

Lived experience of managing paid personal care following a spinal cord injury: An Interpretative Phenomenological Analysis

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Abstract

Background: The nature of relationships that people with spinal cord injury (SCI) have with paid carers may facilitate or interfere with their community participation and quality of life. Learning how to live with this need for assistance, while not compromising autonomy and dignity, can be challenging. The purpose of this study was to investigate the experiences of those with SCI who receive paid personal care in order to better understand the nature of what contributes to a successful working relationship and satisfying life.

Method: Semi-structured interviews were conducted with seven people (four men, three women; aged 21 to 55 years) who had experienced a cervical level traumatic SCI and required support from paid carers. Interpretative phenomenological analysis was employed to analyse the transcripts.

Results: I liken this phenomenon to a challenging '*maze*' with the participants as '*pathfinders*.' Participants followed different paths, yet all regularly made choices about which way to turn at each decision point in managing their paid care. Three master themes emerged from the participant's accounts: 1) **Finding your way amid, challenge, chaos and choice**, 2) **Navigating relationship terrains** and 3) **Warning: potential traps**.

Finding your way amid challenge, chaos and choice encompassed the participants' cognitive and emotional journey of coping and adjustment to life following SCI. In making this adjustment the participants sought ways to maximise autonomy, and even power, within a context of being bodily dependent. **Navigating relationship terrains** captured the participants' thoughts and beliefs regarding the interpersonal relationships they had with paid carers, and included issues such as the role of 'gut instinct' and trust in managing these relationships. Finally, **Warning: potential traps** denotes the perceived threats to individuals' well-being and resultant fear and vulnerability. These threats and fears related to the nature of the relationship itself (e.g. fear of mistreatment).

Discussion: The results from this enquiry suggested that recipients of care face many complexities when managing paid care relationships. Decisions about paid care relationships; particularly when new to their SCI, was based on serendipity and a 'trial and error' approach. Each decision can lead to, and set up a cascade of effects that impact and

shape a person's sense of identity, self-esteem, body image, sense of success or failure, mental and physical health, both in the short and long term. Participants also described mistreatment including intimidation, rough handling, ridicule, and theft, demonstrating abuses of disabled people's human rights in New Zealand (NZ). It appeared that currently people with SCI in NZ, who rely on support from paid carers for basic daily needs, return to the community after injury without adequate opportunities to learn essential skills needed to establish and manage these relationships effectively.

Conclusion: Information from this study could provide some direction (*a map and compass*) for individuals (*pathfinders*) new to SCI who are preparing to enter into an unexplored area outside the hospital environment. Furthermore, research of this nature may raise awareness of issues in the SCI environment and the NZ health care community, which may help to reduce inequalities by advancing knowledge in an area where there has been minimal investment in research. Making more information of this nature available to people with SCI, their families, and health professionals may go some way towards assisting people with SCI to better prepare for formal caregiving relationships within the home environment.

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“I dedicate this ‘my thesis’ to you Keith”

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List of abbreviations

ACC	Accident Compensation Corporation
AD	Autonomic dysreflexia
ASIA	American Spinal Injuries Association
ASRU	Auckland Spinal Unit
BSU	Burwood Spinal Unit
C	Cervical
CHIEF-SF	The Craig Hospital Inventory of Environmental Factors-Short Form
CHART	Craig Handicap Assessment and Reporting Technique
CNS	Clinical Nurse Specialist
FAM	Functional Assessment Measure
FIM	Functional Independence Measure
ICF	International Classification of Functioning
IPA	Interpretative Phenomenological Analysis
MDT	Multidisciplinary team
MOH	Ministry of Health
MVA	Motor vehicle accident
NZ	New Zealand
QOL	Quality of life
SCI	Spinal cord injury
T	Thoracic spine
TBI	Traumatic brain injury
USA	United States of America
UTI	Urinary tract infection
WHO	World Health Organisation

Chapter One: Introduction

1.1 Introduction to research

The central focus for this study was to explore the lived experience of people who had sustained a traumatic spinal cord injury (SCI) and as a consequence now managed relationships with paid carers within their home environment. The International Classification of Functioning, Disability and Health (ICF) highlight the impact that environmental factors, such as support from carers, may have on outcomes following SCI impairment. The success of the relationship between the carer and the person with SCI has a direct influence on the ability of the person with SCI to function as fully as possible in society (Schoop, Clark, Mokelke, Stout & Mazurek, 2007).

A traumatic SCI is one of the most dramatic injuries a person may experience. Changes in an individual's life may encompass, but are not limited to, reduced: life expectancy, health status, occupation, physical function, autonomy and personal control, personal relationships, psychosocial adjustment, leisure participation and quality of life (Charlifue, Lammertse & Adkins, 2004; Riis & Verrier, 2007). These emotional, physical, relational and economic consequences of a SCI are monumental and often continue for the entirety of injured person's life (DeSanot-Madeya, 2006). For an individual coming to terms with the SCI, there is also a need to confront the possibility of having to rely on assistance from a paid carer to complete many functional, everyday tasks. Learning how to live with this newly acquired need for assistance, while not compromising independence and dignity, can be challenging (Burdsall, 1998).

Within the existing literature surrounding paid personal care services there is a general consensus that the work of the paid carer is crucial to the quality of life, health and participation of individuals with SCI and other disabilities (Hagglund, Clarke, Farmer, & Sherman, 2004; Mathias & Benjamin, 2008; Matsuda, Clark, Schopp, Mokelke, & Hagglund, 2005). Whiteneck, Meade, Dijkers, Tate, Bushnik & Forcheimer (2004) conducted a large scale study using The Craig Hospital Inventory of Environmental Factors-Short Form (CHIEF-SF), the Craig Handicap Assessment and Reporting Technique (CHART), and Satisfaction with Life Scale to evaluate environmental factors and their role in participation and life satisfaction following SCI in participants between one and twenty six years post injury. These researchers identified five

environmental barriers reported by subjects with SCI: ‘help at home’ was ranked third as the greatest environmental barrier, coming after barriers in the ‘natural environment,’ and ‘transportation’ for people with SCI having a direct impact on the individuals’ ability to function within the household and community, and from doing what they need or want to do.

However, Schoop et al. (2007) recognised that there is little known about the nature of the relationship between those with SCI and the paid carer. Schoop et al. (2007) suggested that insufficient knowledge of personal care requirements for a person with SCI, or ineffective communication about these activities may increase the incidence of secondary complications thereby affecting employment, and participation in other community activities for the person with SCI. It would seem timely therefore to undertake research in order to better understand how relationships between people with SCI form and are managed and the nature of successful or failed relationships.

1.2 Personal reflections

My interest in research on the relationship between people with SCI, and their carers, emerged from my experiences as a nurse. Currently I am a Clinical Nurse Specialist (CNS) at the Burwood Spinal Unit (BSU). Prior to my current role I worked for 20 years as an enrolled nurse, and on a casual basis as a paid carer for individuals with tetraplegia while undertaking study to become a registered nurse. From this personal experience I quickly learnt that the home environment was significantly different to the hospital setting. In the home environment you work in isolation, with no one available to help you, with difficult tasks such as transferring heavy people with tetraplegia from bed to wheelchair. Many times I felt compromised physically undertaking risky transfers, and feared injury myself and injury to the individual who was trusting in my abilities. On more than one occasion the hours I was scheduled to work were ‘stretched’ for various reasons: waiting for wheelchair transport, or for the carer who was to take over from me, to complete additional tasks, and in some situations due to a sense of moral obligation to remain. This experience opened my eyes to the different dynamics that exist when providing care in the community. As a result I came to believe the home environment posed many challenges both for the individual with disability and the carers. Good communication, empathy between both parties, along with a healthy

measure of ‘good common sense’ and an ability to ‘think outside the square’ were in my opinion essential ingredients for a successful consumer-carer relationship.

Several people with SCI admitted as inpatients for reassessment or pressure area management to the BSU have shared stories with me over the years which have included appreciation, frustration, and, occasionally, despair regarding carers, funders and/or care agencies. They have told of difficulties finding, and retaining carers, and of carers who have let them down or neglected their health needs. Some individuals have also shared that relationships with carers have become more intimate in nature, and this association has had both positive and negative implications with regards to the paid care relationship dynamic. In the 1980’s it was common practice for nursing staff to be encouraged to socialise outside work hours with the BSU inpatients. However, today friendships and intimacy with patients are considered a breach of professional boundaries, and professional misconduct according to New Zealand (NZ) Nursing Council. I now believe maintaining appropriate professional boundaries safeguard both the patients and nurses by controlling or limiting the power differential. However, I am not so convinced such mandates are applicable in the home environment to those with long term disability and their carers (who are not registered health professionals). I am also of the opinion it may not be wise to complicate the formal working arrangement by developing close personal relationships. Nevertheless, consistent with the Independent Living Model (DeJong, 1979) people with disabilities (like people without disabilities) have the right to make their own choices and live with and learn from them.

I am aware that carers are a potential facilitator or obstacle to the level of functioning and participation achieved by a person with SCI when in the community environment. This was cruelly evident when in 2005 a close friend of mine with tetraplegia was murdered by his carer in his own home (van Beynen, 2010). It is impossible for me to illustrate with words my sadness, anger and disbelief that I lost my valued and loved friend in such tragic circumstances. As a regular visitor to his home I had met many of his carers (including the person convicted of his murder) and knew first-hand that he was a pleasure to work for: he was a positive man, who lived a complete and full life that looked forward to the future.¹

¹ Court Case details available at
<http://www.safe-nz.org.nz/Data/smaileric.htm>

Therefore, the development of this research project was influenced as a direct result of both my professional and personal involvement with individuals who have SCI. Using a qualitative research method I hope I can adequately describe the experiences of those persons with SCI who rely on paid personal care services.

1.3 Definitions of key concepts

1.3.1 The concept of care and caring

Definitions of care abound. It is used as a noun, verb, or adjective, and has positive and negative connotations. While reference to the concept of care and caring is widespread in the nursing literature (much of it linked to nursing speciality areas such as palliative care) and in disability studies literature, there is debate over its precise meaning (Kroger, 2009; MacLeod & McPherson, 2007; Stockdale & Warelow, 2000). Although society has a broad understanding of the various meanings of care there is no single definition that is applicable to all situations. By way of care a person is able to display qualities of trust, commitment, and concerns for another individual (Stockdale & Warelow, 2000). Caring, the medium through which care is expressed, allows individuals to serve others needs for protection and love, and in so doing preserve humanity in society (Watson, 1990).

MacLeod and McPherson (2007) stated that in rehabilitation the word care seems to have gained a bad reputation partly linked to efforts to challenge, and remove disabling, stigmatising, and paternalistic language. Disability researchers have voiced the criticism that the concept of care, together with research based on it, consists of the view that disabled people are dependent non-autonomous second-class citizens. For instance, Morris (1997) stated:

People who are said to need caring for are assumed to be unable to exert choice and control. One cannot, therefore, have care and empowerment, for it is the ideology and the practice of caring which has led to the perception of disabled people as powerless (p. 54).

The disability perspective differs from care research which focuses on care relationships, informal and formal care, ‘care-giving’ work and ‘an ethics of care’. Kroger (2009) argued that the two perspectives are not mutually exclusive and gives the following example: the relationship between disabled people and their carers has much the same characteristics as the care relationship and requires balancing of the needs and interest of the two parties. He

then added that on the other hand access to adequate care could be perceived as a basic civil and human right. Likewise, Woodlin (2006) concluded that the term care can be either outright abusive, or pernicious in its ability to undermine social connectedness as well as being helpful and supportive. Like Woodlin, I will also use the term ‘care’ in inverted commas when I wish to remind the reader of its contested meanings.

1.3.2 Carer or caregiver

The terms carer, or caregiver (as typically appears in the literature) are used interchangeably for the purposes of this study. The relationship between carers and the people with SCI that they work with (i.e. the recipient of care) is referred to as the ‘consumer-carer’ relationship. Paid caregivers are however, also known by other titles such as ‘support worker/person/provider/carers’, ‘home-care helpers’, ‘formal caregivers’, and ‘personal care attendant/assistant’. In Boschen, Tonack and Gargaro’s (2005) Canadian study the term ‘support provider’ was considered more appropriate for those with SCI. These researchers emphasised that the nature of the supporting role to an adult with a traumatic SCI (who is typically young, male, cognitively intact, previously healthy and physically active) is likely to be different from that of a caregiver to an older adult with a chronic condition, or a child with a congenital disability, or to a cognitively impaired person with a brain injury. Boshen et al.’s (2005) comment regarding differing population groups who have impairment may be considered slightly judgmental of other populations of people. I am cognisant that in NZ there is no consensus on this topic, therefore choice of terms and their usage vary amongst individuals with disability, different caregiving agencies, funding bodies and rehabilitation providers.

There is a general consensus within the international literature that personal care services are designed to support persons with disabilities in their routine performance of activities of daily living. This support includes assisting consumers in performing instrumental activities of daily living such as preparing meals, housekeeping, laundry, transportation, shopping and personal finances (Schoop et al. 2007). In NZ the Accident Compensation Corporation (ACC) funds support if a claimant with SCI meets certain criteria. ACC calls this funded support ‘attendant care’, and defines this as:

Attendant care is the support that a person with a spinal cord injury needs, in order to do tasks they would have been doing for themselves prior to their accident.

Carers enable consumers with disabilities to compensate for their functional limitations, allowing them to participate in employment, social and recreational activities. The legislation that ACC operates under (the Injury Prevention, Rehabilitation, and Compensation Act, 2001) defines attendant care as:

- Personal care (physical assistance to move around and to take care of basic personal needs such as bathing, dressing, feeding, and toileting).
- Assistance with cognitive tasks of daily living such as, communication, orientation, planning, and task completion.
- Protection of the person from further injury in his or her ordinary environment.

(ACC, 2009, p.5)

1.4 Research aim

The aim of this research was to determine how people with SCI who require daily care experience, make sense of, and manage relationships with paid carers. Findings from this research could potentially shed new light on an otherwise unexplored area of life after SCI in NZ. Information from this study could provide direction to individuals with recently acquired SCI and to health professionals, spinal rehabilitation services, caregiving agencies and funding bodies. Specifically, it is hoped that this study might contribute to development of services to better prepare people with SCI for their role of managing relationships with care providers.

1.5 Structure of the thesis

Chapter Two provides a review of the relevant literature pertaining to SCI within NZ, and paid caregiving for people with SCI to elucidate the specific context in which the study takes place. Chapter Three is where I present the epistemological and theoretical underpinnings of the research followed by the specific research methods used to collect and analyse the data. I report the inductively derived themes from the collected data along with my analysis and interpretation in Chapter Four. Chapter Five discusses the themes and examines these in relation to the existing literature. I also consider the trustworthiness and transferability of the study findings with a view to the implications for further research and practice, and my own reflections on the research, and research process. Finally I summarise the main messages of the research.

Chapter Two: Literature Review

2.1 Introduction

Chapter One established the need to understand more about paid personal care for people with SCI in NZ. In this chapter I provide the context for the research providing an overview of SCI, and how SCI is funded and managed in NZ as well as presenting: the current research and perspectives on paying friends, strangers, or family members to be a carer; relationships between paid carers and people with SCI; mistreatment of people who receive care, and training needs for carers and people with SCI.

2.2 Overview of Spinal Cord Injury (SCI)

A spinal cord injury (SCI) is an insult to the spinal cord resulting in a change, either temporary or permanent, in normal motor, sensory, or autonomic function. Injury can be both traumatic and non-traumatic in origin.

2.2.1 Classification of SCI

The following terminology has developed around the classification of SCI:

Tetraplegia (which replaced the term quadriplegia): Injury to the spinal cord in the cervical region, resulting in paralysis affecting the upper extremities as well as the trunk and lower limbs (Dawodu, 2008).

Paraplegia: Injury in the spinal cord in the thoracic, lumbar, or sacral segments, including the cauda equina and conus medullaris resulting in a level of paralysis of the trunk and or legs but without affecting the upper extremities (Dawodu, 2008).

SCI commonly results from: destruction from direct trauma; compression by bone fragments, hematoma, or disk material and ischemia from damage or impingement on the spinal arteries. Oedema could ensue subsequent to any of these types of damage further compressing the spinal cord (Dawodu, 2008).

The degree of impairment is defined using the internationally recognised American Spinal Injuries Association (ASIA) classification system to describe the level and

extent of injury based on a systematic motor and sensory examination of neurologic function (Maynard, Bracken, Creasy, Dittuno, Donovan & Ducker, 1997). The ASIA impairment scale is a five point scale ranging from ASIA A to E. ASIA A indicates complete loss of motor power and sensation below the level of injury. ASIA B, C and D (often referred to as incomplete injuries), reflect increasing levels of sensation and motor power through to ASIA E, which depicts normal motor power and sensation.

2.2.2 Characteristics of SCI in NZ

The incidence of SCI in NZ, at 17 per million persons per year, is relatively high when compared to the worldwide incidence of SCI in developed countries which is between ten and 83 per million inhabitants a year (Wyndaele & Wyndaele, 2006). However, the prevalence of traumatic SCI in NZ is not well documented as there is no national SCI database at this time. The best indication of the current prevalence of traumatic SCI in NZ is gauged from the serious injury claims lodged with the ACC. This reflects all serious SCI that were the result of an accident, and for which there is a current and ongoing claim. Excluded from this data however are non-traumatic causes of SCI, injuries that occurred to NZ citizens residing outside of NZ at the time of their accident, and accidents sustained prior to the establishment of ACC in 1974 (Sinnott, Cassidy, Nunnerley, Bourke & Kunowski, 2010). Based on the latest statistics, there are currently 1778 SCI consumers (including children) within the ACC National Serious Injury Service (ACC, 2009).

Historically the main cause of SCI in NZ is motor vehicle accidents (MVA) (54%), with falls accounting for just over a quarter (28%), and sporting injuries contributing 7% (Burke, Linden, Zhang, Maiste, & Shields, 2001; Dixon, Danesh, & Caradoc-Davies, 1993; O’Conner, 2002). While trauma is the most common cause of SCI (McKinley, Steel, & Hardman, 1999) other causes of SCI include: vascular disorders, tumours, infectious conditions, spondylosis, iatrogenic injuries and developmental disorders. A recent unpublished audit from the Burwood Spinal Unit in NZ, over a two year period from January 2008 to January 2010, showed 45 individuals, (35% of the total admissions) had SCI from non-traumatic causes (Burwood Spinal Unit Audit, 2010).

The NZ demographics on traumatic SCI can be further divided by sex, age, ethnicity and injury characteristics:

Sex: Dixon et al. (1993) found a higher incidence of SCI in males per year. While this research is dated and may not be a true indication of the current situation, it remains the most comprehensive NZ based study; which reflects all NZ hospital discharges over the period from 1988-1993 (Dixon et al., 1993). This is in line with USA data which has indicated that men sustain injury about four times as often as women per year (Sipski & Richards, 2006).

Age at injury: The age group sustaining the most number of SCI in NZ is those between 15-29 years which is consistent with international statistics (Burke, et al., 2001; O'Conner, 2002). While SCI in children has a very low incidence (Dixon et al., 1993), there is a trend towards increasing numbers of elderly injured through falls (Chester, Wuermeser, Priebe, Chiodo, Scelza & Kirshblum, 2007). It is this trend which may account for the results of a worldwide literature review, determining the mean age of those most likely to sustain a SCI as 33 (Wyndaele & Wyndaele, 2006), an average age higher than that indicated by the NZ data.

Ethnicity: The indigenous Maori population is over represented in the NZ SCI statistics, accounting for 21% of injuries (Acland, 2007) despite only making up 14.6% of NZ general population according to the NZ Census (Statistics New Zealand, 2006).

Injury characteristics: Cervical injuries are the most common SCI in NZ, and the majority of these injuries are incomplete (Dixon et al., 1993). More recently Dunn (2012) iterated that cervical spinal injuries are the most common level of injury in NZ and appear most common in males between the ages of 15-29 years, an observation in line with international trends (Burke, et al., 2001; O'Conner, 2002). However, there is no national SCI database, and research is still in its infancy (Sinnot et al., 2010). Individuals who sustain their SCI in later life are much more likely to have incomplete injuries predominantly affecting the cervical spine (Barrett, Putzke, & Richards, 2002).

In 2010, the average lifetime cost on social rehabilitation for a high level tetraplegic on ACC was \$3.9 million (Dorian, 2010). Eighty five percent of serious injury social rehabilitation expenditure is driven by attendant care: \$255 million per year. As of

2010, the ACC's total social rehabilitation liability for SCI in NZ was \$2817 million (Dorian, 2010). Benchmarking against Transport Accident Commission (in Victoria, Australia) data confirmed that attendant care levels are significantly greater in NZ than in Victoria. It is also recognised that National Serious Injuries Service spinal consumers are an ageing group of people with 20% now aged over 60 years. This group will continue to grow rapidly (ACC, 2010).

2.2.3 Rehabilitation of persons with SCI

Since 1950, the life expectancy of individuals with SCI has increased considerably, and the mean survival rate after trauma frequently exceeds 30 years. This has been largely attributed to improvements in acute care management (Noreau, Prolus, Gagnon, Drolet & Laramee, 2000; Saulino & Vaccaro, 2009; Wyndaele & Wyndaele 2006). For an individual who has sustained a serious SCI it may mean they are unable to perform many tasks as competently as he or she could before the injury. This, in turn, impacts on the individuals' participation in work, family and social roles.

Rehabilitation after SCI has traditionally focused on maximising the individual's recovery from the injury, and returning him or her to home as independently as possible. However, once the milestone of returning home with a new SCI is reached the individual must then conquer the barriers of societal reintegration with his or her altered body (Sipski & Richards, 2006). Therefore, successful rehabilitation involves maximising the ability of the individual to 'participate in community life activities, remain active in family and recreation events, and access local activities and resources' (McKinley & Mead, 2004, p.79).

Cott (2004) identified a disparity between preparation for community life within the hospital environment, and what people with long-term physical disability encountered in the 'real world' outside hospital. Cott's study used a focus group methodology with six groups, where participants had disability from a mix of impairments, including persons with SCI and was framed within the context of symbolic interactionism. Crotty (1998, p.8) suggests that "symbolic interactionism is all about those basic social interactions whereby we enter into the perceptions, attitudes and values of a community, becoming a person in the process". Participants in Cott's (2004) enquiry described being prepared for life in hospital but not life in the community, describing

increased difficulty in daily life when they returned home. Similarly, Dickson, Allan and Carroll (2008), using an IPA methodology to explore the experience of eight people living with SCI in Scotland, reported that their participants had felt well prepared physically for returning to the community from hospital, but were not psychologically prepared for the change in their lives post-injury.

NZ has two specialist SCI rehabilitation facilities: The Auckland Spinal Rehabilitation Unit (ASRU) in Auckland (North Island of NZ) and the Burwood Spinal Unit (BSU) located in Christchurch (South Island of NZ). These facilities are funded by their respective District Health Boards and ACC. The units accept patients on a population basis. ASRU covers the more densely populated upper half of the North Island, while the BSU encompasses a much larger geographical area consisting of the lower half of the North Island and the whole of the South Island. The two units also offer differing facilities. The BSU is situated within the Burwood Hospital. The BSU has 26 inpatient beds, a transitional rehabilitation unit and four self care units; it admits patients from within the first days of their injury. In contrast the ASRU is a standalone 20-bed rehabilitation unit, which is not attached to a hospital, and which admits patients only once they are medically stable and are able to commence their rehabilitation. People with existing SCI who require inpatient reassessment or management post elective surgical procedures are also admitted to the units from the community. The spinal units continue to provide ongoing medical support and life-long follow-up care beyond discharge for all persons with SCI.

2.2.4 Funding of carers for SCI in NZ

Funding and disability services are provided or purchased by Government departments to meet the needs of New Zealanders. The Government determines what groups of people are eligible to access publicly funded disability services in New Zealand and the criteria that must be met to access the service (Disability Resource Centre, 2012). The two primary streams of health funding are each governed by different entities: ACC and Ministry of Health (MOH). While ACC supports those whose condition came about because of an accident, the MOH is responsible for those with congenital conditions, intellectual disabilities, illnesses, and those whose accident occurred prior to April 1974.

At the MOH, Disability Support Services is part of the Health and Disability National Services Directorate, and funds a range of disability support services to help disabled people, and their family to live as others do in their homes and community. These include: disability information advisory services, home-based services such as personal care and home help, residential services, supports for carers in the home, respite services and supported independent living services. It also funds environmental support services, such as equipment and modifications, for disabled people of all ages who meet the eligibility criteria (MOH, 2009).

ACC is a government insurance scheme that provides injury cover for all NZ citizens. This funding body delivers lifelong care and support services to people of all ages who are ACC claimants with SCI including the employment of paid caregivers to assist with personal care and household management tasks. ACC funds two types of personal care providers: contracted providers (which are more expensive) and informal providers, which can include family members and private carers (friends, extended family, privately arranged caregivers). The mix of providers has a big impact on care costs for ACC. Younger consumers are more likely to be cared for by family members. However, as they grow older, it is expected that they may move to agency care, especially if they move out of the family home. ACC payments may also be the primary source of income so family may want the consumer to continue to live at home. The aging of care providers may also have an impact on the mix of providers (Chang & Chapman, 2009).

2.2.5 ACC attendant care guidelines

ACC has developed guidelines to determine the level of carer support required (ACC, 2009). These guidelines aim to increase assessors' and rehabilitation service providers' understanding of the typical range of supports needed by people with different levels of SCI. ACC has classified SCI into sixteen different types and provided specific guidelines for each type. These guidelines include a description of abilities and types of assistance typically required and the recommended total hours of human support the injured person needs. The guidelines were developed from the New South Wales Motor Accidents Authority guidelines for levels of attendant care for people with spinal injuries and modified for a NZ context through consultation with expert informants in a series of workshops. Several considerations are taken into account when ACC

determine the amount of attendant care a person may require. These hours are corroborated by Functional Independence Measure (FIM) and Functional Assessment Measure (FAM) scores. In addition to this, ACC also has listed a number of factors that may decrease or increase the amount of attendant care (whilst not an inclusive list) a person with SCI may receive, including the person's: changing level of functional independence, individual choice, life stage, changing living situations or other major life transitions, changing use of assistive technology and co-existing conditions (see adapted guidelines Appendix I).

2.3 Management of paid care services for people with SCI in NZ

There are various types of paid care service provision including agency based and consumer directed personal care assistance. Each person with a disability might use one or a combination for personal care services. The effects of these two approaches in terms of health outcomes and satisfaction is largely unknown.

2.3.1 Consumer-directed model (Individualised funding)

The consumer-directed model (also referred to as 'individualised funding') is where the recipient acts as the employer of their carers and is fully responsible for locating, hiring, training, supervising, and firing the provider. Consumers are also therefore responsible for managing the finances associated with their carer. This model is sometimes used by ACC. Under this model, ACC undertakes a formal assessment of need; lump sum payments are then made weekly directly from ACC to the person with SCI. This flexible reimbursement policy allows friends or family members to be paid as providers. Similarly, for those funded by the MOH, individualised funding is a way of paying for home and community support services to let disabled people directly manage their allocated resources for carers. The level of individual funding is determined by a Needs Assessment and Service Coordination organisation. However, family members are not currently permitted to be employed as a care provider under the individualised funding scheme.

The consumer-directed model is strongly aligned with the Independent Living movement, which emphasises consumer control over decisions relevant to their lives as disabled persons had felt themselves adversely affected by the dominance of professionals and service providers in the formulation of disability policies and implementation of programmes (DeJong, 1979). The Independent Living movement

was influenced by the civil rights movement; it called for the granting to disabled persons of the prerequisites for living in the community, such as entitlement to income and medical assistance, educational rights, the right to treatment and other social services (DeJong, 1979). Independent living does not require that a person be able to carry out their routine tasks alone without help from someone else. While tasks are completed with some assistance, the emphasis of independent living is placed on the individual's right to decide when, where and how tasks are performed (Litvak, Zukas & Heumann, 1987).

2.3.2 Caregiving Agencies

Alternatively, some people with disability funded by either ACC or MOH obtain their carers through a caregiving agency service that manages the recruitment process, employment and training needs of the carers. Here, the agency controls the funds that are used to manage the employment of carers. Currently, long term Disability Support Services funded home based support services are delivered by independent providers under contract to multiple funders, the District Health Boards, MOH and ACC. The independent providers number about 110 nationally and are a mix of not-for-profit and for-profit agencies within a largely unregulated industry (National Advisory Council on the Employment of Women, 2010). Some of these agencies share similar stated philosophies which are to provide consistent, quality individualised care to their consumers in order to meet their needs, lifestyle, cultural values and spiritual beliefs. Some of these agencies provide services 24 hour per day, seven days per week, with the backup of a registered nurse to be available for their staff and consumers. Other agencies are backed up by area supervisors (who do not necessarily hold a health sector qualification).

Several of these agencies provide an opportunity for the person with SCI to be involved in the recruitment of their potential carers claiming that it is important the person with SCI continues to make decisions regarding their health, and caring for themselves with the appropriate assistance and support. However agency-directed models may offer fewer choices over who is hired, daily scheduling, the types of services to be performed, or how the services are performed (Hagglund et al. 2004).

Based on my experience within the NZ context from the onset it is clearly emphasised the carers are employees of the agency and the agency will manage all employment

matters associated with their carers. Consumers are encouraged to redirect issues such as rosters, wages, and dissatisfaction back to the agency rather than the carer.

Recruitment and retention are ongoing issues for NZ agencies (Managing Directors, Nursing NZ Caregiving Agency & McIsaac's Caregiving Agency, personal communication, 2010). Initial training and mandatory on-going training is provided to carers employed by agencies.

2.3.3 Comparison of consumer-directed and caregiving agency services

Despite the common use of attendant care services, there have been few studies which investigate the outcomes of satisfaction of various types of personal care delivery (Benjamin, Matthias, Frank, 2000). As discussed earlier, two models of obtaining personal care exist in NZ yet there is no known NZ study that has explored and compared the outcomes for these models of personal care delivery in the home environment for those with SCI.

The primary objective of a study undertaken by Hagglund et al. (2004) in Missouri, USA was to compare self-reported outcomes of individuals in consumer directed personal assistance services with outcomes of individuals who use agency-directed personal assistance services. These researchers had hypothesised that persons participating in a consumer-directed programme would report fewer unmet service needs, more empowerment and satisfaction with carers, higher perceptions of safety, and enhanced quality of life than individuals in an agency-directed programme. A convenience sample was used for this cross-sectional study. Sixty one individuals with physical disabilities who received consumer-directed services and 53 individuals with physical disabilities who received services through an agency-directed model were recruited. Face to face interviews were conducted in the home using adapted versions of internationally recognised instruments: The Consumer Questionnaire, The Patient Satisfaction Questionnaire, The National Home Care Survey and The Quality of Life Questionnaire. Based on the existing literature independent and outcome variables such as socio-demographic, health and function, and service experience, empowerment, satisfaction, safety, quality of life, and unmet need factors were chosen.

As hypothesised by these researchers, the results indicated that participants in consumer-directed personal assistance services reported more empowerment and satisfaction compared to those in agency-directed services. Participants in the

consumer-directed program reported more community living satisfaction because their carers were able to leave the home to go shopping or attend medical appointments with them, unlike carers employed through home care agencies who were restricted to providing services in the consumers' home. Whilst there were no differences in the quality of life between the two groups on the direct comparisons, enrolment in a consumer-directed programme was a predictor of enhanced quality of life in the hierarchical regressions. These results were important as they revealed positive outcomes from the consumer-directed group, and in terms of costs, as the consumer-directed programmes do not inherently cost any more than agency-directed services. A strength of this study was one of the inclusion criteria stipulated that all participants had current, or past experience of receiving personal care through an agency-directed programme. A potential bias and limitation of this study is the possibility that this was a self-selecting group (consumer-directed group) who were likely to be more innately autonomous than those in the agency-provided group. This could have been addressed by undertaking a randomised control trial to explore this topic.

Findings in Hagglund et al.'s (2004) study were in line with an earlier observational study by Prince, Manley, and Whiteneck (1995) who wanted to determine whether a population of people with high level tetraplegia in USA had differences in health status, costs and perceived quality of life if they used agencies for their care or used a consumer-directed model. A survey was used and telephone interviews conducted with 29 individuals who received their care through an agency and 42 who managed care independently. Multiple regression analysis was used to control for potentially confounding group differences. The self-managed group demonstrated statistically significantly better health outcomes, such as fewer re-hospitalisations for preventable complications.

It is important to note however that direct payments for personal assistance may not be ideal for people who have difficulty finding a carer, administering their services, negotiating or giving instructions (Pijl, 2000). Many people requiring personal assistance in one form or another do not want or are incapable of assuming complete control over service delivery (Nosek, 1991).

2.3.4 Paying family members, friends or strangers to be a carer

Currently the MOH does not pay family members to be carers to support severely disabled people, but will pay for non family members. In 2010 The Human Rights Tribunal claimed the MOH practice in this area was unlawful discrimination in that otherwise available and willing carers are excluded from being paid for disability support services by reason of their family status. Further, disabled people who are eligible to receive paid disability support services were judged to be denied the opportunity to choose to have their parent, spouse or resident family member as their paid carer by reason of their family status. Family status, in this case being a relative of a person – is a prohibited ground of discrimination in the Human Rights Act 1993. Such an implicit social contract that influences a national consensus was not accepted by the Tribunal, as invoked by MOH as the main reason for its policy precluding payment. The Tribunal noted that there is a general societal expectation for family to be the prime caregiver for infants and children without major disability, and their natural support until they reach adulthood. However, it was not regarded as natural for such support for personal ‘care’ to be carried into adolescence and adulthood.

The Ministry’s justification for its policy and practice is on the basis that it reflects the implicit social contract between families and the state under which families are recognised as the fundamental unit of society. The Crown does not pay families to look after their own. To support the MOH argument a number of other specific reasons to back up this policy were given which included that the policy encouraged the independence of disabled people, avoided professionalising or commercialising family relationships, avoided families becoming reliant on the money, avoided unsustainable ‘care’ burdens and social isolation of family members, and ensured that services met quality standards (Carers NZ, 2010). This Human Rights case of the funding of family carers is currently under review.²

However, unlike the MOH, ACC employs family carers including parents and spouses, to provide disability support services to family members permanently disabled by injury. ACC is required to do so under its own legislation, which was reviewed in the 1990’s as historically it did not pay family members who provided personal care

² On 14 May 2012 the Court of Appeal confirmed that the MOH’s policy prohibiting close family carers from being eligible to be paid to provide care for their adult disabled children is a form of discrimination that cannot be justified. The NZ government accepts the conclusion of the Court of Appeal and has indicated that MOH’s current policy will change.

(ARCIC v CAMPBELL, 2005). More than half of ACC's home support services are provided in this way (Chang & Chapman, 2009), as an integral part of its care strategy in the home setting. It uses a 'reasonableness' test in ascertaining what 'natural supports' are. To date, ACC has considered the age of 14 years as the limit for paid care (Chang & Chapman, 2009).

While not facing the same beaurocratic problems as hiring family members, some authors have suggested that there may be risks associated with hiring friends as care providers (Matthias & Benjamin, 2008; Vasey, 1996). Geron (2000) noted preferences might not necessarily equate with the 'best' quality of care but rather be based on relational aspects of care. The recipient of care might be less likely to complain about the services they receive or to criticise assistance that is less than acceptable. In contrast, it has been suggested that in terms of quality of life, hiring friends as carers may offer an optimal approach to meeting both functional and emotional needs, especially given the high rates of unmet needs for social participation among community-dwelling persons with disabilities (Matthias & Benjamin, 2008).

To investigate this issue, Matthias and Benjamin (2008) surveyed 511 consumers of self-directed home care services in California, USA who hired friends, family members, or strangers as carers. Analysis of the consumer experiences showed statistically significant differences favouring the family group over the friends group which reflected the consumers' assessment of their sense of security and of the workers interpersonal manner in the service relationship. Group comparisons found those who hire friends, when compared with those who hire strangers, were more positive on all satisfaction outcomes. Friends were considered the next best thing to family members as carers in terms of stability: length of employment, being available to provide support at short notice, and the nature of the interpersonal relationships where they value honesty, communication, commitment, and compatibility. As Matthias and Benjamin (2008) suggested, it is perhaps not surprising that family members, who have some additional degree of obligation, are more stable workers over time. Although friends do not necessarily experience the same degree of obligation as family members, friendship ties also appear to matter nevertheless.

2.3.5 Training needs for carers & individuals with SCI

Training which addresses how carers might best facilitate interaction between their clients and others, by learning how to communicate appropriately with people who have a disability and viewing them as experts of their own experience, was the recommendation made by both Bondi (2008) and Schoop et al. (2007). Such skills were considered more important than personal care and technical skills such as knowing how to operate a hoist. Bondi (2008) suggested that when caregivers and care-receivers accurately empathise with each other, or where caregivers empathise accurately with those for whom they care and do not need reciprocation from them, good communication ensues. Conversely, disagreement exists as to whether empathy is an emotion or experience that can be taught as a skill and thus can be made to happen or, alternately that cannot be taught (Davis, 1990).

Boucher et al. (2010) conducted a systematic review of strategies for training carers to improve the quality of service they offered to people with SCI. Six intervention articles involving facilitation of the individual to direct their own attendant care were identified and included in the review. These included one random control trial, one prospective study, two pre-post studies, one case series and an observational study.

The key findings from Boucher et al.'s systematic review were that: goal-directed occupational therapy can achieve gains in role performance and improvements in life satisfaction, participation in an educational intervention may reduce re-hospitalisations; counselling on proper technique and hygiene for at least one session might reduce the risk of UTIs; workshops for carers and consumers can increase knowledge about SCI; and directing, training, and financing one's carer may lead to financial savings, better health outcomes, and increased life satisfaction (Boucher et al., 2010). However, a limitation of this review is that only one study was experimental making it difficult to reach any firm conclusion about what type of training would actually result in improvements in service delivery.

2.4 Issues related to paid care provision

2.4.1 Psychological adjustment and coping following SCI

Another issue when considering outcomes and possible difficulties individuals may encounter when first managing paid care relationships, concerns psychological adjustment to the SCI.

Research has suggested that people generally adjust well after sustaining a SCI (Boschen, Tonack, & Gargaro, 2003; Chevalier, Kennedy & Sherlock, 2009, Galvin & Godfrey, 2001; Krause & Crewe, 1991a; Mayer & Eisenberg, 1982; Siosteen, Lundqvist, Blomstrand, Sullivan, & Sullivan, 1990b; Pollard & Kennedy, 2010). It is however, difficult to determine with any certainty how long this process takes. Studies that have investigated adjustment after SCI utilise a variety of research designs and assessment tools that make comparison difficult. While the Pilsecker (1990) study suggest that problems associated with adjustment may resolve quickly other literature suggests the process might take much longer. For example Fukunishi, Koyma and Tobimatsu (1995) claimed that even seven years after injury, many individuals had still not reached complete psychological acceptance. Nevertheless, many factors have been associated with successful adjustment following SCI including: emotional maturity, education level, level of family or social support, financial status, access to the environment, perceived locus of control, levels of self-esteem and level of participation in leisure activities (Boschen et al., 2003; Dorsett, 2001).

Of particular relevance to this thesis are the papers by Laskiowski and Morse (1993) and Dewar and Lee (2000) because of their unique descriptions based on qualitative studies and their relevance to important aspects of the adjustment and coping experience of persons with SCI in relation to how these possibly impact on paid care relationships.

The central themes of hope and despair emerged in an ethnographic study conducted by Laskiowski and Morse (1993) of people with SCI residing in a long-term facility. Individuals with SCI expressed that they had no choice but to reconcile themselves to their situation and that acceptance was possible even under disagreeable circumstances. These researchers also noted emotional responses to SCI frequently were feelings of anger and helplessness. A common defence mechanism among individuals were swearing and cursing. Swearing was considered an expression of despair. In their view,

expressions of despair were part of the process essential to the modification of hope, and the process of learning to accept a change of life and in some cases dependence on others.

Using a grounded theory method Dewar and Lee (2000) examined how 28 individuals, who had lived with catastrophic illness and injury for duration of three to 25 years, managed their personal and social world. The results from their study indicated individuals experienced three phases in learning to adjust to their situation: *finding out, facing reality, and managing reality*. Rather than the phases progressing through stages, the phases flowed together and were re-experienced continuously. Individuals employed three strategies – *protecting, modifying, and boosting* - in all the phases in order to help them endure their circumstances and improve their feelings. *Protecting*, involved insulating one's self, from experiencing further emotional pain stemming from interactions with others by being as self-reliant as possible. *Modifying* strategies meant learning to manage the physical, emotional, and social aspects of their condition. This involved learning new skills and learning to revalue the abilities they still possessed. The third principal strategy *boosting*, was the efforts made to enhance their self-esteem by developing various self generated strategies to encourage themselves, this often included comparing one's self with others who they believed had worse circumstances to bear.

2.4.2 Relationships between paid carer and people with SCI

Several studies exploring relationships between carers and disabled persons have revealed that there is unique aspects of the relationship between carers and the disabled people they work with (Ahlstrom & Wadensten, 2010; Allen & Ciambrone, 2003; Browne & Russell, 2005; Glendinning, Halliwell, Jacobs, Rummery, Tyrer, 2000; Matsuda et al., 2005; McCluskey, 2000; Meyer et al., 2007, & Woodlin, 2006). The relationship that people who use personal care services have with carers, care agencies and funders may directly or indirectly support or hinder their ability and opportunities to participate in society (Meyer et al. 2007). Whilst several of these published studies have not solely focused on the experience of those with a traumatic SCI the findings have relevance to the SCI population within NZ as some needs are generic.

The next sections (2.4.3, 2.4.4 and 2.4.5) provide an overview of the qualitative research on the perspectives of people with disabilities and paid carers regarding these service relationships. To provide some structure for this section I have put the findings into three main categories. First, maintaining autonomy. Second, relationship boundaries: in terms of friendship and intimacy. And third, the factors that positively influence the relationship and reported obstacles to the success of this relationship.

2.4.3 Maintaining autonomy

Maintaining one's personal autonomy following disability is an area of extensive exploration. In the early days following injury a person with SCI is likely to experience a loss of autonomy. Even the sense of having choices and the opportunities of being able to act on the choices can be lost (Hammel, 2006). Cardol, De Jong and Ward (2002) point out that autonomy is not a state of being; rather something individuals develop in the course of their lives. Being dependent on others in one's daily activities after a SCI has been described as demanding and frustrating when one's autonomy, formally taken for granted, suddenly disappears (Lohne & Severinsson, 2003).

To investigate the experience of disabled people receiving assistance Meyer et al. (2007) conducted a phenomenological study involving in-depth telephone interviews with seven men and four women with a range of physical disabilities including SCI, cerebral palsy, multiple sclerosis and muscular dystrophy. Participants' ages ranged from 27 to 64 years. Participants' accounts included experiences of various types of service provision, including agency-based and consumer-directed personal care assistance. Arguably, face to face interviews may have generated more descriptive data.

A hermeneutic analysis identified eight themes. Participants found the initial introductions and training of new carers as onerous, burdensome and frustrating at times. This stage involved setting ground rules when the consumer and carer first met as strangers, including negotiating issues of privacy and dignity. This enabled the person with disability to train their carer and ensured that they did not take over or treat the consumer's home as their own. Central to this was the emotional and physical energy required to be put into training, and the developing of 'trust' in the carers' ability to help them feel safe when assisted with physical body tasks. However, once carers became familiar with their routine fewer directions were required. Providing

directions and making an effort to control the assistance was correlated to the quality of care the participants received. Vigilance and monitoring what the carer was doing was identified as essential in order to prevent the consequences of secondary conditions. However, it was reported some carers took offence when the person with disability asked for something to be done in a certain way. Misunderstanding occurred when the carer interpreted instructions as being told what to do, thus creating tension between both parties. The results from Meyer et al's (2007) study confirm people with disability want their personal autonomy facilitated when they received assistance.

Interested in learning the perspective of people providing care Ahlstrom and Wadensten (2010) interviewed 32 carers who worked for people with serious neurological diseases living at home in Sweden. Thematic analysis highlighted the importance of empathy and sympathy in the encounter between carers and disabled persons. Carers considered they needed to be perceptive regarding the unique needs of the disabled person, have the ability to understand the situation of the disabled person and to be capable of feeling and thinking as though one were the other person. The carers gave examples of negative experiences in the relationship where they felt like an outsider, felt exploited not only by the recipient of care, but by relatives of the disabled person, and feeling inadequate because of powerlessness and mental exhaustion. The researchers reported carers expressed an aspect of empathy with a tendency to objectify the disabled person, making general statements such as, "I usually try to imagine how I would react if another person helped me at home and made decisions for me" (p.185). Sympathy was expressed as emotional experiences for example: "Her face will light up with a smile and then you melt like butter and that's enough. A small thing like that is enough to live on for a very long time" (p.185).

However, the papers by Meyer et al. (2007) and Ahlstrom and Wadensten (2010) gave contrasting views of what constituted a successful carer relationship. One participant in Meyers et al.'s (2007) study wanted her carers to take the place of her hands and follow her instructions. Conversely the carers in Ahlstrom and Wadensten, (2010) study did not like feeling as if they were being used as 'tools' by their disabled consumers. As one carer put it: "I mean going to a job and being a pair of arms and a pair of legs – well, you can leave your head at home" (Ahlstrom & Wadensten, 2010, p. 184). As a result, this carer may have experienced a sense of being invisible, depersonalised and found her work lacking stimulation and meaning, a situation which perhaps risks higher

worker turnover. Working successfully as a carer, according to Ahlstrom and Wadensten (2010) involved ‘being there’; not just in the physical sense, but also in terms of communication and understanding. Carers have abilities which disabled people lack, which is the primary reason for the relationship. Therefore the relationship is said to be asymmetric (Ahlstrom & Wadensten, 2010, p.185). Ahlstrom and Wadensten (2010) concluded that carers in their study may lack knowledge and experience with respect to how to allow disabled persons their self-determination and power over their own lives. Ahlstrom and Wadensten (2010) suggested further research is required in the area of ‘empowerment’ in respect of the personal assistant service.

Offering a psychotherapeutic perspective Bondi (2000) emphasised the importance of valuing and respecting the knowledge and feedback provided by the recipient of care, and of recognising the complexity, emotional richness, and importance of relationship skills through which care is given and received. Bondi (2000) suggested that wherever interpersonal contact exists, the quality of care relationships is not dependent solely or even primarily upon the ability of the carer to deploy expert knowledge about care needs; the relationship itself is also vital because it is through this that needs and feedback about care are communicated. This communication is multi-faceted and it may be “verbal, visual, tactile, intuitive, tacit, unconscious, emotionally laden and cognitive” (p.62).

2.4.4 Relationship boundaries – friendship and intimacy

The challenges of blurred boundaries between formal assistance and informal care are not a new issue. Health care delivery that occurs in the private home is fertile ground for the convergence of formal and informal roles, and such boundary crossing has even been considered essential to providing enduring personalised care (Allen & Ciambrone, 2003; Matthias & Benjamin, 2008; Woodlin, 2006). Conversely, Vasey (1996) noted that while it may be deemed essential for caregivers and consumers to become friends, many organisations advise against such transactions, believing that consumers and carers may become vulnerable to exploitation and interpersonal consequences.

The literature examining friendship, within or outside care giving, following SCI is sparse. However following a recent Australian study a theoretical framework for understanding friendship processes following SCI was developed (Kendall, 2008). Kendall (2008) adopted a constructivist grounded theory approach to inductively

explore the challenges with maintaining and developing friendships following SCI within hospital and community settings. Diverging life paths for people with SCI and their friends were identified as a particular problem resulting from enforced separation and 'priority drift'. Specifically, following injury, friendships were separated at a physical, social, and cognitive level through processes of environmental separation, role separation, identity separation and interactional separation. From the time of injury, friendships started to experience priority drift, in that friendships declined in priority because of immediate need, the vulnerability of the new world, facing the unknown and reality shifting over time. The diverging life paths presented an ongoing challenge for friendships. This study however, did not explore friendships that began after SCI, such as the complexities of friendships with people who started as carers and became friends.

A comprehensive phenomenological study taken by Woodlin (2006) to explore the relationships between 50 disabled employers in the UK and their carers, family and friends, investigated how and why social relationships develop in circumstances where disabled people employ carers to help with aspects of daily living. Through interpretive analysis of semi-structured interviews, Woodlin (2006) identified that friendship which evolved between carers and their disabled employers had the capacity to develop in a more formal or informal direction over time, and friendship was a consciously chosen relationship.

Friendship has been viewed as important because friends help us understand the purpose of our life (Knickmeyer, Sexton & Nishimura, 2002). Boydell, Gladstone and Crawford, (2002) and Vandell, (2000) both stated that having friends is considered to be a normal and desirable part of life. Becoming and being friends is achieved informally, often initiated spontaneously and developed by mutual negotiation. It would appear friends are typically regarded as friends because of appreciation of something about the qualities of the person and the pleasant quality of interaction with them. Definitions of friendship in the literature range from formal definitions, to lay definitions, and from superficial to intimate (Kendall, 2008), with many elements of friendship and no clear agreement about what makes the greatest contribution to wellbeing. Despite the various definitions of friend, the voluntary nature of the friendship bond appears to be a common factor, with most researchers perceiving friendship as a close, intimate affective relationship between individuals that is based on reciprocity, feeling accepted, a sense of belonging, feeling able to take it for granted

that we are known, valued for ourselves and cared about by people that we know (Boydell et al, 2002; Jamieson, 2008).

Some relationships between consumers and their paid carers who are strangers begin formally and then become friendships, and friendship may have some impact on care (Matthias & Benjamin, 2008; Woodlin, 2006). Allen and Ciambrone (2003) examined five case studies illustrating interactions and relationships between people with disability and their caregivers, using interview data collected as part of a community study of disability conducted in the USA. They found those respondents who lack strong familial and friendship networks came to rely on their formal caregivers for emotional as well as instrumental support. Matthias and Benjamin (2008) similarly reported the consumer can easily begin to perceive the carer more as a family member than as a stranger and paid worker. Such personal bonding may be important for good quality services in the home environment as a caring relationship may contribute to better meeting consumer needs. In counterpoint, becoming friends can result in blurred boundaries, where the consumer may no longer be able to act effectively as an employer/boss and may be less likely to complain about inadequate service.

In addition to tension between the personal and professional roles, there can be problems of asymmetry, where the obligations between consumer and worker cannot be balanced. For example, the consumer may be more self disclosing with the carer than the carer can be with the consumer, where the carer sees their contact with consumers as obligatory, the stuff of their paid employment. This was reinforced by an ethos of maintaining professional distance (Jamieson, 2008; Matthias & Benjamin, 2008). In Ahlstrom and Wadensten (2010) study a good ‘personal chemistry’ was considered important where they were able to share feelings and interests with the disabled person thus providing positive confirmation of his/her relationship with the person. However, the carers’ dilemma is to distinguish between what is a working relationship and what is personal friendship. For some of the carers who found themselves in this borderline area between the paid worker and a friend, feelings and events were viewed as negative and unacceptable (Ahlstrom & Wadensten, 2010).

‘Paid friendship’ was discussed by Woodlin (2006) for several important reasons. First, personal tasks, such as bathing, were considered more comfortable when an informal relationship existed. Second, as the recipients of care could require many hours a week

of assistance, there would be little sense of home life if carers were not incorporated into it. Third, ‘paid friendship’ also arose when the person with disability did not receive enough assistance hours, therefore having a need to ask for favours outside of working time (e.g. driving or other help), and because favours were often returned (e.g. helping carers children with homework). Woodlin (2006) concluded from her study findings that:

The construction of carers as either friends or employees is shown to be a purposeful management strategy for many rather than a personal failing with decisions being made in the structural context of family life and the public understanding of Independent Living (p. ii).

On a related subject, Browne and Russell (2005) were interested in how the sexual well-being of people living with physical disability was facilitated or denied in community care, and what impact these sexual needs had on the relationships with carers. In Browne and Russell (2005) ‘sexual well-being’ was conceptualised broadly as the capacity to enjoy and control sexual behaviour in line with a personal and social ethic. Six men and six women were recruited. Seven had an acquired disability, and five experienced congenital disorders. Each person participated in one personal interview and one teleconference group interview. Participants were also asked how they managed the relationship between carer as worker, and carer as friend, or lover. They were asked whether they had ever ‘crossed the line’ (referring to having a sexual relationship with someone who originally was employed as a carer and not a sexual partner), and how they responded to that situation. All participants acknowledged the importance of drawing a ‘line’ between carer as worker, and carer as friend or lover. However, the data in this study showed that the participants’ ‘line’ was not always consistent with organisational understandings of professional boundaries. For participants, the ‘line’ was dynamic. It shifted depending on a range of personal, social, economic and environmental factors. Examples of crossing the line included participants giving money to carers, providing carers with emotional support, and for some participants engaging in a sexual relationship with a carer. Interestingly, several participants described how they were in control of maintaining this boundary between themselves and their paid carers.

Some participants said they would terminate a carer's contract if they became attracted to a carer. Other participants reported that when they experienced desire for a carer, they would 'cross the line' only in their head rather than act on this desire. The men were also aware of the possibility of sexual harassment claims in such sexual relationship with carers. Only one female participant in Browne and Russell's (2005) study said she had experienced a sexual relationship with a carer. This female participant later married her carer. Most women in this study had not, and said they believed they most likely would not have sex with a professional carer. Female participants all agreed that men with a physical disability had more opportunities to have sex with carers because "most carers were women" (p. 384).

For many with disability the potential to meet new partners, and go on dates would require assistance from their carer. However, findings from the Woodlin (2006) study suggested that the presence of a carer was intrusive and could put off new partners. Some carers resented the appearance of a new partner, although other carers supported, and encouraged sexual relationships. Furthermore, the men in Woodlin's study were more likely to view carers as potential partners: three of the 11 men in the study had formed a personal relationship with a carer in the past, but none of the 19 women. Relationships had also formed between carers and family members in some instances, and when these ended it could cause friction in working arrangements with the recipient of care when these relationships ended. Boundary issues, by their very nature, involve two people. Usually the onus is on the employer in employer/employee relations to behave in a trustworthy manner. However for some this issue is somewhat complicated as the person with SCI has two roles: consumer and employer.

The results from the studies above (Ahlstrom & Wadensten, 2010; Browne & Russell, 2005; Meyer et al., 2007; Woodlin, 2006) and others (Allen & Ciambrone, 2003; Glendinning et al., 2000; McCluskey, 2000) give evidence that inherent to the home environment are a multitude of complexities in these close relationships. The interpersonal nature of these relationships can lead to blurring of boundaries, and dilemmas between maintaining a professional relationship and elements of friendship.

2.4.5 Factors influencing successful consumer-carer relationships

In order to explore the barriers and facilitators to successful carer provision, Matsuda et al. (2005) analysed transcripts from five focus groups conducted with 24 consumers with SCI and 15 carers. Close, positive relations with carers were considered valued by the recipients of care, with consumers preferring carers who demonstrated positive personal qualities including commitment and empathy - people who “would stay in the job” and “people with heart” (p.71). Also desired were trustworthiness, good listening skills, loyalty, compassion, respectfulness, and likeability.

Disabled people in Matsuda et al.’s (2005) study gave preference for carers who were experienced or easy to train, possess a sense of humour and were willing to do more than the job description. Conversely, participants Meyer et al. (2007) study stated a preference for inexperienced carers, citing that this gave them greater control over the formal assistance they received, believing those with prior training tended to not follow their instructions, opting instead to undertake tasks in the manner they had formally been taught. The ability of people with disabilities to articulate their needs to the carer was identified as an advantage and a key aspect of being autonomous when receiving personal care assistance.

Obstacles to a successful working relationship reported by consumers in Matsuda et al. (2005) study were clustered around: carers’ attitudes and aversions to tasks; rules and regulations set down by the care service providers, difficulties finding reliable employees, problems with carer scheduling, dependability, staff turnover, and difficulties for the consumer in finding consistent transportation. Not being able to retain a dependable carer created a crisis for many of the consumers. Low wages for carers saw some consumers personally contributing financially to their carer as a means to retain their services. Poor pay rates for a carer is a well-known issue in NZ and internationally, as are limited benefits, little opportunity for career advancement, and high occupational stress (Jorgensen, Parsons, Gunderson, Weidenbohm, Parsons & Jacobs, 2009).

Having outlined the influences on and characteristics of successful relationships, I now consider abuse relationships.

2.4.6 Mistreatment

Abuse may take many forms, often being subtle, insidious and difficult to recognise (Heilporn, Andre, Didier & Chamberlain, 2006; Macfarlane, 1994). In this thesis the term ‘mistreatment’ encompasses violence, exploitation, theft, neglect and physical and verbal abuse of consumers by their carers. While known to exist, there is a paucity of data available concerning the mistreatment of consumers by their carers.

Adults with disabilities are vulnerable to mistreatment by providers of personal assistance due to their physical dependency, the greater the degree of dependence on others, the greater the potential for abuse and exploitation (Pharris, 1999). A survey of women with disabilities in the 1990s conducted by Berkeley Policy Associates found that women with disabilities were more likely to experience abuse than women in the general population by health care professionals, paid carers, family members, intimate partners, or friends (Curry & Navarro, 2002). Children and elders with disabilities were also identified as particularly at risk of being abused by those responsible for their care.

A USA cohort study of 439 women with physical disabilities and 421 without physical disabilities explored experiences of emotional, physical, or sexual abuse (Young, Nosek, Howland, Chanpong & Rintala, 1997). Young et al.’s (1997) data suggested that husbands or live-in-partners were the most common perpetrators of emotional or physical abuse for both groups. Male strangers were the most common perpetrators of sexual abuse for both groups. Women with physical disabilities also were more likely to be abused by their carers and by health care providers. Thirteen percent of women with physical disabilities described experiencing physical or sexual abuse in the year prior to the study.

Similarly, Saxton, Curry, Powers, Maley, Eckels and Gross (2001) investigated the perceptions and experiences of American women with physical and cognitive disabilities related to abuse by formal and informal personal assistance providers. Focus groups and individual interviews were conducted with 72 women (11 with SCI) to explore how women defined abuse, the barriers they faced in handling abuse and strategies they recommended to prevent or stop abuse. Findings suggested that, with experience, support and appropriate resources, women with disabilities effectively managed this challenge.

Interested in the prevalence and types of mistreatment by carers experienced by disabled adults in the UK Oktay and Tompkins (2004) undertook a telephone survey of 84 adults with disabilities (60 male and 24 female, aged 19 to 78 years) who received personal assistance from family members or agency personnel. Findings showed that 30% reported mistreatment from their primary provider, and 61% reported mistreatment by a secondary provider.

Verbal abuse was the most frequent type of mistreatment reported, with 18% of the respondents reporting verbal abuse by their primary provider and 29% reported by another provider (Oktay & Tompkins, 2004). This included experiences where the carer spoke rudely or harshly, or in a way that made the consumer feel bad about themselves. The most common were reports of being spoken to like a child or having requests ignored. Others examples ranged from minor expressions of irritation to more severe verbal abuse where carers shout insults and curses. Reported examples included: “You’re a crippled bitch!” and “Stick it up your ass!” (Oktay & Tompkins, 2004, p.181).

Neglect, a common type of abuse experienced by children and older adults was also reported by Oktay and Tompkins (2004). The main problem respondents reported were pressure sores caused by a failure to check skin thoroughly. The second most common problem reported was urinary tract and bladder problems caused by carers’ failure to change leg bags promptly or to keep the respondent hydrated. Poor care techniques were reported, for example transfers that resulted in falls, infections and rashes from poor sterilization techniques, burns from being bathed in water that was too hot, and dehydration resulting from improper feeding. There were also reports of carers arriving late or rushing through physical tasks. It was clear from Oktay and Tompkins (2004) that failure to provide prompt, regular and competent ‘care’ can result in serious medical problems for recipients of care. Extortion and theft by carers was also another form of mistreatment that was reported as taking place. Money, jewellery, medicine, clothing and alcoholic beverages were among the things reported as stolen. It seemed that male providers were more likely to mistreat, as were providers who were inexperienced and who provided more than 50 hours of care per week.

The most serious forms of mistreatment reported by the respondents were physical and sexual abuse. Examples were given of physical abuse ranged from rough handling,

hitting, slapping or punching. The reported incidence of respondents having ever experienced sexual abuse in Oktay and Tompkins' (2004) study was 11%. Examples included one case of rape, but in other cases, unwanted sexual advances such as carers who "spend too long bathing certain areas", or "had an oral fixation" (p.182). The researchers highlighted that as with physical abuse, sexual abuse can be complex and difficult to define.

The extent to which New Zealanders with disability experience mistreatment by carers is unknown. Nevertheless, at least four cases of abuse by a paid carer in home environments in the last 13 years were reported to the NZ Health and Disability Commissioner (NZ Health & Disability Commissioner, 2010). These cases included reports of inappropriate sexual relationship, sexual abuse, aggressive and abusive behaviour, theft, arriving late to provide evening care, consuming alcohol, smoking in the consumers' bedroom, staying late to socialise with flatmates, and using inappropriate force during the process of getting the consumer to bed. Some cases of significant abuse had a high profile in national media. In 2005, for instance, a 56 year old man with tetraplegia living in NZ was killed. His paid night male carer for four nights a week at the time and reported longstanding friend was charged and convicted for his murder (van Beynen, 2010).

Mistreatment can occur in either model of service provision (consumer-directed or agency-provided) as Oktay and Tompkins' (2004) study confirms. These researchers recommended that in order to eliminate all forms of abuse and neglect health professionals must partner with disabled consumers for increased advocacy and education with regards to managing paid care services. They also recommended that more oversight may be required, with stronger regulation of criminal background checks for people applying to be a carer. The need for extensive training and supervision of carers was also highlighted and burnout prevention was recommended for those who provide many hours of care.

2. 5 Summary

In this chapter I provided a review of the relevant literature pertaining to SCI within NZ, and paid caregiving for people with SCI, to elucidate the specific context in which the study takes place. Currently a gap exists in this literature with information on experiences of New Zealanders with SCI regarding managing paid carer relationships. In the following chapter I will discuss the methodology and method, the epistemology and theoretical background of the research and the specific methods used to carry out the research.

Chapter Three: Methods

3.1 Overview

This research project set out to explore, describe, interpret and situate the means by which people with SCI make sense of their experiences of managing relationships with paid carers. In this qualitative study I interviewed seven people with SCI about their experiences of managing paid personal care. My intent was to discover how the participants gave meaning to the phenomena of paid personal care in their interview with me. The methodological approach (Interpretative Phenomenological Analysis, or IPA) was congruent with the positioning of this research as constructivist and interpretative.

3.2 Research design

A research design describes a set of guidelines that connect theoretical paradigms first to strategies of enquiry and second to methods for gathering material. For any researcher, defining the strategy of enquiry is imperative in order to show how he or she intends to conduct their study. It comprises of a set of skills, assumptions, and practices that need to be employed in moving from the paradigm to the real world (Denzin & Lincoln, 2004). Crotty (1998, p. 2) has proposed a framework consisting of four elements which inform and influence one another when developing a research proposal.

These are:

- 1) What epistemology informs the theoretical perspective?
- 2) What theoretical perspective lies behind the methodology?
- 3) What methodology governs the choice and use of methods?
- 4) What methods does the researcher propose to use?

Crotty has argued that epistemology and the ontological concept of ‘what is’ are difficult to keep apart conceptually because they merge together in a research project; therefore, Crotty did not include ontology as a separate element in his framework, although some other frameworks have done so (Guba & Lincoln, 1994). I will use Crotty’s (1998) model to explore these four elements and justify my choice of methodology and method in relation to this enquiry.

3.2.1 Epistemology: constructivist paradigm

For this research project I chose the constructivist paradigm. Crotty (1998) and Gray (2004) stated that within the epistemological concept of constructivism meaning is assumed to be constructed not discovered (as it is in positivism). Different people construct meaning in different ways even in relation to the same phenomenon.

Constructivism is the view that all knowledge is reliant upon human culture, being constructed through interaction between humans and their world, and developed and transmitted within a social context. Humans develop a ‘sense’ about what occurs as they engage with the world they are interpreting. As this ‘sense’ is unexposed to subsequent thoughts, self-interpretation, reflection and attribution of meaning, it facilitates an unadulterated experiencing of the phenomenon.

Constructivism can be seen as a counter-reaction to positivism’s fundamental ontological premise where the aim is to be ‘objective’ and use hypotheses, deductive logic, and empirical tests to produce quantitative data that can be analysed with statistics and generalised to other populations (Neuman, 2000). For the purpose of studying the dynamic and subjective nature of people’s beliefs and behaviours, this ordered approach is not well suited. Qualitative research can provide insights about these phenomena in a way that quantitative methods alone cannot. A constructivism epistemology fits with the research aim of uncovering the experiences of people with SCI who manage paid care services in NZ. For this study the participants own experiences are the key area of research.

3.2.2 Theoretical perspective: Interpretive/phenomenological

Crotty (1998) described the second element that influences a research proposal as ‘the theoretical stance of the researcher informing the methodology and thus providing a context for the process and grounding its ‘logic and criteria’ (p.7). When choosing a qualitative methodology it is thus important to consider a number of important issues. What is it that the researcher wants to discover about a particular phenomenon? What kind of data collection is required? Such questions as these are crucial to consider before choosing the particular qualitative analytical approach to be used (Shaw, 2001).

After reflecting on these questions, this project was approached with an interpretivist stance. Interpretivism contends that the world is predominantly what people perceive it

to be because meaning is subjectively created through interpretations of actions. This approach is inductive, context-specific, and rich in detailed description and is commonly used in qualitative research (Gillis & Jackson, 2002; Holloway & Wheeler, 1996). I selected an interpretative/phenomenological stance as I recognised that the intensive dialogue involved in such an exploration could provide deeper understanding and knowledge to what it meant to have a certain lived experience.

3.2.3 Methodology: Interpretative Phenomenological Analysis (IPA)

This project aimed to say something in detail about participants' experiences of managing paid personal care services, in order to make logical contributions to a theoretical understanding rather than broader claims to a general population. The methodology used was IPA. IPA is concerned with the detailed examination of human lived experience. It aims to conduct this examination in a way which as far as possible enables that experience to be expressed in its own terms, rather than according to predefined category systems. This is what makes IPA 'phenomenological' (Smith, Flowers & Larkin, 2009).

Hermeneutics is the theory of interpretation (Smith et al. 2009). IPA involves a double hermeneutic, whereby the participant is trying to make sense of or find meaning in his or her experiences, whilst the researcher is trying to make sense of how the participant is making sense of his or her experiences or world. Thus IPA combines empathic hermeneutics (in that the researcher attempts to take the viewpoint of the participant by close examination of the transcript) with questioning hermeneutics (allowing the researcher to hold a more detached stance to enable a more critical interpretation of what the participant says or is trying to say).

The 'hermeneutic circle' is concerned with the dynamic relationship between the part and the whole. To understand any given part, you look to the whole; to understand the whole, you look to the parts (Smith et al., 2009, p. 28). A key tenet of IPA is that the process of analysis is iterative; moving back and forth through a range of different ways of thinking about the data, rather than completing each step, one after the other. The idea is that the researchers' entry into the meaning of a text can be made at a number of different levels, all of which relate to one another, and many of which will offer different perspectives on the part-whole coherence of the text (Smith et al. 2009). IPA

also permits the researcher to open a dialogue with the existing literature, an interrogation that aims at the illumination of the theories, while at the same time being inductive, allowing unanticipated findings to emerge.

A major influence upon IPA is idiography. Idiography is concerned with the particular (as in the individual lived experience). IPA pursues an idiographic commitment, situating participants in their particular contexts, exploring their personal perspectives, and starting with a detailed examination of each before moving to more general claims (Smith et al. 2009).

IPA aims to explore personal perceptions and discover how individuals make sense of their personal and social worlds (Smith & Osborn, 2003). Therefore I believe the IPA approach incorporating a hermeneutic idiographic methodology is a particularly appropriate means of analysis for this research with the aim to understand the relationship between people with SCI and their paid carers, which will be subjectively defined according to an individual's experiences. IPA explicitly acknowledges that the previous experience of the researcher will influence the interpretation of the data; as such the researcher's own perspective is relevant and should be considered. This is important to me, as it would be unrealistic for me to believe I could separate myself from the knowledge I have gained through previous clinical experience practicing as an enrolled/registered nurse.

3.3 Method

3.3.1 Participant recruitment

Data collection was based on purposive sampling, where participants were selected from the BSU data base, meeting the following inclusion criteria:

- Having tetraplegia resulting from a traumatic SCI at T6 or above with an ASIA classification of A or B
- Living in the community, in a private home (not support accommodation such as a residential or institutional facility)
- Eighteen years old or more
- One year or more post injury
- Receiving more than 20 hours per week paid attendant care

- Able to take part in the face to face interview, in English, without the need for their paid carer to be present.
- Living in the Canterbury or Southern District Health Board regions.

While there are no set guidelines for the ‘correct’ number of participants in an IPA study, Smith et al. (2009) recommends a sample of about three to six people is appropriate as this number is likely to provide a rich description of the experience under investigation. To capture a range of experiences from the SCI population attempts were made to recruit a mixed sample of both sex; ages, those who obtain their carers via care agencies or privately and length of time living with SCI.

The study coordinator for BSU, who was not otherwise involved in this study posted an information pack with an invitation letter (Appendix, II), information sheet (Appendix, III), expression of interest return slip (and phone and email contact for study coordinator), consent form (Appendix IV) and a pre-paid envelope addressed to the BSU Research study coordinator.

Potential participants expressed an interest in the study by returning the expression of interest slip by post to the study coordinator, or by contacting the study coordinator by phone. Once verbal or written permission was gained for the researcher to approach potential participants, the study coordinator forwarded contact information on to the researcher. If no reply was received from the potential participant within ten days, a follow up phone call was made by the study coordinator to ensure that the information was received (but not to further request participation in the study).

I then made contact with participants who had given consent to be contacted, initially by phone. I introduced myself, informing the individual of the study and its purpose, answering any questions they had. At this time if they gave verbal consent to participation, a time and place for the face to face interview was arranged. Participants were sent a demographic questionnaire details and interview schedule (Appendix V & VI respectively) in advance. The interview topics were sent in advance to allow the person time to reflect on these prior to interview. Written consent was obtained prior to the commencement of the face to face interview schedule.

A total of nine potential participants were sent information packages. Of these, seven agreed to participate in the study. Re-checking contact details held in the BSU database two of the potential participants were found to be incorrect which may explain why attempts to contact them failed.

Participant numbers were not pre-defined other than recommendations of approximately up to six individuals by Smith et al. (2009) but determined by ongoing review with the supervisors of this project in terms of the extent and depth of experience recorded in the interviews. This allowed a sufficient body of relevant and detailed data for undertaking an IPA analysis. A review of the quality of the data took place after the completion of the analysis from the first seven participants. It was considered that a sufficient depth of information was collected, resulting in a total of seven participants.

3.3.2 Development of interview schedule

The demographic and interview questionnaires were developed in consultation with the study supervisors and an individual who had SCI and was also a member of the NZ Spinal Trust (see Appendix V). The initial choice of interview topics was guided by a literature review and guidelines for interviewing in the text by Smith et al. (2009). The aim was to develop a schedule of open ended questions to facilitate a comfortable interaction with each participant which would, in turn enable them to provide a detailed account of the experience under investigation.

As part of the preparation prior to data collection, I was also interviewed by one of my supervisors. This was a valuable experience on many levels. Firstly, to have an experience of being interviewed enabled me to learn some of the principles of interviewing by exposure to the interview style of someone with significant experience and expertise with conducting interviews for research purposes. Secondly, in addition this also gave me an opportunity to plan for difficulties that might have been encountered during data collection (e.g. problems with the digital recorder). Thirdly this enabled another opportunity to revise the interview schedule, with topics being arranged in a more logical sequence. Finally, being exposed to the topic in this manner resulted in an opportunity for me to reflect further on my own position and preconceived thoughts regarding the topic prior to engaging with study participants.

3.3.3 Data collection

Multi-region ethical approval was gained in June 2010 (Approval MEC/10/036/EXP, Appendix VII). Data collection took place between July 2010 and September 2010. The interviews were all conducted by the researcher. Participants were invited to take part in a 60-90 minute face-to-face, in-depth, digitally recorded interview. The interviews took place at a time and location that was convenient to the participant. One participant was interviewed at a friend's residence; another was interviewed on the Burwood Hospital campus, and the remaining five in their own homes. Only at one address was a carer present, but she remained in a nearby room during the interview. At the commencement of the interview I sought demographic information from the participants, including information on their past and current paid care arrangements. This interview schedule was used in a flexible manner, allowing me to pursue relevant questions as they arose, maintaining the flow of the interview, and allowing the development of lines of questioning that had not originally been included in the interview schedule. By establishing a rapport with each participant and being an active listener during each interview I engaged the participant in such a way that rich descriptions of the participant's experience were generated.

The audio files of the face to face interviews were downloaded onto a computer and transcribed verbatim by a typist who had signed a confidentiality agreement (see Appendix XI). Electronic versions of transcripts were password protected. Pseudonyms were used to protect confidentiality, and other data were stored in locked filing cabinet.

3.3.4 Data analysis

Demographic and paid care arrangement details provided a descriptive overview of the participants' situation and their past and current paid care arrangements. These data are presented in the following chapter in Table 4.2.

Transcripts were analysed in accordance with IPA principles, starting with content analysis and then continuing on to refine themes using an idiographic approach to examine and interpret the data (Smith et al., 2009). Throughout the analysis process I attempted to stick close to what the participants are saying, however in IPA the emergence of the themes is viewed as drawing heavily on the researcher's own

interpretative resources. Thus, as the researcher, I was an integral part of the analysis process whereby themes are identified and labelled.

In the first stage of analysis I recorded my thoughts and reactions after each interview into a field book followed by writing a background summary account for each participant. These notes were available to me to consider in the context of later interpretations. The analysis in the second stage was the most detailed and time consuming. I immersed myself in the verbatim transcript, reading and re-reading while making notes of the thoughts and observations that came to mind in the margins of the transcript. Line by line analysis involved looking at the language that participants used, thinking about the context of their concerns (their lived world), and identifying more abstract concepts to help me make sense of the patterns of meaning in their account. Different coloured fonts were used to differentiate between descriptive, linguistic and conceptual comments. Smith et al. (2009) suggest that exploratory comments are not intended to be exhaustive or prescriptive but are presented as useful analytic tools which the analyst may wish to employ. In adjunct to this, the digital recordings were played as the transcripts were re-read in order to recall the participants' voices. At this stage of data immersion one of my supervisors read and commented on each transcript independently from me.

In the third stage I looked for connections by identifying themes that captured various facets of the essence of particular passages of the transcript. For each emergent theme I opened a Word file, giving it a theme title, and pasted all the relevant transcript extracts into this file. This process enabled me to see internal consistency, relative broadness, or specificity of each emergent theme. According to Smith et al. (2009) this can also help develop the local analysis of particular themes. The IPA analysis process is cyclical (Smith et al., 2009), so the above procedure was repeated for each participant.

The next stage involved looking for patterns across cases. Microsoft Word documents were created to describe each theme, where themes were grouped together through a process of cutting and pasting on the computer to create a summary table of superordinate and constituent themes, including quotations to demonstrate their grounding in the data. According to Smith and Osborn (2003) it is important to distinguish clearly between what the respondent said and the researchers' interpretation

or account of it. At this stage, themes which did not pertain directly to the question of interest were dropped from the analysis.

The summary tables were combined into an inclusive list of master themes for all participants. Whilst I continued to interpret the deeper meanings embedded in the data, initial themes were refined and reorganised until the underlying themes became apparent. The newly integrated themes now captured something of the essence of the experience shared by all participants.

In a process of verification, one of the research supervisors (not involved in the data collection) acted as a second reader. The second readers' contribution is to contribute to the interpretative work, confirming the multiple layers of meanings disclosed within the narratives. This audit process helps ensure the quality of the interpretation and provides verification that the research is performed in accordance with stated intentions (Conroy, 2003).

3.4 Ethics

A number of ethical issues associated with this project were considered before and during the process of participant recruitment, data collection, and data analysis. Five particularly pertinent to this study are addressed below.

3.4.1 Process of Maori consultation

Early local consultations with Ranga Hauora Service (Maori Health services for the BSU) were fundamental in the design and structure of the project. This group fully endorsed and supported the study (Appendix IX). A submission was also sent to The University of Otago Ngai Tahu Research Consultation Committee during the development of this study. This feedback was incorporated into this study (Appendix VIII).

3.4.2 Clinician researcher interface and implications

I was employed at the BSU as a CNS during the time of the study, and have been employed at the BSU as an enrolled nurse and registered nurse at various times since 1986. As a result many of the participants knew me in my clinical role or might

potentially in the future. This was addressed within the consent form, where the participants were made aware of who I was and position I held, thus having the opportunity not to participate on this basis. Participants were informed that on subsequent visits to the BSU that it would not affect their future treatment in anyway should they participate or choose not to participate in this research. However, in addition to the above strategies, I also sought a ‘clinical mentor’ for the duration of the research in order to provide a forum where I could discuss any role conflicts between my researcher and nurse roles and responsibilities.

3.4.3 Emotional and physical risk management

The subject matter and content of the interview had the potential to cause psychological distress for the participants. To address this is it was decided that if any participant appeared distressed during the interview, I was to reiterate their right to pause or end the interview at any point, with the possibility of continuing later if desired. Participants were reminded that their participation was voluntary and that they were able to withdraw from the study at anytime. Furthermore, in order to manage the risk of distress, information was routinely provided during the study on access to the NZ Spinal Trust, doctor or counsellors for support. No adverse events occurred during this study; an adverse reporting form was available if needed (Appendix XIII).

3.4.4 Identified abuse or risky health behaviours:

The rights of all persons to life, self esteem, self determination, privacy, and protection from all forms of injury and manipulation are values which govern researchers in their conduct towards those whom they involve as participants/subjects and co-researchers. The first requirement for nurse researchers, just as it is for a clinician, is to work within their boundaries of competence, extending the latter as needed. Research has its own body of knowledge and skills which are not subsumed under clinical competence (New Zealand Nurses Organisation, Research Section, 2010). Cognisance must be given to a possible role conflict between the nurse as an advocate and the nurse as a researcher. Thus, prior to the research, I decided that in the event that abuse or risky behaviours were identified whilst collecting data, this was going to be addressed non-judgmentally in partnership with the participant helping them to take responsibility for their decisions and actions. This potentially included providing additional support such

as reading resources or facilitating the participant's referral to a doctor, hospital, district nurse, or other relevant health service.

3.4.5 Preserving anonymity of participants

As individuals with SCI are a reasonably small population in NZ, there was a risk that participants could be identified in a study report. In the dissemination of information (including the writing up of the thesis) I have tried to ensure anonymity by assigning pseudonyms to participants and by removing identifying features such as geographic location or any potentially identifying situation described. I have tried not to alter the meaning of the participants' experience. Participants were offered the opportunity to see illustrative quotes from their transcript so they could (a) check the interpretation was reasonable and (b) check whether they had concerns about being identified on the basis of the quote.

3.5 Summary

The aim of this study was to look at the experiences of individuals who manage paid care services following SCI within NZ. This research is framed around a constructivist theoretical paradigm. In order to uncover rich descriptions of the many varied experiences and perceptions of these individuals a qualitative research perspective was chosen, in particular IPA which has its roots in phenomenology rather than using a quantitative statistical analysis approach which is concerned with counting occurrences or volumes. IPA methodology was chosen because of its congruence to the theoretical paradigm and the research aim. Seven individuals were recruited. Demographic details and information regarding their current personal care packages was obtained prior to an in depth face-to-face interview. Experiential data from the verbatim transcripts formed the basis for the IPA analysis. This chapter presented the epistemological and methodological considerations of the study and the methods used for this enquiry. Chapter Four will present the analysis and interpretations of the data.

Chapter Four: Results

4.1 Overview

This chapter presents findings from analysis of interviews with seven individuals (four men and three women) about their experiences of managing paid personal care services following a SCI. All the participants had tetraplegia at similar levels and consequent neurology due to a traumatic injury, with a range of experiences of duration of life since SCI. They all required more than 20 hours of personal care assistance a week. Four of the participants utilised a care agency (four different care agencies across this sample) and three used the consumer directed model. Table 4.1 provides an overview of the participants' characteristics.

The participants all used the term 'carer', or 'caregiver' in preference to other titles such as 'support provider/worker,' or 'attendant' for their paid care providers. They reported that they did not consider the term 'carer' implied a custodial role or ableist assumption. In keeping with participants' terminology and for ease of reference within the findings I will refer to those who are paid to provide care as 'carer', or 'caregiver'.

The participants talked of managing paid care services as a complex phenomenon. I liken this phenomenon to a '*maze*' and the participants as a '*pathfinder*' (a person finding their way through unexplored areas or fields of knowledge). Participants followed different paths yet all participants regularly made choices about which way to turn at each decision point in managing their paid care. The three main parts of this phenomenon were labelled: 1) **Finding your way amid challenge, chaos and choice**, 2) **Navigating relationship terrains**, and 3) **Warning: potential traps**. An overview of these themes and their subordinate themes are provided in Table 4.2. Exploration of these master themes and their constituent subordinate themes will form the basis of this chapter. Whilst these themes are thought to represent something of the experience for all seven participants there are convergences and divergences between their accounts. As IPA is idiographic and phenomenological in nature (Smith et al, 2009) the aim of this section is not seeking to make generalisations, but instead to explore the similarities and differences that participants describe. Arguably variations between experiences may tell us more about what contributes to the different accounts that people describe. Verbatim extracts will be used to illustrate how the participants experienced each theme, and to demonstrate how the themes have been grounded in the data.

Table 4.1 Characteristics of research participants

Sex	4 men, 3 women
Ethnicity	6 NZ Europeans, 1 Maori
Injury level & ASIA	2 with C5 ASIA A injuries; 3 with C6 ASIA A injuries; 1 with an C6 ASIA B injury, 1 with an C6/7 ASIA B injury
Age at time of injury	Range: 16 - 32 years; Mean: 26.1 years
Age at time of interview	Range: 21 - 55 years; Mean: 39.4 years
Experience living with SCI	Range: two to 33 years; Mean: 13.8 years
Cause of injury	1 sports injury, 1 work injury, 5 Motor Vehicle Accident
Funding body	6 ACC, 1 Private Insurer
Marital status	5 Single, 1 Defacto, 1 Divorced
Social circumstances	2 live with family, 5 live on own
Living arrangements	3 own home, 4 rental home
Pre-Injury employment	6 employed, 1 school pupil
Current employment	1 voluntary work, 2 early self- selected retirement, 4 unemployed
Main source of transport	3 public transport, 4 private vehicle
Assistive technology use	7 Power Chairs, 2 Modified vehicles, 2 Boilers, 5 Dragon Software, 1 Track Ball & I-phone strap
How often the participants get away from home for social or entertainment purposes	2 Rarely 2 2 times per week 1 3-4 times per week 2 5 or more times per week
Care providers - Past	2 Consumer Directed, 2 Combination of Consumer Directed & Care Agency, 1 Combination of Family & Care Agency, 2 Care Agency
Care providers - Current	3 Consumer Directed, 4 Care Agency
Carers in care package	Range: 6 – 8 carers
Length of employment for a carer	Range: one day – 22 years
Funded care hours per/week	Range: 36 – 168 hours; Mean: 99 hours per week
Hospital admissions for secondary conditions since discharge	3 pressure sores (1 participant 3 hospital admissions) 2 urinary tract infections, 3 pneumonia, 1 bowel issues (1 participant 3 times), 1 dysreflexia, 1 infection

Table 4.2 Summary of themes

Master Themes	Subordinate Themes
PATHFINDER	Finding your way amid, challenge, chaos and choice
	Acceptance of bodily dependence – “<i>the turning point</i>”
	Invasion of Privacy; Loss of Dignity – “<i>just part and parcel of life</i>”
	Self-determination within the context of interdependency
	Navigating relationship terrains
	Follow your “<i>gut instinct</i>”
	Friendship ambiguity
	Intimacy – “<i>a natural process</i>”
	Warning: potential traps
	The multiple faces of vulnerability and its consequences
	Mistreatment

4. 2 Finding your way amid challenge, chaos & choice

This theme encompasses the cognitive and emotional journey of the person with SCI in accepting and adjusting to bodily dependence, and their consequent need for carers. In making this adjustment the participants sought ways to have as much autonomy as possible within a context of bodily dependence. Following a period of rehabilitation individuals left the security of a spinal unit to return to either their pre-accident home, or a new home. Many participants felt unprepared for differences between the spinal unit environment and discharge destination, and lacked skills needed to enter comfortably into a variety of dependence relationships within paid care services. The participants' ability to exercise their self-determination and maintain the locus of control in these relationships involved a combination of skills, self-evaluation, knowledge, learning, problem solving, understanding of one's strengths and limitations, and self-advocacy. The experience of learning to adjust to the need to accept the support of paid carers is covered in the subordinate theme outlined in the next section.

4. 2.1 Acceptance of bodily dependence – “*the turning point*”

Acceptance of needing paid carers in the first instance would seem to be an important part of becoming an expert recipient of care, but this is not something that happens overnight. While the participants differed in terms of the exact length of time required reaching this ‘turning point’ (from hatred to acceptance) in the process of ‘finding ones way amid challenge, chaos and choice’, this was for most participants a long process: years rather than months. Individuals developed various coping strategies to deal with this process, but nevertheless the experience was traumatic:

I was scared and vulnerable, I didn't want people to know that and it came out 'watch out for her she's a moody one' or 'she's this that and the other'. I'm just adjusting to it, I don't know me..... it was really hard. Why do I get spasms? What's dysreflexia? Why does my body not work that way anymore? When you don't have the answers and you have carers that aren't quite um.....what's the word for it.....experienced? Yeah it's a very very scary thing. I think if they just had a little bit more understanding about me and actually put themselves in my shoes for a little bit and have somebody come and take their whole household over.It's not that easy,

but I've got.....coming up seven years.....I think I've got it worked out now, I think I've got it sussed out aye. (Chloe)

Participants described in the early period after first returning home they often vented anger about their situation towards their carers. This was from their perspective an emotional reaction to their situation. Participants spoke in rich detail of experiencing a range of emotions as they mourned their former self, and lost independence when first discharged from a spinal unit to this present time:

I wanted that old lifestyle back but I couldn't have it, unfortunately my carers were the closest people there in the morning. I was very frustrated and I was swearing a lot and swearing at them. (Jane)

Participants talked about a journey of self-evolution from the person they were then, when newly injured to the person they had become by the time of interview. As life with SCI progressed participants described coming to the realisation they must reconcile their anger in order to receive the care they needed as being angry did not make the need for care go away. Part of this realisation was reaching an understanding that people with SCI have to actually take some responsibility for their relationships with carers, or they just did not work:

I was pretty much in a place where all the agencies didn't want to take me on and I had to realise that I did need these people in my life and that was probably a very big turning point for me. (Jane)

Nevertheless, the sense of loss associated with SCI did not disappear with this realisation. Repeated use of the word 'hate' by many participants seemed to reflect the magnitude of the 'loss' experienced when they become dependent for even the most taken for granted activities such as showering, dressing, or going to the toilet.

Acceptance and hate appeared to be experienced concurrently. John explained despite the fact 16 years had passed since he sustained his SCI he still intensely hated his need for care, but he had learnt to manage his 'hate':

I hate it basically.....the bottom line is.....I can't do anything about it. I can't get out of bed; I can't lead a life unless I have them do it so it's just a part of the day that you almost shut your mind off and grind your way through it so you can get on with the part of that day you enjoy.....Ohhh.....I still hate

it but I can compartmentalise it better now, I can sort of break it down into small chunks and so yeah.....the hate is there but that's just something I'm dealing with better than when I first had my accident. (John)

As part of dealing with his “*hate*” he described “*compartmentalising*” his care needs. Having compartmentalised his situation in this way there was a sense almost of mourning of his formerly taken for granted independence. This may be considered a coping strategy whereby compartmentalising separates the negative things that need to occur (assistance with personal care) in order to be able to concentrate on the positive. Similarly, Jane clearly recalled her ‘*hate*’ describing early experiences of being with carers. There is a clear theme within her account that resignation to having a carer really was not a choice or option but a necessity that will not go away. Jane coped by reorganising her emotional self as she adjusted to her new situation thus regaining her ability to move on:

I used to be very.....I used to hate it.....I used to absolutely hate it! But then I was 16 and yeah I hated that. But once I got past the fact that there is nothing I can do about it.....I got on with it. Um, it became a lot easier to get along with my carers becauseYeah, you have to pretty much so.... I just had to think well this is a need and I have to do it and you just....I don't know... You don't just switch off but, yeah your mind kinda.....you have to rationalise it as 'you need this and these people are here to help you..... (Jane).

In contrast, Peter, who sustained his injury over thirty years ago, reported he accepted his dependency in the acute phase of his injury as his “*norm*” refuting experiencing any ‘*hate*.’ This may also be considered a different type of coping strategy whereby accepting his situation he embraced, and focused on the positive aspects of his life.

Following an acceptance of their SCI, and feeling at ease with the associated needs there was a sense of entitlement – expectation that carers will support the participants in their activities and enable them to focus on the positives, and live more independently:

I feel independent. They give me that independence by being available and I don't feel anything less by having to ask. I have to ask for a lot of things because I am severely disabled but I don't ever hesitate to ask for what I want. (Tom)

The above narrative demonstrated an active coping style whereby assuming control of the uncertainty Tom identified himself as an active agent in control of employees who do as he asks. The intrusion of needing paid carers following SCI to assist you in activities of daily living and the strategies employed to manage this intrusion are the content of the next subordinate theme, **Invasion of Privacy; Loss of Dignity - “just part and parcel of life.”**

4. 2.2 Invasion of Privacy; Loss of Dignity - “just part and parcel of life”

Participants described multiple pervasive threats to their physical, spiritual, psychological, cultural, social privacy, and concept of dignity, “*Ahhh, I think you lose your dignity pretty quick in this situation*” (*Ethan*) but with a resignation to their loss, making references to it becoming “*just part and parcel of life*” (*Peter*). However, all participants actively tried to employ strategies to maintain as much control as possible over what they could do in order to protect elements of their privacy and dignity, and in some cases that of their family and friends. The intimate nature of what their care entailed was confronting on a regular basis. Whilst participants learnt to manage their ‘embarrassment’ they described an ever present sense of vulnerability when being ‘exposed’. ‘Dignity’ consisted of it overlapping constructs such as respect, privacy, autonomy, and self-worth; is not necessarily surrendered in its entirety when a high level of SCI has been sustained.

In contrast to everyday visitors who commonly have access only to certain parts of a house when invited in, the participants’ entire homes became the carers work environment. Multiple people paid to provide a service entered the private home, previously a sanctuary from public life; in most cases carers did so in the first instance as relative strangers. Chloe described interacting with at least three different carers on a daily basis. This was a physical and psychological invasion on her privacy. Chloe’s account best describes how encompassing this intrusion was:

It was exhilarating to be out of hospital in my own home but it was overwhelming too..... You know the personal side of things and having different people come around all the time. Just everything, every little corner of my.....me, and my house is like my everything.....my purse, my drawers, everything is either cleaned by somebody, used by somebody. Everything is kind of open; I don’t have anything that’s kind of my own

little thing..... But I've got nothing to hide anyway.....It's just that private side of things.....do you know what I mean? (Chloe)

In the above narrative there is a sense of mourning within the words “*but I've got nothing to hide anyway.*” Furthermore, Chloe, (a Maori woman), gave me the sense that by her comment “*my house is like my everything*” and “*do you know what I mean?*” that I understood how invasive the experience of relying on paid carers is in relation to her: te taha wairua; values such as dignity, respect, cultural identity, personal contentment and spirituality; te taha tinana; physical and mental well-being, physical health status; te taha hinengaro; cognition, behaviour, emotions, thoughts, motivation and understanding; te taha whanau; communication, relationships, mutuality and social participation. The daily violation of her “*private side of things*” by many people meant Chloe considered nothing about her was tapu (sacred) any longer; it is a place that everyone knows about now.

Daily bodily privacy is voluntarily sacrificed only as a direct result of having sustained a SCI; individuals had no choice. The intimate care required included bowel evacuations perceived by some participants as a physical violation. This intrusion seemed to have a cascade effect in terms of ongoing emotional violation as was captured in John’s earlier narrative reporting he still “*hates*” it 16 years post injury. Chloe described how a blasé insensitive approach, by some carers to dependent toileting suggest that carers forget those with disability still wish to retain some elements of privacy:

You're on the toilet and they want to talk about a camping do dah that they just had in the weekend. I kinda look at them and say excuse me but um.....I can't talk when I'm trying to go to the toilet ya know. (Chloe)

Women with SCI may have an additional loss of bodily privacy pertaining to their menstrual needs. Amy struggled with her dependency on carers to attend to her feminine hygiene:

When I did have my period it was just embarrassing to ask someone to change me. So I got a hysterectomy cos I was embarrassed to ask to be changed during the day as well. I don't want any more kids anyway cos I've got two..... and if I can't look after them why bring up another child, you know! (Amy)

Amy's account suggested that her decision to have a hysterectomy is outwardly symbolic of her mourning, and is related to letting go of her former life role as mother to perceiving herself now as a mother that cannot care for her children. Participants' discussed their sense of vulnerability being amplified when naked and requiring carers to touch their body. Being unclothed appeared to carry with it an additional loss of power or control in one's life:

There's strangers coming in, the first day they meet you they see you naked, washing parts of your body that you used to be able to wash yourself. That part of it, it took me quite a while to get used to, especially the whole....the first day you meet me you've seen bits of me that I would really rather you not see. Um but I think I just had to get over it. (Jane)

Once participants accepted that such procedures were part of everyday life they were then able to overcome the initial embarrassment, and cope with their dependency on carers. A sense of their core vulnerability remained. Being familiar with the experience of being naked in front of other people did not mean that the participants lost all sense of dignity regarding their bodies:

I've accepted over time, I've lost my dignity with them', I don't mind them uncovering me now, but on the hoist I say to them "it's best if you have it [sling straps] across the nap then it doesn't expose everything. (Amy)

Maintaining privacy was fraught with challenges for the participants in this study. Participants expected that carers would exercise discretion, and adhere to a strict level of confidentiality regarding disclosure of personal information pertaining to them. Two of the participants reported first-hand experiences of being subject of gossip initiated by their carers, which I interpreted as an abuse of power by the carers. Breaching of confidentiality violated participants understanding of trust and respect, thereby, disturbing the equilibrium within the relationship with their carers:

I would expect them to be.....discreet and confidential with regard to my private affairs but in truth and in reality it's not so. People gossip and when you're the subject of that gossip or a target of the gossip it's very, very difficult to keep things private. Whether the gossip be true or not, it gets out there and comes back to you and you think 'what!' Then you think mmmm 'I know where that's come from'. That could make it possibly quite

awkward between me and that carer that possibly could have divulged that information. (Peter)

When people paid to ‘care’ for participants betrayed their rights for privacy understandably this causes emotional distress, and may carry forward the belief that carers in general cannot be trusted. This is discussed further within the subtheme **‘Follow your “gut instinct.”’**

Personal details are shared with another tier of people if carers are obtained via a care agency. Participants described the reporting requirements of care agencies and funders as additional intrusions on their privacy and another potential area for abuse of power:

We have to report creams and everything that I'm using and apparently it has to be documented before they can use it..... They won't dye my hair; they won't trim down below which I prefer down below because the tape doesn't stick around the supra-pubic area. It gets me frustrated.....these damn rules and they did an assessment on me about um ya know personal stuff like masturbating and stuff like that. Ah.....I was quite mortified by it.

(Amy)

Participants also struggled to find a way to have time on their own – particularly those who required around the clock care. Unable to hide from the scrutiny of others, their physical and emotional self was always on show. Chloe described this as upsetting not only for herself but for her carers who often misinterpreted her emotional responses as criticism:

They see everything I do, all my behaviour all my....if I'm in a bad mood they'll hear it, you know, it's not directed at them but there are people in my house all the time and I am who I am you know, sometimes I tell them not to take it personally if you hear me getting upset, angry, crying, whatever, just go in the kitchen.....just do something, just don't take it personally because a couple of them have and they've ended up kind of crying. (Chloe)

Participants described they valued time on their own, and employed various strategies in order to protect, and afford a certain degree of privacy by escaping the presence of carers. This was best described by Peter:

This is awkward with being a high level tetraplegic to rely on a person for so much assistance. I have to moderate my private time, adjust my time during the day when I'm going to be alone, when I know I'm going to be alone or elect to be alone by allowing the carer to leave earlier and that I have my time out.....my space.....in order for me to achieve my private business. Yeah, just anything just to be in my own space without interference or the presence of a person that I don't really want there.

(Peter)

John expressed that despite potential risks to his physical well being when not having another person present it was important for his psychological health to have this private space:

I think it's healthy for me also to have time on my own, so you're not totally reliant on having someone there the whole time, and if I really got into trouble well I'd panic at that stage and work it out. (John)

However, a quest for solitude can be invaded by carers who may assume they can enter into participants home as they please outside the paid working times. One example of this is given where such intrusion was not welcomed, and could be considered an example of an abuse of power, because Amy described submitting to this intrusion rather than confronting the carer:

One carer she lives in [suburb] she had a client around the corner from me so I accepted her coming here early [in the evening] once, but it's got to be every single day just about. (Amy)

The participants who shared their home with others were acutely aware their need for care was an invasion on the privacy for all home dwellers, both visiting friends and family. In an attempt to minimise this intrusion these participants imposed boundaries (house rules) for the carers to abide by:

In a normal situation I wouldn't have people coming in and that's bloody hard and it's harder on my partner than it is on me if they're made

aware of that at the start then they're sensitive to the fact of not intruding on personal space or when I have people aroundI try to keep them separate. (John)

Participants were asked how they communicated their care needs amongst numerous carers. Tom and John were adamant that all communication had to be channelled through them, the suggestion of utilising a ‘handover book’ considered abhorrent as it represented communication between carers about them, but without their knowledge. However, two participants considered the ‘communication book’ a useful tool:

They used to write down everything that I do and I found that quite invasive, I don't need everybody knowing what I was doing, you know? So now I said just write down what my cares are.....just anything to do with my cares. (Chloe)

People need to be free to behave, and to associate with others, but without the continual threat of being observed. Participants described difficulties initiating or maintaining relationships with others is presented within the subtheme – **Intimacy, “a natural process.”**

Being able to be as independent as possible and retain a sense of autonomy within the inter-personal relationships held with paid carers, care agency managers and ACC support coordinators was one of the major challenges following SCI. This is discussed in the next subordinate theme, **Self-determination within the context of interdependency.**

4.2.3 Self-determination within the context of interdependency

This theme described how participants were (or were not) able to maintain their sense of individual self-determination within the context of an interdependent relationship. The term ‘interdependency’ has been used to describe relationships based on respect and reciprocity, one that acknowledges individual autonomy rather than strict independence. The focus is on the participants’ ability to exercise autonomy, control, and right to choose the quality of care received.

There are multi-factorial aspects of the relationship between the person with SCI and their carer. The person with SCI can be in the role of ‘customer’ or ‘employer’. The carers are in the role of ‘employee’. However, given the intimacy of the care tasks in the working relationship, more informal relationships can develop. Sometimes these informal relationships are encouraged, or even pursued, by the person with SCI, but other times the level of friendship being sought by the carer is not what the person with SCI is after in the relationship (described in more detail within the subordinate theme **Friendship ambiguity**).

Through all this run some complex power relationships. The person with the SCI has control over the employment of the carer. If in the role as employer of the carer, this control is direct. However, even if the person with SCI is receiving care provided through an agency, the person with SCI can influence how long the carer has to work and the tasks they might need to do in the job. Conversely, the person with SCI is of course physically dependent on the carer. The carer has physical power over the person with SCI. Furthermore, the person with the SCI does not have unlimited control over when the carers come, how long they come for, or even the quality of the care they receive.

This section conveyed participants’ experiences of both models of service provision. It will include the many challenges participants described in their quest to maintain their independence, participate in the home and community whilst striving to maintain some degree of control. Participants learnt through their own lived experience of what worked best for them. This subordinate theme and its findings are strongly linked to the following master themes **Navigating relationship terrains** and **Warning: Potential Traps**.

When people do not have the opportunity of being able to act on their choices there is a sense of loss of control which gives rise to frustration. Ethan did not have his accident in NZ, and obtained his funding for personal care via an overseas insurance agency said “*I have no choice, I can't go private and do it myself cos I'd much rather do it myself.*” The means by which paid care services were provided was influenced by more than one factor. The first factor Peter suggested is time since injury:

For some people there is a place for agencies. Certainly if you are a new tetraplegic and you don't know very much about your body and how to care for it. (Peter)

Another factor that influenced decisions to be involved or not in management of carers was considered to be the lack of preparation undertaken in the spinal unit for encountering these types of relationships in the community. When initially discharged from a spinal unit, six of the participants felt their rehabilitation had left them unprepared, and not empowered, to manage their paid care services in their 'real' world. Like Amy, Jane described little training was provided regarding alternatives to care agencies or how to manage these relationships:

I was very naïve when I left the spinal unit to what the carer relationship would be like. I think there needs to be education out there for managing privately because I don't think a lot of people know about it....at the moment I'm all agency. (Jane)

However, time since discharge from hospital and perceived lack of preparation were not the only factors that influenced the participants' choices regarding use of a care agency to manage their carers. Chloe had privately employed her carers in the past but preferred not to have the additional responsibilities of managing carers as employees:

I prefer somebody to direct it for me and go through and do the interviews, do the Police check, do all that kind of stuff on the people then send them to me. (Chloe)

The issue of control was paramount for several participants. In contrast to Chloe's account, three of the participants (Tom, John and Peter) perceived their choice to utilise the consumer-directed model gave them more control in their lives overall than afforded to those who use care agencies:

If you're in control of your personal cares.....if I tell them this is how it's going to be then I am more likely to carry that through for the rest of the day. I am more likely to get out and do stuff and tell people this is how it is rather than being.....just a lame duck with other people telling me what to do all the time. I think you're likely to be more proactive in the rest of your life cos you had to be proactive in organising your cares. (John)

John's used the metaphor "*just a lame duck*" which could be interpreted as his determination not to be 'a passive and weak man'; through relinquishing care of himself to the control of others and giving up his personal freedom. Prior to his SCI John was self-employed, retaining all remnants of his former independence was important to preserve his sense of self-identity.

Given the participants' limited ability to physically influence their environment, control over communication was essential to maintain a degree of autonomy within their lives. Thus good communication with those involved in funding, providing, or managing care was considered essential to all of the participants regardless of the method of delivery of care:

I mean you keep the communication channels open, you try and be reasonably agreeable. I haven't really had any dud ones [ACC Support Coordinators] they've all worked well.....we've all worked well together. But I know they're working within a system and I realise that. (John)

The frequent use of the word "*frustrating*" throughout a number of narratives is suggestive that dissatisfaction manifests when communication channels are fractured leading to inevitable consequences as the consumer of care. Participants expressed a level of frustration attached to their need to relying on others. The example below is about feeling mistreated, or disrespected by care agency management practices, and unfairly rejected:

This agency that I am with.....there is one lady; honestly she makes my blood boil. She's just very unreasonable, very argumentative...it's quite frustrating. There are days when I say 'Ok Lord I'm ready to walk now', I'll do this myself thanks, help me do this myself'. That's why sometimes it's hard to rely on people. (Chloe)

In order to exercise autonomy and control over how their personal care is conducted participants made references to needing to be assertive from the onset when working with a new carer. Many of the participants were clear that their needs and preferences had to be met:

You have to be totally in control; how you want things done and your caregiver needs to accept that it needs to be done your way. It may or may

not be the way they do it at home or the way they do it for someone else but it is in your home and it is your care and you need be able to assert that.
(Tom)

Participants' self-determination and attitudes influenced how they created fulfilling working relationships with their carers. While being assertive participants believed in treating their carers fairly. In order to describe their qualities as a good employer the participants often used similar adjectives: *fair, positive, respectful, courteous, independent as possible, generous, assertive, caring, organised, not greedy, straight up, particular, flexible and forgiving* (*Tom, John, Jane, Chloe, Amy, Ethan, Peter*). They argued that failure to demonstrate these characteristics would affect the quality of the care they received, or that it would become difficult to retain carers:

Don't bark orders at them otherwise they're going to hate you and treat you like shit. Yeah, it's a live-and-learn thing alright. Everyone is different. I hear stories about how other people treat their carers and it's crazy, you know what I mean. But.....I don't know.....just be nice to them and tell them what you want with your cares. You gotta direct them obviously how you want them to do stuff and try and be polite as possible. Don't treat them like paid work. (*Ethan*)

Many participants promoted successful relationships through reciprocity, being both the recipient of care and giving care:

You give love or you give advice or you give.....I make sure that they are getting well remunerated for what they do; basically it's reciprocal, totally reciprocal. My caregivers don't feel..... They're not really working for their money. (*Tom*)

Participants talked about times where they are flexible within the paid relationship in terms of doing favours for their carers such as lending money, letting carers leave early, make private phone calls, bringing their children to work, or swapping shifts for example. Peter gave descriptions of doing this with his more valued carers, as well as introducing them as his "*primary caregiver to make them feel a wee bit more important,*" which suggested that it may be important for the recipient of care to show gratitude to those who provided care when able. Peter suggested providing his disability support is not really a 'job' for the care provider. One possible interpretation

of this perspective however, is that there is a desire not to be somebody's chore; that one gives as much to the relationship as one receives:

Ok, you realise that they are a paid employee but you don't mind giving and helping out that person if they require it because it's a give or take situation and therefore the client, service provider thing doesn't really come into it. It's more free, it's helping out each other. (Peter)

The participants however identified some problems associated with being too liberal when 'giving back' to their carers. Accounts ranged from lending money to carers then finding it awkward to get back, allowing carers to bring their children to work on one occasion then finding this was requested several times thereafter, providing food and beverages for the carers that then became an expected norm, or overlooking one or two incidences of arriving late for their shift which then progressed into a frequent pattern:

With one of my old carers I let them go off early. I realised that she started taking advantage of that. If there was an hour and a half left and there wasn't much left to do she would rush through it and kinda....yeah like cut corners and then she'd say "oh right, well I'm off now, see you tomorrow" and still claim full hours. It started getting quite bad to the point where she was trying to really rush me through the shower and everything just so she could leave. (Jane)

Learning to manage these relationships appeared to be a process of trial and error. Most care agencies have policies/rules for 'professional boundaries' that carers and recipients of care are expected to act on. Some narratives evidenced a disregard for the rules set down by care agencies. This suggested that the recipient of care tailored the terms for these relationships to individual carers and simultaneously accepted any consequences to themselves for their actions. This kind of 'rule breaking' is best described by Chloe:

Boundaries are set for very good reasons but rules are made to be broken and the thing about it is sometimes the agency have no idea. They're all about paperwork. They're not here, they're not doing the hands on, they're not having the relationships, so I think sometimes they tend to be just not informed enough; they're not in the know-how. They're just speaking from rules on a piece of paper as opposed to the rules of life. (Chloe)

Like most paid occupations a job description may exist which identifies the key responsibilities of a specific job, and desired knowledge and skills needed for any applicant. A common theme across the participants' narratives was the belief the role of carer was relatively simple, and not an onerous task. Some participants considered carers as an extension of themselves metaphorically, like a human prosthesis:

They are my legs and hand function in the things that I can't do so..... yep that is their reason for being there. But the job, fundamentally, it's not hard, it's not rocket science. It's being vigilant, conscientious and consistent. (Peter)

When discussing the ideal characteristics of a good carer (described in **Follow your “gut instinct”**) the majority of the participants' stated prior experience working with disabled people may be beneficial however, knowledge regarding SCI was not a prerequisite. All the participants felt they could train their carers, and were confident to do so in most areas of their disability. All participants gave strong recommendations for people new to their SCI:

Know your own body. You can't expect someone else to know it if you don't know it yourself and that gives you power cos knowledge is power and then you can impart that onto anyone. Then I guess just try and be as independent as you can. Be in charge of your own space, so don't have people coming and telling you 'this is what you should do, or this is what you shouldn't do' cos slowly but surely that strips away your independence and it feeds on into other parts of your life..... (John)

Regardless of whether initial 'carer' training occurred in the hospital setting, or in the home participants felt the responsibility for teaching fell to them. General consensus across the participants was a new carer would master skills required to attend to their needs within a limited timeframe to a point where they felt confident they were going to be physically kept safe:

I will need at least four days to make sure that they know what they are doing and that I am happy for them to be with me by themselves in the morning and get me up without me ending up on the floor or ending up with a pressure area, and usually my ACC case manager is pretty good about it. (Jane)

Participants believed when teaching new carers they must be fair, exercise understanding, and patience in an effort to establish satisfying long term relationships:

At the end of the day they are only human. Little mistakes will always happen and don't go nut (laughter).....it can be frustrating but with the right training and with a wee bit of time they will catch on. They're not going to get it perfect the first day but if the right skills are there they will get better.

(Jane)

Like all the participants Amy believed that the person with the SCI is the best teacher, but she worried mandatory training courses run by care agencies for carers resulted in the carers thinking they knew better than the person with disability on how to perform their care needs. She also was concerned that such training would result in fewer people being interested in wanting to be employed as a carer in the first instance:

Because they have to do these courses, to me it's not going to help, they're going to be put off. I can talk them through it, but going through a course, you've got to be doing the job as well to understand it. (Amy)

Participants described how their carers got more than just money from these relationships as participants additionally provided emotional support. Participants discussed how they often found themselves in the role of informal counsellor, or being treated as the carers 'friend' to confide in, or as a captive audience forced into the role of listener. In some cases these were not roles the person with SCI wished to fulfil, or fulfil every day. Chloe learnt over time how to redirect carers:

It's ok to be sad, happy, whatever, but don't come in and off load all ya stuff to me because honestly that just really makes my day run quite badly. I don't mind talking; we all talk butsometimes some of them just bring some real heavy stuff in and it's kind of like 'Ohhh, I was just going to tell you about my day' (laughter)..... If I say to them we don't need to talk, we know what to do, we get the cares done and let's do that.....you know what, it knocks off a good hour (laughter). (Chloe)

Participants with SCI can act with agency but operational or organisational limitations may restrict opportunities to enact this capacity. Dependence on others for their most basic needs, and going by someone else's schedule in daily life contributed to feelings of

“powerlessness,” and lack of control over one’s life and body. Chloe said that although she owns a mobility van, some of her carers refuse to drive this vehicle:

You [carers] don’t want to drive it, ok! But at the same time, that means I can’t do this and I can’t do that, ya know? The point is that they get paid to be here to do a job and I just feel that they’re not doing it properly.....the fact that my life is limited because of chairs, because of the disability and having carers, let alone when you do get the carers they limit you more by not being able to help you with your social life, help you with activities, help you to get out and about, ya know, so I guess it’s not fair. (Chloe)

Participants’ ability to get out and about socially was challenging due to many factors such as: difficulties in scheduling activities within paid care shifts, additional expenses involved if travelling away from home, lack of suitable transportation, lack of carer availability in different regions, increased hours of care required due to not being in their modified environment and when they did not have their power chair with them:

If I want to travel now it’s got to be so planned and organised and with carers, if I go on holiday now what happens to the other carers, ya know. I wanted to go to the World Cup and the care agency were saying that the other carers are going to have to find work elsewhere if you go, it’s like, “oh great”, so if I want to go on holiday I lose my carers so I flagged it, it can’t be done. (Ethan)

Participants valued, and respected most of their carers, but ultimately considered themselves in charge, and accepting of any consequences should they not follow the recommendations of carers:

I feel they are offering me their observations and their advice but ultimately I am in charge of my cares and responsible for the consequences. Therefore if I am advised that my skin does not look good and yet I still proceed to get up on it.....well I’ve learnt that’s my fault. (Peter)

Mutuality and negotiation were considered important aspects for successful relationships. Participants described how they made an effort to be fair and reasonable, yet emphasised that carers are paid to provide a service:

If we are out and about and they do see a friend, I wouldn't mind them saying gidday to them and catching up quickly but not for too long because I've got things I want to do. I'm the one they should be focussing on. They are being paid by me. (Tom)

In summary this master theme captured the experience of struggling with the changes, and losses brought about by the SCI, and the consequential need for carers. It also highlighted how being the recipient of care presented a threat to the participants' sense of autonomy, privacy, and dignity. The participants' descriptions suggested they developed various coping strategies as they mourned aspects of their past lives, and as they learned to accept that their disability and impairments were unchangeable; that the need for carers was permanent. As participants gained more experience of living with SCI they increasingly learned to adjust to their circumstances, and developed skills and strategies that provided greater independence, increased control over how they received paid care, and in most cases were able to maintain effective working relationships. For these participants, becoming competent in successfully managing paid care services appeared to be a continuous learning experience based on serendipity and a trial and error approach, for which little formal training or support was provided.

4. 3 Navigating relationship terrains

The second master theme **Navigating relationship terrains** incorporates participants' experiences of their interpersonal relationships with carers, funders and in some cases care agencies. This theme intersected a wide range of topics, encapsulated by three subordinate themes: **Follow your “gut instinct”**; **Friendship ambiguity**, and **Intimacy a “natural process.”** Together the subthemes incorporate individuals' experiences, thoughts, and beliefs regarding relationships held with paid carers including how they supported, or imposed on participants' ability to form relationships with others outside the paid care relationship.

4. 3.1 Follow your “gut instinct”

This subordinate theme refers to the experiences of navigating relationship terrains in the initial phase of selecting and recruiting carers and need to trust carers. Many factors impacted on individuals' decision making regarding carer selection, but ultimately the participants prefer to use intuition when making such choices.

Intuition is an indefinable ‘something’ that gives the person an internal reassurance of the ‘right’ decision, for example, the outcomes will be okay. Participants have a sort of checklist of carer characteristics and, even so make a decision partly based on following their “*gut instinct*.” Interestingly, participants used similar language with the phrases “*gut call*” (*John*) or “*gut instinct*” (*Peter, Chloe, Jane*) and need to “*click*” with potential carers (*Chloe, Peter, Jane*) in the context they believed their “*gut call*” (*John*) will be a reliable indicator for determining a “*good carer*” (*Peter, Chloe, Jane*) from a “*bad carer*” (*Peter, Chloe, Jane*) when selecting carers:

I'll orientate them, show them how it goes, show them what my programme is, see if they fit into it, see if we click, you just know when you first meet somebody if they're suited or not. I think women have got really good instincts haven't we? (Chloe)

Two participants talked about the consequences of their decisions when they failed to follow their initial instincts. Firstly, Jane’s account of being ignored:

I think you know within the first meeting whether you will click or not and I knew that we weren't going to click but I just thought we will see how it goes. And even after the heater incident [sustained burns to her feet despite repeatedly requesting the carer to move the heater] I didn't say anything too much, it all ended after I fell off the bed trying to put my tops on; she was standing right beside me watching TV, not paying attention. But I think you have to be patient but you also have to use your gut instinct to a point and see if your personalities mix.....see if you will be a good match. (Jane)

This is also an example of a form emotional abuse, where the carer disregarded Jane’s directions; the significance of being ignored specifically related to a person with disability can potentially be life threatening. Secondly, Ethan’s account resonates with a similar vein when he failed to listen to his intuition about the suitability of a carer:

My alarm bells rang the first day that she was a bit dodgy..... half way through the car transfer my head was sort of on the seat and my arse is hanging out of the car, luckily some passerby helped throw me in the car. (Ethan)

In contrast, Peter considered he was unsuccessful in the area of intuitive decision making despite being the participant with the most experience of living with SCI. Peter questioned the reliability of his “*gut feeling*” reporting that on many occasions he had made poor judgment calls and selected less than ideal carers:

I would like to think that after so long a time being a tetraplegic that I can read people and go with my gut feeling.....who is going to be potentially a good carer and whose not. But, a gut instinct can only guide you so far you don't know whether this person who will be telling you a real pleasant yarn to get the job might be a psychotic axe murderer. I have learnt that from experience and unfortunately I still fall into the same trap. (Peter)

Peter discussed the quandary he faced when deciding on what sort of person would be the most suitable carer for him:

All the carers I do employ initially are strangersit's quite curious that sometimes you end up employing carers because they are merely answering an advertisement and they may be equipped and qualified to look after you.....And that may work, but they might not be a person that you would choose to have say.....as a flatmate and be living with but essentially they are living with you for short periods of time. So that's rather strange, quite bizarre. (Peter)

All the participants valued the fact that there were people in the community prepared to be a carer in the first instance, as without carers’ their quality of life would be substantially poorer “*you become very close to them because you do rely on them and you do appreciate them cos they give you a lifestyle*” (Tom). However, regardless of geographic location all the participants described difficulties with finding suitable carers. They believed the reason was a combination of poor remuneration and relatively high employment levels. As a result they felt they often had to accept people with fewer skills and less education than was ideal:

You've got to employ the best one that you can get and it might be the best of a very bad bunch. You have to make a hard choice because of the market you've just got to take what you think is the best fit and that may actually not be a great fit anyway. (John)

Participants gave accounts of what they considered important from their own personal experiences of recruiting carers they hoped to “click” with (*Jane, Chloe, Amy, John.*). Participants’ accounts were collectively similar with regards to the desired attributes considered important in a carer. Commonly held values described by all participants included wanting carers to be: reliable; sensitive, honest, consistent, conscientious, respectful, punctual, compassionate and possess a good sense of humour, a good dose of common sense, good listening skills and are caring. Reliability appeared to be weighted as one of the most essential attributes, considering that “*if they just didn’t turn up then you’re kinda lying in bed or left sitting in your chair.*” (Jane)

Within their narratives, participants frequently referred to carers as being a “*good carer*” or a “*bad carer*” (*Peter, Chloe, Jane, Amy, John*). Peter’s definitions of these terms are given below, as representative of all the participants’ view, where it appeared their assessments were based more on the nature of the interpersonal relationship than on the carers’ performance of specific tasks:

A good carer will initially respond to everything that you require for your basic cares, a very good carer will be one that you can click with and develop a good rapport with so that it makes the job of caring for the client not so much a tedious task but more of a nice easy going working relationship. (Peter)

A bad carer will be a person who would see easy opportunities to take advantage of you, knowing that you are vulnerable and dependent upon their care they can manipulate you in such a way that you feel you must go along with them and what they have to do rather than how you really wish to run your own life. (Peter)

Previous life experiences appeared to be one reason why some participants held strong preferences for who they would now have employed as a carer. Four participants spoke of times when they had been let down by younger carers who had proved to be unreliable and taken the most days off. Therefore, mature women were identified as the ideal carer:

Yeah females, I like the.....most of my girls that work with me are fifty. I enjoy that age. It’s that motherly friendly.....they’ve got children of their

own that are probably older as well. They need the job; most of them have mortgages or things to pay and all that. They are good, they are reliable and respectful and I just enjoy.....I find the twenty year olds very alert, kinda here there and everywhere, they take most days off. They are the ones that tend to still want a life and that's fine but it's.....I think their social and personal lives are first and then their work life is second. (Chloe)

Personal preferences can be a crucial factor, impacting on who will be accepted as a carer regardless of potential carers having other desired attributes. Many participants clearly articulated they would only accept female carers. Past negative experiences, and beliefs regarding gender roles seemed to partly account for why women tend to be selected as carers more often than men. For two of the male participants they believed having men as carers made the care more uncomfortably sexual than having women as carers:

Definitely female.....Cos I'm a bloke and some of the private nature of some of the stuff they have to do. I just prefer a female. (John)

However, John did add that this was “*my hang up rather than any bad experience with any menAnd maybe my loss.....I mean they could do some of the work a lot better maybe than the females but it's just a personal preference.*”

Another example of being sexually uncomfortable with male carers is given by Jane: “*a male just creeps me out.*” This may mean that Jane considered any man that wanted to look after a woman (who is not his partner) in such a personal way as ‘creepy’. Notably Peter was an exception in the selection of carers. Peter was open to employing carers regardless of age, sex or ethnicity, but described younger and stronger people as being the ideal carer:

I take on the best person I can find, whether it be male, female, young or old. There is a lot of physical work involved with hoisting; lifting, manoeuvring me in my bed, in my chair, um and I have found that the fitter, stronger, younger people are the better people. (Peter)

I asked participants about their experiences of employing family, friends or strangers to be carers. Tom also gave his view point with regard to the Ministry of Health’s mandate of not paying family members to be carers in comparison to the ACC funding model:

Yeah I do prefer to employ strangers rather than friends just to keep those boundaries. I have employed my daughter and my son to do different shifts of cooking and things that they can do and I have paid them and whether ACC knew about that or not I wasn't going to tell them anyway so it was never an issue. Back in those early years ACC didn't pay family members but they do now (Tom).....Unlike the Ministry of Health who does not pay family members at this current time (Researcher)..... Which is quite blurry.....it's a bit sad really that family members aren't paid because sometimes family members can be the best caregivers and can look after the person a lot better than what an agency nurse or a paid caregiver can do and they should be reimbursed for it really. It just keeps the relationship on a different level. Even though they are family members they are not losing something by giving care. (Tom)

Three of the participants retrospectively considered the assistance family members had given, and suggested it had a detrimental eroding effect on the nature of their next-of-kin relationship when blurred with a carer role:

I wouldn't go down the family track again. I had my aunty pretty much doing all my personal care and that put a big strain on our aunt/niece relationship. I think you need to keep your family your family and have strangers come in but that's just me, some people it works for them and I just didn't like it. (Jane)

Peter described his relationship with his mother and the burden his care needs had on her physically. Peter now had a sense of independence and freedom from his mother that he did not have before as a result of having paid carers:

When the attendant care scheme came into effect I could get care without her [mother] having to wear herself out. We were able to restore our son/mother relationship. I wouldn't expect my family to fill in the gaps. I believe now that those days are gone and I can have family to come and be my family and visit and go away when they want to go away. (Peter)

Informal carer burden is well documented in the literature. Regardless of payment, John was acutely aware of the strains placed on his partner who also provided care in the capacity of paid carer:

My partner always used to put me to bed but now that's just too hard on her and that's sort of crossing.....well it was crossing the boundary a little bit, now I get someone to come and put me to bed. (John)

Similarly, employing friends also caused some consternation because the monetary exchange changed the relationship for some of the participants. Jane struggled to explain this:

I wouldn't get friends in. I wouldn't say it put a strain on our friendship but it definitely altered it because they were there when I needed them there. I didn't.....I don't know.....they weren't kind of there as friends any more, they were there as carers as such and not as friends..... (Jane)

John also strived to keep his care needs private and separate in order to preserve his sense of maintaining a normal life not centred on disability needs. John eliminated his friends from his list of potential carers, saying he led a “*double life*” in this respect.

In contrast Ethan has both friends and family in carer roles:

Obviously with personal cares it's got to be the right kind of friend, mum and dad for sleepovers and why not, they get some sleep and get money for it. I probably wouldn't have a stranger male come into the house for sleepovers that would be a bit funny. (Ethan)

During the orientation phase a need to be able to trust a carer was required and was considered by these participants to be essential before participants felt safe that the carer had their best interests at heart, and were competent to execute practical tasks related to their SCI. Several of the participants gave accounts of having their trust betrayed through gossip (**described in Invasion of Privacy; Loss of Dignity**), stealing and harm (described within the subordinate theme **Mistreatment**). Being suspicious of people’s motives and refusing to trust are strategies to protect ourselves from that which we fear. Participants discussed that the fear that a new carer may betray or harm them is encompassing, but they believed they had little choice but to ‘trust in trust.’ Chloe feels over time she has become more receptive to trusting carers:

It's hard to trust, it's hard to trust people, especially when you've got new people coming on. Sometimes I feel like I'm too trusting but I'm the kind of

person who isn't as trusting. Maybe times have changed as I've got older, I'm a bit more open.....it's a hard one, you've got to try and trust people and at the same time when you get people thieve from you and people don't seem the best of characters sometimes and you've got to try and trust people in your house, trust people to be alone with you in your house.

(Chloe)

Jane's account described how she felt when engaging with a new carer:

It's quite awkward, there is a stranger coming into your house who is performing these very personal cares on you, you really don't have a choice but to trust them and have them done but I think once you get to know them and about them, and their family and what their life's been like it becomes a lot more comfortable and I think once the trust.....you trust them it becomes a lot easierI don't know.....it's very hard to explain.....(Jane)

This account suggested that if 'trust' did not exist, individuals with SCI may manage to accommodate and endure the carers but that these relationships would not be satisfying in the long run. This excerpt also provided an example of 'reciprocity' as discussed within the theme **Self-determination within the context of interdependency** where the exchange of personal information created a more comfortable working relationship for both parties (from the perspective of the person with SCI), where fine lines existed which may or may not be considered friendship (described in the following theme **Friendship ambiguity**) and highlights the uniqueness of these interpersonal relationships that occur in the home environment.

It would seem at the beginning of these relationships where participants have no real knowledge of the carers they must exercise an element of caution as a protective strategy due to the inherent risks involved for them, for example having a carer take advantage of the situation, physically harm them or steal from them. Over time these relationships frequently became more relaxed as the trust grew due to spending time together and gaining insight into the carers' character:

I've got really good carers. They're just lovely, they're really lovely. I trust them, I trust all of the girls and I value their opinions and I respect them.

(Chloe)

The next theme addresses the concept of friendship and its role within the paid care relationship.

4. 3.2 Friendship ambiguity

This subordinate theme related to the participant's perception of the place of friendship within the relationships they had with various carers. As discussed in **Self-determination within the context of interdependency**, participants stressed the importance to being able to exercise both power and control; emphasising the need for there to be an element of formal employment in these relationships - "*they are paid*" (*Tom, Chloe*). Conversely, the participants also described these relationships as being reciprocal in nature, which lends itself to friendship. Whilst friendship maybe characterised as a relationship between equals, ideas about what constitutes friendship varied amongst the participants. It appeared that friendship can make circumstances more comfortable in the sense that the person providing care is not a stranger. For some participants' friendship appeared to be based on the concept of utility where both people derive some benefit from each other, and it changes according to circumstances.

Important characteristics and attributes participants wanted in their carers shared some of the elements commonly inherent and valued within the ideals of friendship (although participants did not directly indicate they were seeking to employ potentially new friends). For some participants who spent large amounts of time with their carers or who had a limited social network, developing friendships with carers was deemed to be important. Amy stated "*I haven't got any friends really, my friends are my carers.*" Ethan's comment below may be interpreted that having a friendship with a carer yields a confidence that they will be 'cared' for rather than objectified as a 'chore' for the acquisition of payment:

If they are your friend and they care about you they are more likely to notice things and do their job properly. (Ethan)

Friendship with carers may therefore be considered a desirable objective for people with SCI. However, in the context of paid care relationships this view can be considered contentious. Agencies were described to consider friendships between carers and clients as a boundary transgression. Therefore, such friendships were discouraged; for example employed carers are not permitted to socialise with the consumers of care

outside of the paid working hours, exchange gifts or form intimate relationships with the people they provide care for. Many of the participants found this unreasonable, and those who used agencies described that they and their carers ‘kept secrets’ from agency management; firmly believing that it is inevitable that personal bonds will form due to the nature of the work occurring in their home environment:

With agencies their contracts are quite detailed about their professional boundaries. I personally think it's ridiculous because you have to become close to the people that are caring for you, you're going to talk about your family, they're going to talk about their family and to a point you feel like you know them and if not just know them, they are almost like a part of your family to a point. (Jane)

The above account suggested that when there is a sharing of mutual interests and exchanges of personal details (hallmarks of friendship) the recipient of care felt more at ease with the personal nature of the care needed. However later in the interview Jane gave a contrary view about the risks of establishing friendships; which demonstrated that social dilemmas may occur when boundaries between paid roles and friendships became blurred:

There are some things that just need to be said and when they are not your friend it's a lot easier to say it to them, one of my carers I would consider her more of a friend than my other carers. In certain situations I have ended up not saying something to her that I would have said to the others. In the future I would prefer not to become friends with them. (Jane)

Participants who characterised all their carers as friends constructed looser boundaries around the duties carers are paid to undertake. It is possible that doing so created a relationship that resembled the platonic ideal of friendship. In Amy’s account it appeared her carers took liberties that would be frowned upon by the agency that employed them, despite Amy sanctioning them:

There's one that's usually late and that but we have a lot of fun together. We watch a movie together and get things done when the ads are on and stuff so at least she has part of a life too cos she's missing out on the programmes as well and we're both watching it, why not you know, but really they're not allowed to do that (laughter). (Amy)

The above account is an example of the recipient of care being in charge of their home, and what occurred within it. By adopting a casual working environment Amy treated her carer more as being there in the capacity of friend rather than paid worker, which thus permitted the care tasks to include ‘fun’. However, Amy also talked about arranging a social evening with all her carers (her friends) outside the scheduled paid employment hours. The carers (friends) did not attend which saddened Amy, citing they had not wanted to break the ‘rules’. A possible interpretation of this account suggested that these carers considered their relationships with the people they care for as pseudo-friendships, distinguished from real friends. In this context the term pseudo-friendships is considered to exist as a requirement due to the nature of the paid work, providing a transient companionship. Both Amy’s accounts also implied whilst carers were happy to ‘break the rules’ within the home environment the risk of being ‘caught’ in the community was too great.

In the below extract Tom described how his carers provided both instrumental support and friendship:

I have had agency nurses the odd time when I have travelled but it's a different relationship.....it's just basically doing a job, where this is more a friendship. I take my girls out for tea, lunch. I would also take them to a show; I do that if I am not taking a friend as I need someone to be with me. It would be more on a social level than a paid.....it would be a paid outing but it wouldn't feel like that. (Tom)

Tom described how these two roles blur into one another, and highlighted the reciprocal nature from his perspective of the paid care relationship. It is difficult to interpret whether Tom judged social friends as being qualitatively different (superior or more personally valued) than friendships with carers that involved the exchange of help for money. Notably two of Tom’s carers had remained employed with him for 22 years which gives testimony that these relationships are indeed mutually beneficial.

Some friendships were described to wax and wane when a carer was no longer employed. For others, friendships lasted a lifetime whether or not the carer continued to be employed. Ethan was devastated when his carer resigned with little warning; he described her as having been a “*good friend.*” In this case the carer may have considered the friendship transient; a pseudo-friendship. So with the disappearance of

the ground for friendship (i.e. employment), the friendship also broke up, because this is what kept it alive. However, not all carers become or were ever considered friends, which may be congruent with other working relationships, where unless the workmate shares other activities in common, interactions remained in the context of the job requirements:

She's a friend, she's a carer; she's just awesome. We're there for each other we go to church together, we interact together, we socialise together, and it's good. Some of my other carers, we have a respect for each other.....I wouldn't call it friends, it's just a good healthy work environment, we respect each other. We know where we stand with each other; we know what's expected of each other. (Chloe)

John gave a similar account that not all carers are or ever will be considered friends which may be based on the fact that he lived with a family therefore does not subscribe to the need for friendship in the same way as those who live alone:

You don't become friends straight away there is no set period, after six months they're either a friend or not a friend but it's like any position some people you gel with quicker than others. And some people you never really gel with but you stick with them I guess 'cos they're good carers. I might have had 15-20; probably more actually.....there are probably two or three that I would quantify as friends. (John)

The following subordinate theme **Intimacy “a natural process”** discusses the participants' views in relation to intimate relationships with carers, establishing intimate relationships when carers are present and carers becoming intimate with family members.

4. 3.3 Intimacy “a natural process”

This subordinate theme described a range of views concerning dating, and the difficulties participants faced when relationships with carers became sexually intimate in nature. It also incorporates the participants' perceptions of carers having intimate relationships with their family members and beliefs regarding care agencies rules forbidding intimate relationships with carers.

As earlier reported in **Follow your “gut instinct”** the women in this study did not employ male carers. When discussing the topic of sexual intimacy with carers the women all identified themselves as heterosexual which meant they had no desire to become sexually intimate with female carers. However, all three women felt men with SCI who seek relationships with woman had more opportunities to have sex with carers as predominately carers are female. All the participants believed it was understandable that sexual relationships would occur, given the nature of the job, regardless of rules set down by care agencies:

It's a natural process that is in human nature and it will happen..... it is very easy to because it's only a small step away. They are doing intimate cares on you, they are seeing your naked body.....it's a different level.....they care for you.....it's a mutual thing.....you can care for them and it's just a very small step to that next level. (Tom)

Although Tom has had intimate relationships with carers in the past his message to others with SCI is to avoid doing so:

I have had intimate relationships with my carers in the early stages after my accident. And it sometimes ruins a caregiver relationship. If you go over that boundary with them it could be lost so it's definitely not a good thing I don't think. Its kinda something.....I wouldn't go there again. That's one of the reasons I don't employ hot spunky chicks. (Tom)

Peter avoided intimate relationships with carers. He pointed out that payment is for care not sex, which suggested a hint of moral conflict; he also alluded to the complications it can entail in the overall management of his care team:

I have tried to keep away from having intimate relationships with carers because I can just see that leading to problems. They're here really to work for me and being paid to do so and this is where the relationship should end. If you should develop a relationship with a carer I think it becomes very awkward.....and also massively awkward for the other carers who will see that particular carer is being a favourite and afforded favouritism. (Peter)

Discussed earlier, participants described associated losses due to their SCI: “*I can't enjoy myself like I used to, you know, like travelling, sport and meeting ladies was a huge part of my life.....that was the main part of my life*” (*Ethan*). Ethan considered the opportunities for meeting women were now limited for him, and in contrast to Peter’s account, Ethan was open to forming a sexual relationship with a carer who could do his cares. In fact, Ethan indicated that this would be ‘ideal’, thus further removing barriers to social participation:

God it would be incredible if I had a partner that could do my cares. I would be like alright, let's go, pack our bags and go travel the world.
(Ethan)

Participants were clear that agencies cannot stop the natural course of intimacy between themselves and carers. Paradoxically, carers’ becoming intimate with family members was not something participants would condone; arguing carers are paid to be there for them alone:

I think one of my carers had a crush on my Dad. It's kind of uncomfortable when she starts talking about sex with your Dad. I would prefer that none of my carers in the future become intimate with my family.... I don't need drama; I need them here for me. (Jane)

As alluded to in subordinate theme **Invasion of Privacy; Loss of Dignity** participants described dating as problematic at times. The presence of a third person was considered an intrusion which could negatively affect how they were viewed by potential partners:

It's very difficult to explain to someone that these people are coming in and doing this and that to you..... a lot of the guys pretty much head for the hills because they are just freaked out, it is definitely difficult to form relationships with carers always there. (Jane)

Jane described how awkward it could be for all concerned when a carer arrived in the morning when she was sharing her bed with someone else:

The carer walks in and there's an extra body in the bed then.....(laughter) it's a wee bit awkward going “yes hello, this is so and so, good morning,

*now can you get out of my room so I can go and have a shower." (laughter)
(Jane)*

Peter emphasised how the degree of intrusion experienced can potentially jeopardise the relationship with another person due to the awkwardness of the situation:

It does become awkward because that friend is suddenly turning up at odd times, or times when the carer should be here and doing my cares and looking after me, um, then we have three people present and that can be quite awkward - I have to say well 'you can go home now' and dismiss that carer, it shouldn't be a real bad thing because then they're still getting paid. (Peter)

Tom presented managing new relationships as “*a delicate situation*” but not overtly problematic. Tom showed consideration for all parties involved:

I will make sure they are out of the bedroom before my caregiver comes in to get me up so that the caregiver is not coming into a situation where it is embarrassing for her or its embarrassing for the partner. But they could still be around in the morning. A new relationship will be a new relationship for them to get used to as well and it will be something that they will have to adapt around and I will make it as easy as possible by talking about it with them so I can make it as easy as possible for my partner so that she can feel comfortable around them as well. I am an open book. (Tom)

It would appear carers vary in the degree to which they will support or hinder the person with SCI with regards to intimate relationships. Peter and Amy found some carers begrimed the appearance of another person on the scene, making disapproving comments, where others supported and encouraged them to pursue sexual relationships. Peter described how he believed his carers thought:

Hold on, who's this person coming into your life? I'm not sure she is appropriate for you and would she care for you as we care for you. Will she stuff up your cares and cause problems for your health and wellbeing which we have to clean up'. They sometimes play a motherly role. (Peter)

Amy enjoyed sexual pleasure with men and wherever possible tried not to involve her carers:

I like the pleasure but the thing is we're going to have to plan it a bit better 'cos I struggled to get back in my chair, trying not to let the carers know I had nothing on. One carer said "I'm not doing you if you have a man in your bed" and I thought to be honest.....well you shouldn't work for me. I mean if I've got a man in the bed then....I could be married to the man.

(Amy)

She was affronted when one carer attempted to deny her this fundamental right. It is possible the carer believed that disabled people should not have sex, as it is well known that disabled people may face unfair discrimination of this nature. However, another interpretation may be the carer is uncomfortable with regards to the discussion or thinking about sexual activities of others.

4. 4 Warning: potential traps

This master theme related to participants' reports of facing multiple threats to their well-being and resultant 'fear' every day and night. All seven participants described situations where they felt "trapped," "vulnerable" and "powerless" (*Tom, Chloe, Jane, Peter, Amy, John, Ethan*), where in some cases the bed or the actual carer is considered the "trap" (*Peter*). The participants' descriptions gave a sense that these threats were another level of paralysis (powerlessness).

4. 4.1 The multiple faces of vulnerability and its consequences

Described earlier in the subordinate theme **Acceptance of bodily dependence – "the turning point,"** participants reported fearing the unknown when first discharged and described occasions when their well-being had been compromised. These included experiences of secondary conditions common to those with SCI: autonomic dysreflexia, pressure sores, urinary tract infections and spasticity. In addition the potential fear of having a bowel accident was always present. This feeling of vulnerability infiltrates all aspects of life, physically, mentally and spiritually. This vulnerability is expressed (depending on the extent of the threat) as everything from frustration and unease, to anxiety, agitation and being scared and fearful. This section will show the progression of vulnerability, the threats and response.

Whilst carers were viewed as providing the participants with a better quality of life they were also presented as a potential source of personal risk. Participants described a vulnerability associated with being in a position where they had no choice but to rely on carers to come into their home:

How much more responsible an area can employer/employee relationship be than a tetraplegic being totally reliant on a carer who has got free reign of the tetraplegics home, contents, vehicles, a hold over his life, his body, his safety? (Peter)

Carer availability offered some peace of mind “*I just need someone to turn up*” (*John*). However, carers could also be directly responsible for causing the complication in the first instance. This was described earlier by Jane who sustained burns to her feet, and also fell from her bed whilst in the ‘care’ of her carer. Amy similarly described an incident regarding her bladder management:

Sometimes I have to give a wee reminder to the carers; they might lose focus on what they're up to. One carer accidentally snipped it [catheter]. I was sent to hospital with dysreflexia and had to stay for a week. (Amy)

The importance of being able to effectively communicate one’s needs to carers appeared to be challenging at times for some participants:

If I'm really sore and uncomfortable it's sometimes hard to get across what you want to say to people and.....I raise my voice.....they come back to me as in 'don't speak to me like that!' and it's like well I just wish you would kind of understand that for that moment I can't be rational with you, I can't be calm with you.... It's just difficult to communicate to people sometimes what your actual needs are; what you want done, especially if you become dysreflexic. I only swear at certain times, one is when I am in pain and the other one when it's just totally, totally frustrating. (Chloe)

The above accounts seem to suggest participants expected it is vitally important that carers are astute, able to employ observational skills to assess if the individual with SCI is indeed compromised, and an ability to provide immediate assistance without always needing to receive verbal instructions.

'Fear' of the known, for example sustaining a pressure sore or experiencing an AD episode appeared as an ever present emotion. Awareness of one's own vulnerability drove participants to do their utmost to avoid threats to their wellbeing. Anxiety due to participants fear about known complications was reduced by having carers they trusted, being an active participant in their own care, understanding their own SCI and related preventative methods in order to avoid complications. Chloe talked about spending a year and a half on bed rest due to pressure sores, "*it nearly killed me, pressure areas and spasms are probably the worst part of my life.*" This account highlights why the scale of fear can be so encompassing when considering how the consequence of sustaining a pressure sore filters into all aspects of a person's ability to participate in activities in or outside the home, and impacts negatively on their emotional, sexual and mental well-being. A further potential scenario to sustaining a pressure sore is a cascade effect – if a hospital admission is required, "*good*" carers seek other employment if the inpatient stay is lengthy, this is followed by the fear of having to engage with new carers when discharged.

Tom talked about how he felt after being burgled. He had always felt vulnerable to SCI complications, and now his fear of being alone was heightened. Like all the participants he believed it imperative another person was in the home overnight to assist you in the event of an adverse event:

I was burgled and I didn't know it until my caregiver came in the morning. It was very, very unsettling, I then found staying by myself I felt so vulnerable.... so vulnerable... for burglary. I always felt vulnerable for having any bowel or bladder problems. When I need someone when I have a bowel accident or a catheter blockage I need someone to be there straight away... I don't have time for someone to come in on call and I have been put in situations where it has been a bit scary going into dysreflexia. (Tom)

Similarly, Peter like all the participants feared fire, and being trapped in their bed with no one to get them out in time:

Mainly for security and safety sake I prefer to have someone in the house. I have quite a fear of being trappedsay in a fire. If I was alone in the home there is absolutely no way that I would be rescued in time. By the time

emergency services arrived.....the house would be well ablaze, if not full of smoke. (Peter)

Several participants' described that they preferred to be left in their wheelchair, rather than "trapped" (*Peter, Tom*) in bed as it enabled their mobility and some level of independence:

Especially when you are in bed, totally vulnerable, trapped in fact. You are more vulnerable when you are in bed. When you are in your wheelchair you feel safer because you can propel yourself wherever you want to, whether it be to another room, outside..... yeah. (Peter)

There was an associated fear of losing funded hours particularly for sleepovers. All participants strongly emphasised replacing human support with assistive technology would not suffice. Tom's repetition of the word "huge" three times highlights this point:

Having someone there overnight is a huge relief, a huge, huge weight off my shoulders, they [ACC] fricken better bloody not take it away. (Tom)

However, Ethan discussed how terrified he would be when in the 'care' of his "dodgy" caregiver at night time after he had been put in bed:

.....yeah there was a lot of drinking going on and some pretty crazy parties and like M & M playing at four in the morning and fights going on outside my bedroom door, like banging into the walls and stuff being broken and the house just getting trashed. (Ethan)

Some participants were fearful they would get funding cuts to their overall current care package, and the resulting consequence of not being able to participate in the activities they choose. One participant worried that it would result in a loss of income for family and friends. However, the majority of participants believed their current level of funding was adequate to meet their needs at this current time, and were not fearful of further cuts, believing and 'trusting' ACC had their best interests at heart and were confident that funding would not be removed arbitrarily:

I've never ever had a problem with ACC, even when that big turnover [ACC restructuring] and everything changed I got hours taken away from me but boy they did everything and anything to help me at times when I needed extra time, when I needed a little bit more hours. (Chloe)

4. 4.2 Mistreatment

Five participants described experiences of being the victim of physical and/or psychological abuse by past paid carers. Examples of mistreatment included: threats of abandonment, carers not turning up for work, not working scheduled hours, failing to perform agreed duties and being ignored. However, some of the participants themselves did not necessarily recognise these experiences as being a form of abuse but as something they just had to put up with. Although, in the context of the discussion it was clear by their words, and body language, these experiences caused them great consternation and are significant barriers to living life in a manner they would like to.

Participants' accounts gave a sense of helplessness, with a resignation that these experiences will not be isolated events. Concerns were expressed about how carers may react when participants voiced dissatisfaction with the 'care' or confronted carers who perpetually arrived late or turned up for work intoxicated, and whether such assertion might put them at further risk. This risk could result in their carer leaving them in a vulnerable position, or the carer might react adversely and cause physical harm.

Power differentials existed when individuals with disability are not able to reciprocate nor able to get immediate help. For some participants the only course of action was to subordinate oneself to the carer, and comply with their wishes by giving in to the carer who has physical power over them or risk responding verbally. Peter described the vulnerable situation those with a high level of disability can find themselves in when exposed to abusive carers:

Generally tetraplegics can only be vocal in their abuse whereas a carer can be vocal, physical and psychological in their abuse, far more dangerous. It certainly makes you wary next time you have to hire another carer. (Peter)

Types of mistreatment vary. Peter described both physical and psychological abuse at the hands of carers:

I have had carers who may be in a bad mood, and that has had an impact on how rough they may be when doing my bowel care.....or rough when doing my transfers. I have had property stolen from within the house.....ah damaged purposely.....um....yeah.....and not looked after. I have had carers who have been drunk or on drugs that have turned up in moderate or bad states.....He [male carer] called me.....mmmm.....fucking C word several times. Probably not less than 25-30 times, in order to have, I guess, a parting shot and in order to try and hurt me psychologically he would make reference to my small organ parts or the fact that I was a cripple that would probably not amount to much..... (Peter)

Peter repeatedly described falling into familiar patterns of tolerating substandard ‘care’:

I know the dangers of mismanagement and rough care and how it can lead onto bigger more traumatic injuries to the body and well your psyche. Sometimes you feel ‘should I let this person go and employ someone new or should I just put up with the devil I know and persevere with it and work in with it. (Peter)

Peter had an inner struggle with himself as he tried to understand his own behaviour (accepting substandard ‘care’) when he also believed those with SCI should expect quality care. It seemed Peter shared similar characteristics to victims of domestic abuse (feeling powerless in their own lives, embarrassed to admit being a victim of abuse, and feeling powerless to change their situation or protect themselves).

“*The devil I know*” is a euphemism for an abusive carer. This suggested Peter balanced a known list of faults against an unknown list in a new person. Peter may believe he could learn to cope with the faults of this carer, and feared that he might not have been able to cope with a new range of fault in a different carer, and find himself worse off. Peter implored others with SCI not to fall prey to abusers and become “*trapped*. ” Peter believed this was best achieved at the onset, when boundaries are set and expected quality of care stated. As Peter discusses any deviation from this must lead to the dismissal of the carer immediately:

You need to keep yourself safe and direct your caregivers to care for you in the appropriate manner. Umm, and if they are not receptive to doing that

then you shouldn't have them looking after you 'cos it can only be detrimental to your health. (Peter)

Not unlike Peter, Amy had several less than ideal carers over the years, and also tolerated them until such time when it became unbearable:

I was on the tilt table; I told her to just make sure that my feet were down flat, she got shitty with me and I said to her "look we cannot communicate, I think you better go home" because she was getting really angry. I didn't care if I was stuck on the table or anything like that. I just wanted her to go, I didn't like the way this carer was treating me and stuff. It seems like she was dominating me. I tolerated her for two years. (Amy)

The line between appropriate touching as an essential part of the job of a carer and inappropriate touching could lead to unwanted or ambiguous sexual connotation. Bathing and dressing are very intimate activities therefore it is understandable that blurry boundaries can create confusion and discomfort:

.....her eyes were directed in the wrong direction, she was looking at my vaginal area, I felt uncomfortable then, and I thought she doesn't need to be looking there so why is she looking there? (Amy)

Chloe also gave examples of mistreatment; below she described a situation when she challenged a carer about alcohol consumption and reports carers have frequently stolen from her:

I confronted her about having alcohol on a shift, she came up to me and tried to throw her weight around with me yelling, swearing at me. I just said to her 'don't you hit me, that'll be the last thing that you do' so she had a big yell at me, went out and screeched her car out of my driveway and around the street so that wasn't very pleasant. I have had staff steal from me..... We've had disagreements.....definitely, that happens. (Chloe)

Chloe also described on more than one occasion she had been rendered to feel "powerless" and "vulnerable." The below account also illustrates Chloe's resilience when faced with adversity:

I was compromised, they've left me before, basically in the shower undressed and just left. There was a big argument and they just left me sitting there. So I think that has happened about maybe three times in the last six years. Um.....powerless, it made me feel totally powerless.....there was nothing I could do about it. I just sat there with a towel over me in the bathroom thinking 'right, you are sitting on a shower chair, there's nobody here, what are you going to do?' So I pushed myself with my hands, I tried to push this blimmen stiff shower chair to my bedroom to get to the phone. ... It made me feel vulnerable, very vulnerable. (Chloe)

4.5 Summary

In Chapter Five the results of this research will be placed in the context of previous research surrounding paid personal care service.

Chapter Five: Discussion

5.1 Overview

The aim of this study was to gain an in-depth understanding of the lived daily experience of managing paid personal care services following a SCI. Of the many issues raised by participants in this study, I have chosen to focus on the five themes which best illustrate the relationships between people with SCI and paid carers: **Acceptance of bodily dependence - “the turning point”**; **Self-determination within the context of interdependency**; **Follow your “gut instinct”**; **Friendship ambiguity** and **Mistreatment**. The study has shown relationships between people with SCI and their paid carers are characterised by complex power dynamics.

This chapter presents these findings in relation to the extant literature. The trustworthiness and transferability of the study are presented, and implications for both research and clinical practice are discussed, followed by some personal reflections on the thesis journey.

5.2 Acceptance of bodily dependence “the turning point”

Participants discussed having mixed feelings about the experience of being initially discharged from the spinal unit and returning to an environment (not necessarily their pre-injury ‘home’) where they were dependent on the support of virtual strangers employed to provide ‘care’. Participants claimed they had felt unprepared, not only for the differences between the environment of the spinal unit, and their discharge destination, but for these formal care relationships. These issues were not unique to this study; Cott (2004), when investigating consumer-centred rehabilitation for those with a range of mixed impairments including SCI reported similar issues.

Adjusting to SCI following discharge was described by participants as being a period of emotional turmoil, disorganisation and chaos, and their world around them appeared fragmented and uncertain. Participants experienced a range of conflicting emotions from a sense of exhilaration at being out of hospital, to numbness, anger, hope and despair. This concurs with observations from individuals with SCI made by Laskiowski and Morse’s (1993) ethnographic study. Laskiowski and Morse (1993) suggested that during such displays of despair the permanence and ramifications of the injury were

being reorganised; both the expression and modification of hope were considered essential for adjustment. It was during these episodes that unrealistic hopes were modified into more realistic goals. In practical terms John hoped for more independence, but pointed out: "*I can't get out of bed; I can't lead a life unless I have them [carers] do it.*" By accepting his dependency on carers in activities of daily living he attached less significance to his hope (or goal) for independence in this physical activity, and focused on making the best of what he could do with his mind and abilities. This finding was similarly reported by Dewar and Lee (2000). Using a grounded theory method Dewar and Lee (2000) examined how 28 individuals, who had lived with catastrophic illness and injury and concluded that coping with disability occurs partially through reducing significance of unattainable goals and development of new goals.

Problems with adjustment can affect other areas of functioning, directly impacting either positively or negatively on relationships held with carers. Some participants in my study reported that they lacked assertiveness when first discharged from a spinal unit; they assumed a submissive attitude allowing the carers to make all the decisions of how their care would be provided. Others adopted an optimistic attitude viewing the injury as their new 'normal,' and took an immediate stance of being in control of their own care and home. Demographic characteristics amongst the participants in this study were diverse (see Table 4.2) which may account for divergences in their reported accounts of adjusting to their SCI and learning to accept their need for carers. This supports findings from Boschen, Tonack, and Gargaro (2003) and Dorsett (2001) who named a range of factors which may influence how a person adjusts to life with SCI, including age, emotional maturity, financial situation and social supports.

Some participants from this study discussed different phases when adjusting to their SCI and accepting the need for carers. In some cases this included angry outbursts as they adjusted to the new situation, finally redefining themselves, and their social roles, in order to regain their ability to move on with their lives. Jane described a "*turning point*" when she had no option but to manage her attitude and modify her behaviour because if she did not, she would have no care. When Jane ceased swearing and projecting her anger and grief towards carers, this change in behaviour appeared helpful in alleviating her stress while she learned to manage life changes and preserve relationships with others. The stage of 'modifying' as described by Dewar and Lee

(2000) parallels this finding. When individuals' in their study identified the need for social support as being permanent, they had to make concessions regarding their conduct and expectations for these support relationships.

In my study Tom said he did not feel any less of a person because he is disabled and has to ask for a lot of things, and John refuses to "*be a lame duck*" and hand over control of how his care is managed. Both these men appeared to have a positive self-schema, and were able to maintain their sense of independence despite their need for care. Both the results from Dewar and Lee's (2000) study and this study indicate that when individuals develop a positive self-image, what Dewar and Lee (2000) called a 'boosting' strategy they adopt a view of being able to take responsibility to make decisions for their own life and manage difficult circumstances such as dependency on formal care relationships.

Overall participants' accounts in my study indicated that as they mourn the loss of their former self they concurrently adopt various coping strategies. This makes it possible to regain their self-control as they emotionally adjust to their situation and accept the need for carers. Being able to do this successfully makes day-to-day existence bearable. The literature indicates that there is a considerable variation in the time taken for individuals to adjust to their dependency. As John commented, "*Ohhh.....I still hate it but I can compartmentalise it better now.*" The study's results support claims made by Fukunishi et al. (1995) that even seven years after injury, many people do not reach complete psychological acceptance.

This study suggests that the "*turning point*" is reached when participants embrace a sense of serenity regarding their situation, without necessarily having to 'like' all aspects of that situation, such as being in a position of physical dependence on others. To borrow the words of Reinhold Niebuhr (1951), this turning point is reached when participants achieve 'the serenity to accept the things [they] cannot change/ courage to change the things [they] can/ and wisdom to know the difference.'

5.3 Self-determination within the context of interdependency

This subordinate theme, **Self-determination within the context of interdependency**, pointed to an important aspect of the power within the caregiving relationship; in order to maintain the locus of control the recipient of care needed to be in charge of their home, engaging in and actively managing how personal care was delivered. This finding of the need for self-determination in a SCI population is consistent with earlier studies about receiving care in mixed disability groups where it was found that self-determination was achieved when people were proactive, and assertive about having control over the process of receiving care (Bleasdale, 2000; Frank & Elliot, 1989; Meyer et al., 2007; Rogers, 1982; Woodlin, 2007). Nevertheless, I found that self-determination was hard won in the context of the participants' vulnerability based on their need for care.

Vulnerability is a threat to autonomy. Some of Chloe's carers, for example, refused to drive her mobility van. A refusal meant that Chloe felt frustrated and could not participate in social activities as and when she wished. This dependence on another was experienced as vulnerability, a lack of self-determination and autonomous life. This is also an example of how paid carers can contribute to disability; a further example was given where the employment needs of the carer meant that Ethan did not get to go to the world cup. With regard to the loss of personal control, similar reports were given by participants in Dickson et al.'s (2008) IPA study of participants with SCI, who were also frustrated by their inability to control their movement, and by their dependence on others. Thus, the findings from my study echo what has previously been reported. That is, carers may lack empathy, knowledge, and experience with respect to how to allow disabled persons to exercise autonomy (Ahlstrom & Wadensten, 2010). One characteristic of relationships that promote autonomy for the person with SCI is that of good communication.

Participants were of the opinion that the establishment of effective working relationships with carers relied on good communication. However, there were many examples of times when communication proved challenging. Chloe spoke of her frustration when carers failed to follow her set routines, to recognise when she was in pain, or dysreflexic; at such times she raised her voice only to have the carers act defensively, or become "*upset and uptight.*" Participants in Meyers et al.'s (2007) phenomenological study, living with a range of physical disabilities including SCI and

dependent on caregiver support, reported their carers frequently felt offended if ‘told what to do’, creating tension between both parties. Bondi (2008), offering a psychotherapeutic perspective about caregiving for disability, suggests that good communication does not guarantee good care; good communication does enable effective feedback about the match between needs and the care available, which may be sufficient to enhance the quality of care received. Schoop et al. (2007) investigated the link between satisfaction with care and a range of caregiver characteristics, and found that perceptions of poor carer responsiveness may be related to low levels of carer training. Both Bondi (2008) and Schoop et al. (2007) recommended training to address how carers might best facilitate interaction between themselves and their clients. Key elements of the recommended training are learning how to communicate appropriately with people who have a disability and viewing the person with disability as an expert based on first-hand own experience.

Communication with powerful others, such as care agencies, was equally important to living an autonomous life. Many care agencies in NZ offering a holistic service claim to be specialised providers within the field of SCI. However, all the participants who received care through a care agency frequently described experiences where the agency managers/co-ordinators were considered disempowering agents, causing them unacceptable frustration and discord, as opposed to their relationships with the ‘hands on’ carers. Their frustration was voiced in relation to issues surrounding the scheduling of carers, not having their genuine concerns listened to, unsympathetic attitudes, and failure to act on complaints. As Chloe commented, “*That’s why sometimes it’s hard to rely on people.*” This dissatisfaction with care agency managers, which does not appear to be previously identified in the literature, suggests that it is essential to have effective communication amongst all stakeholders within paid care services in order to improve outcomes and satisfy the needs of the end-user. In contrast, there were few direct criticisms of any current ACC personnel, (which is an interesting finding in itself as there has been plenty of public criticism in the NZ media that suggests that other sets of people with complex injury in NZ do not find this to be the case); the blame with dissatisfaction regarding care is laid solely with the care agency managers/co-ordinators. When participants are able to effectively communicate and advocate for themselves they retain some locus of control. As Boshen et al. (2003) found, ‘locus of control’ plays an important role in the adjustment to SCI, and ‘locus of control’ is

predictive of quality of life, productivity status, the performance of daily activities, and satisfaction with community integration.

An important element of maintaining one's autonomy is to have the ability to make choices and be able to act on them (Hammel, 2006; Lohne & Severinsson, 2003). It was clear from Ethan's account that not having the option to choose to manage his own paid care caused him frustration. However, for those people funded by ACC they are able to make a choice on how they want to receive their paid care services: consumer-directed model or care agency. Three of the participants in my study used the consumer-directed model and believed it to be empowering, allowing for greater control over care arrangements compared to using care agencies. These participants views were consistent with those of Allen and Ciambrone (2003); Hagglund et al. (2004) and Prince et al. (1995) where persons participating in consumer-directed programmes reported fewer unmet service needs, higher perceptions of safety, and enhanced quality of life compared with individuals in an agency-directed programme. Preference for a consumer-directed model of care appeared to depend on the length of time since sustaining a SCI. Notably; the three participants who utilised the consumer-directed model in this enquiry had lived with SCI for many years. This may mean they were feeling more adjusted, confident, and open to the option of being able to utilise a consumer-directed model to obtain and manage carers. However, when first discharged the added responsibilities that this model entailed may have seemed harrowing and something they could not cope with. As Peter pointed out, often when people are new to their SCI they are still learning how to care for their body, perhaps making the consumer-directed model less desirable when initially discharged. In contrast, Chloe, who was experienced in utilising both the care agency and consumer-directed model of service provision, identified care agency provision as her preferred option, as a consumer-directed approach offered limited back up support if a carer became unwell, or failed to turn up. Chloe also preferred someone else to take responsibility for conducting employment interviews, performing police checks and sorting out wages. Chloe commented "*I just can't be bothered with that kind of stuff.*" The finding is consistent with the literature (Glendinning et al., 2000; Nosek, 1991; Pijl, 2000), which notes some people do not want to, or they have difficulty with taking complete control over service delivery.

Regardless of the service model utilised, all the participants discussed how the work of the paid carer was considered crucial to their quality of life, health and ability to participate in social activities. However, participants' attitudes to carers varied considerably and were not always consistent. Some participants' accounts suggested they thought carers were paid to be present to do a relatively 'easy' job; Peter and Chloe described carers as their "*hands and legs*," representing the carers as 'tools' for the participants' use. It would be interesting to learn if the participant's carers shared this perspective because in Ahlstrom and Wadensten's (2010) qualitative study it was reported that some carers viewed their role as depersonalising, resulting in their work lacking stimulation when they were treated only as a substitute pair of arms or legs. On the other hand this notion of carers being primarily instruments of care was not echoed in other participants' accounts. In fact, in other accounts participants stated that they did not want carers void of compassion and sensitivity. There was a strong sense that most of the participants in this enquiry had a clear understanding of what supporting a tetraplegic in the home might be like for carers to do what they do. Peter, for instance, acknowledged the work of the carer can be physically and emotionally demanding. Peter would introduce his most valued carers "*as my primary caregiver to make them feel a wee bit more important*," and Amy commented, "*you feel you want to give them something in return 'cos they do a lot for us, sometimes we treat them like slaves.*" Amy therefore, often let carers watch television instead of performing domestic chores, or leave early still claiming full hours. Tom said he ensured his carers were well remunerated because he valued their role and availability; the 'extra' that Tom pays his carers is self-funded because he has the means to do so (this kind of freedom is usually not present in agency care, or in many types of consumer-directed care). This finding fits with Glendinning et al.'s (2000) qualitative study which describes the relationship between disabled people who employ carers directly and the carers who provided intimate personal care and domestic help from the perspective of both parties. The disabled people receiving care, recognised the stressful nature of a carer's job, and wanted to be able to reward it accordingly.

All the participants articulated the point that they wanted not only control of what occurs in their home, but control over teaching their carers about their particular SCI and related care needs in the first instance. Therefore when selecting carers participants often gave those with limited experience preference compared to those with SCI knowledge "*not necessary to have spinal cord injury experience, I prefer to train them myself*" (Peter). Participants considered the relationship was better able to be negotiated

when unhampered by a carer's preconceived notion of how care tasks are done. The literature reports similar findings (Glendinning et al. 2000; Meyer et al., 2007, Morris, 1993, cited in Allen & Ciambrone, 2003) where formal training was identified as a potential barrier to responsive support. These sentiments are also shared by those in disability rights and Independent Living movements who believe consumer or provider training may conflict with consumer control of care provision (Saxton, 2001).

The initial introductory phase with a new carer frequently caused great trepidation for all the participants. In the absence of not having had the opportunity to establish rapport and a level of trust, participants were not only fearful that they could be harmed by a new carer (discussed within the master theme **Warning: potential traps**); as Jane pointed out the introductory phase is also "*awkward*," and "*uncomfortable*" given the rapid progression to being naked in front of a clothed carer. It was clear from the participants in this study that they put a lot of effort into making these relationships work, Jane would first be looking for the gut feeling that the relationship could work in the first instance, and knew that working towards creating a successful relationship required her to exercise patience and tolerance, despite some frustration and fear of sustaining injury. This was also highlighted in Meyer et al.'s (2007) study; the initial transitional phase was not only feared but an enormous amount of emotional and physical energy is required by those with SCI when training new carers.

Relationship boundaries are never static and shift according to circumstances. Participants in this study indicated that they were in control of maintaining the boundary between themselves and their paid carers regardless of working relationship rules or care agencies policies that both parties are expected to adhere to. Consumers of care, carers and organisations that hire carers have differing points of view regarding what constitutes professional boundaries and how to manage these. Nevertheless, participants emphasised that in their own home they would determine what was acceptable or not. A finding consistent with Browne and Russell's (2005) qualitative study that explored people with a range of disabilities perspective on the impact their sexual well-being needs had on their relationships with carers.

There appeared to be multiple ways that 'professional' boundaries between the participants and carers are negotiated. Self advocacy involved making decisions and taking responsibility for those decisions even when they yielded negative consequences.

For example participants discussed lending money to carers. However, this resulted in a level of awkwardness in the caregiver relationship when seeking repayment of the loan; lending money to carers was not something they would do again. A further example illustrating boundary dilemmas was given by Tom. Tom, who has experienced sexual relationships with carers in the past, now preferred to avoid such relationships, a finding similarly reported by male participants in Browne and Russell's (2005) study. In contrast Ethan, the participant with the least time of living with SCI, hoped that someday a carer relationship may blossom into a long-term intimate relationship. Male participants in Woodlin's (2006) study were also reported as likely to view carers as potential partners.

Participants in my study made adjustments, and refined how they did things; some decisions often caused difficulties and some distress however, participants accepted this outcome as their mistake to make; experience enabled them to better manage the people paid to be involved in their care. This supports findings similarly discussed by Browne and Russell (2005), Meyer et al. (2007) and Woodlin (2007). It appeared that managing such relationships was based on a process of serendipity and/or trial and error; boundary lines were sometimes drawn in different places depending on what the participants' "*gut instinct*" suggested was safe or desirable.

5.4 Follow your “gut instinct” and Friendship ambiguity

Follow your “*gut instinct*,” and Friendship ambiguity emerged as subordinate themes under the overarching theme of **Navigating relationship terrains**. These two subordinate themes appeared linked to what is involved when receiving assistance and appeared to be intrinsically linked to participants perception of the relationship they have with those involved directly in their care. This relationship was often described as ‘reciprocal’ in nature.

What is not evident in the literature, but novel in this study is the participants' strong belief in their personal intuition when it came to selection of carers and decision making. The 'Collins English Dictionary' (Crozier, Grandison, McKeown, Summers, & Weber, 2006) defines intuition as the "instinctive knowledge of or belief about something without conscious reasoning" (p.499). The role of intuition is perhaps understandable given the importance of carers and, the primary consideration, when making a final selection, is indeed a gut reaction to a potential applicant. Bursdall

(1998) recommended the recipient of care should feel completely comfortable, otherwise the applicant should not be considered for the position. When participants in my study failed to listen to their “*gut instinct*” both physical and psychological consequences could result, as described by Jane who sustained burns and fell from her bed whilst in the ‘care’ of an unsuitable carer, or Ethan who came close to being dropped when transferring into a car. However, in this context what was equally striking was Peter’s perspective of the lack of reliability of his “*gut feeling*” as a guide when hiring new carers. Despite the fact that Peter sustained his SCI 33 years ago, he describes having fallen into the same “*trap*” of employing a “*bad carer*” many times.

Participants discussed how finding people considered suitable to be their carer was challenged in the first instance owing to poverty of choices. Participants often found few applicants applying for the position, and of those who did, many were considered lacking in the qualities being sought. This supports Glendinning et al. (2000); Jorgensen et al. (2009) and Matsuda et al. (2005) who reported caregivers were identified as a ‘vulnerable’ population, poorly paid, and many were minimally educated with little practical knowledge of the job.

Peter used the word “*bizarre*” to describe the conundrum when torn between employing carers who are capable in providing instrumental support, but in the same context wanting the qualities of someone who would provide a level of comradeship such as that of a flatmate. This response implied that these sets of qualities may be in some cases mutually exclusive. All the participants listed a good sense of humour, kindness and compassion as prerequisites sought in a carer. This is consistent with previous research (Allen & Ciambrone, 2003; Eustis & Fisher, 1991; Glendinning et al. 2000; Matthias & Benjamin., 2008; Piercy, 2001 and Woodlin, 2006), where participants found the emotional disposition of the carer mattered more than task-related skills.

Many of the characteristics sought by the participants were based on past experience of what had or not been successful. These included preferences for mature or ‘motherly’ carers as opposed to younger carers who were considered less reliable, not necessarily appreciating the consequences those with SCI could endure if the carer failed to turn up for work; or gender preference based on perceptions of what they considered acceptable

for them in relation to the nature of their intimate care requirements and social participation.

It was clear from the participants' narratives that there are many risks involved when employing strangers to assist with personal care tasks in the home however, the option of employing family members was not considered optimum. Some participants had indeed experienced family members providing care both on a paid and unpaid basis. Some of these participants discussed how this had caused discomfort for both parties, placing a burden and strain on familial relationships, and now they would not chose to have family members as formal care providers now or in the future. This is not congruent with findings in Matthias and Benjamin (2008), where preference was given for family members to be paid carers. Introduction of the attendant care scheme by ACC removed the reliance on family members to provide informal care, enabling access to support outside of familial relationships. Peter believed this enabled him to restore his previous son-mother relationship, thereby possibly removing a burden of gratitude.

The nature of the relationship between the participant and carer is ambiguous. Participants in my study frequently referred to the relationships held with their carers as unique, encompassing elements of both employment and friendship. Browne and Russell (2005), Glendinning et al. (2000), Ungerson (1999), Vasey (1996), Woodlin (2006) and Yamaki and Yamazaki (2004) have given similar descriptions which span a range of commonly described relationships to describe employer personal assistant relationships. When friendships develop contradictions and ambiguities arise due to the carers' workplace being the recipient of cares home. Such friendships formed can be beneficial but can also create stress, role conflicts and propensity for negative consequences for the recipient of care.

Chapter Four details that close physical proximity and assistance with personal tasks meant relationships were likely to be more comfortable when some degree of personal connection with carers was present. The participants in my study discussed how they valued continuity, responsiveness, flexibility, and trust as relationships developed between themselves and their carers. As Allen and Ciambrone (2003) reported, trust characterising friendships may contribute to care recipients' acceptance of dependence, which in turn may alleviate the embarrassment or unease associated with receiving

personal care. However, respondents in my study were divided with regards to what degree of personal connection was necessary, and not all judged friendship as being essential. John, living with a partner and children, believed friendship was not a mandatory prerequisite, nor did it determine what distinguished a “*good*” carer from a “*bad*” carer. In striking contrast Amy stated, “*I haven’t got any friends really, my friends are my carers.*” Allan and Ciambrone (2003) found those who lacked strong familial and friendship networks came to rely on their caregivers for emotional as well as instrumental support. Notably, Kendall (2008) suggested friendships prior to SCI are challenged from the time of injury due to priority drifts; this may account for Amy not having any friendships outside the paid care arrangements.

According to Jane’s account, friendship ambiguity had consequences, for example, tolerating poor ‘care’ owing to difficulties addressing issues, as she felt unable to voice concerns for fear of upsetting the ‘friendship.’ Glendinning et al. (2000) believed there could be subtle shifts in balances of power where consumers were developing a sense of obligation towards their carers, therefore correspondingly less able to exercise control over help received. In my study Jane appeared the most perplexed as she struggled to make sense of her friendships with carers presenting polarising viewpoints during the interview where she considered friendship a desirable outcome for these relationships, and then shortly after considered it ‘best to be avoided’ in the first instance.

My study was limited to the recipients of care. Nevertheless, the findings mirrors those of Woodlin’s (2006) comprehensive study, which gathered data from a far wider number of respondents, including employers, family members and paid carers. Woodlin (2006) proposed the category of ‘paid friendship,’ which arose in these types of relationships where provision of care is in home environments. The features of ‘paid friendships’ include friendship which starts after employment rather than before, which share substantial areas of overlap with social friendship, which has the capacity to develop in a more formal or informal direction over time, and which is a consciously chosen relationship. It shares more characteristics with friendship than employment, and this is recognised by both parties in the relationship.

5.5 Mistreatment

The extent of mistreatment by carers reported in this study was surprisingly, and worryingly high, as five of the seven participants described past experiences of significant abuse of one sort or another. Unfortunately such mistreatment is not uncommon among people with SCI internationally, although its extent in NZ has received little research attention. Participants described mistreatment which included intimidation, rough handling, ridicule, and theft, clearly demonstrating that disabled people's human rights are not guaranteed in NZ. These results suggested there is a high likelihood that such mistreatment may be a wider problem and this warrants urgent further investigation. The theme of **Warning: potential traps** and its subordinate theme **Mistreatment** have a strong relationship with all the master and subordinate themes, owing to their ongoing threat to successful paid care relationships. When mistreatment occurs people's abilities to engage in daily life activities are compromised, along with their personal health and safety.

Because of the small size of this study, it is not possible to draw conclusions about the correlation between mistreatment and age, sex or length of time since onset of SCI. However, all three women in this study reported various forms of mistreatment. In separate studies (Curry & Navarro, 2002; Young et al., 2001) it has been identified that women with disabilities tend to be more likely to experience abuse by health care professionals, paid carers, family members, intimate partners, or friends than non-disabled women.

Interestingly, participants of both genders in this study either hesitated, or answered with a 'no' initially when asked if a carer had ever made them feel uncomfortable or unsafe before moving on to talk of specific experiences of just this. As they spoke of these experiences, only then did they acknowledge them as being a form of mistreatment – a finding similarly reported by Calderbank (2000), Saxton et al. (2001) and Young et al. (1997) although their studies focused solely on women with disability, who struggled to determine if mistreatment was intentional or not. Several alarming findings were noted from the participants' accounts in this enquiry. Firstly, various forms of mistreatment are not formally reported. Saxton et al. (2001) and Young et al. (1997) found women with disabilities may be reluctant to report abuse for many of the same reasons that children and non-disabled women do not report abuse, i.e. fear of retaliation, dependency and shame.

A number of other factors which may influence a person's decision to report abuse has been identified in the literature on mistreatment and disability. First, there is the significance the victim attaches to the incident, and whether the victim feels sympathy for a perpetrator (Jezierski, Lynch, Dexheimer Pharris & Sateren, 2004; Saxton et al. 2000). Second, the traumatic stress of the abuse often compounds the sense of vulnerability that some people with disabilities feel, and coming to terms with this can be intense, and further disabling. People who have just gained some independence may be at risk of losing their newly gained independence and self-confidence (Jezierski et al. 2004). Third, leaving abusive relationships may be more difficult because of the presence of a disability (Curry & Navarro, 2002). Fourth, individuals may not have, or perceive that they do not have, anyone trustworthy to whom to report, or they may be concerned about the probability of being disbelieved (Jezierski et al. 2004). Fifth, concerns such as repeated difficulties finding a quality care provider, or fear that the next carer might be worse, and lack of emergency back-up carers may also influence an individual's decision to report mistreatment or not (Jezierski et al. 2004). Sixth, police are often unaware of, and untrained in issues related to disability, and may not understand the nature of paid care services, and the potential for difficulties (Saxton et al. 2001). Furthermore, prosecuting a legal case may depend on proving the extent of the disability in which case the person may become further stigmatized by the system in the process (Jezierski et al. 2004).

Whilst individuals who employ carers directly by using the consumer directed model may be considered more vulnerable to mistreatment by carers due to lack of supervision and monitoring by outside agencies, this was not evident within the data from my study. It would appear likelihood of mistreatment can occur in either model of service provision. This claim is substantiated by data analysis from separate studies (Benjamin et al., 2000; Oktay & Tompkins, 2004) that identified no increase in harm to consumers who use the consumer directed model for service provision. Participants in my study learnt it was better that a carer who became 'angry,' or was suspected of being intoxicated, left the home rather than continue with provision of intimate cares. Whilst this left the person with SCI in a compromised position, it was considered preferable to the potential for being physically harmed by the angry carer. These management practices for dealing with 'conflict' or a perceived threat to one's immediate wellbeing are congruent with Saxton et al.'s (2001) findings. Individuals in their study developed creative and innovative ways through lived experience to manage difficulties of carer

abuse. Further, participants' behaviour has a substantial effect on whether they are likely to be abused. Tom and John who demonstrated a positive self-schema and 'assertiveness,' expecting nothing less than quality care, appeared less likely to be exploited or mistreated by carers. It could be hypothesized that gender characteristics and/or educational level may also have contributed to their positive sense of self worth. However Peter, also male and apparently well educated, did experience abuse at the hands of his carers. Thus, either education or gender was necessarily protective against abuse.

All the participants in my enquiry addressed their responsibility to be thoughtful and direct in their communications with carers. Participants emphasised the importance of treating carers well, to exercise patience, to not "*bark orders*" (*Ethan*), and demonstrate fairness. Similarly, Saxton et al.'s (2001) participants reported sensitivity to carers' needs greatly enhanced the success of paid care relationships.

Lastly, Peter and Amy described 'tolerating' their abuser for periods of up to two years: "*Sometimes you feel 'should I let this person go and employ someone new or should I just put up with the devil I know and persevere with it and work in with it'*" (*Peter*). This parallels the language used by a participant's in Saxton et al. (2001) study, who stated: "*the devil you know is better than the devil you don't know*" (p. 408). Participants in Saxton et al.'s (2001) enquiry constantly reported weighing up the pros and cons of a relationship that turned abusive. Saxton et al. (2001) believed women sometimes submitted to irresponsibility of carers as a consequence of this balances of pros and cons, and/or projected fears from past experiences onto current carer relationships. Reliance on a spouse, family member or paid carer for personal care can reinforce the classic cycle of domestic abuse. Dependence is not limited to financial or emotional needs, but also requires the basic needs of mobility and physical access (Saxton et al, 2001).

Somewhat surprisingly, recalling these accounts during their interviews did not appear to distress the participants in my study. Possibly the opportunity to vent these specific experiences, perhaps for the first time, was therapeutic or empowering. It could be that one of the reasons for participating in this research was the hope that, by doing so, these issues will be fed back to others in the SCI community who may

learn from, so others might avoid similar situations. One participant asked for the recorder to be turned on again at the completion of the interview, adding to his story of abuse in more detail. Another participant offered more detail about one event only when the recorder had been turned off. Ongoing telephone abuse and threats, suggesting harm, by a carer whose employment had recently been terminated was discussed by a third participant. This participant did not feel he was in any imminent danger, clearly articulating he had safety strategies in place should this carer physically approach him again.

Power and control are basic tools of an abuser as can be seen by research undertaken in other areas. Some paid carers were reported to have used physical, psychological, and emotional tactics, with threats, targeting of vulnerabilities, neglect, ridicule and abuse of privilege. It is a blatant abuse of power when a carer arrives at their paid work environment (the recipient of care's home) intoxicated in the first instance, as this would not be tolerated in other work environments. Narratives from this NZ enquiry, and the known fate of a 56 year old tetraplegic man who confronted his paid carer in 2005 for being intoxicated (van Beynen, 2010) highlight the magnitude of 'vulnerability,' and threat to safety for a person wheelchair dependent as they are physically powerless to defend themselves when confronted with danger in their own home.

There are various 'Power and Control Wheels' that are useful models for better understanding the dynamics of abuse within family violence with one 'Wheel' specifically for older adults and those with disability (see Figure 5.1). The behaviours which form spokes within the wheel depend on and reinforce each other. Sexual and physical violence, forming the outer rim, reinforce the entire system of control. Physical and sexual violence are not always present in abusive relationships, but, emotional abuse is always present. The wheels illustrate the interdependent and systematic nature of violence and abuse within relationships (Jezierski et al. 2004). This model offers a way to think more broadly about abuse than just in terms of physical or sexual abuse.



Figure 5.1 Power and control wheel for elder and disabled. Reproduced with permission from Jezierski et al. (2004)

Violence, particularly domestic violence, is an issue for all of NZ society, not just for disabled people. However, there is a lack of NZ information on which to take effective action for disabled people. Comparative evidence from overseas however suggests that disabled people are at higher risk of domestic violence and abuse than non-disabled people (Calderbank, 2000; Curry & Navarro, 2002; Saxton et al. 2001, Young et al., 2001).

In order to break an abusive cycle it takes the courage and support of others. The NZ Government is working with a collective of non-government organisations to address violence issues against disabled people. Since 2008 organisations such as 'Disability Coalition Against Violence' have led and participated in many anti-violence projects in order to raise public awareness and knowledge about these issues. Calderbank (2000) argues that disability rights campaigners need to put abuse on their agenda not as a sign of vulnerability but as a human and civil rights issue: "Only when disabled people expose abusive practice and situations can a process of practice, policy and attitude change begin" (MacFarlane, 1994, p.85).

My study highlights that regardless of sex, intimate contact by caregivers gives perpetrators access and opportunity to abuse another person. Therefore, intimate contact is crucial to understanding when and where abuse happens regardless of who is perpetrating the abuse. However, limited understanding and acceptance of what some disabled people require in having a domestic household has resulted in some New Zealanders being marginalised and excluded from the protection, safety, support and services provided by the *Domestic Violence Act 1995*. Te Kupenga Whakaoti Mahi Patunga also known as National Network of Stopping Violence, has highlighted the ambiguity of the *Domestic Violence Act* in regards to whether disabled people who require the services of caregivers, receive the safety, protection and the services of the *Domestic Violence Act 1995*. Exclusion in the Act, in 4.2 (a) (ii) says an employer – employee relationship is not regarded as sharing a household. The Act defines meaning of domestic relationships to include, 4.1(c) person who ordinarily shares a house with the other person; or (d) has a close, personal relationship with the person. The *Domestic Violence Act 1995* says that domestic violence in relation to any person means violence against that person, by any other person with whom that person has or has been in a domestic relationship. Participants' accounts in this study clearly described how carers have access to personal space, homes, and bodies, making those living with disability particularly vulnerable to potential mistreatment. Domestic violence is about power and control in homes. When domestic violence is in the different kinds of homes, disabled people need to live as independently as possible, there are the same dynamics (Te Kupenga Whakaoti Mahi Patunga, 2011). Therefore, current definitions of domestic abuse should be expanded to include abuse in carer-consumer relationships. The experiences of women or men with disabilities should not be treated as special cases, but as part of the continuum of eliminating all forms of abuse.

5. 6 Trustworthiness and transferability of findings

This section will provide a critique of the study undertaken reflecting on both the strengths and limits of the work.

This study provides a contribution to an understanding of the phenomenon of managing paid personal care following a SCI, and appears to be the first IPA study of this sort to have been conducted in NZ. Searches of the literature indicate that there is a paucity of qualitative research into managing paid personal care services following SCI generally.

Throughout the study the perspective of the participants has been respected. IPA was chosen because of its congruence to the theoretical paradigm and the research aim. I believe I have presented the participants story in a way which reflects their real life experiences. As described in the Method chapter the themes identified were confirmed by a second researcher (WL) and the quality verified by a third researcher who reviewed the final data (JHS). Therefore, the findings from this study provides a contribution to an understanding of what it is like to manage paid personal care services in NZ and the nature of the relationships held with paid carers; as the idiographic nature of IPA allows the voices of individual participants to be heard.

A primary strength of the study is that the sample was a homogenous group in that all the participants had tetraplegia at similar levels and consequent neurology due to a traumatic injury and required more than 20 hours of personal care assistance a week. Further, it also was composed of both men and women, who had utilised both models of service provision, with a range of experiences of duration of life since SCI. Nevertheless; it is possible that the recruitment procedure influenced the type of data collected for this study. The participants who agreed to partake in the research might have done so because of personal characteristics, or desire to talk about their experiences, and so it is possible they may have been better adjusted to their injuries than most people with SCI, or that they had more dramatic stories they wished to share.

One of the strengths of the study design is the potential to extend the study (as discussed in section 5.7). It is important to extend our understanding of the complexities of managing paid personal care services in the community and its effects on people with disabilities ability to participate in activities that are important to them. In this current study, as suggested by Schoop et al. (2007) it was found that when carers had insufficient knowledge of personal care requirements for a person with SCI, or there is ineffective communication about these activities, increased the incidence of secondary complications. It is hoped that learning about the experiences of the SCI participants in this study may go some way to encourage health professionals to seek to understand the myriad of challenges of being dependent on paid personal care services when discharged from a spinal unit. Some of the themes derived from this research may go some way towards assisting people with SCI to better prepare for formal caregiving relationships within the home environment.

Achieving a representative sample is not the aim of IPA work since the emphasis is on thoroughly analysing the specific participants' accounts (Smith et al. 2009). This study represents only this particular group of SCI individuals' experiences, they are suggestive as opposed to conclusive, and cannot be generalised to the wider SCI population. A further consideration that should be borne in mind by readers of this thesis is my 'closeness' to the subject of this enquiry, which may have influenced my choice of what to ask questions about and what to focus on in my analysis and write up.

5. 7 Clinical implications and recommendations for further research

The current research highlighted the difficulties experienced by participants in maintaining their autonomy, privacy, and sense of dignity following a SCI whilst accepting their dependency on paid carers. Each master theme has highlighted areas for development that services, and individuals with disability, might benefit from. While the findings of IPA studies which utilise small samples should not be considered generalisable, they can provide insight into lived experiences that may be useful for guiding clinical practice. Also, the consistency of these findings with previous international research provides additional support for clinical development in several possible areas within the SCI field.

The results have implications for the importance of support interventions aimed at 'preparing' people with SCI for dependency relationships. Many of the participants in this research suggested that they had not been well prepared for the change in their lives post-injury or for managing future relationships with paid carers. A better sense of what to expect practically, and in terms of psychosocial adjustment to SCI, may be fundamental to optimise adjustment and cope with the demands of managing paid care relationships over time. As identified in this enquiry participants are not hapless victims of abuse, and for most, competence with self-direction of care provision increased with experience.

Carer management preparation packages

Carer management preparation programs prior to discharge however could facilitate faster accrual of competence in real life so that people with SCI could effectively manage the challenge of carer abuse from the onset of these relationships. The results

from this current study have provided some initial guidance for the development of such packages.

Firstly, provision of improved education and resources about paid care services in a wider range of formats may assist in improving individuals' assertiveness, self-esteem, and elaboration of a person's sense of self. Education initiatives may include, but not be limited to the development of digital video discs (DVD) that address various topics regarding community supports. These topics could include information pertaining to learning and exercising disabled people's legal rights and service options, understanding the role of the paid carer and their needs alongside their responsibilities to be thoughtful, and direct in their communications. Information resources on interviewing, hiring, and dismissing carers, consumer directed options, and 'how to' information packs should be provided prior to discharge, and caregiving agency options should be made available.

Secondly, role-play scenarios may be useful in demonstrating ways of dealing with uncomfortable decisions, or using humour with carers as a way to handle minor difficulties. Examples of assisting the carers in communicating their feelings about the job as a way of maintaining effective working relationships should also be included.

Thirdly, effective and adaptive coping strategies while discouraging maladaptive approaches should be taught, thereby empowering individuals in the belief that nothing less than quality care is acceptable, and that mistreatment is not to be accepted. This education should also be accessible for family members who also have to learn to accept and adapt to multiple people coming in and out of their family home.

Lastly, the enthusiasm shown by the participants in this enquiry to share their experiences and understanding with others new to their SCI suggests increased use of peer support, either on a formal or informal basis, may improve the quality of paid care relationships. In fact, ideally people with SCI should be employed to deliver the training in managing paid care providers described.

According to the literature carer training courses may be considered beneficial for the carers, (this was not a finding in my study) and could be mandatory to attend for new carers employed by care agencies. Such courses could offer opportunities for increasing the focus on communication skills, and may improve the quality of the relationships. However, this suggestion is given with much caution; as earlier discussed, training programmes for consumers and carers is controversial as they may conflict with consumer control of care provision (Saxton, 2001).

Care agencies may provide formal training for the carers as an attempt to upgrade the professional status of the carers work and possibly as an objective way to reassure funding bodies that their employed carers are appropriately qualified, therefore able to provide quality ‘care’ to consumers with SCI as a means to secure service contracts. However, as Amy pointed out this training can instil attitudes in the paid carer towards the consumer that does not support a sense of self-direction and self worth. All of the participants in this study believed it was not necessary to have a carer with previous knowledge regarding SCI. In fact, it was a preference that they did not as they preferred to train their carers directly themselves. Innovative methods for training the consumers to train and supervise their carers, and evaluate the carers’ actual ‘job’ performance may be one approach to improve the quality of paid care services within the home/community environment. I suggest further research is needed to investigate the range of types of training for consumers and providers, and the way this may influence consumer control and satisfaction.

Police vetting of potential carers

Participants who privately employed their carers discussed how they were unable to access police vetting which would have offered some reassurance that the potential carer did not have a criminal background. Both Saxton et al. (2001) and Oktay and Tompkins (2004) stressed the importance of rigorous screening in the recruitment, interviewing, and hiring phases where checking references, included a criminal background check with the police, are the status quo.

Future research

Participation action research (Brydon-Miller, 1997) method (in which research participants are included as partners in the research process) maybe appropriate for designing packages to better prepare people with newly acquired SCI for managing

their future paid care relationships. Following implementation, further research should be conducted to evaluate effectiveness of these preparation packages. In terms of further research, longitudinal qualitative research exploring the experiences of both receiving and giving care in a larger study sample, including people with non-traumatic SCI, is warranted. Browne and Russel (2005) also suggested research exploring how service organisations can ensure codes of conduct would be beneficial to both carers and consumers of care. Further, research that investigates how ambiguities in the meaning of professional boundaries can be reduced, and clearer guidelines for practice and consumers established. The development of such guidelines would benefit from input from all stakeholders.

Possible quantitative research options may include an evaluation of experiences of abuse by paid carers nationally. As mentioned above, a randomised controlled trial designed to look at the effectiveness (or cost-effectiveness even) of providing training in management of care providers for people new to SCI should be considered. However, first a tool to evaluate satisfaction with care provider relationships would need to be developed.

There was a notable lack of data in this study on the experience of Maori and Pacific Island people with SCI, with only one participant identifying as Maori. This warrants the need for further research to be conducted targeting these population groups.

Individualised funding quality and standards

Individualised funding may be considered the preferred option for personal care services. Therefore, consideration of how quality and standards can be maintained outside the jurisdiction of the formal care sector is warranted. In some cases a review by funders of current service delivery may be indicated including evaluation of the impact of care delivery on the incidence of preventable secondary conditions related to SCI, and resulting hospital admissions.

Improved remuneration for NZ carers

As earlier discussed the carers themselves are often considered a vulnerable group of people. Currently in NZ there is a focus on the pay rates of carers within the disability support sector, and it has been decided that they should be paid the minimum wage for sleep-over shifts when in people's place of residence (McLean, 2011). This will have a

significant impact in a positive sense for the carers, but will have very significant implications for provider organisations. Increasing carer wages may increase the quality and quantity of the workforce, as the part-time nature of the work does not attract people who stay in the job long enough to become skilled, and low wages do not adequately compensate the majority of dedicated and ‘caring’ individuals who do paid care work. However, an important concern for those with disability (also a vulnerable group) is what might happen if indeed the payment for overnight stays must come from existing budgets if these are not extended?

Models of service delivery

Models for service delivery must afford autonomy to those with disabilities. It is imperative that health professionals who work within the disability sector value the principle of self-determination as one of the key aspects of respecting people’s human rights of expression, association, and decision making. Dissemination of these research results may compel care agency managers and funders to look at their reporting and communication processes in order to minimise the intrusive nature of some current policies.

5. 8 Personal reflections

I began this study because as a health professional working in the BSU setting I knew that paid carers could be both a support and a barrier to individuals’ abilities to live their life in a manner that they would like. In addition the choice of this topic was influenced by the death of my friend, murdered by his paid carer in 2005. I personally found it somewhat disconcerting that his death and very public court case that followed put the spotlight on the pressures faced by paid carers, and the hardships they endured when supporting tetraplegics with high dependency needs. Yet the voice of the person with SCI was not obviously heard. For example, during the court case the paid carer admitted the killing, but said it was manslaughter as he was provoked; this was followed by evidence from carers highlighting that ‘caring’ for a dependent tetraplegic were extremely challenging, and that they had little if any support. What was not well presented was the perspective of consumers of ‘care’ who are faced on a daily basis with a vast number of challenging issues (as evidenced in this study for example) and often very limited choice in how these challenges are managed. It appeared that there was little NZ research that had explored paid ‘care’ relationships with people with SCI from the perspective of the person with

SCI. I consider all forms of mistreatment abhorrent. I strongly believed that this lack of information warranted further exploration.

During the process of carrying out this research I was mindful of any issues that might arise through confusion about my dual role of clinician and researcher, either for me or for participants. Conneeley (2002) has discussed some of the methodological issues that arose for her when conducting qualitative research in the role of both a researcher and clinician, which I found useful when considering my own situation. Some of the participants were well known to me as I had a prior therapeutic relationship with them as a nurse, and as such this may have influenced their responses to the questions. I may also have held assumptions based on previous encounters with the participants that influenced our interactions and my interpretation of what was said. Arguably a better rapport may have been developed on the basis of this pre-existing relationship. I believe that they were more comfortable talking about their experiences knowing that I, as the researcher, was clinically trained with a background in SCI. Explaining related medical terminology and background information was for instance not necessary as participants assumed I knew what they were talking about. Conneeley (2002) similarly believed mutual recognition and acknowledgement of common experience when conducting research often means explicit explanations are unnecessary. However, the dual role of clinician/researcher could have impacted negatively on these relationships if this group of participants had a strong anti-professional stance. This was not the case, but might be considered a possibility with politically active people.

In the capacity of both health professional and researcher, my response to one participant who spoke of ongoing threats was to provide guidance regarding how he could inform the community police of his situation. Both my supervisors considered this action appropriate and was in accordance with my ethical responsibilities when conducting research (see section 3.4.3 Identified abuse or risky health behaviours). Supervision was also used to discuss, as a team, whether any current situations faced by the participants required further action, and where the ethical responsibilities of the researcher in these contexts lie.

Throughout this research I kept a field diary to note and analysed my preconceptions about the topics under discussion as these pre-conceptions became clear to me through completing interviews and analysis. Below is an excerpt from an email I sent to both of my supervisors after completing my first interview. Now that I have interviewed all seven participants my sentiments written here still reflect how I feel today:

I undertook my first face to face interview last night. Driving to where the interview was going to be conducted I was nervous, my thoughts were racing and I doubted my own abilities. The interview ran smoothly, and he poured out his story. To be honest, if his experience is similar to others with SCI, I think it would be fair to say I have underestimated how these relationships impact on a person with SCI. I now have this huge responsibility.....I feel privileged to have listened to his story, excited by it, encouraged to hear others, I hope that after the IPA process I capture the true essence of their experience in my writings.....I have had a ‘moment’.....I never expected it to happen like that, yes I want to successfully complete a thesis.....I just never realised what a profound and rewarding effect the ‘data collection’ process would have on me.

I had hoped that any degree of violence towards those with disability would be isolated. However, participants discussed various forms of mistreatment in the course of the interviews. I found this particularly disturbing, and valued the opportunity to debrief with my supervisors. Whilst ‘mistreatment’ is only one of the themes that emerged from my study, I have found it the most disturbing and worrying. Individuals are discharged from NZ spinal units; an environment where it is expected that they are treated with dignity and receive safe, appropriate ‘care’ and rehabilitation. I find it distressing some individuals safety and wellbeing may potentially at some time come under threat in the community environment due to the appalling actions and behaviour of some individuals who are paid to provide their ‘care’.

Having had the opportunity to present the preliminary findings of this study to peers, it was clear I was not alone at finding the verbatim narratives disturbing. I feel passionately that I have both a professional and personal responsibility to disseminate this research in order to share the participants’ stories. I have actively made contact with disability support groups, sought resources addressing ‘disability and abuse’ for the BSU, met with caregiving agency managers, and engaged in discussions with Burwood Academy Independent Living and NZ Spinal Trust to explore ways of empowering those with disability (not only SCI) to address this issue. These will be ongoing projects for me following the completion of this thesis, and something which I am in a position to begin to address in my current work role.

5. 9 Final summary

This study used Interpretative Phenomenological Analysis (IPA) to explore how those with SCI manage paid care relationships. I liken this phenomenon to a '*maze*', and the participants as a '*pathfinder*'. Participants followed different paths, yet all constantly regularly made choices about which way to turn at decision points in managing their paid care. Their decisions, on which path to take at which point, appeared to be part of a continuum of learning based largely on trial and error. Three master themes emerged from the participant's accounts: 1) **Finding your way amid challenge, chaos and choice**; 2) **Navigating relationship terrains** and 3) **Warning: Potential Traps**. The knowledge gained from this study frames and illuminates the complex aspects of the experience of what it means for those with SCI, to depend on daily care from paid carers and how these relationships can both directly and indirectly impact on opportunities for participation in society.

Information from this study can provide some direction (*a map and compass*) to individuals new to SCI (*the pathfinders*). Furthermore, research of this nature may raise awareness of issues in the SCI environment and NZ health care community. Such awareness will reduce inequalities by advancing knowledge in an area where there has been minimal research by making more information available to SCI people, their families, and health professionals within spinal units who can assist in adequately preparing people with SCI prior to discharge for formal caregiving relationships within the home environment.

Glossary of Terms

ACC: The Accident Compensation Corporation (ACC) administers NZ's accident compensation scheme, which provides personal injury cover for all NZ citizens, residents and temporary visitors to NZ. In return people do not have the right to sue for personal injury, other than for exemplary damages (Accident Compensation Corporation, 2009). ACC was introduced in 1972, and provides no-fault 24 hour insurance provision funded through employment and driver levies, with a contribution from general taxation. It is based on five principles of: community responsibility, comprehensive entitlement, complete rehabilitation, real compensation, and administrative efficiency (McNaughton & McPherson, 2000).

Activity Limitation: The difficulties an individual might have executing activities. For example, difficulty walking (World Health Organisation, 2002).

Adjustment: In psychology, adjustment often refers to a desirable state or endpoint. It can be viewed as the process to maintain a positive view of the self and the world in the face of a health problem (Sharpe & Curran, 2006).

Autonomic dysreflexia: Is a medical term that refers specifically to problems with a person's blood pressure. It is an acute syndrome of excessive, uncontrolled sympathetic output with potentially serious consequences affecting those with SCI above the mid thoracic level typically at T6 or T7, and is most commonly associated with cervical damage (Warise, 2008). It is usually triggered by something like a bladder infection, which people with spinal cord injuries are often unaware that they have. Recognition of the signs and symptoms by both individuals with SCI and their carers is extremely important because although the condition can nearly always be managed successfully, failure to do so can have dire consequences including death. Treatment involves urgently removing the stimuli responsible for the mass reflex.

Burwood Academy of Independent Living (BAIL) is a dynamic organisation committed to improving the life experience of people recovering from serious injury and illness. Based on site at Burwood Hospital in Christchurch, the Academy is dedicated to building a vibrant culture of research and learning. The Academy work to

establish strong links to consumer organisations, universities and rehabilitation professionals.

Clinical Nurse Specialist: Is an advanced practice nurse whose care focuses on a specific patient population.

Constructivism: Constructivism is one of four theoretical paradigms typically used in health research: Positivism, Post positivism, Critical theory and Constructivism (Guba & Lincoln, 1994). Constructivism proposes that knowledge and reality are subjective, mental constructs that are created through social interactions and relationships.

Epistemology: the study of knowing - essentially studying what knowledge is and how it is possible.

Functional Independence Measure (FIM): A measure of disability, not impairment. The FIM measures what a person with a disability actually does, NOT what he or she ought to be able to do, or might be able to do if certain circumstances were different. It assesses the need for assistance, and the type and amount of assistance required for a person with a disability to perform basic life activities effectively. A FIM score of 5 or less indicates a need for human assistance.

Functional Assessment Measure (FAM): The functional assessment measure (FAM) is an expansion of the FIM, which allows for measurement of 12 additional items. The FAM has been designed to measure disability following injury, by assessing the patient's level of independence in a number of daily activities. A FAM score of 5 or less indicates a need for human assistance.

ICF: The World Health Organisation's International Classification of Functioning Health and Disability (ICF) is a theoretical framework, a bio-psycho-social model of health which describes the multi-dimensional consequences of a health condition, such as SCI using a universal language (World Health Organisation, 2001).

Interpretative Phenomenological Analysis: is a form of phenomenology which attempts to explore/understand/make sense of individual participants themselves (Smith & Osborn, 2003).

Maori: Indigenous New Zealander, indigenous person of Aotearoa/New Zealand
(Online Maori dictionary accessed 26th February 2011).

Multidisciplinary team: Where the different professionals work independently of each other providing congruent interventions (Opie, 2000).

New Zealand Spinal Trust: is a registered charity providing information, education, research, advocacy and support for people who have SCI so that they may enjoy independence. The NZ Spinal Trust was formed in 1994 to address the unmet needs of rehabilitation, information, research, advocacy and support for people with SCI throughout NZ. The Trust works in collaboration with a number of entities, including health boards, ACC and the MOH to provide the resources required for people to take control of their own rehabilitation and therefore their lives. The NZ Spinal Trust is firmly focused on supporting independent living and improving the quality of rehabilitation through initiatives, projects and programmes that directly benefit people with spinal cord injuries .

Ontological: is the branch of metaphysics concerned with the nature or essence of being or existence, the opposite of phenomenology, the science of phenomena.

Ontology: the study of being - essentially studying questions of what kinds of entities exist.

Phenomenology: Phenomenology offers a descriptive, reflective, interpretive mode of enquiry from which to derive the essence of an experience.

Pressure sores: (sometimes referred to as pressure ulcers or pressure areas) are defined as an area of localised damage to the skin, and underlying tissue caused by pressure, shear, friction, or a combination of these (Consortium for Spinal Cord Medicine, 2001). Prevention of pressure sores, and quick effective treatment when they do occur, is essential for people living with SCI because the poorly managed sores can result in increasing mortality rates or other health conditions requiring hospitalisation such as sepsis or osteomyelitis. Pressure sores impact on the individual with SCI and those around them. Treatment often necessitates activity modifications, and restrictions that can have a negative psychosocial impact on individuals, and their families including

social isolation, alteration of body image and loss of income (Hopkins, Dealey, Bale, Defloor, Worboys, 2006).

Ranga Haurora: Maori Health services for the BSU.

Rehabilitation: A process aimed at enabling persons with disabilities to reach and maintain their optimal physical, sensory, intellectual, psychiatric and/or social functional levels, thus providing them with the tools to change their lives towards a higher level of independence. Rehabilitation may include measures to provide and/or restore functions, or compensate for the loss or absence of a function or for a functional limitation. The rehabilitation process does not involve initial medical care. It includes a wide range of measures and activities from more basic and general rehabilitation to goal-orientated activities, for instance vocational rehabilitation (World Health Organisation, 2007, p.10).

Spasticity: Spasticity is an expression of the upper motor neuron deficit. Symptoms may include increased muscle tone, uncontrolled muscle contractions, exaggerated tendon reflexes, muscle spasms, scissoring of limbs and possible joint contractures (Dr Acland, personal communication, January 31st 2012).

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Wyndaele, M., & Wyndaele, J. (2006). Incidence, prevalence and epidemiology of spinal cord injury: what learns a worldwide literature survey? *Spinal Cord*, 44(9), 523-529.

Yamaki, C. K., & Yamazaki, Y. (2004). 'Instruments', 'employees', 'companions', 'social assets': understanding relationships between persons with disabilities and their assistants in Japan. *Disability and Society*, 19(1), 31-46.

Young, M., Nosek, M., Howland, C., Chanpong, G., & Rintala, D. (1997). Prevalence of abuse of women with physical disabilities. *Archives of Physical Medicine and Rehabilitation*, 78, 34-38.

Appendix I ACC attendant care guidelines

Changing level of functional independence, for example as people with SCI gain skills and abilities following rehabilitation interventions and over time since their injury their carer needs may reduce.

Individual choice, for example people with SCI may choose to carry out a task with less assistance ACC is prepared to provide funding for.

Life stage, an older individual may have different support requirements than a younger person with the same level of injury. For example:

- An older person may not have the same level of upper body strength as a young person with the same level of injury and thus may require assistance with wheelchair transfers.
- An adult who has been previously independent in transfers and has used a manual wheelchair may over time develop early onset of arthritis or over-use syndrome because of the additional strain on their arms.
- A young adult, who has previously been dependent on their family for support, may reasonably expect to start accessing increasing levels of support in the wider community as they grow older.
- A woman's need for greater flexibility in hours and the provision of services may change during pregnancy and childcare.

Living situation, for example if a person is in a highly modified environment or shares accommodations the requirement for carer support maybe less, whereas less suitable accommodation can increase the need for support.

Assistive technology and modified equipment, for example the communication and transport of a person with SCI may be better addressed with the use of technological aids than reliance on a carer.

Co-existing conditions, such as arthritis, obesity, depression, spasms, contractures, pressure sores, spinal syndromes, or poorly controlled neuropathic bowel dysfunction may require increased care hours.

Major life transitions such as the loss of employment, moving from school to work, relationship difficulties, illness, loss of informal support system, death, separation, divorce, or retirement.

Other variables include: medication administration, the period following hospitalisation, surgery, or acute treatments, geographic location and potential for harm. For example, a person transferring independently can inadvertently damage their skin through a shearing motion, which they might not notice because of lack of sensation. If this person also has very little attendant care, the damage may go unnoticed for some time, thereby risking infection and major skin breakdown. Sleepover care may be required if the person has autonomic dysreflexia and lives alone.

Adapted from the ACC Spinal Cord Injury Guidelines for determining the levels of attendant care for persons with spinal cord injury. ACC, (2009). Retrieved February 2 2011 from www.acc.co.nz

Appendix II Invitation letter



[Name of Potential Participant]

[Address of Potential Participant]

[Date] Kia Ora [name of potential participant]

You are invited to take part in a study looking at the experiences of managing paid personal care following a SCI. We are interested in your opinion on how the nature of these relationships supports (or not) your usual roles and longer term goals. You have been contacted because according to the Burwood Spinal Unit database as a result of an accident you have sustained a traumatic high SCI resulting in changed neurology. It is possible that you may be relying on assistance from paid personal care attendants (Carers) to complete many functional tasks. Enclosed is further information about the research project, expression of interest return slip, consent form and a prepaid reply envelope.

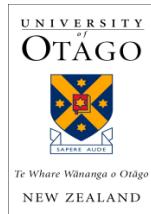
You are under no pressure to take part in the study but we would certainly appreciate your involvement. If you wish to participate in the study please return your expression of interest form within the next 7 days in the enclosed envelope or alternatively contact me via phone or email. Once I have your permission for the primary researcher (Maria van den Heuvel) to approach you I will then pass on your contact details to her accordingly. You can then expect to hear back from Maria within 10 working days.

Please contact me if you have any questions at all about the study.

Yours sincerely

Karen Marshall RN MN
 Acute Clinical Nurse Specialist/Research Study Co-ordinator
 Burwood Spinal Unit
 PO Box 4708
 Christchurch 8140
 Phone: 03 3836 850 EXT – 99682
 Fax: 03 3836 851
[karen.marshall@cdhb.govt.](mailto:karen.marshall@cdhb.govt.nz)

Appendix III Participant information sheet



The experiences of managing of paid personal care following SCI.

Thank you for showing an interest in this project. We are particularly interested in the nature of the relationship between paid personal care attendants and people with SCI and in your opinion what factors contribute or not to the success of these relationships.

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.

Who is doing this study?

The lead investigator on this study is Maria van den Heuvel (formerly Low). Maria is a Clinical Nurse Specialist currently employed at the Burwood Spinal Unit who is completing a Masters of Health Science (Rehabilitation) at the University of Otago. Maria has been employed at the Burwood Spinal Unit as an enrolled nurse and registered nurse at various times since 1986. Her supervisors on this project are Dr William Levack and Dr Jean Hay-Smith.

What is the purpose of this study?

The aim of this study is to gather consumers' experiences of managing paid personal care in the community. By gaining an understanding about the nature of the client-carer relationship, it is hoped that this information may identify facilitators and barriers to a successful working relationship and satisfying community participation. This information may highlight what the two New Zealand spinal units can do to assist in adequately preparing people who will require support for the impending client-carer relationship. It may also provide Caregiving Agencies and funding bodies' information that in turn may shape their training programmes and funding allocation policies. We would value your participation in this study.

Why have I been asked and is participation voluntary?

We have contacted you from information obtained from the Burwood Spinal Unit data base which indicates that you sustained a high SCI and as a consequence a change in neurology. It is possible you may be relying on assistance from paid personal care attendants (carers) to complete many functional tasks. Your participation in this study is

entirely voluntary: you are free to decline. You have the right to change your mind at anytime without explanation. Declining or withdrawal will not affect your future health care in any way.

Who can be involved?

For this study we need participants who fit into the below criteria:

1. Have tetraplegia resulting from a traumatic SCI at T6 or above with an ASIA classification of A or B.
2. 18 years old or more.
3. One year or more post injury.
4. Receive 20 hours or more per week of paid attendant care.
5. Do not live in supported care accommodation (Residential or Institutional).
6. Can take part in the face to face interview without the need for your paid carer to be present.
7. Have a good command of the English language.
8. Live in the Canterbury or Southern District Health Board region.

If I agree to take part, what will the study involve?

If you express an interest in taking part in this study the researcher (Maria) will contact you by phone. Maria will discuss the study and its purpose in greater detail, answering any questions you may have. If you are happy to participate in this study you would be required to meet with Maria for a face to face interview, lasting approximately 60 – 90 minutes to talk about your experience of managing relationships with a paid personal carer/s. You do not have to answer all the interview questions, and you may stop the interview at any time. The interview will be informal and will take place at a time and place convenient for you. You will be sent a copy of the interview schedule in advance. You will be asked to sign a consent form prior to the commencement of the interview.

What will happen to the information I provide?

All information is confidential. The interview with the researcher will be tape recorded, and this recording will be typed out and looked at only by the research team. We will be looking for common themes about the experiences of managing paid attendant carers in the community. Your name will be changed on the typed copy so no-one, apart from the research team, will know who made a particular comment. All information collected for this study is confidential and kept secure, and no material that could personally identify you will be used in any reports on this study. Your interview recording and transcript will not be shared with anyone outside the research team (except for small, selected extracts from the transcripts when the study is published). You will be able to obtain a copy of the results at the end of the study if you wish. Please note: while all efforts will be taken to remove identifying features from the interview data, because the SCI community is so

small in New Zealand, there is always the possibility that someone may recognise (or think they recognise) you from even very small, anonymous extracts of text from an interview. This is something you will need to consider prior to agreeing to participate in the study – although as mentioned above you are always welcome to withdraw aspects of your interview (or your whole interview) at a later date, prior to publication, if you so choose.

Statement of Approval

This study has been approved by the Multi-region Ethics Committee, which reviews studies, to ensure that the rights and well being of patients participating in this research study are protected in New Zealand.

Compensation

‘In the unlikely event of a physical injury as a result of your participation in this research study, you may be covered by ACC under the Injury Prevention, Rehabilitation and Compensation Act. ACC cover is not automatic and your case will need to be assessed by ACC according to the provisions of the 2002 Injury Prevention Rehabilitation and Compensation Act. If your claim is accepted by ACC, you still might not get any compensation. This depends on a number of factors such as whether you are an earner or non-earner. ACC usually provides only partial reimbursement of costs and expenses and there may be no lump sum compensation payable. There is no cover for mental injury unless it is a result of physical injury. If you have ACC cover, generally this will affect your right to sue the investigators.

‘If you have any questions about ACC, contact your nearest ACC office or the investigator.

Who can I ask if I would like to ask more questions about the study?

If you would like any further information about this study or have any questions feel free to contact either:

Maria van den Heuvel - Work phone no.	+ 64 3 383 6850
Fax	+ 64 3 383 6851
Email	maria.vandenheuvel@cdhb.govt.nz
Dr William Levack	
Work phone no.	Phone: +64 4 385 5591 ext 6279

Fax	Fax: +64 4 389 5427
Email	wiliam.levack@otago.ac.nz

Dr Jean Hay Smith:

Work phone no.	+64 3 474 7007 ext 8568
Fax	+64 3 474 7620
Email	jean.hay-smith@otago.ac.nz

What do I do now?

If you wish to participate in this study, please keep this information sheet and return the expression of interest and/or consent form in the pre-paid envelope. It would be preferable if you could do this within the next 7 days, but please do inquire about participation in the study at any point.

Thank you

If you have any questions or concerns about your rights as a participant in this research study you contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioner Act.

Telephone: (NZ wide) 0800 555 050

Free Fax (NZ wide): 0800 2787 7678 (0800 2 SUPPORT)

Email (NZ wide): advocacy@hdc.org.nz

Please refer to the committee as the Multi Region Ethics Committee.

Appendix IV Consent form for participants



Experiences of managing paid personal care following SCI

I have read the Information Sheet dated 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 ten 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.

The lead investigator on this study is Maria van den Heuvel (formerly Low). Maria is a Clinical Nurse Specialist currently employed at the Burwood Spinal Unit who is completing a Masters of Health Science (Rehabilitation) at the University of Otago. Maria has been employed at the Burwood Spinal Unit as an enrolled nurse and registered nurse at various times since 1986. On subsequent visits to the Burwood Spinal Unit this would not affect my future treatment in anyway should I participate or choose not to participate in this research.

- 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 about future research on the same topic.
- I do not agree** to being contacted about future research on the same topic.
- I agree** to have my data used in future related research and to be contacted again to participate in a future related research.
- I do not agree** to have my data used in future related research and to be contacted again to participate in a future related research.

.....
.....

(Signature of participant)

(Date)

.....
.....

(Name and contact details of participant/)

.....

(Name and signature of researcher)

Appendix V Sample questions to obtain demographic details

General introductions

Brief explanation of project and opportunity for participants to ask any questions.

Demographic Information	Details	Comments
Sex	<input type="radio"/> Male <input type="radio"/> Female	
Age at time of accident		
Age at time of this interview		
Ethnicity -(2006 NZ Census question format will be used)		Iwi if relevant
Marital Status		
Year of Accident		
Cause of Accident		
ASIA Classification		
Pre-Injury Employment		
Current Employment		
Living Arrangements	<input type="radio"/> Rents <input type="radio"/> Own Home <input type="radio"/> Temporary Accommodation <input type="radio"/> Other	
Social Circumstances	<input type="radio"/>	
What is your main source of transport?	<input type="radio"/> Private Vehicle <input type="radio"/> Public Transport <input type="radio"/>	
How often do you get away from home for social or entertainment purposes	<input type="radio"/> Rarely <input type="radio"/> 1-2 times per week <input type="radio"/> 3-4 times per week <input type="radio"/> Once per month <input type="radio"/> 2-3 times per month <input type="radio"/> Five or more times per week	
Funding Provider	<input type="radio"/> ACC <input type="radio"/> MOH	
How many times have you been hospitalised for the following since you	<input type="radio"/> Pressure Areas <input type="radio"/> Urinary Tract Infections <input type="radio"/> Pneumonia <input type="radio"/> Infection other than UTI	

discharged from a spinal unit?	<input type="radio"/> Dysreflexia <input type="radio"/> Bowel Issues <input type="radio"/> Accidents/Broken bones	
How many Pressure Areas have you had since discharge from a Spinal Unit?	<input type="radio"/> None <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 or more	
Could you explain how your carers are employed, both in the past and present? For example provided through a Care Agency or privately arranged. Family, friend or stranger?	<input type="radio"/> Care Agency <input type="radio"/> Private Arrangement	<input type="radio"/> Past <input type="radio"/> Current
How many funded allocated hours do you receive per week for personal care		
How many paid attendant carers are involved in your current care package?	<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4 or more	
What length of time has any one carer remained working with you?	<input type="radio"/>	
What is the shortest length of time any one carer has remained working with you?	<input type="radio"/>	
What assistive technology and modified equipment do you currently use that reduces your need for human assistance?	<input type="radio"/>	

Appendix VI Sample questions- face to face interview

I am aware that there are many different names used for describing people who provide paid personal care. Will you tell me what name you use to describe this person/s?

Within the response to this question we may explore the following areas:

- Will you tell me how you introduce your carer to other people? (prompt: to health professionals, to family members, to friends, to strangers).

I'm interested in knowing what a typical day with a carer is like for you. Will you describe what it's like?

Within the response to this question we may explore the following areas:

- What happens? (prompt: time of arrival, throughout the day, duties personal care/domestic assistance, shift changes, varies from day to day).

Will you tell me about what it is you value about your relationship/s with paid personal carers?

Within the response to this question we may explore the following areas:

- Supports or not usual life roles?
- Friendships.
- Does the relationship change over time?

In your experience of SCI and receiving paid personal care can you tell me what characteristics or attributes you consider are important in a carer/s?

Within the response to this question we may explore the following areas:

- Reliability, knowledge regarding SCI, any preference? (prompt: age, gender, ethnicity).
- Interpersonal skills.
- Experiences of a carer who may have upset or embarrassed you by their behavior?

Will you tell me about what it is like having someone else in your life that is paid to help you perform daily activities?

Within the response to this question we may explore the following areas

- Will you tell me about maintaining your independence?
- Will you tell me about maintaining your dignity?

- Needing to have someone with you whenever you go out – Does it interfere when trying to establish new relationships?
- Do you ever feel your carers maybe judging you?

Will you tell me what you think about the ‘boundaries’ around paid care?

Within the response to this question we may explore the following areas:

- Intimate relationships.
- Agency policies and restrictions.
- Carer relationships with your family/friends on a personal level.
- Babysitting, lending money, doing favors’ – (prompt: letting carers go home earlier, start later, or carers being asked to undertake tasks/activities outside of hours).

Will you tell me about how you learned to manage the client-carer relationship?

Within the response to this question we may explore the following areas:

- Preparation prior to leaving the spinal unit?
- Involvement in recruitment process, choices, ACC?
- Carer Training – prior and ongoing.
- Family members, friends or strangers employed as your paid carer?

Will you tell me your thoughts regarding the current amount of funded hours you have allocated for your care package?

Within the response to this question we may explore the following areas:

- Informal care required.
- Consumer Directed or Agency preferences?
- Could assistive technology replace your need for human assistance?
- Communication between yourself, funding agency (ACC) and Care Agency?

You have this experience of managing paid personal care relationships....What would be the most important thing you would tell a person with a new spinal cord injury regarding having a paid carer in the community?

Thank you for taking part in this interview....explain what happens next, i.e. in terms of further contact etc.

Appendix VII Health and Disability Ethics Committee



28 June 2010

Multi-region Ethics Committee

Ministry of Health
133 Molesworth Street
PO Box 5013
Wellington 6145
Phone (04) 470 0655
(04) 470 0646
Fax (04) 496 2340

Email: multiregion_ethicscommittee@moh.govt.nz

Dr William Levack
University of Otago - Wellington School of Medicine
Rehabilitation Teaching and Research Unit
Level G , University of otago (Wellington)
PO Box 7343
Main Street, Newtown, Wellington

Dear William

Ethics ref: MEC/10/036/EXP (please quote in all correspondence)
 Study title: Lived Experience of managing paid personal care following spinal cord injury. An Interpretative Phenomenological Analysis
 Investigators: Dr William Levack, Ms Maria van den Heuvel, Dr E Jean C Hay-Smith

This study was given ethical approval by the Multi-region Ethics Committee on 28th of June 2010.

Approved Documents

- Protocol number
- Sample Questions to obtain demographic details, Version 1, dated 28th of May 2010
- Sample Questions – Face to Face Interview, Version 1, dated 28th of May 2010
- Invitation Letter, Version 1, dated 28th of May 2010
- Information Sheet for Interview Participants, Version 1, dated 28th of May 2010
- Consent Form for Participants, Version 1, dated 28th of May 2010
- Serious Adverse Event Form, Version 1, dated 28th of May 2010
- Transcription Agreement, Version 1, dated 28th of May 2010

This approval is valid until 30th of June 2012, provided that Annual Progress Reports are submitted (see below).

Amendments and Protocol Deviations

All significant amendments to this proposal must receive prior approval from the Committee.
 Significant amendments include (but are not limited to) changes to:

- the researcher responsible for the conduct of the study at a study site
- the addition of an extra study site
- the design or duration of the study
- the method of recruitment
- information sheets and informed consent procedures.

Significant deviations from the approved protocol must be reported to the Committee as soon as possible.

Annual Progress Reports and Final Reports

The first Annual Progress Report for this study is due to the Committee by . The Annual Report Form that should be used is available at www.ethicscommittees.health.govt.nz. Please note that if you do not provide a progress report by this date, ethical approval may be withdrawn.

A Final Report is also required at the conclusion of the study. The Final Report Form is also available at www.ethicscommittees.health.govt.nz.

Requirements for the Reporting of Serious Adverse Events (SAEs)

For the purposes of the individual reporting of SAEs occurring in this study, the Committee is satisfied that the study's monitoring arrangements are appropriate.

SAEs occurring in this study must be individually reported to the Committee within 7-15 days only where they:

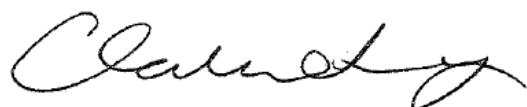
- are *unexpected* because they are not outlined in the investigator's brochure, and
- are not defined study end-points (e.g. death or hospitalisation), and
- occur in patients located in New Zealand, and
- if the study involves blinding, result in a decision to break the study code.

There is no requirement for the individual reporting to ethics committees of SAEs that do not meet all of these criteria. However, if your study is overseen by a data monitoring committee, copies of its letters of recommendation to the Principal Investigator should be forwarded to the Committee as soon as possible.

Please see www.ethicscommittees.health.govt.nz for more information on the reporting of SAEs, and to download the SAE Report Form.

We wish you all the best with your study.

Yours sincerely



Claire Lindsay
Administrator
Multi-region Ethics Committee
Email: craig_lindsay@moh.govt.nz

Appendix VIII Ngai Tahu Research Consultation Committee

NGĀI TAHU RESEARCH CONSULTATION COMMITTEE
TE KOMITI RAKAHAU KI KĀI TAHU

18/05/2010 - 30
Wednesday, 19 May 2010

Dr Levack
Medicine
Wellington

Tēnā koe Dr Levack

Title: Lived experiences of managing paid personal care following spinal cord injury: An interpretative phenomenological analysis (IPA).

The Ngāi Tahu Research Consultation Committee (The Committee) met on Tuesday, 18 May 2010 to discuss your research proposition.

By way of introduction, this response from the Committee is provided as part of the Memorandum of Understanding between Te Rūnanga o Ngāi Tahu and the University. In the statement of principles of the memorandum, it states "Ngāi Tahu acknowledges that the consultation process outlined in this policy provides no power of veto by Ngāi Tahu to research undertaken at the University of Otago". As such, this response is not "approval" or "mandate" for the research, rather it is a mandated response from a Ngāi Tahu appointed committee. This process is part of a number of requirements for researchers to undertake and does not cover other issues relating to ethics, including methodology; they are separate requirements with other committees, for example the Human Ethics Committee, etc.

Within the context of the Policy for Research Consultation with Māori, The Committee base consultation on that defined by Justice McGechan:

"Consultation does not mean negotiation or agreement. It means: setting out a proposal not fully decided upon; adequately informing a party about relevant information upon which the proposal is based; listening to what the others have to say with an open mind (in that there is room to be persuaded against the proposal); undertaking that task in a genuine and not cosmetic manner. Reaching a decision that may or may not alter the original proposal."

The Committee considers the research to be of importance to Māori health.

As this study involves human participants, the Committee strongly encourage that ethnicity data be collected as part of the research project. That is the questions on self-identified ethnicity and descent, these questions are contained in the 2006 census.

The Committee notes the researchers have, "...discussed [the] topic with Ranga Hauroa Services (Burwood Hospital) who agree to support the researcher by being available for consult with in

The Ngāi Tahu Research Consultation Committee has membership from:
*Te Rūnanga o Ōtākou Incorporated
Kāti Huirapa Rūnaka ki Puketeraki
Te Rūnanga o Moeraki*

NGĀI TAHU RESEARCH CONSULTATION COMMITTEE *TE KOMITI RAKAHAU KI KĀI TAHU*

the interpretation analysis of Māori transcripts.", and ask who was consulted and what their advice was.

The Committee suggests dissemination of the research findings to Māori health organisations regarding this study.

We wish you every success in your research and the Committee also requests a copy of the research findings.

The recommendations and suggestions above are provided on your proposal submitted through the consultation website process. These recommendations and suggestions do not necessarily relate to ethical issues with the research, including methodology. Other committees may also provide feedback in these areas.

Nāhaku noa, nā



Mark Brunton

Kaitakawaenga Rangahau Māori
Facilitator Research Māori
Research Division
Te Whare Wānanga o Otago
Ph: +64 3 479 8738
email: mark.brunton@otago.ac.nz
Web: www.otago.ac.nz

The Ngāi Tahu Research Consultation Committee has membership from:

*Te Rūnanga o Ōtākou Incorporated
Kāti Huirapa Rūnaka ki Puketeraki
Te Rūnanga o Moeraki*

Appendix IX Ranga Hauora letter of support

Canterbury

District Health Board

Te Poari Hauora ō Waitaha

7 May 2010

Maria Van Den Heuvel
 CNS
 Burwood Spinal Unit
 255 Mairehau Road
 Private Bag 4708
 CHRISTCHURCH

Tena Koe Maria

RE: Lived experience of managing paid personal care following a spinal injury

Following our discussions, I anticipate that the following has been agreed to:

1. Ethnicity data to be collected.
2. Appropriate Te Reo Introduction included in correspondence and interactions with participants i.e. Maori Greeting e.g. "Tena Koe" or "Kia Ora".
3. At the completion of the project, a presentation of results/findings will be made at the annual Ranga Hauora Consultation Hui, June 2011.
4. Ranga Hauora will provide relevant support to the researcher with interpretation analysis of Maori transcripts.
5. Ranga Hauora will also provide relevant support and input to meet the cultural requirements of the participants throughout the study who identify as Maori.

Ranga Hauora Service consists of a Kaumatua, Kaiwhakahaere and Kaitiaki. All consultation with community groups are accessed through the Office of Ranga Hauora, Burwood Hospital.

We wish you well with your research. Kia tau te rangimarie ki a koe.

Heoi ano

Mere
 Mere Hibbs
 Kaiwhakahaere / Manager
 Email: mere.hibbs@cdhb.govt.nz

Teoti Jardine
 Kaitiaki




Ranga Hauora, Maori Health Service
 Te Whare Toa Takitini, Burwood Hospital
 Private Bag 4708, Christchurch, New Zealand
 Telephone: 64 (03) 383 6873 Fax: 64 (03) 383 9490



Appendix X New Zealand Spinal Trust letter of support



20 May 2010

Auckland: Auckland Spinal Rehabilitation Unit, 30 Bairds Rd, Private Bag 93 319, Otautau, Auckland 1640, New Zealand. T: +64 9 270 9070 F: +64 9 270 9098

To Whom it May Concern:

Re: Maria van den Heuvel's research on the "Lived experience of managing paid personal care following a spinal cord injury"

The New Zealand Spinal Trust wishes to convey to you our full support of Maria van den Heuvel's research project which will use an Interpretative Phenomenological analysis to investigate the Lived experience of managing paid personal care following a spinal cord injury (SCI).

Research into this topic is extremely important to our organisation. The results of her investigations will be very useful when advising both people with SCI and government agencies who may be funding that care, on the best model to adopt for managing personal cares.

When someone has a serious spinal cord injury and becomes 'dependent' on personal care assistance from other people, it is critical they be able to enjoy what ever 'independence' that they still can. It is the NZ Spinal Trust's view that individuals being personally responsible for managing their own personal cares (i.e. hiring, firing, paying, scheduling, training etc.) helps achieve that sense of independence. We feel that it is likely that this independence then results in greater self-determination and therefore self-esteem, improved mental health and probably overall health.

There are however currently considerable challenges in New Zealand to individuals being personally responsible for managing their own personal cares particularly with respect to occupational health and safety, employment law and taxation. These challenges need to be recognised and managed.

Because our organisation is dedicated to assisting people with spinal cord injuries to have the best possible rehabilitation and therefore to enjoy the best possible quality of life, we are wholly supportive of Maria van den Heuvel's research into this topic.

Yours Sincerely

Andrew Hall
Chief Executive
New Zealand Spinal Trust

Appendix XI Transcription agreement



University of Otago Transcription Agreement

Name of Project:

Name of Researcher/Interviewer:

Name of Transcriber:

Agency:

Confidentiality of tapes and information thereon

I agree that I will maintain full confidentiality of material on tapes to be transcribed – under the Privacy Act 1993.

I will ensure secure location for the tapes at all times.

I will return the tapes to the researcher in original condition.

Signature of Transcriber: _____

Signature of Researcher: _____

Date:

Appendix XII: Key to transcription conventions

The transcripts for this study reflected as closely as possible the actual words and speech patterns of the interview participants.

Italics indicate speech of the participants.

Ellipses (.....) have been used to indicate meaningful pauses made by the speaker.

Square brackets [] have been used to insert editorial notes or words not present on the audiotape.

Appendix XIII Serious adverse events form

Lived experience of managing paid personal care following a SCI Participant information

Date of birth: _____

Gender: Male Female

Outcome attributed to the Serious Adverse Event. Tick One Box

- Death
- Dysreflexia episode requiring an emergency change of catheter
- Hospitalisation
- A fall sustaining injury
- Required intervention to prevent permanent impairment or damage (includes referral to relevant health care providers)
- Other event considered serious

Onset date of event: _____/_____/____

Describe the serious adverse event.

Events pre-ceeding serious event?

What exactly

happened?_____

What happened directly after the serious event (i.e. who did what, and when)?_____

Signature of Researcher

Printed Name of person reporting event

Date

