Experiences of Intimacy and Relationship Maintenance in Acute Spinal Cord Injury Rehabilitation: An Interpretative Phenomenological Analysis

Claire Freeman

A thesis submitted for the degree of Master of Health Science (Rehabilitation) at the University of Otago, Dunedin, New Zealand

20 December 2011
Abstract

Sustaining a spinal cord injury (SCI) has a profound impact upon the individual with the injury and their family members, particularly their partner. Little is known about the couple’s experience of injury impact and how this is experienced during acute, hospital-based, rehabilitation. This qualitative study aimed to explore the couple’s experience of intimacy and maintenance of relationships following a SCI within the newly implemented Transitionz Rehabilitation (TR) Programme at Burwood Spinal Unit (BSU).

Five couples participated in semi-structured, in-depth, dyadic (joint) interviews. Couples were recruited from the TR programme and interviewed before discharge home. In each couple the man was the person with a SCI. Drawing on the principles of Interpretative Phenomenological Analysis (IPA) I depict the couples’ experiences in three themes, and one ‘contextual’ theme that describes the couple relationship in the dyadic interview.

‘Grief and loss’ encapsulates the mourning for personal and couple losses associated with injury. Guilt and obligation to the other are felt by both partners as they live with these losses. ‘Loss of autonomy’ describes the restrictive and paternalistic hospital environment that disempowers through a lack of cohesion and distrust in health professionals and problems with privacy and space. ‘Transitioning forward’ represents the current and future hope couples have for their lives ahead as they participate in the TR programme and prepare to leave the acute rehabilitation environment for home. Separate on-site accommodation units provided couples with a window of opportunity to reclaim some privacy, and transition coaches were valued mentors in the struggle to come to terms with the injury and its impact. Couples talked of a new-found closeness in their relationship that came from their efforts to communicate well. The ‘couple relationship’ is a complex interaction of ‘I’, ‘We’ and ‘He/she’.

The couples discussed their different interpretations of intimacy, from sexual intimacy to the act of sharing a meal together, intimacy encapsulated the unique bond and connection they shared with each other. The participants were also positive about
aspects of intimacy with their partner post the SCI, although feelings of grief were experienced relating to their loss of intimacy.

The couple offer each other unrivalled support, and communication is the most important facilitator of relationship maintenance. Thus, health professionals without sufficient sensitivity to the importance of communicating with the ‘we’ (rather than just the person with a SCI), the need for time and space for couple communication, and the primacy of the spousal relationship can negatively affect the couples’ efforts to maintain their relationship in the rehabilitation environment.

Further, the physical hospital environment inhibited the couple’s ability to fully engage with each other, and this was compounded by experiences of a lack of privacy and dignity arising from the way care was provided. The couples wanted to know more about the medical aspects of sex after a SCI, recognising that this expertise would be lost to them once they left the TR programme. Yet the environment was not conducive to exploring sexual expressions of intimacy. More work is needed to address persistent feelings of a loss of autonomy and to enhance coping with the grief and loss following a SCI.
Acknowledgements

I would like to thank Jean Hay Smith PhD and Bernadette Cassidy PhD for their guidance, patience, encouragement and wise counsel regarding this thesis, and to Anne Sinnott for her mentoring, support and friendship throughout this process.

I would also like to thank Barbara Freeman and Jock Vennell for their editing skills, Jo Fadyl for her computer skills, and Trudy Mulligan, John Ottley and Cindy Allison for their support, food packages and encouragement throughout this study. I would also like to acknowledge the late Professor Alan Clarke, my inspiration and mentor, both in life and in death.

Thanks to the Burwood Academy of Independent Living (BAIL) and the Health Research Council (HRC) New Zealand for their financial contributions to this study.

Lastly, I would like to acknowledge my participants for sharing their stories.
# Table of Contents

Abstract ........................................................................................................................................................................ ii
Acknowledgements ......................................................................................................................................................... iv
List of Tables ................................................................................................................................................................... viii
List of Figures ................................................................................................................................................................... vii
List of Abbreviations ........................................................................................................................................................ xi
Glossary of Terms ............................................................................................................................................................. x
Chapter One ...................................................................................................................................................................... 12
  1.1 Research aims ......................................................................................................................................................... 12
  1.2 Literature review ....................................................................................................................................................... 12
    1.2.1 SCI and the impact on physical functioning ........................................................................................................ 13
    1.2.2 Psychological adjustment ......................................................................................................................................... 15
    1.2.3 Partner support and adjustment ........................................................................................................................... 16
    1.2.4 Consequence of SCI for marital relationships .................................................................................................. 17
    1.2.5 SCI demographics in New Zealand .................................................................................................................. 18
    1.2.6 New Zealand spinal units and the rehabilitation team ........................................................................................ 19
    1.2.7 Provision of accommodation and issues associated with travel ........................................................................ 23
    1.2.8 Reintegration and institutionalisation into the community ................................................................................ 24
    1.2.9 The Transitionz (TR) Unit, Burwood Hospital .................................................................................................. 25
    1.2.10 Intimacy and the issue of privacy within a hospital environment ........................................................................... 28
      1.2.10 (a) The physical environment at BSU ........................................................................................................ 28
      1.2.10 (b) Content and delivery of information about sexuality, intimacy and relationship maintenance ............ 29
    1.2.11 Intimacy and relationship maintenance: different models and approaches .................................................. 32
  1.3 Summary .................................................................................................................................................................... 35
Chapter Two ...................................................................................................................................................................... 37
  2.1 Researcher position ..................................................................................................................................................... 37
  2.2 Interpretative Phenomenological Analysis ........................................................................................................... 38
    2.2.1 Theoretical Foundations – Phenomenology, Hermeneutics, Idiography ....................................................... 39
  2.3 Paradigmatic view ...................................................................................................................................................... 41
  2.4 Methods ....................................................................................................................................................................... 43
    2.4.1 Sample ................................................................................................................................................................. 43
      2.4.1 (a) Homogenous sample .................................................................................................................................. 44
    2.4.2 Participants .......................................................................................................................................................... 44
    2.4.3 Recruitment ......................................................................................................................................................... 45
    2.4.4 Interviews ........................................................................................................................................................... 45
      2.4.4 (a) Dyadic interviews ....................................................................................................................................... 45
      2.4.4 (b) Development of interview schedules ...................................................................................................... 48
      2.4.4 (c) Conducting the interviews ....................................................................................................................... 50
  2.5 Data analysis ............................................................................................................................................................. 51
  2.6 Ethical considerations ............................................................................................................................................... 52
  2.7 Maori consultation .................................................................................................................................................... 54
  2.8 Summary .................................................................................................................................................................... 54
Chapter Three ...................................................................................................................................................................... 55
  3.1 The participants .......................................................................................................................................................... 56

# List of Tables

<table>
<thead>
<tr>
<th>Table</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1</td>
<td>The P-LI-SS-IT Model for sexual counselling.</td>
<td>30</td>
</tr>
<tr>
<td></td>
<td>Reproduced from Esmail, Esmail, and Munroe, (2001, p 276)</td>
<td></td>
</tr>
<tr>
<td>2.1</td>
<td>Table of conventions of transcription and extracts used in this thesis...</td>
<td>51</td>
</tr>
<tr>
<td>3.1</td>
<td>Summary of themes and subordinate themes</td>
<td>55</td>
</tr>
<tr>
<td>Figure</td>
<td>Description</td>
<td>Page</td>
</tr>
<tr>
<td>---------</td>
<td>-----------------------------------------------------------------------------</td>
<td>--------</td>
</tr>
<tr>
<td>1.1</td>
<td>Spinal Nerves (minus Coccygeal), Vertebral Column and Skeletal Structure.</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>Adapted from Verkaaik (2004, p 18)</td>
<td></td>
</tr>
<tr>
<td>1.2</td>
<td>Burwood Hospital map</td>
<td>20</td>
</tr>
<tr>
<td>1.3</td>
<td>Tapper and Milner lodges</td>
<td>22</td>
</tr>
<tr>
<td>1.4</td>
<td>TR unit</td>
<td>26</td>
</tr>
<tr>
<td>2.1</td>
<td>Johari Window. Reproduced from Luft (1961)</td>
<td>46</td>
</tr>
<tr>
<td>3.1</td>
<td>Diagrammatic representation of the themes</td>
<td>57</td>
</tr>
</tbody>
</table>
## List of Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABC</td>
<td>Allan Bean Centre</td>
</tr>
<tr>
<td>ACC</td>
<td>Accident Compensation Corporation</td>
</tr>
<tr>
<td>ASIA</td>
<td>American Spinal Injuries Association</td>
</tr>
<tr>
<td>ASRU</td>
<td>Auckland Spinal Rehabilitation Unit</td>
</tr>
<tr>
<td>BAIL</td>
<td>Burwood Academy of Independent Living</td>
</tr>
<tr>
<td>BSU</td>
<td>Burwood Spinal Unit</td>
</tr>
<tr>
<td>C</td>
<td>Cervical Vertebra</td>
</tr>
<tr>
<td>CDHB</td>
<td>Canterbury District Health Board</td>
</tr>
<tr>
<td>Ex- P-LI-SS-IT</td>
<td>The Extended Permission, Limited Information, Specific Suggestions, Intensive Therapy</td>
</tr>
<tr>
<td>HRC</td>
<td>Health Research Council</td>
</tr>
<tr>
<td>ICF</td>
<td>International Classification of Functioning</td>
</tr>
<tr>
<td>IPA</td>
<td>Interpretative Phenomenological Analysis</td>
</tr>
<tr>
<td>NSIC</td>
<td>National Spinal Injuries Centre</td>
</tr>
<tr>
<td>NZ</td>
<td>New Zealand</td>
</tr>
<tr>
<td>NZST</td>
<td>New Zealand Spinal Trust</td>
</tr>
<tr>
<td>P-LI-SS-IT</td>
<td>Permission, Limited Information, Specific Suggestions, Intensive Therapy</td>
</tr>
<tr>
<td>SCI</td>
<td>Spinal Cord Injury</td>
</tr>
<tr>
<td>T</td>
<td>Thoracic Vertebra</td>
</tr>
<tr>
<td>TASC</td>
<td>The Association for Spinal Concerns</td>
</tr>
<tr>
<td>TR Unit</td>
<td>Transitional Rehabilitation Unit</td>
</tr>
<tr>
<td>TR Programme</td>
<td>Transitionz Rehabilitation Programme</td>
</tr>
</tbody>
</table>
Glossary of Terms

**ASIA Classification:** In 1992, in order to systemise the classification of spinal cord injuries, the American Spinal Injury Association (ASIA) developed a comprehensive way to assess the level and extent of injury severity. Motor and sensory tests are conducted on the body and when combined give an indication of the overall neurological level. ASIA A is classified as ‘complete’, meaning there is little to no sensation or movement below the level of injury. ASIA E is at the other end of the scale and is classified as ‘incomplete’, indicating full movement and sensation below the level of injury.

**Client-Centred Care:** The experience of transparency, individualization, recognition, respect, dignity, and choice in all matters related to one’s person, circumstances, and relationships in health care.

**Epistemology:** The theory of knowledge embedded in the theoretical perspective and thereby in the methodology.

**Hermeneutics:** The theory of interpretation.

**Idiography:** Emphasis on the particular as opposed to groups or populations.

**Interpretative Phenomenological Analysis (IPA):** A qualitative research approach that examines how people make sense of life experiences. It acknowledges that the data is influenced by the researcher’s own interpretations of life experiences.

**Medical Model:** The medical model believes in curing or at least managing an illness or disability. It is about normalising an individual to fit into their surroundings and believes the problem is not societal, but is embodied within the individual afflicted with the illness or disability.

**Paraplegia:** Paralysis of the body from the thoracic, lumbar or sacral region, usually affecting the legs and may affect the trunk region.
**Phenomenology:** A particular methodology examining the experience of a phenomenon.

**Ranga Hauora:** Maori Health Service based at the BSU.

**Rehabilitation:** The process of enhancing the physical and psychosocial elements for those with disabilities or illness.

**Social Model of Disability:** This model identifies systemic barriers, negative attitudes and exclusion by society (purposely or inadvertently) that establishes society as the main contributory factor in disabling people. While physical, sensory, intellectual, or psychological variations may cause individual functional limitations or impairments, these do not have to lead to disability unless society fails to include people regardless of their individual differences.

**Tetraplegia:** Paralysis from an injury within the cervical area affecting all four limbs and trunk region.

**Theoretical perspective:** The theoretical perspective is the philosophical stance that lies behind the chosen methodology.
Chapter One

Introduction and Literature Review

1.1 Research aims

This study aims to explore the experience of intimacy and maintenance of relationships following a spinal cord injury (SCI) within the newly implemented Transitionz Rehabilitation (TR) Programme at Burwood Spinal Unit (BSU). There is a shortage of data both internationally and New Zealand wide relating to a couple’s experience of SCI during the acute rehabilitation stage. The specific objectives of the study are to explore how people with a SCI and their partner, perceive and interpret their experience of intimacy and the maintenance of their relationship within the TR programme. This includes their comparative reflections about the TR Programme and the hospital setting at the BSU. It also includes an exploration of what each participant perceives the term ‘intimacy’ to mean for them and the ways in which this is expressed. The study will explore how the attitudes and behaviours of health professionals impact on the intimate relationship of the person with a SCI and their partner, and will discuss how the hospital environment fosters or impedes intimacy for the couple.

1.2 Literature review

This literature review begins with a brief overview of SCI in order to understand the impact it has on a person’s physical capabilities. The review attempts to describe the psychological impact of a SCI, both on the person with the SCI and their partner. It also explores the partner’s adjustment to a SCI within an intimate relationship. This chapter looks at the demographics of SCIs in New Zealand and reveals that many who sustain an injury are male, of working age and are likely to be in a relationship. It explores the environment regarding hospital care in New Zealand for people with SCIs and the amount of support that partners and families encounter, especially in relation to accommodation and travel. Institutionalisation and problems with community
reintegration are discussed along with the attempted solution of the TR programme and unit, which deals with the issue of intimacy and the maintenance of relationships. Following that is a broad look at intimacy within a hospital environment and how New Zealand has addressed this issue. The chapter concludes with different approaches to addressing intimacy and the maintenance of relationships within a hospital environment.

I set out to explore people’s experiences of intimacy, that is, their sexual expression within a sexual relationship and the maintenance of their relationship in an acute setting. In the course of this research, it became clear that each participant’s definition of intimacy was beyond what I had initially envisaged. Subsequently, I have used the term ‘intimacy’ in its broader and wider form as imagined by the participants. Intimacy, as envisaged by the participants of this study, included being physically together and able to converse with each other as a couple. The term ‘maintenance of relationships’ is unwieldy, so in most cases when the term intimacy is used, maintenance of relationships is implied.

Throughout this thesis I refer to the participants with a SCI as ‘clients’ instead of ‘patients’. I feel strongly that the word ‘patient’ is a term that implies a sense of disempowerment or loss of autonomy. The term patient has historically implied passivity and compliance (Hammell, 2006). The term patient is individualistic and negates the holistic view that includes partners and family (Hammell, 2006).

1.2.1 SCI and the impact on physical functioning

The spinal cord is part of the central nervous system that occupies the vertebral canal, a cavity that extends the length of the spinal column (Bateman, 2000). The spinal cord is made up of nerve fibres that transmit messages to and from the brain allowing for movement and sensation. A SCI occurs when the spinal cord encased within the bony vertebrae is damaged. When the cord is cut or damaged the nerve fibres that transmit information to and from the brain no longer operate, causing paralysis and loss of sensation below the level of the cord injury.
The spine is divided into 31 segments (Figure 1.1) based on the existence of 31 pairs of spinal nerves (Kirshblum, Campagnolo, & DeLisa, 2002). Sustaining a cervical injury affects all four limbs so is termed ‘tetraplegia’. A person with a cervical injury is a ‘tetraplegic’. Anyone who has sustained an injury below the cervical region is called a ‘paraplegic’, or has ‘paraplegia’. However, a person can damage a vertebrae but sustain no neurological damage if the spinal cord has not been affected.

![Spinal Nerves (minus Coccygeal), Vertebral Column and Skeletal Structure](image)

An ‘incomplete’ SCI is when the spinal cord has not been completely severed and some messages from the brain still connect with the appropriate muscle or nerve groups. This is a common outcome for many who have sustained a SCI and means the person with the SCI has some movement or sensation below their level of injury. Each SCI is extremely complex and it was realised that a tool to measure the severity of an injury was required.
In 1992, the American Spinal Injury Association developed a comprehensive way to assess the level and extent of injury severity. The new assessment tool was called the ASIA scale. Through motor and sensory tests, clients with a SCI are given points that, when combined, indicate the level of completeness of their injury. A ‘complete’ injury is when there is little to no sensation or movement below the level of injury; this is given the letter ‘A’. The scale ends on ‘E’ and is classified as an ‘incomplete’ injury meaning that the person has retained full sensation and movement (Liverman, Altevogt, Joy, & Johnson, 2005). The ASIA scale is used throughout many countries, including New Zealand.

The physical trauma the body sustains when experiencing an SCI can be substantial. It has been suggested that a SCI is the most devastating form of neurological impairment a person can experience and affects all areas of their life and that of their partner and family (Kennedy, Evans, & Sandhu, 2008; Vocaturo, 2009). Loss of physical functioning is an obvious side-effect of a SCI, depending on the level and severity of the neurological impairment. In conjunction with this, a person can experience impaired bladder and bowel functioning, impaired sexual functioning and pain (Craig, Hancock, Dickson, Martin, & Chang, 1990; Dickson, Ward, O'Brien, Allan, & O'Carroll, 2011). Accompanying the damage sustained physically is the psychological trauma caused by the injury.

1.2.2 Psychological adjustment

A recent review of literature on the psychological adjustment to a SCI suggests that around 30% of individuals with a SCI have significantly elevated anxiety and depression levels during the first two years following their injury (North, 1999). The suicide rate for people with a SCI is about four to five times greater than the general population (North, 1999). Suicide has been reported as the leading cause of death in individuals with a SCI under the age of 55 years (Dickson et al., 2011). People who have had a SCI also have a higher risk of drug abuse than the general population (Kennedy et al., 2008).
Those with a SCI talk about experiencing a multitude of emotions after sustaining a SCI; these include feelings of bewilderment, disbelief, anger, fear, hope and despair (Dickson et al., 2011). Immediately after a SCI, a person experiences a period of emotional turmoil and disorganisation as their new world becomes fragmented and uncertain. Ongoing pain as a result of a SCI leads to depression and a lower quality of life (North, 1999). Other problems encountered are: feelings of isolation, pressure sores from impaired skin sensation, possible cognitive issues from secondary trauma associated with their injury, and medication that interferes with neuropsychological functioning (North, 1999).

Improved levels of adjustment occur for those who have had a SCI if they have positive social support, are younger at the time of injury and are able to secure a positive return to employment (Kennedy et al., 2008). Hope is important in a person’s adjustment to their injury (Kennedy et al., 2008). Kennedy et al. (2008) describes hope as “a person’s overall perception that one’s goals can be met” (page 20). However, the biggest predictor of improved adjustment levels is partner support (Dickson et al., 2011).

1.2.3 Partner support and adjustment

The emotional support provided by a partner forms a crucial part of rehabilitation for an individual with a SCI and supports a successful reintegration into the community (Beauregard & Noreau, 2010). Most of the research on relationship adjustments following a SCI focuses on the person with the SCI. However, this is changing as the importance of partner support is recognised as an essential element of a person’s rehabilitation (Chan, 2000).

In a phenomenological study by Vargo (1983), ten women married to men with a SCI were interviewed. All had at least one child and were married for a period of one to 40 years. The women’s ages ranged from 24 to 63 years old. The study explored the adaptation to a SCI from the wives’ perspective, and it was noted that the majority initially experienced feelings of shock, fear and uncertainty because they did not know whether their husbands would survive. Feelings of frustration, helplessness and the sense of having a full-time burden placed upon them followed. They also expressed
concerns about financial problems and the possible health problems associated with insomnia. In spite of a large number of concerns, many of the wives viewed the experience of having a partner with a SCI as a time of emotional growth. They felt the injury had brought them closer together as a couple, and many spoke about feelings of increased emotional strength and a new-found independence in areas they had previously not explored (Vargo, 1983).

An IPA by Dickson, O'Brien, Allan, and O'Carroll (2010) highlighted the psychological distress the partner felt when they took on the caregiver role. Eleven participants were interviewed. All were married to the partner with a SCI, and ten of eleven partners were women. Most partners found that intimacy was adversely affected as they moved from a ‘partner’ role to a ‘mothering’ role following the injury. Despite this, many participants in the study reported that their emotional relationship with their partner had become stronger as a result of the injury.

Detrimental role changes from ‘partner’ to ‘mother’ is an issue frequently mentioned by researchers, as is caregiver fatigue, or what DeSanto-Madeya (2009) describes as ‘burnout syndrome’. On an individual level, people who have become the injured person’s caregiver report higher levels of depression, stress and anxiety (Beauregard & Noreau, 2010; DeSanto-Madeya, 2009; Dickson et al., 2010; Esmail, Huang, Lee, & Maruska, 2010; Weitzenkamp, Gerhart, Charlifue, Whiteneck, & Savic, 1997). They also tend to ignore or neglect their own health as the needs of the injured partner dominate the relationship (Weitzenkamp et al., 1997).

1.2.4 Consequence of SCI for marital relationships

Adopting the role of the caregiver can adversely affect the couple’s relationship as the role of the partner changes to a mothering role (Dickson et al., 2010). One of the problems associated with the role reversal from partner to carer includes the difficulty of returning to pre-injury levels of intimacy (Beauregard & Noreau, 2010; DeSanto-Madeya, 2009; Dickson et al., 2010; Esmail et al., 2010).
A survey by Kreuter, Sullivan, and Siosteen (1994) used an 80-item questionnaire that addressed experiences of sexual functioning, desire and activity, sexual behaviour, satisfaction with sex life and aspects of the emotional quality of the relationship for people with a recent SCI. The study recruited 75 participants and all had been recent clients of the Spinal Injuries Unit, Sahlgrenska University Hospital, Sweden. One hundred and fifty five people were in the control group. Findings from the study showed that sexual activity and satisfaction were lower among persons with a SCI compared with the control group. However, the emotional quality of the relationship did not differ for couples where one had a SCI. These findings are similar to those discussed by Beauregard and Noreau (2010) - a qualitative study that used in-depth interviews with 24 partners where one had a SCI. Beauregard & Noreaus’s (2010) study suggests that the quality of the emotional component of martial life does not appear to be affected by SCI, although the partners of those with a SCI did report significant issues regarding physical expressions of intimacy.

Divorce statistics after a partner has a SCI vary according to different studies. Studies show a higher rate of divorce occurs amongst couples where one partner has a SCI than in the general population (Urey and Henggeler, 1987, Beauregard and Noreau, 2010). Karana-Zebari, de Leon, and Kalpakjian (2011) comment that divorce rates for couples married at the time of injury are estimated to be 1.5 to 2.5 times higher than that of the general population. Higher divorce rates occur within the first three years after a SCI, and after five years, match those of the general population. This suggests that initially divorce rates for those with a SCI are higher than average. However, for those relationships that survive the first few years, the divorce rates and overall life satisfaction are similar to that of the general population. Intimacy between the couples, however, can remain problematic.

### 1.2.5 SCI demographics in New Zealand

In the absence of a national database, the annual incidence of SCI in New Zealand is estimated to be 17 per million, congruent with current worldwide statistics (Sinnott, 2009). One thousand, four hundred and forty eight people have a SCI in New Zealand, although there is no official database recording the exact number. These figures are
based upon the figures of serious injury claims for Accident Compensation Corporation (ACC) lodged between 1972 to 2007 (Sinnott, 2009). It should be noted this figure does not include spinal cord impairments from disease or illness, which suggests that this figure may be higher. The rate of SCIs in men in New Zealand (7.19 per 100 000) is higher than in women (2.66 per 100 000). This reflects worldwide trends where young men between 15 – 29 years account for 46% of all SCI (Dixon, Danesh, & Caradoc-Davies, 1993).

The most recent data suggest the majority of people with a SCI are married. The findings from a New Zealand dataset for the Development of ICF Core Sets for SCI found that in New Zealand 40% of the participants were married, 32.5% never married and 15% were single (Sinnott, Dunn, & Nunnerley, 2010). The participants of the study were a mean of 4.7 years post-injury. The dataset ran between May 2006 to May 2007. These figures closely match those of worldwide statistics from 14 other study sites collecting the same data (Sinnott, Dunn, et al., 2010).

As shown, most people affected by SCI are men, the majority are of working age and are most likely to be in a relationship. This suggests that the exclusion of families and partners from the lives of men with a SCI will affect them in a detrimental way, especially when the premise is that their main source of support is their partner and family.

1.2.6 New Zealand spinal units and the rehabilitation team

New Zealand has two spinal rehabilitation hospitals – the Burwood Spinal Unit, and the Auckland Spinal Rehabilitation Unit. The BSU is located in the South Island’s largest city of Christchurch and has a 26-bed facility. The catchment area of the BSU goes from Napier across to New Plymouth and everywhere south, including the South Island. The BSU is equipped to care for people who have had a SCI immediately following that injury and approximately 90 clients are discharged per annum (Nicholls, Verkaaik, MacDonald, & Oliver, 2010). The BSU is located in the Christchurch suburb of Burwood and is part of Burwood Hospital, one of four public hospitals in Christchurch.
The other rehabilitation facility is the Auckland Spinal Rehabilitation Unit (ASRU). It services the northern part of the North Island and has a 16-bed capacity. The ASRU is a
separate unit although it is linked with Middlemore Hospital approximately 3.4 kilometres away. The ASRU is based in Otara, South Auckland, and is smaller than the BSU. Auckland is the largest populated centre in New Zealand.

Both spinal units have similar teams of health professionals, although the BSU team is larger due to the greater number of clients using the service. The teams are headed by doctors with specialised skills associated with SCIs, including urologists for bladder and bowel management. Registered and enrolled nurses provide the daily care, such as helping with dressing, bowel and bladder management, and general health maintenance. Physiotherapists concentrate on maximising the physical capabilities of each client. Occupational Therapists focus on daily living tasks that help clients achieve maximum independence. Psychological support is provided by a clinical psychologist, alongside social workers who help with reintegration into the community and any personal or financial issues associated with the injury. Counsellors are also available, and spinal assistants offer support with lifting and transferring clients and travel throughout the hospital campus.

Immediately after a person sustains a SCI, they are taken to the nearest hospital that can accommodate their injury. After stabilisation, the injured person is admitted to one of the two spinal units. In the case of clients who are destined for the ASRU, the stabilisation phase may take a few weeks, depending on the severity of the injury. The ASRU only accepts clients who are ready for rehabilitation and are medically stable, unlike the BSU where they are accepted immediately after their SCI as the unit is equipped to deal with acute cases (Acland, 2010). Rehabilitation can take up to 26 weeks in each unit, depending upon the injury (Sinnott, Cassidy, Nunnerley, Bourke, & Kunowski, 2010). During this time, maximum physical independence is encouraged to enable clients to leave the unit and live as independently as possible.

Although not funded by the District Health Board, the New Zealand Spinal Trust (NZST) offers a range of services such as vocational support, peer support and informational support for clients both at BSU and ASRU. The Burwood Academy of Independent Living (BAIL) was established in 2006, and their objective is to improve the life experience of people recovering from serious injury and illness through supporting research and learning in rehabilitation based on the Independent Living
The NZST and BAIL are both based in the Allan Bean Centre (ABC) located in a stand-alone building next to the BSU (Figure 1.2). The centre was established by the late Professor Alan Clarke, former Clinical Director of the BSU and a paraplegic as the result of a fall. The centre’s ethos founded by Professor Clarke was to create a consumer driven environment that empowered individuals and families to make informed choices regarding their serious neurological injury (Sinnott, Cassidy, Nunnerley, Bourke, & Kunowski, 2010).

Both units receive clients with SCIs from a range of geographic locations. Partners and families have to travel to be with the injured person. Partner and family accommodation at the BSU, includes eight lodges and a nurses’ hostel on the hospital campus. ASRU has four lodges available as emergency accommodation on the hospital site (Figure 1.3). When available, the lodges provide families with a place to stay, although partners are sometimes expected to seek alternative accommodation because of the limited availability of the lodges.

Figure 1.3 Tapper and Milner Lodges
1.2.7 Provision of accommodation and issues associated with travel

I was not able to find any published literature on these topics. Subsequently, the summary of difficulties concerning accommodation and travel that follows is based on personal communication from a single source - a clinical psychologist at the BSU (T. Marshall, personal correspondence, September 14, 2011, BSU). The families and partners of people who have had a SCI report that one of their main concerns is accommodation and the travel difficulties associated with their family member/partner being in hospital. Both the BSU and ASRU have a limited number of accommodation lodges available for family and partners (Figure 1.3). These lodges are constantly in demand and consequently, families, especially partners, are asked to seek accommodation elsewhere, causing them extra stress and anxiety.

Prolonged rehabilitation periods, numbering many months, mean that accommodation needs are of long duration. Family members need to juggle their commitments to family, work and their partner’s needs throughout the rehabilitation period. Added to this is the pressure of travel - often from a geographically distant location - the cost and the time taken.

The cost of travelling to and from the spinal unit is a concern, as is the problem of people wanting to bring other family members to support their injured loved one. The BSU and the ASRU are not centrally located within their respective cities and the closest motels are 5-10 minutes drive away. Families who do not live close to the unit and who do not have a car face added financial pressure.

Other concerns mentioned in addition to travel costs were the separation from children and the fatigue associated with driving to and from the units. This is especially relevant when family members live a few hours’ drive from the spinal unit and flying is not warranted. Occasionally, travel is reimbursed by insurance companies, a sometimes lengthy and complicated procedure, that can also be stressful for the family.

The stress of trying to seek appropriate accommodation, added to travel costs and the time it takes to juggle family commitments, causes much grief and a loss of autonomy for families and partners. In many cases, through necessity, the person with the SCI is
left on their own. Without the support of partners and family, he or she feels isolated. A long-term risk is increased difficulties in integrating back into the community. These people can become institutionalised (Sinnott, 2008).

1.2.8 Reintegration and institutionalisation into the community

Rehabilitation services in New Zealand are based on hierarchical medical models (Sinnott, 2008). Clients with a SCI are placed in multi-bed rooms that offer little privacy and, depending upon the severity of their injury, can stay in that environment for up to 26 weeks. Care packages are homogenised and it is reported that many clients suffer from institutionalisation (Sinnott, 2008). Transition from hospital to the home environment can be problematic, and the low rates of return to employment are an outcome of poor reintegration back into their communities (Sinnott, 2008).

An IPA study by Dickson et al. (2011) explored the difficulties of adjusting to post-discharge life following acute SCI rehabilitation at the Queen Elizabeth National Spinal Injuries Unit, Scotland (QENSIUS). This study explored the lives of seventeen individuals with a SCI who were at least one year post-injury, had a mean age of 42 years and lived in Scotland. The study did not mention whether the participants were with a partner or had family support, although a few participants alluded to having a partner or family member supporting them. Unlike the participants from my study who were still clients of a hospital system, Dickson’s participants had been recently discharged into their communities. The Dickson et al. (2011) study focuses on the difficulties they faced when back in their home environments. Findings from the study included a loss of camaraderie once the participants left the rehabilitation facility. Many found the camaraderie experienced in the unit facilitated their coping through the acute rehabilitation period. Once back in their own environment, many said they felt isolated and this led to feelings of depression. Participants reported that a lack of post-discharge care was also an issue that concerned them. Also, people’s reactions to them using a wheelchair were considerably upsetting. They were made to feel as though they “had two heads”, and many felt they were treated as if they had a cognitive impairment. This they found very demeaning. They often felt inferior and worthless in the presence of others from their community. Of interest was the fact that participants felt
institutionalised as a result of their stay at the QENSUIIS and they found returning to their home environments challenging.

Although the Dickson et al. (2011) study did not explore the participant’s experience of their rehabilitation at QENSIUS, it does raise the possibility that clients of the BSU may also experience similar feelings suggested by participants from Dickson et al’s (2011) study. In fact, recent research (following on from The International Classification of Function, Disability & Health (ICF) Core Sets for SCI study that included New Zealand) identified similar concerns affecting both newly injured clients and those with longstanding SCIs (Sinnott, 2008). In addition, an Academic Framework symposium undertaken by BAIL (Verkaaik & Sinnott, 2007) suggested clients with a SCI had three main areas of concern about their rehabilitation. These were: the maintenance of relationships, the maintenance of hope and the need for smoother transitions from institution to community (Sinnott, Cassidy, et al., 2010). The outcome of these concerns was the implementation of the TR programme and unit. It was anticipated that by concentrating on the maintenance of relationships, hope, and addressing concerns regarding reintegration into the community, people with a SCI would report a higher degree of wellbeing and the transition into their communities would be less problematic (Sinnott, 2008).

1.2.9 The Transitionz (TR) Unit, Burwood Hospital.

BAIL recognised the importance of maintaining relationships and hope, and the importance of the reintegration of clients back into the community (Sinnott, Cassidy, Nunnerly, Bourke, Kunowski, 2010). Subsequently, the Academy developed a programme to address client’s needs and those of their families before they returned to their community after a SCI. The programme structure and content was based on findings from The International Classification of Function, Disability & Health (ICF) Core Sets for SCI project. It also had input from the Spinalis Foundation and Rehab Station Stockholm, a Swedish spinal unit that had already implemented a programme addressing reintegration concerns for those with a SCI (Sinnott, Dunn, et al., 2010).
A ‘preparation for discharge programme’ called ‘The TR programme’ runs for four weeks and clients take part in the programme during the last four weeks of their acute rehabilitation period at the BSU (Figure 1.4). The programme focuses on five key elements. The first, education, aims to create awareness of dependence and independence. It addresses the needs and expectations of clients and the role hope and optimism plays in their recovery. The programme also addresses the importance of relationships in recovery and looks at preserving a sense of self within an institution. The core idea of managing change by taking control is a key element in the education of the client, their partner and family.

The second key element focuses on the environment and the importance of privacy. It recognises that the client’s space needs to look less medicalised and more domesticated. The third element is the step toward independence and includes the expectation that clients can regain control of their rehabilitation and their lives. The forth element is an active return to home. This element seeks to maximise home and community support. The fifth element focuses on using an independent living coach to facilitate the delivery of the programme and act as a motivating instructor and mentor. The coach needs to
have a SCI and must be well-adjusted and comfortable with their injury and their life (Nicholls et al., 2010).

The programme officially began in March 2009 and is staffed and managed by the Canterbury District Health Board (CDHB). The TR programme is based in what was formerly known as the BSU hostel, approximately eighty metres from the acute spinal unit. Changes were made by the CDHB to the original programme envisaged by BAIL with regards to the environment of the TR unit. For example, Spinalis offers clients a bathroom ensuite with their private rooms, and this was one of the recommendations that were not implemented in the TR programme. However, the core elements of the Spinalis programme and subsequent BAIL programme have been retained and implemented in TR programme and unit. The underlying aim of the TR programme is to support and educate clients through practical activities with the hope of an easier transition back into the community.

As the second element stipulates, The TR programme provides clients with a private room for themselves and their partners and offers a comprehensive programme maximising independence through various community activities and seminars called ‘learning sessions’. The Independent Living Coaches, who themselves have a SCI, guide, mentor and educate the clients throughout the four-week programme before their final discharge back into their respective communities.

Sherman, DeVinney, and Sperling (2004) suggest that peer mentoring by those who have experienced the same traumatic situation provides positive role modelling and realistic hope for the client. They suggest the use of peer mentoring as part of clinical intervention. Other studies corroborate these findings, suggesting that peer mentoring promotes healthy living, a better adjustment back into the community and supports an overall psychosocial adjustment for the person with a SCI (Ljungberg, Kroll, Libin, & Gordon, 2010; Veith, Sherman, Pellino, & Yasui, 2006).

The TR programme addresses the benefits gained by peer mentoring through each of the five key elements. All participants in my study were clients of the TR programme and had completed a minimum of two weeks on the programme. As mentioned, a key component in the establishment of the TR programme was the maintenance of
relationships. I was particularly interested to learn of the experiences of the clients with regards to intimacy and the maintenance of their relationship.

1.2.10 Intimacy and the issue of privacy within a hospital environment

Addressing intimacy issues within a hospital environment raises a variety of concerns. Historically, intimacy and relationship maintenance were not a priority for health professionals, who concentrated on physiological rather than psychological aspects of relationship maintenance (Sakellariou, 2006). As more is learned about the importance of intimacy in the lives of those who have had a SCI and their partners, health professionals have attempted to address these concerns and provide support and information (Kreuter, Sullivan, & Siosteen, 1996).

Intimacy can only be achieved when there is a high degree of privacy - which is an essential element in the provision of individualised patient-centred care (Lemonidou et al., 2003). However, the hospital is an environment where people have little control over their privacy (Leino-Kilpi et al., 2001). A lack of personal privacy is for many an expected outcome of being in hospital (Schuster, 1976). Nevertheless, diminished privacy causes distress and anxiety for the individual and stresses the couple’s relationship (Leino-Kilpi et al., 2001; Parrott, Burgoon, Burgoon, & LePoire, 1989).

1.2.10 (a) The physical environment at BSU

The physical environment of the BSU and ASRU does not lend itself to being a suitable place for families or partners of an injured person. Beds are usually single and rooms are shared with others with injuries. Partners are expected to seek alternative accommodation in most cases. The TR programme at BSU does seek to address the issue of privacy and space specifically for the maintenance of relationships, by providing couples with a private room where the programme is based. As illustrated in Figure 1.2 and Figure 1.3, the TR unit is attached to the BSU by a corridor approximately 80-100 metres long. This allows the clients a sense of separation from the BSU, but is close enough to obtain help if required. The Milner and Tapper lodges
are situated within 100 metres of the BSU, but are separate lodges with independent access points.

For partners unable to secure a lodge, accommodation is available on the Burwood Hospital campus. ‘The old nurses’ hostel’, as it is referred to, is situated on the west side of Burwood Hospital and is located in an older building separate to the main hospital block. It is inaccessible for people who use wheelchairs as it is in the top floor of a two-storey building with no lift access (Figure 1.2).

1.2.10 (b) Content and delivery of information about sexuality, intimacy and relationship maintenance

The BSU has established initiatives on intimacy and relationship maintenance for people with a SCI during the past four years. These include educating and supporting people with a SCI and their families. They have appointed a 0.3 full-time equivalent Clinical Nurse Specialist to address sexuality in rehabilitation. Clients also have the opportunity to discuss sexual issues during regular counselling sessions with the Clinical Psychologist or Clinical Nurse Specialist. Medical management involves providing inpatient, outpatient and outreach clinics with a Clinical Nurse Specialist and Spinal Rehabilitation Consultant to whom referrals can be made by a GP. This can also be through self-referral if the person with a SCI identifies sexual concerns. Staff in-service training is practised utilising the P-LI-SS-IT model (Esmail, Esmail, & Munroe, 2001) (Table 1.1).
Table 1.1  The P-LI-SS-IT Model for Sexual Counselling. Reproduced from Esmail, Esmail, and Munroe, (2001, p 276).

<table>
<thead>
<tr>
<th>Level</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Permission</td>
<td>The practitioner brings up the topic of sexuality thereby validating sexuality as a legitimate health issue and giving the client permission to discuss sexual concerns now and later in the programme. Most clients need permission to raise their sexual concerns. Rehabilitation professionals may lack the confidence to discuss sexuality with their clients, however the majority of them have adequate skills and knowledge to provide this level of skill.</td>
</tr>
<tr>
<td>Limited Information</td>
<td>The practitioner addresses specific sexual concerns and attempts to correct myths and misinformation. Much of a health professional’s knowledge and training can be applied to sexuality. At this level the practitioners primary role is that of an educator and therefore should focus on basic sexual information applicable to their area of practice. Many clients would benefit from this level of intervention.</td>
</tr>
<tr>
<td>Specific Suggestions</td>
<td>The practitioner compiles a sexual history or profile of the client: 1. Define the problem 2. Determine the course of the problem 3. Treat the problem 4. Formulate ideas about causes and develop appropriate goals and treatment plans. Fewer clients require this level of intervention and fewer practitioners are qualified to provide this degree of service. The practitioner should possess counselling skills as well as appropriate information and treatment skills in order to provide treatment at this level.</td>
</tr>
<tr>
<td>Intensive Therapy</td>
<td>The practitioner completes a full history of the client and provides specialised treatment. This level has the smallest clientele. Requires special skills of sex therapist or other appropriate professionals.</td>
</tr>
</tbody>
</table>

The acronym P-LI-SS-IT refers to four levels of intervention and was developed by American psychologist Jack Annon in 1974 (Claiborne & Rizzo, 2006). It is based on a vertical structure of emphasis in intimacy therapy, beginning with ‘permission’ to be sexual and discuss sexuality, and proceeds through to ‘limited information’ about sexual matters. Clients are then given ‘specific suggestions’ about ways to address sexual problems. As the level of intervention increases, greater knowledge, training and skills are required to address the needs of the client, so referrals to specialists for ‘intensive therapy’ are scheduled (Claiborne & Rizzo, 2006). The model is received well by both
clients and health professionals, and it allows clients the choice of approaching the person they feel most comfortable talking to about intimacy. Additionally, health professionals are trained to feel more confident and at ease with clients who come to them with their intimacy concerns. The BSU encouraged all health professionals to participate in seminars that teach the P-LI-SS-IT model (M. Van Den Heuvel, personal communication, August 22, BSU).

An extended version of the P-LI-SS-IT model has since been established termed Ex-P-LI-SS-IT (Taylor & Davis, 2007). Key features of this model include explicit permission-giving as a core feature of each stage. It was recognised that a health professional’s silence on the subject of intimacy suggested to clients that it was not appropriate for them to discuss their sexual needs. Therefore ‘permission’ giving at all stages of the model was advised (Taylor & Davis, 2007).

Anecdotal evidence from discussions with the Clinical Nurse Specialist at the BSU suggests that the BSU sexuality programme, including the P-LI-SS-IT model, has been well received by clients. However, the focus is primarily on sexuality and sexual functioning. The broad definition of intimacy as suggested by the participants in this study encapsulates much more than sexual intimacy and the TR programme attempts to address the holistic elements of intimacy, including relationship maintenance. The TR programme also recognises that environment and privacy are essential elements of intimacy and relationship maintenance. Thus it attempts to provide these elements through the use of private rooms and kitchen facilities to encourage independence and relationship bonding. The TR programme and unit is unique to the BSU, as yet, the ASRU has no equivalent programme (M. Van Den Heuvel, personal communication, August 22, BSU).

In terms of addressing intimacy, the ASRU conducts a comprehensive programme for clients with SCIs. Established in 2004, the programme initially involved implementing the P-LI-SS-IT model and training staff according to the principals of the model. Initially, a sexuality rehabilitation trainer from the Queensland Spinal Cord Injuries Service was brought over to Auckland to help implement the model and train other health professionals working at ASRU (Hislop, 2003).
Once the P-LI-SS-IT model has been implemented, other elements are introduced into the programme, such as seminars for the SCI client and their partner. These ‘Spinal 101 Education Sessions’ look at sexuality and intimacy and provide general information about the SCI. Three months following discharge, an outpatient team identifies whether the client’s sexual rehabilitation needs were met while an inpatient. According to the clinical nurse specialist of the programme, the P-LI-SS-IT model is still being implemented annually at the ASRU (D. Hislop, personal communication, September 16, 2011). A website www.sexsci.me set up by the ASRU and the SCI consumer group TASC offers information and forums to SCI clients, their families and anyone who has access to the internet (Hislop, 2003).

1.2.11 Intimacy and relationship maintenance: different models and approaches

A focus on intimacy and relationship maintenance has slowly gained momentum in other parts of the world as health professionals and researchers become aware that by addressing intimacy issues relating to SCIs, the overall health and wellbeing of clients can be improved (Kreuter et al., 1996). Historically, the focus has been on fertility issues and the penile functioning of those with a SCI. Little attention was paid to the psychosocial elements associated with intimacy concerns, and the partners of people with a SCI were excluded from many aspects of rehabilitation that related to their intimacy concerns (Kendall, Booth, Fronek, Miller, & Geraghty, 2003).

Kendall et al. (2003) suggested that the interaction between the rehabilitation professional, the client with a SCI and their family, is very important when addressing intimacy concerns. Clients report feeling disempowered by health professionals discussing intimacy concerns, especially when the health professional is uncomfortable or lacks knowledge about sexual and intimacy issues. Building a rapport with clients is essential if both the health professional and the client are to feel at ease with each other when discussing issues of intimacy, sexuality and the maintenance of relationships (Kendall et al., 2003).

Fronek, Booth, Kendall, Miller, and Geraghty (2005) suggest that clients with a SCI may prefer to talk to a staff member with whom they feel comfortable about intimacy
issues, rather than a person from a particular discipline. The P-LI-SS-IT model (Table 1.1) is a programme designed to address the issue of intimacy for health professionals and clients alike. The model has been applied to various settings in health care and it appears to be gaining popularity in rehabilitation units throughout the world (Botell, 2010; Fronk et al., 2005; Simpson, Anwar, Wilson, & Bertapelle, 2006). A brief single-case research article that examines the model from the client’s perspective suggests that in the case of a 21 year old tetraplegic man with no movement or sensation below his injury, the P-LI-SS-IT model was successful in addressing his intimacy needs with his partner. The study was based at the Casa Colina Hospital for Rehabilitative Medicine in California, United States. The hospital has implemented the P-LI-SS-IT model, although the study does not state when this was put in place (Botvin Madorsky & Dixon, 1983).

Programmes implemented in other spinal units throughout the world have had varying degrees of success. One example is the National Spinal Injuries Centre, Stoke Mandeville Hospital, in the United Kingdom. This spinal unit is one of the oldest and largest spinal injury centres in the world. Founded by neurologist Professor Sir Ludwig Guttmann in 1944, it was initially set up to treat servicemen who had sustained a SCI during World War Two (Buckinghamshire Healthcare NHS Trust, 2011).

A psychosexual counsellor is employed at the centre to talk to clients and their partners about intimacy concerns. She herself has a SCI, so the feedback has been very positive both on her expertise and on their improved comfort levels when talking to someone who also has a SCI. All the information summarised below is taken from personal communication with the counsellor (L. Dutton, personal correspondence, 17 September, 2011). She comes to the unit twice a month and clients and their partners are encouraged to attend these appointments. She also runs the ‘sexuality and fertility’ session groups, one of the topics covered in the ‘patient education’ sessions run at the hospital.

Separate groups for men and women have also been established within the hospital. Former clients with a SCI are invited to contribute to the groups and topic conversations are introduced by the clients themselves. Because women are a minority, single sex groups have been established to discuss women’s issues that were not being addressed.
In the men’s groups it was observed that sex was their main topic of conversation, whereas the women’s groups discussed managing a pregnancy and looking after children and babies (L. Dutton, personal correspondence, 17 September, 2011).

Stoke Mandeville Hospital has a database of former SCI clients who are frequently called upon to mentor newly injured clients. The hospital runs an ‘Independent Living Course’ for those who require a carer. It is strongly advised that clients do not see, or use, their partners as their personal carers as this can have a negative impact on their intimate relationship. For partners, a family counsellor is available if they have anything they wish to discuss, either in the presence of the partner with a SCI or without them (L. Dutton, personal correspondence, 17 September, 2011).

Of particular relevance to my study is the holistic approach to intimacy and relationship maintenance implemented at the Rehab Station Stockholm, Sweden (the TR programme has drawn its inspiration from this facility). Established by Dr Claes Hutling and Dr Richard Levi in 1992, the Rehab Station Spinalis is founded on a fundamentally different approach to rehabilitation than the inherited medical model used in New Zealand. It is centred around a holistic model that incorporates family and client needs into care packages (Verkaaik & Sinnott, 2007).

Although published literature regarding the Rehab Station Stockholm programme is scarce, books published by the Spinalis Foundation specifically for clients with a SCI discuss the unique features of the environment and programme. Unfortunately, the books have not been translated into English but through personal communication with the authors and founders of the programme, Dr Claes Hutling and Dr Richard Levi, an understanding of the programme has been established, providing information on which the TR unit and programme is based (Verkaaik & Sinnott, 2007).

Rehab Station Stockholm is a 27 bed facility, combining charitable, private and public funding that has enabled a dedicated team of health professionals and clients to create an environment that promotes privacy and caters to individual client’s needs. Each client has a private room with an ensuite, and particular care has been taken to ensure the environment is aesthetically pleasing.
The TR programme at the BSU has incorporated elements from the Stockholm model, such as the use of TR coaches, also with a SCI, to educate, support and mentor clients. The TR programme has also attempted to create an environment where clients can maintain a level of privacy that enables them to address relationship issues and explore intimacy. Private bedrooms, a new kitchen and updated living space have been established to provide clients with a more homely environment that allows for an easier transition back into their own home environment (Sinnott, 2008).

1.3 Summary

This literature review suggests that sustaining a SCI is one of the most devastating injuries a person can experience. There are substantive impacts on physical functioning including mobility, bladder and bowel control, and sexual function. The rehabilitation process can take up to 26 weeks, depending upon the severity of the injury. After medical stabilisation, clients with SCI are sent to the BSU or the ASRU, depending upon where in New Zealand the SCI occurred.

The hospital environment is not conducive to the maintenance of relationships and intimacy concerns. Attempts have been made to address these issues within the BSU with the establishment of the TR unit and the implementation of the sexuality education programme. Despite these attempts, little is known about a couple’s experience of their time in hospital. Therefore, this study aims to explore the experience of intimacy and maintenance of relationships following a SCI within the newly implemented TR programme at BSU.

The study looks at how couples perceive and interpret their experience of intimacy within the TR programme and BSU. In addition, each participant discussed what they perceive the term ‘intimacy’ means to them, and the ways in which this is expressed. An exploration of how the attitudes and behaviours of health professionals affect the couple has been conducted and couples discuss how the hospital environment fosters or impedes relationships.
In the next chapter, I outline the chosen methodology and theoretical perspective underpinning my methods (Chapter Two). This is followed by the results chapter (Chapter Three) and discussion chapter (Chapter Four), with recommendations for practice and further research.
Chapter Two

Methodology

This study aims to explore the experience of intimacy and the maintenance of relationships of couples where one partner has sustained a SCI. Interviews with the couples explored their experience of the hospital environment with particular emphasis on their perceptions of the newly implemented TR programme at the BSU.

2.1 Researcher position

I sustained a SCI when I was 17 as the result of a motor vehicle accident, and stayed at the ASRU for my acute rehabilitation for a period of 27 weeks. Although not officially employed to support and mentor clients of the BSU, I work in the Allan Bean Centre (ABC). I am often called upon by health professionals and NZST staff to provide support to those who have sustained a SCI. In particular I am often asked to talk to women with a SCI about their intimacy concerns because of my interest in this topic. Over the six years I have worked at the ABC, I have been privileged to listen to people with SCIs and their partners talk about their rehabilitation and the impact the SCI has on their relationship.

Consequently, their experiences have focussed my attention on the issues of intimacy and the maintenance of relationships, and they have reinforced my opinion that these are some of the most important components of people’s lives. I was not in a relationship when I sustained my SCI so I am unable to draw upon personal experience to understand a couple’s experience of SCI and subsequent rehabilitation. The primary source of my knowledge comes directly from the people I know at the BSU. Talking to couples has emphasised the fact that although intimacy and relationship maintenance is important to them, this does not appear to be an area of high importance for health professionals involved in their care.
This study explores a couple’s experience of a life-changing situation - how they perceive it, how it has impacted on the relationships they share with those around them and their relationship with each other. Also how the environment sculpted their experience. The topic of this thesis was determined after discussions with many couples where one partner had a SCI. The aspects of intimacy and maintaining relationships were repeatedly mentioned throughout these discussions and subsequently initiated my desire to explore the couple’s perspective of what I saw to be an unfavourable hospital environment.

Approaching this study, I realised that although I shared the same injury as half my potential participants, my perspective on the topic of intimacy and the maintenance of relationships might differ from theirs. I believed there was not one single body of knowledge but many, and all experiences, although different, would serve to build a complex and unique picture about how people perceive intimacy and relationship maintenance when one partner has sustained a SCI.

In order to explore the issue of the couples’ experiences of intimacy in an acute rehabilitation facility, I chose a qualitative approach to enquiry. Qualitative research studies things in their natural setting in an attempt to make sense of or interpret phenomena in terms of the meanings people bring to them (Denzin & Lincoln, 2000). From the qualitative methodologies, I chose IPA. IPA and the theoretical underpinnings of the methodology are congruent with what it is I hope to explore.

### 2.2 Interpretative Phenomenological Analysis

IPA is a relatively new methodology that was first used in the mid 1990’s (Smith, Flowers, & Larkin, 2009). Its foundations are aligned with psychology and many of the early studies concerned health psychology. The approach is phenomenological in that it involves a detailed examination of the participants’ lived experience. Phenomenology attempts to explore personal experience, and is concerned with an individual’s personal perception or account of an event or object, as opposed to an attempt to produce an objective statement of the object or event itself (Smith & Osborn, 2008).
IPA attempts to understand the world from the perspective of the participants, while recognising that this cannot be achieved without the interpretative work of the researcher, who is trying to make sense of what the participants are saying. It allows the observer to interpret the data and does not seek to bracket the experiences of the researcher from the collection and interpretation of the data (Smith & Osborn, 2008). The encouragement to examine one’s own influence in the research was one reason for choosing IPA, because my own experiences as a person with a SCI would influence what I asked, heard and understood in the research. The concept of the researcher bringing their own set of experiences, assumptions and preconceptions to the data was first discussed by Martin Heidegger, who, along with Edmund Husserl, contributed to the creation of the methodological principles of phenomenology. Edmund Husserl, considered by many to be the founder of phenomenology, believed in a reflective process by which opinion and prejudice are suspended to focus the attention on what is essential in the phenomena (LeVasseur, 2003). Heidegger, Husserl’s student, took a different stance and felt it important to acknowledge the influence of the researcher on the data, and so linked phenomenology with hermeneutics (Smith et al., 2009).

IPA examines the dialogue from the participants, acknowledging their cognitive, linguistic and physical characteristics. A connection between the dialogue and the participant’s thinking and emotional state is assumed in IPA (Smith & Osborn, 2008). This study employed dyadic (joint) interviews. Dyadic interviewing creates data that is multifaceted and contains many different perspectives. Layers of interpretations are embedded within that data and IPA is an appropriate methodology to use as it seeks to peel back and explore those interpretations. In the case of this research, the analytic process involved an iterative journey. Comments that were descriptive, linguistic, conceptual and unique to the couple were explored, and I feel I was able to capture the uniqueness of that dyadic relationship by using an IPA methodology.

2.2.1 Theoretical Foundations – Phenomenology, Hermeneutics, Idiography

IPA is underpinned by a variety of different theories, namely phenomenology, hermeneutics and idiography, which serve as the philosophical basis for the
Phenomenology was initiated by Edmund Husserl at the beginning of the twentieth century. His idea was to study a particular phenomenon with the aim of capturing, as closely as possible, the way in which the phenomenon is experienced within the context with which the experience takes place (Smith et al., 2009), (LeVasseur, 2003). One of the key elements of Husserl’s phenomenology was that there needed to be a clear distinction between the observer and the participant. Minimising the observer’s influence, and their own presuppositions and constructions on the data, was of paramount importance (Smith et al., 2009).

Following Husserl’s philosophical take on the methodology was Alfred Shutz, who is credited with developing social phenomenology. Like Husserl, Shultz recommended that researchers actively bracket themselves from the life-world they are studying. Bracketing is a method whereby the researcher acknowledges other sources of influence on the data set but chooses not to engage with them so there can be no influence from their own set of assumptions and experiences. What is left is purely the experience of the subject being studied, untainted by outside influences (Smith et al., 2009).

Martin Heidegger, however, believed there was no such thing as pure reflection, because reflection was, as all consciousness is, intentional and, therefore, never completely uninvolved with or separated from the world (LeVasseur, 2003). It was the divergence between Edmund Husserl and his student, Martin Heidegger, that led to the rift in phenomenology and to IPA being acknowledged as a methodology in its own right (Smith et al., 2009).

I set out to explore the phenomenon of a couple’s experience of intimacy and the maintenance of their relationship within a hospital setting, and this is congruent with the core principle of phenomenology. However, I did not choose any of the forms of phenomenology that required me to bracket my own experiences. As a person with a SCI I thought my own experiences would influence my whole approach to the research (from the research question, study design, data collection and analysis). Further, I thought my experiences had the potential to enhance and enrich the data collection and analysis. IPA was my chosen methodology because it has the discovery of participant experience at its centre and encourages the researcher to engage in an iterative cycle of reflexivity to examine their own influence throughout the research process.
Another main theoretical underpinning of IPA is derived from hermeneutics, the theory of interpretation. Schleiermacher, one of the first to write about hermeneutics as a generic form, said that interpretation does not follow a set of mechanistic rules. Rather it combines a range of skills, including intuition, and part of the interpretation process is to understand the researcher as well as the text (Smith et al., 2009). The method used to explore the couples’ perspectives was in-depth interviews that were then transcribed, providing the text for interpretation. IPA combines empathetic hermeneutics with questioning hermeneutics. Empathetic hermeneutics is concerned with understanding what it is like from the point of view of the participants. At the same time, questioning hermeneutics can involve asking critical questions of the data collected from participants (Smith et al., 2009). Further, in seeking the meaning of the text, IPA recognises that there is a double hermeneutic; that is, the researcher is making sense of the participant, who is making sense of their experience. This concept of the double hermeneutic was congruent with my understanding that I was trying to get at the meaning of what the couple said to me, as they made sense of their experience during the interview.

The third theory that supports IPA is idiography. The aim of my study is to say something in detail about the perceptions and understandings of a particular group, rather than making general claims and jumping to generalisations. This is described as a idiographic mode of inquiry (Smith & Osborn, 2008). Idiography is concerned with the particular, which leads to a focus or depth of that which is being studied. This is why I chose only a few couples and talked to them in-depth about their perspective of living within a hospital environment and what impact that had had on their relationship.

### 2.3 Paradigmatic view

Having outlined the methodology of IPA and its theoretical underpinnings of phenomenology, hermeneutics and idiography, I would now like to establish the philosophical stance that has informed my choice of methodology.
The philosophical underpinnings of the research require the researcher to consider their epistemological and ontological stance. Epistemology broadly asks the question, how do we know the world and what is the relationship between the inquirer and the known? (Crotty, 1998). Ontology describes what is out there to know about. Thus epistemology and ontology are broadly about the nature of knowledge and existence respectively. Although viewed by some as separate philosophical stances, I prefer to consider them as a whole, as described by Crotty (1998).

Denzin and Lincoln (2000) identify four basic research paradigms or philosophies and these include positivist, and post-positivist, constructivist-interpretative, critical and feminist-poststructural. This research is congruent with the interpretivist/constructivist paradigm, which recognises multiple meanings and understands that reality is subjective. The interpretivist/constructivist paradigm postulates that reality is not a fixed entity but rather a construction of the individuals participating in the research; reality exists within a context, and many interpretations are possible (Polit & Beck, 2006). Thus the interpretivist/constructivist paradigm is congruent with the position I outlined in section 2.1. For example, I believe each couple has their own experience anchored within the environment (the TR unit and the BSU) and time (acute rehabilitation period) of the interview. Further, the experience of each couple may differ from mine even though we share similar injuries.

Specifically, the constructivist paradigm assumes that when there is a greater understanding between the researcher and participants, knowledge is maximised. This point is particularly pertinent as I shared the same medical condition and experience of acute hospital-based rehabilitation as the people with a SCI who participated in this study. As this research is concerned with exploring people’s experiences, interpretivism (rather than positivism) is appropriate in that I will not be discovering absolute or generic truths. I acknowledge that there is not a single reality and that events and situations are viewed differently by different people. However, I also appreciate that while experiences may be different, the underlying meaning of those experiences may be similar and resonate with the reader. Acknowledging that meanings may be similar and resonate with individuals, there will also be multiple perspectives within the data positions of this research - half way between realism and relativism. Realism maintains that phenomena are seen to be made up of essential structures that can be identified and
described, whereas relativism argues that all experience is relative and constructed (Finlay & Ballinger, 2006).

In summary, my philosophical position (interpretivist/constructivist) is in accord with my choice of IPA. IPA is interpretivist in that it seeks to explore multiple meanings and interpretations of the data, including acknowledging the position of the researcher. Interpretivism also acknowledges the impossibility of capturing the truth, because the truth is relative; however, it is acknowledged that there may be commonalities within the data. IPA is also aligned with the constructivist paradigm in that reality is not a fixed entity but rather a construction of the individuals participating in the research.

2.4 Methods

IPA seeks to analyse in detail how participants perceive and make sense of things that are happening to them. To elicit those perceptions and experiences, a flexible, qualitative data collection method is advised (Smith & Osborn, 2008). There are no rules regarding the application of the methodology, but certain methods are more appropriate to obtaining data. In-depth interviews, semi-structured interviews and diaries, have all been suggested as good methods that elicit rich, detailed, first-person accounts of people’s experiences (Smith et al., 2009).

In the case of this research, dyadic (joint) interviews were used to elicit the experience this study sought to explore, that is, the experience of the couples regarding intimacy and the maintenance of relationships within the hospital environment. Thus participants were a couple (rather than single units of the person with SCI and the partner), because it was the shared experience I wanted to understand.

2.4.1 Sample

Smith (2009) has suggested a number between three and six interviews for an IPA study. In this study, five couples were interviewed - ten participants overall. IPA sample sizes are small in size with an emphasis on quality and depth of data rather than quantity (Smith et al., 2009). IPA is idiographic by nature, focusing on the interplay of factors that may be quite specific to the individual, and it is possible to
make specific statements about the individual. Idiographic studies suit smaller, more homogenous samples.

2.4.1 Homogenous sample

The defining characteristic of all the couples in this study was that one of the partners had sustained a SCI and the other was their partner. Further, all couples had experience of maintaining their relationship in the acute rehabilitation environment of the BSU, specifically the TR programme and unit. Homogenous samples are favoured over heterogeneous samples in IPA. If the participants being studied were vastly different in terms of demographics and the situation being studied, it would be difficult to decide whether patterns of difference and similarities found within the data were to do with the individual characteristics of each of the participants rather than the social variable they represented (Smith & Osborn, 2008).

2.4.2 Participants

A purposive sampling method was used for this study. The primary purpose of sampling is to collect specific cases that can clarify and deepen the understanding of a phenomenon (Smith et al., 2009). Purposive sampling is particularly useful when the researcher is selecting a population that may be difficult to reach or is specialised. In the case of this research, the population of interest was small in number. Because of the small numbers of people with a SCI, every couple who met the inclusion criteria and took part in the TR programme during the data collection phase was asked to participate in the study.

The criteria for inclusion in the project were that the couple needed to be in an intimate relationship and both members had to be over the age of sixteen. Participants were required to speak fluent English because this was necessary to take part in the interview. Lastly, the participants had to be willing to be interviewed together. Because the focus of this research was on the couple’s experience of the acute hospital environment, I recruited couples rather than just one of the two partners in the couple.
2.4.3 Recruitment

I approached the TR co-ordinator every two weeks for a list of clients with SCIs who were currently involved in rehabilitation in the acute spinal unit and who expected to move into the TR programme and unit within the next four weeks. When clients with a SCI who were in a couple relationship were identified, the TR coordinator approached the couple to introduce the study and ascertain interest in participation. This was done in accordance with the Ethics Committee’s requirement that a health professional be involved at the initial point of contact with potential participants. After the first two couples were recruited, the TR co-ordinator changed and another health professional and CDHB employee was recruited for the initial verbal consent phase for the last three couples. If interest was expressed during the initial verbal contact, the research supervisor who works on site at the Burwood Hospital (BC) approached the couple and presented them with an information sheet (Appendix 1) explaining the research in detail and answering any questions they had.

The couple were left with the information sheet for three days, after which I approached them. If the couple indicated that they were happy to take part in the research, a consent form, one for each partner (Appendix 2), was signed and an appropriate time was scheduled for the in-depth interview. In all but two cases, interviews were scheduled for the next day. The other two interviews were completed on the same day the consent form was signed.

2.4.4 Interviews

2.4.4 (a) Dyadic interviews

As previously mentioned, the aim of this study was to explore the couple’s experience of their time at the BSU and TR unit with a focus on intimacy and the maintenance of their relationship. It was decided that the most effective way to elicit information pertaining to the couple’s experience was through joint dyadic interviews. Martin Heidegger, one of the founders of phenomenology and a major influence on the development of IPA, said: “We exist amid a world of shared meanings and understandings” (Taylor & de Vocht, 2011. Pg 1579). These shared understandings
might be more apparent in dyadic interviews where the couple’s experience is jointly described in one shared narrative. Taylor and de Vocht (2011) suggest that interactive topics such as sexuality and intimacy should involve the partner as the topic affects both of them.

As Cort, Monroe, and Oliviere (2004) noted, it is important to include the partner in research as the way the course of illness or disability is negotiated will be influenced by both personalities and their backgrounds. Racher (2003) suggested that when deciding whether to interview the couple together or separately, researchers should look at what it is they are seeking to understand. When exploring the experiences of couples it is appropriate for the research method to focus on the couple as the unit of study. Dyadic interviews are a way to gain an understanding of the experience of the collective perspective of the partners and maintain that focus during data collection and analysis.

Dyadic interviews may also provide insights into the couple dynamics that may be harder to identify in individual interviews (Taylor & de Vocht, 2011). Allan (1980) suggests that by interviewing couples together, the interaction between them can also provide valuable data not readily obtainable in other ways. Taylor and de Vocht (2011) discuss the ‘Johari Window’ (figure 2.1) in relation to the different data collected from dyadic and individual interviews. The Johari Window is a model of awareness in interpersonal relations (Luft, 1961, cited in Taylor and de Vocht 2011). It has four quadrants, a quadrant which holds information that is known by the individual and by others, a blind quadrant which is where information is known to others but the individual is unaware of it, a hidden or ‘façade’ area where information is known by the individual but not by others and an area of unknown activity that neither the individual or others are aware of.
Taylor and de Vocht (2011) compare individual and dyadic interviews in relation to the Johari Window. They suggest that individual interviews have the potential to shed more light on the hidden or ‘façade’ area as individuals are more likely to disclose aspects of their relationship to the researcher if their partner is not present. Alternatively, participants may also conceal information without worrying about being corrected or contradicted by their partner.

With dyadic interviews, partners can reduce each other’s blind quadrant by providing information about their partner that he or she may not be aware of. An advantage of dyadic interviews is that couples can corroborate or supplement each other’s stories, providing the researcher with richer, more truthful data. Similarly, partners often modify their partner’s accounts, helping to correct unacknowledged biases and providing more truthful data (Allan, 1980; Taylor & de Vocht, 2011; Valentine, 1999).

Performing individual interviews allows the participant to speak freely without their partner present, although this can also cause anxiety within couples who may not want their partner to disclose personal ‘secrets’ (Morris, 2001; Taylor & de Vocht, 2011;
Valentine, 1999). Similarly, participants admitted feeling a sense of fear around being judged as a bad or unmatched couple (Taylor & de Vocht, 2011).

The interviewer may be faced with moral issues from both individual and dyadic interviews (Taylor & de Vocht, 2011). One partner may disclose something the other partner does not want to be known to the interviewer, leaving the interviewer with the dilemma of what to include in the transcript. Silent participants may provide a subtle but clear indication that the account given by their partner is incomplete or contested, leaving the interviewer with a similar moral dilemma. In addition, Allan (1980) adds that dyadic interviews may be biased towards the more dominant partner. On the other hand, in performing separate interviews the researcher may have two different accounts and making sense of those accounts can be problematic (Hertz, 1995).

There are a myriad of issues to consider when interviewing couples together or separately, but both approaches can be effective in yielding data of interest to what is being researched (Taylor & de Vocht, 2011). Taylor and de Vocht (2011) suggested that in order to address some of the issues about interviewing couples separately or together, couples should be given the option. Although this may appear to be a logical way to eliminate a lot of the ethical issues involved, it too has its drawbacks. For example, when a partner has chosen to be interviewed individually, this has created suspicion and created anxiety in the other partner (Morris, 2001).

Knowing the pros and cons of dyadic (joint) interviews, I chose this approach because the core purpose of my study was to explore the couples’ experience. I wanted a joint construction of the narrative, and I wanted to observe couple interaction and capture this within their narratives. I also felt ethical considerations were important when considering the method (refer to 2.6 Ethical considerations).

2.4.4 (b) Development of interview schedules

I developed the interview schedule (Appendix 3) in collaboration with my two supervisors (BC and JHS). The main aims of the study were grouped into a series of open-ended questions. It was decided that questions relating specifically to intimacy would be placed towards the end of the interview due to their sensitive nature. It was
recognised that some couples might need time to warm to the interviewer before they felt comfortable enough to discuss such sensitive topics.

The first sets of questions were on the general nature of the relationship. These included basic questions, such as where the couple met, how long they had been together, and whether they had children. I hoped this would ease the couple into the interview process and generate a sense of ease with the interviewer and themselves.

After the discussion about the relationship, issues such as the couple’s experience of being in the acute spinal unit were explored. The couple’s thoughts and experiences of the TR programme were discussed, along with their thoughts about their dealings with health professionals. The couples were then asked about their intimate relationships and sexual expression, whatever they perceived those to be. Due to the sensitive and sometimes upsetting nature of the discussions, it was felt that leaving the participants in a space in which they felt safe and stable was important for their overall wellbeing. Therefore I chose to end the interview by discussing with the couples what they were looking forward to about going home, and whether they had any advice they could give to other couples. In this way, I hoped to end the interview on a positive note.

After the first interview, a few amendments to the interview schedule were made. Clarification of the terms ‘intimacy’ and ‘health professional’ were necessary as these were unfamiliar to the dyad. In later interviews, examples were given and the term ‘health professional’ was expanded to include medical staff, physiotherapists, occupational therapists, social workers, psychologists and any other health professional employed by the hospital who was in direct contact with either partner.

The fifth interview was amended slightly as it was felt there were a few areas of interest that would enhance the data. Issues explored in greater depth included privacy, interactions with health professionals and, specifically, what intimacy meant to the couple.
2.4.4 (c) Conducting the interviews

Ideally, the researcher conducting interviews in qualitative research, puts him or herself in the place of the respondents and attempts to see the situation from their perspective, rather than impose the world of academic preconceptions upon them (Denzin & Lincoln, 2000). Gaining rapport with the participants provides the collection of a rich and more honest set of data (Smith et al., 2009). Because I have a SCI, I hoped to maximise this rapport as there was already a sense of connectedness between me and the couples I interviewed.

This study used semi-structured interviews as a method of eliciting information. Using a flexible set of questions, the researcher allows the participant the freedom to explore areas of importance or relevance to them. The researcher’s job is to facilitate and guide discussion rather than impose guidelines and rules during the interview (Smith et al., 2009).

The interviews took place on the Burwood Hospital campus (Figure 1.2). Four interviews were conducted within private rooms with doors. These included the TR bedroom, the lounge in a BSU lodge and the private counselling room situated within the TR unit. One couple preferred to be interviewed in the public lounge of the TR unit as it was not being used by any other clients of the BSU or TR unit. (Figure 1.4). The length of the interviews ranged from one hour 10 minutes to over two hours. All the interviews were recorded with permission from both participants.

Most of the interviews were completed without interruption, although interview four was broken into two parts because the participating couple had a prior commitment. The interview commenced two hours later in the same location in the TR Unit. This couple said they were glad of the long break as it gave them a chance to collect their thoughts.

Couple two had a small child who was present in the Milner unit during the interview. On three occasions, the wife left the room for short periods to check on the child. This did not seem to affect the interview at all, and dialogue between the researcher and the participants continued without interruption.
Unfortunately, a dictaphone malfunction occurred during the first interview, which meant that only a small portion of the interview was digitally recorded. This meant writing down all that I could remember immediately following the interview and matching this with the small section the dictaphone had recorded.

2.5 Data analysis.

Each of the interviews was digitally recorded. After each interview, the digital files were downloaded into a secure file only accessible to the research team. I transcribed each interview and included pauses, emotions such as distress/crying or laughter and fillers. If one of the partners left the room while the interviews were taking place, this was also included in the transcript. To maintain the confidentiality of the participants, the coding M for men, F for women and R for researcher was used, as was the removal of any other identifying information such as the couples’ place of residence. The names/titles of health professionals, family members or anyone else involved with the care of the person with the SCI, were removed and replaced with a generic term in square parentheses, e.g. [child]. Editorial notes or words implied in the recorded interview were included within rounded parentheses, e.g. (at the BSU). Table 2.1 is a summary of the transcript conventions and extracts used in this study.

### Table 2.1 Table of conventions of transcription and extracts used in this thesis

<table>
<thead>
<tr>
<th>Convention used in transcription or extract</th>
<th>Used to:</th>
</tr>
</thead>
<tbody>
<tr>
<td>[   ]</td>
<td>De-identify a person or place</td>
</tr>
<tr>
<td>….</td>
<td>Small pause</td>
</tr>
<tr>
<td>—</td>
<td>Signify pause or hanging phrase resulting in an incomplete sentence</td>
</tr>
<tr>
<td>(   )</td>
<td>Researcher’s own notes to enhance meaning or clarify meaning</td>
</tr>
<tr>
<td>“words within quotations”</td>
<td>Verbatim quote from participant</td>
</tr>
</tbody>
</table>

Each transcript was double-checked for accuracy, which required listening to the digital recording twice to crosscheck these with the written transcripts. A brief summary of each of the transcripts was then written up to familiarise myself with the data and
capture the distinguishing features (idiographic nature) of each couple’s narrative (Appendix 4).

After each transcript had been checked for accuracy, it was placed into a template with three columns. Each line was numbered vertically and the transcribed interview was placed in the middle column. The transcripts were then subjected to an in-depth analysis. Smith et al. (2009) notes that three different interpretation processes are required to capture any significant themes within the data. They include teasing out the descriptive comments that focus on what the participants have said, linguistic comments that explore the specific use of language used by the participants; and conceptual comments that focus on engaging at a more interrogative level.

For the purpose of this study, I added a fourth element, which was to look for data that gave information about how the couple described themselves, what language they used to refer to themselves, and how they interacted with each other. The fourth element was needed to acknowledge the dyadic nature of the transcripts. Each of the four levels of analysis were colour coded and briefly described in the left column. Descriptive comments were written in black, linguistic comments were blue, conceptual comments were red and couple dynamics were coded in yellow. The last stage of analysis involved looking at the colour-coded comments in the left column and condensing meanings into larger ‘themes’ in the right column. Each transcript underwent this process. I then looked at all the transcripts together to collate the themes into super-ordinate themes. These super-ordinate themes (and their subthemes) are discussed in next chapter.

2.6 Ethical considerations.

The Upper South Regional Ethics Committee granted approval for the study URA/10/04/029 on 24 May 2010, and data collection commenced in June 2010. The last interview was completed in August 2010. The application and confirmation of ethical approval are in Appendix 5.

Two ethical issues were considered at length in preparing the ethical application. These were maintaining the confidentiality of a small sample, and the potential to cause
distress to the participants and to myself. Confidentiality is hard to maintain given the small population of people with SCI in New Zealand. The participants’ narratives could reveal their identities, particularly in qualitative research where obvious details, such as real names, might be revealed despite my best efforts to delete them. Therefore, I offered the participants the opportunity to check all quotes to prevent identity exposure.

Maintaining confidentiality was going to be even more difficult between couples, as each partner is aware of how the other speaks and the content of the interviews. Therefore, because confidentiality between a couple was unlikely, and I did not want them to be anxious about what they might say separately, my philosophical stance regarding dyadic (joint) interviews was endorsed.

I was exploring sensitive issues with vulnerable couples in the early stages of grief after one partner had sustained a traumatic and serious injury, and I needed to be prepared for their possible distress. Prior to each interview, I stated that discussing issues of a sensitive nature could upset them, and asked how they would like me to deal with any difficulties should they happen during the interview. When moments of distress did occur, participants were given the option of a break or resuming the interview at a later date. I took a box of tissues with me in case they were needed. When one partner became upset I observed that the other partner would reassure them either verbally or by touch. These demonstrations of mutual support further served to reinforce my decision to use dyadic interviews.

During the interviews I was at times also at risk of becoming upset by the content being discussed and by my empathy towards the participants. As anticipated, some interviews triggered repressed memories which I found distressing. However, the couples seemed to appreciate that I was being ‘real’ about what I felt, and said this helped them feel more at ease with me. I felt, in turn, that this created data that was truthful and detailed, because they did not have to censor what they said to me.

After each interview, I would debrief with one of my supervisors (BC). I would also schedule a discussion with my Health Research Council (HRC) mentor (KAS) every month to discuss the emotional impact of some of the interviews. I found this helped me to deal with any resurfaced feelings.
2.7 Maori consultation

The research abided by the principles of the Treaty of Waitangi and followed the core principles of Kaupapa Maori Research (see 5.1). The research proposal was submitted to the Ngāi Tahu Research Consultation Committee, University of Otago. Ranga Hauroa, Māori Health Burwood Hospital, was consulted throughout this research project. For any participants who identified themselves as Māori, the services of Ranga Hauroa were available as an additional support measure. No participants identified themselves as Māori, but three were not New Zealand-born. Applying the principles I learned from Ranga Hauroa regarding the holistic view of health and wellbeing helped me approach the interviews with a greater sense of what was important to couples, e.g. the significance of family in constructions of health.

2.8 Summary

This chapter has examined the methodology employed to explore the aims of this study. To obtain information about the couple’s experience of their hospital stay, with an emphasis on intimacy and relationship maintenance, it was decided that the most appropriate methodology was IPA.

The theoretical underpinnings of IPA are phenomenology, hermeneutics and idiography. The paradigmatic view of this study aligns with an interpretivist/constructivist paradigm. The study seeks to explore the many meanings and interpretations of the data, including the acknowledgment of the position of the researcher. It recognises that reality is not a fixed entity but rather a construction of the individuals participating in the research.

Five couples participated in a semi-structured interview using a dyadic interviewing method. A thematic analysis, congruent with the principles of IPA, was used to discover the meaning couples gave to their experiences of intimacy and relationship maintenance within the BSU and TR unit. The results of the analysis are discussed in the next chapter.
Chapter Three

Results

This chapter presents the thematic analysis of the five transcripts. The participant demographics are given along with a brief description of the text. Following this is a diagrammatic representation of the results (Figure 3.1), and the explanation of each theme.

First, I look at the couple who talk of themselves as ‘I’, ‘we’ and ‘he/she’, ‘I’ means the individual’s own voice, ‘we’, illustrates the collective voice of the couple but is spoken by an individual, and ‘he/she’, is what an individual perceives their partner thinks or feels.

Table 3.1 lists the other three themes: ‘Grief and loss’, Loss of autonomy’ and ‘Transitioning forward’ and their subordinate themes. Prior to collating the themes, and in accordance with the idiographic nature of the IPA methodology, I found it helpful to create a summary of the content of each couples’ interviews. These summaries are included in Appendix 4.

The term ‘men’ is used when referring collectively to the participants with a SCI as all people with SCIs were male. ‘Women’ is the collective term used for the partners of those with a SCI. The term ‘couple’ and ‘dyad’ are used interchangeably when discussing issues that affect both partners within the relationship.

Table 3.1 Summary of Themes and Subordinate Themes

<table>
<thead>
<tr>
<th>Theme</th>
<th>Subordinate Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grief and loss</td>
<td>Guilt and obligation</td>
</tr>
<tr>
<td>Loss of autonomy</td>
<td>Lack of cohesion and distrust in relationships with health professionals</td>
</tr>
<tr>
<td></td>
<td>Privacy and space within a hospital environment</td>
</tr>
<tr>
<td>Transitioning forward</td>
<td>Intimacy</td>
</tr>
</tbody>
</table>
3.1 The participants

Six dyads who met the inclusion criteria (see 2.4.2) were approached. Of the six couples, one declined to participate. This couple were in an older age demographic (60-70 years), and the woman had a SCI. She said the reason she had declined to take part was that she was uncomfortable with the dyadic interview.

All participants with a SCI were men, and their partners were women. All five couples were married. Three of the five participants had a cervical injury resulting in tetraplegia. The other two had thoracic injuries and were classified as paraplegics. On average, the men with a SCI had been at Burwood Hospital for approximately 24 weeks at the time of the interview. The region of residence for three out of the five couples was the North Island of New Zealand. Two couples lived in the South Island but only one couple came from Canterbury. Thus for four couples the travel distance to the BSU was substantive. Three out of the five couples were New Zealand European, the other two couples were a mixture of Asian, Indian, English and New Zealand European. There were no Māori in this sample despite there being an overrepresentation of Māori with SCIs within the SCI population in New Zealand (Dixon et al., 1993).

There was a deliberate decision not to tabulate demographics as it was felt that the confidentiality of participants would be compromised due to the small numbers of people with a SCI in New Zealand.

For participants in my study, the causes of SCI fall into two categories - sports injuries and falls. None had sustained an injury because of a motor vehicle accident, the primary cause of SCIs in New Zealand (Acland, 2010).

3.2 Overview and links between the themes

To visually conceptualise the links between the themes induced from the data, I designed a diagram (Figure 3.1). Figure 3.1 illustrates the concept of the couples’ experiences while in hospital when one of them has sustained a SCI, with an emphasis on intimacy.
and the maintenance of their relationship. The diagram is not intended to portray a model or theory.

The inner circle symbolises the couple, with the swirls representing the two partners intertwined within. The red and blue illustrate the man and woman converging to become purple demonstrating the unity of the dyad. The idea of ‘being one’ in their relationship is discussed by the couples in this study. The swirls show the bonding of the couple and in doing so, they refer to themselves as ‘we’.

![Diagrammatic representation of the themes](image)

**Figure 3.1** Diagrammatic representation of the themes
The ‘couple’ is surrounded by a larger circle that symbolises the hospital environment. This circle represents life experiences while in hospital and is shaded with thin lines that represent the bars of a prison. Many participants felt confined during their stay in hospital, and used words such as prison to describe the hospital environment. ‘Imprisonment’ was also a metaphor used to describe the physical constraints of the injured body.

Within the hospital environment the participants experience ‘Grief and loss’ and ‘Loss of autonomy’ and are also ‘Transitioning forward’. The broken line shows these experiences continue beyond the hospital environment and also influence the couple’s view of living ‘outside’ or back in the community.

### 3.3 The couple: I, We, He/She

The interviews contain three distinct viewpoints due to their dyadic nature. For example, Barry and Brenda described a situation where they went on an excursion to the beach which was their first trip away from the BSU as a family, and both realised for the first time, the difficulties they would face because of his SCI. Brenda began by saying:

Yeah, well we went out yesterday to Sumner, I mean, we’ve done lots of excursions here in the transition unit, which is great, it’s wonderful and we’ve really enjoyed them and we’ve learnt a lot but they are very wheelchair friendly excursions, when you go out on your own, you suddenly go, we can’t go out to the beach, we can’t go, get Barry onto the sand to play with [their child] and you know he see’s people riding past on motorbikes and bikes and stuff and it was just outlining all the things that you won’t be able to do (Brenda, page 23, line 14).

When she had finished, Barry reiterated the truth of her recollections and added some more detail, including some information from his own perspective. He added:

Yeah basically everywhere we looked on one particular trip it was like, oh god, can’t do that, can’t do this, and that was pretty hard... and I didn’t have any of that with the excursions I’ve done with the TR, it’s always been quite an easy trip (Barry, page 23, line 28).
In these extracts, he/she was used when one partner talked about the other partner as distinct from themselves. Brenda referred to Barry as ‘he’ in her dialogue, talking about the other as ‘he/she’ was characteristic of talk about the partner, when the partner acted independently. ‘I’ referred to the speaker (the self). Barry owned his action when he said “I didn’t have any of that”. Brenda went on and said “but I guess we’ll also focus on things you can do”. On the other hand, ‘we’ meant the unit of the couple as a whole or as one. So, because they shared the same sense of loss concerning the outing, they both used ‘we’, such as “we can’t do this”.

Occasionally the women referred to themselves as if they were the injured partner as illustrated in Brenda’s quote.

You sometimes realise, oh woops, I’ve left it [the laundry] for two days, I don’t have any tracksuit pants left, you know (Brenda, page 10, line 25)

When Brenda says “I don’t have any” what she means is that Barry doesn’t have any clean tracksuit pants left to wear. On these occasions it became clear how the couple identified themselves as a merged identity, and how much they perceived themselves as a team - one unit.

Reiterating the other partner’s dialogue was employed by one partner to emphasise a point of discussion and to provide support and encouragement to that partner. It was also a sign that both were in agreement with what was being said, and gave the transcript an added level of credibility. I felt repetitions such as these were the sign of both a shared experience and a shared meaning: for example, Darren and Diana shared mutual feelings of anxiety about moving to the TR programme.

Darren: It was their plan; you have to be independent, so they abandon you and you have to look after yourself in many ways and we felt abandoned.
Diana: We felt abandoned. (Darren and Diana, page 15, line 33).

Most often, however, agreement was indicated by utterances such as ‘mmm’ and ‘ahuh’ or by nodding the head.
The couple often demonstrated mutual compassion and a desire to protect one another. For example, when one participant was visibly upset, their partner would often continue the conversation to give the other ‘time out’. Empathic gestures were used such as a reassuring hand on the shoulder or leg of the partner and offering tissues if the other was apparently upset.

In some hospital situations, the women described how they become ‘the voice’ of their partner, especially when the men acknowledged that they did not have the confidence to speak up in front of health professionals. In my field notes, Alison mentioned her concern regarding her husband’s care. If she felt the nurses were not being careful with him, she would often voice her concerns to the relevant health professional. Her partner Andy said that he appreciated her proactive behaviour as he did not feel confident about speaking up when something bothered him because of his reliance on others to manage his diminished physical capabilities.

I observed that couples used the term ‘I’ more frequently when discussing their feelings. An example of this is when Edward said “I’m angry” in reference to the problems they were having regarding the modification of their family home. Darren said “I feel vulnerable” and shared his anxiety regarding his impaired physical functioning. Interestingly, when asked about intimacy, the term ‘you’ was used, Barry said “You’re probably not feeling as attractive about yourself as you would have” or “yeah that would make you think twice about getting intimate”. Similarly, Carl said “you try something else and maybe it might slightly work but not quite and you figure it out and you start talking about it” in reference to the sexual intimacy between himself and his partner Cathy. Both examples used second person to distance themselves from the sensitive issues of intimacy.

Couples also used the term ‘we’ when discussing their perceived mutual understanding of how they were feeling. When referring to the way health professionals often needed to access sensitive and private parts of the body, Cathy said “…yeah, we just make fun out of it” to which Carl replied “we just laugh it off, so, it hasn’t been so bad”. All of the transcripts offer examples of the use of ‘we’ when assuming they shared the same view or feelings. However, when broaching topics that were too sensitive for the term ‘we’, the term ‘you’ is used. Brenda said “…but they don’t fully comprehend how much
you’ve lost, how much you can’t do any more”. Due to the sensitive nature of what is being said, Brenda uses ‘you’ to distance herself from their situation.

### 3.4 Grief and loss

Grief and loss affected all of the participants on an individual level and couples also grieved for the change in the dynamics of their relationship. The couple experienced a sense of disbelief when they gave thought to the enormity of the SCI and the impact it had had on their lives as individuals and as couples. All couples mourned the change the injury had caused to their relationship. Brenda admitted that the effect the injury had had on them was “massive and a bit scary to think about”, Barry agreed with this. Both spoke of their disbelief and fear, and said that the whole ordeal was difficult for them to accept. Barry acknowledged that an injury like his would have a large impact on both himself and his family.

I doubt there are people that fly through you know a spinal injury without any major psychological trauma and things like that you know, it’s a pretty difficult process to get to the other side…. it’s life changing isn’t it (Barry, page 29, line 59).

For Barry, a SCI is a process, a journey where life hopefully improves after a period of time, but perhaps also, there is a feeling that life could not get any worse. He acknowledged that, as well as affecting the body physically, a SCI does have an impact on an injured person’s state of mind. Here, Barry admits to feeling depressed over what he has lost and an eroded self-perception.

I think at the moment um, you know, for myself personally, I’ve lost the ability to walk, I’ve lost the ability to control my bowels and bladder, my legs have shrunk away, um I’m in pain all the time, it’s all these things, I’m just not feeling …you know, there’s just not a good self image at the moment. I’m wearing clothes I don’t normally wear, you know I’m wearing tracksuit pants everyday, you know, I’m not wearing shoes, I’m wearing hospital slippers, so all these things come into play, I think once we go home, I’ll build my own image back up. The other sorts of things that have affected me, you know, I’m not working, you know, so that’s sort of, I’m not the [man in charge at work] anymore, I’m just in a hospital, being a patient, so yeah, I’ll build it up, once I get home, but it’ll take a long time I’m sure, can’t see it being, it’s not a six month fix, a year and a half, two year type thing (Barry, page 22, line 5).
Edward felt a similar sense of loss. “I can’t play [at home], can’t do the water leaks, can’t do this, can’t do that”. A trip to the beach brought home to Barry all the activities he could no longer enjoy. Brenda said, “but they don’t fully comprehend how much you’ve lost, how much you can’t do any more… um and that trip yesterday really highlighted that to us”. She was frustrated that other people did not realise the full impact a SCI had on the person and their family. Also her friends’ naivety regarding Barry’s injury and their lack of acknowledgement of how difficult life was for them after his accident bothered her. It is Barry’s personal account of loss that stimulates Brenda’s comments on how it has affected them as a couple, indicating that she sees his suffering as a continuum of her own suffering; of their shared suffering.

Internal body functions can be affected when a SCI occurs. Some men mentioned the stress they felt over bowel problems.

Edward felt embarrassed at the thought that he might have an unplanned spontaneous bowel evacuation, so he would avoid situations where he was at risk of that event occurring. He was concerned that his partner would see him distressed, knowing it would further upset her, even though he also required her support. Elizabeth however spoke of her frustration over the times he avoided her because of his ongoing bowel problems, and said it was hard not to take his avoidance of her personally.

Bowel issues were a constant theme in the dialogue of Darren, Edward and Barry, all three citing their frustration and sense of loss over not being able to control their bowel movements. All three were also dissatisfied by what they perceived to be a lack of professional knowledge on how to deal with their bowel-related problems.

Another theme was an acceptance that a SCI is permanent and that recovery is more about adaptation than actual physical recovery. Barry would have preferred to have
cancer where “there is a higher rate of recovery for cancer survivors”. Edward spoke of his grief after sustaining a SCI.

I’ve been here four and half, five months before I go home, and I’m still actually broken and I’m still sick, you know my guts are all wrong, you know? And that’s been a bit, I’ve had to get my head around it (Edward, page 12, line 27).

Prior to his SCI, Edward had been treated for an addiction. Coming to terms with the notion that a SCI is not something he would recover from, and not letting anger encroach on his life and his relationship with his partner, was something he actively had to work on.

Sharing intimate moments could also be very frustrating for the couples, and in some cases, it highlighted the loss they shared. Barry felt they had lost their sexual “spontaneity” and the “close bonding you enjoy with sex and being intimate”. Before her husband’s SCI, Brenda said she loved “hopping into bed and being intimate”. Now there were “cushions everywhere and catheter bags”, and it became physically difficult to do so. Barry was frank about the physical side of sexual intimacy as well as the emotional impact it had had on him.

I’ve got low self esteem at the moment, that’s another thing, you know, so all of these things come into play and create issues (Barry, page 21, line 41).

Low self-esteem inhibited Barry’s desire to be intimate with his partner, although he also recognised that once out of the hospital environment, his self-esteem would improve, along with the intimacy between himself and his partner. “I think once we go home, I’ll build my own image back up”. Andy agreed with Barry, adding that having a SCI was “not the end of the world” and that his intimate relationship would get better once out of the hospital environment.

Some of the women felt that they were being over-protective of their partners and that this change in roles had had a detrimental effect on the relationship. Diana suggested that she “needed to let go” but that for her it “was a heck of a big step”. A few women saw the role of the injured man changing from that of partner to that of an invalid and felt that this had affected the dynamics of their relationship.
It’s also important for me not to see him as a patient, you know, he’s still my husband and that sort of thing makes it tricky too doesn’t it (Brenda, page 21, line 45).

Brenda felt that it was important not to see her husband Barry differently to how he was before his accident, although she admitted that it was difficult for her to lose the dependant-husband perception. The physical limitations placed upon the men, however, meant that there were relationship role changes.

Barry would take him on the scary rides cause I don’t like the scary rides and you know all the, you wanted to teach (the child) how to swim and surf and skateboard, and they are all really important things, and while he’ll still be able to do it, it will be different… so I’ve sort of had to take on that role of the more active mummy, which I don’t like (Brenda, page 27, line 22).

During this dialogue, Barry physically consoled Brenda by touching her leg as she became visibly upset about her new role. In my field notes, Alison was worried about who would do the tasks her partner could no longer perform, such as “mowing the lawn”. She suggested the couple would now have to pay “someone else to do all the fix-it jobs” and admitted to a feeling of unease over their changed financial position.

All the losses and changes, both those experienced already and those that were anticipated, were overwhelming. Diana mentioned feeling inundated by the amount of information given to them regarding Darren’s injury, coping with the physical changes to his body was stressful for her and she needed it “drip fed” to her so she could process the changes to his body from the SCI.

This feeling of being overwhelmed appeared to be especially relevant during the first few weeks after sustaining the SCI. Carl mentioned not being in control and forgetting situations and experiences in that initial period. Barry said that things felt like “a blur” to him, and Brenda confirmed that this was because he felt overwhelmed by everything, Barry concurred, “you don’t have a minute to yourself”.

Barry doesn’t handle too much talking talking talking; that’s just, that was probably a bit overwhelming, and then constant family that was a bit overwhelming as well, we had family staying with us the whole time, so that was fantastic for the support, but at the end of it, I thought, I need to put a stop to this, we need some space (Brenda, page 14, line 11).
Although the support of family was important for Brenda and Barry, having extended family around, during a time when there seemed to be constant interruptions from health professionals, was stressful. Brenda admitted her relief at having the opportunity to “hide away in the lodge”, which she said was “fantastic” for the two of them. Diana mentioned her frustrations when the seasons changed.

I walk around the wetlands, do it in fifty minutes, I used to do it twice a week, but the weather is just, and actually since I’ve been here, I get even less time, you know, I don’t get that down time, like go to school, even though I’m teaching, the kids are demanding, I have a bit of down time and sometimes I go off to line dance without him or something, so I had the down time, here it’s even less (Diana, page 40, line 17).

Diana goes on to say “I have extra pressures that do involve him yet don’t involve him, organising what’s going on at home, you know”. She alludes to feeling overwhelmed coupled with having limited spaces to go for “down time”.

Barry referred to other clients as being “patients, or inmates, or whatever they are”. A few participants likened their stay in hospital, and the physical limitations of the injury, to being incarcerated in a prison. Darren, for example, felt “imprisoned” within his body. The terms: ‘inmates’, ‘wards’, ‘imprisoned’, ‘escape’ and ‘curfews’, were used by both the men and women to express the constraints they felt within the hospital environment and how it added to their sense of grief and loss that subsequently, led to a loss of autonomy.

A few participants mentioned their desire to get away and escape. Cathy for example admitted to not wanting to “deal with the world”. This feeling was often discussed in the interviews especially by the men, a few of whom felt overwhelmed during their time in the BSU. Altogether, the overwhelming nature of the injury and coping with it meant the participants felt trapped. For the men, this was a combination of being confined within the hospital and being imprisoned within a body now unrecognisable. For the women, they felt they had to stay with their partner and in some cases, felt trapped, especially when they felt there was nowhere for them to go to get away.
Like being in prison, the participants were unable to escape their feelings and the physical environment of the hospital. All were constant reminders of what they had lost and a common outcome of grieving for these losses were the feelings of guilt and obligation.

3.4.1 Guilt and obligation

For the men, one manifestation of guilt was to talk about what they could no longer do and that they felt bad about the future impact this would have on their partner. Edward said:

That’s what’s gutted me with what’s happened, as the plan was as Elizabeth’s arthritis got a bit worse, then my role was going to be to look after her and so, we started setting it up, yeah so that, everything was there for Elizabeth to enjoy, you know (Edward, page 5, line 19).

Edward was distressed at not being able to look after his partner as her state of health declined. As a result of his accident, he had now become the one who had needed her help. The accident itself was sometimes a source of guilt. It was like the accident was a selfish act:

I was saying you know I don’t feel so bad because I was doing something that I loved and I got hurt, I wasn’t hit by a drunk driver or did something stupid it just happened so I didn’t really feel robbed um, but I didn’t realise Cathy was sitting there going ‘but I feel robbed’ (Carl, page 12, line 9).

A part of the guilt Carl felt as a result of his accident was that his partner had been “forgotten”. Carl said Cathy had felt “underappreciated because the chair’s getting all the sympathy” and only a few friends had inquired into her wellbeing. Cathy agreed with Carl and admitted she “wouldn’t expect anyone to understand” hinting at feeling bitter at not being recognised as also having feelings of loss because of his injury.

Some of the women also shared a sense of guilt regarding the men’s injury; because of the resentment they felt over their altered role, or a feeling that they could have done something to prevent the injury from occurring.
At the accident, I was wheel-barrowing the logs away and stacking them, which is why I wasn’t right close to him (Diana, page 2, line 14).

Here Diana also experienced some guilt associated with the resentment of having to cope with all the consequences of the injury, for herself and for them as a couple. She also commented on the stress she felt after his injury.

But that was all very scary, so I couldn’t put anything else that might stress him on, onto him, so I had to cope with all that, yeah (Diana, page 43, line 28).

Taking on board their partners’ stress was a common theme, as were feelings of obligation towards their partners. Brenda discussed a few of the more challenging aspects of maintaining their relationship such as, “moving him around or cleaning up or whatever”. She talked about their open communication and how she was grateful she could “offload” on her partner if she felt the extra work was too difficult. However, she gave the impression that she felt obliged to do the extra work as the partner of someone who had sustained a SCI.

The men also alluded to not meeting their ‘obligations’ in their role in the relationship. Barry mentions that prior to his accident, he worked and his partner was a “stay at home mum”. He mentioned that he was not a man in charge at work anymore and this appeared to upset him as he recognised he would not be able to contribute financially to the relationship. He also discussed former tasks that he had performed pre-injury such as mowing the lawns, vacuuming and home maintenance and that he felt guilty he would not be able to perform those tasks anymore. Barry continued by saying:

If Brenda has some complications during the pregnancy, can I get her into the car and drive her to the doctors, those sorts of things, I’m also worried about if Brenda has a caesarean or something went wrong …. can I look after the whole household with myself, [his child], Brenda and a new baby, you know, can I cook and clean and keep everything ticking on, ticking over, you know that’s a huge worry (Barry, page 25, line 42).

At this point, Barry cried as he realised how difficult it was going to be for him to continue performing his role and achieve their expectations of that role within their relationship. His frustration over what he felt he would have difficulty achieving is evident. Carl also talked about his diminished capacity to help his partner Cathy with
household tasks during their trips home in the weekend. He talked about his sense of obligation to do his share of the housework and the frustration he felt at being unable to complete all the tasks.

Edward mentioned an occurrence that highlighted his inability to perform tasks he would have normally assumed. The car he and his partner had been driving had developed mechanical problems, Edward tried to give instructions with his partner but had difficulty communicating what needed to be done and this had left him feeling guilty for not being able to physically help her and also frustrated at inability to understand his instructions.

3.5  Loss of autonomy

The participants mentioned that they felt a loss of autonomy during their stay in hospital, both in the acute BSU and occasionally in the TR unit. As discussed in the subordinate themes, a loss of autonomy is generally the direct result of a loss of privacy and dignity, through lack of cohesion and distrust in relationships with health professionals or a restrictive hospital environment.

3.5.1  Lack of cohesion and distrust in relationships with health professionals

The majority of the participants interviewed felt frustrated over what they saw as conflicting information from health professionals, or in some cases, a general lack of knowledge and protocol confusion. Diana voiced her concern: “We’d have one person saying one thing and someone else saying something else and we didn’t know where we were” leading to a loss of autonomy for herself and her partner Darren.

I got very very upset and in the end I said to be honest, I don’t think he’s safe here and I put him in the wheelchair and wheeled him over to the Tapper lodge and I just basically said, to be honest, he’s safer with me in the Tapper lodge, so we went over there (Diana, page 18, line 3).

In short, Diana was so concerned about Darren’s safety that she took him out of the hospital environment and into her own care. This situation arose from a series of situations where the couple had been misinformed and had been given inadequate information about Darren’s care in the TR unit. Eventually a compromise was reached
and the couple were allowed access to a lodge for a week on the condition that, at the end of the week, Darren would attend the TR programme. They were also given assurances that he would have 24 hour care if needed, however, prior to the meeting and subsequent compromise, the situation had caused the couple undue stress for some time during their stay in hospital.

Edward said he had asked four nurses whether he needed to take a particular medication and had received conflicting information from all four.

There doesn’t appear to be anybody, well, doesn’t appear to be, there isn’t anybody monitoring where I’m at, there’s no one person, you know (Edward, page 30, line 32).

This lack of co-ordination caused Edward stress as he felt he had to make decisions about his health that he was unqualified to make. He was also told by health professionals that he “asked for too many people’s opinions” and was confusing himself. His response was that they were the ones who were confused by not synchronising their information and that this, in turn, made him feel concerned about the care he received.

The couples felt that in these situations, the care provided lacked cohesion. Participants were often left to make up their own minds over whose advice was the best and this left them feeling anxious and confused. Andy and his partner Alison mentioned a situation where it was discovered that Andy had a “super bug” and would require isolation. Andy said “no one really knew how to handle the situation” and he said his medical team was “not on the same page”. The couple felt this had caused them unnecessary confusion as they shifted him in and out of different rooms.

Participants also spoke about not receiving information when needed. Edward claimed that he was not told that he was supposed to attend physiotherapy sessions. He “missed out on a week of physio” which made him “really angry” and he felt his long term physical rehabilitation had suffered.

Edward’s partner Elizabeth was so enraged at what she felt was the health professional’s apparent neglect and misunderstanding that she “threatened to write an
induction manual”. Edward felt that “there were times when things just didn’t happen” to the detriment of his care and rehabilitation. Elizabeth felt powerless to help during the times when Edward had received less than adequate care.

Participants frequently spoke about a lack of communication from health professionals. Many felt that in order to elicit information about an injury, they had to be very proactive and often be their own advocate, or their partner’s. There was a concern that a lot of information that couples needed to know was not readily available, or easily accessible.

Yeah I think you definitely have to be your own advocate, it’s something that even the nurses will say to you, if you just accept what they are saying and don’t ask questions and don’t say hey we need to do this and we need to do that, then you won’t get the best care you can possibly get, it’s not until you start asking for it that you get it, and you see a lot of the people the ones that, if you see someone getting a lot more attention than the others because they are being very proactive (Barry, page 53, line 15).

Barry felt that by not asking the right questions, the health and safety of the client was compromised, which was why he and his partner chose to ask questions rather than wait to receive information. Edward said he noticed that the clients who were “nice and polite with their please and thank yous and hadn’t rocked the boat”, had been ignored by health professionals to their detriment. He felt it was important to remember that they were in a “rehab unit, not a hospital” and although difficult, clients had to learn to look after themselves or suffer the consequences.

Elizabeth mentioned a situation where she said that the health professionals had not given her partner pre-procedure drops. She had voiced her concerns only to be told that she was incorrect. Eventually they conceded that her concerns were justified and the problem was rectified. The situation created distrust of the care provided by health professionals. She said she found that the most helpful information came from talking to other clients in the hospital rather than the health professionals.

It’s only when you talking to other people that you can find out where you can get weighed, that you can have doctor’s appointments, what kind of clothes you should buy, all this stuff is actually by osmosis (Elizabeth, page 29, line 43).
“Learning by osmosis” was a phrase Elizabeth used frequently during their interview. Although helpful, she found it frustrating that health professionals were not forthcoming with important information.

At times, the women felt that health professionals did not respect the privacy of their partners, and as a result the men’s dignity was compromised. Brenda spoke of a situation where she felt that a nurse had been insensitive towards Barry and this had made her angry.

There was this one time I came in and a nurse was sort of lecturing Barry about needing to be a bit more positive or something like that, and he was naked on the bed and she hadn’t even covered his groin up and I was furious about that, I was really angry about that, um, um, and it is a bit funny seeing someone do some of the things they do to Barry, but you just have to get used to it, and just go, well, this is the way things are now so yeah (Brenda, page 15, line 10).

Barry, on the other hand, said he was more concerned about his partner feeling uncomfortable. He had accepted indignities as a part of living within a hospital environment and said he would “pick it (his dignity) up on the way out”. This had become his way of coping with situations where his dignity had been compromised by health professionals. Like, Barry, Darren coped with what he perceived to be undignified situations, and invasions of personal privacy by “switching off” and thinking himself to be “somewhere miles away”.

Most interactions with health professionals involved nurses, rather than doctors and there seemed to be a consensus that doctors did not listen and were difficult to engage with.

I think the doctors a lot of the times don’t actually listen, they have so little time that they just walk in, and they will quickly spiel off something, then walk out (Barry, page 16, line 37).

Brenda added that it was to “do with time and money” and that they were “not the only patients there”. Diana made similar comments about the doctors involved with Darren’s care, suggesting it was the doctor’s lack of time that made them inaccessible. Carl felt “ignored” by his doctors, and took it as a personal insult until told by other clients that this was common practice and “not to take it personally”.

One of the biggest issues, the couples felt, was the lack of acknowledgement that the man was part of a couple, or as Diana explained “part of a team”. Excluding the women from important decisions about their partner’s medical care, affected them, they said, in a detrimental way.

Well, I kind of felt I’d missed out on a bit, cause I just got home and said, don’t wake me up, I hadn’t been to sleep for about forty eight hours, don’t wake me up, then [friend] came in with the phone saying oh it’s the doctor, Edward’s just going in to surgery (pause) but it was better that than waiting for a week, yeah (Elizabeth, page 9, line 15).

Elizabeth felt a sense of loss because she was not involved in, what she perceived to be, an important medical decision with regards to her partner Edward. Interestingly, Elizabeth’s sense of loss echoes the loss of autonomy felt by the men when they recognised that the women had been ignored by health professionals. This further illustrates the ‘we’ element of a relationship.

Diana admitted to frustration over the way her partner was treated. With staff constantly changing she would often have to explain to new staff how he preferred to be treated, yet she felt they were often inflexible regarding his care.

You would hit up against a nurse that would tell me to go away and don’t do it, and I’d say but he’s used to, I do it this way, you had all of those frustrations, and they might be nurses that come in for the weekend or something and they got their set way to do it, and they, me as the lay person, haven’t got a clue, you know, I’m silly. Those were the frustrations I had, there was the odd time when I lost it, because basically a nurse or nurses aid would treat me as if I was stupid (Diana, page 45, line 47).

Diana refers regularly to her frustration at being sidelined by health professionals. She felt that without her input, Darren’s health would be compromised. Acknowledging them as a unit was, in her view, imperative.
3.5.2 Privacy and space within a hospital environment

Seeking space to achieve privacy was a concern that many couples had mentioned throughout their stay at Burwood Hospital. Not having the ability to stay together, or finding there were limited places to go for privacy, meant couples suffered from a loss of autonomy. Lodges were often made available for couples with families, but for those without a family, achieving a sense of privacy was difficult. Carl and Cathy mention the difficulty they had in finding private space while maintaining their relationship.

We don’t have a lodge like other people so it’s not that we can escape out for two hours and come back, Carl’s stuck right here so we have to be here and it’s really tough (Cathy, page 7, line 7).

For couples who did not qualify for a lodge, there were very few opportunities for them to “escape” and have some space and privacy together. Feeling entrapped Carl said they “started pushing for car transfers as soon as possible so we could just get out for the afternoon”. Not having their own space caused the couple additional health related problems.

We are kind of attached, so when Carl is not home, I can’t sleep at all and once (Carl) had an accident for the first four months, just got like a few hours a night, maximum, sometimes it’s nothing at all (Cathy, page 4, line 38).

Before Carl’s accident, he and Cathy were rarely apart, so they found it difficult that they had no designated space. Carl said, “you want to be with your partner don’t you so it’s pretty tough seeing them say goodbye every night”. Cathy said, “50% of the time, I walk out crying, I don’t want to go home, don’t want to get out of the car, I don’t want to open the house, it’s very difficult”. The enforced separation from his partner and lack of privacy upset Carl, and they both found it difficult to cope during his time in the BSU. Societal differences stemming from her different cultural background also made the separation difficult for Cathy as she felt very uncomfortable being intimate with Carl in front of others.

Culturally for some people public displays of affection, that just don’t happen, so it’s a bit harder from that respect, I mean, we had a three quarter bed at least, so we could lie down together and watch a movie or something but Cathy
certainly wouldn’t be comfortable doing that with the curtains open, you still get nurses sticking their heads in (Carl, page 8, line 12).

In her home country Cathy said, she was accustomed to a lot more privacy within a hospital setting, and the lack of it here had caused them both a lot of dissatisfaction and anxiety. She alone had lost 12 kilograms as a direct result of the stress she had experienced because of Carl’s accident.

Another couple without children who were unable to use a lodge were Diana and Darren. They found it particularly difficult as winter approached and the outside areas, that had previously provided an opportunity for privacy, became too cold. Diana and Darren felt the lack of space for “couple time”; Diana said, “one of the things I won’t miss, when we’re on the ward, is the lack of privacy, we felt very, um, there was nowhere to go, we used to, in the summer when the weather was nice, we used to disappear into the woods over there or somewhere away”. Here Diana illustrates how the lack of space has an impact on their privacy, and their inability to be together as a couple caused them a loss of autonomy.

Edward was more vocal about the loneliness he felt being in a room on his own during his time in hospital.

Edward: Elizabeth hated it, and it didn’t really bother me at all, in fact, I would rather have it that way than being left alone in my own room, cause as I said, in hindsight, that ten days, I didn't realise it was that long, the fact that I’d spent ten days of my own down there, probably when I think about, was half the reason I was in the mess I was in when I got here, and I was ten days on my own, with a nurse coming and going every once and a while, um, because I’m the sort of guy, if I was in a desert somewhere, I make friends with a lizard or something, would that be right?
Elizabeth: yeah (laughs) or coconuts or something
(Edward and Elizabeth, page 13, line 10).

The loneliness Edward felt was during the times his partner Elizabeth was not with him, which was every second week. Elizabeth wanted more privacy so her preference was for Edward to have a single room. Although Edward preferred a shared room during the times he was without his partner, when they were together, he acknowledged that having a private space for them both was the preferred option.
Although couples with children were more likely to have the use of a lodge throughout the duration of the client’s rehabilitation in hospital, the men were unable to stay in the lodge during their initial admittance into the BSU. The ability to stay in the lodge was only granted by health professionals when they felt the client was medically stable and had achieved a degree of independence. During that initial period, couples mention their struggle to manage the demands of their young families while acknowledging other client’s requirements for privacy and space within the shared rooms of the BSU. For the two couples with young children, sharing a room with others was problematic:

It’s very difficult to keep kids quiet so having a single room; it was much easier for them. You want them around, and they think it’s lovely, but other people don’t think it’s nice to have noisy kids around (Alison, page 2, line 8).

Brenda acknowledged the stress and embarrassment she felt with sharing a room and having her children “playing up”. She felt the other “roommates didn’t want to have to listen to other people’s kids mucking around and opening curtains to have a look through”. She said she was more concerned about her children invading the privacy of others than about her and her partner’s set of problems. Conversely, Diana and Darren were irritated by the lack of privacy within the shared room because of the other roommate’s young children.

We’d come back from gym and find our area was taken over ….. his children had taken over, and Darren’s bed had cardboard up the side and cars parked all over it, and you know, you know what I mean, oh wait a minute, hang on, Darren after gym, he needs to lie down on his bed, he’s absolutely shot (Diana, page 39, line 21).

Both felt that this invasion of privacy had a detrimental effect on Darren’s physical and mental wellbeing as his bed was the only place where he could maintain a sense of privacy. Carl had felt that sharing a room with other clients with a SCI had been “harder on [his partner] Cathy as she was the one who had to deal with it”. Here Carl refers to Cathy’s background, which indicated that she was unaccustomed to sharing a room with others and having no personal privacy and space.

The TR unit offered couples a private room for the last four weeks of their rehabilitation at Burwood Hospital. For the couples with young children, this was not so important as
they also had the use of the lodges. Brenda felt that there was still a lack of privacy in the TR unit, even though they were able to have their own room.

> And then there’s knock knock and open the door straight away, so (laughs) you probably couldn’t really conduct …you know… too much of a relationship over there could you, cause the doors don’t lock, you know, that sort of thing (Brenda, page 9, line 2).

The bedrooms in the TR unit do not appear to offer couples a private and autonomous space, as illustrated by Brenda’s quote. Barry added that the room did not provide a space for their young child, although he said it was “nice not having to be quiet and mindful of roommates or their child being noisy over in the TR unit”. He acknowledged that for couples unable to use the lodges, the TR unit could be very beneficial, as he felt it was for Carl and Cathy.

Carl conceded that having their own room in the TR unit was their first opportunity to be together as a couple. For Cathy, it was an opportunity to get some “much needed sleep”, both felt the TR unit had given them essential privacy and space, away from the constant noise generated in the BSU.

Edward and Elizabeth felt the TR unit had provided an environment that was less clinical and more private than that of the BSU. Elizabeth however felt uncomfortable staying with Edward in his room as she was under the impression she was “not allowed” to stay. It was only towards the end of the four weeks that staff confirmed to her that it was ok.

Unlike the other couples, Diana and Darren found the TR environment stressful. Initially, the environment and lack of perceived support from health professionals caused them to feel “abandoned”. They found that being “locked out” of the lounge area during the weekends was frustrating and confusing, and the lowered bench heights and kitchen utilities were difficult to use for the ambulatory couple. Similar to Elizabeth, Diana initially felt she was “not allowed to stay there anyway” which highlighted the loss of autonomy as a result of perceived hospital rules and regulations. Diana and Elizabeth had both been misinformed regarding the TR programme which stipulated
that bedrooms within the TR unit had been designed with couples in mind, yet both women were unaware of that fact.

Although designed to offer clients more privacy, bathrooms in the TR unit were also shared, as is the case in the BSU. Prior to entering the TR unit, Darren’s shared room in the BSU had been empty and he had the use of his own bathroom. Moving into the TR unit had meant relinquishing his own bathroom and he felt this had affected his personal privacy. Diana was also concerned about the entrance to the TR bathroom which was “off a very public corridor”. Darren admitted to feeling vulnerable both from the lack of privacy the bathroom offered and his concern that it might be occupied by another person when he urgently needed to toilet himself.

The partners of couples without children were required to find separate accommodation (excluding four weeks in the TR unit). Accommodation was available upstairs at the nurses’ hostel on the hospital campus, but the space is not accessible so it does not provide a private space for the couple.

When I was in the hostel, like when he came over and looked at the hostel one day, but he couldn’t like, he had no access to the room, and there’s no where you can actually go and talk, if you happen to be in the dining room and there’s no one else there, you might be able to sit and flick through the paper and have a bit of a chat, but then someone comes wheeling in or something like that, and you weren’t really into going for walks in your wheelchair, or you know, so like we had about two or three months where talking on the phone most probably from home, was most probably the most private (Elizabeth, page 18, line 32).

Elizabeth and Edward also did not have young children so were unable to use the lodge until the latter part of Edward’s rehabilitation. Elizabeth acknowledged the difficulty she had with not having the space to be private with her partner. She said “we had about two or three months where talking on the phone most probably from home, was most probably the most privacy we had”. For Elizabeth, talking on the phone afforded a sense of privacy as it gave her a feeling of control leading to a sense of autonomy.

The lodges had provided couples with a private, autonomous environment. It was the only place within the hospital campus where couples had complete privacy.
Well it is, it’s a place where I can come and relax and nobody’s going to walk past the ward and say ‘oh you’re free.’ right we’ll just discuss this now, bla bla bla, it is a little refuge at times (Barry, page 14, line 26).

Barry’s partner, Brenda, agreed commenting that the lodge had been “fantastic” and was “a great place to hide”. Alison said “It was like having our own apartment”. In my field notes, she stressed that the space was somewhere they could go and “be a family”.

Diana and Darren were offered the use of the lodge a week before Darren was due to start the TR Programme. Diana said that she would “recommend it to any couple, especially someone (with a SCI) who is walking” as it enabled Darren to ambulate in a quiet, safe environment. They both agreed that the lodge had been beneficial for his rehabilitation and her ability to “let go” and stop “mothering him” as he gained more independence.

Apart from the lodges, the hospital environment offered little in the way of a space for clients to go in order to achieve a sense of privacy. For those couples without children who were unable to use a lodge, there was a degree of enforced separation that caused them anxiety and, for some, had repercussions physically. However, when available, the couples had mentioned the benefits of having the space and subsequent privacy offered by the lodges. Couples with children struggled during the acute period when the man was required to stay in the BSU. Not having the space to be a couple caused many to feel frustrated and there appeared to be very few opportunities for couples to explore intimacy due to the lack of privacy and space within the hospital environment.

### 3.6 Transitioning forward

Although participants acknowledged that life was very difficult for them at this stage of their rehabilitation, a sense of hope for the future permeated many of their comments. Moving on and into their own environment was something all couples were looking forward to, underlining the importance they placed on their own personal space and privacy both as individuals and couples.
For some, it was about reaching a level of normality. Barry sums up what many participants alluded to by saying he was looking forward to “getting back to some form of normal life”. “Watching the TV”, “cuddling the cat while having a morning coffee” and “sleeping in” were all mentioned as things people were looking forward to doing. Things that prior to the accident were assumed as normal had become highly anticipated moments. Andy mentioned he was “looking forward to Friday night barbeques with friends to sit and have conversations that do not include anything about SCIs or medical issues”.

Barry spoke of building his “image back up” once he had returned home. He accepted that it “wouldn’t happen straight away and might be a two-year type thing”. However he had an innate sense of hope about his future and admitted looking forward to the birth of his child and other milestones that awaited them as a family. Although Barry admitted to feeling quite depressed about his life in general he felt that once out of hospital, life would improve. His partner Brenda ended by saying “we’ll get there won’t we hon”. They drew strength from knowing they had each other and that, as long as there was open communication between them, their relationship would get them through the difficult times.

The first time Edward had a sense of hope about his future was when he met a vocational consultant at the BSU.

I’m sitting there and I’m saying, what I don’t have is hope, I have no hope at all, and I just didn’t see a future, I saw nothing in front of me that was any good at all, I just was in despair, absolute and utter despair, and the only reason I’m not there now is got to be through Kaleidoscope [vocational rehabilitation firm based at the BSU], through [vocational consultant] (Edward, page 52, line 18).

This sense of purpose appeared to be very important particularly for the men who felt that their position and role within the relationship had changed in a detrimental way since their accidents. Andy, Barry and Edward all retained a sense of hope that their careers would be activated once out of the hospital environment. Having a job, they suggested, gave them a sense of purpose and hope for the future.
Andy and Alison had their own plans for the future, although they were “taking things one day at a time”.

We’ve given ourselves some time to sort stuff out, although Alison does want to get back to part time work pretty quickly (Andy, page 6, line 12).

They were also relieved that Andy’s injury was improving every day, and he was getting stronger and more physically able to achieve tasks. Andy and Alison felt very fortunate compared to others in a similar position, who had less hope for a return to a normal life. Andy’s incomplete break meant that the damage to his spinal cord was minimal, allowing him more movement and the ability to walk.

Perhaps the most coveted element was achieving a sense of privacy. Every couple spoke about their desire for privacy, space and time to be a couple; not living every moment of their lives by someone else’s set of rules. Achieving a sense of autonomy and personal independence, even if that independence came in the form of choosing when to get up in the morning, and choosing when and what to eat, was also important for the couples in this study.

Although it was acknowledged that life would be more challenging, and they would not have the same medical support, every couple mentioned their desire to go home. Coupled with this was the sense of hope the couples shared about their future. It was acknowledged that fear resided in the participant’s perception of how they might cope with living with a SCI. However, their desire to complete their rehabilitation and move forward overran that fear and there was a sense that couples were genuinely looking forward to going home.

Hope for the future was enhanced by the presence of the TR coaches. Transition coaches, all of whom have a SCI and use a wheelchair for mobility, were an integral part of the TR programme and were involved with the participant’s rehabilitation. Both men and women spoke about how helpful they found them to be.

[transition coach] has been showing me how to you know, get off the floor and you know and get into your wheelchair, and do car transfers and things like that, um you know and they are all open and honest, you know, if you ask them a
question, they will tell you the truth, um so yeah, its been really really good (Barry, page 11, line 24).

Barry found the practical advice from the coaches beneficial to his rehabilitation. His partner Brenda explained why the information received was so important for them both.

Someone who’s qualified and has had years of experience can tell you till they are blue in the face this is how you should do it, but until you hear it from someone in a chair, you know, it just seems to make so much more sense, and no matter how much experience they’ve had, they haven’t had the experience of living in a chair so, I just think that’s absolutely fantastic (Brenda, page 11, line 17).

Brenda said that being coached by someone who themselves has had a SCI made the information received relevant and believable. It was also encouraging for them to see others with a similar injury living normal, happy lives. These coaches had given them hope for their own future, especially knowing that it was possible to raise children when one of the partners had a SCI.

Andy and Alison also found the TR coach’s lessons and advice invaluable during their rehabilitation. Andy appreciated the advice given to him by one of the coaches on the benefits of a foam mattress and how to deal with spasms. He found the coaches “inspiring” seeing them living their lives in a happy and fulfilling way, knowing that “a SCI was not the end of the world”, put his “mind at ease”. Additionally, Carl also found the coaches “knowledgeable and helpful”, particularly on various aspects of their injury and agreed that the coaches had been positive role models for both himself and his partner.

### 3.6.1 Intimacy

The couples discussed the impact a SCI had had on their intimate lives. The data also highlighted the many different interpretations of intimacy. From sexual intimacy to the act of sharing a meal together, intimacy encapsulated the unique bond and connection the couples shared with each other. Although the participants expressed feelings of grief and loss of intimacy, many were also positive about aspects of intimacy with their partner post the SCI.
For Darren and Diana, sharing a meal together was their moment of intimacy during the day. It was acknowledged as a time where they could enjoy each other’s company and appreciate the love they shared. The level of openness within the dialogues was encouraging and indicative of their partnership. Couples revealed intimate issues in front of me - a stranger; but also in front of each other.

Yeah just talk, and talk about everything, once you get, if you open up about the thing that you’re most scared of then everything else is pretty easy to talk about, get the big one over and done with then things get a lot easier (Carl, page 22, line 34).

Carl reiterates the point of view that open and honest dialogue with the partner was necessary in maintaining the relationship. When asked about what piece of advice couples would give to others in their position, interestingly, open communication was the one common theme from every interview.

Communication and information were both cited as necessary tools in order to cope with a SCI. For couples wanting to explore the medical issues and subsequent solutions available for pursuing sexual intimacy, a specialised nurse is available at the BSU to provide advice and support. Brenda found this nurse to be “sensitive, honest and open”. Barry said, “it was difficult to shock her”, so they both felt they were able to talk to her about any issue they had, no matter how embarrassing they found it to be. Carl, Barry and Brenda found her easily approachable. Having someone who was personable, they agreed, made the topic of intimacy less stressful and intimidating for the participants. However, it was also evident they needed to be proactive in making enquiries regarding sexual intimacy in order to elicit information.

Many participants also alluded to the importance of sharing space together. Moments where they were able to be with one another were cherished, despite what was often an inhospitable environment. For Elizabeth, who was only able to be with Edward every second week due to home and other commitments, having that time and sharing space was very important to her. She spoke about her frustration when Edward would limit his time with her due to personal medical complications. All she wanted was “to be with him”, especially during the times when they had the use of the lodges which offered
them rare opportunities for privacy and a space to achieve a form of intimacy they both felt comfortable with.

The women’s desire to learn about the injury was one way of showing their partner that they cared and wanted to help. It demonstrated their commitment and for some women, it was their way of displaying their love for their partner. Elizabeth mentioned her frustration over wanting to know everything in order to be able to go home, and know that her partner would be safe.

I’m asking a zillion questions [to the health professionals] and the standard answer is well you’re not home yet (Elizabeth page 43, line 5).

Sharing activities, such as learning about the injury and being actively involved in their partner’s rehabilitation was a subtle form of intimacy for some women. Alternatively, Carl mentioned that he preferred to do everything himself and it was not Cathy’s role to look after him. Although not involved with Carl’s medical care, Cathy preferred to spend as much time with him as she “was allowed” which indicated a loss of autonomy due to her perceptions of hospital rules and regulations, such as evening ‘visiting hours’ that stipulate partners and families must vacate the BSU by 9pm.

During the interview, Carl and Cathy used physical touch in the form of holding hands; putting their arms around each other; or placing a hand on their partner’s leg. A form of intimacy is through physical touch and this was one of the common expressions that the couples shared to demonstrate their closeness. The dyadic interviewing process was an effective method to illustrate couple dynamics. Although not always directly stated in the transcripts, three of the five couples in this study were often in contact with each other showing support and illustrating the intimacy they shared.

For the couples, it appeared to be more important to engage with their partner physically through cuddling or just being close rather than through touch of a sexual nature. Touching in the form of “snuggling”, “hugging” and “kissing” and as one participant put it “some eye-ball-ing” had become their way of expressing intimacy. Brenda spoke of sliding two beds together in their Milner lodge and the joy of being able to “cuddle
and talk”. Both confirmed that this had been beneficial to their relationship. For Barry, spending intimate but not sexual time with his wife Brenda was very important to him, although they were also exploring options for sexual intimacy when the “time was right”.

For all but one couple, sexual intimacy was an issue they were hoping to address at some stage. Andy said he was keen to initiate some form of sexual intimacy with his partner, but they both felt it was not the right time or environment, and that when they got home, things would “fall into place”. Similarly, Carl mentioned his eagerness to address the issue of sexual intimacy, however, although he was exploring his options using various medical techniques, his partner did not see sexual intimacy as a high priority.

Obviously the physical thing’s harder but you know, but that’s what starts the discussion so I guess we try something and it doesn’t work (laugh) and you laugh and you try something else and maybe it might slightly work but not quite and you figure it out and you start talking about it, so, it’s worked itself out (Carl, page 18, line 6).

Carl credited his ability to cope with his impaired sexual functioning as a result of his injury because of his adaptive nature. He goes on to say how travelling and living with other cultures had enhanced his adaptive abilities. His partner Cathy agreed with him.

Barry talked about his attempts to address sexual intimacy while he had medical support available, although he also admitted that physically and psychologically, he was not prepared to prioritise the issue. He also acknowledged that his partner Brenda did not have the energy to address the issue of sexual intimacy and consequently, “did not want to push ‘it’[sexual intimacy with Brenda]”. The consensus from most couples was that intimacy would be explored in depth once the couple had experienced a period of adjustment and were back in their own environment.

For some couples, intimacy had become a celebration of the closeness they shared as a couple and a few felt their intimate lives had actually improved since the accident. Carl said, “a lot more things are open for discussion now than they were, so in a lot of ways
intimacy has improved. We’ve gotten a lot closer”. Diana and Darren also felt that the accident had “brought them closer”.

Darren: cause life is not just sexual you know, there’s more to it, you know, trust, understanding, you know
Diana: I think tolerance too
Darren: tolerating, she likes to talk a lot
Diana: she picked that up dear
Darren: I don’t mind, she compensates for me, I don’t mind it, I just love her to bits … you know so and it’s the other way round too, isn’t it?
Diana: mmm, I love you to bits too
(Darren and Diana, page 34, line 39).

Alison said “if you think you have a good relationship, and you can get through this, it can only make the relationship stronger”. All participants interviewed for this study felt that the SCI, although traumatic, had brought them closer to each other.

Most of the couples felt that the hospital environment had not provided a space where they felt comfortable exploring sexual intimacy. That, and the fact that the participants were not physically ready meant that sexual intimacy had not been fully explored by the couples in this study. Alison, however appreciated the early efforts made by staff to allow her “intimate time” with her husband, moving him over in the bed “to make room for me”. However, she also acknowledged that this did not give them an opportunity for sexual intimacy. Both assumed that sexual intimacy would resume upon returning home.

A few of the couples felt uneasy about cuddling on the hospital bed knowing that even with the curtains drawn, this offered no real privacy. Some couples felt that health professionals were guilty of impinging upon private bed space. Drawing their curtains should have been seen as a sign that they wanted some privacy and space to themselves, but they realised that this privacy was an illusion as the nurses would often “poke their heads in”.

Edward said he felt relieved when one of the nurses gave Elizabeth and him permission to lie on the bed and cuddle. The nurse had opened the curtains to find the couple cuddling and said to them, “Hey guys, that’s fine”. Elizabeth added that this had started a trend with the other couples who, after seeing it was permissible, started cuddling on
their beds too when the opportunity arose. Cathy espoused a different view stating she never felt comfortable displaying intimacy in the shared room space, even with curtains closed. Only in the lodges, or in a private room in the TR unit, did couples without children say that they felt a level of privacy that allowed them intimate time together.

The busy hospital routine gave the couples’ limited time to explore intimacy, especially those with children. Alison said “We also have kids so at the end of the day; we were both buggered and tired”. She said that although the lodges offered family privacy, the space was too small for couple privacy away from the children, restricting their ability to be intimate with each other.

3.7 Summary

When analysing these interviews, to understand more about the couple’s perception of the hospital environment and their experiences relating to intimacy and the maintenance of their relationship, I found the couples talked about themselves as a unit ‘we’ and as partners ‘I’, ‘he/she’ of the unit. They gave and sought affirmation of their narratives within the dyad, providing each other with comfort and support when describing the grief and loss as a consequence of a SCI.

The participants’ lives were substantially changed in a matter of seconds due to a SCI and with this came a sense of guilt and obligation towards their partner as a result of the SCI, especially where the life roles of the partner had changed and would remain so. Rehabilitating post injury in a hospital environment engendered a loss of autonomy for the ‘I’, ‘we’, ‘he/she’. Others controlled decisions regarding the care of the injured men, and the men often mentioned feeling distressed due to their lack of physical control. The women often felt sidelined during this process and couples mentioned the conflict they shared over the care they had received. A lack of privacy and space added to the loss of autonomy as couples struggled with enforced separation and a lack of available space to be together.

Despite this, couples shared an innate sense of hope concerning their future. The couples mentioned their desire to go home and regain a sense of normality. Elements of
hope had come from seeing others, such as the TR coaches who had a SCI, living normal, happy lives. Intimacy in a holistic sense was discussed as important in maintaining a healthy, happy relationship. However, most couples agreed that addressing sexual intimacy would happen once they were in their own home environments. There they would achieve a level of privacy and, have the space and the time to explore it.
Chapter Four

Discussion

In this chapter the four themes are re-examined with specific emphasis on grief and loss, loss of autonomy and intimacy and the maintenance of relationships, and discussed in relation to other literature on the topic. After planning and collecting the data for my own study, I found a paper by DeSanto-Madeya (2006), who published an IPA study of dyads in which one member had a SCI. The similarity in research questions, methodology, and methods mean that the findings of the DeSanto-Madeya (2006) study are particularly important in understanding the wider meaning of the dyadic implications of SCI. Thus, I begin this chapter with a brief summary of the study by DeSanto-Madeya (2006), as I refer to it extensively throughout the remainder of the discussion.

4.1 Summary of DeSanto-Madeya (2006)

One other phenomenological study has explored the dyadic perspectives of people with SCIs and their partner/caregiver. An IPA by DeSanto-Madeya (2006) on the meaning of living with spinal cord injury five to ten years after the injury yielded some interesting results, some of which align with the findings of this research. The study explored the lived experience of an injured person and their family member, either partner or parent. Twenty dyads were interviewed.

DeSanto-Madeya’s (2006) study used dyadic (joint) interviews and explored the lived experience of a person with a SCI from a dyadic perspective. The study by DeSanto-Madeya (2006), however, did not deal exclusively with partners, nor was the focus of the study on the maintenance of relationships and intimacy. Participants included caregivers, such as family members, or the partner of the person with a SCI. The average length of time since the injury was 7.9 years, whereas my study focused on couples during the acute stage of their rehabilitation. Fifteen of the injured participants
were male, the other five were female; all five injured participants from DeSanto-Madeya’s (2006) study were male.

DeSanto-Madeya’s (2006) study appeared robust and well executed, with an in-depth and perceptive analysis of the results that gave the reader a comprehensive insight into the lived experience of a person with a SCI and its impact on the partner or primary caregiver. Two interviews were conducted with the dyads, the first to gain an insight into the experience of living with a SCI, the second to give the injured person and family member the opportunity to reflect and elaborate on issues they felt important.

Although the study had been conducted over a substantive period of time after the initial injury, there appeared to be many similarities in each of the studies. The challenges of living with a SCI did not disappear in the years following the initial injury. Additionally, the dyads still expressed feelings of grief and loss when reflecting on life before the SCI.

One of the similarities with the DeSanto-Madeya (2006) study was the perceived inadequacy of health professionals. The health professionals belief that ‘what works for one, works for all’ had left many people with a SCI, and their families, searching for their own answers. The participants in my study also felt that many health professionals had not managed their care appropriately during their stay in hospital and this had created a loss of autonomy.

Dyads from the DeSanto-Madeya (2006) study who were in an intimate relationship did discuss the change in roles. For some, there had been a shift from wife to caregiver, and this had caused increased stress within the relationship. Couples in my study discussed their concerns about this particular role change and were actively trying to avoid this shift in perception within their relationship. Perhaps one of the more meaningful findings from the DeSanto-Madeya (2006) study was that the couples interviewed felt they had ‘grown closer’ to their partner since the SCI.
4.2 Grief and loss

Having a SCI is one of the most devastating injuries that an individual can experience (Dickson et al., 2011; Sullivan, 1990). It affects every aspect of a person’s life, physically and psycho-socially and was a strong theme in the data. Of the theories of grief and loss, the one that resonated most with my personal experience and participant description was a stage-of-adjustment theory proposed by Vocaturo (2009). It outlines the five stages most people experience when grieving: denial, anger, bargaining, depression and acceptance. ‘Denial’ in relation to SCI is hope of recovery and a return to premorbid functioning; ‘anger’ is an increased awareness and external expression of emotion; ‘bargaining’ is a hope of improvement, and ‘depression’ is uncertainty about the future and a sense of being defeated. Lastly, ‘acceptance’ is a willingness to do things differently.

The couples interviewed for my study all exhibited one or more of these behaviours. Of interest is that the women, who did not have a SCI, also experienced feelings of grief and loss comparable to those of their partners. Together they shared feelings of grief and loss as a consequence of his injury. Couples in my study discussed feelings of anger, depression and acceptance. The other stages of denial and bargaining were not as evident, possibly because the couples were interviewed together. These may have resonated with individuals personally, but they were not something that the dyad discussed with me. The couples’ anger was predominantly directed towards what several believed was a rigid and often disempowering hospital environment. Many couples were angry at being supplied with what they saw as the wrong information, ill-timed information, no information at all, or when health professionals had behaved disrespectfully towards them both as individuals and as a couple.

Although the theory of adjustment stages (Vocaturo, 2009) serves as a broad basis for understanding the grief process, the progression towards recovery and adaptation is not always a linear one. One can move from one stage to another and back again, depending on the individual (Jackson & Hough, 2005). Being in a coupled relationship offers people with a SCI an added level of support that may aid the adjustment process (Gilad, Lavee, & Innes-Kenig, 2009; Kalpakjian et al., 2011; Sand, Karlberg, & Kreuter, 2006; Urey & Henggeler, 1987). However, as is evident from other SCI literature, it would not
be uncommon for participants to revisit other stages individually as they progressed through their lives and encountered situations and environments that might challenge their attitudes and beliefs. One study suggests that it is not until they are out of a hospital environment that people fully realise the extent of the limitations imposed by their injury. The psychological distress that results occurs primarily within three to five years of the injury (DeSanto-Madeya, 2006).

Other qualitative studies indicate that the stages are consistent for anyone who has sustained this type of injury. An IPA study by Dickson et al. (2010) demonstrated that the partner also experiences many of the stages of adjustment, although bargaining was not a feature of it.

The change in role from partner to caregiver is likely to affect the dynamics of the couples’ relationship. ‘Caregiver burden’, ‘burnout’ and ‘caregiver fatigue’ are some of the terms used to describe the effect that a role change can have on the person who is now the caregiver (DeSanto-Madeya, 2009; Dickson et al., 2010). Depression, stress and anxiety have all been cited as outcomes when a partner takes on the caregiver role (Dickson et al., 2010). A high proportion of ‘caregiver’ partners also tend to ignore or neglect their own health problems and needs (Weitzenkamp et al., 1997). Although the couples in this study had not taken on the role of full-time caregiver, a few partners hinted that they would be doing so out of the hospital environment. The women spoke of their worries about the change from partner role to mothering role, their anxiety about their increased workload and the accompanying stress that the role of caregiver entails.

In addition to the distress caused by role changes within the relationship, research also suggests that the partners of those with a SCI may experience added stress due to financial hardship resulting from the loss of the wage-earner (Karana-Zebari et al., 2011; Urey & Henggeler, 1987). In my study, the men in four of the five couples were the primary earners, and some of the women were concerned that a reduced income would have a detrimental impact on their families.

In conjunction with the grief from role changes within the relationship and potential financial hardship as a result of the SCI, physical loss was an issue that all male
participants discussed at length, including the shift towards a negative perception of their bodies. Rembis (2010) discusses the phenomenon of the disabled body no longer being the injured person’s own, but it is constrained by well-meaning, but often misguided, healthcare professionals, family, friends, caregivers and politicians. In the case of the participants in this study, there is a sense that the injured partner feels their body is no longer their own but it has become an integral part of the medical environment. This feeling of having a lack of control over one’s body caused these individuals to feel disempowered and vulnerable.

4.3 Loss of autonomy

Many of the issues pertaining to the grief and psychological stress suffered by the participants in this study arose because of conflicting expectations of care. Often clients’ expectations were different to those of the health professionals involved with their care. This caused conflict that, in turn, gave the clients a feeling of a loss of autonomy. This corresponds to findings by DeSanto-Madeya (2006) who suggest that although nursing and rehabilitation is based around a holistic model that encompasses the medical, psychological and social aspects of care, the clients and their families did not feel they had received holistic care. A package based on homogenised care and a ‘one size suits all’ approach does not seem to work for the majority of individuals who spend time within the hospital system. Couples in my study appeared to be in conflict with the system a lot of the time as it was not meeting their needs and was causing them stress. The fact that clients are ‘assigned’ staff rather than being able to work with staff that they have built a rapport with diminishes their autonomy (Hammell, 2007).

Participants in my study also felt angry that there was little recognition of them as a couple. Partner support and the ability to create a sense of well-being for each other has been found to be more important and efficient than any other support, including that of friends, siblings and parents (Gilad et al., 2009). Yet within a hospital environment, there appears to be little recognition of the partner. Fostering a healthy and balanced relationship appears to be of little concern to health professionals whose attention is focused on the individual with the injury (DeSanto-Madeya, 2009; Ell, 1996; Steinglass, Temple, Lisman, & Reiss, 1982). To combat this, it is recommended that health
professionals view both members of the pair as a unit rather than as separate entities (Chan, 2000; DeSanto-Madeya, 2009; Rosengarten, 2005).

All of the women in my study admitted to feeling sidelined by the health professionals responsible for their partner’s care, and there appeared to be little or no attempt to look at how they were coping with an injured partner. A few of the women felt marginalised by the health professionals, who seemed to regard their care of their partner as obstructive and superfluous. This lack of acknowledgement of the couple’s partnership caused significant anxiety and stress. Steinglass et al. (1982) noted that this lack of acknowledgment led to the unaffected partner feeling frustrated and isolated. In some situations this generated feelings of resentment towards the injured partner. My study does not support Steinglass’s findings, although one participant spoke of her feelings of frustration over the attention her partner received. For the most part, the lack of acknowledgement of the partnership of the couple by health professionals appeared to prompt a stronger bond between the couples.

Couples are generally treated as separate entities throughout the injured person’s stay in hospital, but once he or she is discharged the partner is often expected to become responsible for their ongoing care and rehabilitation (Hammell, 1994). All couples in my study wanted to return to their home environments, but were worried about the loss of specialised medical support. As a result, the withdrawal of specialised care can cause the partner of the injured person psychological distress (Hammell, 1994).

To combat this distress, Dickson et al. (2010) suggests that partners should be more actively consulted by health professionals about their injured partner’s rehabilitation prior to discharge. This would both ease the anxiety experienced by the partner of the injured person regarding their partner’s care once discharged from hospital and acknowledge them as a couple.

In addition to feeling marginalised by health professionals, the care provided by health professionals would often leave couples feeling disempowered. There were many situations, they said, where health professionals had either not provided the right kind of information, or enough information, or the wrong information, or had provided care that had left the client and their partner feeling distressed. However, although there were
many situations where the care provided appeared to be inadequate, couples were able to identify health professionals that had helped them feel they were at the centre of care, and the couples appreciated this. A meta-synthesis of qualitative findings by Hammell (2007) also found that when the staff of a spinal rehabilitation unit worked in partnership with clients, communicated respect and encouraged independent thought and behaviour, clients reported a better sense of overall wellbeing.

Sand et al. (2006) explored an individual with SCIs’ experience of hospital care, their rehabilitation and life post-injury. Using a qualitative phenomenological methodology, 19 participants with SCI were interviewed. Sixteen of the participants were men and three were female; ten were single and nine had partners. The study appeared to be well executed, although no limitations were mentioned and there was little detail regarding the methods used to elicit the information. Although qualitative in-depth interviews were used, there was no mention of employing the specific principles of a chosen methodology, such as phenomenology. The study recruited participants from three spinal units in Sweden.

Sand et al’s (2006) findings suggested that the majority of the participants felt a loss of autonomy because of the hospital environment and the care from health professionals. As a result, they experienced difficulty with adjustment post-discharge. Sand et al’s (2006) recommendations included practising client-centred care to address the many problems that clients alluded to during their rehabilitative care.

Leino-Kilpi et al. (2001) suggest that autonomy can be salvaged through small gestures, such as a nurse asking permission to enter a client’s room. Couples in this study spoke of their irritation at the fact that health professionals often did not knock or ask before opening curtains. This further reinforced the feeling that the couple had no privacy and nowhere to go to achieve it within the confines of the hospital environment. During the initial stage when the injured partner had very limited mobility, the space within the shared room was often all the couple had for privacy and many mentioned their struggle with this.

Another issue that brought about a loss of autonomy was a lack of privacy. Parrott et al. (1989) note that privacy within a medical context has four dimensions: physical, social,
informational and psychological. The physical dimension relates to personal space and the immediate area or ‘territory’ around the individual. Leino-Kilpi et al. (2001) suggest that when physical space is adversely affected, clients often become submissive and withdrawn. When physical space was compromised, clients in my study spoke about feeling ‘trapped’, which left them feeling frustrated. Physical privacy appeared to be the biggest problem couples had with living in the hospital as it had a direct impact on their personal autonomy and freedom to be a couple.

Social privacy includes the individual’s ability to control social contacts. In the context of health care, social privacy can be the degree to which there is a sharing of personal data between the client and health professional, and how health professionals perceive personal displays of affection (Leino-Kilpi et al., 2001). Although there were situations in the BSU where a particular nurse would acknowledge the couples’ need for intimacy through touching, couples in my study suggested they did not feel comfortable openly displaying their affection towards each other because of the perceived rules regarding what was appropriate behaviour within a medicalised environment. Shared rooms, curtains as walls, an absence of locks and unrestricted access for health professionals to most areas within the hospital suggested a low degree of social privacy at the BSU. In addition, although clients generally prefer a degree of formality between themselves and their physician, the couples in this study said they felt insignificant and often “rushed through” by physicians who appeared to have a detached demeanour towards them.

Informational privacy (Leino-Kilpi et al., 2001) relates to personal information held by health professionals which ideally should be held in a secure and confidential manner. This issue did not concern the participants of this study. The fourth dimension is psychological privacy, which concerns the ability of clients to control with whom, and under what circumstances, they will share thoughts or reveal information. In this study, psychological privacy refers to the extent to which clients felt able to express themselves to their partner and others, especially concerning their intimate needs.

Parrott et al. (1989) go on to suggest that privacy and personal space are essential to the provision of individualised client-centred and ethical care. Without these elements people who have had a SCI and their partners reported feeling disempowered and stressed (Leino-Kilpi et al., 2001; Parrott et al., 1989). Although hospitals claim to be
holistic in nature, the Western hospital environment is often seen as being paternalistic, applying a rigid medical model approach to the care of its clients (Sinnott, 2008). Unfortunately, this approach does not encourage an environment that values client-centred care, and does not provide privacy for individuals, their families and partners (Lemonidou et al., 2003).

According to Friedlander (1982) the privacy of an individual is intruded upon in many ways within a hospital, and involves a loss of personal space and environmental privacy. Decreasing an individual’s privacy and dignity has a direct and detrimental effect on his or her autonomy. Friedlander (1982) argues that clients are told to help themselves in order to recover, yet most of the hospital’s actions are directed at doing just the opposite. This reduces their ability to think or act for themselves by decreasing their autonomy.

A lack of personal privacy and dignity was seen by the men in my study as being a reality of living within the hospital environment, one they had come to accept or cope with. Situations that might otherwise have been embarrassing or undignified became manageable as the men accepted the reality of a loss of privacy. The men acknowledged however, that they did feel vulnerable when their personal privacy was compromised. Interestingly, it was often the women who felt upset over their partner’s loss of personal privacy and subsequent lack of dignity.

Diminished personal privacy as an inevitable outcome of living in a hospital environment is a phenomenon discussed by Schuster (1976). In a phenomenological analysis of ‘privacy, the patient and hospitalisation’, Schuster notes that clients showed a sense of camaraderie. This meant that when privacy was compromised, the sense that everyone was going through the same experience made it bearable, and normalised undignified situations.

This lack of privacy, resulting in a loss of autonomy, led many in this study to liken their stay in hospital to that of being in ‘prison’, (another use of the jail terminology that is often used throughout the transcripts by both men and women). Hammell (2007) comments that clients describe the spinal rehabilitation facility as a restrictive environment, ‘like being in a jail’, and that the demands of an institutional bureaucracy
take precedence over the differing needs of clients. This issue resonated with most of the participants in this study, both individually and as couples.

The couples in my study also spoke about a need to ‘escape’ from the hospital environment, and their need to spend time together away from the hospital ward. In this respect, the couples found the BSU lodges extremely helpful. For couples who did not have young children and did not qualify for a lodge, there was an unmet need for a space to themselves and a feeling that their need for privacy as a couple had not been recognised. This caused them stress and anxiety, and for one couple it meant that the partner without the injury suffered from severe sleep deprivation as she felt she was not allowed to spend the night with him during most of his time in hospital.

In addition to the lodges, the TR unit provided couples with their own private rooms during the last four weeks of their stay in hospital. Although the bedrooms in the TR unit offered couples more privacy than the multi-rooms in the BSU, it appeared that health professionals still perceived the rooms to be part of the ‘hospital territory’, consequently, would often enter without the clients permission. Despite the lack of privacy and consequently, loss of autonomy, clients were grateful for the space, especially the couples who had not qualified for a lodge. However, for most of the time couples were expected to seek alternative accommodation separate to that of their injured partner.

Not being able to be with their partner caused many of the couples in this study stress. Enforced separation at a time when support was needed most was one of the biggest problems couples mentioned regarding the immediate impact of a SCI. This corresponds with another study done by Meade, Taylor, Kreutzer, Marwitz, and Thomas (2004). Using a 40 item self report questionnaire (Family Needs Questionnaire) with seventeen family members of people with a recent SCI, Meade et al. (2004) reported that being able to stay with the injured person whenever desired was rated as one of the most important issues for family members.
4.4 Relationship maintenance and intimacy

My observation is that most of the research on SCIs and relationships tends to measure and document issues that focus on grief and loss and yet little is known about maintaining relationships. In the course of my study I found that the couples talked about three main ways in maintaining their relationship; these were support, intimacy, and sexual expression.

A key finding of my study was that couples are a unit and that what affects one partner has an effect on the other. This is true even if the ‘object’ of care is the body of the person with SCI, or the non-injured person is not present. Historically, research and practice has concentrated on the individual with the medical condition or injury (Beauregard & Noreau, 2010). Accommodating and acknowledging the importance of the family and partner support system is a crucial part of the client’s well being, and that of their support structures (Beauregard & Noreau, 2010).

Performing dyadic interviews provided couples with extra support. This was particularly helpful when the topic of discussion was sensitive and could provoke strong emotional responses from the individuals. In situations where participants expressed feelings about personal loss or talked about sensitive issues associated with intimacy, having a partner available for support was invaluable. Using dyadic interviews with phenomenological research is an appropriate method of gathering information, particularly when the couple experience is the topic of interest, as it was with my study (Racher, 2003).

Coyne and Smith (1991) identified three areas where partners of ill or disabled people provide support – *active engagement*, which involves the disabled partner in discussions and uses other constructive problem-solving methods; *protective buffering*, which consists of behaviours such as concealing information, hiding concerns and yielding to the affected partner to avoid disagreement, and *overprotection*, in which the unaffected partner actively restricts activities, underestimating what the afflicted partner can achieve by providing unnecessary assistance.
All five couples in this study appeared to practise active engagement for most of the time they were together. In times of high stress, one of the older couples displayed behaviour of an overprotective nature. This particular couple had been together for fifty years and had already experienced a serious illness. Because of this, she had adopted a mothering role towards him and his accident had simply reinforced that role.

The support couples had for one another appeared to be substantive and helped to maintain their relationships. In conjunction with this support, open communication between them reflected the closeness and the respect they felt for one another, along with a sense of unity that further reinforced their relationship. Interestingly, none of the couples interviewed for my study displayed any ill feelings towards the other partner. All dialogue exchanged was met with approval by the other participant. Occasionally, a situation would arise where the participant challenged their partner’s recall of an event but this would be for clarification purposes rather than opposition to what was being said.

All ten participants in this study agreed that communication was the most important element of a healthy relationship. They credited their skills in communication to the healthy state of that relationship, despite the stress associated with a traumatic injury. Other research exploring key contributions to the survival of relationships in stressful situations has found open communication and honesty to be essential to maintaining a relationship through adversity (Beauregard & Noreau, 2010; Esmail et al., 2001; Esmail et al., 2010; Kreuter et al., 1996; Narum & Rodolfa, 1984).

My study explored the dyadic perspective of a couple where one had sustained a SCI and examined the support from the partner of a person with a SCI. Consequently, it was of interest to compare other phenomenological studies that explored the perspective of the partner. As discussed previously in the literature review (Chapter 1), Dickson et al. (2010) IPA study explored the primary caregiver role which found that the uninjured partner felt closer to their partner after a SCI. Similarly, Vargo’s (1983) phenomenological study (see Chapter 1) which explored how the wives of ten men with SCIs adapted to their disabilities, found that the participants viewed their experience as a time of emotional growth.
This corresponds to the experience of a few of the couples in my study who felt that their intimate lives had actually improved since the accident. They had achieved a level of openness not experienced before and felt closer to their partners as a result. For one older couple, intimacy described a close bond, which, in this case, is not necessarily sexual, but will still be classified as intimate. Sharing a meal together, for example, was this particular couple’s way of expressing their love for each other. Examples such as Dickson et al’s (2010) study, Vargo’s (1983) study and the finding from my study negate the prevailing idea that a SCI has a detrimental impact on a relationship (North, 1999).

The term intimacy covers a plethora of interpretations and meanings for individuals and couples. The term sexuality has many meanings and interpretations. Esmail et al. (2001) divide sexuality into five components: sensuality, which relates to body awareness and exploration of the five senses; intimacy, which is the need to experience reciprocal emotional closeness with another human being; sexual identity, which is a continual process of discovering who we are in terms of our sexuality; and sexualisation which describes our use of sexuality to influence, control and manipulate others. All five components are important to a person with a SCI as they encapsulate the holistic nature of their sexuality. For the purpose of this theme, sexual intimacy is a broad term that encapsulates the five components mentioned above.

It is only recently that intimacy has been included as an important element in the rehabilitation of those with a SCI (Fisher et al, 2002). Sexual rehabilitation has primarily focussed on penile functioning and fertility issues, predominantly in men (Sakellariou, 2006). Interpreting intimacy from a holistic perspective is a relatively new phenomenon in spinal units throughout the world (Esmail et al., 2001; Fronèk et al., 2005; Kendall et al., 2003). Although recognised as important, many hospitals still choose to ignore or downplay the significance of intimacy and sexuality. Subsequently, many couples report feeling that their intimacy concerns during their time in hospital are neglected (Beauregard & Noreau, 2010). Only within the past four years has the BSU appointed a sexuality nurse to educate clients about intimacy after a SCI.

Although the focus of sexual rehabilitation has been on the mechanics of sex rather than the process of regaining closeness and intimacy, at the BSU the Clinical Nurse
Specialist does attempt to approach the topic of intimacy holistically. Sexual function may be impaired physically, but research shows that people with a SCI are able to engage meaningfully with their partners on a psychological rather than a physical level (Esmail et al., 2010; Rembis, 2010). Understanding this can be beneficial to the maintenance of an intimate relationship for people who are physically impaired to the point where they have little or no sensation or sexual functioning.

Some participants were eager to explore medical solutions to their sexual problems. Narum and Rodolfa (1984) suggest, however, that where there has been a loss of sexual function, people might benefit from knowing that a fulfilling sexual intimacy can be achieved by other methods. They suggest concentrating on sensations from parts of their bodies not affected by paralysis, and focusing on fantasy and erotic imagery in order to experience sexual arousal and response. In addition to that, medication is available which may also aid sexual function (Van den Heuvel, 2011).

A few of the women had concerns about the role changes that had occurred as a result of the injury. Research suggests that women who take on the role of caregiver can find it difficult to return to pre-injury levels of sexual intimacy (Beauregard & Noreau, 2010; DeSanto-Madeya, 2009; Dickson et al., 2010; Esmail et al., 2001; Esmail et al., 2010).

During the acute rehabilitation stage, couples in this study were intimate in a less sexualised manner. Snuggling, hugging, kissing, and, as one participant put it, some eye-ballng, had become their way of expressing intimacy. The psychological element of feeling close to another human being appeared to offer the couples a sense of well-being. For those with impaired sexual function, achieving intimacy through psychological means may offer a sense of satisfaction for the individual and, subsequently, the couple. Achieving intimacy this way is said to be a good starting point for couples who may need to change the way they express themselves sexually when one partner has a SCI (Rembis, 2010).

A longitudinal study by Fisher et al. (2002) found that newly injured individuals are not ready to address sexual issues during the inpatient rehabilitation period. The reason for this is that most individuals do not have much interest in sexual activity in the first months after a SCI. The interval between inpatient rehabilitation and six months post-
discharge appeared to be the most desirable period for addressing intimacy issues. The study used a small sample of 40 participants and was a longitudinal study analysing the survey responses of people with a SCI at four intervals between inpatient rehabilitation and eighteen months post-discharge.

Couples in my study suggested that being psychologically ready was an important component of their ability to engage in intimacy of a sexual nature. They referred to power imbalances between themselves and the health professionals, and to feeling overwhelmed and having little privacy. They observed that rehabilitation concentrated on developing the physical capabilities of a SCI. Couples spoke of the stress of having little or no acknowledgement of being a part of a dyad, a complicated and delicate system that required constant maintenance in order to function.

Addressing sexual intimacy during the acute rehabilitation stage was not a high priority for most of the couples in this study, but being together as a couple was. Various reasons were given by couples in this study for the difficulties faced in achieving their desire to be together, such as a restrictive environment, a lack of cohesion and distrust in health professionals and their own psychological and physical barriers. Neglecting intimacy, even in its altered form, meant neglecting an important component of what it meant to be a couple.

I have two interpretations about readiness to address sexual intimacy concerns in the acute SCI rehabilitation environment. First, that some couples were not ready/able to address intimacy and relationship maintenance during rehabilitation within a hospital environment for a number of reasons such as: maximising physical independence, limited energy, stimulus overload, being emotionally overwhelmed and grieving for what has changed and what has been lost. It may be that adjustment to changes in the relationship takes longer than the initial acute rehabilitation period and may not be addressed until the couple is back in their own environment.

Alternatively, couples could address sexual intimacy issues during the acute rehabilitation period if they were not in a disempowering environment where there is little acknowledgment of them as a couple. Other requirements such as the provision of privacy, having space, the right information, nurturing and empathetic care from health
professionals and the time to address intimacy needs are also important in providing couples with what are important elements necessary in order to address sexual intimacy needs during the acute rehabilitation process.

In suggesting these two interpretations, I acknowledge that every couple is unique and will have different needs so there will be couples who fit into the first category and some who fit into the second. However, even with the best possible care provided within a nurturing environment sympathetic to the needs of a couple, some couples may simply need more time before addressing intimacy. For these couples, an outreach clinic or specifically designed programme during reassessment may be better suited to their needs.

Perhaps the most surprising outcome from this research was a challenge to my assumption that the main problem that couples faced in exploring sexual intimacy in hospital was lack of space, privacy and relevant information. After interviewing the five couples, it appeared that in addition to space and privacy and information, the lack of time and emotional readiness was just as important. The prevailing message from participants was that although they appreciated the technical knowledge given to them by health professionals, they would feel more comfortable exploring sexual intimacy in their own environment, and that the hospital did not provide the right elements of privacy, space and time. Many couples indicated that they were eager to learn how intimacy might be achieved when they did have the time and space, and were emotionally ready to explore it.
Chapter Five
Conclusions and Recommendations

5.1 Preface to conclusions and recommendations – reflexive statement

In this section I consider how I have influenced the research question, research process and interpretation of the data. Unlike Husserlian phenomenology (Giorigi & Giorigi, 2008) IPA encourages the researcher to reflect on their positioning within the research. As someone who shares a SCI with half of my participants, I felt I could not be totally objective and bracket my own experiences from the research. Although IPA involves a double hermeneutic whereby the researcher is making sense of the participant who is making sense of the phenomenon, I was acutely aware of not imposing my own set of beliefs and judgements on any interpretation of the data.

I work at the BSU site and my interest in the topic of this study arose from conversations I had had with people with SCIs and their partners. I use a wheelchair for mobility and am occasionally asked to counsel BSU clients with SCIs and their partners. As a volunteer youth counsellor, I have training and experience teaching and counselling people about sexuality and intimacy, consequently, I feel at ease discussing issues of a sensitive nature with people because of my experience as a counsellor. In addition, because of my training, I feel I am able to offer my skills as a counsellor and also utilise my knowledge base regarding intimacy and sexuality concerns.

Sixteen years ago, when I sustained my SCI, the issues of intimacy and sexuality were not discussed and feelings of confusion and a desperate desire for information were the result. Unfortunately information was not readily available at that time. As a result of my experience, I can empathise with others who have a SCI and their families. I am also acutely aware of the paucity of information available with regards to SCI and intimacy. Much of the research I have encountered regarding intimacy and relationship maintenance does not reflect the affirming attributes that a SCI may have on the person...
and their partner/family, thus reinforcing the common perception that a SCI has a global detrimental impact on the person and their partner/family.

I have been influenced by the philosophy of Kaupapa Māori research. One of the main focus of a Kaupapa Māori approach to research is the operationalisation of self-determination (tino Rangatiratanga) by Māori people (Bishop, 1999). The approach challenges the dominance of traditional individualistic research which primarily benefits the researcher and their agenda. In contrast, Kaupapa Māori research is collectivist and seeks to benefit the research participants through involving Maori in every element of the research process (Bishop, 1999). I feel the principles from Kaupapa Māori research should be applied to research involving SCI.

Before undertaking this research, my supervisors advised me to reflect on my beliefs around intimacy and relationship maintenance, with particular relevance to my personal experiences and what, I believed, were the reasons why clients I spoke to struggled with intimacy concerns. I did this by confidentially journaling my responses to a number of questions they asked me. On reflection, many of my assumptions did not match what the participants in this study said. I had assumed intimacy concerns were not being addressed due to the BSU environment and the guardedness of the health professionals. However, what I have learnt from the data, is that grief and a loss of autonomy is the main issue that clients’ face.

Vocaturo’s stage of adjustment theory (4.2), discusses the stages of adjustment people with SCI go through after their injury and I found that the theory resonated with my experience as someone with a SCI. The stages also compliment the findings from this study and are aligned with the results.

Coping with change and a lack of energy often caused clients to reprioritise their concerns. Addressing intimacy, although still important, was something they felt would happen when they had the time, energy and resources available to them. Couples spoke about needing privacy and a secure safe space before being able to engage in any form of sexual intimacy.
My concerns prior to the interviewing process included a fear of my own emotional fragility and my empathy with the couple, particularly the person with the SCI. I was concerned that my distress would add to their distress, however, on the few occasions when I too was brought to tears during the interviews, this had not upset the participants. On the contrary, I had felt a stronger bond with my participants and they appreciated my genuine empathy with them and shared this once the interviews had concluded and the dictaphone had been turned off.

Couples mentioned that they had felt comfortable that the interviewer shared the same injury, and consequently rapport was established almost immediately after introductions had taken place. A few participants thought that I too was a client of the hospital, as opposed to being a researcher, and because of that they felt able to express themselves honestly. However, a bias in the data may also have been created as participants might have felt inclined to tell me what they thought I wanted to hear as someone with a SCI and not what they truly felt.

On reflection I feel that choosing an IPA methodology that encouraged my interpretation of the data without placing bias upon it, has served to enhance the credibility of this study. The sense I am left with, from talking to these five couples is that the rehabilitation process is imbued with a loss of autonomy for those it is supposed to empower and help towards independent living. Consequently, the rehabilitation environment may never be perceived by many clients with SCIs, or their partners, as a safe place for sexual expression and intimacy.

5.2 Limits to the transferability of findings

IPA is idiographic in that its participants represent a perspective rather than a population and the methodology doesn’t assume to give findings that are necessarily transferable (Smith et al., 2009). I recruited a homogeneous sample comprising of five men with SCI who were all married to their partners who were women. Results from the transcripts suggest the relationships used in this study were stable and appeared robust in spite of one partner having sustained a SCI.
I wondered, however, what the results might have been had a couple overtly experiencing relationship difficulties been interviewed, or if the person with the SCI had been a woman, or the couple had been of the same sex. It might have been difficult to recruit a couple with existing relationship difficulties due to the dyadic nature of the interviews as such couples might be less inclined to participate with their partners. I suggest that more research be done with different groups as it would be interesting to note whether the results of this study are representative of couples where the partner is male, married and heterosexual, or whether a wider range of demographics would produce similar results.

5.3 Recommendations

All couples criticised the lack of recognition of their status as a couple by health professionals. The women often felt marginalised and, in some cases, an inconvenience to the health professionals. Exclusion of the women when making important medical decisions during the injured partner’s journey through the hospital system, served to create disharmony and suspicion in the women. These encounters created distrust in the relationship with health professionals that participants had difficulty in overcoming.

Thus recognition that the individual who has sustained the injury may have a partner and may view that partner as an integral part of themselves, needs to be embedded within the construct of care for health professionals. Health professionals would ideally communicate with the couple rather than just the person with the SCI whenever the partners are present. This should be the default position and change only at the request of the couple. At the request of the couple, it may also be beneficial to include the partner of the person with the SCI in the rehabilitation plan. However some couples, be it the person with the SCI or their partner, may prefer to retain their individual status so health professionals must approach the issue on a case-by-case basis.

The BSU attempts to practise a client-centred approach but discussions with the participants in this study suggest this is not how the couples experience care. Clients often felt disempowered because of what they perceived to be inadequate care provided by health professionals. Couples spoke of a hierarchy within the hospital culture which
placed them at the bottom. Practising truly client-centred care may help reduce the loss of autonomy clients feel during their time in hospital. Hammell (2006) suggests that client-centred practice is when health professionals work in collaboration with their clients; understand the link between control and confidence and therefore strive to enable clients to make choices and to be in control of their decisions and lives. Health professionals are neither judgemental nor authoritarian and it is the goals of the clients that are important, not others imposed goals. Much of that loss is due to the actions of the majority of health professionals, which according to the participants of this study, do not practice client-centred care.

Client-centred care also encapsulates a more holistic approach to issues such as intimacy and relationship maintenance. Intimacy in the case of a SCI focuses predominantly on sexual functioning issues and fertility, and does not include other factors, such as the grief and loss associated with being in an intimate relationship. Little thought appears to have been given to the reasons why most couples do not feel ready to explore intimacy during their time in hospital. It is encouraging to note that the BSU has a clinical nurse specialist whom couples feel is accessible and approachable. It is also encouraging to see that the P-LI-SS-IT model has been implemented throughout the unit. However, to truly acknowledge the importance of intimacy in a couples’ life, there needs to be a marriage of appropriate support and information, and a space where couples have the privacy to address their need for intimacy.

A lack of space and privacy was mentioned by all participants as one of the biggest problems they faced during their time in hospital. When couples were unable to go outside, they complained that there was nowhere to ‘escape to’ for privacy. The lodges were a sanctuary for the couples with families that were qualified to use one but only two of the five couples had access to a lodge. Couples mentioned the benefits of having their own rooms in the TR unit, but, these were only available during the last four weeks of their stay. Depending upon the severity of the SCI, this could involve up to 26 weeks in hospital. One solution might be to increase the number of lodges so that couples without families might also have the opportunity to utilise them, additionally, having a private room instead of large open rooms shared with three other clients is another option.
Other clients may decide that they want to address their intimacy needs once they have returned to their home environment. To cater for these couples I recommend an ‘outreach’ programme focussing on intimacy and relationship maintenance be available to couples six months after discharge from the BSU. The programme would incorporate intimacy in its holistic form and be run by health professionals, including a therapist with skills in facilitating family relationships and intimacy. Fisher et al (2002) for example recommends that clients with a SCI and their partners are ready to address these needs six months after the injury. Therefore a suitable time to address intimacy and relationship maintenance issues could be when the couples return to the BSU for their six-month reassessment. A dedicated programme to address such needs would be of benefit to couples who indicate that they are interested. Further research is recommended with couples regarding this issue.

A surprising outcome of this study was the therapeutic benefits of the interview process itself. All couples said how helpful it had been talking to someone about their relationship. They spoke of the benefits of clarifying issues even though there was little dialogue with the interviewer. All couples mentioned feeling closer to their partners after the interview which suggests that discussions with a third party may be therapeutic. Although the BSU clinical psychologist offers counselling, couples may feel more comfortable talking to someone who has also sustained an injury and can empathise with their situation by drawing on personal experience. This may an additional role for the TR coaches if they received appropriate training to facilitate conversations of a sensitive nature with clients with a SCI and their partner.

The Spinalis Spinal Unit based in Stockholm, Sweden, appears to provide many of the elements that participants in my study have identified as necessities for relationship maintenance. The Spinalis ethos is focused on client-centred care and on providing a holistic environment where couples feel comfortable about intimacy (Sinnott, 2008). The unit caters for couples where one has a SCI by providing privacy and an aesthetically pleasing ambience that resembles a medical environment as little as possible. Health professionals acknowledge each client’s individual needs and rehabilitation programmes are created and implemented when the client is ready and willing to undertake their programme (Sinnott, 2008).
Sociologically, Swedish society has a less inhibited and more accepting attitude towards adolescent sexuality (Boethius, 1986). The society has lower rates of adolescent pregnancy, abortion and childbirth than those of the United States; credited with a more open, engaged and realistic attitude to sex and intimacy (Boethius, 1986). With this in mind, sociological norms within a community or population may be a primary influence on how people will interact regarding intimacy within a highly specialised hospital environment.

Because these societal difference in attitudes towards intimacy could limit the transferability of my findings, it would be of interest to replicate this study within a different environment, such as that offered by the Spinalis Spinal Unit. It is possible that couples at Spinalis are more inclined to address their intimacy needs while still clients of an acute rehabilitation facility. A different environment may provide favourable outcomes such as clients perceiving greater autonomy and well-being. A study that explores the experiences of newly-injured clients and their partners who rehabilitate in an environment that recognises their individual needs may give weight to my suggestion that creating a more holistic environment allows couples to explore intimacy within their relationship during the acute rehabilitation period.

5.4 Final summary

This focus of this study was to explore the relationships of five couples during their stay in the BSU and the TR unit. Fostering that relationship should be an important aspect of the rehabilitation process and it is a specific objective of the TR programme. Unfortunately, the health professionals’ neglect of their needs as a couple had a profoundly negative impact on the participants’ sense of autonomy, as did deficiencies in the care provided. The physical environment of the hospital failed to provide the space and privacy needed by the couples. They also faced the constant threat of being interrupted by health professionals during the times when they sought privacy. Couples spoke of the difficulties that they had when exploring sexual expressions of their intimacy. Possible causes of these difficulties included the overwhelming nature of the grief and loss they had experienced, the loss of personal and couple autonomy within the rehabilitation environment; and the lack of a secure, private space. Despite the
adversities that couples experienced within what they perceived to be a disempowering environment, they admitted to feeling closer to each other after a partner’s SCI. Communication and the support of a partner were identified as key elements in maintaining a healthy relationship during the acute rehabilitative phase after sustaining a SCI.
References


Kendall, M., Booth, S., Fronk, P., Miller, D., & Geraghty, T. (2003). The development of a scale to assess the training needs of professionals in providing sexuality rehabilitation following spinal cord injury. *Sexuality and Disability, 21*(1), 49-64.


**Personal Communication**

D. Hislop, personal communication, September 16, 2011

L. Dutton, personal communication, 17 September, 2011

M. Van Den Heuvel, personal communication, August 22, BSU

T. Marshall, personal communication, September 14, 2011, BSU
Appendices

Appendix 1

Information sheet for participants

Thank you for showing an interest in this project. This research is being done as part of a Master of Health Science degree at the University of Otago. Please read this information sheet carefully before deciding whether or not to take part. If you decide to take part we thank you. If you decide not to take part there will be no disadvantage to you of any kind and we thank you for considering our request.

What is the aim of the project?
We would like to find out more about what it is like to try and maintain a relationship when one person in a ‘couple’ is an inpatient in the Burwood Spinal Unit. In particular, we are interested in the experiences of couples within the new Transitionz Rehabilitation Programme at Burwood Spinal Unit. This information will help us continue to develop services that provide better support, information, education and privacy for those with a spinal cord injury and their families to meet their intimacy and relationship needs.

What types of participants are being sought?
To take part in this study you and your partner both need to be 16 years of age or older, and living together in a marriage, civil union or de facto relationship. One person in the couple needs to be in the Transitionz Programme at Burwood Spinal Unit. Both partners need to be fluent in English. We are looking for about 5 couples to take part in this study.

You may decide not to take part in this project without any disadvantage to yourself of any kind.

What will participant couples be asked to do?
Should you and your partner agree to take part in this project, you will be asked to take part as a couple in a face to face, digitally recorded, interview with a researcher (Claire Freeman). The interview will
probably take between one and two hours. It will happen at a time and place at the Burwood Hospital that is convenient to you both.

The purpose of the interview is to find out more detailed information about your experience of maintaining your relationship in the Burwood Spinal Unit. For example, you will be asked to talk about what you do to try and maintain your relationship in the hospital environment, whether this is different to what you would do at home, and how the attitudes and behaviour of the health professionals affect your ability to maintain your relationship. During the interview, you can decide not to answer a question without any disadvantage to yourself of any kind.

Can participants change their mind and withdraw from the project? You may change your mind and withdraw from the project at any time without any disadvantage to yourself of any kind. If one person in the couple decides to withdraw then neither person in the couple will be interviewed.

What data or information will be collected and what use will be made of it? The interview involves an open discussion between the couple and the researcher. The exact questions which will be asked have not been decided in advance. You will be asked about what you do to try and maintain your relationship in the hospital environment, and whether this is different to what you would do at home, and whether the attitudes and behaviour of the health professionals affect your ability to maintain your relationship. The precise interview questions will depend on the way the discussion develops. In the event that a question or question make you feel hesitant or uncomfortable you are reminded of your right to decline to answer any particular question(s) or stop the interview, and also that you may withdraw from the project at any stage without any disadvantage to yourself of any kind.

The only people who will have access to the data are the researchers involved in the study. The data collected will be securely stored in such a way that only the researchers will be able to gain access to it. At the end of the project any personal information will be destroyed immediately except that, as required by the University's research policy, any raw data on which the results of the project depend will be retained in secure storage for five years, after which it will be destroyed.

The results of the project will be published. Every attempt will be made to preserve your anonymity. When the results are being prepared for publication the researcher may select something you have said to help explain her point. If you wish the researcher will show you the quote. If you think you might be identified by what you have said then you can ask to have this removed or changed.

You are most welcome to request a copy of the results of the project should you wish.

If you have any questions about our project, either now or in the future, please contact:

Alike Dierckx, Administrator, Upper South A Regional Ethics Committee:
Email: alieke_dierckx@moh.govt.New Zealand

Jean Hay Smith, Research supervisor, Rehabilitation Teaching and Research Unit, University of Otago:
Work phone no. 03 474 7007 ext 8568
Fax: 03 474 7620
Email: jean.hay-smith@otago.ac.New Zealand

Claire Freeman, Researcher and MHealSc candidate:
Work phone no. 03 3837540
Emergency no 021 0452849
Fax: 03 3837500
Email: claire.freeman@cdhb.govt.New Zealand
Bernadette Cassidy, Research supervisor, New Zealand Spinal Trust
Work phone no.  03 3839492
Emergency no.  022 6006630
Fax:                 03 3837500
Email:               bernadettec@burwood.org.New Zealand

If you have any questions or concerns about your rights as a participant in this research study you can contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioner Act.
Telephone: (NEW ZEALAND wide) 0800 555 050
Free Fax (NEW ZEALAND wide):  0800 2787 7678 (0800 2 SUPPORT)
Email (NEW ZEALAND wide):  advocacy@hdc.org.New Zealand

This study has been approved by the Upper South A Regional Ethics Committee.

Thank you.
Appendix 2
Consent form for participants

UNIVERSITY
of

OTAGO
Te Whare Wānanga o Otago

Experiences of intimacy in acute spinal cord injury rehabilitation
1.2.10.1.1.1
1.2.10.1.1.2 CONSENT FORM FOR PARTICIPANTS

I have read the Information Sheet dated 29 April 2010 concerning this project and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.

I know that:-

1. My taking part in the project is entirely voluntary;
2. I am free to withdraw from the project at any time without any disadvantage;
3. Any raw data on which the results of the project depend will be retained in secure storage for five years, after which time it will be destroyed;
4. The results of the project will be published but every attempt will be made to preserve my anonymity.
5. Anything I have said that is quoted in a publication of this project will be checked with me first if I wish.
6. If I agree, I might be contacted again about future research on the same or similar topic.

☐ I agree to take part in this project.
☐ I do not agree to take part in this project.
☐ I do wish to see any quotes from my interview before publication.
☐ I do not wish to see any quotes from my interview before publication.
☐ I do wish to be sent a summary of the findings of this project.
☐ I do not wish to be sent a summary of the findings of this project.
☐ I agree to being contacted again in the future about research on the same or similar topic

☐ I do not agree to being contacted again in the future about research on the same or similar topic

☐ I agree that my interview data from this study could be used again in future related research

☐ I do not agree that my interview data from this study could be used again in future related research

...........................................................................  ..........................................
(Signature of participant)      (Date)

...........................................................................................................................................
(Name and contact details of participant)

...........................................................................................................................................
(Name and signature of researcher)
Appendix 3
Interview schedule

Experiences of intimacy in acute spinal cord injury rehabilitation
Interview schedule for couples

Thank you for agreeing to be interviewed about what it is like to maintain a relationship as a couple in the Transitionz Rehabilitation Programme at Burwood Spinal Unit. There are no right or wrong answers in an interview; any information that you can provide about this subject will be useful in developing a better service for people with SCI and their families. If there are any questions you would rather not answer or that you do not feel comfortable answering, please say so and we will stop the interview or move on to the next question, whichever you prefer.

The couple
I would like to know a bit about you as a couple. Please tell me about yourselves as a couple, such as how long you’ve been together, where you live, and what you enjoy doing together.

Prompts might include topics such as:
- Length of relationship
- Living arrangements prior to injury
- Living with or without other dependents (e.g. children)
- Shared activities
- Life roles, occupation, household tasks and who did what
- Support structures

Being in the acute spinal unit
When you first came to Burwood [name] was in the acute spinal unit. When you think back to that time, how was that for you as a couple?

Prompts may include topics such as:
- Amount and quality of time spent together
- Time restraints/curfews, and visiting hours
- What to do as a couple in Burwood environment
- Personal space, and sharing space (with others and equipment)
- Freedom of expression
- Sharing joys and disagreements – constrained, unrestrained?

Being in the Transitionz Rehabilitation Programme
When you moved from the spinal unit to the transitions programme what was the effect of that on your relationship as a couple?

Prompts may include topics such as:
- Privacy
• Time spent together while in the TR programme, how much, more/less than acute BSU
• Partner on site or not
• Having your own private room, thoughts/issues
• Activities shared as a couple
• Priorities as a couple
• Peer support of trainers who also have a SCI, thoughts/issues
• Inclusion of partner in activities, thoughts/issues
• Differences of TR programme compared to being in BSU
• Given chance to focus on relationship more in TR environment
• Elements of TR that have been helpful/insightful/problematic for relationship

Health Professionals
Being at Burwood Hospital means there are health workers around you a lot of the time, such as doctors, nurses, physiotherapists, and so on. How is it as couple living in this environment with other people, such as health professionals around you most of the time?

Prompts may include topics such as:
• Freedom/intrusion
• Communicating with health professionals, and behaviour of health professionals around the couple
• Involvement of health professionals in giving care, including intimate tasks
• Role of health professionals in giving advice and information
• Health professional involvement with regards supporting intimacy

Intimacy and sexual expression
The relationship between a couple could be described as an ‘intimate’ relationship. What are some of the times during your stay at Burwood where you have felt that intimacy as a couple?

Prompts might include:
• What is the range of ways you like to express your intimacy as a couple?
• How is the expression of your intimacy as a couple here in the TR programme the same, or different, from your home environment or acute hospital environment?
• How does the SCI itself affect your expressions of intimacy?
• What about the TR programme environment? (or the health professionals)?

Going forward.
This is called the Transitionz programme because it is between the spinal unit and going home. What are you are focussing on now as a couple in anticipation of going home?

Prompts might include:
• What do you think might be the biggest challenges for you as a couple when you leave the Transitionz programme and go home?
• What might be some of the main differences in everyday life as a couple, compared with before the injury?
• What concerns do you have as a couple?

Ending the interview
• What are some of the things you are looking forward to most as a couple about going home?
• If you were talking to another couple, who have just arrived at Burwood, what would you most want to say to them?

Thanks to participants.
Appendix 4

Brief description of each interview

Couple one: Andy and Alison

NB Information gained from fragmented transcript.

The couple met in 1995, went out together in 2002, got married, bought a house, had children then Andy had the accident. Both were very active and Andy’s job, prior to his SCI involved sports. They felt they were ready for some “down time”. His roles were, taking out the garbage and looking after the kids. Their biggest challenge was not having family around for support as Alison’s parents live overseas.

Her family came straight away after the accident. During that initial period, they were able to spend quite a bit of time together as he was in the acute ward at Christchurch hospital. The health professionals were pretty relaxed about her staying with him during this time. However the family did not like staying in town because the hospital was next to a busy road and there were concerns for the children’s safety. Staying at the BSU was better, and spending time together initially was very important to Alison and his schedule allowed them to be together.

Andy was on bed rest for 6 weeks as the doctors opted not to do surgery. After the six weeks the staff moved him out of his own room into a room with three others. He was there for four nights but was then shifted again into a double room after it was found he had a contagious bug. This was frustrating because he preferred a single room. Alison commented that it was very difficult to “keep the kids quiet” so having a single room would have made things easier for them. “You want them around, and they think it's lovely, but other people don't think it's nice to have noisy kids around” - Alison.

After Andy was cleared of the bug, he was moved into the Milner lodge with Alison. Although they were on hospital grounds, having the unit was extremely important to them and they were very grateful for it especially Alison who said “it was like having their own apartment”.

Andy’s roommate, an older lady, got “very funny one night” when Andy and Alison were together. They were just watching TV but the lady thought something else was going on “and she got all upset”. They thought she was a bit strange. After an exhausting day, he had not taken the old lady’s “whinging” so well. She had got the wrong idea and he apologised to her the next day. He said, “It’s fine if you get on with the people you are in the room with, but it's terrible if you don't get on well”.

It was different for Andy working with the transition staff in chairs as he said “I’m not going to end up in one as I can walk”. However, he had mentioned that a particular TR coach had “been awesome”. The coach had been very encouraging especially when Andy started getting some function back. He decided it was good to have the coaches there for “little bits of advice and support, such as their own issues with spasms etc such as having a mattress made of memory foam, yet the downside was that you can't move
so easily on it, so that was good to know”. Having experienced what the clients were experiencing was found to be helpful. Andy said the coaches “helped with their tips on medication and spasms.” It was comforting for him to see “people who had been through it (a SCI) and done well, maybe not had a full recovery, but they moved on and are very well adjusted. Seeing them happy, successful in their job, was very inspiring”. They thought it helped seeing the people with a SCI doing things fairly easily and knowing “it wasn’t the end of the world”.

For the most part, they found the health professionals very helpful. However, early on, it was very hard for Alison to watch the nurses moving Andy or washing him, like she would have done. She felt more at ease with the nurses who had spent time getting to know Andy’s specific needs.

He mentioned he was very scared of being moved. "If they do mess up, it's me that's affected, and I don't know what I can and can't move" Andy.

When they were in a situation with a nurse whom they did not have confidence in, it was Alison who would “speak out”, Andy “kept it in”. Alison told him "you do have to speak up"

Communication between the different departments at the BSU appeared to be problematic. Andy said “So we get told one thing by one set of health professionals and something else by another, although the bug thing was an issue as no one really knew how to deal with it anyway”. "We don't want to speak negatively, as for the most part it was great, but we can speak honestly and there were issues with getting the right information, and the teams working together, such as urology, nurses, doctors..." Alison said. Different health professionals had their own plans for managing the contagious bug. They felt the different teams were not communicating well with each other.

Andy said “We had couple time at the start, but it wasn't what you call intimate time. The nurses were very respectful, they knew she would come over and they would move me over in the bed to make room for her”. They both appreciated this gesture. In terms of sexual intimacy, he probably would have liked to rush it a bit more, but they did not get too many opportunities where everything was right.

Andy felt he received enough information and he read most of it, but he did not want to get caught up with information when he did not know how much movement he might get back. He read 'Back on Track' but he did not want to get too far ahead of himself as it was too early after the accident to be concerned and he felt “things were changing all the time”. He said “Ok, let's not think of this now, things are changing; we don't want to go down what we might have to do until we have to do it. The best thing for them has been not to think about what might happen, but to just stay with what was happening right now. One day at a time”. When asked whether the SCI had affected their intimate lives, Andy said: "Obviously it has been affected up until now and will carry on and affect us for a while, you know self confidence and stuff plays into it”.

The couple talked about how cold it was at the BSU, and how they missed their home. When asked about their concerns, Alison mentioned her concern about switching medical teams once they were home.”One of the doctors has been there from the first moment he broke his neck. I know it will be fine, but change is always scary. Childcare
and lawns are an issue, he usually fixes things but can't right at the moment, so might be a problem. I used to get pretty cheap labour from him and now we'll have to pay".

Alison also said "We'll both return back to work eventually, although how and when he does is still unknown. He doesn't think he'll be able to participate in his chosen sport again. Coaching is a big part of his job, but he's not ready to do that yet. He isn't confident to do that yet, so there's a lot of those issues to think about, but I'm not too worried, we've given ourselves some time to sort stuff out, although I do want to get back to part time work pretty quickly. We obviously have to go back to work, but not going to rush it". Andy mentioned he wanted to focus on maximising his physical strength first.

In terms of being a couple, they felt confident and thought for both of them their attitudes of taking one day at a time and not looking too far ahead had helped them both substantially. “If you think you have a good relationship, and you can get through this, it will only make the relationship stronger” said Andy.

Field notes

I had an initial time frame of 30 minutes, as the couple were extremely busy packing for discharge and only had two days a week where they were free to do the interview. Their children were at playcentre during that time. Interestingly, the interview took over an hour and after the tape was stopped, the couple continued chatting. I came away from the interview feeling satisfied and happy as we all left on a very positive note. They also reiterated how they were really keen to give back as much as they could to the SCI community and thought this study was a great way of achieving their goal.

As a couple, there was a sense of cohesion and friendship. They worked together as a team really well. Alison did seem a little concerned throughout some of the interview when Andy talked about certain events, such as the situation with the old lady next door; they both seemed concerned when saying anything bad about people or their experience as a whole.

It was difficult arranging a time for an interview and I had to ring several times before it was arranged. Because of this, I did not probe as much as I could have during the interview as I was acutely aware of their limited time. Both of them were very sporty but Alison did mention that even if Andy had been worse, they would have found a way around things and it would be alright. There was an amazing sense of resilience in both of them with his relaxed and hopeful attitude and her positive frame of mind. They agreed however, that they felt they were due a break from a few stresses, saying that buying a house, having kids then having this happen had made their lives very busy.

After the Dictaphone was turned off they did inquire about my injury that, in hindsight, I should have talked about with them at the beginning of the interview. I also think the term intimacy confuses people as I had to elaborate on its meaning.

I felt they were more comfortable talking together which supported my feelings about dyadic interviews. They were able to bounce off each other and when one stopped, the other would carry on so there were no uncomfortably long pauses. I also needed to reiterate the fact that I was not a health professional associated with the BSU. When
Alison suggested that they “not bad mouth the unit” I suspected that she had assumed I might discuss what had been mentioned in the interview.

**Couple Two: Barry and Brenda**

The interview was conducted in the Milner lodge. Their young child was asleep in the other room and occasionally would cry out and Brenda would have to interrupt the interview to go and see if the child was alright. We started the interview with a brief discussion about where and how they met each other and the level of support they had received from friends in their home town. They briefly discussed their roles within the relationship and how she had been a stay at home mum and he had been the manager of a business. They saw themselves as a stereotypical New Zealand couple.

They talked about their hospital experience, what had happened directly after Barry’s accident and how the logistics of travelling to the hospital and managing a young child had been difficult. Brenda mentioned that her supportive friends had looked after the child initially which had been a big relief for her as all she cared about was her husband. He mentioned he did not remember much of what had happened during the initial weeks after his accident.

Initially, she had found the staff of Christchurch Hospital wonderful as they had let them stay together. Barry was then admitted to Burwood Hospital and placed in a shared room in the BSU. He mentioned his concern about the lack of privacy in the shared room and Brenda agreed stating how difficult it had been, especially having a child who did not understand privacy. They mentioned their relief at obtaining a lodge and how that had allowed them much needed privacy.

They spoke about how they felt the Transitional unit was a wonderful idea; however, they did not feel comfortable there as they felt it was like staying in someone else's home. It did however teach Barry to be more independent although he felt frustrated at times with the extra tasks he had to do; it was helpful in the longer term. They appreciated the TR coaches and found them invaluable, especially for information about raising children when one partner has a SCI.

They remembered feeling overwhelmed by all the things they needed to learn and how it had been difficult hearing a constant stream of the problems he would face, this had overwhelmed and upset them. It was during this stage that they had to tell extended family members to stop visiting them as they needed time out to be a family. They felt they had needed to be proactive about finding information relating to his injury, which they had found frustrating. They wondered what a timid couple would be like and whether they would receive inadequate care.

Intimacy for the couple had been spending time in bed cuddling; they suggested sexual intimacy would happen for them once they had been discharged. However, they had found the sexuality nurse very helpful and approachable. Barry mentioned how he wanted to have a discussion with the psychologist about any possible head trauma he may have received. He then reverted back to the former conversation and talked about the fear he had regarding intimacy and the physical loss he now had as a result of his SCI.
When asked what they were looking forward to, they mentioned going home and being able to catch up with friends. Barry then went on to say how he was not looking forward to seeing all his, now unusable, sporting equipment. He went on to talk about all the things he would no longer be able to do and this caused him grief.

Both were concerned about the lack of medical care they would have back home and Barry worried about the state of his bowels. They were also concerned about how differently people would treat him now he was in a wheelchair, and Brenda mentioned how it really upset her the way people stared at him. She went on to talk about the change in roles and how she would have to become the "active mummy" which she was not looking forward to. They had found other people working at the BSU, who also had a SCI, inspiring and this put their minds at ease about the possibility of achieving a normal life in spite of his injury.

**Couple Three: Carl and Cathy**

The couple began the interview talking about their marriage, how long they have been married, and the location of family who all lived some distance away from them. They then talked about their life overseas in Cathy’s home country. They mentioned that they always ate out and how they found it different in NZ eating and cooking at home. They talked briefly about a family feud that had occurred directly after his accident that had upset them. They felt that hospital staff had been very helpful on this occasion.

She talked about being at his side 24/7 and he did not like it when he awoke to find her not there. However she had become very tired because she could not sleep in the hospital with him. They then talked about when they lived overseas and ran their own business. Then they had always been together which they preferred.

In the ICU at Christchurch Hospital Carl had his own room but when he arrived at the BSU, he was in a shared room which Cathy did not like. She found she became more exhausted running back and forth to be with him. She was irritated because she was not used to so little privacy. She thought the system was terrible and shared rooms would not happen in her home country unless the person was very poor. To obtain some sense of privacy, they spoke a different language with each other.

They often wanted to snuggle up together but she had not felt comfortable because of the lack of privacy. When Carl was able to leave the BSU, he had found it good to have some privacy and space together. They then talked about the TR programme and how wonderful it had been having their own room. She enjoyed coming back from physiotherapy with him and having a sleep together during the afternoon.

They talked about how, essentially, they were an antisocial couple but they had appreciated the support of the TR coaches and the other people with SCIs in the hospital. He had made an effort to ask as many questions as he could especially when talking to others who had a SCI.

Carl went on to talk about how he felt bad that no one asked about Cathy and whether she was alright; all the attention had been directed towards him. She agreed with him. He also felt guilty as the accident had happened when he was doing something he loved,
and he felt she had been thrown into a role she had not anticipated or wanted. Cathy went on to say how difficult it had been saying good night to him and how she had hated leaving him every night.

They had enjoyed being able to go out of the hospital on the TR trips and they had really liked some of the health professionals involved with their care. They really appreciated the physiotherapists but felt the doctors were unfriendly.

In terms of intimacy, Cathy struggled at first seeing other nurses do Carl’s intimate cares, but she quickly realised it was alright and was able to laugh when an embarrassing moment occurred. They had been able to try a few intimate moves when they went home for the weekends, but not in the hospital because of the lack of privacy. They both felt closer to each other since the SCI as communication between them had improved. They both really liked the sexuality nurse and were trying various medical techniques to facilitate sexual intimacy.

Carl appreciated that his level of injury meant he did not require the services of a carer so the transition home should be easier. Both were really looking forward to just going home and being private. Their advice to others in their position was to keep communicating. Cathy jokingly mentioned that she was irritated by his positive outlook on everything but Carl said part of the reason he had coped so well was because he was so good at adjusting to situations. He had travelled and lived in a variety of cultures where adaptation was a necessity.

**Couple Four: Diana and Darren**

The couple discussed the demographic form that I had given them in order to gather some basic details. They then talked about their marriage and the substantive period of time that they had been married. Diana did most of the talking and mentioned that they did everything together which is why she felt partly responsible for Darren’s injury as she had not been there to help break his fall. Diana talked about their house and how together they had added rooms to it. Both then discussed their roles where he was retired and she was a part time teacher. They mentioned that she looked after their small block of land. They and talked about their family and where, geographically, their children lived. They then went back to discussing their house and how proud and beautiful they both thought it was. Diana then talked about her concerns about ACC and the threat of losing his meagre allowance. She mentioned that they were fortunate as Darren appeared to be getting some movement back therefore they might not have to move from their idyllic home into modified accommodation.

Diana talked about Darren’s injury and what had happened once they arrived at the hospital. It appeared there had been a lot of confusion about his condition and how initially he had not been able to move any part of his body. When the doctors finally diagnosed what was wrong, she said “all hell broke loose” as they finally took his condition seriously. Suddenly he was rushed to Christchurch and she was given very little time to pack her bags, pick up her prescriptions and join him on the flight.

When they arrived in Christchurch and he was settled into his room at Christchurch Hospital, she realised he was suffering from a diabetic attack. She was grateful that she had picked it up as the doctors had not recognised his strange behaviour. He was then
transferred out to Burwood Hospital and that was when they decided he needed extra surgery to stabilise his spine. She felt the decision was very rushed and they both had not liked the loss of autonomy they felt. They stated that they had needed more time to process the huge decision of neck surgery.

Diana did acknowledge that the care at the BSU was much better and they had even ascertained that Darren had a pressure sore as a result of the inadequate care at the other hospital. She was quite angry about this. They both appreciated the fact that she was initially able to stay with him although she had become annoyed with his demands and he was annoyed with his lack of power and control over his situation.

He talked about wearing an abdominal binder and how this had caused pain that the health professionals were unsure how to deal with. This frustrated him. Diana talked about Darren sharing a room and described the room as being like “Piccadilly circus” with all the “comings and goings from other room-mates”. One of them had had a problem with snoring that had kept Darren awake. He said the lack of privacy did not bother him when it was compromised because he was so used to having none. She mentioned she appreciated it when the other nurses asked for her permission if they needed to touch him in a private area.

When I asked them about the TR unit, Diana became very angry stating that the whole concept had caused them stress. They had assumed that Darren would be left on his own in the TR unit and she felt he was unable to look after himself and so might die. They mentioned feeling abandoned in the unit. Diana also mentioned her concerns about ACC and the payments she was receiving that were cut without warning at one stage. She then reverted back to talking about the TR unit saying that she was worried Darren would not be fed as he was a diabetic and that could kill him. She did not feel that it was alright for her to stay in the TR unit. She became so worried that she eventually wheeled him over to one of the lodges and told the staff she would be in charge of his care. An emergency meeting was called and the solution was to allow the couple one week in the lodge, then Darren would move into the TR unit and the health professionals would look after him. She suggested that couples needed more information about the support available in the TR unit and it was not necessarily a bad place. Both appreciated having the week in the lodge and believed Darren’s walking had improved as there was no one there to trip him over.

_A three hour break followed._

The couple discussed where they had met and how difficult it had been in the early days living with young children with Darren studying. They then talked about moving to NZ and living in Wellington. Both loved Wellington and spoke about loving the kiwi culture. They talked about the TR coaches and how helpful they had found them, and the other TR staff were very helpful and pleasant too.

Darren discussed the benefits of physiotherapy and the problems he was having with his sore arm that he suspected was hurt in the initial accident. He talked about being in a dark place and knowing the only way to improve was through physiotherapy. Diana talked about their ACC case manager and how very sweet and helpful she had been despite her initial fears and judgments.
Darren talked about his concern at the placement of the TR bathroom and his constant worry about having a bowel accident. Diana goes on to say the kitchen and lounge of the TR unit were terrible for them as they were designed for someone in a wheelchair and they both got sore backs trying to use the lowered benches. She was also concerned that he might be pushed over accidentally by one of the other client’s children.

Diana did appreciate an omelette that Darren had made for her in the occupational therapy kitchen and she also talked about how she had huge difficulty operating new technology, especially the new appliances in the TR unit. She discussed how the nurses had a tendency to do everything for Darren so attending the TR programme could be useful as he attempted to become more independent.

When asked about intimacy, they said they kissed each-other and shared meals whenever possible. She talked about how handy the pre-frozen meals were for her to cook for them. Darren talked about how much he loved Diana and appreciated her. He also spoke about his anger and frustration over things he had no control. This irritated her as she perceived him as being picky and bossy.

Diana talked about her concerns going home and not having access to the same medical support. She was trying to learn as much as she could about his care although she struggled with tasks that caused him pain. She also worried about the possibility of him sustaining another injury. Seeing the cat and watching Sky TV were also things Diana was looking forward to. She said she missed not having time to herself and she was already feeling the burden of having to care for him and perform tasks like changing his night-bag.

They both talked about their irritation over the lack of privacy especially when he shared a room and the room-mate’s children used his bed as a playground. She spoke about how she hated leaving him although he did not seem to mind. They spoke of an incident where a friend had been looking after their house and had left it in a bad state because they had turned the power off and defrosted the freezer.

Diana talked about feeling stressed and unable to tell Darren as she did not want to cause him further stress. The travel difficulties she had encountered getting to Christchurch had upset her. She also did not appreciate it when the nurses assumed she did not know what she was doing regarding his care; she felt she was much better than they were a lot of the time as she knew him best. When asked about what advice they would give others in their position, they said, to have faith in each other, take one day at a time and to avoid overloading themselves with too much information.

**Couple Five: Edward and Elizabeth**

Edward spoke about his job as a farm manager up north and how he had gone onto a dating website where he had met Elizabeth. He had then started working for her and they eventually got married. They spoke about his family and the tragic death of his child. Edward was dealing with an addiction at the time of his child’s death. They talked about their support systems - friends from their church and, he said, she had a larger support system of friends.

They had bought a lifestyle block and wanted to “live off the land”. His job would be to
manage the block of land. They spoke about how he was often grumpy and she therefore, preferred having him out of the house. He admitted he had a tendency to become grumpy and knew this was an issue he needed to work on.

They talked about their life in their home town and how they enjoyed going into town and having lunch in the park. He then went into detail about his accident and the pain as a result of his fall. They were flown to Christchurch suddenly and Elizabeth had literally just taken her handbag with her so had arrived in Christchurch with no clothes or supplies. She also discussed her anger at the fact that she was not told that Edward had been taken into surgery, but conceded that it was the right medical move to take.

Edward talked about his anger at being roughly handled in hospital; he felt they had not appreciated the severe pain he was experiencing as a result of his injury. He also talked about his room at Burwood that was either too hot or too cold, subsequently; he was shifted into another room. Elizabeth felt that many medical decisions regarding Edward’s care were handled unprofessionally and she threatened to write an “induction manual”. This would include their not being told when he was to attend physiotherapy. No one informed him about his sessions or that he could have attended his sessions in his hospital bed.

They spoke about Edward’s shared room which Elizabeth hated, but he did not mind as he was prone to feeling lonely. She said they had no privacy at all and the other clients talked about a lot of negative issues that made her feel depressed. He talked about hating the weekends as there was nothing for him to do and she had usually gone back home so he was alone.

ACC had said that they could modify their house, but Edward did not think this was a good idea as he was now physically unable to work on the land so “what was the point”. They had to make the decision to sell their house very quickly, which they found extremely stressful. He felt guilty as he saw the accident as his fault and Elizabeth was going to lose her house that she had paid for. All he could think about was what he would not be able to do.

Edward talked about the new roles Elizabeth would have to assume such as doing some of the jobs related to their business yet all he could focus on was his pain, spasms and not being able to help her. She had found it frustrating that he was unable to access the nurses’ hostel where she was staying, so they had no privacy.

They spoke about an incident where they had been lying on his bed in his shared room and a nurse had come in and said it was fine for them to have a cuddle. They had felt much better having been given permission and even felt that it had started a trend with the other couples. He hated that she had to leave him at night and also that she had to go home and attend to things back home. He said he felt very lonely without her.

They talked about an outing where they had gone for a coffee in a borrowed car and it had broken down. He had felt frustrated that he was unable to help her fix it. He had felt proud though that he had not become angry and yelled at her. He also spoke of an incident where he had wet himself at a rugby game and again had not yelled at her. They both felt they were working better together as a team.
Edward had been over to the TR unit during the times he was bored and prior to their admittance into the programme, so he had an idea of what the TR programme involved. They both mentioned the new kitchen and how it was not good for her sore back as it was set up for people who used a wheelchair.

Edward spoke about his pain and how he found the nurses’ care substandard. Elizabeth said she had become “the wife from hell” trying to sort out some of his pain issues. They were also frustrated with the lack of information saying they found out more from other clients than they did from staff. Edward mentioned the huge problems he was having with his bowels and he did not think there was enough attention paid to bowel related issues. The staff in the TR unit were very helpful, especially the coaches.

When they had the use of a lodge, they mentioned how fantastic that was but Edward often felt uncomfortable staying with Elizabeth as his bowels were “playing up a lot”. She would often beg him to stay with her in the lodge. They both appreciated the staff member that organised the bookings of the lodges as they really felt he was working for them. Elizabeth discussed her concerns about getting home and not knowing enough information to care for Edward properly. She was trying to learn as much as she could before they were discharged from the BSU.

They had been hugging a lot and, as Edward mentioned, doing “some eye balling”. Both felt they were getting on a lot better together and said that open communication was very important to them. Edward felt that he had done a lot of personal reflection and had decided not to get so angry over small things. They both felt they had worked better as a team since his injury.

Edward talked about the impact of Kaleidoscope, a work programme organised by the NZST. Talking to a vocational worker had given him hope and a sense of purpose regarding his future for the first time. They spoke about having faith in themselves and how, if they thought their care was substandard, they had the confidence to mention it. It was important to be proactive about what they needed rather than passive.
Appendix 5
Ethics Approval

24 May 2010

Dr E Jean C Hay-Smith
Dept Women’s and Children’s Health
Dunedin School of Medicine
P O Box 913
DUNEDIN

Cc: Claire Freeman by email

Dear Dr Hay-Smith

Ethics ref: URA/10/04/029
Study title: The experience of maintaining an intimate relationship for people with spinal cord injury and their partner during acute rehabilitation: an interpretative phenomenological analysis.
Investigators: Dr E J C Hay-Smith, Ms C Freeman, Dr B Cassidy, Ms A Sinnott
Localities: Burwood Spinal Unit

The above study has been given ethical approval by the Upper South A Regional Ethics Committee.

Approval is given with the understanding that point 3 of the consent form will be amended to reflect that data will be stored for 10 years. Please email me a final copy of the consent form for our records.

Approved Documents
Information sheet and consent form, version 1 dated 29 April 2010
Interview schedule for couples, version 1 dated 29 April 2010

Certification
The Committee is satisfied that this study is not being conducted principally for the benefit of the manufacturer or distributor of the medicine or item in respect of which the trial is being carried out.

Accreditation
The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, April 2006.

Progress Reports
The study is approved until **30/09/2011**. The Committee will review the approved application annually and notify the Principal Investigator if it withdraws approval. It is the Principal Investigator’s responsibility to forward a progress report covering all sites prior to ethical review of the project in May 2011. The report form is available on [http://www.ethicscommittees.health.govt.New Zealand](http://www.ethicscommittees.health.govt.New Zealand). Please note that failure to provide a progress report may result in the withdrawal of ethical approval. A final report is also required at the conclusion of the study.

**Requirements for SAE Reporting**

The Principal Investigator will inform the Committee as soon as possible of the following:

- Any related study in another country that has stopped due to serious or unexpected adverse events
- withdrawal from the market for any reason
- all serious adverse events occurring during the study in New Zealand which result in the investigator breaking the blinding code at the time of the SAE or which result in hospitalisation or death.
- all serious adverse events occurring during the study worldwide which are considered related to the study medicine. Where there is a data safety monitoring board in place, serious adverse events occurring outside New Zealand may be reported quarterly.

All SAE reports must be signed by the Principal Investigator and include a comment on whether he/she considers there are any ethical issues relating to this study continuing due to this adverse event. It is assumed by signing the report, the Principal Investigator has undertaken to ensure that all New Zealand investigators are made aware of the event.

**Amendments**

All amendments to the study must be advised to the Committee prior to their implementation, except in the case where immediate implementation is required for reasons of safety. In such cases the Committee must be notified as soon as possible of the change.

**Please quote the above ethics committee reference number in all correspondence.**

The Principal Investigator is responsible for advising any other study sites of approvals and all other correspondence with the Ethics Committee.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

We wish you well with your study.
Yours sincerely

Alieke Dierckx
Administrator
Upper South A Ethics Committee
Alieke_dierckx@moh.govt.New.Zealand