>
<td>Hope</td>
<td>9, Range 3-4 yrs</td>
<td>SCI only Incomplete: n=5 Complete: n=4 (range C5-L4)</td>
<td>Life-related hopes, body-related hopes, creative and expanding hopes.</td>
</tr>
<tr>
<td>8  Mundle (2015), Canada</td>
<td>Longitudinal, case study</td>
<td>Spirituality</td>
<td>1, unknown</td>
<td>SCI, stroke</td>
<td>Narratives of chaos, restitution and quest, leading to an emerging narrative of testimony.</td>
</tr>
<tr>
<td>9  Smith (2005), UK</td>
<td>Cross-sectional</td>
<td>Hope</td>
<td>14, NR</td>
<td>SCI only Injury details not reported.</td>
<td>Three kinds of hope: concrete hope, (restitution narrative), transcendent hope (quest narrative), and despair (chaos narrative).</td>
</tr>
<tr>
<td>First Author Year, Country</td>
<td>Study Design</td>
<td>Construct/ s of interest</td>
<td>N, TSI</td>
<td>Injury Characteristics</td>
<td>Key Themes</td>
</tr>
<tr>
<td>---------------------------</td>
<td>-------------</td>
<td>--------------------------</td>
<td>-------</td>
<td>------------------------</td>
<td>-----------</td>
</tr>
<tr>
<td>10 McColl (2000) Canada</td>
<td>Cross-sectional</td>
<td>Spirituality</td>
<td>16, &lt; 2 yrs</td>
<td>Mixed diagnostic groups SCI, n = 8</td>
<td>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.</td>
</tr>
<tr>
<td>11 Papadimitriou (2011) 2011, USA</td>
<td>Cross-sectional</td>
<td>Meaning</td>
<td>10, 14, 12, NR</td>
<td>SCI only Injury details not reported</td>
<td>SCI understood as disruption in human temporality: disconnection from a future and from one’s past.</td>
</tr>
<tr>
<td>12 Parashar (2015), India</td>
<td>Longitudinal</td>
<td>Hope</td>
<td>20, &lt; 2 yrs</td>
<td>SCI only Paraplegia: n=14 Tetraplegia: n=6</td>
<td>Three stages along the Continuum of Hope: Inevitable optimism, Tempered optimism, Inevitable realism. Religion and spirituality were tools utilised in the first stage.</td>
</tr>
<tr>
<td>13 *DeSanto-Madeya (2006) 2006, USA</td>
<td>Cross-sectional</td>
<td>Meaning</td>
<td>40 (20 family dyads), Range 5-10 yrs</td>
<td>SCI only T10: n=3 T8: n=2 C6-7: n=1 C5-6: n=11 C4-5: n=3</td>
<td>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.</td>
</tr>
</tbody>
</table>

Note. *Included individual with SCI and family member. SCI=Spinal Cord Injury; NR=Not reported, TSI= Time since injury; PTG= Post traumatic Growth
Longitudinal studies were represented among the qualitative studies on hope. In a cross-sectional report from a series of papers over time, Lohne and colleagues (Lohne, 2009; Lohne & Severinsson, 2005) observed that individuals with SCI associated hope 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 (2010) 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”.

Lastly, in a longitudinal study conducted over two years with individuals with SCI in India, Parashar (2015) considered the continuum of hope and influencers of hope. They found that early in rehabilitation participants were hopeful and optimistic, which Parashar labelled “inevitable optimism”. During this period religion and spirituality were tools several participants relied upon. As time since SCI increased and participants realised more fully the extent of their injury, hope moved to a more “tempered optimism” where the focus shifted from “recovery to rehabilitation”. Finally, according to Parashar, the continuum of hope brought participants to a stage of “inevitable realism” where participants “aligned their expectations to the challenges, as well as the possibilities of the present” (p.567). In the words of one participant, hope moved “onto something else”. Interestingly, Parashar (2015) was one of the few authors to indicate the importance of family and friends as influencers of hope, or hope agents, providing a support and an incentive not to become a burden. These four longitudinal studies demonstrated how hope can change over time, and although initial hopes for
recovery may fade, hope does not disappear, but often is invested in one’s quality of life or returning to activities one previously enjoyed.

Clinical implications drawn from the qualitative studies. A few authors among this group of qualitative studies drew specific clinical implications from their studies. Angel et al (2009) 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 (2008) and Papadimitrou and Stone (2011) 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 (2010) 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. Like the quantitative studies represented in the scoping review, none of the qualitative studies were intervention studies, and none specifically considered how findings regarding the concept of spirituality might contribute or be applied formally within SCI rehabilitation.

2.2.2 Objective 3: Spirituality within the family after SCI. Of the 32 studies identified only two adopted a systemic (whole of family) approach (DeSanto-Madeya, 2006; Feigin, 1998). 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 (1998) 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. All participants in this study identified as Jewish. Significantly, this was the only
study in the review to consider the interrelationships between couples adjusting to
disability. A significant relationship between SOC and adjustment was identified for the
total sample, and this was also identified within each group. Although there was no
significant relationship between the SOC of one spouse and the adjustment of the other
and vice versa, Feigin did observe that there was a significant correlation between the
SOC of both members of the couple. A similarly strong relationship was found with
regards to the adjustment of both spouses. Feigin then considered couples where one
member of the couple had a higher SOC than the other. 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.
Furthermore, when the healthy 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. No group comparison was conducted between the
individuals with disability and the spouses. Feigin’s study demonstrated the relational
aspect of SOC and its impact upon the adjustment of both members in the marriage. It
also highlighted that adjustment to disability is a shared experience within a couple.

**Qualitative study.** The other report to incorporate the perspective of family
members was a qualitative study by DeSanto-Madeya (2006), who sought to explore
“the everyday world” of living for families affected by SCI. DeSanto-Madeya
interviewed 20 dyads (individual with SCI and a selected family member) five to ten
years after the SCI had occurred. According to De-Santo-Madeya, the identified themes
coexisted simultaneously for both individuals with SCI and their family members,
emphasising the shared meaning making experience of SCI. Seven themes were
identified which related to meaning-making after SCI, and included: 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. De-Santo-Madeya noted that there were no observable differences related to time since injury or level of injury. Like the quantitative study conducted by Feigin (1998), a systemic approach was taken. However, unlike Feigin’s study the interrelationship between members of each dyad was not considered. 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”. No demographic data was reported regarding participants’ religious beliefs. The findings reported by both De-Santo-Madeya and Feigin suggest that there is much to learn from the family experience of meaning making and its relationship with adjustment, however very little research to date has been conducted in this area.

2.2.3 Objective 4: Spirituality and resilience. Only one of the 32 studies considered spirituality and its relationship with resilience. In their study of resilience and indicators of adjustment after SCI, White et al (2010) reported significant positive correlations between resilience, life satisfaction, and intrinsic spirituality. As a correlational study, no theoretical ordering of relationship between the variables was tested. 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 was recommended by the authors, particularly regarding the relationship between resilience and spirituality. This study focused upon
the experiences of individuals with SCI alone, and no family or systemic perspective was provided.

2.3 **Quality Appraisal**

To conduct a quality appraisal of both the qualitative and quantitative studies contained in the scoping review, the guidelines suggested by the National Institute for Health and Care Excellence (NICE) (National Institute for Health and Care Excellence, 2012) were adopted. These guidelines have been used to appraise both qualitative and quantitative studies across the United Kingdom, and were found to be helpful in assessing the studies across a number of domains. Other quality appraisal tools such as the STROBE (von Elm et al., 2008), CASP (Critical Appraisal Skills Programme, 2014), Risk of Bias (Viswanathan M et al., 2012), and COREQ (Tong, Sainsbury, & Craig, 2007) were considered, but found to be either suitable for one methodological approach only, focused upon addressing issues for randomised control studies or intervention studies (which were not represented here), or specifically designed for reporting criteria rather than appraising studies (Da Costa, Cevallos, Altman, Rutjes, & Egger, 2011).

As others have noted, appraising the quality of qualitative studies poses a number of challenges due to the range of different methodologies within the broader qualitative research field (Greenwood, Mackenzie, Cloud, & Wilson, 2009). This has resulted in a number of adaptations among qualitative appraisal tools. The NICE approach is used within a public health context, and has provided guidance which aims to encompass a number of different approaches. As the NICE guidelines include some items pertaining to intervention studies, these items were not included in the appraisal. Table 3 and Table 4 outline the findings of the quality appraisal across the quantitative and qualitative studies.
There were some similarities across both quantitative and qualitative studies in this scoping review. As has already been noted, no studies were identified as intervention studies. All of the studies were observational studies, and most of these were cross-sectional. In general, few authors provided adequate information regarding their sampling strategy. Such a finding has been observed in other reviews (Mackenzie & Greenwood, 2012). As NICE uses different guidelines for qualitative and quantitative studies, the remainder of the findings of the appraisal pertaining to the two groups will be considered separately.

2.3.1 Appraisal of quantitative studies. NICE has developed a quality appraisal checklist for quantitative studies reporting correlations (National Institute for Health and Care Excellence, 2012, p. 214) (see Table 3). This checklist consists of 19 items over five sections encompassing population, method of selection, outcomes, analyses, and summary. Each study receives a score per item as follows: “++” study design minimises risk of bias; “+” the answer is not clear, or the study may not have addressed all potential sources of bias; “-” significant sources of bias persist; “Not Reported” study fails to report sufficient detail regarding bias; “Not applicable” for studies where the criteria is not applicable. Scoring guidance is provided for each item.

Among the quantitative studies few outlined how samples were recruited, and what information was presented to participants. This meant that it was difficult to determine whether the selected participants were representative of the eligible population or area. In such cases, there was no obvious attempt by authors to minimise selection bias. Furthermore, another area of weakness among the studies was the absence of theory, with at least seven of the 19 studies making no reference to the theoretical underpinnings of the explanatory variables being investigated.
A consistent area of strength among the quantitative studies was the use of reliable measures and procedures, though whether the measures were completed by participants was rarely reported. Multiple regression was used in most studies, demonstrating that a number of explanatory variables were considered in the analyses. Meaningful associations were clearly provided in the majority of the studies. Most articles were clearly presented, except for one where the poor English of the authors was evident.

Table 3

*Quality appraisal checklist – quantitative studies (NICE) (n=19 studies)*

<table>
<thead>
<tr>
<th>Item</th>
<th>++</th>
<th>+</th>
<th>NR</th>
<th>-</th>
<th>NA</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1</td>
<td>10</td>
<td>7</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.2</td>
<td>4</td>
<td>5</td>
<td>7</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>1.3</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>2.1</td>
<td>4</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>2.2</td>
<td>10</td>
<td>2</td>
<td>4</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>3.1</td>
<td>16</td>
<td>2</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.2</td>
<td>5</td>
<td>13</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.1</td>
<td>2</td>
<td>1</td>
<td>15</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.2</td>
<td>10</td>
<td>1</td>
<td>5</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>4.3</td>
<td>11</td>
<td>3</td>
<td>3</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>4.4</td>
<td>17</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.1</td>
<td>8</td>
<td>9</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.2</td>
<td>4</td>
<td>11</td>
<td>4</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note.* NR=Not reported, NA=Not applicable.

2.3.2 **Appraisal of qualitative studies.** The NICE for qualitative studies (National Institute for Health and Care Excellence, 2012, p. 221) (see Table 4) uses different rating scales to the checklist used for quantitative measures. The checklist for
qualitative studies consists of 14 items over seven sections, which include: theoretical approach, study design, rigour of research design/methodology, data collection, trustworthiness, analysis, and ethics. Like the quantitative checklist, scoring guidance is provided for each item. An overall score is generated (“++” all or most of the checklist criteria are fulfilled, “+” some of the checklist criteria have been fulfilled, “-” few or none of the checklist criteria have been fulfilled).

For almost all of the qualitative studies, a qualitative approach was deemed appropriate. The majority were also clear in what they set out to do. However, the role of researcher was only clearly described in just over half the qualitative studies, suggesting that the relationship between the researcher and the participants had not been adequately described. This is an important aspect of qualitative research (Darlington & Scott, 2002), and may raise ethical considerations around power.

Among the qualitative studies few authors considered the diversity among responses, or provided any comparison or contrast been differing responses (Q9). On whether the analysis was reliable, only seven of the 13 studies reported using more than one researcher to theme and code data. Once again this is a significant oversight within qualitative research, as the utilisation of such processes have important implications for reliability, rigour and validity of the findings (Carey, 2012). General coherence, relevance, and clarity of the reporting was good across the studies, as well as the adequacy of the conclusions.
Table 4
Quality appraisal checklist – qualitative studies (NICE) (n=13 studies)

<table>
<thead>
<tr>
<th>NICE Item</th>
<th>NICE Criteria</th>
<th>Overall Scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Is a qualitative approach appropriate?</td>
<td>Appropriate</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>Not Sure</td>
<td>1</td>
</tr>
<tr>
<td>2. Is the study clear in what it seeks to do?</td>
<td>Clear</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Mixed</td>
<td>2</td>
</tr>
<tr>
<td>3. How defensible/rigorous is the research design/methodology?</td>
<td>Defensible</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Indefensible</td>
<td>4</td>
</tr>
<tr>
<td>4. How well was the data collection carried out?</td>
<td>Appropriately</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Not Sure</td>
<td>2</td>
</tr>
<tr>
<td>5. Is the role of the researcher clearly described?</td>
<td>Clearly</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Unclear</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Not described</td>
<td>3</td>
</tr>
<tr>
<td>6. Is the context clearly described?</td>
<td>Clear</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Unclear</td>
<td>2</td>
</tr>
<tr>
<td>7. Were the methods reliable?</td>
<td>Reliable</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>Not Sure</td>
<td>1</td>
</tr>
<tr>
<td>8. Is the data analysis sufficiently rigorous?</td>
<td>Rigorous=10</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Not rigorous</td>
<td>3</td>
</tr>
<tr>
<td>9. Is the data ‘rich’?</td>
<td>Rich</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Poor</td>
<td>6</td>
</tr>
<tr>
<td>10. Is the analysis reliable?</td>
<td>Reliable</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Unreliable</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Not Sure</td>
<td>5</td>
</tr>
<tr>
<td>11. Are the findings convincing?</td>
<td>Convincing</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Not convincing</td>
<td>2</td>
</tr>
<tr>
<td>12. Are the findings relevant to the aims of the study?</td>
<td>Relevant</td>
<td>13</td>
</tr>
<tr>
<td>13. Conclusions.</td>
<td>Adequate</td>
<td>13</td>
</tr>
<tr>
<td>14. How clear and coherent is the reporting of ethics?</td>
<td>Appropriate</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Not sure/Not reported</td>
<td>3</td>
</tr>
<tr>
<td>Overall assessment: As far as can be ascertained from the paper, how well was the study conducted?</td>
<td>++</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>+</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>-</td>
<td>1</td>
</tr>
</tbody>
</table>
2.3.3 **Quality appraisal conclusions.** This brief qualitative appraisal of the articles in the scoping review revealed that the studies which were included in the review were appropriate in most aspects, and of moderate to good standard. The findings of most of the studies were relevant to the aims of the study, and the use of quantitative or qualitative approaches were generally appropriate to the research question. A number of weaknesses however were identified. Many of the studies lacked important information regarding recruitment, eligibility criteria, and the relationship between the researcher and the participants. The appraisal demonstrated the paucity of studies using rigorous sampling techniques or incorporating interventions.

2.4 **Scoping Review Discussion**

The results of this scoping review support the claims that spirituality plays an important role in contributing toward individual adjustment after SCI. However, it was also apparent that there exist a number of significant gaps in the literature. The following observations were made, and will be discussed in further detail below: i) both quantitative and qualitative research is required to fully address the topic of spirituality, ii) spirituality studies in the area of SCI have focused predominantly upon the injured individual, rather than family members, iii) only one study could be identified which has considered the relationship between spirituality and resilience after SCI, iv) research approaches to spirituality vary between different cultural and religious contexts, and this has affected how spirituality is conceptualised, v) the role of hope was highlighted in the studies, and appeared to be closely related to spirituality, vi) studies tended to adopt a cross-sectional approach, rather than a longitudinal one, vii) negative aspects of religious faith have only been explored by a few authors, and not in depth, and finally, viii) further research is required which addresses the clinical implications of the role of spirituality after SCI. Limitations of this scoping review will also be outlined.
2.4.1 **Quantitative and qualitative approaches.** 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 regarding how spirituality and related constructs have been understood as part of a process, narrative, or journey leading to growth and positive change. Only two studies of the 32 incorporated both quantitative and qualitative methodology (C. G. Davis & Novoa, 2013; Feigin, 1998), and in these cases one approach was dominant within the study. As it is apparent that the two approaches provide different, yet complementary information, this paucity of mixed method studies reveals a significant gap in the literature.

2.4.2 **Focus upon the individual.** Spirituality has been proposed as a key process of family resilience (Walsh, 2003). However of the 32 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 (DeSanto-Madeya, 2006; Feigin, 1998). The only study to specifically consider spirituality as a relational concept was that by McColl et al (2000), 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 (2003), this lack of research in the area of SCI represents another significant gap.
2.4.3 **Spirituality and resilience.** Another important finding from the scoping review was the lack of studies found to have specifically considered the relationship between spirituality and resilience after SCI. The only study which set out to consider spirituality and its relationship with resilience (B. White et al., 2010) used correlational data only and did not examine the ordering of the two variables, or how one might contribute towards the other. To address these gaps in the literature this current study aimed to include family members as participants, and to test the relationship between spirituality, resilience, and the key outcome variables, using regression analysis.

2.4.4 **Cultural and religious contexts.** 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 were conducted within a predominantly Christian context. The only contrast to this were studies conducted within the Middle East (Akbarpour et al., 2015; Babamohamadi et al., 2011; Feigin, 1998; Rahnama et al., 2015) where participants from Jewish and Muslim backgrounds were represented. Babamohamadi et al (2011), were the only authors to consider Muslim beliefs in detail, 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 understanding in this area.

2.4.5 **Hope.** The role of hope was often discussed in the studies. It was apparent from this review that spirituality and hope 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 (DeSanto-Madeya, 2006; Smith & Sparkes, 2005).
Further investigation of the relationship between spirituality and hope would potentially assist health professionals to better facilitate adjustment for both individuals and families affected by SCI.

2.4.6 Time since injury. The only two studies which considered 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 spirituality is most important during the early stages of rehabilitation, but this is yet to be determined.

2.4.7 Negativity towards God. 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 may affect adjustment is unknown. A bi-directional relationship between spirituality and trauma has been identified by others and is illustrated well by Mitchell (2002) 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 (2013) which found that whereas finding meaning was associated with improved adjustment, more frequent searching was actually associated with declines in adjustment after SCI. The dynamic nature of spirituality was also well illustrated in the case study provided by Mundle (2015). The 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.

2.4.8 Clinical implications. 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 (Chun &
Lee, 2008; DeRoon-Cassini et al., 2009; Lustig, 2005; Marini & Glover-Graf, 2011; Matheis et al., 2006), draw upon meaning-making tools such as narrative therapy (Angel et al., 2009), incorporate peer support (Chun & Lee, 2008; Papadimitriou & Stone, 2011), and assist clients who report a decline in spirituality to manage such emotions as anger or abandonment (Marini & Glover-Graf, 2011). Although these recommendations were generated, in none of the studies were health professionals interviewed about their experiences of spirituality in spinal rehabilitation practice.

2.4.9 Limitations. A challenge for this scoping review was deciding which meaning-making terms to include 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.

2.5 Summary of Chapter

This scoping review demonstrated 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. From a total of 34 studies, only two included family member participants.
(DeSanto-Madeya, 2006; Feigin, 1998). Furthermore, no studies were identified which incorporated the perspectives of health professionals.

The contribution spirituality may make 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? This study has been conducted to investigate how spirituality might contribute to family resilience after SCI. It would appear that it is the first empirical investigation to consider such a question. The next chapter will provide information regarding the methods adopted to achieve these aims and objectives.
Chapter Three: Methods

3.1 Introduction

A mixed methods approach was adopted in this study to address the research question ‘how does spirituality contribute to family resilience after SCI?’ This chapter will first outline the key elements of quantitative and qualitative methodologies, and provide a rationale for adopting a mixed methods approach. Information will then be provided on the research design, the research context, and ethical considerations which were taken into account when planning for the study. The sampling strategy, procedures, data collection and data analysis for each of the three components of the study (the quantitative component and the two qualitative components) will then be considered separately.

3.2 Methodological Approaches

Over many years the field of empirical research has been dominated by two paradigms; quantitative and qualitative methodology, each with their corresponding philosophy (Johnson & Onwuegbuzie, 2004). Long standing debates have been held over the different approaches, their ontological and epistemological differences, and which approach is deemed most appropriate or successful in the field of research. When these two approaches are combined in the one study the research methodology is typically referred to as ‘mixed methods’. Johnson and Onwuegbuzie (2004) have argued that the mixed methods approach has introduced a third research paradigm, one that incorporates the strengths of both quantitative and qualitative research. The main tenets of the three methodologies are considered below, and are followed by a rationale for the mixed methods approach adopted for this study.

3.2.1 Quantitative research. Quantitative approaches to social research have been in existence since the eighteenth and nineteenth centuries, and have been strongly
influenced by the belief that social phenomena should be studied using the same scientific techniques as those employed in the natural sciences (Alston & Bowles, 2003; Johnson & Onwuegbuzie, 2004; Minichiello, Aroni, & Hays, 2008). The quantitative research paradigm assumes that an objective reality exists, and that this reality can be measured. Quantitative data consists of numbers, and statistical techniques are adopted to identify relationships between variables (Braun & Clarke, 2013; Johnson & Onwuegbuzie, 2004). Scientific rigour is paramount. Beginning with a testable proposition or theory, quantitative researchers set out to empirically test ideas or theories in particular contexts (Alston & Bowles, 2003). Such an approach has been described as ‘deductive’.

Measurement of data in quantitative research is often conducted via surveys or questionnaires. The impact of the researcher is considered minimal or non-existent, and therefore it is assumed that any researchers who conduct the same research under the same conditions will come up with similar or identical findings. Statistical analysis is conducted to determine whether findings are significant or non-significant. According to researchers who adopt such an approach, comparisons between defined variables are possible if the measure of such variables has been demonstrated to be both valid and reliable (Alston & Bowles, 2003). As seen in the scoping review in Chapter Two, variables such as spirituality, life satisfaction and resilience have been considered measurable within the field of SCI, and within the area of health in general.

One issue for those adopting a quantitative methodology is that of internal validity, which considers whether the chosen measures are appropriate for the construct being studied. Such questions may lead to further research and experimentation with alternative measures. Although those embracing a quantitative research paradigm would emphasise the importance of objectivity, Johnson and Onwuegbuzie (2004) have
pointed out that many subjective decisions are made during the research process, including the choice of topic and when developing or choosing instruments to measure the target construct.

One advantage of a quantitative approach is that comparisons between studies can be easily made. Furthermore, when findings are replicated within many different populations, these findings can be generalised to larger groups. Quantitative approaches are appropriate with large groups of participants, and when using survey tools which have been deemed valid and reliable across a number of studies (Johnson & Onwuegbuzie, 2004; Neuman & Kreuger, 2003).

One drawback of a quantitative approach is that little is known about processes, or how and why changes occur for participants. Limited information is available regarding the lived experience of participants, and the meaning behind the response they make (Braun & Clarke, 2013). This would appear to be a significant weakness when studies are conducted in different cultural settings or research contexts, and further exploration of cultural beliefs and influences may be required.

3.2.2 Qualitative research. In contrast to quantitative methods, which rely upon measurement and testable propositions, qualitative research allows for a topic to be explored from the subjective perspective of the participant. Multiple meanings may be given to an experience, and a range of perspectives and opinions may be collected in depth (Darlington & Scott, 2002; Johnson & Onwuegbuzie, 2004). Qualitative research seeks to “uncover the thoughts, perceptions and feelings experienced by informants” and allows participants to use their own words to describe what is meaningful or important to them (McEvoy & Richards, 2006; Minichiello et al., 2008, p. 9). Rather than assuming an objective reality exists, qualitative researchers allow for the possibility of multiple versions of reality. Reality is generally considered by qualitative
researchers to be socially constructed and, therefore, perceptions of reality will vary from individual to individual, or even for the same individual (Braun & Clarke, 2013). The focus of such research is on the subjective meanings held by the participants.

Qualitative research is generally considered to be ‘inductive’, moving from ‘specific observations or interactions to general ideas and theories’ (Alston & Bowles, 2003). Techniques such as in-depth interviews, case studies, surveys or questionnaires with open ended questions, and focus groups are utilised. Thematic analysis is one type of qualitative analysis, among many (Braun & Clarke, 2013).

A range of theories underpin qualitative research including phenomenology, ethnography, symbolic interactionism and hermeneutics (Alston & Bowles, 2003; Braun & Clarke, 2013). Within a qualitative research paradigm, the influence of the researcher is openly acknowledged, with some suggesting that the researcher themselves is the instrument (Minichiello et al., 2008). In some cases, the researcher is considered to hold ‘insider status’ and share a group identity with their participants (Braun & Clarke, 2013). Such an insider perspective can be considered a strength, aiding interpretation of the data. In such situations, however, the researcher is expected to acknowledge their own values and bias in relation to the research.

An important strength of a qualitative approach is that it is possible to explore meaning from the perspective of the participants themselves, providing rich and dense data to better understand the phenomenon under investigation. A drawback of this is that sample sizes tend to be small due to the time and involvement required from participants, and therefore may not adequately represent the range of beliefs or ways of thinking within a study population (Johnson & Onwuegbuzie, 2004). Within qualitative research the concept of ‘saturation’ is referred to, where additional data is considered to provide no new information (Braun & Clarke, 2013). However, even after reaching
saturation, it may be difficult to generalise findings to other settings or draw comparisons with other studies. Despite these limitations, qualitative research is considered to provide rich data and insights which cannot be obtained by a quantitative approach.

3.2.3 Mixed methods research. A mixed methodology may be the most effective strategy for research questions with a range of objectives or considerations, (Darlington & Scott, 2002; Punch, 2000). Mixed methods research has been defined by Moran-Ellis, Alexander, Cronin et al (2006) as “the use of two or more methods that draw on different meta-theoretical assumptions” (p.46). Mixed methods research builds upon the strengths of quantitative and qualitative approaches, by triangulating or seeking convergence across the different methods (Cresswell, 2009; Johnson & Onwuegbuzie, 2004). Rather than viewing quantitative and qualitative research as “incompatible opposites” it can be argued that these different approaches, when combined, complement each other and add depth to the research (Alston & Bowles, 2003; Foss & Ellefsen, 2002; Johnson & Onwuegbuzie, 2004).

A mixed methods approach may raise epistemological questions about how different paradigms can co-exist in the one study (Foss & Ellefsen, 2002). However, for a growing number of proponents of mixed methods research, this issue is not a problem (Johnson & Onwuegbuzie, 2004). One epistemological position described as spanning both quantitative and qualitative research is critical realism (McEvoy & Richards, 2006). According to McEvoy and Richards (2006) a critical realist perspective allows for a point of reference from which theories can be tested; real phenomena do exist. However, they argue, apprehending this reality completely is impossible due to the impact of our perceptions. The goal of research therefore is to “develop deeper levels of explanation and understanding” of existing phenomena (McEvoy & Richards, 2006, p. 78).
Like McEvoy and Richards (2006), Foss and Ellefsen (2002) have also adopted an epistemological stance which embraces both quantitative and qualitative approaches. These authors argue for a comprehensive and new epistemological position which acknowledges that “within a complex and differentiated reality…different and various types of knowledge” are required (p.244). Qualitative and quantitative approaches are therefore seen to provide different, but complementary types of knowledge with “equal importance and weight”. The arguments of these two groups of authors demonstrate that epistemological issues do not need to be perceived as a barrier to mixed methods research; moreover, such research may make a significant contribution to the research field because of this broader perspective.

### 3.2.4 Rationale for methodology

Methodological approaches among the studies reviewed in Chapter Two varied. The 19 quantitative studies incorporated measures pertaining to life satisfaction, quality of life, depression, spirituality, and resilience. Statistical analyses demonstrated positive relationships between spirituality and quality of life, life satisfaction, and emotional and physical adjustment. A variety of measures were used by researchers to test these relationships. In contrast, the 13 qualitative studies considered spirituality within broad contexts of meaning making, hope, and posttraumatic growth. Semi-structured interviewing was the technique most frequently utilised. The term “spirituality” was not used in all cases by the researchers, though direct reference to the term was sometimes made by the participants themselves.

These contrasting approaches within the existing literature illustrate how quantitative and qualitative methodologies, together with their associated epistemologies, can approach the same topic area very differently. Although different findings were obtained by quantitative and qualitative studies within the scoping review, it was clear from both that spirituality and its related meaning-making
constructs are important to the area of SCI rehabilitation and worthy of further exploration. The different findings of the studies provided complementary evidence of the important role such factors can play, both for individuals with SCI and their family members.

A mixed methods approach was selected for this project because it would provide insight into the complex concept of spirituality. Quantitative data would potentially provide useful information regarding the variables of spirituality and resilience, which have been widely measured within the disability field. Specifically, a quantitative approach would test the relationship between spirituality, resilience and a range of adjustment outcomes. The qualitative aspects of the study would provide rich detail regarding the meaning of these concepts for different individuals and families, and within different cultural traditions and faiths, providing an avenue to further explore the concepts measured through quantitative methods (Whitley, 2007). How spirituality might contribute towards resilience after SCI is a question which can be addressed using quantitative or qualitative methods. A mixed method approach arguably enhances both methods, and provides a more robust understanding of the complex questions such as those raised in this study.

3.3 Research Design

The overall research design of this study was observational, prospective and longitudinal. Three key elements of this study’s design were: i) the use of concurrent triangulation, ii) the adoption of a longitudinal approach to study the changes in spirituality over time, and iii) the incorporation of a range of perspectives, that of individuals with SCI, family members and staff.

3.3.1 Concurrent triangulation. Among the many different approaches within a mixed methods framework, the concurrent triangulation design outlined by Creswell
(2009) was deemed best suited to the approach used within this study. In the concurrent triangulation design the researcher collects both quantitative and qualitative data concurrently, and then compares the results. Such an approach allows each component of the study to exist independently, so that comparisons can be made with other like studies. For instance, the quantitative component of a study can be compared with other quantitative studies that have used similar variables or measures. However, the benefits of collecting both quantitative and qualitative data mean that results from one component can also provide further explanation and understanding regarding other components in the study. In this study the qualitative approach was used to “illuminate and explore” the findings of the quantitative results (Whitley, 2007). As already discussed, such level of explanation and understanding is crucial in an area as complex as spirituality.

3.3.2 Longitudinal. In addition to the richness provided by a mixed methods approach, researchers have advocated for longitudinal studies to investigate the concept of spirituality over time (Matheis et al., 2006). A longitudinal approach is particularly important after a traumatic injury such as SCI. Initially the individual with the injury may spend many months in hospital, and prognosis is often unknown for a significant period of time. Adjustment studies have demonstrated that the period leading up to discharge from hospital is associated with high levels of depression and anxiety among individuals with SCI (Kennedy & Rogers, 2000). Furthermore, the first year to two years post injury can be pivotal in long term coping and well-being (Bonanno et al., 2012; Middleton et al., 2014). For this reason, this study incorporated a longitudinal element, to capture some of the changes for families during the transition from hospital to discharge into the community.
3.3.3 **A range of perspectives.** Lastly, in this particular study, the perspectives of individuals with SCI, family members, and health professionals were deemed significant and worthy of investigation. This study sought to capture these different perspectives to provide a rich and in-depth picture of how spirituality and its contribution to family resilience is understood within spinal injury rehabilitation.

To comprehensively investigate the contribution of spirituality towards resilience after SCI a mixed methods design incorporating both cross-sectional and longitudinal components was selected as most appropriate, to address the multifaceted nature of the phenomena being investigated. The project was exploratory in nature, due to the very limited literature which currently exists in the field, and consisted of three concurrent components. Each component addressed a main objective of the study:

*Administered surveys (C1): Quantitative, cross-sectional component.* The first component of the study drew upon quantitative techniques to test whether spirituality was associated with increased resilience among families affected by SCI. Furthermore, how the relationship between spirituality and resilience might contribute towards other outcomes within the family was also considered. To test these relationships, validated measures of spirituality, resilience, emotional well-being, life satisfaction, and functional independence were administered, and statistical analysis employed.

*Family interviews (C2): Qualitative, longitudinal component.* To explore how interactions between the injured individual and their family members foster spirituality within the family over time, encompassing a sense of meaning, hope and purpose, the second component of the study consisted of two qualitative, semi-structured, in-depth interviews. These interviews were conducted with family dyads (the individual with SCI and a close and supportive family member) and were held approximately six months apart. This interval between interviews was selected as a realistic timeframe.
within the time constraints of a doctoral project, while still being a long enough period to allow fluctuations in participant adjustment and outlook to be captured. It was hoped that after six months the majority of participants would be discharged, thereby providing additional insights regarding family adjustment during the process of transition from inpatient facility to the community.

**Staff focus groups (C3): Qualitative, cross-sectional component.** To explore the understandings of spirituality held by the rehabilitation team, and to consider how the role of spirituality could be enhanced for spinal clients and their family members after SCI, the third component of the project utilised qualitative research methods and consisted of two staff focus groups with health professionals (HPs).

### 3.4 Research Context

Study participants for the first two components of this study (C1, C2) were clients of Royal Rehab, a specialist rehabilitation inpatient facility in Sydney NSW. Royal Rehab has both an inpatient unit (Spinal Injury Unit, SIU) and a community spinal injury service (NSW Spinal Outreach Service, SOS). Typically, individuals who have sustained a SCI are transferred to the SIU, Royal Rehab after a period of two to three months of acute care at Royal North Shore Hospital. Once discharged from the SIU, the community team (SOS) provide ongoing review of the individual for up to 12 months. SOS also accepts clients who have been readmitted to spinal services after several years living in the community.

Study participants for the third component of the study (C3) were members of the multidisciplinary team at the SIU, Royal Rehab. This multidisciplinary team consists of health professionals from a range of disciplines including Medicine, Nursing, Physiotherapy, Occupational Therapy, Psychology, Social Work and
Recreational Therapy. The team works with inpatients and their family members while they undertake their rehabilitation program at the SIU.

3.5 Ethical Considerations

Ethical approval for this study was obtained from Griffith University Human Research Ethics Committee (HREC) and the Northern Sydney Local Health District (NSLHD) HREC. The project was assessed to be low/ negligible risk by NSLHD HREC, and was therefore exempt from full HREC review. The project was granted ethical and scientific approval on 6th November 2013. Site specific approval was then obtained from the SIU and SOS via Royal Rehab. Conditional approval from Griffith University was also obtained in November 2013, and full approval was obtained on 10th March 2014. The following considerations were addressed during the process of obtaining ethical approval.

3.5.1 Consultation with the participant population. Although no formal consultation occurred with the participant population regarding the development of this study, views of the participant population were obtained in two previous studies (Simpson & Jones, 2013a, 2013b). These two projects investigated resilience among family members of individuals with SCI. In one of the projects (Simpson & Jones, 2013a), family members completed surveys, attended focus groups, and participated in a trial program titled “Strength 2 Strength”, which aims to build resilience among family members after spinal cord injury or traumatic injury. The findings of that project contributed to the development of the current study. The second project surveyed 61 family members, after a relative had sustained either SCI or traumatic brain injury, and found that family members with higher resilience scores used different carer management strategies to those with lower resilience scores.
In addition to these previous projects, treating clinicians provided valuable input regarding the current study. The project was presented for feedback to the Unit Management Team on the Spinal Injuries Unit (SIU), and to the Social Work team leaders of both SIU and the Spinal Outreach Service (SOS). Feedback was also sought from Social Workers across all units at Royal Rehab, and from spinal Social Workers across NSW at their bimonthly meetings. Positive feedback was received during all of these consultations.

3.5.2 Minimising the impact of the unequal relationship between researcher and participants. It was anticipated that ethical issues may arise due to the researcher’s dual roles as clinical Social Worker at the SIU and study investigator. For this reason, the voluntary nature of participation was carefully explained to all potential participants, and they were provided with an information sheet before consent was obtained. These information sheets were provided by their treating Social Worker at the SIU or SOS. An initial invitation letter was sent from the Medical Director at the SIU or the Manager of SOS.

No undue pressure was applied to clients to agree to participate. Prospective participants were reassured that participation was purely voluntary and that declining to participate or subsequent withdrawal would not jeopardise any services being provided by the Social Work team or the SIU. After they agreed to be involved in the project, participants were once again reminded that they could withdraw at any time during their involvement in the project. The staff at the SIU were invited to participate in the focus groups by their team leaders, and contacted the researcher directly to indicate their willingness to be involved.

3.5.3 Privacy and confidentiality. All participants were informed that the data they provided would be confidential, and none of their personal details would be identifiable.
Pseudonyms were used in all reporting of data. Confidentiality was protected by the researcher ensuring that all material (surveys, recordings, session notes) were coded with ID numbers. Interviews were transcribed at the first opportunity available using a password protected computer. The personal details for participants and the ID number to identify participants were stored in separate files on a password protected computer at Royal Rehab. Study materials were stored in a locked filing cabinet that could only be accessed by the researcher and other associated investigators.

3.5.4 Risk of harm for study participants. It was not anticipated that there would be any risk of harm for participants in this study. Participants were reassured that if they experienced any distress during either the interviews or when completing the measures, they were free to stop at any stage. If participants did become distressed, they were provided with initial support by the researcher who is a qualified and experienced Social Worker in the field of SCI. If they required further support, counselling was available from their Social Worker or the clinical Psychologist at the SIU. The possibility that this need might arise was discussed with the two clinical Psychologists at the SIU, and they confirmed their availability in such circumstances. However, this offer was not taken up by participants during the project. For clients of SOS supportive counselling was available from their Social Worker, who was independent of the researcher.

To minimise any potential financial burden upon participants, travel costs were kept to a minimum by the use of phone contact for administering surveys, and the provision of prepaid reply envelopes. Follow-up interviews were conducted at a time and location convenient to the participants. In some cases, this involved the researcher travelling to a hospital nearby the participant’s residence. The rest of this chapter will consider the sampling strategy, data collection, procedures, and data analysis for each of the components of the research.
3.6 Research Methods for Component 1 (C1): Administered Surveys

3.6.1 Sampling strategy (C1). Sampling techniques used within social research include random, convenience, consecutive, snowball, and purposive sampling (Alston & Bowles, 2003). Different techniques are suited to different contexts, methodologies, and research questions. Random sampling is a form of probability sampling where each unit or participant has an equal chance of selection. Convenience, consecutive, snowball and purposive sampling are all types of non-probability sampling (Lund Research Ltd, 2012).

Convenience sampling refers to the process of selecting a sample because of its accessibility to the researcher. It is a sampling technique utilised within both qualitative and quantitative research (Braun & Clarke, 2013). Consecutive sampling, though similar to convenience sampling, is stronger because it seeks to recruit all eligible participants as part of the sample (Flinders University, 2013).

Given the observational nature of the study, a consecutive sample was recruited in the quantitative component (C1). This was deemed to be the most efficient and rigorous sampling approach available within the context of this project. All eligible clients, admitted to the two participating services (SIU, SOS) during the course of the study, were invited to participate. Those recruited from SOS included both new admissions who had been discharged from the SIU, as well as readmissions from the community.

The sample size for the quantitative component of the study was chosen due to the low prevalence of SCI in the community (Access Economics, 2009), the limited time available for this doctoral study, and the exploratory nature of the regression analyses; no previous studies in the field of SCI have investigated the specific association between variables that were tested in this study. Fifty individuals with SCI
and 50 of their family members were recruited from both the SIU (inpatient program) and SOS (community program). Although some dyads also participated in the family interviews, there was no expectation that potential participants would be involved in both components.

For both the quantitative component and the family interviews, each individual with SCI was invited to nominate a family member who would be willing to participate with them in the research. Eligible participants met the following inclusion criteria: i) adults (aged 18 years and over), ii) individuals with traumatic or non-traumatic SCIs (or their family members), and iii) able to speak English fluently. Potential participants were excluded if they had been diagnosed with a mental illness or intellectual disability, or were unable to nominate a family member who could be included in the study (due to family members being unavailable, or unwilling to participate). Potential participants diagnosed with a mental illness were excluded due to the increased likelihood they may find some of the survey questions distressing.

3.6.2 Data collection and measures (C1). Demographic data protocols were administered to all participants in C1 and C2, including items relating to participants’ age, time since injury, level of injury, education level and religious beliefs (see Appendix B). Demographic data regarding non-consenting clients was also collected. A number of validated self-report measures were administered to participants and included measurement of the two predictor variables, spirituality and resilience and a range of outcome variables, including emotional well-being, life satisfaction and functional ability (see Appendix B). Descriptions of each measure are included below:
**Predictor variables**

*Spirituality.* The Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale (FACIT-Sp) (Peterman et al., 2002) is a reliable (Cronbach’s α = .81-.88) and valid 12 item scale which assesses spirituality across a range of religious traditions, and is suitable for participants who identify as religious as well as those who do not. Possible scores range from 1-48, with a mean score among cancer patients recorded as 38.5 (SD 8.1) (Peterman et al., 2002). The scale is specifically designed for use in health, and although it has been widely used within the field of chronic illness, and particularly oncology, it also has been validated for use in the context of SCI (Forchheimer & Tate, 2007). The FACIT-Sp contains two subscales, Meaning and Faith. An expanded version of the FACIT-Sp, the FACIT-Sp-Ex has been developed, and consists of 23 items. This expanded version includes additional questions focusing upon relationships with others, including forgiveness, thankfulness, and compassion.

The FACIT-Sp-Ex was chosen for the quantitative component of this study because it has been used in other SCI research (Forchheimer & Tate, 2007; Siddall et al., 2016), it does not assume a God-centred or monotheistic world view, acknowledges a range of sources of spirituality, and includes a relational component. This measure seemed most appropriate in a context such as Australia, where a range of cultural beliefs are represented in the general population. The total scores (FACIT-Sp-Ex, FACIT-Sp) and the two subscales scores were employed in this study.

Permission from the author of the scale, David Cella, was sought to make two slight alterations to the FACIT-Sp-Ex. First, the word “illness” was replaced with “spinal cord injury” throughout the measure. This alteration was also made by Forchheimer and Tate (2007) in their paper of spirituality after SCI. Second, on the version of the scale administered to family members, item 12 was changed from “My
spinal cord injury has strengthened my faith or spiritual beliefs” to “My relative’s spinal
cord injury has strengthened my faith or spiritual beliefs”. Permission for both changes
was granted.

**Resilience.** Two measures of resilience were included in this study, the Connor
Davidson Resilience Scale (CD-RISC) (Connor & Davidson, 2003) and the Resilience
Scale (Wagnild & Young, 1993). The psychometric properties of these two measures
were rated highly by Windle, Bennett, and Noyes (2011) in their review of resilience
measures. The CDRS was used as the primary measure of resilience in this study as it
was rated slightly higher than the Resilience Scale by Windle et al (2011). The
Resilience Scale, however, was also administered to participants due to its inclusion of
“levels of resilience” used for group analyses.

The Connor Davidson Resilience Scale (CD-RISC) (Connor & Davidson, 2003)
measures the resilience of an individual and comprises five factors, including 1)
personal competence, high standards and tenacity, 2) trust in one’s instincts, tolerance
of negative affect, and strengthening effects of stress, 3) positive acceptance of change
and secure relationships, 4) control, and 5) spiritual influences. The measure consists of
25 items using a 5-point Likert scale ranging from 0 (not true at all) to 4 (true nearly all
the time). Evidence for the scale’s reliability and validity has been provided for adults in
the general population (Cronbach’s α =0.89), with the mean total score calculated as
80.4 (SD 12.8) (Connor & Davidson, 2003). The CD-RISC was included in this study
as it specifically incorporates one item related to spirituality: “When there are no clear
solutions to my problems, sometimes fate or God can help”. Furthermore, it has been
used in other resilience research within the field of SCI (B. White et al., 2010). Total
scores on the CD-RISC were employed in this study.
The Resilience Scale (Wagnild & Young, 1993) is a 25-item measure that evaluates five interrelated components of resilience, namely equanimity, perseverance, self-reliance, meaningfulness, and existential aloneness. Participants rate their response to items (e.g., ‘When I make plans I follow through with them’) on a 7-point Likert scale, anchored at the two poles (‘disagree’ and ‘agree’). Scores range from 25-175, with higher scores representing higher resilience. Good reliability (Cronbach’s α =.91) and concurrent validity have been reported (Wagnild & Young, 1993). The Resilience Scale has been used in other research with family members of relatives with SCI (Simpson & Jones, 2013b). Levels of resilience and their corresponding resilience scores are outlined in the Resilience Scale User’s Guide (Wagnild, 2009): very low (25-100), low (101-115), moderately low (116-130), moderate (131-144), moderately high (145-160) and high (161-170).

**Outcome variables**

*Emotional Well-Being.* Three measures were included to measure emotional well-being. The Positive and Negative Affect Scales (Watson & Clark, 1994) is a reliable and valid 20-item measure of emotional well-being that has been widely used across a range of clinical populations, and with the general population as well. Participants rate a series of 20 adjectives (10 Positive affect, 10 Negative affect) on a 5-point Likert scale (“very slightly or not at all” to “extremely”) producing two scores that range from 10-50, with higher scores representing greater positive or negative affect. The scales are independent (inter-correlation -.09) and have good internal consistency (Cronbach’s α of .86 and .87 for Positive and Negative Scales respectively). Scale norms have been reported for Australian adult men (Positive affect, M=32.6, SD=5.9; Negative affect, M=16.3, SD=4.7) and Australian adult women (Positive affect, M=30.7, SD=7.1; Negative affect, M=15.8, SD=4.9). These values were calculated on
the basis of participants affect from the “past week”, whereas in the current study, scores were based on affect from the “past few weeks”, so direct comparison of scores with an Australian population is not possible. According to the scale authors, affect scores over longer periods of time are likely to be slightly higher, due to the probability that participants will experience a greater amount of a particular affect over a longer time period (Watson & Clark, 1994).

The Depression and Anxiety Stress Scales (DASS-42) (Lovibond & Lovibond, 1995) is a valid and reliable 42-item questionnaire which includes three self-report scales designed to measure the negative emotional states of depression, anxiety and stress (Cronbach’s α = 0.96, 0.89, and 0.93 for Depression, Anxiety, and Stress, respectively, within a clinical sample) (Brown, Chorpita, Korotitsch, & Barlow, 1997). Each of the three scales contains 14 items. The Depression scale assesses dysphoria, hopelessness, devaluation of life, self-deprecation, lack of interest/involvement, anhedonia, and inertia. The Anxiety scale assesses autonomic arousal, skeletal muscle effects, situational anxiety, and subjective experience of anxious affect. The Stress scale assesses difficulty relaxing, nervous arousal, and being easily upset/agitated, irritable/over-reactive and impatience. Respondents are asked to use 4-point severity/frequency scales to rate the extent to which they have experienced each state over the past week. The Manual for the depression anxiety stress scores (Lovibond & Lovibond, 1995) outlines clinical severity levels for each scale, generated from normative data: Depression – Normal (0-9), Mild (10-13), Moderate (14-20), Severe (21-27), Extremely Severe (28+); Anxiety – Normal (0-7), Mild (8-9), Moderate (10-14), Severe (15-19), Extremely Severe (20+); Stress – Normal (0-14), Mild (15-18), Moderate (19-25), Severe (26-33), Extremely Severe (34+). Intercorrelations between
the scales have been reported (Depression-Anxiety=0.51, Anxiety-Stress=0.65, Depression-Stress=0.64) (Brown et al., 1997).

The brief 21-item version of the DASS-42 (DASS-21) has been used as a measure in studies with individuals with SCI (Mitchell, Burns, & Dorstyn, 2008) and was the version used for this study. Raw scores on the DASS-21 are doubled, so that clinical severity is accurately represented on the bands outlined above. The DASS-21 was included as a measure in this study due to its measure of all three states; depression, anxiety and stress, in relation to spirituality and resilience.

Life Satisfaction. The association between spirituality and life satisfaction (Brillhart, 2005; Chlan et al., 2011; Kortte et al., 2010; Riley et al., 1998; Tate & Forchheimer, 2002; B. White et al., 2010) is well documented in the literature. The Satisfaction with Life Scale (SWLS) (Pavot & Diener, 1993) is a valid and reliable measure of life satisfaction which has been widely used in SCI research, as identified in the Scoping Review (Chapter Two). Scale norms within a SCI sample have been reported (Dowler, Richards, Putze, Gordon, & Tate, 2001), ranging from 17.33 (SD 7.78) to 22.34 (SD 7.10) according to injury duration (one year to >20 years, respectively). It is a five-item global quality of life measure assessing life satisfaction across many domains using the participant's own criteria. Items are rated on a 7-point Likert scale ranging from 1 (strongly disagree) to 7 (strongly agree). Scores range from 5 to 35, with higher scores associated with higher levels of life satisfaction. Validity has been established by comparisons with other measures of well-being (moderate to strong correlations). Reliability (test-retest reliability 0.82) and internal consistency (0.87) have also been demonstrated (Diener et al., 1985).

Functional Independence. Functional Independence Measure (FIM) (Uniform Data System for Medical Rehabilitation, 1997) is a widely used measure of functional
independence in inpatient rehabilitation. The validity and reliability of FIM has been
demonstrated among SCI inpatients (Hamilton, Granger, Sherwin, Zielezny, &
Tashman, 1987). The FIM is an 18-item scale with scores for each item ranging from 1
(total assist performing less than 25% of tasks) to 7 (complete independence). The FIM
includes both motor and cognitive subscales, with motor items pertaining to such
activities as self-care and mobility, and cognitive items gauging performance on
communication and social cognition. Scores are routinely collected at the SIU by the
multidisciplinary team and are available for research and clinical purposes. The most
recent FIM score was obtained for each participant from their Medical Record.

3.6.3 Procedures (C1). Potential participants were provided with brief information
about the project in the form of a letter from the Medical Director of the SIU or the
Manager of SOS, inviting them to participate. In the SIU, all eligible clients were
provided with the letter by their treating Social Worker. If clients expressed a verbal
interest in participating, they were provided with more detailed ‘participant information
and consent forms’ (PISCF) by the researcher (see Appendix B) and given an
opportunity to ask any questions. All SOS clients who met the eligibility criteria
received their letter of invitation by mail. The researcher contacted them by telephone
one week later to follow-up the invitation. If participants did not wish to proceed or
were still unsure, they were thanked for considering the project and no further
discussion regarding the project took place.

Written consent was obtained from participants where possible. If a client was
unable to sign due to functional limitations, verbal consent was obtained in the presence
of an independent witness. Verbal consent was also obtained when surveys were
administered by phone. In the case of the individuals with SCI, consent was obtained to
access the participant’s medical record so that information regarding injury severity could be retrieved. All data was collected by the researcher.

On most occasions, surveys in the quantitative component of the study were administered either in person (SIU) or by phone (SOS). At the SIU, the researcher met with the individual with SCI and their family member in the participant’s hospital room. The researcher was available to provide assistance to participants as they completed the surveys, such as in those instances where an individual with SCI did not have adequate hand function to complete the surveys manually. In these instances, the researcher read out each question and marked the participant’s answers. The surveys took approximately 20 minutes to complete. If family members were not available at the time of the meeting, they were provided with the surveys and asked to complete them in their own time. The researcher then collected the surveys from the family members within the following week.

The majority of SOS participants completed the surveys with the researcher over the phone. In a few instances participants completed the surveys and returned them to the researcher in person or by post (in a provided prepaid reply envelope). When administered by phone, the surveys were mailed to the participant a week before the interview, so that the participant had the opportunity to review the measures prior to the phone call. FIM data and injury details for both the SIU and SOS participants were collected from the medical record.

3.6.4 Data analysis (C1). In the quantitative component, data collected from the administration of the surveys was entered using a statistical package (SPSS for Windows version 24). The following steps were taken to conduct the analyses.

1) Descriptive statistics were generated for all the key variables. Prior to conducting the main analyses, the scales producing the predictor and outcome
variables were tested for normality, linearity, and the presence of outliers. Variables that were non-normally distributed underwent a square root transformation.

2) Correlation tests (Pearson product-moment) were conducted to examine the strength of association among the study variables, with the strength of the correlation coefficient classified using the effect sizes provided by Cohen (1992).

3) Between-groups analyses were employed to test for differences on the key outcome variables between the participants with SCI and their family members. Where necessary, a Bonferroni correction was applied to the significance level to control for Type 1 error arising from multiple tests.

4) Finally, a series of multivariate regressions employing a forward step-wise procedure were conducted. These tested the relationship between the predictor variables of spirituality and resilience and the outcome variables.

3.7 Research Methods for Component 2 (C2): Family Interviews

3.7.1 Sampling strategy (C2). Carey (2012) has suggested that a typical sample size for a small qualitative study be anywhere from four to 18 participants. He emphasised that the quality of the data, rather than the quantity, remains the most important factor. The number of participants recruited for C2 was based on the following study-specific factors: (i) the window for recruitment to the study; (ii) the need to allow for 6 months before the second interview; and, (iii) the standard flow of new admissions to the unit who would meet the study inclusion/exclusion criteria and agree to participate (so factoring in a certain percentage of refusals).

Given the relatively low incidence of SCI, and the usual flow of admissions to the SIU, 10 dyads (10 individuals with SCI, 10 family members) was judged to be a
feasible number to recruit within the study time frame, and appropriate within a qualitative study (Braun & Clarke, 2013; Carey, 2012). The individuals with SCI were in the process of receiving inpatient rehabilitation at Royal Rehab at the time of being interviewed. Unlike C1, none of the sample were recruited from SOS, as it was intended that the longitudinal aspect of C2 would capture the transition from inpatient rehabilitation to the community. The same eligibility criteria as C1 was used for C2, however the criteria of being able to speak English fluently was not as strictly adhered to. This flexibility enabled the views of participants from different cultural backgrounds to be represented.

Purposive sampling is often used within qualitative research, and is aimed at recruiting a sample which will provide information-rich data (Braun & Clarke, 2013). One type of purposive sampling is maximum variation, designed to collect a wide range of perspectives (Lund Research Ltd, 2012). Maximum variation was adopted in this study to ensure a wide range of family backgrounds and faith traditions/perspectives were represented. Families from a range of religious beliefs were selected, including several who identified as non-religious. The researcher ensured that different family relationships were also represented among the dyads (i.e. spouse, parent, adult child).

3.7.2 Data collection (C2). Data collection for the family interviews employed a semi-structured interview schedule, consisting of approximately five to six key questions which were then explored with each dyad. These questions were piloted with clients and family members at the SIU prior to the commencement of the study. All family interviews were joint interviews, held with both the individual with SCI and their chosen family member present. Each interview lasted between 1 and 1.5 hours.

In the first interview, participants were invited to describe their relationship, how their relationship had been affected by the SCI and what they understood by the
term ‘spirituality’. A broad definition of spirituality, encompassing elements of meaning, hope and purpose, was provided during this first interview. This was incorporated to encourage participants to further reflect upon ways spirituality might be relevant in their lives. Both members of the dyad were then invited to consider in what ways, if any, they had found meaning and purpose (either individually or together) following the SCI. Participants were also invited to reflect upon strengths they saw in one another, and the hope they held both as individuals and as a family (see Appendix C for C2 interview protocols).

In the follow-up interviews six months later, participants were asked to again reflect upon their relationship, and any meaning or purpose they had drawn from their situation since the last interview. Data collected during the first interviews was used to refine the questions asked during the second interviews. As with the first interview, participants were invited to reflect upon strengths they had noticed in themselves or their family member, and hopes for the future. An additional aspect of the second interview was a question aimed at exploring any strength they had drawn from either God, their perspective on life, or other sources of spirituality identified in the first interview. As the nature of this question was dependent upon content from the first interview, it varied with each dyad. If participants indicated ways they had found meaning they were invited to expand upon this, and comment whether spirituality had played a role, and if so, how.

Interviews were audio-recorded with the consent of participants, and were transcribed by the researcher. To increase the validity of the findings and improve the rigour of the study, a copy of the interview transcript was shared with participants after the interviews. They were invited with an opportunity to make any adjustments or changes. This process was undertaken after both interviews with each family.
3.7.3 **Procedures (C2).** Participants were advised that two interviews would be conducted, the first during their rehabilitation program at the SIU (approximately 3-4 months after injury), and the second once they returned to the community or six months after the first interview (whichever occurred first). The first interview was either held in the hospital room of the individual with SCI or an office at the SIU. If discharged, the follow-up interview was either held at the SIU (in conjunction with an outpatient appointment), held at the family’s home, or conducted by phone. The two interviews were held within six to eight months of each other to reduce attrition rates and to ensure the study was manageable within the proposed timeframes.

3.7.4 **Data analysis (C2).** A thematic analysis, as outlined by Braun and Clarke (2006), was conducted for data collected in the qualitative components of the study. Thematic analysis is a widely-used method used to identify, analyse and report patterns within qualitative data. Themes are identified according to the pattern or meaning within the data set. In this study an inductive thematic analysis (as opposed to a theoretical thematic analysis) was adopted. Inductive analysis is “a process of coding the data without trying to fit it into a pre-existing coding frame or the researcher’s analytic preconceptions” (Braun & Clarke, 2006, pp. 79-83).

Braun and Clarke (2006) describe six phases of thematic analysis: familiarisation with the data; generating initial codes; searching for themes; reviewing themes; defining and naming themes; and producing the report. The first phase was achieved through the transcription of the data. How the next four phases were addressed is outlined below.

During the second phase, as outlined by Braun and Clarke (2006), preliminary codes were generated from the transcripts using line-by-line analysis. Terms, phrases or descriptions which recurred on a regular basis were flagged. These initial codes were
considered by the researcher to represent key findings from the study, and to hold significance as they related to understanding spirituality and its relationship with perceived strengths within the family (Carey, 2012). A coding system was developed, and adjusted during the coding process. This resulted in some codes being merged with others. Qualitative data analysis software (NVivo 10 for Windows) was employed to assist with this analysis.

To check the validity of the coding, a sample of coding was reviewed by an independent coder (PD) and where discrepancies arose these were discussed and adjustments made. Coding summaries were reported at regular intervals, and provided to all three supervisors (PD, LB, GS) for feedback and checking. These processes were aimed to enhance the rigour of the study, and ensure the reported findings represented the participant accounts as closely as possible.

Patterns or trends among the codes were noted, and later developed into potential themes (Bazeley, 2013), the third phase proposed by Braun and Clarke (2006). According to Braun and Clarke (2006) themes represent “some level of patterned response or meaning within the data set” (p.82). These potential themes were then applied to relevant excerpts of the data, to test their validity.

Themes were reviewed and refined, and core themes and subthemes delineated, the fourth phase outlined by Braun and Clarke (2006). Interactions between the codes and themes were considered, and a ‘coordinated network of understanding’ developed (Bazeley, 2013, p. 193). Interviews were analysed successively and data from a new interview was compared with data from previous interviews.

The fifth phase involved naming and defining themes, and then comparing codes and themes generated from initial interviews with codes and themes generated from follow-up interviews. This was a critical component of the longitudinal analysis, and
was conducted on a case by case basis, so that all contextual information could be taken into account. This information was then tabulated, the early stages of the sixth phase outlined by Braun and Clarke (2006).

3.8  **Research Methods for Component 3 (C3): Staff Focus Groups**

3.8.1  **Sampling strategy (C3).** Like the family interviews, to ensure a range of disciplinary backgrounds was represented, the purposive sampling strategy of maximum variation (Lund Research Ltd, 2012) was used to recruit Health Professionals (HPs) to the staff focus groups. Two focus groups were held in the Spinal Injuries Unit (SIU), with each group consisting of six HPs. Between five to seven participants is recognised in the research literature as “standard” for conducting focus groups (Minichiello, Aroni & Hays, 2008), and was also a realistic number of participants to recruit from among the staff at the SIU. Eligible participants were members of the multidisciplinary team at the SIU who had worked in the area of SCI for at least 12 months.

3.8.2  **Data collection (C3)**

Each focus group consisted of a semi-structured interview. All participating HPs completed demographic data protocols which included items on their age, religious beliefs, years of education, qualifications, and number of years working in SCI (see Appendix D). Both staff focus groups were audio recorded and transcribed by the researcher, and all participants were provided with a copy of the transcript for feedback and comment.

A focus group interview protocol was developed. The questions for this protocol were generated through expert consultation between the researcher and the three supervisors (PD, LB, GS). In the first focus group participants were invited to respond to five questions: i) how would you describe spirituality? ii) how have you seen spirituality make a difference among spinal clients and their families during
rehabilitation? (a broad definition of spirituality was provided to participants to assist
them to answer this question), iii) do you think spirituality has a role in spinal
rehabilitation, and if so, what do you think its role is? iv) how is this role incorporated at
present? v) what do you think are some ways that spirituality could be enhanced during
inpatient rehabilitation? (see Appendix D for focus group interview protocols).

The second focus group was held just over seven months after the first. By this
time, initial interviews with eight of the ten dyads from C2 had been held, and early
data analysis had commenced (initial coding). To enhance the process of reflexivity, it
was considered important by the researcher to share some of these findings with the
HPs. It was hoped that inclusion of such data would enable the HPs to reflect upon these
findings, and share more specific insights with relation to their own practice.
Consequently, an additional section was added to the second focus group interview
protocol. In this section, key findings from C2 were shared with participants and they
were invited to comment upon this data. All other questions in the second focus group
interview protocol remained the same as for the first. Both staff focus groups were
audio recorded and transcribed.

3.8.3 Procedures (C3). The two staff focus groups were conducted at the SIU with
HPs from a range of disciplines. Each disciplinary team leader at the SIU was provided
with a letter of invitation to nominate representatives from their team. If HPs were
interested in participating they were then approached by the researcher, who provided
them with further information and consent forms. The focus groups were held at the
SIU in a common meeting room. The duration of each focus group was approximately
one hour.

3.8.4 Data analysis (C3). As with C2, a thematic analysis was undertaken with the
focus group data in C3 (Braun & Clarke, 2006). Preliminary codes were generated for
the first focus group, and then added to after the second. NVivo software was utilised again, to provide assistance with the management of codes. From the initial codes, themes and patterns were identified in relation to the perceived role and value of spirituality by HPs. Themes which had emerged during the first focus group were raised for further discussion in the second group. These included those pertaining to the perceived role of spirituality in clinical practice, HPs comfort and knowledge around the topic of spirituality, and identified challenges in incorporating it in rehabilitation.

During the process of analysing focus group data, regular feedback on coding and the generation of themes was provided by all three supervisors. Implications for spinal injury rehabilitation were identified from this focus group data.

3.9 Triangulation of Data Across All Study Components

To complete the data analysis of the mixed methods study, the findings of all three components of the research were considered together. Recurring patterns, themes, and key points of interests were examined and documented. Quantitative data was reviewed in light of the findings from the two qualitative components of the study, to consider whether such data provided further explanation and understanding. Likewise, the qualitative data was re-examined within the context of the quantitative results. Implications for rehabilitation practice were drawn from data provided by individuals with SCI and their family members, and viewed in light of current practice, as described by staff in the focus groups.

3.10 Summary of Chapter

This Methods chapter has outlined the rationale for a mixed methods approach, and provided information regarding the sampling strategy, data collection, procedures and data analysis for all three components of the study. Ethical considerations of the study have also been summarised. The next three chapters will present the results
pertaining to the three components of the research, beginning with the quantitative results.
Chapter Four: Results – Quantitative Component (C1)

Administered surveys

4.1 Introduction

In the quantitative component of the study (C1), validated measures were administered to individuals with SCI and their family members to investigate the relationship between the predictor variables of spirituality and resilience, and outcome variables pertaining to emotional well-being, life satisfaction and functional independence. The same measures were administered only once to each participant (both the individual with SCI and the family members). Measures were completed independently by each participant, rather than together as a dyad.

The following investigations were conducted and will be reported here. First, descriptive data on the sample and measures was generated. Following this, an item by item analysis of the FACIT-Sp-Ex was conducted. Differences between the individual with SCI and the family member, males and females, those with religious affiliation and those without, and between those with high and low resilience scores, were examined. Correlational and stepwise multiple regression analyses were then conducted for both the individuals with SCI and their family members.

4.2 Sample

Between November 2013 and August 2015 a total of 50 individuals with SCI and 50 family members were recruited to participate in the quantitative component of the study. During the recruitment period 160 admissions (including readmissions) were recorded at the inpatient service. An additional 83 admissions were recorded by the community team. Those who were discharged from the inpatient unit and admitted to the community team during this period are only included once in these figures. Of these 243 admissions, 115 met the inclusion criteria for the study. Reasons for exclusion
included: no suitable family member available; insufficient fluency in English; or mental health issues which had been identified by the treating team.

Of the 115 individuals with SCI who met the inclusion criteria, 66 agreed to participate and 48 declined. Sixteen of the 66 who initially agreed to participate were not able to complete due to illness, withdrawal of consent prior to data collection, or lack of availability. This resulted in a total of 50 dyads who took part in the study, each dyad consisting of the individual with SCI and their family member. There were no significant differences between the individuals with SCI who participated in the study and those who declined in terms of age, gender or SCI level (chi-square and t tests).

4.3 Descriptive Statistics

4.3.1 Sample profile. Each dyad consisted of the individual with SCI and a close and supportive family member who they invited to participate with them (see Table 5). Of the 50 SCIs, 38 were traumatic injuries, the most frequent injuries being road-related or falls. In about one quarter of cases the SCIs were non-traumatic and these were caused by a medical condition or surgery. Just over half the individuals with SCI were diagnosed with quadriplegia and the rest with paraplegia. The majority of SCIs were incomplete lesions.

The most common relationship of the family member to the individual with SCI was spouse, followed by parent, adult child or sibling. There were no significant differences between the individual with SCI and the family member on age or education level (t-test). More individuals with SCI were male, and more family members were female, which is a typical profile in this field. More than half the participants (both individuals with SCI and family members) held a religious affiliation, and of these, Catholic, Anglican or ‘Other Christian’ were nominated most frequently (see Table 5).
Table 5  
Demographic, injury and psychosocial characteristics of individuals with SCI and family members

<table>
<thead>
<tr>
<th></th>
<th>Individual with SCI (n=50)</th>
<th>Family Member (n=50)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationship of family member</td>
<td>Parent</td>
<td>10 (20)</td>
</tr>
<tr>
<td></td>
<td>Spouse</td>
<td>32 (64)</td>
</tr>
<tr>
<td></td>
<td>Adult Child</td>
<td>5 (10)</td>
</tr>
<tr>
<td></td>
<td>Sibling</td>
<td>3 (6)</td>
</tr>
<tr>
<td>Sex, n (%)</td>
<td>Male</td>
<td>36 (72)</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>14 (28)</td>
</tr>
<tr>
<td>Age at interview (years), Mean (SD)</td>
<td>47.71 (19.25)</td>
<td>49 (16.04)</td>
</tr>
<tr>
<td>Age, Range</td>
<td>65</td>
<td>69</td>
</tr>
<tr>
<td>Education (years), Mean (SD)</td>
<td>12.24 (2.91)</td>
<td>12.38 (2.61)</td>
</tr>
<tr>
<td>SCI Injury Level, n (%)</td>
<td>Paraplegia complete</td>
<td>6 (12)</td>
</tr>
<tr>
<td></td>
<td>Paraplegia incomplete</td>
<td>17 (34)</td>
</tr>
<tr>
<td></td>
<td>Quadriplegia complete</td>
<td>3 (6)</td>
</tr>
<tr>
<td></td>
<td>Quadriplegia incomplete</td>
<td>24 (48)</td>
</tr>
<tr>
<td>Injury Circumstance, n (%)</td>
<td>Road-related</td>
<td>16 (32)</td>
</tr>
<tr>
<td></td>
<td>Fall</td>
<td>11 (22)</td>
</tr>
<tr>
<td></td>
<td>Struck by Object</td>
<td>2 (4)</td>
</tr>
<tr>
<td></td>
<td>Gunshot</td>
<td>1 (2)</td>
</tr>
<tr>
<td></td>
<td>Paragliding</td>
<td>1 (2)</td>
</tr>
<tr>
<td></td>
<td>Football</td>
<td>1 (2)</td>
</tr>
<tr>
<td></td>
<td>Water-related</td>
<td>5 (10)</td>
</tr>
<tr>
<td></td>
<td>Non-traumatic (Medical*, surgical)</td>
<td>13 (26)</td>
</tr>
<tr>
<td>Time since injury (months), Med (IQR)</td>
<td>8.95 (14.15)</td>
<td>-</td>
</tr>
<tr>
<td>Religious Affiliation</td>
<td>Yes (n, %)</td>
<td>30 (60)</td>
</tr>
<tr>
<td></td>
<td>No (n, %)</td>
<td>20 (40)</td>
</tr>
<tr>
<td>Religious Affiliation (If yes), n (%)</td>
<td>Catholic</td>
<td>8 (16)</td>
</tr>
<tr>
<td></td>
<td>Anglican</td>
<td>7 (14)</td>
</tr>
<tr>
<td></td>
<td>Uniting Church</td>
<td>1 (2)</td>
</tr>
<tr>
<td></td>
<td>Presbyterian</td>
<td>3 (6)</td>
</tr>
<tr>
<td></td>
<td>Other Christian</td>
<td>4 (8)</td>
</tr>
<tr>
<td></td>
<td>Islam</td>
<td>4 (8)</td>
</tr>
<tr>
<td></td>
<td>Jewish</td>
<td>1 (2)</td>
</tr>
<tr>
<td></td>
<td>Mormon</td>
<td>1 (2)</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>1 (2)</td>
</tr>
<tr>
<td>Marital Status n (%)</td>
<td>Married/Defacto</td>
<td>32 (64)</td>
</tr>
<tr>
<td></td>
<td>Not in relationship</td>
<td>18 (36)</td>
</tr>
</tbody>
</table>

Note. * Medical conditions included meningitis, transverse myelitis, spinal abscess or tumour, spinal stroke (spinal artery infarct), spinal epidural haemotoma, and neuromyelitis optica.
4.3.2 Measures. Descriptive statistics were generated for the predictor variables, spirituality (FACIT-Sp-Ex) and resilience (CD-RISC, Resilience Scale), and the seven outcome variables, depression, anxiety and stress (DASS-21), positive and negative affect (PANAS), life satisfaction (SWLS) and functional independence (FIM) (see Table 6). For both individuals with SCI and family members, spirituality scores tended to be towards the upper end of the possible range of scores for the Meaning/Peace factor (0-32). Scores on the Faith factor were relatively lower, with average scores for both individuals with SCI and family members at about the mid-way point on the possible range (0-16). Average scores for both groups overall were also towards the upper range (FACIT-Sp, 0-48; FACIT-Sp-Ex, 0-92).

As outlined in Chapter Three, established clinical bands were used to provide more insight regarding results on the Resilience Scale (Wagnild, 2009) and the DASS-21 (Lovibond & Lovibond, 1995). On the Resilience Scale, average scores for both groups tended to be classified as Moderate (family members) to Moderately High (individuals with SCI). Just over half the individuals with SCI and family members were classified as scoring High or Moderately High resilience levels.

On the DASS-21 D, almost three quarters of both the individuals with SCI and family members were in the ‘normal range’. On the DASS-21 A just over half the individuals with SCI were in the normal range and another third were classified with mild or moderate symptomology. Of the family members, most fell in the normal range. On the DASS-21 S, again, the scores for both individuals with SCI and family members were mostly in the normal range.
Table 6
Ratings on resilience, spirituality, positive and negative affect, depression, and life satisfaction

<table>
<thead>
<tr>
<th>Variables</th>
<th>Individual with SCI (n=50)</th>
<th>Family Member (n=50)</th>
<th>Global (n=100)</th>
</tr>
</thead>
<tbody>
<tr>
<td>FACTIT-Sp-Ex, Mean (SD)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meaning/Peace</td>
<td>24.28 (5.85)</td>
<td>24.48 (4.82)</td>
<td>24.38 (5.33)</td>
</tr>
<tr>
<td>Faith</td>
<td>8.72 (5.04)</td>
<td>9.54 (4.95)</td>
<td>9.13 (4.98)</td>
</tr>
<tr>
<td>Total (1-12)</td>
<td>33.00 (8.55)</td>
<td>34.02 (7.64)</td>
<td>33.51 (8.08)</td>
</tr>
<tr>
<td>Extended (1-23)</td>
<td>66.06 (14.89)</td>
<td>68.42 (13.75)</td>
<td>67.24 (14.13)</td>
</tr>
<tr>
<td>CD-RISC, Mean (SD)</td>
<td>76.68 (13.88)</td>
<td>76.64 (11.75)</td>
<td>76.66 (12.80)</td>
</tr>
</tbody>
</table>

Resilience Scale Global, Mean (SD)

| Resilience Level, n (%)                       |                             |                      |               |
| Very low                                     | 1 (2)                       | 1 (2)                | 2 (2)         |
| Low                                          | 3 (6)                       | 3 (6)                | 3 (4)         |
| Moderately Low                               | 3 (6)                       | 5 (10)               | 4 (8)         |
| Moderate                                     | 14 (28)                     | 16 (32)              | 30 (30)       |
| Moderately High                              | 15 (30)                     | 21 (42)              | 36 (36)       |
| High                                         | 14 (28)                     | 6 (12)               | 20 (20)       |

DASS-21 D, Mean (SD)

| Severity Level, n (%)                        |                             |                      |               |
| Normal                                       | 35 (70)                     | 34 (68)              | 69 (69)       |
| Mild                                         | 6 (12)                      | 6 (12)               | 12 (12)       |
| Moderate                                     | 7 (14)                      | 8 (16)               | 15 (15)       |
| Severe                                       | 1 (2)                       | 2 (4)                | 3 (3)         |
| Extremely Severe                             | 1 (2)                       | -                    | 1 (1)         |

DASS-21 A, Mean (SD)

| Severity Level, n (%)                        |                             |                      |               |
| Normal                                       | 29 (58)                     | 39 (78)              | 68 (68)       |
| Mild                                         | 7 (14)                      | 6 (12)               | 13 (13)       |
| Moderate                                     | 8 (16)                      | 2 (4)                | 10 (10)       |
| Severe                                       | 3 (6)                       | -                    | 3 (3)         |
| Extremely Severe                             | 3 (6)                       | 3 (6)                | 6 (6)         |

DASS-21 S, Mean (SD)

| Severity Level (n, %)                        |                             |                      |               |
| Normal                                       | 39 (78)                     | 39 (78)              | 78 (78)       |
| Mild                                         | 4 (8)                       | 4 (8)                | 8 (8)         |
| Moderate                                     | 7 (14)                      | 6 (12)               | 13 (13)       |
| Severe                                       | -                           | 1 (2)                | 1 (1)         |
| Extremely Severe                             | -                           | -                    | -             |

PANAS, Mean (SD)

| Positive                                     | 37.02 (7.45)                | 36.90 (7.21)         | 36.96 (7.29)  |
| Negative                                     | 18.16 (6.50)                | 17.92 (5.63)         | 18.04 (6.05)  |

SWLS, Mean (SD)

|                                    |                             |                      |               |
| Positive                           | 21.74 (8.23)                | 23.70 (7.20)         | 22.72 (7.76)  |

FIM, Mean (SD)

|                                    |                             |                      |               |
|                                    | 81.74 (25.92)               | -                    | -             |

Note. FACIT-Sp-Ex=Functional Assessment of Chronic Illness Therapy Spiritual Well-being Extended (Peterman et al., 2002), CD-RISC=Connor Davidson Resilience Scale (Connor & Davidson, 2003), DASS-21 D=Depression Anxiety Stress Scales (Depression), DASS-21 A=Depression Anxiety Stress Scales (Anxiety), DASS-21 S=Depression Anxiety Stress Scales (Stress) (Lovibond & Lovibond, 1995), PANAS=Positive and Negative Affect Scales (Watson & Clark, 1994), SWLS=Satisfaction with Life Scale (Pavot & Diener, 1993), FIM=Functional Independence Measure (Uniform Data System for Medical Rehabilitation, 1997).
Between-group analyses for the study variables found no significant differences between the individuals with SCI and the family members (t-test). This was the case for both the predictor and outcome variables. For this reason, global scores for the combined groups were also reported (see Table 6).

4.4 The Relationship Between Individual FACIT-Sp-Ex Items and Resilience

Prior to conducting correlational and regression analyses, the twenty-three individual FACIT-Sp-Ex items were examined for any significant differences in relation to demographic variables, and those scoring high versus low resilience. The cut-off between higher and lower resilience scores was determined using The Resilience Scale (Wagnild & Young, 1993). For the purposes of this study, scores over 145 were grouped as ‘Higher Resilience’ (HRS; RS bands Moderately High 145-160 and High 161-170), and lower than 145 as ‘Low to Moderate Resilience’ (LMRS; RS bands Very low, 25-100, Low 101-115; Moderately low 116-130, Moderate, 131-144).

Three demographic variables were of interest (individual with SCI versus family member, gender, and religious affiliation). After Bonferroni adjustment ($\alpha =0.5/23$, $p=.002$) there were no significant differences (t-test) found between the FACIT-Sp-Ex scores for the individuals with SCI and family members. On four items of the FACIT-Sp-Ex there was a trend to significance ($p<0.05$) between the two groups (see Table 7). The only FACIT-Sp-Ex item which was significantly different on gender was Item 1, ‘I feel peaceful’ ($t=3.88$, $p<0.00$), with males scoring significantly higher. Those with religious affiliation scored significantly more highly on the Faith Subscale items of 9, ‘I find comfort in my faith or spiritual belief’ ($t=-3.77$, $p<0.002$), and 10, ‘I find strength
in my faith or spiritual beliefs’ (t=-3.74, p<0.002), with a trend to significance on item 11, ‘My or my relative’s SCI has strengthened my faith or spiritual beliefs’ (t=-2.80, p<0.05).

The global scores for each item (individual with SCI and family member combined) were then grouped into a ‘higher resilience score group’ (HRS) and a ‘low to moderate resilience score group’ (LMRS). There were no significant differences between these groups for individuals with SCI versus family members, gender, or religious affiliation (chi-square test). Differences between the HRS and LMRS were then considered for each of the individual FACIT-Sp-Ex items. The HRS group scored significantly higher on 11 items relating to peace, purpose, connectedness with others, hope, thankfulness and appreciation, and compassion (see Table 8). The largest differences between the LMRS and the HRS were on items relating to peacefulness and harmony (Item 1, Item 7), a sense that life had been productive (Item 3), connectedness with others (Item 14), and hopefulness (Item 21). Interestingly, none of the items on the Faith subscale showed significant differences between the HRS and the LMRS.

4.5 Correlation analysis

Correlational tests were conducted to examine the strength of association among the study variables for both the individuals with SCI and the family members. The analyses were also performed to help select the variables to be tested in the subsequent regression analyses. All demographic, predictor and outcome variables were tested in the correlation analyses, with the exception of the Resilience Scale. As outlined in Chapter Three, the CD-RISC was used as the primary measure of resilience and the Resilience Scale was used to group participant according to levels of resilience. Due to
Table 7
FACIT-Sp-Ex items – Individual with SCI and family member scores

<table>
<thead>
<tr>
<th>FACIT-Sp-Ex Items</th>
<th>Individual with SCI M (SD)</th>
<th>Family Member M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I feel peaceful *</td>
<td>2.84 (.93)</td>
<td>2.42 (.95)</td>
</tr>
<tr>
<td>2. I have a reason for living</td>
<td>3.60 (.70)</td>
<td>3.68 (.55)</td>
</tr>
<tr>
<td>3. My life has been productive</td>
<td>3.12 (1.02)</td>
<td>3.24 (.89)</td>
</tr>
<tr>
<td>4. I have trouble feeling peace of mind (r)</td>
<td>2.98 (1.27)</td>
<td>2.84 (1.00)</td>
</tr>
<tr>
<td>5. I feel a sense of purpose in my life*</td>
<td>2.94 (1.20)</td>
<td>3.46 (.71)</td>
</tr>
<tr>
<td>6. I am able to reach down deep into myself for comfort</td>
<td>2.60 (1.16)</td>
<td>2.58 (1.05)</td>
</tr>
<tr>
<td>7. I feel a sense of harmony within myself</td>
<td>2.74 (1.19)</td>
<td>2.52 (1.00)</td>
</tr>
<tr>
<td>8. My life lacks meaning and purpose (r) *</td>
<td>3.46 (.73)</td>
<td>3.74 (.69)</td>
</tr>
<tr>
<td>9. I find comfort in my faith or spiritual beliefs</td>
<td>2.14 (1.60)</td>
<td>2.30 (1.57)</td>
</tr>
<tr>
<td>10. I find strength in my faith or spiritual beliefs</td>
<td>2.04 (1.60)</td>
<td>2.34 (1.57)</td>
</tr>
<tr>
<td>11. My (or my relative’s) SCI has strengthened my faith or spiritual beliefs</td>
<td>1.56 (1.64)</td>
<td>1.90 (1.61)</td>
</tr>
<tr>
<td>12. I know that whatever happens with my/my relative’s SCI things will be okay</td>
<td>2.98 (1.17)</td>
<td>3.00 (1.16)</td>
</tr>
<tr>
<td>13. I feel connected to a high power (or God)</td>
<td>1.58 (1.72)</td>
<td>1.86 (1.64)</td>
</tr>
<tr>
<td>14. I feel connected to other people</td>
<td>2.88 (1.10)</td>
<td>3.00 (0.97)</td>
</tr>
<tr>
<td>15. I feel loved</td>
<td>3.64 (.69)</td>
<td>3.48 (.79)</td>
</tr>
<tr>
<td>16. I feel love for others</td>
<td>3.64 (.66)</td>
<td>3.70 (.58)</td>
</tr>
<tr>
<td>17. I am able to forgive others for any harm they have ever caused</td>
<td>2.78 (1.18)</td>
<td>2.80 (1.11)</td>
</tr>
<tr>
<td>18. I feel forgiven for any harm I may have ever caused</td>
<td>2.36 (1.35)</td>
<td>2.46 (1.23)</td>
</tr>
<tr>
<td>19. Throughout the course of my day, I feel a sense of thankfulness for my life *</td>
<td>2.78 (1.17)</td>
<td>3.24 (.94)</td>
</tr>
<tr>
<td>20. Throughout the course of my day, I feel a sense of thankfulness for what others bring to my life</td>
<td>3.36 (.75)</td>
<td>3.42 (.76)</td>
</tr>
<tr>
<td>21. I feel hopeful</td>
<td>3.36 (.83)</td>
<td>3.32 (.74)</td>
</tr>
<tr>
<td>22. I feel a sense of appreciation for the beauty of nature</td>
<td>3.14 (1.20)</td>
<td>3.48 (.79)</td>
</tr>
<tr>
<td>23. I feel compassion for others in the difficulties they are facing</td>
<td>3.54 (.71)</td>
<td>3.64 (.66)</td>
</tr>
</tbody>
</table>

Note. FACIT-Sp-Ex = Functional Assessment of Chronic Illness Spiritual Well-being Extended. SCI = Spinal Cord Injury. (r) Items are reverse scored. Trend to significance: *p<0.05: Item 1, t= 2.22, p=0.028; Item 5, t=2.64, p=0.01; Item 8, t=1.96, p=0.05; Item 19, t=-2.174, p=0.03.
Table 8
FACIT-Sp-Ex items – High vs low resilience group

<table>
<thead>
<tr>
<th>FACIT Item</th>
<th>LMRS (n=44) M (SD)</th>
<th>HRS (n=56) M (SD)</th>
<th>t stat</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I feel peaceful</td>
<td>2.20 (.95)</td>
<td>2.96 (.83)</td>
<td>-4.25**</td>
</tr>
<tr>
<td>2. I have a reason for living</td>
<td>3.50 (.67)</td>
<td>3.75 (.58)</td>
<td>-2.01*</td>
</tr>
<tr>
<td>3. My life has been productive</td>
<td>2.68 (1.03)</td>
<td>3.57 (.68)</td>
<td>-5.18**</td>
</tr>
<tr>
<td>4. I have trouble feeling peace of mind (r)</td>
<td>2.61 (1.06)</td>
<td>3.14 (1.15)</td>
<td>-2.36*</td>
</tr>
<tr>
<td>5. I feel a sense of purpose in my life</td>
<td>2.80 (1.15)</td>
<td>3.52 (.76)</td>
<td>-3.76**</td>
</tr>
<tr>
<td>6. I am able to reach down deep into myself for comfort</td>
<td>2.14 (1.05)</td>
<td>2.95 (1.02)</td>
<td>-3.90**</td>
</tr>
<tr>
<td>7. I feel a sense of harmony within myself</td>
<td>2.05 (1.12)</td>
<td>3.09 (.84)</td>
<td>-5.33**</td>
</tr>
<tr>
<td>8. My life lacks meaning and purpose (r)</td>
<td>3.45 (.82)</td>
<td>3.71 (.62)</td>
<td>-1.80</td>
</tr>
<tr>
<td>9. I find comfort in my faith or spiritual beliefs</td>
<td>2.39 (1.60)</td>
<td>2.09 (1.56)</td>
<td>0.93</td>
</tr>
<tr>
<td>10. I find strength in my faith or spiritual beliefs</td>
<td>2.34 (1.60)</td>
<td>2.07 (1.58)</td>
<td>0.84</td>
</tr>
<tr>
<td>11. My (or my relative’s) SCI has strengthened my faith or spiritual beliefs</td>
<td>1.70 (1.64)</td>
<td>1.75 (1.63)</td>
<td>-.14</td>
</tr>
<tr>
<td>12. I know that whatever happens with my SCI things will be okay</td>
<td>2.61 (1.24)</td>
<td>3.29 (1.00)</td>
<td>-2.99*</td>
</tr>
<tr>
<td>13. I feel connected to a higher power (or God)</td>
<td>1.89 (1.69)</td>
<td>1.59 (1.67)</td>
<td>.88</td>
</tr>
<tr>
<td>14. I feel connected to other people</td>
<td>2.36 (1.06)</td>
<td>3.39 (.76)</td>
<td>-5.67**</td>
</tr>
<tr>
<td>15. I feel loved</td>
<td>3.45 (.73)</td>
<td>3.64 (.75)</td>
<td>-1.26</td>
</tr>
<tr>
<td>16. I feel love for others</td>
<td>3.52 (.76)</td>
<td>3.79 (.46)</td>
<td>-2.14*</td>
</tr>
<tr>
<td>17. I am able to forgive others for any harm they have ever caused me</td>
<td>2.55 (1.15)</td>
<td>2.98 (1.10)</td>
<td>-1.93</td>
</tr>
<tr>
<td>18. I feel forgiven for any harm I may have ever caused</td>
<td>2.11 (1.26)</td>
<td>2.64 (1.27)</td>
<td>-2.07*</td>
</tr>
<tr>
<td>19. Throughout the course of my day, I feel a sense of thankfulness for my life</td>
<td>2.64 (1.10)</td>
<td>3.30 (.97)</td>
<td>-3.22**</td>
</tr>
<tr>
<td>20. Throughout the course of my day, I feel a sense of thankfulness for what others bring to my life</td>
<td>3.11 (.84)</td>
<td>3.61 (.59)</td>
<td>-3.44**</td>
</tr>
<tr>
<td>21. I feel hopeful</td>
<td>2.89 (.87)</td>
<td>3.70 (.46)</td>
<td>-5.98**</td>
</tr>
<tr>
<td>22. I feel a sense of appreciation for the beauty of nature</td>
<td>2.93 (1.17)</td>
<td>3.61 (.78)</td>
<td>-3.46**</td>
</tr>
<tr>
<td>23. I feel compassion for others in the difficulties they are facing</td>
<td>3.34 (.81)</td>
<td>3.79 (.49)</td>
<td>-3.40**</td>
</tr>
</tbody>
</table>

Note. FACIT-Sp-Ex= Functional Assessment of Chronic Illness Spiritual Well-being Extended. SCI = Spinal Cord Injury. LMRS=Low to Moderate Resilience Score group, HRS=Higher Resilience Score group. (r) Items are reverse scored. *p<.05 Trend to significance, **p<.002 (Bonferroni correction).
some outliers with time post injury (TSI) (for eg. 7.92 years) this variable was grouped into three ordinal categories (0-6 months, 7-12 months, over 12 months).

Correlation analyses were conducted between the predictor variables of spirituality (FACIT-Ex), resilience (CD-RISC) and the outcome variables (demographic variables, DASS-21, SWLS, PANAS). Effect size was measured using the parameters provided by Cohen (1992). Only effect sizes >0.3 were reported.

Two sets of analyses were conducted to consider the relationship between the predictor and outcome variables, first for the individual with SCI, then for the family member. For both the individuals with SCI and the family members a number of strong correlations were observed (see Table 9 and Table 10). These correlations are reported in more detail below.

To provide further information on the interrelationships between variables for the individual with SCI and the family member, three additional items were added to the correlation analyses. For the individuals with SCI, correlational data was also obtained for the depression, anxiety and stress (DASS-21) scores of the family member. Likewise, for the family members, depression, anxiety and stress (DASS-21) scores of the individual with SCI were included in the analyses, as well as their functional independence (FIM).

4.5.1 Correlations – individual with SCI. A series of five correlation analyses were conducted to investigate the relationship between variables for the individual with SCI. The most significant of these analyses are reported in the correlation matrix (see Table 9). First, correlations between the demographic and outcome variables were considered. Second, this was followed by an examination of the relationships between functional independence (FIM) and the outcome variables. Third, intercorrelations between the spirituality scales and subscales (FACIT-Sp-Ex, FACIT-Sp, Meaning/Peace, Faith)
were considered, followed by an investigation of the relationships between overall spirituality scores and the outcome variables. Fourth, the relationships between spirituality, resilience and the outcome variables were examined. The last analysis involved introducing key variables about family member emotional well-being (depression, anxiety, stress), to explore any relationships with variables pertaining to the individuals with SCI.

There were very few significant correlations between the demographic and outcome variables, and therefore demographic variables were not included in the correlation matrix. For the individuals with SCI, there were no significant correlations between outcome variables and sex, age, years of education, or whether or not they held a religious affiliation. A few associations of small to medium strength were observed between time since injury (TSI) and some dependent variables. The only correlational co-efficient greater than 0.3 was between TSI and negative affect (-.389, p<0.01), indicating that longer TSI was associated with decreasing levels of negative affect. Interestingly, functional independence (FIM) was not significantly correlated with any of the outcome variables, and therefore was not reported on the correlation matrix.

As might be expected, there were strong relationships between the overall spirituality score (FACIT-Sp-Ex), the standard FACIT-Sp (12 item), and the two subscales of Meaning/Peace and Faith. However, there was a non-significant relationship between the two subscales. It was also observed that the Meaning/Peace subscale had a different relationship with the outcome variables than that of the Faith subscale. Whereas Meaning/Peace was strongly associated with all the outcome variables, Faith was only significantly associated with positive affect and life satisfaction.
Meaning/Peace was the only measure of spirituality to be significantly (negatively) associated with the variables of stress and anxiety, which had no strong correlations with any of the other measures of spirituality (FACIT-Sp-Ex, FACIT-Sp, Faith). No significant relationships were observed between either the FACIT-Sp-Ex overall score or the FACIT-Sp Faith scale and religious affiliation (Religious affiliation: Yes=1, No=2). For the overall spirituality score (FACIT-Sp-Ex), significant correlations with medium large effect size (>0.3) were observed with scores of depression (DASS-21 D, negative correlation), positive affect (PANAS Pos scale, positive correlation), and life satisfaction (SWLS, positive correlation) (see Table 9).

Spirituality strongly correlated with resilience (CD-RISC), and this was true of all the four spirituality scales (FACIT-Sp-Ex, FACIT-Sp, Meaning/Peace, Faith). The correlations with all but the Faith subscale were large and significant at p<0.01. The relationship between scores on resilience and faith were the least strong, but still significant at p<0.01 with a medium size.

A few strong relationships were also observed between resilience and the outcome variables. For the individual with SCI a medium effect was observed between resilience and depression (DASS-21 D) scores. Large positive correlations were observed between scores on resilience and positive affect (PANAS Pos), and resilience and life satisfaction (SWLS). There were no other significant relationships observed between resilience and the outcome variables. Furthermore, in the case of the individuals with SCI, there were no significant correlations between outcome variables and the emotional well-being of the family member (see Table 9).
Table 9
Correlations - Individual with SCI
Note. *p<0.05, **p<0.01

<table>
<thead>
<tr>
<th>Variables</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. FACIT Ex</td>
<td>1</td>
<td>.730**</td>
<td>.752**</td>
<td>.942**</td>
<td>.712**</td>
<td>-.404**</td>
<td>-.164</td>
<td>-.089</td>
<td>.651**</td>
<td>-.165</td>
<td>.553**</td>
</tr>
<tr>
<td>2. FACIT Meaning/Peace</td>
<td>1</td>
<td>.229</td>
<td>.819**</td>
<td>.634**</td>
<td>-.559**</td>
<td>-.332*</td>
<td>-.330*</td>
<td>.665**</td>
<td>-.392**</td>
<td>.682**</td>
<td></td>
</tr>
<tr>
<td>3. FACIT Faith</td>
<td>1</td>
<td>.746**</td>
<td>.454**</td>
<td>-.105</td>
<td>.002</td>
<td>.137</td>
<td>.426**</td>
<td>.061</td>
<td>.317**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. FACIT Standard</td>
<td>1</td>
<td>.701**</td>
<td>-.444**</td>
<td>-.226</td>
<td>-.145</td>
<td>.706**</td>
<td>-.232</td>
<td>.653**</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. CD-RISC</td>
<td>1</td>
<td>-.503**</td>
<td>-.209</td>
<td>-.267</td>
<td>.709**</td>
<td>-.027</td>
<td>.548**</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. DASS-21 D</td>
<td>1</td>
<td>.409**</td>
<td>.555**</td>
<td>-.536**</td>
<td>.232</td>
<td>-.420**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. DASS-21 A</td>
<td>1</td>
<td>.733**</td>
<td>-.129</td>
<td>.453**</td>
<td>-.169</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. DASS-21 S</td>
<td>1</td>
<td>-.115</td>
<td>.367**</td>
<td>-.073</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. PANAS Pos</td>
<td>1</td>
<td>.030</td>
<td>.788**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. PANAS Neg</td>
<td>1</td>
<td>-.209</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. SWLS</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
4.5.2 Correlations - family member. Correlation analyses were also conducted to investigate the relationship between variables for the family members (see Table 10). The same steps in the correlation analyses were conducted as for the individual with SCI. First, correlations between the demographic and outcome variables were considered. Second, the relationships between functional independence and other variables were examined. After this, intercorrelations between the spirituality scales and subscales (FACIT-Sp-Ex, FACIT-Sp, Meaning/Peace, Faith) were looked at, and this was followed by an examination of the relationships between overall spirituality scores and the outcome variables. Fourth, the relationship between spirituality and resilience was considered, together with other relationships between resilience and the outcome variables. The last analysis explored relationships between the outcome variables of the family member, and the emotional well-being of their injured relative.

For the family members a number of the correlation coefficients between some of the demographic items and the outcome variables had medium or greater effect sizes (r>.30). To ensure readability, these coefficients have not been included on the correlation matrix. Being female was negatively correlated with the stress score of the family members’ relative with SCI (r=-.346, p<0.05). Years of education of the family members correlated negatively with scores on PANAS Pos (r=-.423, p<0.01). TSI was positively correlated with scores on the DASS-21 A (r=.350, p<0.05).

Among the family members, the functional independence (FIM) of the injured individual was more closely associated with emotional well-being than had been observed for the injured individuals themselves. For the family members, negative correlations with medium effect sizes were observed between functional independence (FIM) and the anxiety (DASS-21 A) and stress scores (DASS-21 D) of the family member. Furthermore, a positive correlation between the functional independence
(FIM) of the individual with SCI, and the life satisfaction (SWLS) of the family member was noted (see Table 10).

For the family members a similar set of relationships to those reported among individuals with SCI was observed among the spirituality subscales. The FACIT-Sp-Ex and FACIT-Sp correlated strongly with each other and both subscales, Meaning/Peace and Faith. However, the relationship between Meaning/Peace and Faith was not significant. In contrast to the individuals with SCI, the overall spirituality score (FACIT-Sp-Ex) \( r = -0.336, p < 0.05 \) and the FACIT faith scale \( r = -0.494, p < 0.01 \) were significantly associated with whether the family member identified with a religious affiliation (Religious affiliation: Yes = 1, No = 2).

Like the individuals with SCI, spirituality scores for the family members were significantly related to key outcome variables. A significant negative relationship with medium effect size was observed between spirituality (FACIT-Sp-Ex) and scores of depression (DASS-21 D). Positive associations with medium effect sizes were also observed with positive affect (PANAS Pos) and life satisfaction (SWLS), though these were not as strong as those reported for the individuals with SCI. Additionally, for the family members significant correlations with medium effect size were observed between spirituality (FACIT-Sp-Ex) and stress (DASS-21 S) (negative correlation), and spirituality (FACIT-Sp-Ex) and negative affect (PANAS Neg) (negative correlation).

The association between resilience and spirituality for the family members was weaker than that observed for the individuals with SCI, though still large. A correlation with large effect size was observed between resilience and FACIT-Sp-Ex. Correlations with medium effect size were observed between scores on resilience and the Meaning/Peace subscale and the FACIT-Sp (Standard Scale). There was no significant correlation between the Faith scale and resilience scores.
As observed with the individuals with SCI, for the family members a significant negative correlation with large effect size was observed between scores on resilience (CD-RISC) and depression (DASS-21 D). Additionally for the family members, there were also significant negative correlations with medium effect size observed between resilience (CD-RISC) scores and anxiety (DASS-21 A) and stress (DASS-21 S). Less strong, but nevertheless similar to the results for the individuals with SCI, a significant positive correlation with medium effect size was observed between resilience (CD-RISC) scores of the family members and their scores of life satisfaction (SWLS).

As reported earlier, no significant correlations between outcome variables for the individuals with SCI and the emotional well-being of the family member were identified. Importantly, this contrasted with the findings for the family members. For the family members, a significant negative correlation with medium effect size was observed between the life satisfaction (SWLS) of the family member and the depression (DASS-21 D) score of the individual with SCI. This finding suggested that the adjustment status of the family members was more closely associated with the emotional well-being of the injured relative, rather than vice versa. No other correlations with medium or large effect sizes were detected.
Table 10
Correlations - Family member

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. FACIT Ex</td>
<td>1</td>
<td>.741**</td>
<td>.734**</td>
<td>.943**</td>
<td>.506**</td>
<td>-.480**</td>
<td>-.014</td>
<td>-.311*</td>
<td>.402**</td>
<td>-.381**</td>
<td>.354*</td>
<td>.254</td>
<td>.025</td>
<td>-.086</td>
<td>.215</td>
</tr>
<tr>
<td>2. Meaning/Peace</td>
<td>1</td>
<td>.223</td>
<td>.775**</td>
<td>.488**</td>
<td>-.587**</td>
<td>-.293*</td>
<td>-.465**</td>
<td>.528**</td>
<td>-.393**</td>
<td>.508**</td>
<td>.211</td>
<td>-.047</td>
<td>-.069</td>
<td>.131</td>
<td></td>
</tr>
<tr>
<td>3. Faith</td>
<td>1</td>
<td>.788*</td>
<td>.121</td>
<td>-.115</td>
<td>.292*</td>
<td>-.043</td>
<td>.027</td>
<td>-.198</td>
<td>.082</td>
<td>.136</td>
<td>.123</td>
<td>.044</td>
<td>.281*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. FACIT Standard</td>
<td>1</td>
<td>.386**</td>
<td>-.445**</td>
<td>.004</td>
<td>-.321*</td>
<td>.351*</td>
<td>-.376**</td>
<td>.374**</td>
<td>.221</td>
<td>.050</td>
<td>-.015</td>
<td>.265</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. CD-RISC</td>
<td>1</td>
<td>-.504**</td>
<td>-.404**</td>
<td>-.309*</td>
<td>.642**</td>
<td>-.248</td>
<td>.443**</td>
<td>.262</td>
<td>-.193</td>
<td>-.180</td>
<td>-.034</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. DASS-21 D</td>
<td>1</td>
<td>.346*</td>
<td>.624**</td>
<td>-.421**</td>
<td>.581**</td>
<td>-.523**</td>
<td>-.296*</td>
<td>.105</td>
<td>.195</td>
<td>.040</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. DASS-21 A</td>
<td>1</td>
<td>.496**</td>
<td>-.307*</td>
<td>.208</td>
<td>-.441**</td>
<td>-.305*</td>
<td>.100</td>
<td>-.047</td>
<td>-.119</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. DASS-21 S</td>
<td>1</td>
<td>-.357*</td>
<td>.537**</td>
<td>-.387**</td>
<td>-.325*</td>
<td>.104</td>
<td>.134</td>
<td>-.136</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. PANAS Pos</td>
<td>1</td>
<td>-.329*</td>
<td>.359*</td>
<td>.185</td>
<td>-.289*</td>
<td>-.175</td>
<td>-.107</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. PANAS Neg</td>
<td>1</td>
<td>-.564**</td>
<td>-.267</td>
<td>.059</td>
<td>.002</td>
<td>-.242</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. SWLS</td>
<td>1</td>
<td>.328*</td>
<td>-.330*</td>
<td>-.088</td>
<td>-.006</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. FIM</td>
<td>.</td>
<td>.328*</td>
<td>-.330*</td>
<td>-.088</td>
<td>-.006</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. DASS-21 D of SCI</td>
<td>1</td>
<td>-.095</td>
<td>.109</td>
<td>.037</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. DASS-21 A of SCI</td>
<td>1</td>
<td>.520**</td>
<td>.628**</td>
<td>.733**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. DASS-21 S of SCI</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. *p<0.05, **p<0.01
4.6  **Multiple Regression Analysis**

A series of stepwise multiple regression analyses were then conducted. The model that was tested comprised three blocks of predictor variables (demographic items, spirituality, resilience) and was successively tested against each of the outcome variables (emotional well-being and life satisfaction). The first block comprised any demographic variables which had significant correlations with the outcome variables. The second block comprised the spirituality variable, and the third block the resilience variable. However, not every regression analysis included a variable from these three blocks. Predictor variables were only included if there had been a significant correlation of $r>.3$ with the relevant outcome variable. This approach had the advantage of limiting the number of variables that were tested, which was important given the modest sample size. As with the correlation analyses, the regression analyses were conducted first for the individuals with SCI, then for the family members.

4.6.1  **Regression analyses - individual with SCI.** As there were no demographic variables which significantly correlated with emotional well-being or life satisfaction for the individuals with SCI, only spirituality and resilience were included as predictor variables. Spirituality scores (FACIT-Sp-Ex) were entered at Step 1 of the regression analysis. Resilience scores (CD-RISC) were entered at Step 2. Based on the outcomes of the correlation analyses, the outcome variables of interest for the individuals with SCI were depression (DASS-21 D), positive affect (PANAS Pos) and life satisfaction (SWLS). The outcome of these three regression analyses are outlined below.

**Depression (DASS-21 D).** The first regression analysis for the individuals with SCI tested the extent to which the model predicted depression scores (see Table 11). At Step 1 spirituality scores contributed significantly to the model, $F(1,48)=9.387$, $p<0.01$, and accounted for almost 15% of the variance in depression scores. Introducing resilience scores at Step 2 explained a significant additional 9.4% of the variance in depression scores,
F(2,47)=8.137, p<0.01. When both variables were included at Step 2 of the model, spirituality was no longer a significant predictor of depression. Resilience accounted for all the variance between spirituality and depression.

Table 11
Results from the regression model predicting depression scores (Individual with SCI)

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>β</th>
<th>t</th>
<th>R²</th>
<th>Adjusted R²</th>
<th>Δ R²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FACIT-Sp-Ex</td>
<td>-.102</td>
<td>-.404</td>
<td>-3.064**</td>
<td>.164</td>
<td>.146</td>
<td></td>
</tr>
<tr>
<td>Step 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FACIT-Sp-Ex</td>
<td>-.024</td>
<td>-.095</td>
<td>-.529</td>
<td>.226</td>
<td>.226</td>
<td>.094*</td>
</tr>
<tr>
<td>CD-RISC</td>
<td>-.118</td>
<td>-.435</td>
<td>-2.434*</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. * p<0.05, **p<0.01

Positive affect (PANAS Pos). The second regression analysis for the individuals with SCI tested the extent to which the model predicted positive affect scores (see Table 12). At Step 1 spirituality scores contributed significantly to the model, F(1,48)=35.382, p=<0.01, and accounted for just over 41% of the variance in scores of positive affect. Introducing resilience scores at Step 2 explained a significant additional 12.2% of the variance in positive affect scores, F(2,47)=28.259, p<0.01. At Step 2 of the regression model both spirituality and resilience were significant predictors of scores of positive affect.

Table 12
Results from the regression model predicting positive affect scores (Individual with SCI)

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>B</th>
<th>t</th>
<th>R²</th>
<th>Adjusted R²</th>
<th>Δ R²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FACIT-Sp-Ex</td>
<td>.326</td>
<td>.651</td>
<td>5.948**</td>
<td>.424</td>
<td>.412</td>
<td></td>
</tr>
<tr>
<td>Step 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FACIT-Sp-Ex</td>
<td>.149</td>
<td>.298</td>
<td>2.132*</td>
<td>.546</td>
<td>.527</td>
<td>.122**</td>
</tr>
<tr>
<td>CD-RISC</td>
<td>.266</td>
<td>.496</td>
<td>3.548**</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. * p<0.05, **p<0.01

Life Satisfaction (SWLS). The third regression analysis for the individuals with SCI tested the extent to which the model predicted life satisfaction scores (see Table 13). At Step
1, spirituality scores contributed significantly to the regression model, $F(1,48)=21.199$, $p<0.01$, and accounted for just over 29% of the variance in life satisfaction scores.

Introducing resilience at Step 2 explained a non-significant additional 4.8% of the variance in life satisfaction scores, $F(2,47)=12.913$, $p<0.01$. At Step 2 of the regression model neither spirituality nor resilience were significant predictors of scores of life satisfaction.

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>B</th>
<th>$t$</th>
<th>$R^2$</th>
<th>Adjusted $R^2$</th>
<th>$\Delta R^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FACIT-Sp-Ex</td>
<td>.306</td>
<td>.553</td>
<td>4.604**</td>
<td></td>
<td>.292**</td>
<td></td>
</tr>
<tr>
<td>Step 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FACIT-Sp-Ex</td>
<td>.355</td>
<td>.327</td>
<td>1.985</td>
<td></td>
<td></td>
<td>.048</td>
</tr>
<tr>
<td>CD-RISC</td>
<td>.183</td>
<td>.331</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note. * $p<0.05$, **$p<0.01$*

### 4.6.2 Regression analyses - family member.

For the family members, significant correlations ($r>0.3$) were observed between predictor variables and six outcome variables. These outcome variables included depression, anxiety, stress, positive and negative affect, and life satisfaction. Demographic items were included in the stepwise regression for all analyses except for those relating to depression and negative affect, where there were no significant correlations. Demographic items were added at Step 1 of the regression analysis. Spirituality scores (FACIT SP-Ex) were entered at Step 2, and resilience scores (CD-RISC) at Step 3.

**Depression (DASS-21 D).** The first regression analysis for the family members tested the extent to which the model predicted depression scores (see Table 14). At Step 1, spirituality scores contributed significantly to the model, $F(1,48)=13.374$, $p<0.01$, and accounted for just over 21% of the variance in depression scores. Introducing resilience at Step 2 explained a significant additional 9.2% of the variance in depression scores,
F(2,47)=11.162, p<0.01. At Step 2 of the regression model both spirituality and resilience were significant predictors of depression scores.

Table 14
Results from the regression model predicting depression scores (Family member)

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>β</th>
<th>t</th>
<th>R²</th>
<th>Adjusted R²</th>
<th>Δ R²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FACIT-Sp-Ex</td>
<td>-.117</td>
<td>-.480</td>
<td>-3.791**</td>
<td>.230</td>
<td>.214</td>
<td></td>
</tr>
<tr>
<td>Step 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FACIT-Sp-Ex</td>
<td>-.074</td>
<td>-.303</td>
<td>-2.175*</td>
<td>.322</td>
<td>.293</td>
<td>.092*</td>
</tr>
<tr>
<td>CD-RISC</td>
<td>-.097</td>
<td>-.351</td>
<td>-2.520*</td>
<td>.328</td>
<td>.293</td>
<td></td>
</tr>
</tbody>
</table>

Note. * p<0.05, **p<0.01

**Anxiety (DASS-21 A).** The second regression analysis for the family members tested the extent to which the model predicted anxiety scores (see Table 15). Time since injury (TSI) and FIM was entered into the first block of predictor variables for scores on anxiety (DASS-21 A). At Step 1, TSI and FIM contributed significantly to the model, F(2,47)=7.747, p<0.01, and accounted for just under 25% of the variance in anxiety scores. Introducing resilience at Step 2 explained a non-significant additional 6.3% of the variance in anxiety scores, F(3,46)=6.920, p<0.01. At Step 3 all three predictor variables made significant and unique contributions to predicting variance in scores on anxiety (p<0.05).

Table 15
Results from the regression model predicting anxiety scores (Family member)

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>β</th>
<th>t</th>
<th>R²</th>
<th>Adjusted R²</th>
<th>Δ R²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TSI</td>
<td>1.404</td>
<td>.397</td>
<td>3.113**</td>
<td>.248</td>
<td>.216</td>
<td></td>
</tr>
<tr>
<td>FIM</td>
<td>-.041</td>
<td>-.357</td>
<td>-2.796**</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TSI</td>
<td>1.190</td>
<td>.337</td>
<td>2.653*</td>
<td>.311</td>
<td>.266</td>
<td>.063</td>
</tr>
<tr>
<td>FIM</td>
<td>-.032</td>
<td>-.279</td>
<td>-2.157*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CD-RISC</td>
<td>-.068</td>
<td>-.267</td>
<td>-2.051*</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. * p<0.05, **p<0.01

**Stress (DASS-21 S).** The third regression analysis for the family members tested the extent to which the model predicted stress scores (see Table 16). The functional
independence (FIM) of the individual with SCI was included in the first block of predictor variables for scores on family member stress (DASS-21 S). At Step 1, FIM contributed significantly to the model, F (1,48)=5.651, p<0.05, and accounted for just over 8% of the variance in stress scores. Introducing spirituality at Step 2 explained a non-significant additional 5.6% of the variance in stress scores, F(2,47)=4.515, p>0.05. Introducing resilience at Step 3 explained a non-significant additional 1.9% of the variance in stress scores, F(3,46)=3.361, p<0.05. At Step 3 the unique contribution of all three predictor variables was non-significant.

Table 16
Results from the regression model predicting stress scores (Family member)

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>β</th>
<th>t</th>
<th>( R^2 )</th>
<th>Adjusted ( R^2 )</th>
<th>(\Delta R^2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FIM</td>
<td>-.040</td>
<td>-.325</td>
<td>-2.377*</td>
<td>.105</td>
<td>.087</td>
<td></td>
</tr>
<tr>
<td>Step 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FIM</td>
<td>-.032</td>
<td>-.262</td>
<td>-1.900</td>
<td>.161</td>
<td>.125</td>
<td>.056</td>
</tr>
<tr>
<td>FACIT-Sp-Ex</td>
<td>-.058</td>
<td>-.244</td>
<td>-1.769</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FIM</td>
<td>-.029</td>
<td>-.239</td>
<td>-1.712</td>
<td>.180</td>
<td>.126</td>
<td>.019</td>
</tr>
<tr>
<td>FACIT-Sp-Ex</td>
<td>-.040</td>
<td>-.169</td>
<td>-1.081</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CD-RISC</td>
<td>-.043</td>
<td>-.160</td>
<td>-1.022</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. * p<0.05, **p<0.01

Positive affect (PANAS Pos). The fourth regression analysis for the family members tested the extent to which the model predicted positive affect scores (see Table 17). Years of education (YE) of the family member was included in the blocks of predictor variables for scores on family member positive affect (PANAS Pos). At Step 1, YE contributed significantly to the model, F(1,48)=10.458, p<0.01, and accounted for just over 16% of the variance in positive affect scores. Introducing spirituality at Step 2 explained a significant additional 11.7% of the variance in positive affect scores, F(2,47)=9.864, p<0.01. Introducing resilience at Step 3 explained a significant additional 21.6% of the variance in positive affect scores.
scores, $F(3,46)=16.039$, $p<0.01$. At Step 3 the unique contribution of only YE and resilience was significant ($p<0.01$). Spirituality was no longer a significant predictor of positive affect.

Table 17

**Results from the regression model predicting positive affect scores (Family member)**

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>β</th>
<th>t</th>
<th>$R^2$</th>
<th>Adjusted $R^2$</th>
<th>$\Delta R^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Years of Ed</td>
<td>-1.169</td>
<td>-</td>
<td>-3.234**</td>
<td>.179</td>
<td>.162</td>
<td></td>
</tr>
<tr>
<td>Step 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Years of Ed</td>
<td>-1.023</td>
<td>.081</td>
<td>-2.989**</td>
<td>.296</td>
<td>.266</td>
<td>.117**</td>
</tr>
<tr>
<td>FACIT-Sp-Ex</td>
<td>.186</td>
<td>.543</td>
<td>2.791**</td>
<td>.511</td>
<td>.479</td>
<td>.216**</td>
</tr>
<tr>
<td>Step 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Years of Ed</td>
<td>-.851</td>
<td>-</td>
<td>-2.927**</td>
<td>.511</td>
<td>.479</td>
<td>.216**</td>
</tr>
<tr>
<td>FACIT-Sp-Ex</td>
<td>.044</td>
<td>.308</td>
<td>.675</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CD-RISC</td>
<td>.333</td>
<td>.081</td>
<td>4.505**</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. * $p<0.05$, **$p<0.01$

**Negative affect (PANAS Neg).** The fifth regression analysis for the family members tested the extent to which the model predicted negative affect scores (see Table 18). At Step 1, spirituality contributed significantly to the model, $F(1,48)=8.166$, $p<0.01$, and accounted for almost 13% of the variance in negative affect scores (PANAS Neg). Introducing resilience at Step 2 explained a non-significant additional 0.4% of the variance in negative affect scores, $F(2,47)=4.132$, $p>0.05$. At Step 2 only spirituality made a significant and unique contribution to predicting variance in scores on negative affect ($p<0.05$).

Table 18

**Results from the regression model predicting negative affect scores (Family member)**

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>β</th>
<th>t</th>
<th>$R^2$</th>
<th>Adjusted $R^2$</th>
<th>$\Delta R^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FACIT-Sp-Ex</td>
<td>-.160</td>
<td>-.381</td>
<td>-2.858**</td>
<td>.145</td>
<td>.128</td>
<td></td>
</tr>
<tr>
<td>Step 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FACIT-Sp-Ex</td>
<td>-.145</td>
<td>-.344</td>
<td>-2.204*</td>
<td>.150</td>
<td>.113</td>
<td>.004</td>
</tr>
<tr>
<td>CD-RISC</td>
<td>-.036</td>
<td>-.075</td>
<td>-.479</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. * $p<0.05$, **$p<0.01$
Life satisfaction (SWLS). The sixth regression analysis for the family members tested the extent to which the model predicted life satisfaction scores (see Table 19). The FIM of the individual with SCI was included in the blocks of predictor variables for scores on life satisfaction (SWLS) of the family member. At Step 1, FIM contributed significantly to the regression model, $F(1,48)=5.799$, $p<0.05$, and accounted for just under 9% of the variance in life satisfaction scores. Introducing spirituality at Step 2 explained a significant additional 7.8% of the variance in life satisfaction scores, $F(2,47)=5.362$, $p<0.05$. Introducing resilience at Step 3 explained a significant additional 7.3% of variance in life satisfaction scores, $F(3,46)=5.356$ ($p<0.05$). At Step 3 only resilience was a unique predictor of life satisfaction scores.

Table 19
Results from the regression model predicting life satisfaction scores (Family member)

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>β</th>
<th>$t$</th>
<th>$R^2$</th>
<th>Adjusted $R^2$</th>
<th>$\Delta R^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FIM</td>
<td>.091</td>
<td>.328</td>
<td>2.408*</td>
<td>.108</td>
<td>.089</td>
<td></td>
</tr>
<tr>
<td>Step 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FIM</td>
<td>.071</td>
<td>.255</td>
<td>1.873</td>
<td>.186</td>
<td>.151</td>
<td>.078*</td>
</tr>
<tr>
<td>FACIT-Sp-Ex</td>
<td>.156</td>
<td>.289</td>
<td>2.122*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FIM</td>
<td>.058</td>
<td>.037</td>
<td>1.575</td>
<td>.259</td>
<td>.211</td>
<td>.073*</td>
</tr>
<tr>
<td>FACIT-Sp-Ex</td>
<td>.075</td>
<td>.080</td>
<td>.940</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CD-RISC</td>
<td>.195</td>
<td>.091</td>
<td>2.130*</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. * $p<0.05$, **$p<0.01$

4.7 Summary of Chapter

The findings from the quantitative component of the study clearly demonstrated that spirituality was strongly associated with resilience for both individuals with SCI and their family members, and together with resilience contributed to a number of positive adjustment outcomes. The descriptive data revealed that ratings on resilience, spirituality, positive and negative affect, depression and life satisfaction were very similar for both the individuals with SCI and their family members, and in general, indicated positive levels of adjustment.
Scores on the individual FACIT-Sp-Ex items were very similar across both the individuals with SCI and the family members. When all the scores were collated, and grouped into a high and a low resilience scores group, the group scoring higher on resilience scored significantly higher on 11 FACIT-Sp-Ex items relating to peace, purpose, connectedness, hope, thankfulness, appreciation, and compassion.

As with the above results, the correlational findings identified similar patterns between the individuals with SCI and the family members. For both groups, strong correlations between spirituality and the dependent variables of depression, positive affect, and life satisfaction were observed. Likewise, for both groups, spirituality correlated positively with resilience, though the correlations were less strong for the family members. Interestingly, one of the few differences between the individuals with SCI and the family members was in relation to the FACIT-Sp-Ex Faith scale. Whereas there was no correlation between resilience and the faith scale for the family members, there was for the individuals with SCI. Furthermore, family member spirituality scores were negatively correlated with scores of stress. An interesting finding was that the depression score of the individual with SCI correlated negatively with the life satisfaction of the family member.

Step-wise multiple regression analyses revealed that for the individuals with SCI, spirituality, together with resilience, was a significant predictor of positive affect. For the family members, spirituality, together with resilience, was a significant predictor of lower levels of depression. Spirituality was also a significant predictor of anxiety for the family members, together with resilience and TSI. For family members, spirituality alone made a significant contribution towards negative affect.
Chapter Five: Results – Qualitative component (C2)

Family Interviews

5.1 Introduction

The scoping review in Chapter Two revealed how few studies have considered the family interactions concerning spirituality and meaning-making after SCI. Of the 32 articles identified pertaining to spirituality and other meaning-making processes after SCI, only two included family members as participants. Only one of these studies, a quantitative study, provided data regarding the interactions between the meaning making and emotional well-being of both members of the family dyad (the injured individual and their spouse) (Feigin, 1998). These findings are consistent with other research within the field of SCI, where the emphasis has largely been placed upon individual, rather than family adjustment.

The findings from the quantitative component of this study, outlined in the previous chapter, suggested that systemic factors may be at work as families adjust to life after SCI. For instance, it was observed that the coping and adjustment levels among individuals with SCI and their family members were very similar. Individuals with SCI and their family members reported comparable levels on measures of spirituality, resilience, depression, stress, anxiety and life satisfaction. For both individuals with SCI and their family members, spirituality correlated strongly with resilience, as well as other outcome variables such as life satisfaction, depression, and positive affect. These similarities led to a number of analyses being conducted with the global group. In addition to these findings, some interesting interactions were observed between the functional independence of individuals with SCI and the emotional well-being of their family members. Although these findings highlighted some trends, it was apparent that the full breadth of family interactions could not be captured by the quantitative component alone. Furthermore, the cross-sectional design of the quantitative component prevented consideration of these factors over time.
Further qualitative exploration of the interactions between family members around meaning-making over time was deemed to be an important second step in better understanding the role of spirituality after SCI. Therefore, the objective of the second component of this study (C2) was to further investigate the relationship between spirituality and resilience, using qualitative methods, to explore the interactions between the individual with SCI and a nominated family member. A longitudinal design was employed.

To achieve the objective of this second component of the study, two semi-structured interviews were held with ten family dyads from a range of cultural and religious backgrounds. Conducting a second interview provided two benefits; the consolidation of codes and themes identified in the first interview, and an opportunity to observe any changes in outlook occurring over time. Each dyad consisted of an individual with SCI and their family member. In all the information presented in this chapter, names have been changed to protect confidentiality. Quotes are included in the participants’ own words, to add validity to the themes being discussed. Such quotes have been italicised for ease of reading. A description of the sample data will be presented first (see Table 20). Following this, the emergent themes are outlined (see Table 21), and the relationship between them described (see Figure 2). Observations from the longitudinal data will be provided in the next chapter.

5.2 Sample Description

Demographic and injury details of the 20 participants are outlined in Table 20. The average age of the individuals with SCI was 45 years, and the family members was 51 years. Six participants had been diagnosed with a paraplegic level of injury and four with a quadriplegic level of injury. A range of different relationships between the individual with SCI and their family members were represented. Half of the family members were the spouse of the injured individual, with other family relationships (parent, adult child) represented among the rest. Just over half (55%) of the participants identified as holding a religious
affiliation. For most of the dyads, the same religious affiliation or spiritual outlook was reportedly held by both the individual with the SCI and the family member. Only in one case did the family member identify as holding a distinctly different religious affiliation (Christian) to the individual with SCI (Atheist). Nine of the ten families completed both the first and follow-up interview. Due to a family being overseas for an extended period, one of the ten dyads did not complete the follow-up interview.

5.3 Themes

Data from the family interviews was analysed and grouped into five overarching themes (see Table 21, Figure 2). The first overarching theme related to the different sources of spirituality the participants described drawing upon, both prior to the SCI and afterwards. Valuable insights emerged regarding how participants viewed spirituality, and what they considered to be their own sources of spirituality, both individually and as a family. The second and third overarching themes incorporated both how the participants’ sources of spirituality were tested by the SCI, and how they, the participants, responded to these tests through a process of meaning-making. These two overarching themes are outlined separately in Figure 2 but documented together in Table 21 and below due to the close relationship between them. Fourth, themes were then identified which pertained to the key outcomes of this testing process; namely gratitude, hope, and deepening connections with others. These three themes were identified as key contributors to a fifth theme, that of ‘moving forward on the journey’. Meaning-making was considered to be a significant aspect of all of these themes, and integral to how spirituality contributed towards family resilience.
Table 20
Demographic and injury characteristics of individuals with SCI and family members

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

Note. *Pseudonyms used, **Only completed the initial interview, ***ASIA Score missing or not recorded. SCI=Spinal Cord Injury, ISCI=Individual with Spinal Cord Injury, FM=Family Member, ASIA=American Spinal Injury Association Impairment Scale.
Table 21
Themes and sub-themes identified in the data

<table>
<thead>
<tr>
<th>Overarching Theme 1: Sources of spirituality drawn upon</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Religious Faith</td>
</tr>
<tr>
<td>- Personal relationship with God or Spirit</td>
</tr>
<tr>
<td>- A source of meaning and hope</td>
</tr>
<tr>
<td>- Protection</td>
</tr>
<tr>
<td>- Comfort (prayer, scriptures)</td>
</tr>
<tr>
<td>- Acknowledgment of God/Spirit</td>
</tr>
<tr>
<td>- Guidance</td>
</tr>
<tr>
<td>2) The Natural World</td>
</tr>
<tr>
<td>- A sense of perspective</td>
</tr>
<tr>
<td>- A source of restoration/refreshment</td>
</tr>
<tr>
<td>3) An Inner Strength</td>
</tr>
<tr>
<td>- Inspiration from others</td>
</tr>
<tr>
<td>- Determination to keep going</td>
</tr>
<tr>
<td>4) Meaningful connectedness with others</td>
</tr>
<tr>
<td>- A reason for living</td>
</tr>
<tr>
<td>- Long standing commitment over time</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Overarching Themes 2 and 3: Sources of spirituality tested/meaning-making response</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Religious Faith</td>
</tr>
<tr>
<td>- Why did this happen?</td>
</tr>
<tr>
<td>- A ‘second chance’ at life</td>
</tr>
<tr>
<td>- A test of belief</td>
</tr>
<tr>
<td>- Prayer for healing</td>
</tr>
<tr>
<td>- What have we done wrong? Role of karma</td>
</tr>
<tr>
<td>- Honouring God</td>
</tr>
<tr>
<td>2) Inner Strength</td>
</tr>
<tr>
<td>- Questioning whether to ‘go on’</td>
</tr>
<tr>
<td>- Positive thinking/Comparison with others</td>
</tr>
<tr>
<td>3) Meaningful connectedness with others</td>
</tr>
<tr>
<td>- ‘Being there’ for one another</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Overarching Themes 4: Key outcomes of testing process</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Gratitude</td>
</tr>
<tr>
<td>- For life</td>
</tr>
<tr>
<td>- For others</td>
</tr>
<tr>
<td>- For community support</td>
</tr>
<tr>
<td>- Giving back</td>
</tr>
<tr>
<td>2) Hope</td>
</tr>
<tr>
<td>- For physical recovery</td>
</tr>
<tr>
<td>- Prayer for healing</td>
</tr>
<tr>
<td>- Physical recovery observed</td>
</tr>
<tr>
<td>- For deeper and stronger relationships</td>
</tr>
<tr>
<td>- Deepening of current relationships</td>
</tr>
<tr>
<td>- Potential relationships in the future</td>
</tr>
<tr>
<td>- For a fulfilling life</td>
</tr>
<tr>
<td>- A ‘new normal’</td>
</tr>
<tr>
<td>3) Deepening relationships with others</td>
</tr>
<tr>
<td>- Whole family change</td>
</tr>
<tr>
<td>- Parent/adult child, siblings</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Overarching Theme 5: Moving forward on the Journey</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Acceptance: ‘it just happened’</td>
</tr>
<tr>
<td>2) The Journey</td>
</tr>
</tbody>
</table>
5.4 Sources of Spirituality Drawn Upon

Analysis of the data revealed that participants drew widely upon different sources of spirituality. Participants reported accessing these prior to the SCI, but even more so as they adjusted to the impact of the SCI. Sources of spirituality included: religious faith; the natural world; an inner strength; and meaningful connectedness with others. Mostly, these sources of spirituality were shared by dyads, but in some cases family members drew upon different sources of spirituality to the individual with SCI. One other source of spirituality mentioned was music; however, as this was only mentioned by one participant it is not included here.

5.4.1 Religious faith. For those participants who held religious beliefs, a relationship with God or some other Spirit, was key to their spiritual source of strength. This was the case whether their religious beliefs were Christian, Hindu or Muslim. In contrast, there were other participants who acknowledged the presence of God or a Higher Power or Spirit, but who did not perceive this person or entity to be relational. These two different perspectives are discussed here.

Personal relationship with God or Spirit. According to participants, a personal and close relationship with God provided them with three key benefits, which are identified as sub-themes in the analysis: i) a source of meaning and hope; ii) a sense of protection; and iii) comfort. Comfort was primarily received through two specific practices; prayer, and meditation upon scripture (see Table 21).

A source of meaning and hope. Meaning making occurred for many via their religious faith and associated belief system. For instance, Mike, Lena’s husband, explained what spirituality meant to him as a Christian in this life, and for a life beyond this one.

I believe in Jesus, that he lived on the earth. I believe that He died, that He rose again that [pause] that there’s something after we die. So, I guess for me my spirituality is linked to that, that I have something, someone other than what we can see or touch
that I can meditate, commune, pray with or to, that I derive some meaning from

(Mike, interview 1).

From the quote from Mike above, it was evident that his beliefs provided a source of meaning, and hope of something beyond this life. Lena shared these same beliefs. For the dyad from a Muslim background, a belief in an afterlife also provided a source of meaning. Ulrich and his father Momimi described how they believed that all of their efforts in this life would be rewarded. Such meaning and hope assisted these participants to transcend, or move beyond, the current circumstances they found themselves in, as they looked forward to an eternal future.

A sense of protection. A second aspect reported by participants, was the sense of protection they felt as they reflected upon God’s power and oversight of their situation. Suresh’s daughter Anushka, spoke of a trust in God’s goodness and power. She explained how she had consulted a number of psychics who informed her that “all the stars, the planets, they’re supporting you, they’re guiding you”. Her faith that good would overcome evil sustained her through many challenges, including the experience of her father’s SCI. A sense of God’s protection was also cited by Ulrich and Momimi. They strongly expressed the view that God’s will would always occur, in all circumstances, and that His will was predetermined. This belief provided them with acceptance, reassurance and comfort.

Comfort. Many of the participants who held religious beliefs shared how their beliefs provided them with a sense of comfort. Lena described her experience of God’s presence early after her injury. In the initial days after her SCI, she was unable to even communicate with her family, and yet felt very supported by God:

I felt so completely supported and could almost feel this physical comfort...And I felt like I was being held with two hands and just little me right in there and I felt so safe and secure and loved and I knew that ... everything would be fine (Lena, interview 1).
Lena told of how her experience led to her feeling confident about the future as she put her trust in God, who she believed would look after her.

Participants from a range of religious beliefs spoke of how they received comfort through prayer. Prayer provided a way to connect with God and ask for help. Ulrich commented on the importance of prayer to him and his family:

...you pray and after you pray you sit and maybe read some Koran and just pray to him (God) to say "Help me to do this help me to do that". That is the way we ask God to help us (Ulrich, interview 1)

Another participant, Michelle (family member), spoke of how prayer just gave her “peace of mind”. Generally, prayer was referred to by participants as an individual practice, one between the individual and God, rather than a shared practice undertaken with others.

Another way participants described receiving comfort was via religious texts or scripture. Those families conveyed how their relationship with God was deepened through a Holy Book, such as the Bible, the Koran, or the Bhagavad Gita. Lena described how Bible verses such as ‘I’ll never forsake you and I’ll never leave you’ (Deuteronomy 31) encouraged her greatly. Other verses, she felt, were like God’s answers to her prayers; “the answers aren’t like an audible voice or anything [laughs], sometimes it’s a passage in the Bible that relates to what my thing is that I’m going through ...and I think ‘ok, yep there’s my answer’” (Lena, interview 1). Lena’s husband Mike found great comfort in Psalm 23 from the Bible. He explained how this scripture helped him to meditate on how God was walking with him through this time. Suresh spoke of how the Hindu Bhagavad Gita provided “answers to a lot of questions” and reassurance that whatever was happening to you was “good for you in the future”. The Koran was an important accompaniment to prayer for the dyad with Muslim beliefs. These varied religious texts were sources of comfort, hope and peace, and were described as a way to connect with God.
For the participants above, ‘God’ was the higher power who they related to. For one participant, however, it was the spirit of his mother. Ted’s mother had died many years before, but he continued to hold a perceived relationship with her. Ted, a proclaimed atheist, felt that his mother’s spirit sustained him, protected him, and, like the accounts relating to God above, was a person he spoke to for comfort. Ted commented that he had felt the presence of his mother’s spirit at earlier challenging times of his life, during a period of depression and a car accident. Ted’s account demonstrated how two contradictory belief systems (atheism and a belief in a spirit world) could be held simultaneously, and how belief in a spirit (that of his mother), could provide meaning and comfort in a similar way to those with religious beliefs.

**Acknowledgement of the existence of God or Spirit.** Other participants expressed a different perspective regarding the role of God in their lives. These participants acknowledged that God or some other Higher Power existed, but was not someone or something they wished to have a personal relationship with. For one participant, this Higher Power provided a sense of guidance. Clive shared how although religious beliefs were no longer important to him, he continued to hold a belief in “something”, and attributed this view to his religious upbringing. He suggested that spirituality was about having something which would “guide you through good and bad times”. Whether that something was God or “some other being” was irrelevant to him. Another participant, Matthew, also associated spirituality with religion. Like Clive, although he believed in the existence of a higher power, “something out there”, it was not something he was interested in pursuing, either before or after his accident.

To summarise, the family interviews demonstrated that a significant source of spirituality for some participants was religious faith. For the majority of these participants, religious faith consisted of a relationship with God or a Spirit. This source of spirituality had
been there for them at other times in their life, providing them with meaning, a sense of protection and comfort. This was apparent not only from those with formal religious beliefs, but also for those who trusted in a spirit world, such as Ted who believed in the presence of his mother’s spirit. Prayer and scripture were two activities cited by participants as ways they experienced comfort from God. Although many of these beliefs were shared beliefs within each dyad, the relationship with God or a Spirit was typically described as a personal, individual relationship. Others acknowledged an awareness of God or some Higher Power in their lives, but such an awareness was not of high importance or relevance.

5.4.2 The natural world. Several participants described the natural world to be an important source of spirituality in their lives. Aspects of the natural world which participants identified included birdlife, dragonflies, flowers, sunsets, stars, and being in the bush or on the ocean. Two key sub-themes were identified as to how the natural world was experienced as a source of spirituality: i) by providing a sense of perspective, and ii) as a source of restoration and refreshment.

A sense of perspective. The first way the natural world was described as a source of spirituality by participants was by providing a sense of perspective, the notion that they were part of something bigger than themselves. Ted enjoyed watching birds. “I’ve always loved animals and [pause] in hindsight I’ve always noticed birds but I just like nature, yeah really we’re not the only beings on the planet and that’s what it is...”. Bill and his wife Pat related how a similar perspective to Ted’s was gained by looking upwards, towards the stars. They commented on how much they enjoyed looking at the stars at their home, a rural property. Stars provided perspective, the possibility for Bill that “there’s more to life than just me”. For his wife Pat the stars brought her to a realisation that: “...life’s not so bad after all, and that’s helpful. Because ...it’s just lovely to know that all that stuff’s out there. Big wide world
out there”. Seeing themselves as a small part of something much bigger provided perspective and reassurance.

**A source of restoration and refreshment.** Other participants reported how they experienced the natural world as a tangible and refreshing source of restoration. Lena related an experience during her time as a client at the acute hospital, where there was “nothing green anywhere”. Her first day home was “an utter onslaught. There were trees along the sides of the street and I hadn’t seen a tree for so long I could barely breathe” (interview 1). Lena described how nature had also been an important source of spirituality in the past, prior to her SCI. Using words such as ‘regenerative’ and ‘restorative’ Lena described a time when she had met her sister at a National Park. “I’m in this magnificent beautiful bush surroundings and it’s, it is restorative and [pause] kind of centres me again”. Lena’s husband Mike spoke of being out on the ocean near to where they lived and windsurfing. His experience of nature helped him to connect more deeply with another source of spirituality, his relationship with God.

> And you know you can’t see the wind but you can see what it does and so...I can meditate on that...God’s Spirit I can’t see but I can see what it does...it certainly restores, helps me to think about, helps me to understand how those things might conceptually work.

A love of the natural world was evident among these participants, and something generally shared together as a dyad. Enjoyed prior to the SCI, the natural world now provided a sense of perspective, and a source of restoration and refreshment.

**5.4.3 An inner strength.** For several participants, it was from within themselves where they drew upon a source of spiritual strength. One participant observed how people he knew could “be very spiritual and have incredible inner spirit without being of any particular religious sect or belief”. Two key sub-themes were identified from participants’ accounts: i)
the inspiration which could be drawn from the example of others; and ii) a determination to keep going.

**Inspiration from others.** A number of participants described how they had been inspired by others in the SIU facing challenges or hardship. Such comparisons helped them to gain perspective, and draw strength. Bill reported how the stories of how others surviving incredible hardship in the Australian outback had encouraged him to draw upon his own reservoirs of strength: “...you also realise that people survived through those times, in some very heavy duty dramas... and they survived. An amazing amount of endurance and the will to keep going, the will to survive” (Bill, interview 2). Comparing oneself to others assisted this participant to draw inspiration, and rely further upon his own “will to survive”.

**Determination to keep going.** A determination to keep going after SCI was discussed by several participants. Ted reflected on how the accident had been “just another kick in the guts”, but of which he could immediately say “I can get over this”. He later said:

> The thing that gets me through life is you look life right in the eye and go for it. See I’ve read a couple of self-motivational books and I learnt some good lessons from them... It gives you that confidence to realise that if you try you can succeed...but if you don’t try you won’t (interview 1).

Like Bill, Ted also gained inspiration from others, in his case, authors of motivational books, which helped him to draw upon his inner strength.

Inner strength was identified as an important source of spirituality by a number of participants, one that had assisted them both in the past and now, as they adjusted to their lives after SCI. It was a source of spirituality that was accessed through inspiration from others, and motivational books and resources.

### 5.4.4 Meaningful connectedness with others.

The previous sections illustrated how participants drew upon a number of sources of spirituality including religious faith, the
natural world, and their inner strength. Another source of spirituality shared by almost all the participants was meaningful connectedness with others. Although not always identified by the dyads themselves as a source of spirituality, their varying accounts are consistent with the broad definitions of spirituality provided in Chapter One, encompassing ‘connectedness with others’. Meaningful connectedness was often referred to in relation to the other member of the dyad, however strong relationships with other family members were also reported to be significant. Two key sub-themes were identified from the participants’ accounts.

Connectedness with others; i) provided a reason for living, and ii) was defined by longstanding commitment over time.

A reason for living. Many participants spoke of how their relationships with others provided meaning and purpose, and ultimately a reason for living. One participant, Michael, believed the relationship he held with his brother and his mother kept him alive in the early days after his injury. According to Michael, these relationships also meant that he had a reason to continue living, beyond his current circumstances. This meaning-making was also experienced by others within the family. Michael’s mother Karen spoke of how her relationship with Michael and his brother gave meaning to her life. Having raised them as a single mother, she reflected on how her relationship with them had helped her through many challenging times in the past, and continued to do so now, “they are my life”. Other participants also described such connectedness with others. For Bill, his family provided him with a will to get up each morning and persevere through the demands of his rehabilitation program. Similarly, when James was asked what made life worth living it was waking up each day and seeing his young son. As these examples demonstrate, the connection between the individual with SCI and their family members was often a source of strength, and experienced by both members of the dyad.
Longstanding commitment over time. Another sub-theme identified as part of meaningful connectedness with others, was the longstanding commitment evident between the members of each dyad. This was particularly so among the couples. Of the five couples interviewed, four had been married for more than twenty years. In many cases these relationships had already withstood several challenges and tests prior to the SCI, including drought (on a rural farming property), health challenges, miscarriages, and financial hardship.

The couples spoke simply and in heartfelt ways of their love for one another, commitment and friendship. In Ted’s words, the love between he and his wife was “just the essence of why we’re together”. Likewise, Mary and her husband Stan spoke of openness, respect and honesty and “just a loving relationship between the two of us”, which had lasted over 40 years. Mary commented: “I’ve always thought about working through the ups and downs and never thought about leaving him, because I believe him to be my soul mate that I’m walking through my life with” (Mary, interview 1). Reciprocating these feelings Stan referred back to his marriage vows, “I’ll stick to my vow and to death do us part”. Despite the ups and downs of their marriage and the challenges facing them after the SCI, he said earnestly “I don’t know what I’d do without her”.

Like Mary and Stan, Lena and Mike reflected on how they had overcome previous challenges together: “Yeah, there’s certainly been ups and downs in that time [35 years of marriage] …but we’ve always been committed to each other, been committed to the relationship and [pause] yeah …you’re my best friend” (speaking to Lena) (Mike, interview 1). According to Mike, the SCI was “just another little step in our journey together”. Also evident within this sub-theme was the commitment of parents to their adult children, and from adult children towards their parents. Such commitment involved financial provision, emotional and practical support.
These examples demonstrated how relationships between members of the dyads were characterised by both a deep sense of meaning (a reason for living) and long standing commitment over time. In almost all cases the relationships were reciprocal, with both members of the dyad receiving and providing support at different times. How connectedness with others, and other sources of spirituality, were tested by the SCI will be considered next.

5.5 Sources of Spirituality Tested/meaning-making Responses

As outlined above, participants in this study referred to a number of sources of spirituality, including religious faith, the natural world, an inner strength, and meaningful connectedness with others. During many of their accounts, however, it was also communicated that these sources of spirituality had been tested in some way, particularly in the early days and weeks after the SCI occurred. In this section, participants’ reports of the impact of the SCI upon three sources of spirituality will be reported; religious faith, meaningful connectedness with others, and inner strength. The participants’ experience with the natural world was not referred to as something ‘tested’ or challenged after the SCI, and therefore is not included here. It was identified that in most cases, the responses of participants to these tests then assisted them in their meaning-making process (see Figure 2). Both the tests themselves and the participants’ responses to these tests are reported here.

5.5.1 Religious faith.

Religious faith tested. According to participant accounts, religious faith was tested or challenged in a number of ways after a SCI. These included i) struggling with “Why did this happen to me (or us)?”, ii) a testing of beliefs, and iii) questioning “What have we done wrong?”. Meaning-making responses to these tests included perceiving the SCI as a “second chance” from God, praying for healing, and seeking to honour God in the midst of their circumstances. For a few participants, the SCI resulted in questions being raised regarding their lack of religious belief. These examples are also included here.
“Why did this happen?” For one family member, the SCI raised significant questions about God’s involvement in his life. Mary’s husband Stan reported how he had recovered from cancer just prior to her SCI. Attributing this recovery to God, Stan struggled to comprehend why God had then allowed the SCI to occur.

He made me recover. Then He gives me this [laughs]. So, you do question it, don’t get me wrong. Anybody says they doesn’t, there’s something wrong ... I’d like to know what the answer is. There’s got to be an answer. At this stage I haven’t got an answer, I don’t know. But I do question it sometimes yes (interview 2).

Mary’s high level SCI brought about many changes which significantly impacted upon their plans for retirement. Throughout the interviews, the meaning and purpose Stan drew from his circumstances appeared to mainly derive from the hope that Mary would recover, and that God might provide recovery as He had for Stan. This ongoing hope for a miracle tested his faith on a daily basis.

Yeah, my faith is being tested every day. Sometimes I feel like giving up. We do. I even say to myself sometimes well maybe I should go on the devil’s side, maybe he can help me [laughs] you know but I mean that’s just that’s the way it is...Some days that’s how you feel, yes you do. But then you come back (Stan, interview 1).

These comments from Stan reveal that despite his questions, and the temptation to abandon his faith, there was also a desire to hold onto his faith, “come back” and continue to hope.

For two other participants, the SCI raised similar existential questions, even though religious faith was not important to them. After the SCI, Michael’s mother, Karen, found herself asking “why my son?” She reflected that if she had been ‘religious’ it may have been easier “because you believe someone out there is making that decision and that is the reason. Probably when you’re not religious it’s harder to deal with ‘why did that happen to my
son?’” (Karen, interview 1). Even without religious faith the question was still an important one for Karen, and one for which she felt there had been few answers.

For another participant, the notion that the accident could be attributed to God’s will only strengthened his atheist position. Michael described how he felt after finding out that his brother Scott had become a Christian, an event which occurred after Michael’s accident.

“So, I asked him if God’s real why did this happen to me? And he said to help other people so they can see what speeding or drink driving can do. But why was it necessary? … Like why, why would He go that far if this God character’s real. And [small laugh] yeah why would He put my family through the stress my family went through just to teach other people (interview 2).

Michael found the reasons his brother gave to explain his accident to be incompatible with the idea of a loving God. This last example shows how change of faith for one member of the family affected others in the family, bringing them to also re-evaluate their own beliefs.

*A test of belief.* In contrast to Stan, who struggled to maintain his faith after the SCI, others perceived the SCI to have happened as a test of belief sent directly from God. Anushka’s belief in a battle between good and evil, and positive and negative forces, gave her comfort that God was in charge of her father’s circumstances. Anushka felt that God was testing her, and she felt confident that good would overcome evil.

“Maybe there was a bad element somewhere, but the bad element turned out to be a good. Because that’s why we say it’s God’s doing because God has created devil...God tests everyone so devil tries to be God but devil can’t take his place”

(interview 1).

Anushka, Suresh’s daughter, felt that she was being tested not only with regard to her father’s injury, but also with other events occurring in her life at the same time, including the break-up of a relationship. She tearfully shared: “... I was the one who was tested. I was tested from
the day one when my Dad fell. I was tested big time...But I still believed in God. Whatever happens it happens for a reason” (interview 1). And for Ulrich and his father Momimi with their Muslim faith, the circumstances of the SCI were also a test to see “if I believe in everything or not” (Ulrich, interview 1). Their faith led them to attribute everything that happened to them to God. Ulrich explained: “…whatever I have is from God. God write down before I come out you know before I was born, whatever you gonna have that is from God”. Momimi added, in agreement: “God always will be there for you”. According to this dyad, a belief and trust in God, and God’s plans, was what was important.

Similarly, Mary felt that ‘bad things’ came to test her religious faith. Unlike her husband, Stan, her faith in God’s will did not appear to waver during their interviews. She explained how she maintained her Catholic faith.

And you know when the bad times come you don’t throw God away and say well I don’t want you this week because all these bad things have happened. The bad things that happened test your religion...you still believe even though things aren’t so good (interview 1).

Mary was also able to reflect upon the positives of her situation. She commented on the many different people she had met in the SIU, some of whom she had been able to help. “I’m on a journey for a reason. Don’t know why. ...I suppose I’ll find out as time goes on” (interview 2). For all these participants, although the SCI was perceived to be a challenge sent from God, the belief that the test was from God also helped these participants enormously as they made meaning out of the event.

“What have we done wrong?” One question which surfaced after the SCI for two families was “what have we done wrong?” It was an early question grappled with by Hazel and her partner as they made sense of the accident that had caused their son James’ SCI.

“Yeah, we went down to the chapel, me and James’ father, and we sat in the chapel, [pause]
“What did we do?” We thought we did something wrong”. Likewise, for Suresh, the belief that he had done something wrong to cause the SCI lingered. At the second interview, he explained:

Every day when I sleep, sometimes I sleep less hours, when I wake up I think what have I done wrong in my life or something, or some prayer I’ve missed, something I haven’t done it in my life, which I was supposed to do it (Suresh, 2)

Whereas Hazel described how she and her husband moved on from these questions, they continued to trouble Suresh.

Responses to the testing of religious faith. On the whole, most participants who held faith in God chose to focus upon the positives of their situation and trust that there was some meaning in their faith being tested. Four responses to the testing of religious faith were identified; i) to reframe the experience of the SCI as being given a second chance of life, ii) to place hope in God’s healing through prayer, iii) to consider the experience of SCI as an opportunity to honour God, and iv) to incorporate both good and bad karma into one’s belief system.

A ‘second chance’ at life. James described how his survival after the accident could be attributed to God choosing to give him a ‘second chance’ at life. “Like (long pause) there’s a lot of people that love like Lord Jesus…stuff like that. [pause] And yeah, I love him too…cause…he gave me a second chance” (interview 1). For James, his SCI brought about a significant spiritual change, from a place of no or little religious faith, to a place of fervent religious faith. This was most evident in the first interview. The changes for James between the first and second interview are discussed in more detail in the next chapter.

Hope that God would provide healing, through prayer. The prayers of Mary and her husband Stan strengthened their hope that her physical condition would improve. Mary’s high level of injury resulted in her using a chin-controlled motorised wheelchair. At the SIU
she was dependent upon nurses for all tasks of daily living. Mary and Stan spoke of how their faith in God and prayer helped them to remain strong. For Stan, prayer was a call of help to someone “upstairs” who might be able to “come down and give me a hand and help me”. Mary drew strength from her Catholic faith, and her prayers to the Virgin Mary and Jesus. A small statue of the Virgin Mary was with her in her room at the hospital. When asked how her prayers to Mary or Jesus helped her, Mary commented “well it keeps me strong. Because I believe in them. Even though I haven’t had any result, only a thumb” (interview 1). Despite few physical changes, Mary’s faith in God was stronger than her faith in the prognosis of doctors.

Ulrich and his father Momimi spoke about the hope their Muslim faith provided. They strongly believed that God had provided Ulrich with healing, and that He would continue to do so. Recovery was seen both as a result of belief in God and hard work. Already this young man was walking, something he attributed to a combination of God’s intervention and his own hard work. “And I'm walking, it's not like 100 per cent good, but I'm walking good... I'm training hard...I'm walking. That mean because I believe in God I know it will come” (interview 1). Adhering strongly to their Muslim traditions, Ulrich and Momimi found prayer to be a way of asking for help from God, and they did so according to their custom, five times a day. They explained these regular prayers were part of being a ‘good Muslim’. Ulrich was encouraged by the prayers of his stepmother and his grandfather back in his home country to get “my health back”. Prayer was an expression of hope, and a way to connect with others, even those living far away.

Lastly, prayer was a way to seek a sign from God. Hazel recounted how James father began praying every night, and went on to find something which would tell him “that James is going to get through all this and he is going to be back to the old James”. According to
Hazel, these signs were provided through occurrences such as a lightning flash at the time of his prayer.

*An opportunity to honour God.* Unlike several of the other participants with religious beliefs, Lena and her husband Mike avidly stated that they felt there was no spiritual reason for what happened to Lena. However, they both spoke of their response to the situation, and the challenge it presented as they sought to honour God. For Lena’s husband, Mike, their circumstances were an opportunity to step up in his role as husband. At the second interview Mike spoke of how he felt challenged to “*stand up and be strong*”.

... *I feel that there’s a role for me spiritually I guess to step up and to [pause] be strong, walk the walk that goes along with all the words about love and cherish, you know in sickness and in health and for better for worse, all those sorts of things that there’s a real opportunity here for me to prove that and to stand up and be strong.*

Mike specifically reflected upon his roles as a father and husband, and what this meant.

*So, I hope that I can be a good husband. I hope that I can reflect some of God and his love to other people...Yep hope that I would be a good husband...I hope that I would be a good Dad* (Mike, interview 1).

Lena commented on how she also felt challenged about the impact the SCI had on her life, and her response to it. “...*It has happened so let’s respond in a way that honours God*”.

Although they did not perceive the SCI to be a test from God, and did not use such language, like others the SCI provided an opportunity to respond well, and through that, meaning and purpose were created.

*Good and bad karma.* As a meaning-making response to her father’s questions as to what he might have ‘done wrong’, Suresh’s daughter spoke of both good and bad karma, and her belief that although bad karma had brought about her father’s SCI, good karma could result in recovery. She also explained how she believed that karma could be carried over from
a past lifetime. Therefore, one might not even know the reason for why something had happened.

*I think it has because Dad’s alive to begin with, because if we were not spiritual, if we were not good people, things could have happened to him on that day, he would have died. But…Dad was taken to the best care, best hospital and even today he’s in the best rehab as well, so it’s all about his good karma that brought him here.*

(interview 1)

Anushka drew peace and comfort from the belief that ‘good karma’ had been at work, and through this belief she was able to encourage and reassure her father.

Like Anushka, Matthew’s mother Lucy also believed that good things could come back to you.

*I sort of more believe in you know what you put out there you’ll get back… like if you are a bad person bad things will happen to you eventually but, you know, if you are good and you’re good to other people…those things will come back to you…*

(interview 1)

Although Lucy identified with no traditional religious beliefs, she held a general view that there was good and bad in the world, and that you would receive back what you gave.

5.5.2 Inner strength.

**Inner strength tested.** Inner strength was another source of spirituality which participants reported being tested. Although this was not spoken of by many participants, at least two participants reported having questioned whether they could ‘go on’. Bill’s wife Pat stated: “…you’ve got to have that [inner strength] otherwise you just fall in a heap I guess. But…I think probably we all have that and it’s only when it’s tested that we decide whether or not we can go on”. As reported earlier, although Bill felt the SCI was another “kick in the guts”, he could also say to himself “I can get over this”. Participants spoke of two key
meaning-making responses to the testing of their inner strength. The first was by adopting positive thinking, the second was to compare oneself with others who were deemed to be more worse off.

**Responses to testing of inner strength.**

*Positive thinking.* Positive thinking in response to the SCI, was clearly present among those who relied upon inner strength as a source of spirituality. This included looking ahead to the future, rather than dwelling on the past. Suresh’s daughter Anushka put it frankly. “And you know, be positive...don’t give up, one shit has happened doesn’t mean that every day is going to be shit” (Anushka, interview 2).

Michael’s mother Karen found that looking forward in life provided her with anticipation, and the expectation that “tomorrow’s going to be better”. She described how as a child she enjoyed looking at a picture on her grandmother’s wall of a long winding road where you couldn’t see what was around the corner. After telling her grandmother one day that she would like to find out what was around the corner, she remembered her grandmother responding: “it’s wonderful that you can think that way...always remember whatever happens in your life or how bad it gets you need to stay living to see what’s around the corner” (interview 2).

Matthew and his mother Lucy also spoke of remaining positive, and looking ahead to the future. They looked forward to Matthew being able to move out on his own, one day getting a job, and forming a relationship with a future partner or spouse. Lucy commented, “I’ve always sort of been more of a positive person trying to look at the positive sides of what’s happened rather than you know the negatives” (Lucy, interview 1). These extracts illustrated how one response to having inner strength tested was to think positively and look ahead.
Although many of the responses regarding positive thinking were focused upon the inner strength of the individual, there were clear indicators that thinking positively was also something which was encouraged within the dyad. This suggested that positive thinking was something that could be shared through family interactions, consequently building the inner strength of both members of the dyad. The following three extracts provide evidence of such interactions. Karen spoke of how her son’s smile encouraged her each morning as she arrived on the SIU. “One of the things that amazes me about Michael is that I get up here every morning to ‘good morning Mum’ and a big smile” (interview 1). Likewise, for Mike, it was the smile of his wife Lena, and her optimism which encouraged and surprised him.

“I come in here and sometimes take a moment before I come in to think ‘ok this is my time with you, I don’t want to bring a dark cloud in with me’ and I walk in here and you’re full of smiles and optimism ‘guess what I can do today’ and ... it helps me enormously” (interview 1).

And for Bill, visits from his wife Pat lifted his mood every day. He spoke emotionally about these visits. “She always comes up smiling and happy (pause, teary) turns up every day bright and cheery” (interview 1). These interactions demonstrated the importance for both members of the dyad to spend time together with one another during the inpatient stay.

Receiving positivity from others was not restricted to members of the dyad. James’ mother Hazel reported that surrounding themselves with positive people assisted her in “pushing away all that negativity”. Another family member found that people around them got them “to find the positive of most things”. Positivity dominated the accounts of many of the participants.

Comparison with others. Closely associated with positive thinking, and another response to the testing of inner strength, was the tendency of participants (both individuals with SCI and family members) to compare themselves with others who they considered to be
in a more difficult or challenging position than themselves. This tendency has been referred to in the literature as ‘downward comparison’ (Buunk, Zurriaga, & Gonzalez, 2006). Here it assisted participants to feel better about what they had, to feel lucky, and to be grateful.

Matthew, who had sustained a paraplegic level of injury, compared himself with others on the SIU who did not have use of their hands. He noted that unlike them he could pick up the phone, write a message, even write his name. Matthew’s mother Lucy agreed with her son’s outlook and reflected upon her own perspective of his situation, focusing on the positives: “you know he’s still alive, he’s got use of his arms, you know just things like that that you know could have gone either way…” (interview 1). Comparisons with others was not limited to observations regarding physical abilities. For Lena, comparing herself with a client in the hospital who had attempted suicide helped her to realise that: “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” (interview 1). She laughed as she reflected on how this perspective resulted in her feeling unexpectedly lucky. Compared to others she felt her experience “hasn’t been on the whole a difficult time”. Her husband Mike agreed, sharing how seeing people worse off than Lena in the rehabilitation unit made him thankful for Lena’s circumstances, and thankful every day that she was alive, “we’ve still got her”.

In comparing themselves with others, participants in this study also spoke of how inspired they were by others on the SIU. Karen, mother of Michael, commented that after meeting others on the SIU she realised how much she had, how little she had to complain about and “how lucky I am”. For Karen, others on the SIU were an inspiration. “My whole life’s changed. My whole attitude to life… being with all of the clients here. Meeting people and watching how they get over some of the most amazing hurdles” (interview 1). This resulted in her feeling less tolerant of people considered to be “whingers”. Lena’s husband Mike suggested those with much more minor injuries should “come and see these people and
see what they’re going through every moment of every day” (interview 2). These experiences suggested that comparisons with others assisted participants to gain perspective, to feel lucky, and to be thankful.

5.5.3  Connectedness with others.

Connectedness with others tested. In addition to participants discussing the testing of their faith and their inner strength, participants also spoke of a testing of their relationship with others. The main way this source of spirituality was tested was via the implied question, “who will be there for me?” ‘Being there’ encompassed both a physical presence and the assurance of love and support. In almost every family, participants provided evidence of how they had overcome the test, and ‘been there’ for one another during this time.

Response to testing of meaningful connectedness with others.

Being there. Some of the most poignant expressions of this deepening commitment were from three mothers who spoke of the importance of ‘being there’ for their adult sons after the SCI. Michael almost lost his life after the motor vehicle accident which injured his spinal cord. In the early days in hospital while Michael was in a coma, Karen reported maintaining a constant presence by Michael’s side. According to Michael, later during rehabilitation Karen strongly conveyed the impression to him and his brother that she was not about to go anywhere, even if they had asked her to. “Mum just wants to be there and we want her to be there, but say we didn’t and we said ‘Mum, go home’ she wouldn’t. She’d just stay and turn up the next day” (interview 1). Reflecting upon his mother’s presence at his bedside, and throughout rehabilitation, brought Michael to the conclusion that what he previously may have hoped for or expected of his mother prior to the SCI, had occurred in practice: “I always could imagine, but now can see that when push comes to shove Mum is going to be there for me” (interview 2). His mother’s commitment reinforced the strength of their relationship, and a sense for Michael that she would be there for him in the future as
Another mother, Lucy, reported saying to her son Matthew “your family will always be there”. Such commitment was also demonstrated when the family moved house, so that Matthew could live with them in accessible accommodation.

Providing a perspective from a different cultural background, Momimi, father of Ulrich, spoke of how the expectations of a father within their culture included helping a son to ‘stand up’ on his feet again, both literally and metaphorically. Momimi demonstrated this support through a physical and emotional presence, as well as spiritually through prayer and practically via financial support. “You know because if someone like him is injured ...who's supposed to put him up is me. ...Be there for him so he can be standing on his feet again” (interview 1). Once again, the notion of a family member ‘being there’ for the injured individual was present within family interactions.

Examples of family members ‘being there’ were also identified among the couples. On several occasions, Mary described her husband Stan as her ‘soul mate’. For Mary, ‘being there’ physically for one another was more important than the words they might share. Even though it was Mary who had sustained the injury, she felt supporting Stan was just as important as Stan providing support to her. “Well sometimes it could be just being there, because sometimes it might be that he doesn’t want to talk about it....so it’s just a matter of being there” (interview 2). This couple demonstrated how ‘being there’ for one another was a reciprocal experience, where they could each provide support. Weekends together and time together on the SIU were extremely important to this couple, and to others, for this reason.

The testing of meaningful connectedness with others was not contained only to the dyads. As well as family members ‘being there’ for one another, some also spoke of how friends or a spiritual community, such as a church, had been there for them as well. Michael’s mother Karen observed that it was already apparent who their real supporters were among their friends and family. Such supporters were those who would be there for them in the long
term when they got home, not just those who would turn up once and say “aw aw aw and we’ll never see them again”. Such a comment provided an example of those whose friendship or connection had been tested, but rather than growing stronger, had weakened and in some cases, even ended.

This section has provided examples of how the sources of spirituality identified by participants, and outlined in 5.3, were put to the test in some way by the SCI. It should be noted that the testing of sources of spirituality was not necessarily a phase that families moved through in a linear progression. For some, it might be an experience that would be returned to, either through the experience of living with SCI, or through other challenging circumstances. The next section will consider how these sources of spirituality, and the testing of these sources, led to deepening relationships, hope, and gratitude, three key outcomes which assisted families to ‘move forward on the journey.’ These processes are depicted in Figure 2.

5.6 Key Outcomes of Testing Process

Sources of spirituality accessed by participants, and having been tested, were identified to build family resilience, and assist them to move forward together in three key ways: i) gratitude; ii) hope for the future; and, iii) deepening relationships with one another and others. These contributions spirituality made towards strengthening family relationships and family resilience were interwoven with one another, and formed part of an ongoing and evolving process (see Figure 2).

5.6.1 Gratitude. Many of the participants in this study spoke of feelings of thankfulness, new appreciation, or gratitude, since their SCI. It was apparent that various sources of spirituality developed gratitude, including a relationship with God, connectedness with others, and a connection with nature. Four sub-themes pertaining to gratitude were identified from the data: i) gratitude for life itself, ‘life as a gift’, ii) gratitude for others within the
family, iii) gratitude for community support, and, iv) a desire to give back in some way. Feelings of gratitude were directed towards God, one another, or others who had provided support. In some cases, feelings of thankfulness or gratitude were expressed without reference to any particular benefactor. At least three families spoke of a desire to give something back, to return the kindness they had received, demonstrating yet again the reciprocal nature of many of these relationships.

**Gratitude for life: Life as a ‘gift’**. After sustaining such a life-threatening injury, many individuals with SCI spoke of their thankfulness to have survived the experience. A few participants reported that the survival of the individual with SCI led to a new appreciation of life; they no longer took things for granted, and felt lucky to be alive. This was the case for both the injured individuals themselves and for their family members. For some, this thankfulness was directed towards God, others were just grateful, and made no reference to God or the spirit world.

Matthew described how his perspective on life had changed since the SCI. Whereas he previously focused on making money “and you know having a good time” he now cared about getting married one day and having children. He now considered life to be a “gift”, something to be valued and appreciated so much more than he had previously. When he was asked about what he appreciated more he responded:

...you know [pause] being alive. You know, your family, just everything really. And you know it’s kind of made me realise well you know, how do I put it, [pause] yeah just [pause] lucky to be here…I should be dead. I really should be. I don’t know how I’m alive but you know, that’s exactly why I’m grateful (interview 1).

Having lived independently from his family prior to his SCI, at the second interview Matthew was now living with his family again. This resulted in him spending more time with
younger siblings and his mother, increasing his appreciation for family members and the support they provided.

Family members also expressed a thankfulness for life, both for the life of the injured individual, and for their own. Like Matthew above, Lena’s husband Mike expressed an increased awareness that life could no longer be taken for granted. He spoke of how Lena’s SCI had increased his appreciation of life, and particularly the life he had with his family, leaving him with a ‘thankful mindset’. At the second interview, he reflected:

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

Just reading a newspaper now caused Mike to reflect on the impact of catastrophic events in other people’s lives, and how one should appreciate and enjoy the relationships one had, every day.

Religious faith was evident among participant’s reports of gratitude. Ulrich and his father Momimi, as Muslims, believed that one should not only give thanks to God for good things, but for all things in life, both good and bad. They considered everything in life to be a gift from God.

> Because He is the one, is up to Him to decide what He want to do. You can't just say 'Oh God give me good thing'... and when you do bad things say not thank you God. Can't say like that. You have to thank Him for everything (Momimi, interview 1).

According to Momimi, both Ulrich’s accident, and his subsequent recovery were attributable to God, and something to be thankful for.

In addition to gratitude for surviving the accident, thankfulness was also expressed for other aspects of life. For example, Mary expressed gratitude for the natural environment, and
commented on the wonders of watching birds, flowers, and dragonflies from her room at the SIU. This enjoyment of the natural world was central to how Mary coped with her SCI:

you’ve got to find the strength to get through the bad times ...whether it’s a beautiful flower or whether it’s a lovely sunset ...you have to see the good things and enjoy them and that’s how I go through my life (interview 1).

Another family member described how just walking down the beach was now something she now appreciated so much more. As seen earlier, appreciation for the natural world whether it was birdlife, stars, or the bush, was both a source of spirituality, and something which enabled participants to express gratitude and appreciation for everything around them.

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 after the SCI. Several family members spoke at length about how they felt after almost losing their loved one, and how this then impacted upon their relationship. For many, the event led to an increased appreciation and closeness within the family.

At their second interview Michael’s mother Karen spoke of how nearly losing her son after a motor vehicle accident had changed her outlook on life. “It just makes you ... feel totally differently [pause] I mean I came pretty close to losing him...when you’ve come that close to losing one and realise what it would mean, you appreciate them a lot more”. Lena and Mike also became aware of a deeper appreciation of each other after Lena’s SCI. Mike expressed gratitude for the love they had shared for many years, thankfulness that Lena was still with them, and thankfulness for her role as a wife and mother in their family. His gratitude was directed both towards God and Lena.

And [long pause] I guess I attribute it to God but I had peace at that time [time of the SCI], a real, real deep peace that whatever happened was going to be ok um and if I lost her that we’d had a wonderful life together [teary] that had so much more than so
many people would ever have, that I was so grateful to know you and to have you and now to have you back... (interview 1)

In response to Mike, gratitude also dominated Lena’s story. Her gratitude focused particularly on Mike’s love and support during her experience of rehabilitation.

I’m just overwhelmed with gratitude and love. Mike’s been so [pause] overwhelmingly loving and supportive and... you’re kind of my biggest fan, you’re cheering me on when I don’t think I’m going well...and I’ve felt like I’ve had nothing to give, nothing to offer because I’m just this kind of blob you know, broken body and everything and um and yet you just love me (interview 1)

These accounts illustrate the role of gratitude in deepening connections with one another, and bringing about new appreciation for one another and for life. It also demonstrated that although they are reported as separate themes here, there was a very close relationship between gratitude and deepening connections with others (see Figure 2).

Gratitude for community support. In addition to gratitude for one another, participants reported a greater awareness and appreciation for others in their community. Two families spoke specifically about how members of the local Christian community were there for them, providing practical support. Hazel spoke of meeting her children’s Sunday School teacher from years ago:

They heard about what happened to James and they came to the house and because it was so close to Christmas, she had a boot load of pressies in the back yeah, and we stood out on the road and we said a little prayer together (interview 1).

James’s mother Hazel believed that God had “put these people around us to help us get through this”. Lena and her husband Mike spoke of the support they received from their local church, a community they had been members of for many years. Mike spoke of how overwhelmed he had been with the support.
It’s been an incredible um journey with them, and you know I open the freezer door at home and the meals are just falling out on top of me, of people providing for us and asking what they can do to help (interview 1).

Sharing a similar perspective, but from a Hindu faith, Suresh’s daughter Anushka also considered that support from others was a gift from God: “Like they say God will not come on the Earth to help you, He will put some people of his kind to help you, this is what another thing I believe. It’s God coming in a human form”. The connections formed by participants with others in the community demonstrated how a SCI affects many people, including those beyond the family unit.

A desire to give back. Emmons proposed that gratitude motivates us to “share the goodness we have received with others” (Emmons, 2007, p. 4). Throughout the family interviews, it was apparent that feelings of gratitude encouraged participants to want to return the kindnesses they had received from others. The giving back was not directed specifically at those who they had received from, but could be to others in some sort of need. Clive reflected on the amount of support he had received from others after his SCI and how this led to him wanting to give back.

A lot of the people were [pause] I never would have dreamt they’d come and see me sort of thing, people from work and friends and stuff and [pause] willing, wanting to help you know some of the people 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 (interview 1).

In response to these offers of help Clive contemplated how he and his wife Sarah had found ways to give back already. Clive and Sarah told of how they held barbeques for others at the SIU. They enjoyed bringing together people who didn’t usually interact, and were pleased that there was “one cranky fellow that was happy for a change”. At the second interview
Clive spoke of his experiences at an informal peer support group where he could both give to (and receive back from) others facing similar circumstances to himself.

Others reported a desire to give back to those they had received from during earlier times in their life. For Anushka, providing support to her father was one way she could express her gratitude for all he had done for her over the years. She stated that “it’s my turn to pay back Dad”. This paying back was in some ways literally a financial task, as she saved money for him and gave him what he needed. Rather than feeling resentful about these changes, Anushka expressed a sense of gratitude that she was able to provide for her family. She earnestly explained this new awareness at the second interview:

Don’t rely on life, don’t take life for granted. That’s a major message because when I was about to get married...but it didn’t happen that way...what you dream of never happens. You know, I didn’t get settled down. The money that I had to save for my future is the one I’m not saving it anymore, I’m spending money, you know [on her father]. But then, I don’t feel bad. I won’t feel bad at all because I’m still grateful that I’m able to do it. And I’m surprised that I’m able to do it.

In her grief and sadness Anushka was able to adjust to and accommodate the needs of her family, while also expressing a sense of gratitude. This gratitude further contributed to the deepening of family relationships.

For Lena, a desire to volunteer her time to care for others was perceived as one way she could honour God with what He had given her, “by using it for someone else’s benefit”. At the first interview, she expressed a desire to return to phone counselling, something she had volunteered for prior to her SCI. Upon discharge home, this had not yet happened, however she reported how she had found opportunities to listen and provide support to friends, as they gave her lifts to appointments.
In summary, gratitude was identified as an important theme for participants, both for those with religious beliefs, and those without. Both the individuals with SCI and their family members expressed feelings of gratitude, both for life itself and for one another. Such gratitude could be seen to strengthen connections between family members, increasing their appreciation for one another and for life itself. Furthermore, this led to some participants desiring to give back in some way, whether to others in the community, to friends, or to one another, as an indication of their thanks.

5.6.2 Hope. Another way spirituality was identified to build family resilience, was through hope. Hope included; i) shared hope for recovery, ii) hope for relationships with others, and iii) hope for a fulfilling life together. The sources of spirituality which strengthened these hopes included faith in God, existing connectedness with others, and inner strength. For some, strong feelings of determination accompanied these hopes, for others, hope was more tentative.

Hope for recovery. Hope for recovery varied among families. Differences were expressed regarding how much recovery was hoped for, what was hoped for, and who or what hope was placed in. Although several families discussed hope for recovery, only two families spoke of hope for complete recovery and the individual ‘getting better’. Other families hoped for any improvements, no matter how small. It was hoped that small improvements in mobility would make big differences in potential functional ability, and therefore quality of life. Two important sub-themes were identified among participants reports regarding hope for recovery; the role of prayer in building hope, and the importance participants placed upon physical recovery which had already occurred.

Role of prayer in building hope. As discussed earlier, and illustrated in Figure 2, one of the identified meaning-making responses to the testing of religious faith, was to pray for healing. Such responses were described by participants as a way to ask God for help. Prayer
was also linked directly to hope, and a deep desire for recovery. Such prayers indicated a belief in a powerful God, who was able to intervene, and who took a personal interest in an individual’s welfare. Such hope was represented among a range of religious faiths, encompassing Christianity, Islam, and Hinduism. For others without religious belief, prayer was still of some comfort, with one family member describing feeling supported by the prayers of others, even though she did not share the same beliefs.

One family demonstrated how different religious faiths could be brought together under one belief system. Hazel reported how after her son’s SCI her family placed hope both in the Christian God and in the spirits of their indigenous culture. She recalled a time shortly after James’s accident when he lay in a coma in hospital. An indigenous pastor came to pray with them. “Then she sprinkled some holy water on him. And she did a smoking thing as well. So, she did like the indigenous side and God’s beliefs. She brought them together. Over him” (interview 1). As they reached out for comfort in a time of crisis, the family held onto hope through beliefs in both traditions.

Like Hazel, distinguishing between different religious traditions held little importance for Suresh’s daughter Anushka. She perceived God to be the same entity across many religions, one she described as “the light” or “the source”. It was to this ‘light’ that she offered her prayers, believing that God would respond by providing healing for her father, and guidance and direction. Anushka described how she felt her prayers were being slowly answered, though possibly not in the way she had expected.

It’s very disguised, like you can’t see it straight away, but I think still when you go back and look at a lot of things to how negative I was back then to what I feel now it’s like [pause] yes it has been answered, in a different way (interview 2).

This observation from Anushka showed how hopes might alter or change, but a faith in God continued to fuel hope that things would get better, even if that was not immediately evident.
A contrasting perspective on the role of God in physical healing was provided by Lena and Mike, a Christian couple. Although they considered God to have contributed to Lena’s recovery and believed that a miracle was possible, their hope was placed in trusting that God would be with them on the journey. Mike explained it this way:

*Personally, it might be a lack of faith um I would love for Lena to get up and walk again but I [pause] my hope is that God will be with us in our journey and if he chooses to perform a miracle on Lena, I’m there I’m really happy (laughs) about that, um I’m not claiming it* (interview, 1).

This perspective of Lena and her husband Mike differed from those of other dyads with religious beliefs, who associated their faith in God with the hope for some recovery. Instead, the foundation of this couple’s hope was that of an ongoing relationship with God.

The perceived benefits of prayer were not restricted to those with religious beliefs. Michael’s mother, Karen, was encouraged whether people prayed for them or just thought of them. As Michael was not religious she said they had asked people “to pray or cross your fingers and toes for us please”. Prayer in any format was received as a form of support, a way of being cared for and a source of hope for further recovery. Likewise, Suresh did not mind Christian friends praying for him, even though his own beliefs were Hindu. And Hazel found prayers of family and friends who had never prayed before to be of great comfort. Mary was encouraged by the prayers of her adult children, even though she did not consider them to be active followers of God.

*Observing physical recovery which had already occurred.* In addition to participants’ prayers, hope was also raised by observing physical recovery that had already occurred, especially if this recovery surpassed initial expectations of the medical professionals. For example, at the first interview Michael reported his functional recovery was well beyond the early prognosis given.
Like, at one stage they said [of Michael] ‘he’ll never get outta bed’ [pause] and I passed that. And then they said ‘he’ll be in a power chair for the rest of his life’. I passed that. And now I’m walking.

Like Michael, Mary also felt that she had also surpassed initial medical expectations. After only seeing movement in her thumb at the first interview, six months later she reported seeing signs of further progress. “I can flick my toes up and down and I can pull the feet together but I can’t lift them. I’m just starting to see my knees move” (interview 2). Mary’s husband Stan spoke of what these small signs meant to him.

I mean every little thing that happens it’s, it’s a step forward. You know she moved her toes. So, it enlightens you, makes you feel good. To other people, or to the doctors here it probably means nothing. To me it means a lot (interview 2).

By that time, Mary had been at the rehabilitation unit for twelve months. At both interviews the couple expressed frustration at how they felt their hopes were being discouraged by staff. Stan commented that Mary would go backwards “tremendously and quite quickly” if they were not able to stay positive about potential recovery. He described his feelings after a meeting with the treating team:

To me it was very, very, very difficult because you know ever since we’ve gone through this…nothing has actually gave us anything positive of hope … all they’re doing is refreshing my memory to the first day it happened…as I said if you don’t believe and lose hope you’ve lost everything…what you’re going to say to yourself ‘oh well there’s no hope we’ll just sit back and just let things go as they are’. You can’t. You’ve got to try and move on. Walk forward…otherwise …you’re going to go backwards and you think to yourself maybe it’s (points finger towards head, makes pistol sound) (interview 1).
Even though Stan struggled with accepting what had happened to Mary, he considered it important to move forward, holding onto the hope he had. It was clear that for Stan, a hope for recovery was the main thing enabling him to cope in the present circumstances.

In summary, hope for recovery was often associated with religious faith, and in particular, prayer. Prayer was an important aspect of this relationship, as participants sought help from God. Hope was also drawn from physical recovery that had already occurred, even if this was perceived differently to the rehabilitation team. Hope for recovery provided some participants, like Stan, with a way to move forward. Interestingly, no participants in this study expressed hope that a cure for SCI would be found, which differs to the findings from other SCI studies on hope (Dorsett, 2010).

**Hope for deeper and stronger relationships with others.** In addition to hopes for recovery, participants expressed hopes for other areas of their life. One significant area of hope raised by participants was hope for relationships with others, both for the deepening of those currently enjoyed and for potential relationships in the future. The source of this hope was often the deepening of relationships which had occurred since the SCI. Deepening relationships with others (see 5.6.3) developed hope for the future, however hopes were also expressed that these deepening relationships might stay strong. It was a two-way interaction, as depicted in Figure 2.

Two families clearly expressed hope regarding the existing relationships in their family. As Lena thought about getting older with her SCI she looked forward to one day being a grandmother. The thought of getting older was daunting, but the hope of being surrounded by her loved ones, even as this occurred, provided some comfort. “If I’m a grandmother in a wheelchair with grandchildren and children and a husband who love me then that’s better than being some old woman who you can’t be around, and nobody loves them (interview 2)”.
Another family member who spoke of her hope that the close relationships in the family would continue, was Hazel. Conflict had engulfed the family just prior to the injury, and through the subsequent forgiveness and love shared between them, family relationships had grown much closer.

*But we’re also hoping that the united stand between us all stays ... that’s something I’m really adamant about when we get home, that this is not, it’s not going to change. We’re all still going to be a close family* (interview 1).

Hazel’s desire and hope was that the closeness developed between family members would continue.

Two young men spoke of their hopes for future relationships, specifically that they would find a marriage partner and be able to have children. “*I want to be able to have a normal life you know after the accident ... get married, have kids [pause] job, you know*” (Matthew, interview 1). Michael expressed similar hopes, and these were specifically related to the hope that he would find a partner who accepted him how he was. “*You know find someone who doesn’t see me as that different, that I can have a relationship with maybe, marry, have kids. That’s sort of what I hope for cause I’ve always wanted kids*” (interview 2). These hopes were similar to the hopes of others, who expressed that they would be able to live a fulfilling life together, one that was ‘normal’.

*Hope for a fulfilling life together.* Drawing upon strength from within themselves, several participants spoke of a determination to return to a fulfilling life with their loved ones. As one family member said “*we’re determined it (the SCI)’s not going to mess our lives up*” (Michelle, interview 1). Another individual with SCI declared “*I want to start living again*” (Mary, interview 2). Many participants’ hopes were placed in being able to return to the things they enjoyed doing, even if this meant doing things a little differently. These included going home to family, travelling, and getting out into the community.
As noted above, for Michael, living a ‘normal’ life and being accepted for himself was of great importance. At the second interview, he explained how one of the highlights of his week was attending a local nightclub.

This’ll make me sound like an alcoholic but [pause] every Saturday night me and David (friend, carer) go out [pause] and to be able to go out the night club is upstairs. Security’s happy to carry me in the chair up the stairs so once I’m in there I feel normal (interview 2).

Likewise, Michael’s mother Karen said her hopes were merely that his friends would “still just view him as Michael and not as Michael in a chair...and not feel they need to I guess treat him differently because of that”. Acceptance from peers was of great importance to young men like Michael and Matthew, and was a hope shared by their mothers.

Others also expressed hope that they could be ‘normal’, whatever it was that ‘normal’ now looked like. Clive looked forward to a ‘new normal’ where all the adjustments of life with SCI become ‘second nature’. Living a fulfilling life meant a life without restrictions.

It would be nice in the future to be able to...just not be restricted in doing anything, pretty much be able to do anything that we want to do...just want to get on a plane and go somewhere...ok it can be done so it’s just about me being strong enough to do it. And pack enough bags. (interview 2)

Pat and Bill were on the verge of retirement at the time of his injury, ready to sell their farming property. Pat spoke of how she hoped they would be able to fulfil one of their previous plans, that of becoming ‘grey nomads’.

A fulfilling life was contrasted by some with the lack of fulfilment experienced on the SIU. For Mary, it was a very long stay in rehabilitation, and both her initial and follow-up interviews were held at the SIU. At the second interview, she expressed how getting back home was about getting back to life.
For one year all I’ve done is go home and here. I haven’t been to my daughter’s house. I haven’t been to my son’s. I haven’t visited any friends. Haven’t seen the beach, the ocean, the river, the water. I haven’t seen anything. I want to start living again.

For Mary, her love of the natural world made her long for her home and community. Such aspects of a fulfilling life could not be provided in the SIU, but only among her family back at home.

In summary, sources of spirituality such as a relationship with God, inner strength, and connectedness with others, assisted participants to hold onto hope. This hope encompassed hope for recovery, for existing and future relationships, and to be able to return to a fulfilling life together. These hopes were, at times, at odds with the views of the rehabilitation team, and some hopes were frustrated by the confines of the SIU.

5.6.3 A “deepening of all of our relationships”. As outlined earlier, a key source of spirituality identified here in this study was meaningful connectedness with others. Commitment, love and togetherness characterised many of the dyadic relationships between couples, and between parents and adult children. Furthermore, when this commitment was tested by the event of a SCI, the majority of participants reported an increased commitment, and desire to ‘be there’ for one another. Importantly this was identified to lead to a key outcome, the deepening of relationships within the family. As many of the couples already spoke of deep and committed relationships over several decades, the focus here will be on the deepening relationships observed between parents and their adult children, and other reports of growing relationships between siblings. For the couples, the main aspect of growth in their relationships was gratitude, which was discussed earlier in this chapter.

One of the prominent findings of the research, were the reports of deepening relationships between parents and their injured adult children. Two parents spoke of how
their relationship had changed from one between parents and their children, to adult friends. Hazel described her relationship with James as being “…best friends rather than mother and son” (interview 1). She also reported that the relationship between James and his father had grown much closer. She described how James and his father now “…just sit and they talk. They never used to talk. They used to get angry at each other. And now they actually sit down and talk and enjoy one another’s company”. Like Hazel, Karen also noted a deepening of relationships between herself and her son Michael. She explained that the relationship between her two sons, Michael and his brother, had always been close. After the SCI, however, Karen noticed how the relationship between herself and her sons had grown much closer. “I always thought it was wonderful to see two brothers so close. But now I think it’s the three of us that are so close” (interview 1). She commented how there was more openness between them all, and the ability to talk of things that they would not have discussed in the past. This new experience of openness was also observed by her son Michael. “I’ve always felt loved and valued by Mum but I can see it in a different light now. Like it’s a better love, I feel more close to Mum”. Once again, the reciprocal nature of the relationships was demonstrated.

References to changes in parent-child relationships were not confined to the dyads. Similar changes to those observed by Karen and Hazel were reported by Lena and her husband Mike, regarding their daughters. Lena said of her daughters, “I would say our relationship has turned more into being adults that talk together rather than child and adult… they’ve had to grow up very fast through this” (interview 2). Mike concurred with this observation.

In addition to deepening relationships between parents and adult children, there were also reports of deepening relationships between siblings. After James returned home, his mother Hazel described how the whole family, including James’ father and his siblings, had
all grown closer to one another. Conflict had been experienced by this family just prior to the SCI. Hazel considered the family to now be marked by forgiveness, appreciation and love, changes which were sustained at least until the second interview six months later. Likewise, Lena and Mike observed changes in the relationships for the whole family, and a new strength evident among them. Speaking about his daughters Mike said at the second interview:

I think all of them have shown incredible strength and a deepening of all of our relationships ... there’s a strength now that they are aware of that they can draw on that I don’t think they were aware of before.

Such reports highlight the systemic changes which can occur within families after a traumatic injury such as SCI, and the strength which can be developed during this process. Among these families, shared experiences, increased opportunities to demonstrate commitment, and a growing closeness and openness, brought about significant changes in the whole family.

Among the five couples who were interviewed, all described their relationship as very strong prior to the SCI. This was evident as they described how they had overcome previous tests together, and how their love and commitment had been tested by the SCI. Rather than a deepening or changing relationship with one another, as seen among the parents and adult children, the couples tended to focus mainly upon expressing gratitude for what they already had together. The close association between deepening relationships and gratitude is illustrated in Figure 2.

In summary, it could be identified among the dyads that a key source of spirituality was meaningful connectedness with others. After this connectedness was tested by the SCI, participants reported many ways they chose to ‘be there’ for one another, offering physical, emotional, and spiritual support. This time of testing led to a deepening of relationships, most evident among parents and their adult children. Couples reported increased levels of
gratitude, which were also evident among the other dyads. Importantly, gratitude, hope and deeper relationships, assisted families to move forward on their journey together, which will be discussed next.

5.7 Moving Forward on the Journey

The concept of spirituality is closely associated with finding meaning and purpose in life (Canda & Furman, 2009) and this is of heightened importance for many who are faced with a health crisis (Cobb et al., 2012). For these reasons, it was expected that in this study of families affected by SCI, most participants would be seeking some meaning or purpose from their situation. Initially, a theme appeared to emerge, that of participants finding meaning and purpose through the experience of the SCI. However, after further analysis and reflection, meaning making was identified as a key part of each theme, culminating in the family ‘moving forward on the journey’ after SCI (see Figure 2). This last theme will outline how participants referred to this process of ‘moving forward’ in their journey, and what significance it held in the meaning-making process.

As outlined earlier, many of the sources of spirituality drawn upon by participants were tested in some way after the SCI. For some with religious beliefs, this was the testing of their faith or trust in God’s will. Others observed that their own inner strength or will power had been tested. Others again looked back and could see that the strength of their relationships with others were tested after the SCI. Although participants commented upon this process of testing, the majority of participants rejected the notion that the reason for the SCI occurring was solely to test their faith, relationships, or inner strength. Instead, there was an emphasis from both the injured individuals and the family members on i) accepting the situation by looking ahead, and ii) ‘moving forward’ on the journey, rather than dwelling on the circumstances of the SCI or pondering existential reasons for it.
5.7.1 **Acceptance of the accident that “just happened”**. When reflecting upon the physical cause of the SCI, many participants adopted the attitude that ‘it just happened’. Three participants who were injured on motorbikes expressed a determination not to dwell on the circumstances of the accident, suggesting that to do so would be unhelpful. Matthew, one of the three men injured put it this way:

> You know you can’t look back and think about what you could have done. I don’t do that anymore cause you just think ‘fuck, I should have done this, I should have done that, or if this happened’... I’m just thinking ‘no I can’t think like that’. You know you started bringing yourself down. You get really depressed” (interview 1).

Matthew’s outlook was shared by his mother Lucy. “I just think well it’s happened let’s just move on, let’s just try and get your life back together...what’s happened, happened and you’ve just got to move on”. Likewise Clive and his wife Sarah believed that dwelling on the circumstances of the accident could drag you “into a place where you don’t really want to be”. Rather than looking for reasons for the motorcycle accident, his perspective was “it just happened. There’s no reason or anything for it, that’s just something ah life throws at you”.

Bill and his partner Pat also felt that dwelling on the accident was unhelpful, and according to Pat, “dangerous territory”. Together they shared a determination not to look back. As Pat explained:

> I think it comes down to an acceptance type of thing, and if you can accept the situation as it is, just...try not to dwell on the emotional side of it. Try and be positive and try and just look forward and not look back at all I guess. Yes, you can’t really think you know ‘well if this hadn’t happened we would have been doing such and such’ because that sort of tends to lead you down the wrong path (interview 2).

Bill agreed with Pat’s attitude, and provided an illustration, as he called it, from “the highway of life”. Bill stated:
... you can’t drive down the highway of life looking in the rear-view mirror. You’ve got to look ahead to see what’s in front of you and adjust the steering accordingly...If you drive up the highway looking in the rear-view mirror all the time, you’ll run into the next truck coming the other way (interview 2).

For this dyad and others, their life now looked quite different to the one they had envisioned prior to the SCI, but this did not mean things were insurmountable. As Pat described it, they were heading towards the “same destination, but just (on) a different road”. While many still hoped for some recovery, it was not the centrepiece of their future lives together. Accepting the situation and moving forward together was what mattered.

Among those who believed the accident or injury ‘just happened’ were two families who held Christian beliefs. These dyads rejected any idea or suggestion that God was somehow responsible, or had caused what happened. Michelle spoke of how her husband Ted had fallen from their roof. Was there a reason this had occurred? She laughed as she said “Yeah the reason it happened was that he didn’t listen to what I told him. I told him not to get on the roof!” More seriously she reflected:

I just believe you know that there is a God. And as much as people say ‘if there’s a God that wouldn’t have happened to Ted’...I don’t believe that’s the way things are anyway. I think a lot of your life depends on you yourself, it’s not someone higher than you telling you that this is what’s going to happen to you... you make your own fate in this world (interview 1).

Like Michelle, Lena and her husband Mike felt that God was not responsible for what happened to Lena. Lena explained:

There’s no logic in what I’m about to say. I think all good things come from God. But I don’t think bad things do. So, I think the fact that I got this [SCI] it wasn’t God punishing me or saying this family needs to go through something difficult so they can
get to something better, nothing like that...I was unlucky enough that I was one of the people who got one (interview 1).

Lena’s husband Mike reported how a number of people asked him why he thought it was that this had happened to Lena. He wondered why this question of ‘why’ was so pertinent, rather than all the other questions one could ask about life. Reflecting on these questions during the second interview he commented:

*Why were we born in Australia? Why did we never have to go, for a man to go to war? Why do I get three gorgeous, loving children? Why do I have a wonderful relationship? There’s so many good ‘whys’ that you can’t say ‘oh one bad thing happened to you, that’s awful’...if we’d been born in Somalia or in West Africa now or Syria, you know we wouldn’t be talking about ‘why’, we’d be fighting for our lives you know so I think in many ways it’s a luxury to ask in a way” (interview 2).

Mike described feeling lucky compared to many others around the world, and interestingly this provided yet another example of downward social comparison. Like other participants, Mike doubted that asking ‘why’ took you to a helpful place, and preferred to look forward on the journey rather than back.

5.7.2 The ‘journey’. Accompanying participants’ accounts of accepting the situation, looking ahead and moving forward, was imagery associated with being on a journey. Many participants in this study referred to being on a ‘journey’, or used language that depicted them being on a journey. Although this was not a concept referred to by the researcher in the family interviews, either the concept itself, or others closely associated with it, repeatedly emerged in the interview material. The journey metaphor was underlying many of the accounts, and moving forward on the journey appeared to provide many dyads with meaning and purpose.

Sometimes direct use of the word ‘journey’ was used by participants. In her second
interview Mary shared her belief that she was “on a journey for a reason”. Hazel commented in her first interview that “we know our little journey hasn’t ended”, and in his first interview Mike hoped that “God will be with us in our journey”. At other times words were used to describe the process of moving forward on the journey, including phrases such as: “taking that next step”, “around the corner”, working “our way around it”, “looking forward”, or being able to “just get on with it”. Moving forward might mean taking a “different direction” or “different road”, but moving towards the same destination nonetheless. And others again spoke of metaphorically travelling on roads or highways, and heading towards destinations as they spoke of the future.

Accepting what had happened seemed to assist families to ‘look ahead’ and actively ‘move forward’ on their journey. Moving forward was about not dwelling on the past, and not giving up. Gratitude, hope, and deepening connections with one another, assisted participants to move forward on the journey after SCI. For some like Stan, it was hope in recovery that assisted them to keep moving forward. Others looked forward to closer relationships, and new relationships, while holding onto a new appreciation and gratitude for life. As has been seen, religious faith was an important source of spirituality for some, but not the only one. Meaningful relationships, inner strength, and the natural world, all assisted participants in this meaning-making process.

5.8 Summary of Chapter

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. The use of terms associated with the quest narrative (Frank, 1995) such as ‘journey’ and ‘hope’, suggested that there was a desire to accept what had occurred, and move forward. Few adopted a ‘restitution narrative’, placing hope in a return to life as it had been prior to the SCI. Furthermore, in this study there was no evidence of the ‘chaos narrative’, where all hope is abandoned (Frank, 1995).

Several of these themes could be seen to overlap or contribute to one another. In particular, it could be seen that deepening connections with others was closely associated with experiences of hope and gratitude (Figure 2). 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’. As many similar themes arose during both the first and second interviews, this chapter has incorporated data from both. There were some observations made from the longitudinal data however, which will be reported in the next chapter. A case study is also included in that chapter, further illustrating some of the changes which occurred for one family over time.
Figure 2: The Spirituality Model: Moving forward on the journey – how spirituality contributes towards family resilience after SCI
Chapter Six: Results – Qualitative component (C2)

Longitudinal change

6.1 Introduction

The analysis of the interview data outlined in Chapter Five demonstrated that religious faith, the natural world, inner strength, and meaningful connectedness with others, were sources of spirituality participants drew upon both before and after SCI. In many cases these sources of spirituality were tested, as families sought to make meaning of their lives after SCI. This testing process was shown to assist families to move forward in their journey together, as they expressed gratitude, held onto hope and deepened connections with one another.

Data from both interviews with each dyad was analysed to identify these themes. However, as outlined in the Methods Chapter, it was considered important to also investigate how spirituality and family resilience changed over time. The experiences of families as they transitioned from inpatient rehabilitation to the community were of particular interest, due to the challenges associated with this period identified in the literature (Kennedy & Rogers, 2000; Middleton et al., 2014). Consequently, further analysis was conducted regarding longitudinal themes which could be identified between the first and second interviews. These themes are the focus of this chapter.

As outlined earlier, the first interview with participants was held at any point during their admission to the Spinal Injuries Unit at Royal Rehab. This resulted in a sample which varied in time since injury, ranging from two to 11 months (see Table 20, Chapter Five). The second interview occurred between six to eight months after the first. The majority of participants were discharged home during this time, however one participant was still at the hospital, and another had been discharged only a few weeks prior to the interview being
conducted. For one dyad (Dyad 3) a second interview was not held, due to lack of family member availability (had moved overseas).

The key findings from the analysis of the longitudinal data are presented in Table 22. The first column in Table 22 depicts the sources of spirituality drawn upon by each dyad. The next two columns highlight the spiritual themes which were identified during the first and second interviews. If these themes were only relevant for one member of the dyad, this is indicated in brackets. The fourth column outlines some of the challenges encountered by participants between the two interviews. These findings draw attention to important aspects of the transition process from inpatient rehabilitation to community, such as increased fatigue, readmissions to hospital, or difficulties encountered maintaining carers. The final column highlights the changes observed between the interviews, and the impact such changes may have had upon the dyad’s experience of moving forward.

During the analysis of the longitudinal data it was identified that overall many aspects of the participants’ perspective and outlook remained stable, from the time in the inpatient unit and until after transition into the community. Data collected at the second interview tended to reinforce or emphasise themes identified in the first interview, rather than raise new themes. For many participants, the outlook and sources of spirituality they reported drawing upon at the first interview were very similar to the outlook and sources of spirituality described six to eight months later. Those who held religious beliefs tended to hold them six months later. Other sources of spirituality, such as the natural world, inner strength, and meaningful connectedness with others, also remained stable. Likewise, similar themes were identified at both interviews regarding how participants responded after the experience of SCI. Those who had described hope, gratitude, and deepening connections with others at the first interview, continued to express such sentiments at the second. As indicated in Table 22
however, changes were observed among a small number of families, and are discussed in further detail below.

This chapter concludes with a case study, outlining the changes over time reported by James and his mother Hazel. This family provided a helpful illustration of many of the stages outlined in Figure 2 (Chapter Five), and demonstrated how a family could experience profound spiritual changes after a SCI. How these changes were affected after transition into the community was also apparent.

6.2 Longitudinal Themes Arising From the Data

The key theme identified from the longitudinal data was a decrease in spiritual intensity from the first to the second interview. This was only apparent among those dyads where significant change in this area was observed. Within this key theme, two sub-themes were identified: i) moving from dependency upon God to a desire to honour Him, ii) changed priorities, leading to a decrease in spiritual practices such as meditation. Another significant change, a decrease in religious faith after unexpected challenges were experienced in the community, is included in the case study.

6.2.1 Dependency upon God to a desire to honour Him. A change from feeling dependent upon God, to a desire to honour Him, was most evident from the analysis of the interviews with Lena and her husband Mike. This change related to a change of focus, rather than belief. At both interviews they described their Christian faith and relationship with God as very important.
<table>
<thead>
<tr>
<th>Dyad</th>
<th>Names*</th>
<th>Sources of Spirituality</th>
<th>Spiritual themes – Interview 1</th>
<th>Spiritual themes – Interview 2</th>
<th>Challenges between Interview 1 and Interview 2</th>
<th>Significant changes observed between interviews 1 and 2</th>
</tr>
</thead>
</table>
| 1    | James/Hazel | ● Religious faith (new)  
● Meaningful connectedness | ● Prayer, faith  
● Gratitude, appreciation  
● Hope for recovery  
● Hope for relationships  
● Purpose | ● Prayer, faith (FM only)  
● Gratitude (FM)  
● Hope for recovery  
● Hope for relationships | ● Friend’s suicide (ex-client)  
● Death of family member  
● Breakup with girlfriend  
● Difficulty keeping carers  
● Feeling overwhelmed | ● Diminished intensity of new religious faith (Individual with SCI only) |
| 2    | Michael/Karen | ● Meaningful connectedness | ● Gratitude for relationships  
● Hope for new relationships | ● Gratitude for relationships  
● Hope for new relationships | ● Living back with mother  
● Brother becoming a Christian post SCI | ● Questioning of religious faith due to brother’s conversion |
| 4    | Mary/Stan | ● Natural world  
● Meaningful connectedness (FM) | ● Hope for recovery  
● Hope for new relationships | ● Hope for recovery  
● Hope for new relationships | ● Participant still an inpatient at time of second interview | ● Frustrations due to delayed discharge and lack of access to natural world |
| 5    | Lena/Mike | ● Religious faith  
● Meaningful connectedness  
● Natural world | ● Dependency upon God  
● Desire to give back  
● Journey with God  
● Gratitude  
● Hope for relationships | ● Honouring God  
● Gratitude  
● Hope for relationships  
● Tiredness | ● Physical challenges  
● Tiredness | ● Changed focus from dependence upon God to honouring God |

*FM: Family member, SCI: Spinal Cord Injury
<table>
<thead>
<tr>
<th>Dyad</th>
<th>Sources of Spirituality</th>
<th>Spiritual themes – Interview 1</th>
<th>Spiritual themes – Interview 2</th>
<th>Challenges between Interview 1 and Interview 2</th>
<th>Significant changes observed between interviews 1 and 2</th>
</tr>
</thead>
</table>
| 6       | Bill/Pat                                                                               | • Inner strength  
• Natural world  
• Meaningful connectedness                                                                | • Hope for recovery in hands  
• Hope for relationship and a fulfilling life                                            | • Hope for recovery in hands                                                                 | • Several re-admissions to hospital  
• Less recovery as had hoped  
• Feelings of disappointment regarding minimal recovery, but hopeful still of further gains  
• Minimal change in outlook  
• Less time to meditate                                                                 |
| 7       | Clive/Sarah                                                                             | • Inner Strength  
• Meditation (FM)  
• Acceptance – ‘just get on with it’                                                                 | • Desire to give back  
• Acceptance                                                                 | • House not ready so living in apartment in city  
• FM returning back to work, assisting with care                                                                 | • No changes                                                                                                                   |
| 8       | Suresh/Anushka                                                                         | • Religious faith  
• Hope for recovery - walking                                                                 | • Hope for recovery  
• Living in temporary accommodation  
• Some recovery                                                                 |                                                                                                                                 |                                                                                                                                          |
| 9       | Matthew/Lucy                                                                            | • Inner strength  
• Meaningful connectedness  
• Appreciation for life and family  
• Desire to meditate (FM)                                                                 | • Hope for future relationships  
• Appreciation for life and family  
• No time to meditate (FM)                                                                 | • Moving back with family into new accessible home  
• Less time to meditate – FM busy with house renovations                                                                 |                                                                                                                                          |
| 10      | Ted/Michelle                                                                            | • Religious faith (FM)  
• Inner strength (client)  
• Hope for a fulfilling life                                                                 | • Hope for a fulfilling life                                                                 | • Readmissions to hospital for skin, bladder                                                                                     | • No changes                                                                                                                   |

*Note: *Pseudonyms used. FM=Family Member only
At the first interview Lena described how she felt God had brought about significant healing in her body, and this was even more the case in the early days and weeks after her injury. By the second interview she explained that she felt God was asking her to be more actively involved. Similarly, in the second interview 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”. The role he referred to was that of husband and father. He expressed that his main desire in the second interview was to honour God in his circumstances.

Both Lena and Mike reported feeling that God was now asking more of them, and they were being called to respond rather than just depend. Immediate dependency upon God, both physically and emotionally, had lessened. They both continued to report a very strong relationship with God.

6.2.2 Changed priorities leading to decrease in spiritual practice. For several family members, it was observed that once the individual with SCI was discharged to the community, their lives became much busier. In some cases, family members were responsible for providing practical care. Unlike at the SIU where they could leave their injured relative with a team of nurses and therapists, now the injured individuals were much more reliant upon the family member’s support and assistance. Furthermore, activities in the family member’s own lives had resumed, including caring for other children, and returning to work.

When Clive was in hospital Sarah explained that she had found time to meditate during the long trips to and from their home and throughout long periods at home on her own. After discharge, there were no more long car trips, and she found much of her time at home was spent assisting Clive. Furthermore, at the time of the second interview she was about to return to part-time work.
Likewise, at the first interview Matthew’s mother Lucy spoke of her desire to meditate. By the second interview, she laughed at such a thought. Lucy described feeling busy and overwhelmed with the house they had recently built so that Matthew could return to live with them. She was also busy with younger children, and her husband was away for work. Although she acknowledged the importance of meditation, she felt that it had lessened in importance among the priorities in her life.

6.3 Case Study on Longitudinal Changes – James and Hazel

6.3.1 Background. The two interviews held with James and his mother Hazel, helpfully illustrated the meaning-making process which occurred after SCI (see Figure 2, Chapter Five). These changes were mostly reported by Hazel, James’s mother. As will be apparent in this case study, she was the spokesperson in the dyad, as well as the member of the dyad who seemed to gain most strength from her sources of spirituality. She was also an observer of other changes in the wider family unit, including those pertaining to James’ father and his siblings.

James was a young man who had been living with his parents prior to his SCI. He was in a relationship with a girlfriend, and they had a young son together. When his SCI occurred the family was in the midst of a time of conflict, which according to James and Hazel mainly centred upon the relationships between James and his father and brother. Hazel reported that hurtful words had been exchanged only moments before the accident occurred.

The first interview with this dyad was held at the SIU about one year after James’ injury had occurred. He was close to discharge, and ready to return to his family home, a significant distance from Sydney. The second interview took place close to his home town, at a local venue. The following case study outlines James and Hazel’s accounts of the impact the SCI had upon them as a family.
6.3.2 **Existing sources of spirituality.** During the first interview, Hazel reflected upon religious faith. She described how although the children had all attended Sunday School, religious faith was seemingly not important to them prior to the SCI. Primarily, their source of spirituality was the meaningful connectedness with one another. They were a large, close family who considered relationships with one another to be of high importance, despite the significant conflict also reported.

6.3.3 **A new source of spirituality.** Hazel recounted how she and her husband had been amazed by the number of off-duty helping professionals (paramedic, nurse) who had arrived at the scene of the accident within minutes. These circumstances led to a profound meaning-making response.

*We talked about it all week and just said ‘Is this just so strange that all those people, with all those, with all that profession, were there, in that place, at that time’...that’s why me and my husband, SCI’s father, believe that He [God] was there watching over us and everything. We really believe that He put those people there.*

As she and her husband reflected upon this in the Intensive Care Unit and during the early weeks of James’ hospitalisation, they drew the conclusion that God had looked after James. Such a conclusion led to significant changes for several members of the family, including James, Hazel, her husband, and one of her daughters. Each sought out a deeper religious faith, primarily through prayer.

6.3.4 **Faith tested.** At the same time that a new religious faith was developing, it was also tested. When James’ SCI occurred, it happened suddenly and in the midst of an argument with his father. In the early days after the SCI, Hazel reported how she and James’ father tried to make sense of what had happened. Dominating their discussions were a number of questions. “These things happen for a reason. But at first it was like
‘why?’ Why did it have to be this bad?’” (Hazel, interview 2). They began to ask themselves whether they had done something wrong which had brought the SCI about.

“Yeah, we went down to the chapel, me and SCI’s father, and we sat in the chapel, [pause] “What did we do?” We thought we did something wrong”.

As the family sought answers to the questions they were faced with, they cautiously tested out their new-found faith. Hazel recounted how James father began praying every night, and went on to seek signs from God, something which would tell him “that James is going to get through all this and he is going to be back to the old James”. According to Hazel, these signs were answered through experiences such as a lightning flash at the time of his prayer.

6.3.5 Family Relationships tested. In addition to reassessing their faith in God, relationships with one another were also tested. During the early period after James’ SCI, Hazel recalled the whole family’s response: “So, after sitting back and talking about, discussing, analysing... we came to a peace within ourselves to [pause] to just be there to support him, to be there behind him, we’ll get him through this” (interview 1). The family’s desire to ‘be there’ for James, and to support him, was something which was arrived at together, through a process of discussion and analysis. This family made a conscious decision to turn from conflict, to one of love and support.

6.3.6 Sources of spirituality strengthened. As James became conscious of having sustained a SCI, he also experienced a new-found faith in God. Like Hazel, James reported that he had felt watched over at the time of the accident, and spoke of a new belief and confidence in God. “Believed that he was there, and he was looking over us...and he was going to be there for me, and for my mother, for my Dad, for all of us, for my family”. When asked how he felt about God, James said “I love God now, because he was there, he was there. He’s been there my whole life.”
The family’s newfound religious faith led to gratitude for a second chance at life, and a greater appreciation for life and others. The impact the accident had upon the relationships within the whole family was noticed by Hazel. In Hazel’s words, “we have a new appreciation of each other”. She went on to say: “And there’s a much more grasping...grasping every moment that you can [pause]. And saying, you know, telling the people that mean the most to you ...we’re always making sure we tell them we love em” (interview 1). Hazel also described feeling grateful to God, and during the first interview expressed the desire to attend church as a family, on at least an occasional basis, “to give our thanks”. At the second interview six months later, Hazel admitted that they had not made it to church as she had thought they might. However, she stated that she continued to feel grateful, giving “thanks to Him [God] every day”. Six months later, her thanks was directed to the help she perceived God provided getting James up every morning and participating in life. When asked what message she could take away from this time, Hazel’s response was “Yeah, just to not take life for granted. You know, live every day like it’s your last and get out there and get involved”. Like other participants commented, life was perceived now by Hazel to be a gift, and relationships with one another a significant part of that gift.

Hazel observed changes in James too. According to Hazel, when James heard his younger siblings arguing or saying ‘I hate you’ he would respond with “you shouldn’t say that. That could be the last thing you say to your brother”. While in hospital away from his family, Hazel described how James would send messages every night telling his siblings that he loved them. Hazel’s desire to remind her family to love and appreciate one another daily was still very present six months later. “Love the people around ya. You know that’s my biggest thing that um I think the whole family’s gotten stronger in that way in that sense, real closer, we talk to each other you know”
(interview 2). Hazel’s hope was that this growing closeness and love for one another would continue to be sustained in the family beyond the immediate crisis of the SCI.

6.3.7 Decrease in religious faith. When asked about his faith during the second interview, James reported that he had not prayed for a long time. He did not answer several questions about his faith, and in these pauses it was Hazel who provided an explanation. Hazel described a number of challenges they had encountered after discharge, including difficulty finding and keeping suitable carers, a delay in finding accessible accommodation, the suicide of another SIU client post-discharge, and the death of a family member. Prior to discharge, James had been in hospital for a year. His mother Hazel likened discharge to being released from jail. She described James feeling overwhelmed, and struggling with a lack of motivation, “...you come out but it’s overwhelming. It’s ‘what do we do now?’, you know. Which direction do we go?”. Hazel expressed the belief that these challenges had been very difficult for James, and had possibly discouraged his newfound faith in God. James declined to comment on these challenges himself.

In contrast to James, Hazel reported that her own newfound faith continued to be important in her life, and described that this was also true for James’ father. Hazel continued to express gratitude to God. She also spoke of a church group who visited her husband at their home, something which had commenced after the SCI.

6.3.8 Moving forward on the ‘journey’. Like others, the language used by Hazel depicted the sense of them being upon a journey. “There’s a road for him to travel, and he’s not going to do it alone”. James was on a journey with his family, and also with God. This belief assisted Hazel particularly, to find comfort and meaning in the circumstances of the injury and move forward. The experiences of James and Hazel demonstrated how sources of spirituality, such as a relationship with God and
meaningful relationships with one another, built gratitude, hope and deepening connections between them. The family became stronger, and more resilient, by drawing upon and deepening their sources of spirituality.
Chapter Seven: Results - Qualitative component (C3)

Staff Focus Groups

7.1 Introduction

The first two components of this study highlighted the important role spirituality plays after SCI in building family resilience. The first component of the study (C1) demonstrated that spirituality was strongly associated with resilience, life satisfaction and positive affect for both individuals with SCI and their family members. The thematic analysis conducted during the second component (C2), highlighted the different sources of spirituality participants drew upon, their meaning-making responses towards the testing of these sources, and how this then assisted them to move forward as they expressed gratitude, held onto hope and deepened connections with others. In light of these findings, it was considered important to investigate the perspectives of health professionals (HPs) regarding the role of spirituality during inpatient spinal rehabilitation, and to explore the relevant clinical implications and service applications. To do so two staff focus groups were held.

7.2 Sample

Each focus group consisted of six HPs recruited from a single centre (the Spinal Injuries Unit at Royal Rehab). HPs from Occupational Therapy (4), Nursing (3), Psychology (2), Medical (1), Social Work (1), and Physiotherapy (1) were represented. 11 of the 12 HPs were female. Years working in the field of spinal cord injury ranged from one to 21 (years of experience: M=7.9, SD=8.2). From a list of possible religious backgrounds, eight HPs identified as ‘Catholic’, one as ‘Anglican’, and three as holding ‘No religion’.
7.3 The Focus Group Interview

Each focus group interview consisted of a number of questions, aimed to explore the topic of spirituality with HPs (see Appendix D). At the beginning of each focus group, HPs were invited to express their own understanding and perceptions of the word ‘spirituality’. Other questions included in the focus group interview included:

- What difference do you think spirituality makes in spinal rehabilitation?
- How are the spiritual needs of clients and their families currently addressed in spinal rehabilitation practice?
- How could the spiritual needs of clients and their families be better addressed?

As outlined in the Methods Chapter, the second focus group incorporated material from the responses of HPs in the first focus group, in addition to data collected from the family interviews. The duration of each focus group was approximately one hour. Thematic analysis of the data generated from the two focus groups is presented in Table 23 and discussed in detail throughout this chapter.

7.4 Identified Themes

7.4.1 Conceptualisations of spirituality. HPs’ conceptualisations of spirituality were wide-ranging. While a few HPs had very clear ideas about the meaning of spirituality, others were more tentative, and a few described how their understanding of spirituality had changed over time. From the thematic analysis, three key sub-themes were identified. Spirituality was conceptualised by HPs as: i) a sense of meaning or purpose; ii) a belief in, or connection to, something or someone; and iii) life values or ‘goodness’. Although there was no specific reference towards religious beliefs or doctrine, during the focus groups a strong association was made between spirituality and religion. Furthermore, most of the examples provided by HPs during the groups were of clients who held religious beliefs.
Table 23

*Themes identified from the focus group data*

<table>
<thead>
<tr>
<th>Theme 1: HPs conceptualisations of spirituality</th>
</tr>
</thead>
<tbody>
<tr>
<td>• A sense of meaning or purpose</td>
</tr>
<tr>
<td>• A belief in, or connection to, something or someone</td>
</tr>
<tr>
<td>• Life values or goodness</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Theme 2: Spirituality perceived as a help, providing:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Support from a spiritual community</td>
</tr>
<tr>
<td>• Hope</td>
</tr>
<tr>
<td>• Purpose</td>
</tr>
<tr>
<td>• Family connectedness</td>
</tr>
<tr>
<td>• An ability to cope</td>
</tr>
<tr>
<td>• A way to move on</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Theme 3: Spirituality perceived as a hindrance</th>
</tr>
</thead>
<tbody>
<tr>
<td>• God will heal me</td>
</tr>
<tr>
<td>• Anger towards God</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Theme 4: Ways spirituality is currently addressed</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Enabling clients to participate in religious activities</td>
</tr>
<tr>
<td>• Assessment (Psychology, Social Work only)</td>
</tr>
<tr>
<td>• Formal groups – meditation/relaxation</td>
</tr>
<tr>
<td>• Informal ‘chats’</td>
</tr>
<tr>
<td>• Imparting hope</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Theme 5: Perceived barriers to incorporating spirituality into practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>• A private matter</td>
</tr>
<tr>
<td>• Professional boundaries</td>
</tr>
<tr>
<td>• Staff discomfort</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Theme 6: How spirituality can be better incorporated into practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Creating spiritual space</td>
</tr>
<tr>
<td>• Incorporation into rehabilitation processes</td>
</tr>
</tbody>
</table>

*A sense of meaning or purpose.* Spirituality was described by one HP as “something that gives you meaning in life”. Others agreed with this definition and could provide examples of clients with spiritual or religious beliefs who believed their SCI had occurred for a reason. According to the HPs such clients construed the SCI as meaningful because it was part of ‘God’s plan’. They had survived the SCI and now had
a ‘second chance’ at life. Spirituality was also described as something for clients and their family members to hold onto during a “really awful time”.

**A belief or connection to something or someone.** Second, spirituality was described as a belief in, or connection to, something or someone. Two contrasting perspectives were expressed by HPs regarding the relationship between spirituality and religion. Whereas some HPs believed that the two concepts were interchangeable or very closely associated, others considered them to be separate entities. One HP described how she believed spirituality to be very closely related to religion: “Yes, I link it to God. For me it’s a religious thing. But a deep, meaningful, almost a core feeling”.

For others, the meaning of spirituality was more diffuse. Spirituality was considered to be a belief in *something*, whether it be God, the ‘supernatural’, something ‘beyond this world’, or just something bigger or greater than oneself. This belief was considered to be a source of hope and comfort. As one HP put it: “… it’s that overall sense of belonging or a belief in something …yeah, generally a belief in something or connection to something”. What that ‘something’ was, was not specified.

**Life values or ‘goodness’**. Several HPs expressed that they perceived spirituality to relate to how people lived out their beliefs, or applied them in their lives. This was particularly so in relation to care or compassion for others. One HP focused on the concept of ‘goodness’, a word also used by a family member during the interviews.

*I see it as ‘spirit’, as a good thing within your (pause) soul. And so that spirituality is how you bring that goodness out… I think it’s that sense of wanting to look out for other people. How can you help somebody else? Or finding the goodness in other people: so, treating people well, with respect, with kindness, for me that’s… what the basis behind religion I guess was and still is....*
It was also suggested that spirituality was closely associated with one’s life values or morals.

7.4.2 What difference does spirituality make? When HPs were asked to consider what differences they perceived spirituality to make for clients and their family members on the SIU, responses varied. Although examples could be provided of how spirituality was a help for many after SCI, there were also accounts of times that HPs felt spirituality, or more specifically, religion, had been a hindrance during the rehabilitation process. The ways that HPs perceived spirituality to be a help will be considered first.

Spirituality as a help. Six sub-themes were identified from the data, which depicted how HPs perceived spirituality to be a help during rehabilitation. Spirituality was observed to provide: i) support from a spiritual community, ii) hope, iii) purpose, iv) family connectedness, v) an ability to cope, and, in some cases, vi) a way to ‘move on’. These are discussed in further detail below.

Support from a spiritual community. During both focus groups, HPs could recollect situations in which SIU clients had received both practical and emotional support from their spiritual community. For instance, examples were given of priests visiting congregation members to give communion, or fellow believers arriving to conduct a Bible-study. There were also examples of such communities providing an incentive for SIU clients to take leave from the hospital to attend a religious service. In one focus group, HPs discussed the needs of a current client who was a Catholic nun. This client’s spiritual community was described as being like family to her, and a key support after discharge.

Hope. Many HPs considered spirituality to be closely associated with hope, whether it was hope for a miraculous cure, or for other things in life. Spiritual beliefs
were seen as one way that a “sense of hope and positivity” could be provided “through a really awful time”. Although HPs could recollect situations where they felt hope was unrealistic and unhelpful during the rehabilitation process, there were also accounts of those whose hope helped them, and continued to help them in the community. Examples were provided of community clients whose hope in recovery had changed, but who remained hopeful. As one HP put it, “they’re still living the hope of a miracle, but they don’t know what the miracle is”.

**Purpose.** Providing purpose or meaning in life was another way that HPs perceived spirituality to help SIU clients and their family members. This was deemed to be particularly true for those clients with spiritual or religious convictions. It was thought that clients who believed this was “part of the plan for them” were less frustrated and more accepting of challenges that they encountered. One HP suggested that trusting in God assisted clients by taking away:

> that focus of me, me, me, me, me, me, why’s this happened to me? I can’t believe this happened to me. But yeah okay it has happened to me, I’ll work hard and God will then somehow show me how I can, you know, continue living my life.

HPs could recall times when clients told them how the SCI had changed the direction of their lives and put “meaning into their life after the SCI”. According to the HPs, for these clients and their family members the SCI was viewed as a “second chance”, and the best thing that had ever happened to them.

**Family connectedness.** For the most part, focus group discussion focused upon the coping and adjustment of the individual with SCI, rather than their family members, or the family as a whole. However, in one focus group, further reflection upon the family experience of spirituality was provided by a Social Worker. This HP expressed
how she felt spirituality assisted the whole family to make sense of life after SCI. Her observation was that those families with spiritual beliefs had a greater connectedness, a connectedness on “another level” almost “above the family”. Such connectedness within the family system assisted the family to “make meaning of what’s going on”. As the needs of family members are often considered the domain of Social Workers within spinal rehabilitation, these comments by the Social Worker were considered to offer valuable insight and worthy of inclusion.

*An ability to cope with SCI.* Spirituality was also viewed by HPs to provide clients and their family members with a way to cope, “something to hold on to or to help you through it [the experience of SCI]”. One of the Psychologists indicated how the practice of prayer or meditation could assist individuals in their process of adjustment.

*When I talk to clients about their coping approaches, even though they might describe not being religious at all they might still use that term [prayer] and just some of the cognitions or the self-talk that they’re doing in their own mind as well which gives them comfort.*

Such an example demonstrated how a practice associated with religious activity was perceived to be a strategy which could be used by others to help them cope.

Another HP provided the example of how a client’s religious faith had helped the client to cope, not only through the experience of his SCI, but his house burning down shortly after discharge. “*But it was like what else can life throw at this man, and for him to retain his faith? You just go well there’s a strength in there somewhere that’s getting that man through life. He hasn’t given up*”. As an interesting aside, the HP suggested that it was one of the therapists working with this client who found his perspective most challenging.
But I saw the therapist really struggle with this guy who was ‘I’m going to be saved it’s all going to be alright in the end’ and then I think back and I go well... life is alright for him in the end because he is still alive and he still has his faith...and his wife and his family, and they were the important things.

The sub-themes of hope and purpose outlined above, were closely associated with this ‘ability to cope’ which HPs perceived religious faith to provide.

A way to ‘move on’. Lastly, spirituality was observed by HPs to be something which helped SIU clients to accept their situation and move forward. Although some HPs clearly associated this attitude with spirituality, others were uncertain about what it was that helped clients to arrive at a place of acceptance and move on.

I see some clients who deal with their situation remarkably well and there doesn’t appear to be any spiritual link or any belief, but there must be something for them to believe like that, but I don’t know what it is.

One client who was perceived to have coped well was described as an “Aussie bloke” with a “get on with life” attitude’. HPs expressed admiration for such clients who could move on from the SCI. One HP suggested that not knowing how people coped, or the patterns “behind how they accept it and how they get on with things”, led to a dynamic workplace which was enjoyable to be a part of.

Spirituality as a hindrance. Rather than a help, some HPs viewed spirituality, and specifically religious faith, as a hindrance during the rehabilitation journey. Two sub-themes were identified. HPs perceived spirituality to be a hindrance when: i) clients believed they would be healed by God, and disengaged from rehabilitation processes, and ii) spiritual questioning resulted in anger or blame towards God which consequently affected other parts of an individual’s life.
God will heal me. The strongest sub-theme pertaining to spirituality as a hindrance, was the notion that clients might disengage from rehabilitation processes because they believed God would heal them. In such cases, HPs considered an interaction to occur between a client’s spiritual beliefs and their motivation for rehabilitation.

…the control is outside of them, it’s in a higher being, it’s in God, and they put everything in God’s hands. And so, although on the one hand that’s positive because it gives them hope and it keeps them going…on the other hand they do sometimes seem to sit back a bit and think ‘It’s okay, I’m going to get better because God’s going to heal me’.

The HPs expressed how such perspectives were frustrating at times. For instance, ordering equipment was difficult for an individual who did not think they would need it. It was also noted by HPs that those who hoped for healing would take longer to get closer to a point of acceptance because they “they don’t seem to be able to hear what the team is saying to them about their situation”.

Anger towards God. HPs cited examples of clients who expressed anger towards God, or blamed God for their SCI. This blaming could become an “I hate everything” attitude. In some cases, this anger at God had was perceived to have brought about division amongst family members, rather than connectedness. Of one family member it was said:

He was kind of very cross with God that this had been allowed to happen to their family member (injured relative), whereas the other part of the family were saying, you know it’s okay, we’ve got hope, we’ve got belief.

Such anger was seen to be associated with the question, ‘why me’, or possibly ‘why them’ or ‘why us’ if the SCI had occurred to a relative.
7.4.3 How is spirituality currently incorporated into rehabilitation practice?

When asked how spirituality was incorporated into current practice, most of the HPs reported that spirituality was not a topic directly addressed in their work with clients or their family members. Five subthemes were identified regarding ways that spirituality was currently addressed by HPs. These included: i) HPs facilitating clients to participate in religious activities, ii) through assessments conducted by Psychologists or Social Workers, iii) via meditation in therapeutic groups iv) during informal ‘chats’, and v) by HPs imparting hope.

**Facilitating clients to participate in religious activities.** As mentioned earlier in this chapter, one of the clients mentioned during the focus groups was a Catholic nun. HPs described how they had incorporated the role of this client’s religious community into her rehabilitation goals, therefore acknowledging the importance of this support in her life. Others cited examples of enabling clients to be able to access their churches, or how they had accommodated particular dietary restrictions which were part of a client’s religious beliefs. One HP spoke of a client who had a Bible study timetabled into her weekly program.

**Assessment by Psychologists or Social Workers.** Both the Social Worker and two Psychologists attending the focus groups spoke of how clients’ spiritual beliefs were recorded in their initial assessments. Psychologists in both groups spoke about an initial assessment with clients which addressed their life values. This assessment was conducted early in their admission to the SIU. One Psychologist explained: “Yes, so it’s looking at what’s most important to them and areas of their life that are most important to them whether it be family, education, work, community, environment, and spirituality is one of those domains”. Furthermore, at the time of the groups, the SIU was conducting multidisciplinary assessment meetings with each client shortly after
admission. Although spirituality was not specifically referred to during this assessment, HPs acknowledged that such topics might arise. “I think in the multidisciplinary assessment ...we tap into it to a certain degree when we ask who are your support systems or some of that”.

Other HPs believed that raising spirituality in the first few interactions was too early: “…it’s not a question you can ask straight up”. Instead, they suggested an awareness of client’s beliefs emerged over time as they got to know the client and their family better. “…I think sometimes it’s something that emerges in the person and you see it through their behaviours or their decision-making process…”. This information might also be provided through Social Work reports, information in the file, or by observing religious objects in the client’s room.

**Relaxation/meditation group.** One other formal intervention regarding spirituality was mentioned by HPs. The Psychologists reported how they ran a relaxation group program for clients which incorporated the practice of meditation. One of the Psychologists explained that although it was called ‘relaxation’, “it’s actually meditation, because most people go ‘ooh, don’t want to meditate’. Well they are”. No other formal staff interventions were mentioned.

**Informal chats.** HPs stated they were more likely to discuss spirituality with clients and their family members during informal ‘chats’. This was contrasted with formal assessments, where it was felt asking a client directly about their spiritual beliefs might be too direct or confrontational. Informal chats occurred when the HP had more time, such as during a car journey for a home visit, or when assisting a client with personal care tasks. One nurse commented that at these times it was also easier to share about oneself:
Like I have a habit, if I’m … doing something that takes a long period of time with the client I will engage in just general social conversation. You know what I did on the weekend … and then you will find that they will share information about their families and things like that as well… it’s amazing sometimes what you do pick up and what you do learn about clients and their families.

One of the Occupational Therapists described how helpful it could be to find out about clients during visits to their home, especially during the car journey. “And you’re sitting in the car with them driving for an hour and all sorts of conversations come up”. The same HP noted that awareness of what was happening in a client’s life could direct what was discussed in therapy sessions. Acknowledging that the individual “might be on a rollercoaster ride of belief, spirituality, acceptance…” led to the HP being ready to “jump on the ride at any particular point”. So, this HP suggested, finding out more personal information, possibly gained from home visits or informal chats, could be very useful in directing therapy.

**Imparting hope.** Finally, one participant commented that they believed part of the role of the HPs was to impart hope to clients on the unit. This wasn’t a role the HP currently associated with spirituality, but she deemed it to be very important in assisting clients to realise that life was still worth living. She put it this way:

> Cause we always want to give hope…and being positive is not about, again, everything’s going to be okay… but it’s about yeah being positive that whatever you want to do is still possible in a different way but it’s still possible… these are tools that we use to keep them involved and keep them motivated and to keep them going.

Such a perspective aligned closely with the theme identified during the family interviews, that of ‘moving forward on the journey after SCI’.
7.4.4 Perceived barriers to incorporating spirituality into practice. In their discussion of how spirituality was currently addressed in the rehabilitation unit, HPs identified three perceived barriers regarding the incorporation of spirituality during their practice. These were: i) spirituality was considered to be too a private matter to include in rehabilitation, ii) professional boundaries limited the amount of personal information that could be shared, and iii) staff discomfort when religious beliefs were shared by clients.

A private matter. One HP commented that she felt spirituality was a topic too personal for her to discuss with clients: “I personally try not to sort of pry on that level. If they want to bring it up they can bring it up but I don’t really ask those sorts of questions”. Others reflected how everything else about an individual’s life is discussed with the team, including sexuality, and bowel and bladder management. “Yeah, they can have [spirituality] to themselves, because now everything else to do with their body is tapped into and out in the open for the whole team to know about”. For these reasons, spirituality was considered by some HPs to be one thing the client should be able to maintain as a private matter.

Professional boundaries. Associated with the notion of privacy, was the idea that therapist-client boundaries hindered discussion of such topics. As one HP commented, “I don’t talk about myself to clients… but that probably hinders how much they share with us”. The discomfort caused when clients did share beliefs with HPs also resulted in them being more cautious about what to discuss during therapy sessions.

Staff discomfort. Lastly, HPs mentioned that unwelcome sharing of beliefs between clients and staff increased their reluctance to discuss spirituality. One HP spoke of her discomfort when a current client shared Bible verses with her.
I often feel very uncomfortable when I’m in a room and she likes to share verses with me and that’s not my belief, and I support her in whatever belief but feel awfully uncomfortable sometimes when it’s kind of forced at you.

Examples were also provided of family members attempting to share their beliefs with clients. Family members with strong religious beliefs had been observed to “try and present that to the client who may not be religious”. One client in particular was identified as having made derogatory remarks about his “religious sister”.

7.4.5 How can spirituality be better incorporated in rehabilitation practice? It was agreed by most participants that spirituality could be better addressed at the SIU with both clients and their family members. The HPs made a few observations regarding how spirituality could be better incorporated, and these have been grouped into two sub-themes: i) creating spiritual space, and ii) rehabilitation processes.

Creating a spiritual space. It was observed during the focus groups that clients of the SIU did not have access to a chapel or prayer room. This lack of physical space, specifically dedicated to meet clients’ spiritual needs, was perceived to be a limitation. HPs commented that they had been to larger hospitals where chapels and prayer rooms existed, and were well used by clients and their family members. One HP recalled seeing a prayer room at a theme park when on holidays with her family, and had reflected on the absence of such space in her workplace: “... we don’t have a room for anybody to pray to Mecca we don’t have a prayer room...we don’t have a chapel. We have nowhere that people could meditate...”. Furthermore, it was noted that there was also no chaplain, Rabbi or Imam at the hospital. All such roles were provided by volunteers from outside the centre.

Another feature of the SIU identified by HPs was the lack of access to the outdoors in the evenings, especially for those with high level SCIs. In response to the
findings from the family interview data one HP pointed out that clients who wished to gaze at the stars in the evening must overcome the challenge of the SIU being locked. If they wanted to look at the stars, a special request would need to be made to the staff. This HP commented:

*I think the system probably doesn’t allow them the freedom to tap into their spirituality ... If lock down’s 8 o’clock... but they want to look at the stars they can’t do that. However, if we know that that’s something that’s important to that person then we can probably accommodate it.*

HPs could identify clients they had worked with who had benefitted greatly from the natural environment. They described one particular client who couldn’t “*see any green from her room*” when she arrived at the unit. Because this was such a significant source of spirituality for her, her need was addressed by moving her to another room. However, it was acknowledged that such needs were not always so easily accommodated.

*Rehabilitation process.* Spirituality was considered to be a topic which was often forgotten because “*it’s not embedded in our processes*”. The second way that HP considered spirituality could be better incorporated at the SIU was through formal client meetings such as the multidisciplinary assessment meeting. This meeting occurred early in a clients’ admission. It was noted that no formal questions regarding a client’s spirituality was asked during this meeting, though the topic might arise during the general discussion. A few HPs suggested that introducing formal questions might be helpful:

*It’s maybe something we could incorporate at the beginning of our process, at the MDA [multidisciplinary assessment meeting] we could certainly put something in there. Because I’m thinking there’s other ways people express*
such a perspective contrasted with the opinions of other HPs, who as noted earlier, considered spirituality to be something which was best addressed over time.

Another rehabilitation process referred to was client goal planning meetings. These meetings were held on a monthly basis, and were attended by the client and the team. The aim of the meetings was to review the client’s goals and discharge plans. It was suggested by HPs that spirituality could be included as a topic at such meetings. This might assist clients to know what was available to them at the SIU, for instance, knowing they could invite a priest from their own church to visit. Currently, HPs reported, clients would just arrange this themselves “very quietly”.

While HPs were willing to consider ways that spirituality could be better incorporated and addressed during rehabilitation, there was also some hesitation. The perception of several HPs was that spirituality is not relevant for everyone, and the topic required some delicacy when raised. In some cases, it was believed it should not be asked about at all. Furthermore, in both groups, spirituality was considered to be a difficult construct to quantify or measure, posing challenges in goal planning and outcome measurement.

7.5 Summary of Focus Group Component

Spirituality was considered by HPs to play an important role during after SCI, and could potentially provide clients and their family members with hope, comfort, and the ability to cope. However, spirituality, and specifically religious faith, was also at times viewed to be a hindrance, and a source of tension in families and between clients and staff. Although it was not generally incorporated into formal sessions, HPs were able to identify times that spirituality was discussed with clients during more informal
periods, when time was available. HPs identified that spirituality could be better incorporated into rehabilitation practice by providing a spiritual space for clients and their family members, and included in rehabilitation processes such as the multidisciplinary assessment and goal planning meetings.
Chapter Eight: Discussion

8.1 Introduction

This study investigated the contribution of spirituality toward family resilience after SCI by adopting a mixed methods approach incorporating both quantitative and qualitative data. In a number of ways this study was unique. It is the first study to have specifically considered the construct of spirituality within the family after SCI and to have investigated spirituality among health professionals (HPs) working within a spinal rehabilitation context. It is only the second known study to have investigated the relationship between spirituality and resilience, and the second to have investigated spirituality after SCI within an Australian context. Furthermore, adopting a robust mixed methods approach incorporating data from multiple stakeholder perspectives, including individuals with SCI, their family members, and health professionals (HPs), allowed spirituality and other closely associated concepts to be explored in greater depth than in previous studies.

Findings from the quantitative component of the study demonstrated that spirituality was significantly associated with other measures of positive adjustment, including resilience, positive affect, and life satisfaction. This was the case for both individuals with SCI and their family members. Furthermore, regression analyses revealed that spirituality, together with resilience, made a significant contribution to positive affect among individuals with SCI, and to lower levels of depression among family members. Spirituality alone made a significant contribution to decreased levels of negative affect among family members.

Findings from the family interviews, held with 10 individuals with SCI and their family members, revealed that participants drew upon a range of different sources of
spirituality after SCI. Identified sources of spirituality included religious faith (encompassing a personal relationship with God), the natural world, inner strength, and meaningful connectedness with others. Testing of these sources of spirituality led to a number of meaning-making responses, which resulted in families expressing gratitude, holding onto hope, and deepening connections with one another. These outcomes assisted the family to make meaning from their experience, and move forward in their journey following SCI. Positive and meaningful interactions between the injured individuals and their family members demonstrated the importance of taking a whole family approach.

The two focus groups with SIU staff highlighted that although spirituality was observed by health professional (HPs) to play an important role in spinal injury rehabilitation, it was not well addressed in practice. Most interactions between staff and clients regarding spirituality were informal, rather than specifically incorporated into the rehabilitation process. HPs suggested that rehabilitation processes and the use of physical space at the SIU could be reviewed, so that the spiritual needs of clients and their family members could be better addressed. HPs identified a number of perceived barriers to incorporating spirituality into their practice, including staff discomfort and time.

One of the benefits of a mixed methods approach is that deeper explanation and understanding can be achieved, as different components of the research are compared and contrasted with one another (Cresswell, 2009). This study provided different yet complementary findings from the quantitative and qualitative components, and up until this point they have been reported separately. In this chapter, key issues across all three components will be considered, and compared and contrasted with current theory and research within the fields of SCI and disability. These key issues are: spirituality and its
relationship with religion; the strong association between spirituality and positive adjustment after SCI; and barriers encountered by HPs regarding incorporating spirituality into their practice. Following discussion of the findings in relation to these issues, specific implications for SCI rehabilitation will be considered. Lastly, limitations of this study and recommendations for practice and future research in this area will be outlined.

8.2 **Spirituality and its relationship with religion**

As alluded to in Chapter One, and demonstrated by the scoping review in Chapter Two, much of the debate surrounding the conceptualisation of spirituality centres on its relationship with religion. Despite broad and inclusive definitions of spirituality, which have incorporated elements such as connectedness, meaning, and transcendence (Canda & Furman, 2009; Hungelmann et al., 1985; Meraviglia, 1999), a recurring issue has been how such definitions either encompass, or are set apart, from religion and religious belief. Clarifying the relationship between these two entities is arguably central to future research in the area.

Unlike most other studies in the area of spirituality and SCI, this study adopted a mixed methods approach to the topic. This enabled different types of data to be collected from participants, which together provided valuable insights regarding how participants understood the concept of spirituality. Specifically, quantitative data which measured spirituality via the FACIT-Sp-Ex (Peterman et al., 2002), could be triangulated with qualitative data, which explored participant understandings of spirituality in greater depth. From the data, the following key findings emerged, and will be discussed below:

i) Different conceptualisations exist regarding spirituality and religion; and this has important implications for measurement and future research
ii) For many, religious faith plays a unique and important role after SCI

iii) Religious faith can lead to existential questioning and struggle

8.2.1 Different conceptualisations of the relationship between spirituality and religion. As highlighted in Chapter Two, the majority of studies on spirituality after SCI have been conducted within either the USA or the Middle East. The samples in these studies have tended to be from similar cultural religious backgrounds, predominantly Christian (USA) or Muslim (Middle East). In contrast, research conducted in an Australian health setting has reported how a multitude of different faiths and cultural backgrounds can be represented at the one hospital (Hilbers et al., 2010). This multi-faith context raises particular challenges for the study of spirituality in Australia.

This study provided some original findings on how the relationship between spirituality and religion was experienced, conceptualised and understood by participants. Relevant findings from each component of the study on this issue will be presented first. This will be followed by a discussion of the implications these findings and others have for the measurement of spirituality.

Administered surveys: Contrasts between spirituality and religious faith.

Among the participants who completed surveys in the quantitative component of this study, 58% (n=50) of the individuals with SCI and 74 % (n=50) of the family members identified with a religious affiliation. The Muslim, Jewish, Mormon and Christian faiths were represented. In contrast to most other studies investigating spirituality after SCI, a wider range of faiths were represented in the current study, and a larger proportion of participants identified as non- religious; 42% (n=50) of individuals with SCI, 26% (n=50) of family members. For instance, Matheis, Tulsky and Matheis (2006) reported that 98.7% of their sample engaged in some type of religious beliefs or practice, and
Marini and Glover-Graf (2011) that 72% of their sample believed that God or spiritual beliefs gave them meaning and purpose. The figures in this current study are comparable with, or higher than, Australian census findings. According to the 2011 Australian Bureau of Statistics, 22.3% of Australians identified as non-religious. This was an increase from 18.7% in 2006 (Australian Bureau of Statistics, 2011). Although such figures reveal information about the status of religious faith within Australia, they do not provide insight regarding other sources of spirituality that the ‘non-religious’ might access.

The administered surveys revealed some interesting findings regarding the perceived relationship between spirituality and religious faith. Surprisingly, there was no association between FACIT-Sp-Ex scores (overall or Faith subscale) and religious affiliation among the individuals with SCI. A different pattern was observed among the family members, with strong correlations observed between religious affiliation and both the overall FACIT-Sp-Ex score and the Faith sub-scale. The reason for the difference between the individuals with SCI and the family members cannot be determined from the findings of this research. As already pointed out, no other research has been conducted among the spirituality of family members after SCI. Therefore, there were no other studies to compare these results with. A confounding factor might be that the majority of family members in this study were female, whereas the individuals with SCI were predominantly male. This is typical of other SCI populations. Further research would be required to explore whether gender, together with other factors such as age, might influence findings on spirituality.

Further demonstrating the complexity of the relationship between spirituality and religion were contrasting findings on the two FACIT-Sp sub-scales. Different associations were observed between the FACIT-Sp Meaning/Peace sub-scale and
outcome variables, and the FACIT-Sp Faith sub-scale and these same outcome variables. Although the Meaning/Peace sub-scale correlated highly with resilience, life satisfaction, positive affect and depression for both the individual with SCI and their family members, the Faith sub-scale of the FACIT-Sp did not. Similar results have been observed by others. In a study of religiosity and depression in patients with prostate cancer, Nelson et al (2009) found, as this study did, that whereas the FACIT-Sp Meaning/Peace sub-scale was a significant predictor of depression, faith was not. However, other studies have reported different results. In their recent Australian study among individuals with SCI, Siddall, McIndoe, Austin and Wrigley (2016) found the FACIT-Sp Faith sub-scale, although demonstrating slightly weaker correlations, was still significantly correlated with life satisfaction, depression, interference with life, pain self-efficacy and pain intensity. Such disparate findings suggest that experience and understanding of religious faith may vary between different samples (and even within the one sample), bringing about different, and in some cases contrasting results.

The findings of the quantitative component highlight the challenges of understanding the relationship between spirituality and religion. Unexpected findings between the relationship between nominated religious faith and spirituality, between individuals with SCI and family members, and between this study and others, emphasised the importance of exploring this relationship further using a qualitative approach. How the qualitative findings complemented the quantitative results is outlined next.

**Family interviews: Perceived meaning of spirituality and its relationship with religion.** A range of religious faiths and cultural backgrounds were represented among the 10 family dyads who participated in the interviews. These included Christianity, Islam and Hinduism. Many similarities among the participants with religious faith were
observed. For those with strongly-held religious faith, spirituality was closely associated with religion, and considered to be very important to their worldview and to how they sought meaning. For instance, a key source of spirituality for such participants was their religious faith and personal relationship with God.

Importantly, many of the participants with religious faith trusted God with their situation, and experienced a sense of protection either at the time of the SCI or afterwards. This was evident in the interview with a dyad who held Muslim beliefs, who attributed all things to God and believed that everything in their lives had been already decided for them. The attitude of this dyad was consistent with other research conducted within a Muslim context (Babamohamadi et al., 2011; Parashar, 2015) where the SCI (and possible healing and recovery) were considered to be completely in the hands of God. Another similarity among those with religious faith was the value placed upon connection with God, through prayer or religious Scripture. The role of prayer is discussed more fully later in this chapter.

Despite the similarities among the participants with religious faith, participants also expressed differing ideas regarding their perception of God’s role in the SCI. Whereas some hoped for healing and anticipated that God would provide such help, others placed hope in God being with them on the journey, or looked towards heaven. The role of hope and how the findings of this study compare with other hope studies, is explored in more detail later in the next section. Although some participants sought meaning in the events of the SCI, others accepted the SCI as having ‘just happened’. These differing notions regarding the role of God and religious faith impacted upon how these participants viewed spirituality.

Like Hilbers et al (2010) these findings demonstrated that religious faith is not a concept which can be easily contained to only one understanding, or definition, and that
its meaning varies greatly among different individuals and families, and between
different religions. Hilbers and colleagues, found that among clients in a health setting
there could be “huge diversity” even within the one faith group, and that “understanding
the meaning of spirituality/religion from the patients’ perspective” was crucial (p.7).
These findings suggest that further exploration of individual experiences of religious
faith is required.

The range of perspectives expressed regarding religion in the family interviews
raised some challenges in this study. For some participants, substantial exploration and
explanation around the concept of spirituality was required, so that discussion regarding
sources of spirituality other than religious faith could occur. As noted in the Methods
Chapter, a broad definition of spirituality was included in the interview protocol, to
assist participants to think about different sources of spirituality. As this same issue
around understanding of spirituality did not seem to be encountered in other studies, it
highlights another factor to consider for studies conducted within a diverse cultural and
multi-faith context.

**Staff focus groups.** Further insight into the complex relationship between
spirituality and religious faith was provided during the two staff focus groups with HPs.
Like the individuals with SCI and family members, HPs too held different
understandings of the relationship between spirituality and religion, and therefore
different conceptualisations of spirituality itself. For some HPs, spirituality was seen to
be closely associated with religion and this was apparent from the examples shared with
the group. The religious faith of clients was perceived to be both a help, and at other
times, a hindrance, in the rehabilitation unit. For others, however, spirituality was
conceptualised as separate to religion, and associated with connectedness, hope, and
moral goodness. Royal Rehab is not an organisation with any religious associations,
However, a relatively high proportion of the staff participants (9/12, 75%) identified as holding a religious affiliation (predominantly Catholicism). Whether such a finding is typical of health professionals in general would require further investigation.

**Implications of this study’s findings for the measurement of spirituality.** The findings of the qualitative components of this study suggested that measurement of the construct of spirituality is not a straightforward task. The varying perspectives identified among participants demonstrated how many individuals closely associate spirituality with religion, yet at the same time, hold very different views and experiences regarding religion itself. Cultural background, individual experience, and different outlooks, all seemed to influence this viewpoint.

A clear argument exists for a multidimensional measurement of spirituality that captures the different experiences among those who hold religious faith. Furthermore, the spirituality of those identifying as “non-religious” needs to also be taken into account. Many of the existing measures of spirituality do not encompass these differences, and therefore miss important data regarding the spirituality of participants. For instance, the Brief Multidimensional Measure of Religiousness/Spirituality (BMMRS) (Fetzer Institute & National Institute on Aging Working Group, 1999), used by Franklin (2008) in a study of spirituality among individuals with SCI, includes questions regarding congregational support and other religious activities strongly associated with the Christian faith. In that study, 96% of SCI participants identified as Christian. It was clear that the distinctions made by this measure may lack validity in other cultural contexts where many do not attend church, or receive that particular type of support. In this current study, only one of the 10 dyads described specifically receiving support from a church congregation. Many others, however, spoke of receiving significant spiritual support from friends or family, which would not have
been captured in the BMMRS.

Another way spirituality has been measured is by distinguishing between two types of spirituality; religious and non-religious. This approach is evident in the Spiritual Wellbeing Scale (SWBS) (Ellison & Smith, 1991), and was utilised by Matheis, Tulsky and Matheis (2006) in their study of spirituality and quality of life among individuals with SCI. The SWBS contains different subscales for religious and existential well-being. Within this measure, faith in ‘God’ is distinguished from general meaning-making about life (with no reference to God). However other sources of spirituality such as connectedness with others, nature, or oneself, are not incorporated. Like the BMMRS, such a measure also raises challenges in a context such as Australia, and other countries where a diversity of faiths are represented and where many different sources of spirituality drawn upon.

One of the most important aspects to arise from the family interviews was evidence that participants drew upon a variety of different sources of spirituality. A relationship with God was one of at least four sources of spirituality, alongside meaningful connectedness with others, inner strength, and the natural world. Yet, as observed by Davis et al (2015), the focus on religious spirituality within the wider spirituality literature has meant that other sources of spirituality have been excluded from consideration. For instance, even the FACIT-Sp-Ex includes two other sources of spirituality (connectedness with others and nature), but only in the extended version of the scale. Therefore, they are not represented alongside the Meaning/Peace sub-scale and the Faith sub-scale, on the original 12 item measure.

From the findings of a series of studies among undergraduates, Davis et al (2015), have argued for a “more flexible and fluid way of thinking about what spirituality is” (p.512). These studies led to the development of the Sources of
Spirituality (SOS) Scale. The SOS consists of five factors including: transcendent spirituality, theistic spirituality, self, nature, and humanity. These factors, and the sources of spirituality identified in this study, are consistent with the broad definitions of spirituality outlined in Chapter One, encompassing connectedness with God, others, self and nature (Hungelmann et al., 1985; Meraviglia, 1999). But despite this emerging research into spirituality, sources of spirituality other than religious faith are rarely acknowledged among measurement tools.

As reported in Chapter Five, for some participants in this study, looking up at the stars and realising there was more to life than just themselves, or connecting deeply with another person, were other ways of finding meaning and purpose, and transcending their situation. Further supporting the conceptual approach of Davis (2015), and unlike other studies which have considered it important to separate religion from spirituality (Matheis et al., 2006), this study considered religious faith to be a key, but not the only, source of spirituality. It is argued here that spirituality is a broad and fluid concept which encompasses meaning making and purpose across both secular and religious beliefs. Religious belief is indeed a very important source of spirituality, but is one of several sources of spirituality which individuals with SCI and family members may draw upon.

From this study’s findings, it could be seen that different sources of spirituality assisted individuals with SCI and their family members to move forward in their journey after SCI. Greater acknowledgement of the breadth of these sources of spirituality within various measures is warranted, to increase understanding of the extent of the concept. This is particularly so in contexts such as Australia, where large proportions of the population do not consider themselves to be religious.
8.2.2 The unique and important role of religious faith after SCI. Despite the complexity of the relationship between spirituality and religion, there was strong evidence across the qualitative components of this study that religious faith assisted many participants to move forward in their journey after SCI. As Figure 2 depicted, religious faith, and the subsequent testing of this faith, could lead to gratitude (for “a second chance”), hope (via prayer for healing), and deepening relationships (through a desire to honour God). The staff focus groups demonstrated that HPs also observed religious faith to be an important factor in providing hope, and therefore assisting families to move forward. Two of the key aspects of religious faith identified from the qualitative data are considered here: the importance of trust in a personal God; and the value of prayer.

Trusting in a personal God. For this Australian study, what seemed most important to participants was not the traditions associated with religion, such as whether they attended church, but whether they were in relationship with God. As outlined in Chapter Five, across many of religious faiths represented in this study was a belief in a personal God who provided comfort, hope and meaning. Participants with religious faith were often observed to be trusting of God, even in the midst of a test or challenge, hopeful of recovery and grateful. Observations from the staff focus groups further supported these findings. HPs suggested that religious faith helped families to trust that the SCI was part of God’s plan, that “there was something better for me around the corner”, or just to be able to “move on”.

Although some participants with religious faith sought a reason or purpose for the SCI, others considered a reason unimportant. For these participants, what was important was knowing God was on the journey with them. Like other sources of spirituality, religious faith provided a relationship or connection to something, which
enabled families to move forward with greater gratitude, hope and connection with others.

This study’s findings emphasise the point that religious faith is more than a public practice, or something only associated with social support, and that a personal relationship with God is a key aspect. However, few studies within SCI have specifically considered the latter. The two dimensions are often grouped together, and this is particularly evident in quantitative studies (Franklin et al., 2008; Matheis et al., 2006). In contrast, quantitative studies in the broader area of traumatic injury have supported the findings of this study that it is a personal relationship with God which is the significant factor in religious faith, rather than religious tradition or church attendance. In their study of religion and spirituality among individuals with traumatic brain injury (TBI), Waldron-Perrine et al (2011), found that subjective feelings of connectedness to a higher power were a unique predictor for life satisfaction, distress and functional ability. This was significantly more important than public religious practice or existential well-being. The only qualitative SCI study to specifically consider the positive aspect of religious faith from the scoping review was by McColl et al (2000), where participants’ trust in God’s plan and purpose was evident. Further studies exploring these different aspects of religious faith (personal relationship with God versus religious activities), utilising both quantitative and qualitative approaches, and conducted within an Australian context, are clearly warranted.

**Connection with God through prayer.** One aspect of religious faith which has received little attention in the area of SCI, yet emerged as an important aspect of many of the participants’ accounts in this study, was the practice of prayer. Prayer was described by the family interview participants as a way to connect with God, to ask for help and to receive comfort. Prayer was perceived as something individual and
personal, rather than a shared practice within the family. However, prayer from others was often appreciated, even if the individual being prayed for was not a believer. Several participants believed that God could bring about recovery in response to prayer. Prayer or meditation was also identified to be a helpful coping strategy by HPs. Once again, different participant experiences were evident among responses, with some participants gaining comfort from prayer, and others finding that prayers were left unanswered.

Although prayer has repeatedly been found to be an effective coping strategy for those confronted by both chronic illness and disability (J. Hampton & Weinert, 2006; Meraviglia, 1999) there is little research pertaining to it within the field of SCI. The only study in the scoping review to mention prayer was a study from a Muslim context (Babamohamadi et al., 2011). Lack of acknowledgement regarding the importance of prayer was not only evident in the literature, but also in practice, as highlighted by the observation of HPs that there was no designated place for prayer at the SIU.

The BMMRS (Fetzer Institute & National Institute on Aging Working Group, 1999) considers prayer to be one of the components of private religious practice. The findings of this study, however, suggested that prayer is more than just religious practice, is inherent to connection with God and others (through receiving prayers), and an important channel of hope. The FACIT-Sp-Ex does not specifically ask about prayer, so there was no quantitative data available on this particular topic in this study. It is another area where further investigation could occur.

### 8.2.3 Religious faith and existential questioning and struggle

The qualitative component of this study allowed issues of religious faith to be explored in depth and demonstrated how religious faith could also raise questions and doubt for participants. For those with religious faith, God was generally considered to be someone who one
could be tested, healed, and journeyed with, bringing meaning and hope. However, for at least one participant, God was also somehow responsible for the SCI occurring. Such a perspective led to a struggle of faith. A further example was provided another participant, who reacted strongly to the religious conversion of his brother. In that case the spiritual change in his brother raised questions for this participant about the existence of God, something he continued to deny. For both these participants the SCI raised existential questions which were left unresolved. Although HPs did not refer to examples of spiritual or religious doubt being experienced by clients or their family members, there was mention of at least one family member being angry with God.

As others have identified, the relationship between spirituality, resilience and other constructs such as posttraumatic growth needs to be approached with some caution (Pargament et al., 2006). An event such as a SCI may impact upon one’s religious faith in negative, as well as positive, ways. As identified in Chapter Two, the SCI literature includes some examples of individuals with SCI who have undergone a questioning of their religious beliefs (Mundle, 2015), however these are few.

8.3 Positive Adjustment and Moving Forward

Millard (2002) has described human beings as “meaning-makers and meaning-seekers with an innate desire to transcend or move beyond situations of hardship or suffering” (italics added). Across the three components of the study, which incorporated administered surveys, family interviews, and staff focus groups, it became clear that many individuals with SCI and their family members thrive after SCI, and, as Walsh (2003) puts it, ‘bounce forward’ in the midst of adversity. These findings were consistent across both the quantitative and qualitative data, and are similar to what other researchers have found from studies pertaining to family member adjustment after SCI (Middleton et al., 2014; Simpson & Jones, 2013b).
This section will provide an overview of how spirituality was identified in this study to contribute to positive adjustment and moving forward. First, the findings pertaining to positive adjustment from the quantitative component will be discussed. These findings will then be further considered in light of the qualitative findings, with particular reference to the three key outcomes; gratitude, hope and deepening connections with others. The theme of ‘moving forward on the journey’, and specifically the ‘Spirituality Model’ proposed in Chapter 5 (see Figure 2), will then be considered in light of two other models identified in the literature: The Resiliency Model outlined by Richardson et al (1990); and the Hero’s Journey, put forward by Campbell (2008).

8.3.1 Quantitative findings. The finding of this study that individuals with SCI and their family members exhibit positivity and strength after their experience of SCI is consistent with other quantitative research in the SCI field (Kennedy et al., 2013; McMillen & Cook, 2003; Middleton et al., 2014). Mean resilience scores (CD-RISC) for both the individuals with SCI and family members were found to be comparable to those reported in others studies (B. White et al., 2010). Likewise, spirituality scores (FACIT-Sp) were similar to those reported in the literature (Tate & Forchheimer, 2002).

Depression, stress and anxiety scores were all largely within the “normal” band (Lovibond & Lovibond, 1995). As reported in Table 6 (Chapter Four) among the individuals with SCI, 70% (35/50) scored in the normal range for depression, 58% (29/50) for anxiety, and 78% (39/50) for stress. These mean scores for the individuals with SCI were similar to those reported by Mitchell, Burns and Dorstyn (2008), in their study of the DASS-21 among individuals with SCI. The family member participants in this study scored similarly to the individuals with SCI on depression and stress, and
lower on anxiety. On the whole, these findings revealed a positive picture regarding the adjustment levels of participants.

This study set out to investigate the relationship between spirituality and resilience, and the relationship these constructs have with other outcomes of positive adjustment. Across both individuals with SCI and family members the data demonstrated strong correlations between spirituality and resilience, and between these two predictor variables and a number of key outcome variables. Furthermore, both spirituality and resilience were strongly associated with positive affect, life satisfaction and depression for both individuals with SCI and family members. The lack of correlation between functional independence and other outcome variables related to emotional adjustment reported in this study, is similar to the findings of other studies within SCI (DeRoon-Cassini et al., 2009; B. White et al., 2010).

In the correlational data, the relationship between spirituality and positive affect was observed to be stronger than the relationship with negative affect, suggesting spirituality may play a particularly important role with regard to positive affect and adjustment (rather than the alleviation of negative affect). The relative contribution spirituality and resilience might make to other outcomes of positive adjustment was further tested in the regression analyses. The only other SCI paper to consider both resilience and spirituality in the one study (B. White et al., 2010), used correlational analyses only, and therefore these results appear to be the first in the SCI field to fully explore such relationships.

From the regression analyses it was determined that spirituality alone made a unique contribution to lower levels of negative affect among family members. Resilience alone accounted for lower levels of depression among individuals with SCI, and together with fewer years of education, accounted for positive affect among family
members. Spirituality and resilience together, however, made a unique contribution towards positive affect for the individuals with SCI, and towards lower levels of depression and anxiety for the family members. These findings suggest that spirituality and resilience play an important role together in increasing positive affect, and lowering levels of depression and anxiety. As this study is the first to explore this relationship among individuals with SCI and their family members, the implications which can be derived from these findings are tentative. The qualitative data discussed next suggests that spirituality leads to meaning-making processes. It is this meaning-making which may be the key factor explaining these quantitative findings.

8.3.2 Qualitative findings. One of the most interesting aspects of this study was the congruence between particular items of spirituality measured by the FACIT-Sp-Ex, and the themes which arose in the qualitative interviews with families. Specifically, items relating to gratitude, hope and connectedness with others were all rated more highly by participants scoring highly on resilience. These three themes were also identified as making key contributions to a family moving forward, as was illustrated in Figure 2.

Gratitude. The theme of thankfulness or gratitude arose in both the quantitative and qualitative components of the study. FACIT-Sp-Ex items associated with thankfulness for life, thankfulness for what others bring to life, and appreciation for the beauty of nature, were all rated significantly higher by those participants with higher resilience scores. Many of the dyads in the family interviews spoke of increased closeness, appreciation for life, appreciation for one another, appreciation for nature, and, in some cases, gratitude to God. The most significant report from the dyads was that they had grown in their connectedness and appreciation for one another. Participants were also observed to adopt downward social comparison, assisting them to be grateful for their circumstances.
Gratitude has been defined by the Oxford English Dictionary as “the quality of being thankful; readiness to show appreciation for and to return kindness” (Angus, 2010). This definition indicates that gratitude is a complex construct, encompassing both appreciation for what is received, and a desire to give back in return (Emmons, 2007). Gratitude is becoming an area of increasing interest within the field of positive psychology and posttraumatic growth, with a recent study identifying it as a component of spiritual resilience (Manning, 2014). However it appears to be a topic only just emerging within the areas of health and disability (Elosua, 2015). The relationship between spirituality and gratitude is one yet to be fully explored.

Only one study on gratitude could be identified within the field of SCI. In their study of gratitude in everyday life after SCI, Chun and Lee (2013) identified five themes of gratitude or appreciation: i) everyday life, ii) family support, iii) new opportunities, iv) positive sense of self, and v) gratitude to God. Participants enjoyed a new appreciation regarding everyday activities such as spending time with grandchildren, reading a newspaper, and watching birds. These were similar to findings in this current study.

Gratitude has been studied within the broader field of health. Investigating the role of gratitude in spiritual well-being among patients with heart failure, Mills et al (2015) found that patients expressing more gratitude slept better, were less depressed, and less fatigued. They found that gratitude “fully mediated the beneficial effects of spiritual well-being on sleep and depressed mood and partially mediated the relationship between spiritual well-being and fatigue and spiritual well-being and cardiac specific self-efficacy” (p.12). Such research emphasises the potential importance of gratitude within other areas of health and disability.

In some instances, the gratitude expressed in this study was the outcome of
participants comparing themselves with others who were perceived to have less; for example, a greater level of impairment, or less social support. In an interesting study of social comparison among individuals with SCI, Buunk, Zurriaga and González (2006) found that downward contrast (‘a positive response to seeing others who were worse-off’) was associated with constructive coping. This strategy included being able to focus on the positive aspects of the situation. Such a strategy was evident in this study with many participants reporting they were thankful for what they had in comparison to others.

Another aspect of gratitude highlighted by Emmons (2007), is the desire to give back. In this study, family interview participants spoke of receiving from others within and outside their family, and subsequently desiring to give something back. For some this was through the opportunity of peer support. Meeting with others in a similar situation, receiving and giving, was, for some, a way to connect with others who were in a similar situation. Participants also spoke of wanting to give back to the many family and friends who had supported them since the SCI. For some it was paying back these people specifically, for other participants it was finding others, such as lonely clients at the SIU, that one could be kind to. There were also indications from some participants that they wanted to give something back to the community. All these examples of ‘giving back’ showed a tendency among participants to not only receive, but to contribute to the lives of others in some way, and return something of what they had received.

Little research has been conducted into the family experience of gratitude. It was apparent in this current study that gratitude was expressed both by the individual with the SCI and by the family member, and that this gratitude and appreciation could not be easily isolated from the deepening connection between these members of the dyad.
These interactions brought the family closer together, so that in some cases the whole family was changed after the SCI. Although hope is included alongside optimism and spirituality within the family resilience framework proposed by Walsh (2003), gratitude is not. This is surprising, because as this current research demonstrated, gratitude is closely associated with spirituality, and also something typically experienced in relationship with others (Emmons, 2007). In her study of spirituality among individuals with SCI and TBI, McColl (2000) found that participants experienced a greater closeness with and appreciation of others. Similarly, in their study of gratitude after SCI Chun and Lee (2013), found that participants were grateful for family support. In neither of these studies however was the perspective of the family member included.

**Hope.** Hope was a theme that also spanned all components of the study. In the administered surveys, the FACIT-Sp-Ex item relating to hope was scored more highly by those who also scored high on resilience. In the family interviews, hope emerged as one of three key outcomes which contributed to resilience and the family moving forward. Families spoke of hope for further recovery, hope for deeper and stronger relationships, and hope for a fulfilling life together. The HPs in the staff focus groups identified hope as a component of spirituality which they perceived to be both a help and a hindrance during rehabilitation. Although spirituality was perceived to contribute to hope by providing someone or something to hope in, HPs also referred to occasions where hope in a miracle led to a disengagement in the rehabilitation process. Religious faith was identified as playing a significant role in building hope, both by family interview participants and by HPs. The practice of prayer was identified as one way that hope was maintained.

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 et al., 2009; Kortte et al., 2010; Lohne, 2009; Smith & Sparkes, 2005). As outlined in Frank’s restitution narrative (Frank, 1995), initial hope after SCI often appears to be focused upon a cure or full recovery (Dorsett, 2010). Later, as other studies have shown and this study has confirmed, hope is often placed in quality of life, relationships with others, and the journey itself. As one HP put it, hope for a miracle might continue, without knowing what the miracle was. This notion of hope changing over time, but continuing to be very important in the lives of individuals after SCI, is consistent with other hope literature in the area of SCI (Dorsett, 2010; Lohne, 2009).

For a significant proportion of interview participants, hope was placed in a relationship with God, one of the key aspects of religious faith. However, hope was not limited to those with religious beliefs, and it could be seen that hope was also generated through relationships with family members, and fostered by inspiration drawn from others who had gone before.

A key finding in this study was that hope is often shared. Shared hopes were expressed by a number of dyads in the family interviews, and highlighted the value of research where the family member perspective is obtained. Another study to interview family dyads after SCI was that by DeSanto-Madeya (2006). In DeSanto-Madeya’s study, one of the key themes identified from the analysis of interviews was “moving forward in a new way of life”. Like that study, family interview participants in this study also spoke of the need to move forward. Hope was not just for restitution, or a return to how things were. Instead, hope was for recovery of function (to do more), for relationships, activities, and for life itself. Family dyads looked forward to doing life together again, whatever that looked like.

The differing reports on the value of hope by HPs during the staff focus groups
demonstrated that in spinal rehabilitation the topic of ‘hope’ is approached with some caution. While some suggested that “unrealistic hope” could be unhelpful, others believed that the hope brought about by spirituality gave the clients “something to hold on to”. This latter perspective was supported by the example of Mary and her husband Stan in the family interviews, who hoped for a miracle. The reported attempts of the treating team to dampen such hope were strongly rejected by the couple. For them, hope was the only way to “move forward” and an essential aspect to their ability to cope with the situation they had found themselves in. Further understanding of the value of hope in such situations may assist the rehabilitation team to support clients and their family members better.

It was beyond the scope of this study to explore how hope might change over a longer period of time. Mary and Stan hoped for a miracle, and this helped them to “move forward” in their journey during the time of Mary’s hospitalisation (Mary was not discharged until after the second interview). How this couple, and others like them, cope if such desired hope is unrealised after one, two or three years, would require exploration within a longitudinal study conducted over a significantly longer duration.

**Deepening connections with others.** Throughout this study, it was evident that meaningful connectedness with others was a key source of spirituality. Furthermore, through the testing of sources of spirituality, and subsequent meaning-making responses, it could be seen that relationships with others were deepened. Such deepening relationships were closely linked with the other two key outcomes, gratitude and hope.

Connectedness with others is a key component of definitions of spirituality (Canda & Furman, 2009; Hungelmann et al., 1985; Meraviglia, 1999). Yet as demonstrated in Chapter Two, much of the research in the area of spirituality after SCI
has focused upon the individual. This trend of focusing upon individual adjustment, rather than family adjustment, has also been identified within the context of resilience and SCI (Kate Jones, 2009) and generally within the area of posttraumatic growth (Berger & Weiss, 2009). There is a strong argument for relationships with others to be considered in all these areas of research.

The importance of connectedness with others was apparent across all components of the study. From the survey data, it was evident that connectedness with others was strongly associated with high levels of resilience. Those scoring more highly in resilience also scored highly on FACIT-Sp-Ex items relating to connectedness with others, thankfulness for what others brought into their lives, and compassion for what others were going through.

Throughout the family interviews there was a strong emphasis on family members “being there” for one another, or having “been there” on the journey. Participants spoke, at times emotionally, about the deep connections they had with one another, and how these connections were deepened even further after the SCI. The “being there” for one another was suggestive of much more than the ‘social support’ which is often referred to in the literature (N. Z. Hampton, 2004; Isaksson et al., 2008; Pelletier, Alfano, & Fink, 1994), but a deep spiritual support. Connections were of an intimate nature, and for many participants provided meaning and purpose for living.

Although much of the attention in the staff focus groups was placed upon the individual with SCI, there were also reports of families who were observed to connect well with one another, and support each other throughout the SCI journey. Interestingly, HPs referred to the spiritual community of a Catholic nun, who they described as being like “family” to her. Such a reference highlights the importance of future research incorporating broad definitions of family which include “families of choice” (Ferris et
Deepening connections with others were shown in this study to enhance other aspects of individual adjustment and coping after SCI. For instance, family interactions were shown to significantly and positively impact upon the perspective of the individuals within each dyad. Family members enabled others to remain positive, cheering one another along in the journey through “dry gullies and rough roads”. References in the family interviews to smiles, cheerfulness, love, humour, positivity and optimism, supported the quantitative results which found that spirituality was strongly associated with positive affect and life satisfaction. Studies of resilience, and the area of positive psychology in general, has focused upon these elements, but again, the majority of these have focused on the individual.

In her framework of family resilience Walsh (2003) suggested that ‘family beliefs’ assist families to “make meaning of crisis situations; facilitate a hopeful, positive outlook; and offer transcendent or spiritual moorings”. Yet not much focus is placed upon connectedness within this domain of family beliefs. Walsh includes family connectedness as a key process under her domain of “Organisational Patterns”, however connectedness within that domain refers more to mutual support, respect, and reconciliation. The deep meaningful connectedness that was depicted in this study is not evident. As noted in Chapter One, the importance of the role of family within the literature pertaining to spirituality has been a neglected area (Wright, 2009). This study underscores its importance.

Moving forward on the journey. During the family interviews a number of participants made reference to being on a ‘journey’. This was either through use of the word ‘journey’ to describe their experience after SCI, or through other illustrations depicting journey imagery. For one participant, it was a picture on her grandmother’s
wall which helped her to hold onto hope and anticipation, looking forward to what the next day would bring. Another participant spoke of travelling on the ‘highway of life’ and not looking in the rear-view mirror. Other phrases and words also indicated a desire of participants to move forward.

As outlined in Chapter One, the notion of being on a journey is a key aspect of the ‘quest narrative’ proposed by Frank (1995), and investigated among individuals with SCI by Smith and Sparkes (2005). Contrasted with the ‘chaos narrative’, and the ‘restitution narrative’, the individual who adopts a ‘quest narrative’ embraces the challenge of the illness or injury, and focuses upon gains rather than losses. Growth is an important part of this narrative.

In Chapter Five, the journey process undertaken by the dyads participating in the family interviews was depicted in “The Spirituality Model: Moving forward on the journey” (see Figure 2, reproduced on p. 234). In this proposed model, for simplicity referred to here as the “Spirituality Model”, individuals and their family members draw upon existing or new sources of spirituality, then respond to the testing of these sources of spirituality, which leads to gratitude, hope, and deepening relationships with others. These outcomes then assist families to move forward on the journey, contributing to family resilience. It is argued here that there are clear parallels between the Spirituality Model and two other models represented in the literature: the ‘Resiliency Model’, by Richardson et al (1990); and the ‘Hero’s Journey’, by Campbell (2008). These parallels are discussed below.

*The Resiliency Model (Richardson et al., 1990).* In their Resiliency Model, Richardson and colleagues suggested that after a stressor (SCI) occurs, interactions take place between that stressor and a number of biopsychospiritual protective factors. This can lead to a process of disruption and a period of disorganisation. The authors
proposed that this period of disorganisation leads to reintegration. The individual or family may then follow one of four paths; dysfunctional reintegration, maladaptive reintegration, homeostatic reintegration, or resilient reintegration (see Figure 3).

In comparison, instead of biopsychospiritual protective factors, the Spirituality Model refers to ‘sources of spirituality’. The period of disruption outlined by Richardson could refer to the ‘testing’ of these sources in the Spirituality Model. The subsequent reintegration aligns with the meaning-making responses, which in the Spirituality Model lead to gratitude, hope and deepening relationships. Resilient reintegration, it could be argued, is illustrated in the Spirituality Model by the family ‘moving forward on their journey’.

![Figure 2: The Spirituality Model: Moving forward on the journey – how spirituality contributes towards family resilience after SCI](image)
A significant difference between the Resiliency Model and the Spirituality Model is that alternative outcomes such as dysfunctional reintegration, maladaptive reintegration, and homeostatic reintegration were not identified among the participants in this study. All families in this study chose to ‘move forward’, even if this was on the basis of hope for a miracle. This raises the question whether the group of families participating in this study were particularly resilient or representative of the majority of families affected by SCI? Recent literature, both quantitative (Middleton et al., 2014; Simpson & Jones, 2013b) and qualitative (DeSanto-Madeya, 2006), together with the findings of this study, suggest that families affected by traumatic injury are more resilient and more likely to do well than is generally expected (Perlesz et al., 1999). However, it must also be acknowledged that families struggle at times; and this was also
apparent in this study. Further research could extend the scope of the Spirituality Model to include those cases where families feel they are not moving forward, and capture the experience of those who may require greater support.

*The Hero’s Journey (Campbell, 2008).* Another framework which appeared to have parallels with the Spirituality Model is that of Campbell (2008) (see Table 24). As outlined in Chapter One, Campbell was one of the major proponents of the journey metaphor. Campbell argued that all world myths and religions contain the story of a journey, that of a hero embarking on an adventure. Campbell’s journey stages were considered within the context of chronic illness by Frank (1995), and, as this study showed, can also be applied to SCI. According to Campbell, the ‘thread of the hero-path’ is there for all to follow, an indication of a ‘universal adventure’ (p.18, 28).

Campbell suggests that the hero (or family) begins their journey with a departure, encompassing: the call to adventure; some resistance; the assistance of supernatural aid; the crossing of some threshold; and, ultimately surrender or submission. In the Spirituality Model these various components of the ‘departure of the hero’ are reflected in the process of ‘sources of spirituality (being) tested’ and the ‘meaning making response’ of participants towards these tests. For instance, a number of participants spoke of how they perceived the SCI as a test from God. Like Campbell’s Hero, in some cases these tests brought about questioning or resistance, leading to the strengthening of their sources of spirituality through prayer (assistance of supernatural aid), a decision to go on, or ‘being there’ for one another (crossing of some threshold). This led to a desire to accept the situation and ‘move forward’ (submission or surrender).

Similar parallels between the Hero’s Journey and the Spirituality Model can be identified in the second stage of the journey for Campbell’s Hero, the ‘Process of
Initiation’. According to Campbell (2008), this stage involves trials, suffering, and an eventual ‘boon’. Within the context of chronic illness Frank (1995) suggested that the various challenges which eventually lead to some insight could apply to this part of the journey. In the Spirituality Model the ‘meaning-making responses’ which resulted from the process of testing, brought about insight as well, leading to gratitude, hope and deepening relationships with others, all ‘boons’. From their meaning-making responses there was a clear indication that participants desired to focus on the positive aspects of their journey.

After the process of initiation involving trials, suffering, and an eventual ‘boon’ Campbell’s hero returns from the journey with something beneficial to offer the rest of humanity. Frank (1995) suggested that an individual desiring to give back in some way after their experience of chronic illness fits with the return of the hero, who returns with something which will aid or contribute to others. Similarly, a desire to give back was evident among a number of accounts in the family interviews. Both the individuals with SCI and their family members sought ways to ‘give back’ to others, both within the family and outside to others, such as through peer support.

Although the journey after SCI had not ended for the participants in this study (unlike Campbell’s hero who returns from the journey), there was a desire for life to go back to normal, even if this meant that a ‘new normal’ was established. For one participant, the end of the initial adjustment was a milestone, and he looked forward to returning to his life with new insights to impart. While Campbell’s journey metaphor cannot be applied unconditionally to the experience of SCI, it does helpfully depict some aspects of the journey for individuals with SCI and their families and resonates with the accounts represented in this study. What is most important from the findings is that although there were different experiences of the journey for members of the dyads,
most perceived they were on a journey together (i.e. not alone). Admittedly, each individual with SCI who participated in this study had a supportive family member to share their journey with. The presence of such family support and connection cannot always be assumed.

Table 24
Comparisons between the Hero’s Journey (Campbell, 2008) and the Spirituality Model

<table>
<thead>
<tr>
<th>Stages on the Hero’s Journey</th>
<th>Examples from the Spirituality Model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Departure</td>
<td></td>
</tr>
<tr>
<td>• The call to adventure</td>
<td>• Testing of sources of spirituality</td>
</tr>
<tr>
<td>• Resistance</td>
<td>• Meaning-making response (e.g. prayer)</td>
</tr>
<tr>
<td>• Assistance of supernatural aid</td>
<td></td>
</tr>
<tr>
<td>• Crossing of some threshold</td>
<td>• Gratitude and appreciation, hope, deepening connections</td>
</tr>
<tr>
<td>• Surrender or submission</td>
<td>• Giving back</td>
</tr>
<tr>
<td>Process of initiation</td>
<td></td>
</tr>
<tr>
<td>• Trials</td>
<td></td>
</tr>
<tr>
<td>• Suffering</td>
<td></td>
</tr>
<tr>
<td>• Eventual “boon”</td>
<td></td>
</tr>
<tr>
<td>Return from the Journey</td>
<td></td>
</tr>
<tr>
<td>• Something to contribute to others</td>
<td></td>
</tr>
</tbody>
</table>

8.4 Barriers Encountered by HPs Incorporating Spirituality into Rehabilitation Practice

Despite the associations identified between spirituality and positive adjustment among individuals with SCI and their family members, it was also observed in this study that HPs encountered a number of barriers addressing spirituality in their practice. These barriers included the perception that spirituality was a private matter, concerns around professional boundaries, and staff discomfort in raising the topic. Furthermore, there was acknowledgement in the focus groups that the rehabilitation unit did not offer spiritual space, such as a chapel or prayer room, and spirituality was not embedded in rehabilitation processes.

Other studies have noted some similar trends among HPs within an Australian context. In their study among physicians working in palliative care, Best, Butow and
Olver (2016) reported that physicians were reluctant to discuss spirituality with their clients due to the perception that spirituality could be confused with religion, peer pressure, the personal spirituality of the physicians, institutional factors (such as whether the institution was faith-based), and historical factors (such as a focus upon the medical model). In the results of a systematic review of the literature the same authors (Best, Butow, & Olver, 2016) observed that religion and spirituality were discussed infrequently by physicians in palliative care, physicians preferred chaplain referral to discussing the topic with clients themselves, and reported barriers included lack of time and training. The training needs of HPs regarding spirituality have been addressed in one study (also conducted in Australia) and will be considered further in the next section (Meredith et al., 2012). The above studies were conducted in the area of palliative care, demonstrating the need for further exploration of these issues within other health contexts such as rehabilitation.

### 8.5 Implications for Practice

The findings of this study demonstrated the significant role spirituality plays in contributing to family resilience, for both the injured individual and their family members after SCI. The findings also revealed that spirituality was a poorly addressed topic during spinal rehabilitation and was not well incorporated into rehabilitation processes. This section will consider five implications for practice, identified from the findings of this study:

i) spirituality plays an important role in SCI rehabilitation, and can be better incorporated into rehabilitation practice;

ii) training for staff could focus upon raising awareness of the role of spirituality, and assisting staff to confidently assess and address the spiritual needs of their clients where appropriate;
iii) hope has a significant role to play, even when it is deemed unrealistic by the rehabilitation team;

iv) Social Workers have a unique opportunity to assist both clients and staff address spirituality in SCI rehabilitation better;

v) the use of physical space to facilitate spirituality should be considered.

8.5.1 The important role of spirituality, and incorporating it into rehabilitation practice. Across the three different components, this study demonstrated that spirituality plays an important role after SCI, among the lives of both the injured individual and their family members. This may be particularly so in the early stages after SCI, as the longitudinal findings implied. Awareness of the important role of spirituality is growing in other areas of health (Best et al., 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 et al., 2010). According to an Australian study which considered the spiritual needs of patients with advanced cancer diagnosis (Best et al., 2014), patients expected medical staff to ask them about their spiritual sources of support, and to facilitate access to such support. This was consistent with the findings of another Australian study by Hilbers et al (2010), who found that hospital patients believed that staff should address issues of spirituality. Although this topic was not raised in the current study, the findings of other studies are helpful in understanding how this issue might be better addressed within SCI rehabilitation settings.

One way forward may be to consider how to better assess the spiritual needs of clients and their family members. Assessment of spiritual need for individuals and their family members during a health crisis or challenge is an area which has only recently
been explored. Hodge (2015) has proposed that a two-stage spiritual assessment take place in a healthcare setting; a brief initial assessment, followed by a second more in-depth assessment of spiritual needs. Hodge proposed that the second stage of the assessment only be conducted if significant spiritual needs of the individual were identified during the initial assessment. Measurement tools such as the Sources of Spirituality Scale (D. E. Davis et al., 2015) may also be appropriate within a rehabilitation setting. As there is so little data on gratitude in the area of SCI, further investigation in this area would also be worth conducting. A gratitude measure such as the GQ-6 used by Mills et al (2015) is one tool which may be suitable.

As noted during this study, for a few family members a SCI raised spiritual questions which brought about significant struggle. This was the case for one family member who found himself questioning his faith and God’s purposes in bringing the SCI about. This led to a strong hope for miraculous healing; yet this family member felt such hope was discouraged by the rehabilitation team. Such family members could be better supported if the spiritual aspects of a family’s journey are acknowledged and addressed by the staff involved. It may be that this is a task best managed by the Social Workers, or Psychologists, or together as a multidisciplinary team. Such decisions would need to be made according to each rehabilitation context, and the relevant processes in place.

8.5.2 Addressing staff training needs. According to Walsh (2009a), spirituality has long been considered to be a taboo topic in family therapy. Findings from this study supported Walsh’s observation. The staff focus groups revealed that although HPs considered spirituality to be very important in assisting clients and their families to cope and adjust after SCI, there was reluctance by some to embrace it as part of their role. HPs described feeling uncomfortable with the topic of spirituality, or not having time to
address the area with their clients in sessions. The impression given by some staff was
that discussion of personal spiritual beliefs was beyond the scope of rehabilitation
clinical practice.

Despite the reservations expressed by some HPs to incorporate spirituality into
their role, it was evident that informal conversations on the topic were occurring
relatively frequently between clients and staff, and that when it did arise these were
fruitful times of sharing and connection. This raised the question, do HPs feel prepared
to discuss these topics when they arise? While attending to clients’ personal care needs,
assisting with showering, or attending to home visits, conversations naturally occurred.
It was this informal sharing that provided a space for clients and their families to share
meaning, their fears and concerns, and their hopes for the future. As one of the focus
group participants commented, addressing spirituality upfront in an initial assessment
may not be the most appropriate time to do so. But as HPs build relationships with
clients and their families, further information on beliefs or life perspectives emerge and
could be addressed more naturally.

One way this issue may be addressed is through better staff training and
education. According to Walsh (2009a), most family therapists in the area of mental
health “feel ill equipped in their training, constrained from broaching the subject with
clients, and uncomfortable when it does arise”. She suggested that because of this
reluctance by staff to raise spiritual issues, clients “may censor themselves from
bringing this aspect of their lives into the therapeutic conversation” (p.91). In their study
among health professionals working in palliative care, Meredith et al (2012) conducted
four workshops to improve the confidence and knowledge of staff around the topic of
spirituality. They observed significant increases in staff levels of Spirituality, Spiritual
Care, Personalised Care, and Confidence, directly after the workshops. Three months
later improvements in Spiritual Care and Confidence were maintained. Such an intervention in the area of palliative care suggests that similar staff training could be implemented in the area of SCI.

Drawing upon the work of Meredith et al (2012) and the findings of this study, two ways that training could enhance the ability of staff to address the spiritual needs of clients in spinal rehabilitation would be to raise awareness and to increase confidence. The findings of this study demonstrated that spirituality is often associated only with religious faith by staff. In some instances, the religious beliefs of clients led to staff discomfort. Greater awareness of the role of all sources of spirituality in contributing to family resilience (through gratitude, hope and deepening connections) could assist staff to feel more confident in addressing the broad range of spiritual needs of the clients they work with. Training which raises staff awareness of the diversity of spiritual backgrounds and provides them with information and strategies on how to respond to the various spiritual needs of clients, would potentially be a helpful way forward.

8.5.3 Embracing the role of hope. Another reason HPs cited for being cautious about spirituality was the perception that, in some instances, the religious faith of clients and their families led to a disengagement with the rehabilitation process. A belief in unrealistic healing, it was suggested, meant that some clients ceased interest in discussing how they might return to the community using equipment and services. Despite these observations, the literature pertaining to spirituality after SCI suggests that in most cases both spirituality and hope have a very positive effect upon adjustment. This was reported in both quantitative and qualitative research identified in the scoping review. Given the lack of attention given to this proposed disengagement in the literature pertaining to spirituality and SCI, and the lack of evidence for it in this
current study, further research would be needed to clarify whether this is a frequent concern which needs to be addressed.

8.5.4 The role of Social Workers. For Social Workers who work in the area of SCI rehabilitation, the results of this doctoral study provide further evidence that taking the needs of the whole family into consideration when addressing spirituality is imperative. Both individuals affected by SCI and their family members share hope, express gratitude towards one another and others, connect deeply with each other, and encourage one another to move forward. Although spirituality is sometimes a personal, individual matter, much of the spiritual journey, and journey of life itself, is shared.

Given the reluctance of some HPs to incorporate spirituality into their practice at the SIU, one way forward may be for Social Workers to introduce the topic. A number of authors have highlighted the importance of spirituality being better incorporated and addressed by the Social Work profession (Crisp, 2010; Lindsay, 2002; Rice, 2002). Although these authors have not specifically focused upon the Social Work role within health, they have raised valuable points regarding the fit between spirituality and Social Work practice, education and values.

A brief spiritual assessment conducted by SIU Social Workers would allow the topic to be raised without the need of an intensive assessment early in the rehabilitation stay. Further assessment and intervention could then take place on the basis of the results of this initial assessment. As outlined earlier, such a two-stage process has been recommended by Hodge (2015), and would provide Social Workers with a central role in the assessment of spiritual needs among both clients and their family members. Alternatively, a tool such as the Sources of Spirituality Scale (D. E. Davis et al., 2015) may be appropriate for Social Workers to incorporate into their practice.

8.5.5 Physical space. Although this current study did not explore the spiritual needs
of clients within the health system, it could be identified that access to a number of
sources of spirituality such as religious faith, or the natural world, were not well
facilitated in the rehabilitation unit due lack of resources or delegated space. Lack of a
chapel or prayer room was the most obvious missing physical feature, but other aspects
of the rehabilitation unit including restricted access to outdoors at night were also
highlighted. How the spiritual needs of clients of the SIU and their family members
could be met through the physical environment of the SIU is worthy of further
investigation and exploration.

8.6 Limitations

A number of limitations were encountered throughout this project. First, due to
the low numbers of SCI sustained per year, recruiting sufficient numbers of participants
took a considerable period of time. Because of recruitment and the time limitations of a
doctoral study only 50 individuals with SCI and their family members participated in
the quantitative component of the project. This was relatively low, and further research
could seek to add to these numbers so that more sophisticated statistical analyses could
be performed. Repeating the measures, in addition to the family interviews, at a six
month follow up (or longer) would also provide more information regarding changes
over time. Another study could also consider extending the qualitative component to a
third interview, or extending the period between the first and second interviews. This
would provide greater insight into the changes experienced over time, as individuals
with SCI and their family members transition into the community.

Recruitment was further hindered by a significantly large number of potential
participants who declined to proceed with the study. Although the reasons for
participants declining were not recorded, such information may have been helpful in
further understanding how individuals respond to the topic of spirituality. According to
the Social Workers on the SIU several potential participants expressed a disinterest in
the topic of spirituality, often associating it as synonymous with religion and something
they were not interested in discussing further. Such a reaction to the topic of spirituality
may have led to some bias, resulting in a sample more inclined to participate due to
their own experience of religion or spirituality.

Other factors were also influential during the process of recruitment. As the
primary researcher was also one of the Social Workers on the SIU some participants
were more willing to be involved than others due to a known relationship. This may
have had some impact upon participant comfort levels during the family interviews.
Attempts were made to put all participants at ease, and build rapport prior to the
interviews, but this was understandably easier with those participants who were already
in an established professional relationship with the researcher. This in itself may have
affected some of the discussion in the interviews, and the willingness of participants to
share openly.

Similarly, interviewing the members of the family together may have influenced
what topics were or were not discussed in the interviews. The positive outlooks adopted
by members of each dyad may have been exaggerated due to the presence of the other,
and a desire to ‘put on a brave front’. Whether this was the case cannot be known
without conducting further research where members of each dyad are interviewed both
together and separately.

Lastly, in the staff focus groups it was apparent that those who participated were
those most interested in the topic of spirituality. This resulted in some potential bias,
with almost all the participants in the staff focus groups identifying with some religious
affiliation (predominantly Catholic). The focus groups were also dominated by allied
health staff, with only one member of the medical profession represented, and two
nurses. 11 of the 12 participants were female. As the researcher and facilitator of the groups was also a member of staff, discussion in the group was at times informal and very specific to the context of that particular rehabilitation centre. Although this was in some ways an advantage, an outsider may have gleaned more objective and general observations from the participants in the group.
Chapter Nine: Conclusion

The purpose of this study was to investigate the contribution of spirituality toward family resilience after SCI. This study made a number of unique contributions to the literature. First, the methodology of this study stood out from other existing studies. From the scoping review, which was conducted early in the study it was identified that this was the first Australian study to consider spirituality within the family after SCI, and one of the first studies to do so internationally. It was also the first study to include not only the views of individuals with SCI and family members, but also health professionals on the topic of spirituality after SCI. The mixed methods approach adopted in this study provided an opportunity for triangulation, and revealed further insights regarding both the quantitative and qualitative data.

The findings of this study also provided new insights on the topic of spirituality after SCI. The importance of gratitude and its relationship with spirituality, which emerged in both the quantitative and qualitative data, does not appear to have been considered widely within the field of SCI rehabilitation, and at all in relation to family resilience. Only one other existing study within SCI could be found on this topic, and this was focused upon individuals with SCI only and not family members. Yet in this current study, gratitude was identified as a key outcome of the meaning-making process after SCI, and a contributor towards building resilience and assisting families with adjustment.

Another key finding was the relevance of connectedness with others, both as a source of spirituality and a contributor to family resilience. These relationships with others went beyond merely practical or emotional support, and suggested a deeper spiritual connection which provided participants with meaning and purpose for living. Such connections, and the significance of positive interactions between family
members, is also an area to be more fully explored.

A number of studies and policy papers suggest that the importance of spirituality within health settings is increasingly being acknowledged within Australia. However much more investigation is required. As highlighted in this study, there may be unique cultural factors which bear upon how discussions about spirituality are received within an Australian context, and these factors are different to those identified in other countries such as the USA and within the Middle East. Yet this does not mean such discussions are any less important than in these other countries. It could be argued that spirituality, like sexuality in the past, is a taboo topic which staff avoid, yet with training and resources, is something which can be incorporated into practice.

In summary, future research could further explore the meaning spirituality holds for Australian families within a spinal rehabilitation context, consider how the spiritual needs of individuals with SCI and their family members could be better incorporated into practice, investigate the concept of gratitude and its relationship with spirituality and resilience, and examine how sources of spirituality can be made accessible to clients within healthcare settings. This study demonstrates the importance of a whole family perspective, inclusive of client, family member and staff perspectives, and the benefits of a mixed methods approach. All these findings provide rich foundations for meaningful future research.
Bibliography


Appendix A: Published Article (Scoping Review)
Does spirituality facilitate adjustment and resilience among individuals and families after SCI?

Kate Jones¹, Grahame Kenneth Simpson², Lynne Briggs³, and Pat Dorsett⁴

¹Spinal Injuries Unit, Royal Rehab, Ryde, New South Wales, Australia; ²Brain Injury Rehabilitation Research Group, Ingham Institute of Applied Medical Research, Liverpool, New South Wales, Australia; ³School of Human Services and Social Work, and ⁴School of Human Services and Social Work, Griffith Health Institute, Griffith University, Southport, Queensland, Australia

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.

Keywords

Family, resilience, spinal cord injury, spirituality

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 in 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 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 their study of rural women, Hampton and Weinert [19] 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. 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 perspectives 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 meta-theory 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 of these 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...
Disability and Rehabilitation: A Scoping Review of Spirituality After Spinal Cord Injury

Kara J. Lewis, Laura B. S. Blyth, and Penny D. Duggan

DOI: 10.3109/09638288.2015.1066884

Spirituality after SCI: a scoping review

Kara J. Lewis, Laura B. S. Blyth, and Penny D. Duggan

Faith [16], meaning making [37,38], purpose in life [39], sense of coherence [40], post-traumatic 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.

Post-traumatic growth

Post-traumatic 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]. Post-traumatic growth has been measured by the post-traumatic growth inventory (PTGI) [50].

Hope

According to Dufault and Martocchio [51], hope is “a multidimensional 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 mitigate the effect of depression” (p. 89). Measures of hope include the Herth Hope Index [53] and the Hope Scale [54].

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 the area of spirituality and healthcare [18,55]. The search terms “spirituality”, “meaning”, “purpose in life”, “sense of coherence”, “post-traumatic 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: Psychinfo, 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.

Study selection

Studies were excluded if they focused upon a diagnosis other than SCI, centered only upon one specific aspect of SCI adjustment (e.g. research procedures, pain management, sexuality, continuity, 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 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 was taken. Reference lists of selected articles were also reviewed to identify any further studies on the topic.

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, post-traumatic growth, hope), sample size, study location, sample characteristics, methodological quality, and aims of the study. The scoping review’s aim was to: (1) identify the range of studies; (2) determine the key findings of these studies and develop a thematic map; and (3) identify research gaps. To address the first objective, the primary focus was on the identification of studies. To address the second, a thematic map has been created using chicken wing diagrams. This method is a pictorial way of illustrating the relationships and connections between constructs, and is developed from the literature. The third objective was to identify and describe research gaps. This was achieved by engaging in a data synthesis process, which has involved making sense of the data through thematic analysis. This approach enabled the research team to extract meaning from the data, which in turn, has allowed the research team to generate a thematic map.
(ii) Collating, summarising and reporting results

The results were grouped according to the four study objectives, and the study results were 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.

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, post-traumatic 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 subgroup 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...
Table 1. Quantitative studies.

<table>
<thead>
<tr>
<th>First author, year, country</th>
<th>Study design</th>
<th>Construct/s of interest</th>
<th>N, TSI</th>
<th>Injury characteristics</th>
<th>Measure/s of spirituality and/or meaning</th>
<th>Significant outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Bliss [60] 2005, USA</td>
<td>Cross-sectional, prospective</td>
<td>Spirituality</td>
<td>230, NR</td>
<td>SCI only</td>
<td>QLI [79] - Factor III includes ‘‘peace of mind’’ and ‘‘faith in God’’.</td>
<td>QLI psychological/spiritual factors correlate with SWLS ( r = 0.60 ).</td>
</tr>
<tr>
<td>2 Chlan [58] 2011, USA</td>
<td>Cross-sectional, prospective</td>
<td>Spirituality</td>
<td>298, M 16.6, (SD 6.5), Range 6–38 yrs</td>
<td>SCI only, Pediatric-onset</td>
<td>(i) Brief COPE [80] (spiritual coping domain only) ( r = 0.14 ). Spiritual coping predictor of SWL. ( r = 0.17 ).</td>
<td>( 55% ) of participants used spiritual coping ‘‘a medium to a lot’’. Importance of religion correlate with SWL ( r = 0.14 ), spiritual coping with SWL ( r = 0.17 ). Spiritual coping predictor of SWL, religious coping ns.</td>
</tr>
<tr>
<td>3 Davis [67] 2013, Canada</td>
<td>Mixed method, longitudinal, prospective</td>
<td>Meaning, PTG</td>
<td>67, &lt;1 yr</td>
<td>SCI only</td>
<td>(i) Assessment of meaning making (five questions with coded responses) (ii) PTGI [50] ( r = 0.70 ); PIL scale [47] -measures the degree to which an individual believes they are living a meaningful life.</td>
<td>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.</td>
</tr>
<tr>
<td>4 DeRoon-Cassini [36] 2009, USA</td>
<td>Cross-sectional, prospective</td>
<td>PIL</td>
<td>79, M 17.5 months (SD 14.7 months), Range 0.1–62 months</td>
<td>SCI only</td>
<td>PIL scale [47] -measures the degree to which an individual believes they are living a meaningful life</td>
<td>PIL correlate with psychological well-being ( r = 0.70 ); PIL accounted for an additional 42% of the variance in psychological well-being after perceived loss of physical function was entered.</td>
</tr>
<tr>
<td>5 Forchheimer [57] 2007, USA</td>
<td>Cross-sectional, prospective</td>
<td>Spirituality</td>
<td>444, Range 10–30 yrs.</td>
<td>SCI only</td>
<td>FACT-SP [63] -spirituality total and two scales: meaning and faith</td>
<td>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.</td>
</tr>
<tr>
<td>First author, year, country</td>
<td>Study design</td>
<td>Construct/s of interest</td>
<td>N, TSI Injury characteristics</td>
<td>Measure/s of spirituality and/or meaning</td>
<td>Significant outcomes</td>
<td></td>
</tr>
<tr>
<td>----------------------------</td>
<td>-------------</td>
<td>-------------------------</td>
<td>-----------------------------</td>
<td>----------------------------------------</td>
<td>----------------------</td>
<td></td>
</tr>
<tr>
<td>6 Franklin [62] 2008, USA</td>
<td>Cross-sectional, prospective</td>
<td>Religious Beliefs</td>
<td>25, M 133.5 months (SD 51.9 months), Range 7–564 months</td>
<td>SCI only Injury details not documented</td>
<td>BMMRS [81] - Scales include: meaning, values/beliefs, daily spiritual experiences, forgiveness, religious support, private religious practices, organisational religiousness, religious and spiritual coping</td>
<td></td>
</tr>
<tr>
<td>7 Kennedy [1] 2009, UK</td>
<td>Cross-sectional, prospective</td>
<td>Hope</td>
<td>54, &lt;1 yr</td>
<td>SCI only Tetraplegia: n = 27 Paraplegia: n = 27 Complete: n = 22 Incomplete n = 32</td>
<td>State Hope Scale [82] - measures a person’s current evaluation of their goal-directed thinking. Subscales: (i) agency, (ii) pathways</td>
<td></td>
</tr>
<tr>
<td>8 Kennedy [65] 2010, Europe</td>
<td>Longitudinal prospective</td>
<td>SOC</td>
<td>237, &lt;1 yr</td>
<td>SCI only Complete paraplegia: n = 74 Incomplete paraplegia: n = 52 Complete tetraplegia: n = 41 Incomplete tetraplegia: n = 68</td>
<td>SOC scale [83] - measures comprehensibility, manageability, and meaningfulness</td>
<td></td>
</tr>
<tr>
<td>9 Kortte [66] 2010, USA</td>
<td>Longitudinal, prospective</td>
<td>Hope</td>
<td>87, Range 7–61 days in inpatient rehab unit</td>
<td>SCI only Complete paraplegia: n = 18 Complete tetraplegia: n = 9 Incomplete paraplegia: n = 31 Incomplete tetraplegia: n = 29</td>
<td>Hope Scale [54] Benefit Finding Scale [84]</td>
<td></td>
</tr>
<tr>
<td>10 Lustig [38] 2005, USA</td>
<td>Cross-sectional, prospective</td>
<td>SOC</td>
<td>48, M 106 months (SD 99 months), Range 1 mth-27 yrs</td>
<td>SCI only Injury details not documented</td>
<td>SOC scale [83]</td>
<td></td>
</tr>
</tbody>
</table>

Higher hope agency/higher challenge appraisals had positive correlation with higher levels of acceptance. Threat appraisals best predictors of anxiety and depression. 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.

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.

Strengthened SOC group had negative correlations with anxiety ($r = -0.63$), depression ($r = -0.59$), shock ($r = -0.58$) and internalised anger ($r = -0.50$).

BMMRS religious support correlate with SF36 General Mental Health Scale ($r = 0.70$). Participants with SCI received significantly more religious support than healthy controls.
<table>
<thead>
<tr>
<th>No.</th>
<th>Author [Year]</th>
<th>Study Design</th>
<th>Topic</th>
<th>Sample Size</th>
<th>SCI Only</th>
<th>SCI Levels</th>
<th>SCI Survey</th>
<th>Other Measures</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>11</td>
<td>Marini [56] 2011, USA</td>
<td>Cross-sectional, prospective</td>
<td>Spirituality</td>
<td>157, &lt;2 yrs, 2–5 yrs, &gt;5 yrs</td>
<td>SCI only</td>
<td>T 1 or below: n = 65</td>
<td>SWBS [64]</td>
<td>Measures existential spirituality (life connection and purpose) and religious spirituality (relationship with God, sense of satisfaction and positive connection with God)</td>
<td>Weakened SOC group correlation with anxiety (r = 0.48), internalised anger (r = 0.48), depression (r = 0.47), externalised anger (r = 0.45), shock (r = 0.36) and negative correlation with acknowledgement (r = -0.59) and adjustment (r = -0.55).</td>
</tr>
<tr>
<td>12</td>
<td>Matheis [61] 2006, USA</td>
<td>Cross-sectional, prospective</td>
<td>Spirituality</td>
<td>75, M 7.56 yrs, Range 1–32 yrs</td>
<td>SCI only</td>
<td>Low quadriplegia: n = 31</td>
<td>SWBS [64]</td>
<td>Measures existential spirituality (life connection and purpose) and religious spirituality (relationship with God, sense of satisfaction and positive connection with God)</td>
<td>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.</td>
</tr>
<tr>
<td>13</td>
<td>Riley [59] 1998, USA</td>
<td>Cross-sectional, prospective</td>
<td>Spirituality</td>
<td>216, NR</td>
<td>Mixed diagnostic groups</td>
<td>SWBS [64]</td>
<td>Measures existential spirituality (life connection and purpose) and religious spirituality (relationship with God, sense of satisfaction and positive connection with God)</td>
<td>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 non-spiritual group.</td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>Tate [14] 2002, USA</td>
<td>Cross-sectional, prospective</td>
<td>Spirituality</td>
<td>208, NR</td>
<td>Mixed diagnostic groups (including SCI)</td>
<td>SWBS [64]</td>
<td>Measures existential spirituality (life connection and purpose) and religious spirituality (relationship with God, sense of satisfaction and positive connection with God)</td>
<td>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.</td>
<td></td>
</tr>
</tbody>
</table>

(continued)
<table>
<thead>
<tr>
<th>First author, year, country</th>
<th>Study design</th>
<th>Construct/s of interest</th>
<th>N, TSI</th>
<th>Injury characteristics</th>
<th>Measure/s of spirituality and/or meaning</th>
<th>Significant outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>15 Thompson [39] 2003, USA</td>
<td>Cross-sectional, prospective</td>
<td>PIL</td>
<td>1391, M 8.9 yrs (SD 7.3 yrs)</td>
<td>SCI only Paraplegia 45% Tetraplegia 55%</td>
<td>PIL scale [47]</td>
<td>PIL negative correlation with neuroticism-anxiety ($r = -0.46$), aggression-hostility ($r = -0.20$), chance of health locus of control ($r = -0.20$), powerful others health locus of control ($r = -0.12$), positive correlation with activity ($r = 0.34$), sociability ($r = 0.45$), health locus of control ($r = 0.22$).</td>
</tr>
<tr>
<td>16 White [13] 2010, USA</td>
<td>Longitudinal</td>
<td>Spirituality</td>
<td>42, Range 29–107 days in inpatient rehab</td>
<td>SCI only Injury details not reported</td>
<td>Intrinsic Spirituality Scale [87] -measures intrinsic spiritual beliefs with six questions</td>
<td>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 ($r = 0.35, 0.29, 0.56$).</td>
</tr>
<tr>
<td>17 Feigin [26] 1998, Israel</td>
<td>Cross-sectional, prospective</td>
<td>SOC</td>
<td>$N = 80$ people with disability $N = 72$ non-disabled spouses, Range 2–12 yrs</td>
<td>Mixed diagnostic groups SCI = 73%, Injury details not reported</td>
<td>SOC Scale [83]</td>
<td>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 partners.</td>
</tr>
</tbody>
</table>

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]; FACT-SP = Functional Assessment of Cancer Therapy – Spirituality [63]; BMMRS = Brief Multidimensional Measure of Religiousness/Spirituality [81]; SF36 = Medical Outcomes Study Short Form [89].
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 previously. Only two quantitative studies [56,57] made specific comparisons between participants who had been injured for different lengths of time.

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 also 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 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. [61] 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. 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 among 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. [65] 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), Lustig [38] found that perceived strengthened SOC was associated with adaptive adjustment, whereas perceived weakened SOC was associated with non-adaptive 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). DeRoon-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 qualitative 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 post-traumatic 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 DeRoon-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. As seen in Table 2, constructs of interest within this group included spirituality, meaning, hope and post-traumatic 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 perspectives, 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 9 to 232. 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, three with participants injured for longer than two years, and one study with a sample containing both newly injured participants and those who had been injured for a number of years.

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 post-traumatic 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] concluded 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 was seen to be a part of the process of building alternative life stories that “characterise a renewed sense of personal agency and fulfillment 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
<table>
<thead>
<tr>
<th>First Author, Year, Country</th>
<th>Study design</th>
<th>Construct/s of interest</th>
<th>N, TSI</th>
<th>Injury characteristics</th>
<th>Key themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Angel [71] 2009, Denmark</td>
<td>Longitudinal</td>
<td>Meaning</td>
<td>12, &lt;2 yrs</td>
<td>SCI only: n = 9 (3 severe) Complete lesion: n = 3</td>
<td>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.</td>
</tr>
<tr>
<td>2 Babamohamadi [76] 2011, Iran</td>
<td>Cross-sectional</td>
<td>Religious Beliefs, Hope</td>
<td>18, Range 2.5–26 yrs</td>
<td>SCI only: Paraplegia 83.3% Quadriplegia 16.7%</td>
<td>Three coping strategies; seeking help from religious beliefs, hope, making efforts towards independence.</td>
</tr>
<tr>
<td>3 Chun [70] 2008, Canada</td>
<td>Cross-sectional</td>
<td>PTG</td>
<td>15, M 10.7 yrs</td>
<td>SCI only: Paraplegia: n = 19 Quadriplegia: n = 27 Complete: n = 16 Incomplete: n = 30</td>
<td>Experience of meaningful family relationships; experience of meaningful engagement; appreciation of life.</td>
</tr>
<tr>
<td>4 Dorsett [52] 2010, Australia</td>
<td>Longitudinal</td>
<td>Hope</td>
<td>46, Range 6 months – 10 yrs</td>
<td>SCI only: Paraplegia: 51.83% Tetraplegia: 47.71%</td>
<td>Hoping for complete recovery, hope for a cure, hope for a satisfying quality of life.</td>
</tr>
<tr>
<td>5 Kennedy [72] 2013, UK/Europe</td>
<td>Longitudinal</td>
<td>PTG</td>
<td>232, &lt;2 yrs</td>
<td>SCI only: Paraplegia: 51.83% Tetraplegia: 47.71%</td>
<td>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.</td>
</tr>
<tr>
<td>6 Lohne [77] 2005, Norway</td>
<td>Cross-sectional</td>
<td>Hope</td>
<td>10, &lt;1 yr</td>
<td>SCI only: Incomplete lesion: n = 6 Complete lesion: n = 4 (range C5–L4)</td>
<td>“The vicious cycle” – suffering (loneliness, impatience, disappointment, bitterness, dependency); “longing” - former experiences and source of new hope</td>
</tr>
<tr>
<td>7 Lohne [73] 2009, Norway</td>
<td>Cross-sectional</td>
<td>Hope</td>
<td>9, Range 3–4 yrs</td>
<td>SCI only: Incomplete: n = 5 Complete: n = 4 (range C5–L4)</td>
<td>Life-related hopes, body-related hopes, creative and expanding hopes.</td>
</tr>
<tr>
<td>8 Smith [75] 2005, UK</td>
<td>Cross-sectional</td>
<td>Hope</td>
<td>14, NR</td>
<td>SCI only: Injury details not reported</td>
<td>Three kinds of hope: concrete hope (restitution narrative), transcendent hope (quest narrative), and despair (chaos narrative).</td>
</tr>
<tr>
<td>9 McColl [69] 2000, Canada</td>
<td>Cross-sectional</td>
<td>Spirituality</td>
<td>16, &lt;2 yrs</td>
<td>SCI, n = 8</td>
<td>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.</td>
</tr>
<tr>
<td>10 Papadimitriou [37] 2011, USA</td>
<td>Cross-sectional</td>
<td>Meaning</td>
<td>10, 14, 12, NR</td>
<td>SCI only</td>
<td>SCI understood as disruption in human temporality: disconnection from a future and from one’s past. 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.</td>
</tr>
<tr>
<td>11 DeSanto-Madeya [28] 2006, USA</td>
<td>Cross-sectional</td>
<td>Meaning</td>
<td>40, Range 5–10 yrs</td>
<td>SCI only</td>
<td>SCI understood as disruption in human temporality: disconnection from a future and from one’s past. 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.</td>
</tr>
</tbody>
</table>

SCI = Spinal Cord Injury; NR = Not reported, TSI = Time since injury; PTG = Post-traumatic Growth.
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 Papadimitriou 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 2: Spirituality among family members alone

No studies were identified which addressed this objective.

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. Similar to 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 seem to be 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 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, post-traumatic 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

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

References


79. Carver CS. You want to measure coping but your protocol’s too long: consider the brief COPE. Int J Behav Med 1997;4:92–100.


Appendix B: Letter of Invitation, Information and Consent Forms, and Survey Pack for Component 1 (C1)

Date

Dear

I am writing to invite you and a close family member of your choice to participate in a research project titled 'The Contribution of Spirituality toward Family Resilience after Spinal Cord Injury'. This study is being conducted by Ms Kate Jones in partial fulfilment of her PhD with Griffith University. Ms Jones is an experienced Social Worker at the Spinal Injuries Unit. Ms Jones will be supervised by Dr Pat Dorsett (BSW, PhD), School of Human Services and Social Work, Griffith Health Institute, Griffith University.

This project will involve you and your family member completing a number of short surveys which should take no longer than 30 minutes of your time. The surveys can be completed with you in person at the Spinal Injuries Unit or over the phone.

If you would like to discuss this study further or have any questions, please contact Kate Jones on 9808 9269 or via email on kate.jones@royalrehab.com.au. You may also wish to discuss this project with your Social Worker. If you do not wish to receive any further contact regarding this study you can contact Ms Jones on the above details. Your Social Worker or Ms Jones will contact you either by phone or in person approximately one week after you receive this invitation to ask whether you would like to participate in the study. If you are interested in participating further information and consent forms will be provided at that time.

Yours Sincerely,

Dr. Gerard Weber

Medical Director, Spinal and Rehabilitation Medicine Physician

Spinal Injury Unit, Royal Rehabilitation Centre Sydney

Ph: 9808 9269 Fax: 9809 9062

Email: Gerard.Weber@royalrehab.com.au
PARTICIPANT INFORMATION SHEET AND CONSENT FORM

The contribution of spirituality toward family resilience after Spinal Cord Injury
Phase 2

Invitation

You are invited to participate in a research study which will investigate how families make sense of life after a spinal cord injury (SCI), and how this assists them to cope and manage. The results will help staff to provide better treatment and support for families during this difficult time.

The study is being conducted by Griffith University:

Kate Jones, Social Worker and Doctoral Student – Spinal Injuries Unit, Royal Rehabilitation Centre Sydney
Dr Pat Dorsett (primary university supervisor), School of Human Services and Social Work, Griffith Health Institute, Griffith University
Dr Lynne Briggs (primary university supervisor), School of Human Services and Social Work, Griffith Health Institute, Griffith University
Dr Grahame Simpson, Brain Injury Rehabilitation Research Group, Liverpool Brain Injury Rehabilitation Unit
Diane Turner (primary site supervisor), Social Work Professional Leader, Royal Rehabilitation Centre Sydney
Helen Oosthuizen, Social Worker, Spinal Injuries Unit, Royal Rehabilitation Centre Sydney
Cathie Valenzuela, Social Worker, Spinal Injuries Unit, Royal Rehabilitation Centre Sydney
Candice Unger, Social Worker, Spinal Outreach Service, Royal Rehabilitation Centre Sydney
Angela Pong, Social Worker, Spinal Outreach Service, Royal Rehabilitation Centre Sydney

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

1. ‘What is the purpose of this study?’
The purpose of the project is to investigate how families make sense of life after a spinal cord injury, and how this might assist them to cope and manage.

2. ‘Why have I been invited to participate in this study?’
You are eligible to participate in this study because you have (i) either sustained a SCI or are providing support and assistance to a relative with SCI, and (ii) meet the following criteria:

- have sufficient English fluency to understand the surveys,
- have no major psychiatric condition, and
- are over the age of 18 years

3. ‘What if I don’t want to take part in this study, or if I want to withdraw later?’
Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not affect the treatment you receive now or in the future. Whatever your decision, it will not affect your relationship with the staff caring for you or your relative.
If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason.

4. ‘What does this study involve?’
If you agree to participate in this study, you will be asked to sign a Participant Consent Form. You will then be asked to complete six short questionnaires which will seek information about ways you cope and manage after you or your relative’s SCI. The questions on the surveys are not hard to answer and are unlikely to take more than 30 minutes to complete. The surveys will be either provided to you in person, or sent to you in the mail. You will also be asked to provide some brief demographic details about yourself, including your date of birth, injury details, education level and qualifications. These details are known to play an important role in how people cope and adjust after a traumatic event. As the topic of this study is on spirituality, we are also interested to know of any religious beliefs you may hold.

The survey forms can be completed with the researcher in person, or with assistance from the researcher over the telephone. A mutually convenient time will be arranged, where the researcher will meet you in person at the Spinal Injuries Unit or call you by phone. Each SCI participant and family member will complete their own set of surveys with the researcher. Surveys can either be returned in person to the researcher during the meeting, or in the case of a phone call, returned in a stamped envelope provided.

If you are the SCI participant, the researcher would like to have access to your medical record for the purposes of obtaining information regarding your functional independence. This information is provided by the Functional Independence Measure, an outcome measure completed upon your arrival at the Spinal Injuries Unit and prior to your discharge.

5. ‘How is this study being paid for?’
The study is part of the doctoral studies of the researcher and is being funded by a small grant from Griffith University.

6. ‘Are there risks to me in taking part in this study?’
The anticipated risks from participating in this project are none at all or very minimal. If you experience any distress in completing the questionnaires you are free to stop at any stage. If needed, supportive counselling can be arranged for you via the Social Workers or Psychologists at the Spinal Injuries Unit, or the Social Workers at the Spinal Outreach Service.

7. ‘Will I benefit from the study?’
This study aims to further knowledge about family interactions after Spinal Cord Injury and may improve future rehabilitation programs, however it may not directly benefit you.

8. ‘Will taking part in this study cost me anything, and will I be paid?’
Participation in this study will not cost you anything nor will you be paid.

9. ‘How will my confidentiality be protected?’
Of the people treating you, only the researcher and your Social Worker will know whether or not you are participating in this study. Any identifiable information that is collected about you in connection with this study will remain confidential and will be disclosed only with your permission, or except as required by law. Only the researcher named above will have access to
10. ‘What happens with the results?’
If you give us your permission by signing the consent document, we plan to discuss/publish the results in peer reviewed journals or at national or international conferences. In any publication, information will be provided in such a way that you cannot be identified. Results of the study will be provided to you, if you wish.

11. ‘What should I do if I want to discuss this study further before I decide?’
When you have read this information, the researcher Kate Jones will discuss it with you and any queries you may have. Ms Jones can be contacted on 02 9808 9269. If you would like to know more at any stage, please do not hesitate to contact the coordinating investigator at Griffith University, Dr Pat Dorsett, on 07 3382 1483.

12. ‘Who should I contact if I have concerns about the conduct of this study?’
This study has been approved by the HREC of Northern Sydney Local Health District (NSLHD). Any person with concerns or complaints about the conduct of this study should contact the Research Office who is nominated to receive complaints from research participants. You should contact them on 02 9926 4590 and quote LNR/13/HAWKE/213. If you have any concerns about the research conducted at the Royal Rehabilitation Centre Sydney, please contact the Research Governance Officer on 9808 9286.

Thank you for taking the time to consider this study.
If you wish to take part in it, please sign the attached consent form. This information sheet is for you to keep.
CONSENT FORM

Royal Rehabilitation Centre Sydney

The contribution of spirituality toward family resilience after Spinal Cord Injury

1. I, ..........................................................................................................................
of..................................................................................................................agree to participate as a participant in the study described in the participant informationstatement attached to this form.

2. I acknowledge that I have read the participant information statement, which explains why I have been selected, the aims of the study and the nature and the possible risks of the investigation, and the statement has been explained to me to my satisfaction.

3. Before signing this consent form, I have been given the opportunity of asking any questions relating to any possible physical and mental harm I might suffer as a result of my participation and I have received satisfactory answers.

4. I understand that I can withdraw from the study at any time without prejudice to my relationship to the Royal Rehabilitation Centre Sydney.

5. I agree that research data gathered from the results of the study may be published, provided that I cannot be identified.

6. I understand that if I have any questions relating to my participation in this research, I may contact Dr Pat Dorsett on telephone 07 3382 1483, who will be happy to answer them.

7. I acknowledge receipt of a copy of this Consent Form and the Participant Information Statement

Complaints may be directed to the NSLHD Research Office on 9926 4590.

Signature of participant Please PRINT name Date

_______________________________________________________________

Signature of witness Please PRINT name Date

_______________________________________________________________
The contribution of spirituality toward family resilience after Spinal Cord Injury

REVOCATION OF CONSENT

I hereby wish to WITHDRAW my consent to participate in the study described above and understand that such withdrawal WILL NOT jeopardise any treatment or my relationship with the Royal Rehabilitation Centre Sydney.

Signature

Date

Please PRINT Name

The section for Revocation of Consent should be forwarded to Kate Jones, Spinal Injuries Unit, Royal Rehabilitation Centre Sydney, PO Box 6, RYDE, NSW, 1680.
Spirituality and resilience study - data protocol

Date of interview: □□- □□-□□□□

Family Member

1.1 Sex:
- Male .................................. 1
- Female.................................. 2

1.2 Date of Birth: □□- □□-□□□□

1.3 Relationship to person with SCI:
- Parent.................................. 1
- Spouse.................................. 2
- Grandparent.......................... 3
- Sibling.................................. 4
- Adult child............................ 5

1.4 Marital status of family member
- Single................................. 1
- Separated / divorced ............ 2
- Widowed................................ 3
- Married / de facto.............. 4

1.5 If partner of person with SCI, years of relationship (marriage or de facto) □□

1.6 Years of education (Completed High School = 12 years) □□

1.7 Qualification (circle the highest level of attainment only)

- No formal education ...................... 1
- Complete primary school ............. 2
- Did not complete high school .......... 3
- Completed Year 10 school certificate .. 4
- Completed Year 12 higher school certificate ... 5
- Completed trades qualification .......... 6
- Completed certificate / diploma ......... 7
- Completed undergraduate degree or higher ........ 8

1.8 Living with person with SCI at time of injury?
- Yes .................................. 1
1.9 Living with person with SCI now?
(If in hospital, will they be discharged to live at home with you?)

- Yes: 1
- No: 2

1.10 Religion

- Catholic: 1
- Anglican: 2
- Uniting Church: 3
- Presbyterian: 4
- Buddhism: 5
- Greek Orthodox: 6
- Islam: 7
- Baptist: 8
- Lutheran: 9
- Other: 10
- No religion: 11

If other: ___________________________________________

1.11 Current Employment Status

- Not currently employed: 1
- Employed part-time/casual: 2
- Employed full-time: 3
2. Individual with SCI

2.1 Sex:
- Male --- 1
- Female --- 2

2.2 Date of Birth:
- Day
- Month
- Year

2.3 Date of injury:
- Day
- Month
- Year

2.4 Injury:
- Paraplegia Complete --- 1
- Paraplegia Incomplete --- 2
- Tetraplegia Complete --- 3
- Tetraplegia Incomplete --- 4

SCI Level
ASIA Score

2.5 Injury circumstances:
- MVA driver --- 1
- MVA passenger --- 2
- MBA --- 3
- MVA pedestrian --- 4
- Pushbike --- 5
- Fall* --- 6
- Struck by object** --- 7
- Gunshot --- 8
- Other SCI --- 9
- Water-related injuries --- 10
- Other --- 11

If other: _______________________________________

* include work, home, sports, intoxication, other
** assault, at work, accidental, other

2.6 Marital status of person with SCI
- Single --- 1
- Separated / divorced --- 2
- Widowed --- 3
- Married / de facto --- 4

2.7 Years of education (Completed High School = 12 years)
- 8
- 9

299
2.8 Qualification (circle the highest level of attainment only)

- No formal education 1
- Complete primary school 2
- Did not complete high school 3
- Completed Year 10 school certificate 4
- Completed Year 12 higher school certificate 5
- Completed trades qualification 6
- Completed certificate / diploma 7
- Completed undergraduate degree or higher 8

2.9 Current Living situation

- Own home 1
- Parent’s home 2
- Boarding house 3
- Rent 4
- Nursing home 5
- IP rehabilitation 6
- Transitional living unit 7
- Other 8

If other: _________________________________

2.10 Religion

- Catholic 1
- Anglican 2
- Uniting Church 3
- Presbyterian 4
- Buddhism 5
- Greek Orthodox 6
- Islam 7
- Baptist 8
- Lutheran 9
- Other 10

If other: _________________________________

- No religion 11

2.11 Current Employment Status

- Not currently employed 1
- Employed part-time/casual 2
- Employed full-time 3
### FACIT-Sp-Ex (Peterman et al., 2002) (Individual with SCI)

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>I feel peaceful</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>I have a reason for living</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>My life has been productive</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>I have trouble feeling peace of mind</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>I feel a sense of purpose in my life</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td>I am able to reach down deep into myself for comfort</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td>I feel a sense of harmony within myself</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td>My life lacks meaning and purpose</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td>I find comfort in my faith or spiritual beliefs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td>I find strength in my faith or spiritual beliefs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11.</td>
<td>My spinal cord injury has strengthened my faith or spiritual beliefs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12.</td>
<td>I know that whatever happens with my spinal cord injury, things will be okay</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13.</td>
<td>I feel connected to a higher power (or God)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14.</td>
<td>I feel connected to other people</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15.</td>
<td>I feel loved</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16.</td>
<td>I feel love for others</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>A little bit</td>
<td>Somewhat</td>
<td>Quite a bit</td>
<td>Very much</td>
</tr>
<tr>
<td>---</td>
<td>------------</td>
<td>--------------</td>
<td>----------</td>
<td>-------------</td>
<td>-----------</td>
</tr>
<tr>
<td>17. I am able to forgive others for any harm they have ever caused me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. I feel forgiven for any harm I may have ever caused</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19. Throughout the course of my day, I feel a sense of thankfulness for my life</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. Throughout the course of my day, I feel a sense of thankfulness for what others bring to my life</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21. I feel hopeful</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22. I feel a sense of appreciation for the beauty of nature</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>23. I feel compassion for others in the difficulties they are facing</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>A little bit</td>
<td>Somewhat</td>
<td>Quite a bit</td>
<td>Very much</td>
</tr>
<tr>
<td>---</td>
<td>------------</td>
<td>--------------</td>
<td>----------</td>
<td>-------------</td>
<td>-----------</td>
</tr>
<tr>
<td>1.</td>
<td>I feel peaceful</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>I have a reason for living</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>My life has been productive</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>I have trouble feeling peace of mind</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>I feel a sense of purpose in my life</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td>I am able to reach down deep into myself for comfort</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td>I feel a sense of harmony within myself</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td>My life lacks meaning and purpose</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td>I find comfort in my faith or spiritual beliefs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td>I find strength in my faith or spiritual beliefs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11.</td>
<td>My relative’s spinal cord injury has strengthened my faith or spiritual beliefs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12.</td>
<td>I know that whatever happens with my relative’s spinal cord injury, things will be okay</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13.</td>
<td>I feel connected to a higher power (or God)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14.</td>
<td>I feel connected to other people</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15.</td>
<td>I feel loved</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16.</td>
<td>I feel love for others</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>A little bit</td>
<td>Somewhat</td>
<td>Quite a bit</td>
<td>Very much</td>
</tr>
<tr>
<td>---</td>
<td>------------</td>
<td>--------------</td>
<td>----------</td>
<td>-------------</td>
<td>-----------</td>
</tr>
<tr>
<td>17. I am able to forgive others for any harm they have ever caused me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. I feel forgiven for any harm I may have ever caused</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19. Throughout the course of my day, I feel a sense of thankfulness for my life</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. Throughout the course of my day, I feel a sense of thankfulness for what others bring to my life</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21. I feel hopeful</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22. I feel a sense of appreciation for the beauty of nature</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>23. I feel compassion for others in the difficulties they are facing</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### The Resilience Scale (Wagnild & Young, 1993)

<table>
<thead>
<tr>
<th></th>
<th>Statement</th>
<th>Disagree</th>
<th>Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>When I make plans I follow through with them</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>I usually manage one way or another.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>I am able to depend on myself more than anyone else</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Keeping interested in things is important to me</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>I can be on my own if I have to</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>I feel proud that I have accomplished things in my life</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>I usually take things in my stride</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>I am friends with myself</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>I feel that I can handle many things at a time</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>I am determined</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>I seldom wonder what the point is</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>I take things one day at a time</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>I can get through difficult times because I’ve experienced difficulty before</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>I have self-discipline</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>I keep interested in things</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>I can usually find something to laugh about</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>My belief in myself gets me through hard times</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>In an emergency, I’m someone people generally can rely on</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>I can usually look at a situation in a number of ways</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>Sometimes I make myself do things whether I want to or not</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>21</td>
<td>My life has meaning</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>I do not dwell on things that I can’t do anything about</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>23</td>
<td>When I’m in a difficult situation, I can usually find my way out of it</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>24</td>
<td>I have enough energy to do what I have to do</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>25</td>
<td>It’s okay if there are people who don’t like me</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
</tbody>
</table>
**Connor-Davidson Resilience Scale (CD-RISC)**

Please indicate how much you agree with the following statements as they apply to you over the last month. If a particular situation has not occurred recently, answer according to how you think you would have felt.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Not true at all</th>
<th>Rarely true</th>
<th>Sometimes true</th>
<th>Often true</th>
<th>True nearly all the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I am able to adapt when changes occur</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. I have at least one close and secure relationship which helps me when I am stressed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Where there are no clear solutions to my problems, sometimes fate or God can help</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. I can deal with whatever comes my way</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Past successes give me confidence in dealing with new challenges and difficulties</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. I try to see the humorous side of things when I am faced with problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Having to cope with stress can make me stronger</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. I tend to bounce back after illness, injury, or other hardships</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Good or bad, I believe that most things happen for a reason</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. I give my best effort, no matter what the outcome may be</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. I believe I can achieve my goals, even if there are obstacles</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Even when things look hopeless, I don’t give up</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. During times of stress/crisis, I know where to turn for help</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Under pressure I stay focused and think clearly</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not true at all</td>
<td>Rarely true</td>
<td>Sometimes true</td>
<td>Often true</td>
<td>True nearly all the time</td>
</tr>
<tr>
<td>---</td>
<td>----------------</td>
<td>-------------</td>
<td>----------------</td>
<td>------------</td>
<td>-------------------------</td>
</tr>
<tr>
<td>15.</td>
<td>I prefer to take the lead in solving problems, rather than letting others make all the decisions</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16.</td>
<td>I am not easily discouraged by failure</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17.</td>
<td>I think of myself as a strong person when dealing with life’s challenges and difficulties</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18.</td>
<td>I can make unpopular or difficult decisions that affect other people, if it is necessary</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19.</td>
<td>I am able to handle unpleasant or painful feelings like sadness, fear and anger</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20.</td>
<td>In dealing with life’s problems, sometimes you have to act on a hunch without knowing why</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21.</td>
<td>I have a strong sense of purpose in life</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22.</td>
<td>I feel in control of my life</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>23.</td>
<td>I like challenges</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>24.</td>
<td>I work to attain my goals, no matter what roadblocks I encounter along the way</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25.</td>
<td>I take pride in my achievements</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
DASS-21 (Lovibond & Lovibond, 1995)

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you over the past week.

0 Did not apply to me at all - NEVER
1 Applied to me to some degree, or some of the time - SOMETIMES
2 Applied to me to a considerable degree, or a good part of the time - OFTEN
3 Applied to me very much, or most of the time - ALMOST ALWAYS

1 I found it hard to wind down      0  1  2  3
2 I was aware of dryness of my mouth     0  1  2  3
3 I couldn’t seem to experience any positive feeling at all      0  1  2  3
4 I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)  0  1  2  3
5 I found it difficult to work up the initiative to do things     0  1  2  3
6 I tended to over-react to situations 0  1  2  3
7 I experienced trembling (eg, in the hands)    0  1  2  3
8 I felt that I was using a lot of nervous energy 0  1  2  3
9 I was worried about situations in which I might panic and make a fool of myself 0  1  2  3
10 I felt that I had nothing to look forward to 0  1  2  3
11 I found myself getting agitated 0  1  2  3
12 I found it difficult to relax 0  1  2  3
13 I felt down-hearted and blue 0  1  2  3
14 I was intolerant of anything that kept me from getting on with what I was doing 0  1  2  3
15 I felt I was close to panic 0  1  2  3
16 I was unable to become enthusiastic about anything 0  1  2  3
17 I felt I wasn’t worth much as a person 0  1  2  3
18 I felt that I was rather touchy 0  1  2  3
19 I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat) 0  1  2  3
20 I felt scared without any good reason 0  1  2  3
21 I felt that life was meaningless 0  1  2  3
PANAS (Watson & Clark, 1994)
This scale consists of a number of words and phrases that describe different feelings and emotions.
Read each item and then mark the appropriate answer in the space next to that word. Indicate to what extent you have felt this way during the past few weeks. Use the following scale to record your answers:

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Very slightly</td>
<td>A little</td>
<td>Moderately</td>
<td>Quite a bit</td>
<td>Extremely</td>
</tr>
<tr>
<td>______</td>
<td>attentive</td>
<td>______</td>
<td>excited</td>
<td>______</td>
<td>strong</td>
</tr>
</tbody>
</table>
Satisfaction With Life Scale (SWLS) (Pavot & Diener, 1993)

Below are five statements with which you may agree or disagree. Using the 1-7 scale below, indicate your agreement with each item by placing the appropriate number on the line preceding that item. Please be open and honest in your responding. The 7-point scale is as follows:

- 7 - Strongly agree
- 6 - Agree
- 5 - Slightly agree
- 4 - Neither agree nor disagree
- 3 - Slightly disagree
- 2 - Disagree
- 1 - Strongly disagree

___ 1. In most ways my life is close to my ideal.

___ 2. The conditions of my life are excellent.

___ 3. I am satisfied with my life.

___ 4. So far I have gotten the important things I want in life.

___ 5. If I could live my life over, I would change almost nothing.
Appendix C: Letter of Invitation, Information and Consent Form, and Interview Protocols for Component 2 (C2)

Date
Dear ,

I am writing to invite you and a close family member of your choice to participate in a research project titled 'The Contribution of Spirituality toward Family Resilience after Spinal Cord Injury'. This study is being conducted by Ms Kate Jones in partial fulfilment of her PhD with Griffith University. Ms Jones is an experienced Social Worker at the Spinal Injuries Unit. Ms Jones will be supervised by Dr Pat Dorsett (BSW, PhD) School of Human Services and Social Work, Griffith Health Institute, Griffith University. This project will involve you and your family member participating in two interviews, six months apart. The first interview will take place at the Spinal Injuries Unit, the second will also take place at the Spinal Injuries Unit at a time suitable for you, or via Skype on your computer. If you do not have access to Skype, and you are not able to attend the Spinal Injuries Unit in person, alternative arrangements will be made. Each interview will take no longer than two hours.

If you would like to discuss this study further or have any questions, please contact Kate Jones on 9808 9269 or via email on kate.jones@royalrehab.com.au. You may also wish to discuss this project with your Social Worker. If you do not wish to receive any further contact regarding this study you can contact Ms Jones on the above details. Your Social Worker or Ms Jones will contact you either by phone or in person approximately one week after you receive this invitation to ask whether you would like to participate in the study. If you are interested in participating, further information and consent forms will be provided at that time.

Yours Sincerely

Dr. Gerard Weber
Medical Director, Spinal and Rehabilitation Medicine Physician
Spinal Injury Unit, Royal Rehabilitation Centre Sydney
Ph: 9808 9269 Fax: 9809 9062
Email: Gerard.Weber@royalrehab.com.au
PARTICIPANT INFORMATION SHEET AND CONSENT FORM

The contribution of spirituality toward family resilience after Spinal Cord Injury
Phase 1

Invitation

You are invited to participate in a research study investigating how interactions between family members foster a sense of meaning, hope and purpose over time after Spinal Cord Injury (SCI).

The study is being conducted by Griffith University:

Kate Jones, Social Worker and Doctoral Student – Spinal Injuries Unit, Royal Rehabilitation Centre Sydney
Dr Pat Dorsett (primary university supervisor), School of Human Services and Social Work, Griffith Health Institute, Griffith University
Dr Lynne Briggs (primary university supervisor), School of Human Services and Social Work, Griffith Health Institute, Griffith University
Dr Grahame Simpson, Brain Injury Rehabilitation Research Group, Liverpool Brain Injury Rehabilitation Unit
Diane Turner (primary site supervisor), Social Work Professional Leader, Royal Rehabilitation Centre Sydney
Helen Oosthuizen, Social Worker, Spinal Injuries Unit, Royal Rehabilitation Centre Sydney
Cathie Valenzuela, Social Worker, Spinal Injuries Unit, Royal Rehabilitation Centre Sydney
Candice Unger, Social Worker, Spinal Outreach Service, Royal Rehabilitation Centre Sydney
Angela Pong, Social Worker, Spinal Outreach Service, Royal Rehabilitation Centre Sydney

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

1. ‘What is the purpose of this study?’
The purpose of this study is to investigate how interactions between individuals with SCI and their family members foster a sense of meaning, hope, and purpose over time.

2. ‘Why have I been invited to participate in this study?’
You are eligible to participate in this study because you have (i) either sustained a SCI or are providing support and assistance to a relative with SCI, and (ii) meet the following criteria:

- have no major psychiatric condition, and
- are over the age of 18 years

3. ‘What if I don’t want to take part in this study or if I want to withdraw later?’
Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not affect the treatment you receive now or in the future. Whatever your decision, it will not affect your relationship with the staff caring for you or your relative.
If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason.

4. ‘What does this study involve?’
If you agree to participate in this study, you will be asked to sign the Participant Consent Form. You will then be invited to participate in two interviews with your relative. The first interview will be conducted at the Spinal Injuries Unit, and the second will occur approximately six months later either at the Spinal Injuries Unit at a time convenient for you, or by Skype if you would prefer. If you do not have access to Skype, alternative arrangements can be made to meet you at a mutually convenient location, or for the interview to be conducted by phone. Each interview is expected to take between 1-2 hours to complete, and will be audio recorded so it can be transcribed. All transcripts will be de-identified and no identifying information will be stored with the transcripts of your interview.

You will also be asked to provide some brief demographic details about yourself, including your date of birth, injury details, education level and qualifications. These details are known to play an important role in how people cope and adjust after a traumatic event. As the topic of this study is on spirituality, we are also interested to know of any religious beliefs you may hold.

If you are the SCI participant, the researcher would like to have access to your medical record for the purposes of obtaining information regarding your functional independence. This information is provided by the Functional Independence Measure, an outcome measure completed upon your arrival at the Spinal Injuries Unit and prior to your discharge.

5. ‘How is this study being paid for?’
The study is part of the doctoral studies of the researcher and is being funded by a small grant from Griffith University.

6. ‘Are there risks to me in taking part in this study?’
The anticipated risks from participating in this project are none or very minimal. If you experience any distress in completing the questionnaires you are free to stop at any stage. If needed, supportive counselling can be arranged for you via the Social Workers or Psychologists at the Spinal Injuries Unit.

7. ‘Will I benefit from the study?’
This study aims to further knowledge about family interactions after Spinal Cord Injury and may improve future rehabilitation programs. Although the research may not directly benefit you, you and your relative may gain further insight from discussing these topics together.

13. ‘Will taking part in this study cost me anything, and will I be paid?’
Participation in this study will not cost you anything nor will you be paid.

14. ‘How will my confidentiality be protected?’
Of the people treating you, only the researcher and your Social Worker will know whether or not you are participating in this study. Any identifiable information that is collected about you in connection with this study will remain confidential and will be disclosed only with your permission, or except as required by law. Only the researcher named above will have access to
your details and results, and these will be held securely at the Royal Rehabilitation Centre Sydney.

15. ‘What happens with the results?’
If you give us your permission by signing the consent document, we plan to discuss/publish the results in peer reviewed journals or at national or international conferences. In any publication, information will be provided in such a way that you cannot be identified. A summary of the results of the study will be provided to you, if you wish.

16. ‘What should I do if I want to discuss this study further before I decide?’
When you have read this information, the researcher Kate Jones will discuss it with you and any queries you may have. Ms Jones can be contacted on 02 9808 9269. If you would like to know more at any stage, please do not hesitate to contact the co-ordinating investigator at Griffith University, Dr Pat Dorsett, on 07 3382 1483.

17. ‘Who should I contact if I have concerns about the conduct of this study?’
This study has been approved by the HREC of Northern Sydney Local Health District (NSLHD). Any person with concerns or complaints about the conduct of this study should contact the Research Office who is nominated to receive complaints from research participants. You should contact them on 02 9926 4590 and quote HREC project number LNR/13/HAWKE/213. If you have any concerns about the research conducted at the Royal Rehabilitation Centre Sydney, please contact the Research Governance Officer on 9808 9286.

    Thank you for taking the time to consider this study.
    If you wish to take part in it, please sign the attached consent form.
    This information sheet is for you to keep.
Royal Rehabilitation Centre Sydney

CONSENT FORM

The contribution of spirituality toward family resilience after Spinal Cord Injury

1. I, ..................................................................................................................
of..................................................................................................................
   agree to participate as a participant in the study described in the participant information
   statement attached to this form.

2. I acknowledge that I have read the participant information statement, which explains
   why I have been selected, the aims of the study and the nature and the possible risks of
   the investigation, and the statement has been explained to me to my satisfaction.

3. Before signing this consent form, I have been given the opportunity of asking any
   questions relating to any possible physical and mental harm I might suffer as a result of
   my participation and I have received satisfactory answers.

4. I understand that I can withdraw from the study at any time without prejudice to my
   relationship to the Royal Rehabilitation Centre Sydney.

5. I agree that research data gathered from the results of the study may be published,
   provided that I cannot be identified.

6. I understand that if I have any questions relating to my participation in this research, I
   may contact Dr Pat Dorsett on telephone 07 3382 1483, who will be happy to answer
   them.

7. I acknowledge receipt of a copy of this Consent Form and the Participant Information
   Statement.

Complaints may be directed to the NSLHD Research Office on 9926 4590.

Signature of participant Please PRINT name    Date

__________________________________________________________________________

Signature of witness Please PRINT NAME    Date

__________________________________________________________________________
The contribution of spirituality toward family resilience after Spinal Cord Injury

REVOCATION OF CONSENT

I hereby wish to WITHDRAW my consent to participate in the study described above and understand that such withdrawal WILL NOT jeopardise any treatment or my relationship with the Royal Rehabilitation Centre Sydney.

Signature          Date

Please PRINT Name

The section for Revocation of Consent should be forwarded to Kate Jones, Spinal Injuries Unit, Royal Rehabilitation Centre Sydney, PO Box 6, RYDE, NSW, 1680
Family Interviews _ First interview

Thanks so much for your willingness to participate in this research project. The project I am working on is about how families make meaning together after spinal cord injury. I am really interested in the ways that the event of a SCI not only affects the person with the injury, but also the people in your family, and the relationships you have with those people.

1. To start with I was wondering if you could tell me a little about your relationship?
   - If someone were to ask you to describe your relationship with one another, what are some words that you might use?
   - What has your relationship been like in the past?
   - What is it like now?

2. How has your relationship been affected by the SCI?
   - What changes if any have you noticed?

3. What does the word ‘spirituality’ mean to you?

4. One way people think of spirituality is as a sense of harmony and connectedness with one’s self, others, nature, and God or a higher power, and something which is part of a growth process that leads to ultimate purpose or meaning in life.
   - In what ways have you found meaning, hope and purpose since the SCI?
   - How does it fit in with your life story and purpose right now?
   - How does this make a difference in how you manage day to day challenges?
   - How does this meaning affect others in your family?
   - Do others in your family see things in the same way or differently, and how do these differences affect you?

5. What strengths have you noticed in yourself since the SCI? What strengths have you noticed in the other person?

6. What hope do you hold for the future? How does the hope of the other person help you or challenge you?
Family Interviews _ Second Interview

Thanks again for your willingness to participate in this research project. As you may remember from our first interview the project I am working on is about how families make meaning together after spinal cord injury. I am really interested in the ways that the event of a SCI not only affects the person with the injury, but also the people in your family, and the relationships you have with those people.

1. I was wondering if you could tell me a little about your relationship since last time we met?
   - What changes if any have you noticed?
   - How have you provided support to one another?
   - How have you encouraged one another?

2. As a family, what sense have you made of this time in your lives together?
   - What if anything has helped you make sense of it?
   - Has spirituality played a role, and if so, how?
   - What makes life worth living?

3. Are there any messages or challenges you have taken from this experience of SCI? If so, what are they?
   - How do these affect you on a day to day basis?

4. What strengths have you noticed in yourself since the SCI? What strengths have you noticed in the other person? As a family?
   - What strength have you drawn from one another?
   - What strength have you drawn from others? From God, or your perspective on life?

5. What hope do you hold for the future? How does the hope of the other person help you or challenge you?
Appendix D: Letter of Invitation, Consent Form, Demographic Protocol and Focus Group Interview Protocol for Component 3 (C3)

Date

Dear team member,
You are invited to participate in a focus group investigating the role of spirituality within spinal rehabilitation. This study is being conducted by Ms Kate Jones in partial fulfilment of her PhD with Griffith University. Ms Jones is an experienced Social Worker at the Spinal Injuries Unit. Ms Jones will be supervised by Dr Pat Dorsett (BSW, PhD), School of Human Services and Social Work, Griffith Health Institute, Griffith University.
This focus group will take approximately one hour, and will include health professionals from a range of disciplines. If you would like to discuss this study further or have any questions, please contact Kate Jones on 9808 9269 or via email on kate.jones@royalrehab.com.au. You may also wish to discuss this project with your team leader. If you do not wish to receive any further contact regarding this study you can contact Ms Jones on the above details. Your team leader or Ms Jones will contact you either by phone or in person approximately one week after you receive this invitation to ask whether you would like to participate in the study. If you are interested in participating further information and consent forms will be provided at that time.
Yours Sincerely,

Diane Turner
Primary on-site supervisor
Social Work Professional Leader
Royal Rehabilitation Centre Sydney
PO Box 6, Ryde, NSW 1680
Tel: 9808 9052  Fax: 9809 9027
PARTICIPANT INFORMATION SHEET AND CONSENT FORM

The contribution of spirituality toward family resilience after spinal cord injury

Phase 3

Invitation
You are invited to participate in a research study which will investigate how spirituality contributes to family resilience after a spinal cord injury (SCI). The results will help spinal rehabilitation staff to provide better treatment and support for families during this difficult time.

The study is being conducted by Griffith University:
Kate Jones, Social Worker and Doctoral Student – Spinal Injuries Unit, Royal Rehab
Dr Pat Dorsett (primary university supervisor), School of Human Services and Social Work, Griffith Health Institute, Griffith University
Dr Lynne Briggs (primary university supervisor), School of Human Services and Social Work, Griffith Health Institute, Griffith University
Dr Grahame Simpson, Brain Injury Rehabilitation Research Group, Liverpool Brain Injury Rehabilitation Unit
Diane Turner (primary site supervisor), Social Work Professional Leader, Royal Rehab
Helen Oosthuizen, Social Worker, Spinal Injuries Unit, Royal Rehab
Cathie Valenzuela, Social Worker, Spinal Injuries Unit, Royal Rehab
Candice Unger, Social Worker, Spinal Outreach Service, Royal Rehab
Angela Pong, Social Worker, Spinal Outreach Service, Royal Rehab

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

4. ‘What is the purpose of this study?’
The purpose of the project is to investigate how spirituality contributes toward family resilience after spinal cord injury (SCI). Specifically, this study will consider staff perceptions of the role of spirituality within spinal rehabilitation, and how this role may be enhanced.

5. ‘Why have I been invited to participate in this study?’
You are eligible to participate in this study because you are a health professional working in the field of spinal rehabilitation and have been working in this field for at least 12 months.

6. ‘What if I don’t want to take part in this study, or if I want to withdraw later?’
Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not at all affect your relationship with the researcher or any other staff, nor will it in any way affect your employment at the Royal Rehab. If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason.

4. ‘What does this study involve?’
If you agree to participate in this study, you will be asked to sign a Participant Consent Form. You will also be asked to provide some brief demographic details about yourself. You will then be invited to participate in a focus group which will be approximately one hour in duration.

The focus group will be conducted at the Spinal Injuries Unit, Royal Rehab, and will be held at a time convenient for all participants. Each focus group will consist of approximately 5-6 participants. Focus groups will be audio recorded and transcribed. The transcripts will be de-identified and no identifying information will be stored with the transcript of your focus group.

5. ‘How is this study being paid for?’
The study is part of the doctoral studies of the researcher and is being funded by a small grant from Griffith University.

6. ‘Are there risks to me in taking part in this study?’
There are no anticipated risks from participating in this project.

8. ‘Will I benefit from the study?’
This study aims to further knowledge about family interactions after Spinal Cord Injury and may improve future rehabilitation programs, however it may not directly benefit or influence your work practice.

18. ‘Will taking part in this study cost me anything, and will I be paid?’
Participation in this study will not cost you anything nor will you be paid.

19. ‘How will my confidentiality be protected?’
Any identifiable information that is collected about you in connection with this study will remain confidential and will be disclosed only with your permission, or except as required by law. Only the researcher named above will have access to
your details and involvement, and these will be held securely at the Royal Rehab.

20. ‘What happens with the results?’
If you give us your permission by signing the consent document, we plan to discuss/publish the results in peer reviewed journals or at national or international conferences. In any publication, information will be provided in such a way that you cannot be identified. Results of the study will be provided to you, if you wish.

21. ‘What should I do if I want to discuss this study further before I decide?’
When you have read this information, the researcher Kate Jones will discuss it with you and any queries you may have. Ms Jones can be contacted on 02 9808 9269. If you would like to know more at any stage, please do not hesitate to contact the co-ordinating investigator at Griffith University, Dr Pat Dorsett, on 07 3382 1483.

22. ‘Who should I contact if I have concerns about the conduct of this study?’
This study has been approved by the HREC of Northern Sydney Local Health District (NSLHD). Any person with concerns or complaints about the conduct of this study should contact the Research Office who is nominated to receive complaints from research participants. You should contact them on 02 9926 4590 and quote .

Thank you for taking the time to consider this study.
If you wish to take part in it, please sign the attached consent form.
This information sheet is for you to keep.
CONSENT FORM

The contribution of spirituality toward family resilience after Spinal Cord Injury

1. I, ....................................................................................................................
of ................................................................................................................
agree to participate as a participant in the study described in the participant information statement attached to this form.

2. I acknowledge that I have read the participant information statement, which explains why I have been selected, the aims of the study and the nature and the possible risks of the investigation, and the statement has been explained to me to my satisfaction.

3. Before signing this consent form, I have been given the opportunity of asking any questions relating to any possible physical and mental harm I might suffer as a result of my participation and I have received satisfactory answers.

4. I understand that I can withdraw from the study at any time without prejudice to my relationship to or employment with the Royal Rehab.

5. I agree that research data gathered from the results of the study may be published, provided that I cannot be identified.

6. I understand that if I have any questions relating to my participation in this research, I may contact Dr Pat Dorsett on telephone 07 3382 1483, who will be happy to answer them.

7. I acknowledge receipt of a copy of this Consent Form and the Participant Information Statement.

Complaints may be directed to the NSLHD Research Office on 9926 4590.
<table>
<thead>
<tr>
<th>Signature of participant</th>
<th>Please PRINT name</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>__________________________________________________________________________</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Signature of witness</th>
<th>Please PRINT name</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>_____________________</td>
<td>__________________</td>
<td>_______</td>
</tr>
</tbody>
</table>
The contribution of spirituality toward family resilience after Spinal Cord Injury

REVOCATION OF CONSENT

I hereby wish to WITHDRAW my consent to participate in the study described above and understand that such withdrawal WILL NOT jeopardise any treatment or my relationship with the Royal Rehab.

Signature  Date

Please PRINT Name

The section for Revocation of Consent should be forwarded to Kate Jones, Spinal Injuries Unit, Royal Rehab, PO Box 6, RYDE, NSW, 1680.
## Spirituality and resilience study - data protocol

### Health Professional

**Date of focus group:** □□-□□-□□□□

1.1 **Sex:**
- Male ───────────────────── 1
- Female ─────────────────── 2

1.2 **Date of Birth:** □□-□□-□□□□

1.3 **Health Discipline:**
- Physiotherapy ───────────── 1
- Social Work ─────────────── 2
- Psychology ─────────────── 3
- Occupational Therapy ───── 4
- Recreation Therapy ─────── 5
- Nursing ───────────────── 6
- Medical ───────────────── 7

1.4 **Years working in Spinal Injury** □□

1.5 **Years of education** (Completed High School = 12 years) □□

1.6 **Qualification** (circle the highest level of attainment only)
- Completed undergraduate degree ───── 1
- Master Degree ───── 2
- PhD ───── 3

1.7 **Religion**
- Catholic ───────────────────── 1
- Anglican ─────────────────── 2
- Uniting Church ───────────── 3
- Presbyterian ─────────────── 4
- Buddhism ───────────────── 5
- Greek Orthodox ───────────── 6
- Islam ───────────────── 7
- Baptist ───────────────── 8
- Lutheran ───────────────── 9
- Other ───────────────── 10

If other: _____________________________________________

No religion ───────────────── 11
Focus Group Interview Protocol: First group

Thank you for coming to this focus group today. The purpose of the group is to discuss how the role of spirituality is incorporated into the spinal rehabilitation process now, and whether it could be enhanced. I would like to include spirituality for both clients and their family members in this discussion.

1) How would you describe spirituality?

2) One way spirituality has been defined is: “the sense of harmony and interconnectedness of the self, others, nature, and the ultimate Other” achieved “through a dynamic and integrative growth process that leads to the ultimate purpose and meaning of life” (Brillhart, 2005). Using this definition how have you seen spirituality make a difference among spinal clients and their families during rehabilitation?

3) Do you think spirituality has a role in spinal rehabilitation?
   • If so, what do you think its role is?

4) How is this role incorporated at present?

5) What do you think are some ways that spirituality could be enhanced during inpatient rehabilitation?
**Focus Group Interview Protocol: Second group**

Thank you for coming to this focus group today. The purpose of the group is to discuss how the role of spirituality is incorporated into the spinal rehabilitation process now, and whether it could be enhanced. I would like to include spirituality for both clients and their family members in this discussion.

1) How would *you* describe spirituality?

2) One way spirituality has been defined is: "the sense of harmony and interconnectedness of the self, others, nature, and the ultimate Other" achieved "through a dynamic and integrative growth process that leads to the ultimate purpose and meaning of life" (Brillhart, 2005). Using this definition what are some ways you have seen spirituality make a difference among spinal clients and their families during rehabilitation?

3) I’ve now conducted interviews with 8 families in the spinal unit. These families include those with Christian, Hindu, and Muslim beliefs, as well as those who don’t follow any religion. Here are some of the themes that have come up in the interviews:

i) **Did the SCI happen for a reason?**

- It’s always a ‘why?’ You’re not going to get away from it. As she said, this happened for a reason. I’d like to know what the reason is
- Client: it’s just some people think that everything happens for a reason um I don’t really think this happened for a reason.

- Family member: I was tested big time. Something that I didn’t expect in my life. I was tested at work, I was tested in relationship, I was tested with my father, the
responsibility, everything it was just thrown in my face. But I still believed in God. Whatever happens it happens for a reason.

ii) **Spirituality as a source of strength**—prayer, meditation, bible verses, religious or secular community groups, and just connecting with nature

- You know I mean to say it’s it’s believing that sometimes things are bad but you’ve got to find the strength to get through the bad times and you enjoy every day that you have in your life because you know whether it’s a beautiful flower or whether it’s a lovely sunset I mean to say you have to see the good things and enjoy them and that’s what I how I go through my life

- I mean there you’ve got the open space. Particularly at night you go out there and you look up and you think, oh yeah life’s not so bad after all
- so I’ve drawn strength, great strength from a number of different bible verses um because I believe that that’s one of the ways God answers prayers

- So you sort of say a few prayers, try to ease things off a little bit. Try and get try and get a little bit of support from (pointing up) up above (laughs) if you know what I mean

- And in times of real trouble I ask Jesus for help as well

iii) **Hope for healing or recovery.**

- So is because I believe in God and God is helping me to do all those things.

- So I kind of feel like we’re working in partnership now whereas previously he was doing every single thing. I would go to sleep, do nothing, the next morning I would wake up and my toes could move. There was nothing, I did nothing! He did it all.

- Kate: tell me what are they specifically praying for when they pray for you (friends)?
  Client: (pause) to get quicker healing

iv) **The value of positive thinking**

- Well yeah if I meditate if I feel good or positive I do feel stronger.

- Family member: Because I think if I do (pause) don’t believe and I don’t think positive I think I’ll go backwards.
Family member: But then I suppose over the time too, over the years there’s been a few bad years hasn’t there.
Client: Oh yeah, we’ve had a few dry gullies and rough roads. Anyway, she still comes up smiling.
Family member: Well, there’s not much point not doing that, is there?
And that’s why I think we’re stronger as far as (client’s) accident because we’re going to, yeah I think we’ve got a point to prove to people you know (pause) there’s no need to be negative you’ve got to be positive.

v) **Connection with others**

- ‘family is everything and its family that gives us our strength’
- ‘Cause to be honest (pause) because of that relationship I don’t wanna die’.

vi) **A sense of being on a journey.**

- ‘my grandparents had a painting on their wall many, many years ago that’s a long winding road, and you can’t see what’s around the corner and I remember saying to my grandmother one day I’m going to find out what’s around the corner ….I would have been 7 or 8 and she said ‘but it’s wonderful that you can think that way and always remember whatever happens in your life or how bad it gets you need to stay living to see what’s around the corner’
- So you know for me it’s been a really uplifting (laughs) journey (laughter) weird you know?

vii) **A new appreciation for life** – leading to gratitude towards God, family members, or others

- There’s a much more appreciation of it. And there’s a much more um grasping…grasping every moment that you can (pause). And saying, you know, telling the people that mean the most to you …we’re always making sure we tell them we love em.

What do you make of these reflections on spirituality? Are these important in your own work with clients and family members?

4) **Do you think spirituality has a role in spinal rehabilitation?**

   - If so, what do you think its role is?

5) **How is this role incorporated at present?**
6) What do you think are some ways that spirituality could be enhanced during inpatient rehabilitation?