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**LIVING WITH A DAMAGED BODY**

A thesis presented in partial fulfilment of the

requirements for the degree of

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## Abstract

Quadriplegia subsequent to cervical spinal cord injury is now survivable because of advances in medical technology. Nurses are closely involved with these injured people yet few studies on the condition are reported in nursing literature. In this limited study, using grounded theory methodology, findings, important to nursing, emerged that quadriplegic people, despite their dependence, strive to live as independently as possible. From this a theoretical model was developed and diagrammed to demonstrate the continuing movement which quadriplegic people constantly experience of fluctuations between the two polarities of dependence and independence.

From nine participants, selected by snowball sampling, data were collected in a semi-structured interview and analysed by constant comparative analysis. The core process which emerged was categorised as 'living with a damaged body'. This is the given of quadriplegia, a constant, irreversible biological condition which enforces dependence on others for life sustaining care. Four subsidiary processes were identified, three, which contribute to movement towards independence, were categorised as, 'discovering life', 'generating family and social support', and 'seeking satisfaction from work and play'. The remaining process which opposes movement toward independence is categorised as 'battling the odds', and drags quadriplegic people towards dependence. Disability is a socially constructed notion which creates many barriers or 'odds' against which they must constantly battle. Validation to confirm these findings and the theoretical model was obtained from two, non-participant, well-adjusted, long term, quadriplegic professionals.

Nurses are in an ideal position to contribute to the movement of quadriplegic persons towards their desired state of independence and to prevent as much slippage back to dependence as is possible, given the core process of living with a damaged body. To make an effective contribution nurses need to know and understand the five categories of process. The model is designed to assist nurses to do this.

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## INTRODUCTION

Spinal cord injury is a devastating experience. People who survive this injury are unlikely to do so without fast and expert emergency rescue, followed by acute medical and nursing management. There can be no preparation for this ordeal, either by the person concerned or by the immediate family. Richmond (1990, p.57) writes "Trauma to the spinal cord is a severe unisystem injury resulting in significant physiologic derangement and intense psychosocial responses". The derangement and psychosocial responses are usually long term and in many situations there will be permanent disability.

Nurses care for people with spinal cord injury at varying stages of their lives, yet in the nursing literature there is no theory of the adjustment processes such clients go through following discharge from hospital. With improved rescue services and emergency care more people with spinal cord injury will survive the initial phase and continue to live in the community. Therefore nurses and other health care workers are now more likely to care for those people who have been injured and live with paraplegia or quadriplegia. The term quadriplegia means that all four limbs are affected following a cervical level injury of the spinal cord, resulting in a more extensive disability. Paraplegia is the term used for a lower level of injury with only the lower limbs affected. To provide effective care, nurses and other health workers need to appreciate the consequences of living in the community with a severe disability. In undertaking this study I set out to use the process of grounded theory to develop a theoretical model of adjustment for quadriplegic people as they return to live in the community.

### **Personal interest in this topic**

As a student nurse in the 1950s I met and still vividly remember a young Englishman who was on holiday in New Zealand. He was admitted to the orthopaedic ward with a broken neck following a fall while he was tramping. He was quadriplegic. I have never forgotten him nor have I forgotten how alone he was. He lay in bed and no one expected him to live. I remember how much he sweated and I remember how much nursing care he required. I did not know what to say to him given his gloomy prognosis. His eyes seem to say to me, "I'm still human". Neither doctors or registered nurses seemed able to speak with him.

Years later, as a new teacher, I had a nursing student who was looking after another person who had a cervical spinal injury and was in skull tongs. Even though I knew differently, it seemed to me that those tongs went right through the person's brain. I noticed that I experienced some personal discomfort while being around this particular patient. As I reflect now, it seems as though I have been professionally confronted and challenged by people with quadriplegia for most of my nursing life.

In January 1987, my experience of spinal cord injury became personal. My 21 year old daughter dived through a large breaker hitting an unexpected sandbank and instantly became quadriplegic with a complete spinal cord injury.

McLernon (1988, p.45-53), reporting in a magazine article, describes my daughter's first year or so after her accident in an accurate and sensitive style. To sum up the personal

difficulty resulting from the injury McLernon quotes part of a letter which my daughter wrote to her friends.

It has been four months since my accident, the hardest months of my life. I can't even begin to describe the changes that I have had to make. Everything I do is difficult, but that is just the reality of my injury. I am constantly deeply moved by the friends that I have. I can not write it more simply than that.

The experience of a complete spinal cord injury with the total loss of sensation is graphically captured in the story of my daughter's first bath as recounted by McLernon,

I kept thinking it would feel great - relaxing, warm - that for me was what a bath was . . . Three people lifted me into a bath trolley. And it was terrible, one of the worst things I have experienced, because I couldn't feel anything. There I was in the bath - I could see myself in the water - but I couldn't feel anything apart from a little bit on my shoulders. What kind of bath is that? I cried my eyes out (McLernon, 1988, p.49).

I have accompanied my daughter on her journey of successful reintegration and retraining for the last nine years and I have become passionately interested in the experience of people who live with a cervical spinal cord injury.

### **Organisation of this research study**

This study will unfold in the following chapters. After this introduction there is a literature review of relevant and related material. The extant literature on the topic of

living with a spinal cord injury is scant. To familiarise the reader with this area of human life the review includes background information about the condition. The second chapter is an explanation of the research methodology and the process employed in the present study. Justification of grounded theory methodology is included. The next six chapters discuss the findings and the model which emerged from the data. The final chapter addresses the limitations of this study, its recommendations and implications for nursing, and ideas for further research. In conclusion there is an evaluation of the study.



## **Chapter 1**

### **LITERATURE REVIEW**

This chapter is divided into sections, beginning with background information. In order that the reader may fully appreciate this study, this chapter will begin with a review of anatomy and physiology of the spinal cord and spinal injury. Next is a discussion of the management of the acute spinal cord injury and the long period of reintegration which follows such an injury. The remainder of this chapter includes sections which deal with the literature related to the experience of a spinal cord injury, living with a chronic illness, family involvement and the provision of health services.

#### **Review of anatomy and physiology**

The anatomy and physiology of spinal cord injury extends beyond the spinal cord itself. The entire body is affected in some way. However, it is the central nervous system and the autonomic nervous system which are central to the injury. Prior to injury, the person's intact spinal cord, as part of the central nervous system functioned like a main electrical cable supplying messages to and from important sub-stations. The response of the autonomic nervous system to spinal cord injury affects the functioning of glands and organs.

The spinal cord is the primary vehicle for connecting the brain to peripheral neurons as well as organs and other body parts for sensation and for movement. It is made up of countless neurons which transmit impulses between the brain and receptors at varying

levels within the spinal cord. The spinal cord is encased, and therefore protected, by thirty three vertebrae which together are known as the vertebral column or spine. Between each pair of vertebrae there are spinal nerve roots which communicate with specific parts of the body. The sensory fibres from each nerve serve a particular skin area known as sensory dermatomes. Each spinal cord nerve segment contains afferent (sensory) and efferent (motor) nerves. The origin of movement is situated in the cerebral cortex. Impulses from the cerebral cortex are conveyed by neural pathways which are made up of neurons with long axons crossing to the opposite side of the body within the medulla of the brain and then descending to the various spinal cord nerve segments. The chain of neurons eventually terminate in striated muscle (Mathews, 1987).

The neck region of the vertebral column is made up of seven cervical vertebrae. The spinal cord is situated in the centre of the vertebral column and is about the thickness of an adult's little finger. For purposes of the assessment of damage following injury the cervical spinal cord is divided into eight segments. These segments are numbered in relation to the spaces between each cervical vertebrae. The higher the level of damage, the greater is the loss of sensation and/or movement to the upper limbs. Damage to the spinal cord in the cervical region will usually involve hands, arms, trunk and legs. The bowel, bladder and sexual organs are affected by most spinal cord injuries because the nerve supply to these organs comes from the lower end of the spinal cord (Rogers, 1986, p.38).

The autonomic nervous system innervates glands, smooth muscle and cardiac muscle. It consists of two parts, namely the sympathetic and the parasympathetic systems. These

two parts tend to balance each other: when one accelerates the other inhibits. Structures innervated by the sympathetic and parasympathetic divisions are reached by two chains of neurons; pre and post ganglionic fibres. The sympathetic division preganglionic neuron cell bodies are in the intermediolateral gray column of the spinal cord. The chain of ganglia are near the spinal cord and are interconnected by nerve fibres. The parasympathetic division concerning the spinal cord is limited to the sacral segment which innervates the smooth muscle of the bowel, bladder and reproductive tract (Matthews, 1987).

It is obvious that the complexities of the human body are profound and the central and autonomic nervous systems play a major part in the maintenance of health and well-being. Damage to either of these systems is to be avoided.

### **Spinal Cord Injuries**

Trauma is the leading cause of spinal cord injury and is generally associated with fracture dislocation injuries. There are two types of lesions and for treatment planning it is essential to understand the diagnosis accurately. These are complete and incomplete lesions. Simply put, a complete lesion damages the spinal cord right across its width cutting off all nerve impulses. An incomplete lesion leaves some part of the spinal cord intact allowing some nerve impulses to pass. Matthews (1987, p.41) provides a functional classification as follows:

*ankel Grades:*

- Complete - no preservation of any motor and/or sensory function below the injury.
- Incomplete - preserved sensation only--preservation of any demonstrable sensation, excluding objective phantom sensations. Voluntary motor function is absent.
- Incomplete - preserved motor (nonfunctional) -- preservation of voluntary motor function which performs no useful purpose except psychologically. Sensory function may or may not be preserved.
- D. Incomplete - preserved motor (functional) -- preservation of voluntary motor function which is useful functionally.
- E. Complete recovery - complete return of all motor and sensory function, but still may have abnormal reflexes.

Morris (1989, p.2) describes spinal cord injury this way:

Spinal cord injury can be at different levels and cause varying degrees of paralysis. Some of us can walk with crutches and calipers; some are wheelchair users but with a range of abilities, from having full use of our hands and arms to very little use of either. Paralysis also affects the bladder and bowels, making incontinence a major part of disability.

Maddox (1990) provides a statistical picture for spinal cord injury in the United States of America. His figures suggest that twenty five percent of people with a spinal cord injury

have a complete lesion and are quadriplegic, twenty eight percent have a complete lesion and are paraplegic, twenty eight percent have incomplete lesions and quadriplegia, and nineteen percent are incomplete and paraplegic. This is predominantly a male injury. Eighty two percent of those with spinal cord injuries are male, with sixty one percent of these injuries occurring in men between the ages of sixteen and thirty years. Forty eight percent are caused through motor vehicle accidents. In the state of Colorado, which has approximately three million people (similar to the population of New Zealand) about one hundred new spinal cord injuries are expected each year.

### **Immediate concerns and management**

Initial assessment of the patient with an actual or a suspected spinal cord injury must include a total assessment consistent with the approach to resuscitation. Life threatening injuries must take precedence but strategies for the stabilisation of the spine are included. Medical diagnosis is generally made following radiographic assessment and evaluation. The primary goal of management is to prevent further deterioration and to maximise functional outcomes (Richmond, 1990, p.58).

Respiration management depends on the level of injury. All cervical lesions involve a decreased vital capacity. If the lesion is above the fourth cervical vertebra the patient will require intubation and ventilation. When the cervical lesion is at or below the fourth cervical vertebra, the patient often develops diaphragmatic fatigue and may require temporary ventilation. Physiotherapy and nursing management are necessary to prevent pulmonary complications (Richmond, 1990 ).

Spinal shock begins immediately following injury in the cervical and upper thoracic area. This is caused by the normal swelling following any fracture of bone. The triad of hypotension, bradycardia and warm, dry extremities typify spinal shock. Spinal shock tends to peak on the fourth day and to resolve gradually over the following ten days. The cardiovascular system is highly dependent on the autonomic nervous system. Autonomic dysreflexia (also known as hyper-reflexia) occurs in up to eighty percent of patients who have a high spinal cord lesion. This is a life threatening event which may result in stroke, subarachnoid haemorrhage and seizures. Early signs are a pounding headache, severe hypertension, bradycardia and vasodilatation above the level of the lesion. The exact mechanism is complex, but it is triggered by a relatively minor problem lower than the level of injury, such as a kinked catheter or constipation.

Potential additional complications include deep vein thrombosis, stress ulcer and gastrointestinal bleeding, and secondary complications related to immobility (Richmond, 1990). Another set of complications is likely if poor healing of the vertebral fracture occurs.

### **Stabilisation of the fracture**

Surgical intervention may be used to stabilise the fracture depending on the level at which it occurs and the presence or absence of additional injuries. Initial reduction of a cervical fracture is likely to be done through the application of weights to skull tongs or to a Halo ring with frequent radiographic examinations. It is important that there is good alignment and healing to prevent unnecessary complications at the fracture site (Richmond, 1990).

### **Potential long term complications of spinal cord injury**

There are many possible medical complications following a spinal cord injury. In addition, of course, people with spinal cord injury may also experience non-related forms of health problems such as cancerous tumours.

Morris (1989) conducted a survey of two hundred and five paralysed women who returned her questionnaire. The participants identified the medical complications they experienced resulting from paralysis. Morris, (1989, p.168) grouped these medical complications as follows:

1. Bladders and kidneys - urinary tract infections associated with incontinence were reported to be a frequent problem. These difficulties may be compounded by kidney infection or reflux. Kidney and bladder stones resulting from a build up of calcium from bone tissue also cause problems.
2. Pressure and other skin problems - one in four of the respondents mentioned having pressure sores. A sore can lead to an abscess and on to bone infection. Skin rashes were a common problem. Burns were not uncommon because of lack of sensation.
3. Circulatory conditions - reduced mobility leads to a sluggish blood flow and the potential for thrombosis.
4. Respiratory problems - it is not uncommon for a cold to become a chest infection because of impaired respiratory ability. Several respondents reported bouts of pneumonia.
5. Contractures, arthritis and scoliosis - long term use of crutches or a wheelchair creates strain on body parts. Broken bones, usually legs, were not uncommon because

of weaker bones as a result of immobility, increased vulnerability arising from lack of sensation and the possibility of falling awkwardly while on crutches or in a wheelchair.

6. Spasms - some women reported having considerable difficulty with involuntary muscle contractions, some of which were very painful.

Pain was included in Morris's survey. In general pain is a long term complication.

Morris (1989) states:

Pain is a small word with many implications. For some of us, pain permeates all aspects of our lives: our family, work, social and sexual lives. It is an intrusive by-product of spinal injury which has the potential to damage us physically, emotionally and socially.

She writes, "the responses to the question, 'where is the pain?', indicate that 'pain is anywhere or everywhere'" (p.175). Pain was described as degrees of aching, burning or discomfort in nearly all parts of the body. Pain did not seem to follow any set pattern to match the level or the nature of the spinal cord injury. She distinguished pain to some extent, as being (a) root pain; that is pain which comes from the parts of the body which no longer experience normal sensation, (b) hypersensitivity which seems to be very difficult to manage and almost impossible to explain, or (c) aches and pains which are associated with altered posture and the overuse of muscles and joints (p.176).

From a medical perspective there are many complications from spinal cord injury. Jeffrey (1986, p.59) identifies a list of a dozen serious complications arising from reduced mobility as a result of spinal cord injury. These range from osteoporosis and muscular atrophy to impaired temperature control. Rogers (1986, p.154) adds to the list of



complications syringomyelia which is a chronic and progressive disease of the spinal cord below the level of injury.

According to Maddox (1990) problems related to the urinary and renal systems are the most likely cause of death during the next five to eight years in people who survive the first two weeks after spinal cord injury. There are few data to indicate the likely cause of death for people who are quadriplegic following spinal cord injury and who survive ten or more years. There is the suggestion that those quadriplegic people who take responsibility for their own health are likely to live for many years (Maddox, 1990, p.73).

It is obvious that the presence of serious complications for people with spinal cord injury adds to the challenges of life. One or more of these complications may become a life long problem for those with quadriplegia.

### **Reintegration**

The term 'reintegration' is used by Nelson (1990, p.44) to describe the process of preparing individuals for "coping with physical limitations, architectural barriers, and societal prejudices while simultaneously making them feel intact and valued." Reintegration is a long slow process. It is both physical and psychological and begins once the patient is medically stable, but this does not imply that medical care is completed. According to Maddox (1990, p.39) a person who is paraplegic can expect to be in a United States hospital for about eighty four days and for quadriplegia about one hundred and sixteen days. The hospital stay in New Zealand tends to be longer than that described by Maddox. Goals for reintegration are to maximise the remaining

abilities the person has, to minimise their deficits and to reduce the potential for complications. Richmond (1990, p.66) writes "The primary goal of rehabilitation is to assist the patient and family to provide self-care at the maximal functional level".

Richmond and Metcalf (1986, p.183) discuss the psychosocial responses to spinal cord injury. The individuality of each patient is emphasised, but in general the writers suggest that patients may need help in managing some of the following problems: disturbance in self-concept, disturbance in body image, disturbance in self-esteem, disturbance in role performance, powerlessness, functional grieving and alteration in family process. These writers describe a series of strategies for how nurses can assist patients to make progress in these areas. Some of these strategies include assisting the grieving process, teaching about changes to the body as a result of spinal cord injury, developing short term goals, distinguishing the locus of control a patient has over his/her life and involving the patient in decision making.

As useful as Richmond and Metcalf's strategies are, I believe, there are additional areas where a person with a disability must reintegrate. These are the important areas of sexuality, and masculinity or femininity. There may also be issues of a religious/spiritual nature to attend to especially if the injury included a near death experience or other people died in the accident.

For the patient, a large amount of time is spent engaged in physiotherapy (PT) and occupational therapy (OT). Maddox (1990) writes:

PT does its best to get patients' muscles working as well as possible. OT, which overlaps to some degree with PT, helps patients get along outside the hospital by teaching skills for everyday living with a disability (p.29-30).

Physiotherapy begins in the acute care phase especially working with the respiratory and vascular systems. Range of motion exercises are important while the person is limited to bed rest. After several weeks the person begins to sit up and is transferred to a wheelchair. Episodes of postural hypotension are likely to occur during this process. Active muscle strengthening exercise programmes are established and finally patients begin endurance training. For a person who has a spinal cord injury physiotherapy is very demanding work and does not stop when the person leaves hospital.

Reintegration continues after the person leaves hospital. The social side of reintegration may have begun in the hospital but returning to work or school and being part of society is far from easy. Nelson (1990, p.132) states

Successful reintegration assures the newly injured SCI [Spinal cord injury] patient returns to a viable occupation, feels physically attractive, participates in a rich full social life, and maintains family ties.

People with spinal cord injury are faced with several major transitions. Before their accident they live with a body which takes care of itself and for which they have to give little conscious thought. They survive a major accident and lengthy hospitalisation, and then adjust to living with a body which requires thoughtful, meticulous and regular care just to stay alive. Writing about thoughtlessness, Maddox (1990, p.30) says, "Self neglect can evolve into a form of 'passive suicide'". I next turn to active suicide.

### **Choosing death**

Active suicide is the choice of a few with severe spinal cord injury. In the devastating circumstances of quadriplegia the power of one of the two great unconscious drives

recognised in classical Freudian psychology, the death wish or *mortido* is overwhelming for some people (Reber, 1985). While most people with a spinal cord injury work very hard to make the adjustment, there are those who choose not to live and intentionally commit suicide, sometimes with assistance.

In a New Zealand newspaper, Duff (1994, p.C1) is described as tackling his most controversial topic to date in writing the script for the film, *Mates*, which is about euthanasia and is based on a true story. The two mates are Warren Ruscoe and Greg Nesbit. Nesbit became quadriplegic after a construction accident in 1990. Nine months later he asked his friend Warren to "take me out", a euphemism for assisted suicide, which Warren did, feeding Greg 50 tablets of an unspecified drug while they talked and drank.

Coddington (1989, p.101) writes about another New Zealander with quadriplegia who "died from a suicidal ingestion of fatal quantities of Paraquat" (a lethal weed killer). This man, who was a successful lawyer, carefully planned his life and also his death. He also planned the writing of the article with the author at the same time as he planned his death. Coddington (1989, p.107) quotes this man "I don't see life as some great sacred thing, so special that we should be grateful for it in any form. I died 15 months ago. Now I want to kill the quadriplegic that is left." It seems he was unwilling to accept a life that he considered to be less than perfect or was unable to make the adjustment to living with quadriplegia.

These two accounts of the choice of suicide following quadriplegia indicate how extensively deranging the consequence of the injury is for some people. The road to reintegration is long and hard and it is a testimony to the human spirit that so many choose to follow it.

### **The experience of spinal cord injury**

Rogers (1986) provides a personal account of his experience following an attack on his spinal cord in 1960 by an unidentified virus which left him paralysed. His paralysis involved all four limbs. Rogers is acknowledged as one of the longest surviving people with quadriplegia. His book addresses all aspects of living with quadriplegia. Rogers (1986, p.13) describes his early experiences of quadriplegia this way:

I spent 18 months in St Mary's where despite conscientious and devoted care, I developed many of the now known to be avoidable complications of paralysis. Although my stay there was, on occasions, quite horrific, as my life frequently hung in the balance, in an ironical way it could be loosely construed as an extension to my education.

During his eighteen months in hospital, Rogers describes how he counted the spots of the ceiling material to assist him to deal with the loneliness and the despair of facing his future. The complications he experienced were severe chest and urinary tract infections and pressure sores because of his paralysed body. The extension to his education occurred while he was used for purposes of medical education and he explains that this was preferable to being alone in his room. He learned about his paralysis by repeatedly hearing the medical instructor's lecture about his own body.

Throughout his book Rogers emphasizes the theme, "Know your paralysis".

1 another personal story, the every-day difficulties of living with quadriplegia are graphically described by Powell (1993) who is ventilator-dependent and is cared for at her Australian home by elderly parents. The theme of this article is that if things can go wrong, they will, for people who live with quadriplegia. This writer provides useful background for the present study because the practical difficulties of living in the community are described at length. Amongst other details, Powell describes her frustration and disappointment at not being able to attend a family social gathering because of pain and a leaking catheter at the time of the event. None of the nine participants in the present study are ventilator-dependent. However, the data in the present study tends to support the notion that if things can go wrong they do for quadriplegic people.

The cover article of Time magazine (August 26, 1996) written by journalist Rosenblatt, is devoted to quadriplegia. It focuses on the high level spinal cord injury of Christopher Reeve, the actor made famous by playing the title role in the movies of Superman. The Time cover is headed *Super Man* and the sub-heading reads, "*An intimate look at Christopher Reeve's heroic battle to rebuild his life and champion the quest to cure spinal-cord injuries. Will he ever walk again?*" The answer to this question is that no one knows. It is my opinion that this story will contribute positively to the common and professional knowledge about and to the respect for people who live with quadriplegia. Rosenblatt (1996, p.40) writes of Reeve:

When he speaks, he must catch the ventilator on the outward breath, finish one sentence and get at least a word into the following sentence to signal his

listener that he has something more to say. 'You're sitting here fighting depression,' he says. 'You're in shock. You look out the window, and you can't believe where you are. And the thought that keeps going through your mind is, 'This can't be my life. There's been a mistake.'

Already Reeve is politically active in assisting future research for the treatment of spinal cord injury and also investigating the financial difficulty of living with a spinal cord lesion. Rosenblatt (1996, p. 42) states that Reeve is fighting on two fronts. The first is preventing health insurance companies from capping compensation for spinal cord injury care and the second is fund raising for research into spinal cord injury.

Richmond (1990) in her review of the literature on spinal cord injury provides accurate and specific medical and nursing information. She states that the Edwin Smith Surgical Papyrus written in 2500BC identified spinal cord injury as an untreatable injury. In relation to cure, this is still more or less true. Up until reasonably recently, there was little hope of surviving the spinal cord injury itself nor the likely complications which followed. Years ago, it was common knowledge that if a man broke his neck he was expected to die from the injury. Now more and more people who sustain a spinal cord injury are rescued and benefit from improved medical, nursing and rehabilitation services. Ferry (1989) reports that even though cells within the central nervous system make some very small attempt to regrow following injury, they are faced with an impossible task of navigating through a pathless jungle of nervous tissue to find their targets. Recently, however, there have been new medical discoveries reported. As mentioned earlier, Rosenblatt (1996, p.45) discusses research in relation to the fund raising work being done by the actor Christopher Reeve: "Methylprednisone is a major advance in the spinal



cord research for which Reeve is now seeking support.” Methylprednisone, if administered within eight hours of injury, can save 20% more neurones. Rosenblatt reports a medical expert in this field as saying “It’s a source of great hope ... it means that you don’t have to preserve, restore and regenerate so many axons in order to get functional recovery”. It is important to note that this medical scientific work is focused on reduction of damage and is very different from the notion of cure.

In her review Richmond (1990) emphasizes a multidisciplinary approach which is essential to assist the patient in maximising functional outcomes. However, she concludes her article by stating “The nurse, who deals with the human response to the injury, is in an ideal position to help the patient and family realise their life potential” (p.67).

Kurtz (1993) describes the situation of a fifteen year old who had a self-inflicted gunshot wound which left her quadriplegic. Her injury had occurred after she had been involved with her friends in illegal activities and had received a threatening phone call from one of the group’s parents. This teenager had a bright and cheerful personality but little family support at the time of her injury. When she was required to engage in any physical activities she would scream and attempt to bite staff members. The teenager was highly resistant to therapy and Kurtz’s case study describes the nursing management for this teenager. Management was based on behaviour modification with firm limits and enough choice to encourage participation in the rehabilitation programme. The writer describes how she worked as the teenager’s primary nurse, which involved dealing with her resistance, finding solutions to psychological problems including her suicide attempt and



establishing learning priorities for the teenager and her family. This study is useful because the writer includes the reported experience of the teenager. The article concludes that the teenager had a better outcome than was expected by the rehabilitation team. However, it is important to remember that this is the opinion of the primary nurse and is not necessarily the experience of the individual herself. To establish credibility it is important that the opinion of the teenager was obtained.

These accounts of dealing with quadriplegia indicate that life becomes dominated by the injury and its consequences. Complications of the injury and the adjustment to living as a quadriplegic person are enormously challenging. The literature provides evidence that spinal cord injury is a threat to survival and to life and that these people are a challenge for nurses and other members of the health team because of the enormity of their adjustment process and the ongoing medical complications. Since the literature provides only a limited number of articles specifically on this topic, of living with a spinal cord injury, the next section reviews articles concerned with living with a chronic illness or disability.

### **Living with a chronic health problem**

There are some similarities between chronic health problems and quadriplegia resulting from spinal cord injury. Recently, the nursing literature has contained an increasing number of studies (Crigger 1996; Leidy & Haase 1996; McWilliam, Stewart, Brown, Desai & Coderre 1996; Nelson 1996; Newby 1996; Paier 1996) on the human experience of certain health problems. Schaefer (1995) studied women living with fibromyalgia. She found that over time the illness moves from being a primary life focus

to being part of the background in the lives of these women. Brown and Powell-Cope (1993) found that there were common strategies used by families to cope with the situation when a member has AIDS. They found that these families revise their plans for living in the world because of the possible death of the affected member. This revision includes the two categories of "facing loss" and "transformed time". The family members reported three strategies which assisted them cope with these two categories, "taking one day at a time", "living fully in the moment", and "actualizing future dreams" (p. 188).

Morse and O'Brien (1995) conducted open-ended, unstructured interviews with patients who had survived serious injury. The researchers traced the psychological process of 'preserving self' through the phase of the critical injury to the acceptance of being a disabled person (p.888). However, none of these patients were spinal cord injured people and this present study strongly supports the importance of further nursing research in this process of patients accepting quadriplegia.

Maynard and Roller (1991) work extensively with people who have survived polio. They have recognised that there are emotional patterns which appear to result from characteristic styles of living with a chronic disability. These authors characterised people as "passers" "minimisers" and "identifiers" (p.70). Whilst labelling groups of people can have detrimental effects, their study uses these terms as a means of grouping behaviours and coping mechanisms. In this way awkward repetitive descriptions have been avoided. "Passers" are those people who have mild effects of polio and tend to work hard at hiding their long-term disability. They do not think of themselves as having

a disability and they believe that if they "blow their cover" they will become stigmatised as part of society's disabled minority. "Minimizers" are those who have moderate effects of polio. The disability is known to themselves and to others. The study shows that the polio "minimizers" feel uncomfortable around people who are severely disabled, particularly wheelchair users. "Identifiers" are those people who are sufficiently disabled to use a wheelchair. This group have had to integrate their disability into their self image in order to live their lives in a successful way. The majority of people who recover from a spinal cord injury have no choice but to use a wheelchair for mobility.

### **Family Involvement**

Spinal cord injury not only affects the individual, the family also is required to make changes because of this situation. Richmond (1990, p.65) writes "Spinal cord injury occurs not just to the individual but to the entire family." There appears to be little research in the nursing and nursing related literature on the topic of family involvement following the event of a spinal cord injury.

Lapham-Randlov (1994) describes the major challenges which faced her family following her husband's spinal cord injury. She reports that she initially found the effect of the injury to be devastating. She describes how the family managed soon after the injury and how they experienced the process of rehabilitation. She makes a useful statement when she writes, "Although I was a nurse . . . I soon realised, however, that if we were to survive this injury as a couple, I could not be Allen's nurse" (p.80). The overlap between family member and care-giver is an interesting outcome in the present study and

is discussed in detail in a later chapter. Lapham-Randlov and her husband had to deal with the various medical complications which he experienced following his spinal cord injury: infections, chronic pain, osteoporosis, broken skin and bowel management.

In the psychosocial area, Lapham-Randlov (1994, p.82) sensitively describes how independence was encouraged and how her husband returned to the normality of going to work. Finally, she describes the importance of Barnum, the service dog, who became her husband's "willing and faithful friend". She provides general guidelines for "clients floundering in the healthcare system" (p.83) and for nurses who work with people who are quadriplegic. Lapham-Randlov (1994, p.83) emphasizes the individuality of people. Each patient requires time to talk, each patient has individual problems from spinal cord injury and nurses need to explore these and where possible keep solutions to problems simple and inexpensive. Above all, she suggests to , keep an open mind and to learn from other people with quadriplegia. The present study findings support Lapham-Randlov's guidelines.

Killen (1990) conducted an investigation to determine how family roles changed after a spinal cord injury to a child or a spouse. The results indicate that spinal cord injury was initially perceived as a severe crisis that became less over time. Mothers fulfilled traditional roles and became very involved with the care of the injured person. One wonders what would happen if it was the mother of the family who had been injured. Killen (1990, p. 21) writes "In spite of the fact that parental and spousal roles did not significantly change in relation to traumatic spinal cord injury, many respondents reported a profound change in family functioning".

It is significant to note that Kreutzer, Marwitz and Kepler (1992, p.776) suggest in a review of the literature on family outcome following traumatic brain injury, that most of the research has been done with female family members. There is little research regarding marital stability and little is known about the reactions of fathers and children to traumatic brain injury. The findings in the present study indicate that most of the caregiving is performed by women, either as employees or as family members. The overall lack of information on the impact on the family of permanent disability in a family member is confirmed by the work done by Robinson and Steele (1995, p.93) who write that "understanding family processes inherent in caregiving is of growing importance in caregiving research".

The extant literature contains some material on the effects on the rest of the family when one member suffers from a physical or psychological disability or disease. Gillies (1988, p.19) provides two case studies on her work with families using role supplementation. The second of Gillies' case study work is with the mother and brother of a 20 year old spinal cord injured man, her first is that of a junior college student's family following his head injury. Gillies (1988, p.21) concluded that role disturbances developed in the disabled individual and his significant others. Flannery (1990, p.92) describes her work with families who are troubled by feelings of guilt. Her model contains five stages. Flannery (1990, p.92) writes that she has often heard family members say, for example "If I had just done . . ." while waiting to see if the patient will survive the impact of a traumatic brain or spinal cord injury.

Researchers have investigated how parents and families deal with serious and chronic childhood illnesses. For example, Cohen (1995, p.39) used grounded theory to collect and analyse data to illuminate a perceptual-interpretive-behavioral process in the pre-diagnostic phase of a chronic life-threatening illness of a child, concluding that there could be up to three stages in this pre-diagnostic phase: lay explanatory, legitimately and medical diagnostic (p.39). There is some similarity in waiting for the exact diagnosis following spinal cord injury. Canam (1993, p.46) describes the common adaptive tasks which face parents of chronically ill or disabled children. These adaptive tasks were delineated from the literature dealing with the effects of chronic illness and disability on children and their families. The tasks are as follows: accept the child's condition; manage the child's condition on a day-to-day basis; meet the child's normal developmental needs; meet the developmental needs of other family members; cope with ongoing stress and periodic crises; assist family members to manage their feelings; educate others about the child's condition; and establish a support system. There is a similarity in the data which are reported by participants in this study about family experiences following a spinal cord injury.

Snelling's (1994) study on the effects of pain on the family unit using grounded theory provides useful information for this current study, since chronic pain is a complication of spinal cord injury. The findings in Snelling's work demonstrated that all manner of relationships within the family unit are affected by the experience of chronic pain in one of the family members. Snelling lists social isolation, role tension, marital conflict, reduced sexual activity and feelings of anger, anxiety, resentment and despondency as the effects of chronic pain in the family unit (p.543). Further research is required to

validate whether there is a relationship with the findings of Snelling's work and the present study.

### **The Provision of Health Care**

Newby (1996, p.786) writes "Recent changes in the financing of health care have resulted in an escalation of reliance on families for long term care". Newby uses family systems theory and the family life-cycle perspective to demonstrate how families adapt to chronic conditions and provide care. Nurses have a responsibility to assist families in adapting to these conditions and to provide essential support to the family system. Newby indicates that families are expected to be dynamic and flexible and to be able to manage the stresses and crises of unusual happenings, such as chronic illness.

There is no published research about the provision of health care for spinal cord injured people who are living in the community. However, a study was carried out by Litchfield, Connor, Eathorne, Laws, McCombie and Smith (1993) known as the Professional Nurse Case Management Project. One of the recommendations of this study was the concept of a Family Nurse who would provide a home-based service to address the complexity of the health circumstances of the whole family when a member has a serious disability/illness. This study is relevant to the present one because of the focus of the adjustment to living with family and in the community following a spinal cord injury. The findings (1993, p.vii) state "It was apparent that the very costly, highly technical hospital treatment and rehabilitation programmes are meaningless unless there is support for family and home life and community service."



Litchfield et al's New Zealand project was evaluated by the family participants. One person spoke from her own experience and said (1993, p.38) ... "I needed help when ... was still in hospital then maybe I wouldn't have had to live a living hell. There is a definite need to bridge the gap between hospital and home ..."

The need for family support when there is a disabled child or a child with a chronic illness in the family has been reviewed by Hartman, Radin and McConnell (1992, p.55). These writers found that there are five core elements: (p. 58) (a) family centered care; (b) philosophy of parent-to-parent support; (c) the process of grieving; (d) communication and problem solving skills; and (e) national, state and community resources available. Hartman, Radin, and McConnell's study could provide a model for those living in the community following spinal cord injury based on the findings of the present study.

Several researchers (Brillhart, 1988; Callahan, 1988; Evans, Bishop & Ousley, 1992) have explored the general topic of the provision of care for disabled people. Each of these authors contributed to the background of this present study in limited ways. Callahan (1988, p.323) in particular, raises issues of an ethical nature in that, from his perspective, there is a disturbing trend of returning chronically ill and disabled people to families on the assumption that families have "the moral, psychologic, and spiritual strength" to manage. In contrast Evans et al. (1992, p.144) suggest that family assessments may help clinicians to use family strengths in rehabilitation and these assessments could also be used to identify families who might benefit from intervention in the long term.



A grounded theory and ethnographic study was carried out by Nelson (1990) in order to explore the subculture of a Spinal Cord Injury unit so as to describe the process of rehabilitation. Nelson's model of reintegration (1990, p.44-45) offers guidelines for nurses who assist individuals to cope with physical limitations, architectural barriers, and societal prejudices while simultaneously making them feel intact and valued. This assistance is composed of four phases: buffering, transcending, toughening and launching. While the first three phases refer more particularly to hospital inpatient care, the phase of launching refers to the person with a spinal cord injury returning to live in the community.

Once the phase of launching has occurred, the process of integration continues as the person continues to live in the community as a person with quadriplegia. It is this process which the present study describes.

### **Summary**

This chapter has examined literature in relation to spinal cord injury. Sections include a review of anatomy and physiology, the classification of spinal cord injury and the immediate concerns and management of the acute phase following the injury. There are sections on the possible medical complications and on reintegration for people who experience a spinal cord injury resulting in quadriplegia. Next there was a short section on those quadriplegic people who choose suicide, and an account of three people who have survived and are living with quadriplegia as a result of a cervical spinal cord injury.

Literature was briefly reviewed in relation to the present study in the following areas: living with a chronic health problem; family involvement in living with chronic conditions; and finally, the provision of health care for people with a severe disability or a chronic illness.

The present study is important for nursing because in the future there are likely to be more quadriplegic people in need of acute and long term nursing care. In spite of preventative measures, spinal cord injury will continue to occur.

Nurses will also be required to nurse quadriplegic people who live in the community when complications of spinal cord lesion arise. With excellent rescue services for accident victims, more people are likely to survive, and if spinal cord injured people live through the acute phase, their life expectancy appears to be within the normal range (Maddox 1990, p.73). Therefore there will be a higher percentage of people with quadriplegia living in the community.

The study presented in this thesis is important, as it adds to the available resources in nursing literature. With increasing numbers of quadriplegic people living in the community, nursing needs to have a greater understanding about their lives so that appropriate care can be provided. Increased resources should benefit nurses who work in the community and are therefore in a position to influence the quality of life for people who live with quadriplegia.

## **Chapter 2**

### **RESEARCH METHODOLOGY**

#### **Introduction**

This study was conducted in order to understand the process of adjustment for people with a spinal cord injury as they return to live in the community. Following analysis of data, I will present a theory which may guide nurses who work with people who become disabled as a result of a spinal cord injury. The theory may also be useful for families and for professional health workers who assist people with quadriplegia to live in the community. This qualitative field research study uses grounded theory as its method to achieve this aim.

In this chapter I will explain the use of grounded theory method for the study. The specific methodology will be discussed in detail. The process for the selection of the participants will be described and a brief profile of each will be presented. Later in this chapter, the reader will be introduced to how the data were analysed in this study and how the ethical considerations were addressed.

#### **Rationale for Using a Qualitative Method**

Research aims to discover or verify knowledge. Research can be used as a means to test theoretical relationships and as a method for the generation of theory. There are basically two types of research which are found in the field of nursing and other human sciences. These are quantitative and qualitative research methods or paradigms. In

quantitative research, a question will arise from theory and then the research is conceptualised so that it fits the theoretical framework. Following the review of literature in the specified field of interest, a concise researchable problem is stated and the project is then developed using an appropriate design such as a survey or a laboratory experiment. The data are collected and then analysed using statistics; the results are extracted and conclusions drawn. There is an emphasis on measurement or on determining the relationships under scrutiny. The results are evaluated in terms of the validity of the study, in relationship to other research in the field and to their contribution to knowledge.

According to Roberts (1995, p.218) in qualitative research, "there is much less emphasis on measurement and much more on meaning". The process is quite different from that of quantitative methods. One goal in using qualitative methodology is to develop theory rather than be driven by an existing theoretical framework. Among approaches to qualitative methods are ethnography and grounded theory. Glaser (1992, p.11) states "Qualitative analysis means any kind of analysis that produces findings or concepts and hypotheses, as in grounded theory, that are not arrived at by statistical methods". Data may be collected through interviews or observation. The data are analysed and theoretical insights drawn from the data (Roberts, 1995).

Chinn and Kramer (1991, p.74) argue that research paradigms are also described in terms of traditional natural science and human science. In the view of traditional natural science, the researcher is separate from the study and therefore his/her behaviour and values do not influence the discovery of knowledge. Therefore there can be a high

gree of predictability and control. In comparison, human science includes research methods which acknowledge the intimate connection between the researcher and what is being studied. This shift from the traditional natural science is appropriate for nursing because there is an emphasis on understanding rather than on prediction and control. This is because the development of theory in nursing seeks to provide knowledge which can be applied in human situations where the aim is to empower rather than restrict.

Campbell (1995) discusses difficulties faced by the early sociologists in the nineteenth century when the methods of natural science were applied to human study. They attempted to treat human subjects as objects. Later there was a move against this 'positive' certainty through the methods of natural science by a German group (Wilhelm Dilthey and others) who "deplored the scientific approach to human study"(Campbell, p.61). Dilthey argued that 'human studies arise out of lived experience'. He believed that the writing of autobiography and biography was the best means of developing human knowledge. Martin Buber was a student of Dilthey and referred to his teacher as 'the father of philosophical anthropology'. Dilthey argued that 'understanding is a rediscovery of the I in the Thou'. Buber then carried this idea of the 'I in the Thou' into the "I-Thou" of human relationships. Campbell (1995, p.62) writes "The science of objectivity had reduced human relationships to the 'I-It'". This distinction has contributed to major philosophical thinking and to developments in the human sciences of this century.

Buber's "I-Thou" concept in human science is important because this philosophy removes the objectivity from qualitative study. The theoretical underpinnings of "I-

Thou” allows people as whole entities to be studied within their human context. This is a very different scientific method than the “I-It” approach which concentrates on measurement and not on meaning. The present study examined human participants within their environment so that others can understand their lives.

In her qualitative study Nelson (1990, p.12) developed a model for spinal cord rehabilitation. She justified the use of qualitative research methods as being appropriate “when the phenomena to be studied are complex human and organisational interactions not easily transferable into numbers.” Prior to developing any theory of adjustment, it is essential to understand the experience of the participants. As Morse (1991, p. 21) writes “Qualitative methods provide rich description of what it is like to be sick or for example, suffering with cancer, pain, or altered body image.” Qualitative methods allow for description of what it is like to live as a disabled person. There is an emerging group of researchers who are disabled themselves or who are interested in the lives of those with a disability. Boyles ( 1995, p.143-144) writes:

The challenge to those of us wishing to undertake research is to use our skills and expertise to create a situation which would enable people with disabilities to acknowledge and develop their own resources (Oliver, 1992). The feminist approach to research has much to offer in terms of the principle of a non-exploitative relationship between researcher and researched based on collaboration, co-operation and mutual respect.

The research participants in the present study were people with quadriplegia and therefore it was essential that the research design was respectful to this population.

Keddy, Sims and Stern (1996) discuss grounded theory as feminist research methodology. They write:

It is interesting to note that nursing is in large part a social science, and nurses have sought to hear the voices of those with whom they work. In league with the current feminist research approach, grounded theory allows for the voices of the participants to be heard as they tell their stories (p. 450).

The research design for the present study was dependent on the co-operation of the participants and the context of mutual respect was essential to avoid exploitation by the researcher.

My desire was to choose a qualitative methodology for this study. My interest was of a human nature. I had no intention of reducing my participants to objects. I wanted to learn from and to understand the lived experience of the participants and then to draw a theory from the data. I expected to be involved in complex life events and processes of the participants and I expected measurement would not be ideal as a means of accessing such understanding.

### **Grounded theory method**

Grounded theory research is one example of qualitative methodology and is appropriate when there is a lack of published material for the specific area of interest. Stern (1980) writes that the strongest case for the use of grounded theory is in investigation of relatively uncharted waters. She suggests that this methodology is very appropriate where there are complex human situations involved.

Glaser (1992) argues that grounded theory allows the researcher to discover what is going on in a particular social situation. The purpose of this present study was to understand the process of adjustment for people with a spinal cord injury as they adjust living in the community. Grounded theory allows for the discovery of relevant social and psychosocial aspects of the processes being studied.

Glaser (1992, p.5) writes "Grounded theory does justice to the data". In Glaser's view emergence of the theory from the data is an essential process. The data contain the evidence from the participants. Baker, Wuest & Stern (1992, p.45) state that the purpose of grounded theory method "is to explain a given social situation by identifying the core and subsidiary processes operating in it." The core process is the underlying principle which dominates the analysis and links most of the subsidiary processes within an explanatory network. Thus the grounded theory method is inductively based, and generates theoretical explanations of human processes.

Grounded theory method was developed by the sociologists Glaser and Strauss (1967) to study the experience of people who were dying. Their methods involve developing theory by systematically collecting and analysing data. Grounded theory methodology focuses on the processes involved rather than on static conditions, and was introduced to nursing research through the involvement of Strauss and Glaser in the doctoral programme at the University of California in San Francisco. The grounded theory research methodology is appropriate for nursing research because the practice of nursing occurs in a social context and is based on process rather than in a set of fixed and measurable conditions. Grounded theory methodology has been widely used in nursing



research in recent years ( Baker, Wuest & Stern, 1992; Brown & Powell-Cope, 1993; Schaefer, 1995; Snelling, 1994).

The origins of grounded theory lie in the symbolic interactionist school of sociology. This 'new sociology' concentrated on everyday life and on the social construction of human reality. Woods (1995, p.90) writes "Symbolic interactionism holds that human beings act toward things on the basis of the meaning that things hold for them." In other words, reality is a social construction and is nothing more than a social construction. Baker, Wuest and Stern (1992, p.44) state "Symbolic interactionism focuses on the meanings of events to people and the symbols they use to convey that meaning." Therefore in order for meaning to occur, it is necessary that humans have the ability to communicate with others. Very simply put, meanings are developed through interaction.

In order to function in families and within society, humans have found ways to develop the sharing of meaning. This, in terms of sociology, is through a common language and through socialisation. Interaction forces these socially constructed meanings to be constantly updated. This perspective of reality has lead to a process orientation which has required grounded theory methodology to focus on meaning rather than measurement (Baker et al 1992). Social interactionism has contributed to qualitative research methodology in ethnography as well as grounded theory because of the focus on meaning, participation and discovery (Hutchinson, 1995). Grounded theory provides for discovering the world of the participants through analysing their experiences.

The intention of this present study was the generation of theory. Glaser (1992) suggests that grounded theory can be used by people from many disciplines and should not be bound by that discipline or the data collection. There is creativity involved in allowing the researcher to "break out" from older concepts and to let new categories emerge through the constant comparisons of incidents and concepts "so others will feel their grab". However, the validation of the fit and relevance of these new categories is important as the emerging theory develops. Thus Glaser writes (1992 p.18) "the researcher has to be continually coding, comparing, analysing and memoing while asking the sole question of data: What category or property of a category does this incident indicate?"

While it did not apply to the present study, it is not uncommon in grounded theory that the emerging theory is different from the concern which prompted the research. As Glaser (1992, p.18) writes, "Truth is stranger than fiction or the emergent is stranger than the forced". It was important not to force the data to fit my expectation.

The details of the method for grounded theory are described by Stern (1980, p.29) in "a fresh style, translating from the original sociological language, a jargon confusing to the uninitiated, into more familiar terms" so that nurse researchers may find this method less problematic. Stern (1980, p.32-38) describes five stages in the research process. The first stage is the collection of data, usually from interview or observation or more usually a combination. The data are coded using line by line examination and processes are identified within the data. Codes are known as substantive codes because they come from the substance of the data. The treatment of data in the mind of the researcher in the

continuous comparative method of grounded theory is similar to factor analysis using a computer. The data are coded, compared with other data and assigned to clusters or categories according to obvious fit. Therefore the term 'category' is the cluster of coded data which seem to cluster together.

The second stage is the generation of a tentative conceptual framework using the data as reference. The researcher attempts to discover the main problems in the social scene which the participants experience and how the problems are managed. This phase is the outcome of coding and categorising.

The third stage contains three steps which serve to both expand and densify the emerging theory. The processes of reduction and selective sampling of the literature can be thought of as inductive because they are searching for clues, but the third step is a deductive process because the formed concept is now verified. Reduction is the process where the researcher deals with the question: How does everything fit together? Sampling the literature implies that relevant literature is scrutinised and the concepts compared as data. Selective sampling is where additional data are collected to advance the theory. This process is also called theoretical sampling. Following these three processes the conceptual framework attains consistency but suffers from loose construction. The researcher then integrates the categories into a manageable theory.

Two processes make up the fourth stage: memo writing and theoretical coding. It is through these processes that the emerging theory is finally integrated. It is important that the process of continuous comparative analysis is a matrix operation and not a linear

happening. Memos are written to record ideas which are sparked by the data and are therefore grounded in the data. Theoretical coding refers to codes which are theoretical in nature rather than descriptive. The fifth stage is the production of the research report which, in grounded theory, is the substantive theory.

Grounded theory was the method of choice in the present study. The next section explains how the study was carried out.

### **Selection of the Participants**

There were nine participants in this study, all living in the Auckland region at the time the interviews took place. The participants are living with quadriplegia as a result of spinal cord injury at the level of their cervical vertebrae.

The first participant was contacted by phone on the basis of a past social connection. This person was an acquaintance of mine whom I had met some years ago in a social situation and who had also contacted me twice in my employment role asking me to put a notice on the student notice board advertising for weekend attendants. The additional participants were gained through the sampling strategy known as snowballing.

Snowballing was the most appropriate means of obtaining a sample for the present study because of the established informal networks. According to Morse (1991, p.130) "Nominated, network, or snowball sampling is a common method of obtaining a qualitative sample". Snowballing means that the first informant who is interviewed is asked to suggest another participant, and the researcher uses this referral to solicit the

second person to be part of the study. This process was followed with modification when one suggested person refused to become a participant. One participant made two suggestions of potential participants. The process continued until there were nine participants; three women and six men. Three of the participants have children. Bach and McDaniel (1995, p.252), who also studied people who were quadriplegic, describe snowballing as an ideal convenience sampling strategy especially when a participant pool is limited, as the pool of potential participants in this study was considered to be.

There are strengths and weaknesses in the snowballing method of sampling (Morse, 1991). This is due to the fact that the identification and selection of participants is controlled by the population of potential informants. One advantage is that the researcher can gain access to a group of people by gaining the trust of one member of that group. One disadvantage of snowball sampling is that the researcher meets only those potential participants who agree to contact after being nominated by others. It is acknowledged that no representativeness of the general population can be claimed, but this is not sought in grounded theory where selective sampling is the usual procedure.

The nine participants came from a variety of socio-cultural backgrounds and life experiences.

### **The participants.**

All nine participants had experienced a spinal cord injury which resulted in quadriplegia. By definition each participant had reduced function in their upper limbs as well as their lower bodies. The individual level of injury (for example C6) refers to the site of injury and indicates neurological damage. The higher the level of injury to the spinal cord, the

greater the neurological loss of function. Injury levels were between C4 and C7. All but one participant broke at least one vertebra as well as sustaining permanent spinal cord damage.

At the time of the study the participants ranged in age between twenty-four and forty-seven years of age. The age range at their time of injury was between thirteen and thirty-two years. Their injuries had been sustained between six and thirty one years ago and there was a large variation in the length of time the participants had been living in the community.

### **The setting**

The setting for the present study was particularly important because the participants use wheelchairs for mobility. Bach and McDaniel (1995) emphasise the importance of attending to location in interviewing quadriplegic people because of weather and transportation difficulties. Auckland, by reputation, has a poor system of transport for people who use wheelchairs and taxis are expensive. This city is built on extinct volcanoes and therefore has many hills and limited level areas. Auckland is also surrounded by ocean and other bodies of water which contribute to the difficulties participants face because of bridges and causeways. Distances, especially by wheelchair, are not easy. The region has a moderate climate but with a heavy rainfall.

In order to minimise difficulties for the participants, the interviews took place in their homes at times convenient to them. The participants would have been greatly inconvenienced if I had asked them to meet me in my office, at my home or at a public

ocation. In addition the majority of the participants rely on another person for transportation by private car. Interviewing for this study occurred between January and June and the weather in Auckland is wet for a part of most days during this time of the year. Rain causes additional hardship for these participants because of lack of shelter; often there is nobody to hold an umbrella and the wet tyres of wheelchairs take rain water into houses and other buildings.

### **Data Collection**

Data were collected through the use of semistructured interviews. In grounded theory research, data can be collected from participants by a variety of methods including observation and interviewing. My initial observation of the participant in his or her home provided useful cues about how best to proceed with interview questions, however these observations did not contribute formally to the data in this study.

At the beginning of each initial interview, I asked the participant about the cause and nature of his/her spinal cord injury. Considering the purpose of my visit, this seemed to be an appropriate and necessary starting point, and without exception participants freely provided details of their experiences. The first response lead into my next question and then on to the next response and so on. There were two central questions in each interview. The first was "How has your spinal cord injury affected your relationships and your lifestyle with members of your family?" The second question which was introduced much later in the interview was "What more, if anything, could have been done by nurses and others to assist you and your family to adjust to this new situation?" These two questions generated a range of responses from the participants. At times the



participants responded to a relatively straight forward question from the researcher with strength and expression of passion as if an untapped source of emotion had been released. I considered that some of the participants had a powerful hunger to talk about their life situations and to be heard.

In the process of data collection, I found there was the need to be both flexible and yet stay focussed with the area of interest. May (1991) writes that the challenge in interviewing in qualitative research is to maintain a balance between flexibility and consistency. My central question referring to the impact of the injury was asked of each participant. This question was important to provide consistency and focus in each interview. Consistency has to do with the major elements of the study. May (1991, p.193) writes "One strategy in dealing with the problem of consistency is systematic preparation for each interview ... making notes about which questions should be asked ..." For a solo investigator consistency can be difficult to achieve, because as May (1991) suggests participants may be very insightful and able to achieve considerable depth very quickly. This occurred for some participants in the present study. A few of the participants had little to say about the impact of their injury on family members. These participants emphasised the effect of their injury on their lifestyle.

It is important that the researcher has enough information from the participants so that the major elements of the study can be compared. Yet each interview was different because of the human nature of the interview process. Grounded theory allows for a human interaction as part of the data collection. It is a human process between a human researcher and a human participant (Bartell, 1982).



During the interviewing process I became very interested in the individual lives of these people. Each participant provided opportunity to explore a particular aspect of his/her lifestyle and family situation. The first interview was judged to be complete when the participants appeared to have nothing more to add. Second interviews were used to follow up specific areas of interest and also provided the opportunity to explore some of the concepts which were beginning to emerge from the data. After each interview the transcripts were given to the participants to read and change. The transcripts were corrected by each participant.

### **Memoing**

During the data collection and analysis process I wrote many memos. Memos were written at the conclusion of each interview and while I read and listened to the interviews. Memos were also recorded as reflection progressed, with notions of what could be further investigated. An example of an early memo is:

*I wonder about what really goes on with this man. He was hosing the windows when I arrived and told me after the interview that he had changed his wheel-chair tyre without help. Too tough and I hope this man is not the expected standard for quadriplegic people. Is what I was told and what I saw, really how it is?*

These notes are the researcher's record of observations, reflections, hunches and abstractions. Memos were sparked by the data and written on cards or paper immediately the thought has occurred to the researcher. Memos become the researcher's contribution to the emerging theory and as suggested by Glaser (1978) they

were kept separate during this study, from the data. During the process of the study it was important to write memos so that ideas did not get lost. Memos became living items, in that they became extended and altered. They were sorted into clusters and eventually become 'saturated' when nothing new had been added by the researcher. Some were set aside from this present theory and used towards suggestions for further research in this thesis (Glaser 1978).

Following my first interview in this present study, I was struck with how keen the participant had been to talk to me and how fast she told me her stories. The memos I wrote following this interview are:

*Gee - she is so lonely - a very isolated life - yet she has so many people coming and going - perhaps adjustment is mainly sociological.*

*Imagine the major thing in anyone's life being attendants!!*

As the data collection and analysis continued, I found that my mind was dominated by the study. Memos are necessary to keep track of the ideas. After an interview where I was told how good one participant found it was to spend time painting "with an artist up the road". I wrote this memo:

*Perhaps people with a spinal cord injury really need a few extra good people to provide something.*

This memo was a catalyst in my thinking. I moved from concentrating on an individual model of adjustment to a more sociological position. This position might require others to be involved with quadriplegic people on a long term basis.

There was one participant who lived with very little involvement with other people. He told me that he was content with life. Yet my observation of him was very different. In my view, this participant had made little social or psychological adjustment following his injury. After this interview I wrote the following memo:

*A very different life philosophy than I have. Perhaps some people  
do not expect very much from life, or is he still in a state of denial?*

Following the writing of this memo I found myself looking at people generally and wondering about their life philosophy. I made the decision not to follow this lead with my participants, because of the time constraints for this study.

As the analysis drew towards its completion before the real writing began, I became aware of what seemed to be the emerging of a possible central theme. This memo reads:

*I see clearly that the process of Spinal Cord Injury adjustment is to do  
with dependence to independence (or at least as independent as possible)  
I draw some diagrams - and suddenly it seems as though there are categories  
which will subsume the codes.  
I feel very excited, as though "its happened".*

### **Transcribing the interviews**

The interviews were carried out over a period of six months. The timing of second interviews was inconsistent because of the pace of transcribing and the slow return of the read and corrected transcripts from the participants. Several participants gave very careful and detailed attention to the transcripts before being prepared to return them to me.

Transcription was done by an experienced typist but was not without problems. Following transcription of all the interviews I listened to the tapes again at the same time as reading the scripts. In some cases I made corrections and completions to the transcripts. This was necessary because of occasional interference on the tape and because the transcribing typist was not familiar with the language and experiences of the participants. In retrospect, I consider that it might have been better had I transcribed the tapes myself. The transcription would have been more accurate because I was familiar with the content of the interviews and with the participants and their speech.

### **Data Analysis - Constant Comparative Analysis**

Constant comparative analysis is the fundamental activity in grounded theory. Glaser (1978) discusses the term comparative analysis specifically in relation to grounded theory. He contrasts the use of this term in grounded theory to its other uses such as the achievement of accurate evidence or the verifications of an hypothesis. Glaser (1978, p.149) writes "Generation of theory both subsumes and assumes these other uses but only to the extent that they are in the service of generation. Otherwise they are sure to stifle it." Because comparative analysis is a general method it can be used for units of information of any size. The process of comparison in grounded theory is logical in just the same way as experimental and statistical methods are based on logic. Glaser (1978, p.150) writes "The basic criterion governing the theoretical sampling of comparison groups in order to compare conceptual units for generating formal as well as substantive theory is their theoretical relevance for furthering the development of emerging categories, properties, hypothesis, and integration of the theory."

As was discussed in an earlier section, the question which is constantly being asked during this process is: What category or property of a category does this incident indicate (Glaser 1992, p.18)? Constant comparative analysis combines an analytic procedure of constant comparison with a coding procedure for data.

According to Streubert and Carpenter (1995) there are three levels of coding in the process of constant comparative analysis. In this present study the coding of data began following the return of the transcripts from the participants. The first level of coding began with the data from the transcripts and many codes were discovered. There was a process of increasing abstraction in coding. Codes were constantly compared and assigned to clusters. These cluster titles contributed to the titles of the central themes which emerged from the data.

### **Substantive Coding**

In this study, data were broken into small units and these units were coded and known as substantive codes, because they “codify the substance of the data” (Stern, 1980). As each interview was transcribed and had been returned from the participant, it was copied and the process of line by line analysis began. The transcripts were cut into strips of paper. Each piece of paper contained a single unit of information. A system of small plastic bags was used as a means of organising these slips of paper. Each plastic bag was labelled with the substantive code. Labelling of the codes tend to convey action and catch the flavour of the data, for example ‘cruising along’.

The following is an excerpt of an interview with one participant, which began as a response to a question about what he thought his life style would be like if his injury had not occurred:

*I was going to be a builder because I used to enjoy that sort of stuff*

*When I was young I used to go to work with him [Dad], before my accident*

*I used to help him out*

*I went back to school and stayed until the 6th form*

*I didn't worry about getting a job or anything*

*I was just sort of, oh well, cruised along*

*I lived with my parents*

*I just used to pot about*

*I'd go out with Mum, wander about and go shopping.*

The following list of units of information from the data are from more than one person but the substantive code is added in bold type .

*I was going to be a builder because I used to enjoy that sort of stuff...***Pre injury**

*When I was young I used to go to work with him, before my accident..* **Pre injury**

*I'd have had a job, then gotten married and had kids...***Pre injury**

*I used to help him out* **Pre injury**

*I'd only been working for 5 weeks at the freezing works...***Pre injury**

*I went back to school and stayed until the 6th form...***New life/Old life**

*I was an outdoor person I lived for sport...***New life/Old life**

*I didn't worry about getting a job or anything...***Time filling**

*I want to work in an audit company...***Satisfaction with work**

*I was just sort of, oh well, cruised along...***Cruising along**

*I lived with my parents...***Family adjusting**

*I just used to pot about...***Time filling**

*I just read or watch TV, I do as I like...***Time filling**

*I'd go out with Mum, wander about and go shopping...***Family adjusting / Time filling**

*Everything was different for my family members to...***Family adjusting**

Stern describes this process as applying open coding (1980, p.33) and Struebert & Carpenter use the term Level 1 Coding (1995, p. 156). At the completion of this phase there were thirty five substantive codes.

### **Theoretical Codes**

Throughout the process of analysis the substantive codes were constantly compared. They were grouped, ungrouped and combined to form a smaller number of clusters. The thirty five substantive codes were written on a large sheet of paper and this paper was put on the kitchen wall, so that I, as the analyst, could reflect and make new and different combinations. At the same time the plastic bags were grouped in clusters and held together with a spring clothes peg. At one stage there were ten clusters and six individual codes which did not cluster with any shared meaning. Over time and several diagrams on the wall I was able to alter the clusters and make new connections between the thirty five codes.

The data contained information about the **body** of the participants as a result of the spinal cord injury. The theoretical cluster a **damaged body** emerged from a number of substantive codes. Examples were *body care, faster aging, pain and exercise*.

Examples of actual data from the interviews which generated the substantive codes, which support this theoretical code of a **damaged body** are as follows:

- \* Since I've come home from the U S I've had to rest up. I got a red area from sitting on the plane for so long.
- \* The first night was very freaky. Second night got better, third night I said to myself, what the hell I'm by myself, who cares, if they're going to get in they will, don't worry about it. [This participant would be unable to get away if an intruder entered his house].
- \* It seems to be getting to a reasonably manageable area now and getting wet is not the problem it used to be. However it does happen when there is a build up of pressure in the bladder because the supra-pubic catheter is introduced into the body straight through the abdominal wall.
- \* Into bed, I roll out of my chair and she puts my legs on the bed and tips my bum over.
- \* Yes, I can transfer, I can get up in the morning but it takes me a long time.
- \* I am faced with the fact that over 30 years of tetraplegia [quadriplegia] my body has aged at a faster rate than my numerical.
- \* I would consider my pain quite serious.

As can be seen, these extracts from the data cover a number of different concerns, ranging from dealing with skin problems or getting in and out of bed, to fear about intruders, and the experience of chronic pain. All of these are considered to be related to the central theoretical code 'damaged body'.



during the process of constant comparative analysis I explored the nursing literature in relation to the data. Reading literature, especially research studies, promoted further reflection and therefore contributed to the analysis. The use of literature forms part of the constant comparative analysis but it is important not to force the closure but rather to allow the data to produce the theory (Glaser 1992).

### Categories

Gradually, as the theoretical coding continued, and I followed the method faithfully, recurring themes began to emerge. For example, the codes relating to a variety of complementary therapies at one stage seemed to be emerging as a category. However, with further processing and sorting these codes around complementary therapies became absorbed with another cluster centering on managing pain. Over time the code of pain clustered with other codes to become a recurring theme, the damaged body. The codes which clustered into this theme were:

Cause of injury

Incomplete

Body care

Exercise

Faster aging

Pain

Complementary Therapies

This particular theme grew to become a category, living with a damaged body. It developed along with four other categories which had emerged in the same way by clustering codes into themes. The five categories were:

Living with a damaged body

Discovering life

Generating family and social support

Seeking satisfaction from work and play

Battling the odds

Of these five categories 'living with a damaged body' emerged as the core process. This core process is the underlying principle which dominates all the analysis and links all the other subsidiary processes within an explanatory network (Baker, Wuest & Stern, 1992, p.45). In the case of quadriplegia living with a damaged body is the core process because it is the given which is unchangeable and influences all the other categories. Quadriplegia means living with a damaged body. Living with a damaged body influences what it means to discover life, to generate family and social support, to seek satisfaction from work and play and to battle the odds. In the following chapters these categories or core and subsidiary processes will be elaborated, explored and discussed.

From these categories a theoretical model evolved. This is explained and discussed in Chapter Eight. Because of their severely damaged bodies, the core process, all the participants are in a state of dependence. They all want to achieve as much independence as possible. The extent to which they accomplish this depends on how well they manage the four subsidiary processes, the categories of Discovering life, Generating family and social support, Seeking satisfaction from work and play and Battling the odds. Each of these four categories can be highly variable and can change from time to time because of factors both within and beyond the participants' control.

Thus there is a constant movement to and fro between the two states of dependence and independence.

### **Ethical Considerations**

This study involved collecting data from people who live in the community. The research focussed on the experience of nine people who are quadriplegic following injury to their spinal cord. Permission to conduct this study was obtained from Massey University Human Ethics Committee and from North Health's Ethics Committee. North Health is the Regional Health Authority with responsibility for the provision of community and hospital health care for the people who live in the region. Ethical approval was necessary from North Health because of the potential health needs of these participants, and because the Regional Health Authority sees itself as responsible for the ethical approval of health related research conducted within its geographical area.

### *Informed Consent*

The process of informed consent occurred in the following sequence:

1. The name of each possible participant was suggested to me by a participant.
2. Each possible participant was contacted by phone and asked whether he/she would be willing to consider taking part in the study.
3. If this person was interested an information sheet ( as appended as appendix A) was mailed to him/her. A few days later I consulted the potential participant by phone to see if she/he was willing to proceed as a participant in the study. If the person was willing I arranged to meet with him/her.

4. I visited the potential participant. The nature of his/her involvement in the study was discussed. The participant had the opportunity to ask questions and to have their questions answered to her/his satisfaction.
5. Informed consent was obtained from individuals in a written format, as attached in Appendix B. This occurred at the first meeting.
6. Arrangements were made with each participant regarding her or him receiving a copy of the findings of the study.

### *Confidentiality*

The interviews were carried out between each participant and the researcher, usually with no one else in the room. On two occasions there was one other person present, at the participant's request. Each interview was tape recorded. During three of the interviews there were several interruptions either by the phone, a family member or a visitor at the door. On these occasions the tape recorder was turned off during the interruption, but no participant requested that the recorder be turned off during the actual interview. Interviews lasted between one and a quarter hours and three hours in length. A coding system was used to identify the tapes and the participants and this system was known only to the researcher.

After each interview, the recorded data were transcribed by a typist, who agreed to maintain confidentiality, and had no contact with the participants. Names were changed to protect the identity of the participants. Any third party mentioned in the interviews is also referred to by a pseudonym. Sealed envelopes were used when transcripts were returned to each participant for reading. The completed transcriptions have been seen by

only my supervisor and myself. Tapes and transcripts were kept separate from each other and in secure locations.

### **Summary**

This chapter has focused on the research methodology as carried out in this particular study. Actual examples of data and of the process are included for illustration. There are sections on research methodology in general, grounded theory in particular, the participants and how they were selected, data collection and analysis, on coding and the development of categories and on memoing which is an essential aspect of this research process. Overall the theory emerges from the data in partnership with the ongoing process of memoing by the researcher.

Chapters Three to Seven of this report describe the findings of this study. Chapter eight is an explanation of the model which emerged from the study. The theoretical model of adjustment may be used by nurses and others to assist quadriplegic people as they return from hospital to live in the community.

### **Chapter 3**

## **LIVING WITH A DAMAGED BODY**

“I was on a ventilator at first because the lungs and the diaphragm weren’t working properly”.

### **Introduction**

Living with a damaged body emerged as the core process in this study; that is, the underlying principle which dominates the analysis. The body of a person who has had a spinal cord lesion resulting in quadriplegia is significantly different than it was before the accident. In this study this core process is unlikely to change. In the present state of medical science the damage caused by the injury to the spinal cord is irreparable and permanent. This chapter describes the participants and the details of their injuries, the nature of spinal cord lesions, their reliance on the health services, their everyday personal care, and their management of pain.

### **The participants**

The participants in the study were all active young people who were engaged in ordinary activities at the time they were injured. Each person told me in some detail about the cause and nature of the injury. Several participants discussed their experience of being near death, or of knowing that they were seriously hurt at the time of the impact. They did not always know that their injury was of a serious permanent nature.

They reported memories such as:

The first four days I was in x Hospital then I was flown by private plane to y Hospital. My sister accompanied me as she was a nurse. I had a little make up mirror so I could see the flight controls and panels, and that was fun, I'm a fairly active person, the plane ride was a lot of fun ... I don't think I was aware of the implications that my injury were about to bring upon me.

Because of the severe physiological and psychological shock of the injury, the participants often did not remember the first few weeks of being in hospital during which time they received intensive medical and nursing care. One person said that he didn't remember much for the first three months following "hearing a crack" (which I understood to mean the breaking of his fifth cervical vertebra) in what he described as a freak accident playing rugby . There is no doubt that the participants' injuries were caused by situations which were unexpected and for which they could not have been prepared. The impact of spinal cord injury is life threatening and life changing.

### **The Nature of Spinal Cord Lesions**

The participants taught me a great deal about the individual implications of the neurological damage to their spinal cords. Each of these nine people has a distinctively different pattern of sensation and motor ability as a result of his/her spinal cord lesion. As described in Chapter One, spinal cord lesions are classified as either complete or incomplete. Total loss of sensation and inability to move is the result of a lesion completely severing the spinal cord and is described as "complete".

Then participants were asked questions about the effects of their neurological damage, they tended to be very specific in their responses but at the same time found difficulty in finding actual words to describe their experience. The English vocabulary does not have enough words to define the subtle nuances of the different sensations experienced by the damaged nervous system. One participant said that he had very little feeling, and then said "I can't feel pain or anything like that, .... more just a touch really, and its very weak". He later described himself as being "a little bit incomplete, but pretty complete for my level of injury, which is about C5".

An incomplete lesion was described by a participant this way. He said that he was incomplete because he has some movement in his left leg at the level of C7 and on his right side he is C6. He said that he had feeling all over, and described the feeling as being like pins and needles all over from his chest down. He said that he had patches that had absolutely normal sensation experienced through undamaged nerves. In describing the control he has over his left hand, he said "it's not completely normal, its got normal movement but its only about seventy percent strength". He told me that he was left handed before his accident and added, "a spot of good fortune there". In comparison his right hand is affected to the point where he can't close it properly and can only grip a glass if he forces the glass into his right hand.

A participant with an incomplete lesion told me that when he dropped a pot of hot spaghetti on his lap he did not feel pain just "really uncomfortable". He also said that he can change his position when he feels pressure and admitted that having some sensation was an advantage. One of the women said that she has full sensation and this enabled



her to take very good care of her body with regard to pressure and other damage . Having any sensation is beneficial to the participants.

Changes of sensation are difficult to generalise following spinal cord injury especially where the lesion is incomplete. A participant described his experience with sensation. He said "its a funny thing, sensation. Its two different things. Before your accident and after your accident - your body's paralysed, it works but doesn't work. Hard to explain". This participant also told me of his spasms. He says he experiences more muscle spasm on his left side because of the incompleteness of his spinal cord lesion. He stated " .... if I have a spasm everything goes on the left, my leg will kick out and all my muscles and everything is a lot stronger, they've got more feeling because of the incompleteness of my break". His right side was "more complete", and he told me that the differences between the sides were hard to describe. Of the sensation in the complete side he said, "feeling dead is the only way I can describe it".

Sacks (1984), a professional neurologist and eminent author wrote about his personal experience of a devastating injury to his left leg. He describes his paralysed leg "*as if dead*" (p.43). He writes that it was the deadness of the muscle which so unnerved him, saying that the deadness was something *absolute*, not like tiredness and sickness. "It was as if dead, and not just asleep; and, being 'dead', it could not be 'awakened' - it would have to be - . . . - *quickened* - to restore it to life. Awake and asleep: the quick and the dead." For those of us who are not paralysed, having a muscle "as if it was dead" is difficult to appreciate.

### **Reliance on the Health Service**

The participants all told me stories of their experiences of the health services. These stories reflect the very best of the health service as well as the very worst. They span the phase of care immediately following the injury to experience in the health service as a consequence of recent medical problems.

### **Reliance on the Health Service - In the Beginning**

A young participant remembers his experience of being X-rayed on arrival in hospital. He reported to me that a doctor turned his head to the right and to the left and moved his shoulders up and down to get a variety of pictures. This doctor then told his parents that he either has “spinal shock or is putting it on”. Twenty minutes later, the senior doctor told the same parents that he “has broken his neck”. Given any possibility of him having suffered a spinal cord injury, the initial medical interventions he describes and the statement he reports as having been made to his parents by the junior doctor were both potentially dangerous and insensitive.

Three of the nine participants required medical and nursing care in an intensive care unit for longer than a few days but did not volunteer to tell me much of this experience. I did not think to ask and made an educated guess that they would have been acutely ill and probably have little or no memory of this period of time following their injury. I did hear statements such as “I was in ICU for a while because I nearly died a few times”. This participant acknowledged requiring ventilating because of respiratory difficulties, probably caused both by the high level of his injury and the presence of sea water in his lungs.

Several participants described doctors and nurses as being well meaning. The data indicate that while the participants appreciated what was done for them, they did not experience many health professionals who related to them in a sensitive way. Conversation with the participants indicated that doctors and nurses were unwilling or unable to share the sad fact that the permanent disability could not be cured. This inability leaves a gap between the patient and professional which can lead to patients feeling alienated and not cared about. The participants recounted many stories which indicated that being well meaning is simply not good enough. Choosing the appropriate language and timing is important when establishing interaction with a person newly admitted with a spinal cord injury. Two days after his injury, one participant was asked by a nurse if he wanted to talk about "grief". He told me that "she was doing her job but my experience with grief was death, and I got very upset with this. I'm not dead, I'm crippled and still alive". For this person, the nurse created additional distress for the participant, who was himself dealing with monumental difficulties.

#### **Reliance on the Health Service - In the Short Term:**

Coming to terms with the permanence of a spinal cord lesion takes time. Psychologically it is a massive challenge. One participant did not believe he was disabled until he was put in a wheelchair seven weeks after his injury. He told me that the nurses were all "pretty good". He also said that one nurse promised to take him out as soon as he got up in his wheelchair - and added "Unfortunately it never happened". It is a betrayal of trust when nurses make statements which patients believe, unless they can be fulfilled.

The physiological adjustment following spinal cord injury is also massive. The sitting up process is explained by one participant. She told me that it took three years to stop getting dizzy because the staff didn't understand that quadriplegic people can not be simply transferred from being flat in bed to sitting up in a chair. A quadriplegic body needs time to adjust from a horizontal position to a sitting position because of postural hypotension, and nurses should have an understanding of this. She explained that while she never passed out, she experienced being in a thick white fog. She said "I knew my way to the bathroom by instinct, not by seeing".

All the participants declared that health professionals have much to learn about interacting with persons who have a spinal cord lesion. For example, a participant ten weeks after his injury thought he had some feeling coming back into his legs, which can happen during the resolution of spinal shock. He waited to be sure before he mentioned it to the doctor. The doctor replied that that was great, "You will be able to tell when you get pressure sores". The participant thought his return of feeling was great news. He found that the doctor did not share his joy and his enthusiasm was crushed.

This same participant shared several stories of mixed communication with nurses over bladder and bowel training. He hoped for clear and accurate information and said that people should be treated as individuals. Treating individuals with respect has now been regulated as the first 'Right' in the Code of Health and Disability Services Consumers' Rights (1996).

Along the same line another participant said that doctors do not really understand - they have seen it all before. He said "It's like a woman having her first baby, and the midwife says 'everything is fine' - and the woman doesn't think it is. The midwife has seen it many times, but it's a first for the woman". Participants told me positive comments too, such as the appreciation of an excellent nurse who was the first person to say "I want to understand how you feel" instead of saying "we know what you are going through".

### **Reliance on the Health Service - In the Long Term:**

The participants spoke in terms of finding a suitable general practitioner. The participants who were receiving ACC (Accident Compensation Commission) funding went to their doctor every three months. "I go every three months just to keep ACC happy". For ACC funding to continue it is a requirement that disabled people must be seen by a doctor every three months and certified as still disabled. Other participants were glad to have not only a good doctor, but also one who is a good person. The participants needed medical assistance for colds, flu and other chest conditions such as asthma, as well as being available for anything which could go wrong in relation to paralysis. "My doctor here is really terrific, a great back up ..... she's also hard case, and just a year older than I am". It is important that people who live with a damaged body have a doctor with whom they can relate, and who will give them the medical attention they need. One person told me that he was slowly educating his doctor because the doctor had not had a quadriplegic patient before.

### **Medical Complications:**

To continue the review of what it means to live with a damaged body I will give examples from the participants of three areas of complication arising from spinal cord injury. These are the areas of urinary, skin and the injury site complication. Examples of these follow, to continue the review of what it means to live with a damaged body. The majority of the participants had had serious problems with their urinary system. One participant energetically told me that his life is dominated by urology. The range of urological problems included blocked supra-pubic catheters, renal stones, urinary tract infections, chronic wetting and autonomic hyper-reflexia and unsuccessful penile silicone implants (an attempt to establish the opportunity for using an external urinary drainage mechanism). These serious complications of a spinal cord lesion greatly influence the quality of life of the participants.

Several of the participants were strongly critical about the lack of a competent and reliable urological service for long term spinal cord injured patients. When problems occur, these people go to the Accident Departments, rely on family members or their general practitioner. The supply of equipment and regular bladder irrigations tended to be in the domain of District Nurses.

One participant reported having had major skin grafting surgery to deal with a pressure sore and to "pad my tail bone - cos I was very skinny". Another reported major spinal surgery to repair a dislocation of his neck several weeks after he came out of skull traction. These descriptions of the complications the participants experience as a result of their spinal cord injury illustrate the general theme that living with a damaged body

has enormous consequences for those with quadriplegia. Because of their damaged bodies there are continuing serious medical problems which often become chronic and severely affect the quality of their lives.

### **On Showering, Shaving and Excreting**

The hygiene routines of looking after our non-damaged bodies are learned as children, become automatic, and are considered to be private by the majority of people. Following injury, these nine participants were forced to accept that their intimate routines no longer existed as an automatic and private matter. When acutely ill and confined to bedrest as part of medical treatment immediately following a spinal cord injury it is simply impossible to do anything for oneself.

The nine participants told me details of their personal care. All were now less dependent than they were at the time when they were acutely ill. For example, all are now physically able to clean their teeth providing they can turn on and off the water and put the toothpaste onto their toothbrushes. The majority of these nine people can not use toilet paper independently after a bowel motion. All needed assistance with urine drainage such as a uri-tip (a urinary condom drainage system) or a supra-pubic catheter (a urinary drainage tube inserted through the lower abdominal wall) which drained into leg bags or night bags. One man explained to me that he had a 5 litre plastic container which plugged into his uri-tip so that he did not have to worry about some one having to empty it at four in the morning. The participant had had constant urinary management difficulties. During the interview he told me that whether or not he had a urinary leak was probably the most dominant factor for him. "It's on my mind 24 hours a day".



Dealing with the everyday automatic matter of urination, has for this man, become the major problem, which still dominates his life nearly ten years after his injury.

Showering, shaving and bowel management tended to be topics grouped together during the interviews. For each of these people, an episode of diarrhoea or constipation can become a major worry or actual problem. Lapham-Randlov (1994) writes that the regulation of bowel function and the prevention of constipation is an ongoing big problem. The majority of participants volunteered that they had found routines for themselves which minimized this potential difficulty. One participant told me that he did not use suppositories or anything, whereas some do. This same person told me several stories of how he and his attendant managed when the shower facility was too small for the wheelchair. "She transferred me in and out of the bath - and we did that every day.

Showering and shaving is a time consuming business. One participant estimated that three or four hours was necessary if he was alone and going somewhere important. This period of time does not allow for an unexpected problem either. He said, for example:

You might be leaning down to do up your shoe laces and your bladder wants to go and because there's a blockage and you're leaning on your tube, it blows up and boof it comes off and its back to square one, everything off, into the shower.

He told me that because he could not wash his back "once a week I have my attendant give me a back wash when I'm in the shower". Most abled bodied people perform these activities without a lot of concern in comparison with the time consuming and difficult



problems which are faced on a daily basis by this group of people who live with quadriplegia.

### **In and Out of Bed**

Two participants live alone and are able to move themselves from chair to bed and from bed to chair. Another two live alone and are unable to move themselves from bed to chair and vice versa, and have care givers to assist them begin and end their day. The participants who live with a partner or with family tend to be assisted by a family member. "My father puts me to bed at night and that has not been easy". Other participants told me how family members either transfer (a learned technique either using a sliding board or a standing procedure) or "carry me like a baby" when they go to bed.

### **Living with Pain and Managing the Pain**

Pain is a very significant problem for several of the participants. According to France & Krishnan (1988) pain is a secondary phenomenon for a proportion of people who have a spinal cord lesion. The actual mechanism of what is termed central pain in spinal cord lesion patients appears to be unknown, but evidence suggests a loss of descending inhibitory influences and the loss of sensory inputs. These writers state that there are three types of pain reported by people who have a spinal cord lesion. They are:

1. Phantom body pain in areas of complete sensory loss.
2. Visceral pain, which is associated with abdominal fullness, or sensation in the hypogastric area.
3. Root pain, which is located near the level of the spinal cord lesion.

It is reported in the literature that twenty seven percent of paraplegic patients complain of some type of pain below the level of injury. Of this twenty seven percent, between five and ten percent report that the pain is severe central pain. It is acknowledged by France and Krishnan (1988) that the pain experienced by patients with a spinal cord injury is remarkably varied and individual and is therefore difficult to treat by the usual pain management methods.

Several of the participants in this current study experienced pain. One said: "I can be in pretty excruciating pain, which I was in last night, and I still go out to rugby and charge around there, because it beats sitting around thinking about it". Later he told me that he feels stupid going to his doctors with pain and the doctors "shrug their shoulders and say there's not really a lot we can do for you".

As well as the central pain described above, several participants told me about their management for pain above their level of injury. This pain could be understood as being caused by overuse and unusual positioning of joints and muscles, as described in chapter one. One participant told me that her brother had been giving her acupuncture for her painful shoulder. This participant also told me that her degree of sensory feeling is such that at times it is painful to be touched and she expected this to get worse as she became older. Another participant discussed the differences between osteopathy, chiropractic treatment and massage. He had found "massage to be very helpful" and another had found that chiropractic treatment had been beneficial in reducing spasms and increasing his flexibility.

One participant was very active in managing his pain. This man had discovered a clinic in California for “rebuilding paralysed muscles”. He had arranged to visit this clinic in 1992 after raising the necessary \$90,000. He said “you get very stiff and very sore, you get in so much pain and this relieves me a lot, just total pain relief after you do a full session”. A full session, completed on most days, included a programme of muscle stimulation “just to keep my muscles like normal ... and to keep my bones strong. ...” He also has a standing frame and likes to stand every day, “to prevent osteoporosis which is a very big worry for people who have a spinal cord injury”.

One participant told me that pain was the major difficulty for him. “It can really alter my day”. This person has been assessed and treated by the hospital pain clinic without success. He described being referred to a psychologist who recommended self hypnosis. “You spend an hour listening to a tape telling you that you’ve got no pain. You turn the tape off and I’m sure I can feel pain!” This man requires MST (morphine) for pain relief three or four times a week. He said,

MST gets rid of most of the pain .... it’s still a hard day because I’m under the effects of MST ... I’m fairly well disciplined ... I deliberately go without it some days to get back in touch with my real body”.

Pain is a consequence of a damaged body and living with severe and/or chronic pain makes life very difficult and is a constant challenge for these people.

**Conclusion**

This chapter described living with a damaged body as the permanent consequence of quadriplegia resulting from a spinal cord lesion. The severity of damage caused by cervical spinal cord injury was emphasized. The chapter contained sections concerning the participants, their level of injury, the variation between complete and incomplete lesions, the participants' reliance on the health service, their every day personal care, and, finally living with and managing pain.

## **Chapter 4**

### **DISCOVERING LIFE**

**“the old life has died”**

#### **Introduction**

In this chapter I discuss the aspect of adjustment which contributes to the participants discovering of life in spite of living with quadriplegia. The data in the present study indicate that the adjustment to quadriplegia is massive. There is a major challenge as participants are forced to move from their old self identity as able bodied people to their new identity. In overcoming this challenge they are able to accept living in the future with a permanent physical disability. This chapter includes sections on the participants' expectations before injury, the transition to their altered life and the benefits they had achieved.

Benner and Wrubel (1989, p.313) discuss the challenge people experience with illness when it is of a neurological nature in comparison with illness in general. People with neurological illness sustain damage to their “selves” in a way that does not occur with illness in general. These writers conclude “Even if the personality and linguistic abilities are spared, there can be motoric or sensory damage, damage of the sort that makes people feel that they are trapped in someone else's body”.

The participants in this present study all had significant motor and/or sensory damage to approximately eighty percent of their body. The adjustment process is massive for them. It was my observation that the challenge the participants faced was beyond words and for some of the participants beyond their awareness.

Perhaps this process of adjustment can be compared to that described by Sacks (1995, p.134) who discusses the demands in people who are newly sighted as a result of medical intervention. ".... learning to see requires .... a radical change in psychological functioning, in self, in identity. The change may be experienced in literally life-and-death terms." A patient is quoted as saying "One must die as a sighted person to be born again as a blind person or vice versa.... It is the interim, the limbo - 'between two worlds, one dead / the other powerless to be born' - that is so terrible."

Sacks suggests that although blindness is at first a terrible loss, it may become less with the passage of time. He also indicates that a process of deep adaptation or reorientation occurs and that this may result in a different form of being (Sacks, 1995). The depth of psychological adjustment may be similar for those with quadriplegia and more research is required in this regard. The participants in the present study have progressed through the stage of being 'between two worlds' as described by Sacks and it is my view that for some of the them this stage might have extended for several weeks immediately following injury.

The notion of preserving self was explored in a study by Morse and O'Brien (1995, p.894). These authors indicate that tremendous effort, energy and will are required by

anyone who recovers from injury and must then accept the role of a disabled person. It is suggested that this process of preserving self is directly related to the degree to which rehabilitative efforts are successful.

### **Pre-Injury**

All of the participants told me something of their lives before they were injured. Without exception they were active young people. They seemed typical of people of their age group. For example, "I did my apprentice [ship], lots of hours and very interested in nice cars and stuff". One of the women had imagined that she would become a bride and have children. She said "I presume this is exactly the way my life would have gone - I probably would have got pregnant through sheer ignorance ...". A young man was boarding with his aunty down south, and had been working in the local freezing works for five weeks ... "then I had my accident". Later he said "I was an outdoor person - I lived for sport".

### **From the old life to the new life**

The data provide descriptions of a variety of experiences in this category which explain the transition from the old life (i.e. before injury) to the new life with which the participants were faced afterwards. One participant said that she was "still me". She insisted that she was still the same person and doing the same things. She said "Most people around me do more adjusting than I do".

In contrast, another participant told me that the adjustment for him was "like the old life has died". For the first couple of years he did not want to know about the future.

Another participant said “ .... you have two lives, it's like dying and being reborn again into a completely different life. It's the before and the after and you're two people. One has nothing to do with the other”.

One participant had a very succinct answer to the question concerning this adjustment “If you lose something, you gain something”. He described that while he knew that he has lost his ability to walk and run as a result of the accident, he had gained an ability to discover and to extend other parts of life such as art and ‘quad’ rugby.

Another participant spoke at length about the adjustment process following his injury. He said “ I knew that it wasn't the end of the road, it was just a new road that I had to take”. This young man set goals for himself during his physical rehabilitation. He said that he would do what his body would allow him to do. He worked on little parts at a time to “build on your successes”. He knows his life expectations have changed because of his injury. He said “Pre-injury I took my life for granted”. Now he has had to learn how to cope with how his body works and how to get on in social situations. He described his pre-injury life by saying “I was in my other world” with regard to a circle of friends. Now his major concerns are his health and his dignity. His accident had made him grow up pretty quickly “if you are young at the time of your accident you really have to become your own master at possibly an age which you wouldn't normally, so that you can have a quality of life ...”.



### **Discovering life - the process**

The data indicate that either participants had a lot to say about their adjustment process or did not appear to understand the issue. One participant told me that the best psychological help he received came from his brother who was a Jesuit priest. He remembers an occasion about two months into his rehabilitation programme when he “hit bottom”. The staff believed that he was a suicidal patient. He told me that given his religious background and belief in life, suicide was not an option. However, the staff contacted a psychologist who came in, but “I believe I was more screwed up after he had come and gone than I was before”. This participant then rang his brother and said “I need help”. As a result of his brother’s visit, a past patient with a similar injury was contacted to visit. This participant told me “... he came in and saw me and he was running his own farm ... I saw hope again, I saw what I could do rather than trying to work out what I could do when I didn’t even know where the heck I was or where I was going ...” His brother’s response initiated the new beginning of enabling this participant to see that he could have a future life.

Another participant shared something of his adjustment process with me. He said, “I used to write it down when things went wrong, until I decided that it probably wasn’t a good idea as it was probably encouraging things to go wrong.” This man was able to reflect on his transition from the early days when “I’d much rather have been completely out of it and to hell with the whole deal” through to having “a pretty good lifestyle now”. His transition included five years of psychotherapy which was “all hard going”. He told me that he needed lots of assistance with his changed body image and self concept. He strongly recommended that people need psychological help from therapists

following spinal cord injury. He said "you still get the silly macho image that they will not talk to these people, they say they can sort themselves out. Well, there are a lot of things you can't sort out yourself, you need help".

One of the woman participants had received books and videos from her sister and uncle which had helped her a great deal. In particular she had found the works of one popular writer very helpful. She described John Kehoe as "a brilliant man" and since reading his books she has changed her outlook towards being more positive about life. She told me, in a very positive manner, that as a result of reading Kehoe's work her motto now is, "No problems only opportunities". Kehoe's book (1989) is a self help manual aimed at assisting people to create new realities for themselves. This is an example of bibliotherapy where reading can be a helpful contribution to assist people who are facing a major challenge in life. In a study on bibliotherapy Cohen (1994) found that "the experience of therapeutic reading was marked by a recognition of self, evolving into ways of feeling and ways of knowing" (p.41). Nurses might make more use of sensitively recommending appropriate literature as they implement care for people in their practice.

In contrast, one participant reported that he made up his mind to "get on with it". He left the hospital early and made arrangements for his physical training in his own way. He arranged for many volunteers and paid care givers to exercise his damaged body for many hours each day. His past and present determination to develop his muscles is very impressive and this determination appears to me to have strongly influenced him towards his discovery of life, in spite of his damaged body.

The participant who was injured many years ago believes she has survived because of her independent spirit. She thinks that a lot of people would simply have given up, especially the battles of pneumonia and bronchitis. When the going is tough as it has been at four in the mornings, "you just don't give up". She also told me that she has been helped a great deal by people coming into her life to "push me further". This has meant growth and life for her. She has said 'yes' to these psychological growth opportunities and believes that "this is the way life is" and it has nothing to do with her disability. All people can say 'yes' or 'no' to life. It is my view that this fundamental choice which people have, that is, to say 'yes' or 'no' to life's opportunity, is a topic worthy of future investigation in nursing research. (See section - Choosing Death in the Literature Review)

Several participants appear to live one day at a time. The data indicate that for these people, 'one day at a time' was how they managed themselves, especially in their early days at home. Living with a damaged body creates huge difficulties for the participants, and in my view the current and the potential problems for 'today' are more than enough to face on a single occasion. It is as if the unknown and potential difficulties which may arise 'tomorrow' can not be faced today. Other expressions which support this concept are "I take things as they come along" and "I have to be flexible". Living one day at a time may well be an approach taken by many able-bodied people too. This was one of the findings in the study done by Brown and Powell-Cope (1993) with family members of a person with AIDS.

### **A better life:**

One of the participants surprised me when he said that he had a better life now than before his injury. He said that he appreciates a lot of different things, especially interaction between people. Before his accident he said that he took life and people all for granted. Now he deliberately chooses to do things which he enjoys and gets something from and he avoids places and people which annoy him or make him angry. He explained that prior to his injury, he was non-selective and did not make choices about his activities, but rather just participated as things happened around him. This change in life position could be examined from the psychological theory of external versus internal locus of control (Wade & Tavris, 1993, p.545). The term internal locus of control means that individuals have internal authority for decision making and meaning and when this sense is gained from an outside authority, the phenomena is known as an external locus of control. Richmond and Metcalf (1986) suggest that one strategy which nurses can use to assist a person with spinal cord injury is to work on external language patterns (such as, 'they made me..') to ones of ownership and responsibility. An internal locus of control tends to increase one's self control and self esteem.

During the data collection phase, there was a story in the local paper concerning a man who had survived an horrific air crash. This man, who was reported as being a committed Christian before the plane crash (NZ Herald), says that, if anything, his faith has been strengthened since he sustained a spinal cord injury.

A lot of people ask 'why do these things happen?' but that's never been an issue for me. God doesn't pull strings and control what happens in this world. In a

funny kind of way I'm sort of thankful that the crash has happened, because a lot of things have happened in the last few months which would never have happened before. New opportunities have arisen, especially opportunities to talk about spirituality, and it's been a wonderful chance to take stock of my life and reassess it completely. It's been good.

In discussing, why bad things happen to good people, Kushner writes (1980, p.46) that nothing makes bad luck happen, things just happen, because of the way the universe is. The universe has a few rough edges. Kushner does not believe that when bad things happen, they are the will of God. Kushner's view appears to be increasingly discussed in popular literature today, as people struggle to understand the nature of why nasty things occur within our universe. Years ago I heard a talk given by Ivan Illich where he suggested that in general people expect life to be easy and when something difficult happens to us, we appear to have lost the art of suffering. There is an art to live with a difficult situation.

Wane (1996, p.19) discusses a television series *Against the Odds*, which tells the stories of a number of New Zealanders who have survived, life-threatening trauma. The producer of this programme calls this ability, the survivor mentality. "It's something in their make-up," he says. "Courage, faith, endurance, integrity - they all had some special quality which carried them through". This so called 'survivor mentality' is limited to the acts of survival and is not necessarily the same as the ability to benefit from the traumatic experience. Wane introduces her article with a quote from the 19th century philosopher Friedrich Nietzsche who said "That which does not destroy me, makes me stronger." This view is supported in the same article by Barry Kirkwood, a senior lecturer in

psychology at Auckland University who believes that "One of the things about adversity is that people drop petty concerns and sort their priorities out." The present study provides some evidence that this is true.

## Conclusion

This chapter has included discussion on the process of discovering life. This is an important adjustment when living with a damaged body following spinal cord injury. There are many unanswered questions about this process and further research would assist nurses to participate in it. For example, in the matter of timing interventions, Price (1996, p.278) suggests that because individuals with chronic disabilities tend to focus their sense of identity on their body disfigurement they must first come to terms with this change. He writes "... that efforts to help patients refocus on other attributes, skills and personal appearance may be premature until such time as they have worked through grief for their disability".

The writing of Moore (1992, p.5) is helpful in this study. In discussing 'the care of the soul' he defines care this way:

Care is what the nurse does, and "nurse" happens to be one of the early meanings of the Greek word *therapeia*, or therapy. ... *Cura*, the Latin word used originally in "care of the soul", means several things: attention, devotion, husbandry, adorning the body, healing, managing, being anxious for, and worshipping the gods.

Whether we think of the process of "Discovering life" as having to do with 'the soul' of a person, or whether we think of it in a more holistic way, there is profound relevance

for this study in these early meanings of the words 'nurse' and 'care'. To nurse people who live with quadriplegia to come to the point of 'discovering life' is a challenge which is not easy, and requires nurses to have a deep understanding of the processes involved. This nursing expertise is essential if quadriplegic people are to move towards maximum independence.

In the next chapter, the findings concerning generating family and social support will be discussed in relation to quadriplegic people moving towards independence.

## Chapter 5

### GENERATING FAMILY AND SOCIAL SUPPORT

“Everybody’s got to change”

#### Introduction

The last chapter discussed the connections between living with a damaged body and the adjustment process of discovering life, as quadriplegic people move towards independence. This chapter examines the category concerned with generating family and social relationships, including primary relationships and/or marriage. The chapter is ordered in sequence from the time of the spinal cord injury. It is important to note that this chapter contains the perspective of participants only. In a future study it would have been useful to explore issues of relationship from the perspective of family members. Intimacy and the need for intimacy was disclosed by only a few of the participants.

#### In the Beginning

Participants were asked for their opinion of the effect of spinal cord injury on their immediate family. I heard very graphic descriptions from the participants. There is no doubt that spinal cord injury resulting in quadriplegia is a huge challenge for members of the immediate family. Examples of these challenges are:

“My father was devastated really, hit him like a ton of bricks, he’d lost my mother about a year before ...”.



"My wife was good in the beginning - she sat at the bedside and did all that sort of stuff. It's tough on the family ... because before, you are independent and adult and don't need much in the way of help like you do now".

"It must have been a hell of a strain, my dad is a self employed builder and mum used to do the odd jobs and stuff. I've got a twin sister and I think it knocked her around a bit ...".

One participant told me that his injury had brought his family closer together. He remembers his aunty "racing off to buy a book" and learning about people with special needs generally. He told me about the hopes his father had for his sporting achievements, being a top New Zealand player in his sport and the difficulty his father had in approaching him after the injury, as if he was "afraid of the situation".

One participant was adamant that she "wouldn't have got here without my family and my daughter". She reported that she was injured in a car accident caused by a drunk driver. She explained that there was a long waiting period "to see if I was going to make it". Her whanau (family) slept "all over the place" at the hospital and they found this awkward and very uncomfortable because of the presence of security staff. Later, family members reported to her that they did not feel welcome at the hospital. She herself remembers that hospital staff did not want her family around, however, she said to me, "when you do get an injury, you need that constancy of family and feeling like at home, the more you've got that around the less likely you'll give up hope". In relation to the accident she spoke, at some length, about the male members of her family needing "to have someone to blame". It seems as though being able to blame someone for the accident legitimated the release of anger in the men of this family. She said that her

family placed blame on a certain person external to the family and feelings of hostility towards this outside person lasted for a long period of time. This process was confusing and difficult for her because “they took it so hard and ... kept digging up the past”.

Towards the end of the second interview, she told me that her family members had recently cleared up a lot of the difficult confusion concerning blame, in relation to her accident. Now her family are able to function toward her in a healthy and supportive way.

### **In the Short Term**

For the purpose of this section, the short term is defined as that period of time immediately following the participant's discharge from inpatient services. The participants told me of many experiences which reflect very strong connections with their families and of the hard physical work demanded from them. One participant was 14 years of age when he went home from hospital. There appears to have been no outside help for his parents. He said “Dad sort of went to work so it was basically mum that was there the whole time”. He deeply appreciates how hard it would have been for his mother to look after him at that time. He said: “Then we had heavy wheelchairs and stuff and lugging out of the cars, those big old bloody chrome hospital things, not like the nice lightweight ones that are around now, it must have been hard”. Later he spoke of his mother as a “great person”.

Most of the participants told me of how family members had changed as a result of the injury. As highlighted at the beginning of this chapter, one woman said “Everybody's got to change, do things differently, handle situations differently. I've had a lot of

support from my family and my friends". Another put the same notion this way: "Everything is different and everything was different for my family members too". Later he said, "I get on well with my brother now because of the injury. He helps me from time to time. Not that we have ever been close, but we are closer now because of the situation I am in".

Another participant, said that his family had a lot of new things to get used to, and it was really hard on them. There were battles to fight and things to find out. He spoke of his two sisters who helped him a lot, even though one was still at school. After discharge from hospital, he went home to his mother's house which was a rented property and so couldn't be altered in any way. He said that it was a big old house, "totally inaccessible really" - the entrance was inadequate, there was no space in the house for his wheelchair, and no suitable bathroom facilities, but there was a spa pool which was a help.

One participant fell out of her chair and was on the floor for four hours soon after she came home from hospital. On that occasion she was home alone. Since then the family always have someone at home just in case she falls again.

Two of the participants were parents at the time of their injury. For both these participants, the children were cared for by members of their extended family. It seems that very young children have little trouble accepting a parent using a wheelchair. One father said of his younger son, "He has never known me any other way than in a wheelchair, so he has always been all right about it". This father thinks there could be

other effects on his two sons later on, but is not sure what these might be. He said, "They are very normal sort of kids". Long term effects on children which relate to the injury of one parent would be an interesting study, but difficult to investigate because of the many variables which impact on family life and on the development of children generally.

### **In the Long Term**

In the main the participants reported that their families had developed satisfactory patterns of supporting and relating to them. However, there were great differences in the frequency of contact and the activities which took place. All participants told me that they had very supportive families, in spite of the differences of family involvement. More investigation is required to fully discover the type of support and activity which is useful in enabling the families to contribute to the independence of the person with a spinal cord lesion.

One of the participants told me that he was still getting considerable support from his parents. They visit him every other day, and they all play indoor bowls together every week. This man found his activity at an able bodied club to be very useful to him. He had been asked to be on the committee and takes part in all the activities. Even though he played differently, he can play the game just as well and that was a release of tension. He said "Some times I sort of think it's too big an effort to go along, but as soon as I get there the feeling overwhelms me of support and encouragement".

Not all the participants had the same support locally. One told me that family members were available for him. He said, "we always keep in contact". On further inquiry, he told me that none of his family were local but some of his social activities were family occasions and his sisters would come and see him from further north.

Several participants have family members living in the same area of town and spoke of the kind of help they receive. This ranged from, "Dad helping with building jobs", to ".... uncle mowing the paddock and .... grandparents bringing vegies, a bunch of beans or a bowl of passion fruit or what ever out of the garden ....".

For two participants, who were Maori, the proximity and involvement of family was reported as being very important. "I've got a good support unit, . . . my family, my mother, my brothers and sisters .... my brother has just moved down the road from me, everyone's sort of close enough." She then told me about her little sister as being "hard case" at aged 13 and said that "she's good help". Later when asked how she spent her time, she said "I spend a lot of time with my family".

One of these two participants told me that she was the eldest of three siblings and as well she had an older half brother and sister who live in one big family with "Mum". She said that her mother and her brothers keep a good eye on her and she had plenty of male friends. She considered them all "mates" and they were all protective of her. She liked her "mates" as a group and it is her brothers who do transfers (techniques to assist a quadriplegic person to move from one position to another). She said "A lot of the transfers that I learned I don't really use. My brothers find it easier to just pick me up. They literally can just chuck [throw] me". She admitted that her small build was an advantage for people except for her mother who is shorter so her mother "sort of does a transfer - I go over her back".

The most profound data in the area of family support came from the woman who has been quadriplegic for many years. She had not lived with her parents since leaving hospital. She said that after she moved to her present house she was used to her parents "popping" in to see her every week. They would usually bring her some vegetables. This participant told me that she wanted to "give them their freedom from me" and wrote a letter to them. She was seemingly aware that her parents had been as supportive to her as they could be and now that they were older she chose to inform them that she was no longer dependent on them. She told me that she wrote about the fun things the family used to do, especially the memories she had of family holidays. In this letter to her parents she reflected on the period of life with her family. Then she told me that she next wrote "at age 16 I had my accident". It was as if she was unable to share in this letter to her parents anything about the effects of her injury on her adult life. She had simply decided that life with her parents at a meaningful level, ceased at the time of her accident. In this sense I wondered whether her accident years ago was more than the family could deal with. Perhaps her situation had never been a family conversation. A month after her parents received this letter she was surprised and amazed when they put their house on the market and moved to a smaller city further north. A year later her mother died which she said was "the real pits" for her. At the time of the interviews, she told me that she rarely sees her brother because he is so busy and her father visits occasionally when he is in Auckland. However, she said that her father (now aged over 70) had become closer to her since his wife died, in the sense that he rings more frequently.

## **Primary Relationships**

This section deals with the data concerning the special relationships of the participants. Thousands of years ago, it was recognised by the ancient Hebrews that “It is not good that the man should be alone ....”(Genesis, 2:18). In more recent times, developmental psychologists have written about relationships and the need for intimacy during the stage of life which is referred to as early adulthood (Erikson, 1963). The second part of this section will discuss the kind of accommodation in which participants and their partners lived at the time of this study.

## **Intimacy and the like**

Each of the participants was injured at the stage in life when primary relationships are being established. The data suggest that relationships are very important to these people. A spinal cord injury is a test to any relationship, for the obvious reason that there is an unexpected change in one of the couple and that the life of the other cannot but be significantly affected by this unplanned change.

The desire for a soul mate was shared with me by one of the participants. He travelled overseas with his parents for a family reason, but his private reason was in the hopes of developing a long term relationship with Sarah (pseudonym), his “special woman”. For eighteen months before Sarah left for her overseas experience, he believed their friendship to be “terrific”. When he and Sarah met overseas, “we hit it off within thirty seconds, back on a beautiful relationship, it was really neat, we had a great time ....” and then he had to come home and Sarah remained overseas. This is a fairly common situation for young people since relationships are usually complicated in some way for most people. This man believed that Sarah loved him, and that she would come back.



This has not been the case. I asked him whether he thought this was the nature of the relationship or was it linked with his disability. He replied strongly:

Oh no, it's the disability. There is no other reason. She was told by her parents ... you don't want somebody like that, you want a normal person, ... you don't want somebody that's going to pull you down ... it was her parents that said no.

All he wanted, he said, was "I wanted to be her friend, I wanted her to be mine ... to have a friendship". This participant has a philosophy of life which focuses on interaction with other people. He believes that life is not for individuals, but that life happens when interaction occurs between people - family, friends, and a soul mate. He remembers this friendship as containing "magic", as well as a lot of understanding.

A relationship which is described as containing a miracle, was reported in the New Zealand Listener recently, and reads as follows: "In the best of romantic traditions, the couple fell in love ... I never saw his disability as being a problem because it wasn't to him" (Wane, 1996, p.20). Wane describes the miracle within this relationship as being the birth of their child. Intimate relationships for people who are quadriplegic and the degree to which disability is perceived to be a problem within a relationship are two topics worthy of further study.

One participant was married at the time of his accident. He told me:

Well I think the breakdown was related to the injury - but how would I know for sure? A bloke likes to think that his marriage won't end so there is a bit of self protection in my belief. ... I was pretty low at the time about everything and she decided that she could not hang in there so it was a pretty rough time.



participant contributed a sense of joy and happiness to the data. I asked him when and Gillian (pseudonym) were married. "About six weeks ago" was the response. I told details of their wedding in which their small daughter was flowergirl, and was seen in the photographs. He told me a lot about his relationships both before and after accident. About the time of his injury he was engaged to be married, but this relationship did not last. Again, further investigation is necessary to understand the nature of this breakdown and its relationship to spinal cord injury. Gillian came into his life as a care-giver while she was a student nurse. He told me that their relationship developed about a year after they first met. Since they met, Gillian continues to be his care-giver and she has also been his fiancée, his wife and the mother of their daughter. I was asked about how it was to have Gillian being his care-giver as well as his wife. His reply was "We do get on good, it wouldn't work if we didn't". The role of care-giver is dealt with in another chapter, and the complexity of care-giving being provided by a significant person in the life of the disabled individual is discussed later in this section. I consider it a privilege to have met this delightful trio of people. A memo written the day of the first interview reads: *What a lot Gillian has to do but they are a delightful family who are really positive about most things.*

In sad contrast, when another participant was telling me about being more lonely now that he lives alone, he told me that it had been over 10 years since he had been "out with a girl" and that "I would love to have a girl-friend". The data indicates that where intimate relationships exist for quadriplegic people, there are additional relationship difficulties involved. However, for those people who 'wish' to have a 'special friend' the data indicates that creating a relationship is extremely challenging.

### **lating with care-givers who are friends and family**

gers (1986, p.151) writes about the "army of unpaid workers" who provide the bulk care for a newly disabled person following discharge from hospital. Rogers emphasizes that it is only the wife, the husband, the mother and the father, and other close friends and relatives who provide the care which is required twenty four hours a day, three hundred and sixty five days a year for a severely disabled person living at home. Several of the participants in this study had arranged to have family members paid as their care-givers. In other arrangements it seemed to be that the money for care-giving (provided either by ACC or another Government agency, discussed in a later chapter) became part of the family income and went into a common financial pool and any family member provided the care. For example, one participant told me that Gillian provides him, and their daughter, with full-time care-giving twenty four hours, seven days a week. She is paid the care-giving money and he said "Luckily I had a good job so I'm on Employment Related Compensation".

Two of the participants, both Maori women, told me about members of their extended family being their care-givers. These people included cousins, a step-sister, an aunty and a mother. Both indicated that they were grateful that they did not have to employ outside people. For example, one said "I've tried nurses in the past, but it didn't work mainly because its harder to tell a stranger what to do - I know my family and they know me". The present study did not extend to interviewing these family members who acted as care-givers. There may well be cultural factors in all family arrangements but determining that is beyond the scope of this research.

The data indicate that sometimes there are unclear boundaries between care-giver and friend but there is no evidence to suggest that this lack of clarity creates any difficulty.

Several discussions provided data which very clearly show that from the perspective of the participant, the blurring between staff and friend was not considered. In responding to questions about receiving care, one participant said that his partner puts him to bed, and gets him up and the funding agency "doesn't really know it's a relationship, they just think she works here". Later he added " ... that works out well. I've got her around here most of the time and stuff and so I can do heaps and she's just part of it. I've got a lot of people that I use as well." When asked whether these people were staff or friends he said, "I suppose technically they're staff, I never see it as serious enough to see it as you're the employer and they're your staff you know its more like a friendship". Even though these people get paid for their care-giving he considered them all as friends. He seemed to thrive on contact with many people. "I use various people ... student job search and those sort of people come for a short period ... then they go and you get someone else".

The employment and management of care-givers tends to be more difficult when care is not provided by family members. This topic is dealt with in a later chapter, titled Battling the Odds.

## **Housing**

Nelson (1990, p.106) writes of people 'being launched' into the community, which implies that people with a spinal cord injury have a home to go to on discharge from

hospital care. The data provide evidence that housing was not a straight forward matter for the participants in the present study. Accommodation for these participants naturally depended on their social relationship at the time each person was released from hospital accommodation. Two of the participants were in hospital accommodation for years following their injury, and a third was in a "hospital unit" for several months before going home to her parents. The data show that the need to change accommodation is a common feature for people after they become quadriplegic. Generally the determining factors were the need for optimal access for a wheelchair and appropriate bathroom facilities.

Currently, two of the participants live with partners. The other seven either live alone or with their extended family. Sometimes finding a house which is suitable is easy. One participant told me that he had an application in with the Housing Corporation (Government agency) to get rental accommodation and then

... out of the blue me and .... my girl friend .... got a letter saying that they had something for us .... bloody amazing as the whole place is set up, we didn't have to do a thing ... that was seven years ago".

This house had been bought from a family who had a daughter who used a wheelchair. The house was equipped with a wheel-in shower and ramps.

One participant and his wife live in a house which they have designed and built themselves. He said,

We went flatting first ... I had my deposit (lump sum insurance payment) from when I first had my injury. So that was the deposit on this land. ... it was a lot of

work ... luckily I had building experience so I did my own quote and I did the supervision of the building.

He described it as being fully accessible without looking as if it had been built for his wheelchair.

The accommodation for the rest of the participants ranged from a large purpose-built house complete with an internal elevator, to rental units from the Housing Corporation which were minimally accessible for the wheelchair user. One participant said that the Housing Corporation was putting the rent up again and that the only chance he had of owning his own house would be to win Lotto (a gambling game of chance) and if that occurred he would not hesitate to purchase. Another participant who does own his house said that his parents gave him very good advice by encouraging him to use his lump sum insurance pay out for a deposit, and "it was the best move that I ever made".

It is obvious that housing is not a straight forward matter for quadriplegic people. It is not easy to alter an existing house so that it is suitable for a person who uses a wheelchair for mobility. The planning and building of a purpose-built house is easier when the land is level, but usually flat land is more expensive and difficult to find. There are many details to be considered. For example, an external entrance without steps, for wheelchair use, must be designed in a way which avoids rain water entering the house. The importance of toilet and bathroom facilities being suitably functional for quadriplegic people can not be over emphasised. For example the toilet chair must fit exactly over the toilet whilst being used.

## **Conclusion**

This chapter began with a discussion about the immediate effect of the participants' injuries on their families. According to the participants in this study, their families experienced a great deal of difficulty at the time of their injury, but also rallied to provide much appreciated support for the participants which became ongoing. The short and long term effect on family and primary relationships were discussed. In general terms, there are added difficulties to the complexities of normal relationships because of the complications of one partner living with a damaged body. Satisfying the needs for intimacy was a concern for several participants. Housing and the complex overlap of the care-giving role by family members and friends concluded this section. Suitable accommodation, family and social support are very important considerations for individuals who are living with quadriplegia as they move towards independence.

The next chapter discusses the importance of work and play in relation to quadriplegic people who are aiming towards independence.

## **Chapter 6**

### **SEEKING SATISFACTION FROM WORK AND PLAY**

“I’m not satisfied with just sitting doing nothing”

#### **Introduction**

This chapter discusses the data which relate to the seeking of satisfaction from work and play as people with quadriplegia live between the states of dependence and independence. This category includes preparing for a financially rewarding career and participating in a rich and full social life including sport, travel and other activities. The data provide evidence that the participants are involved in activities which are moving them towards employment and challenging leisure activities. However, it is significant that none of the participants was in employment at the time of this study.

#### **Working before the injury**

Prior to injury five of the participants were in full time employment, and two others had definite plans for training for a particular job. The two youngest participants (at the time of injury) were students at high school. The industries in which they were employed included construction, insurance, freezing works and manufacturing. All five reported that they were certain they were now unable to continue in their previous work. One participant told me that he had had to find out the hard way that he was unable to continue his former occupation. He had returned to his business six months after his injury and experienced difficulties for the next 18 months. He was adamant that he had gone back too soon. Initially he thought his work would to some degree fast-track the process of recovery from his injury. He now sees that he went back to work before he

was ready and was unable to function because the stress of meeting his former clients was too great. He had not been able to respond to their concern about his new situation and therefore was unable to manage their customer needs in an adequate manner. This man now advocates that first priorities should be on practical skills such as driving a car and dealing with social outings, rather than getting back to work. He has not returned to business, even though this type of work may be quite possible for him to accomplish. I did not ask him why he had not returned to his former work.

### **Preparing for a financially rewarding career**

Two participants are both preparing to make their living through painting pictures. Both currently have scholarships with an overseas organisation for Foot and Mouth Painting and are hopeful of becoming successful. One has been painting for four years and is appreciative of the help and encouragement he had received from a local artist. "She built this big studio ... and I go down normally about nine o'clock in the morning and paint until about twelve thirty every day with her". Later in the interview, he told me that he had been "pretty arty" at school, but had never developed it. After his accident he went back to High School and did School Certificate Art, drawing with his hands, but it was always a bit tricky ... I had trouble holding things properly and then my mate Sam (pseudonym) said you should have a go at painting with your mouth and I did this and I had a hell of a lot more control over the brush. Both these participants are hopeful of becoming financially independent through their mouth painting.

One participant was preparing to go into the army before her accident. She received her notice of acceptance "the day I sat up after the accident". At present she does not have



any long term plan but works for the family transport business as she is needed, doing the dispatch work from her home. She is also doing a correspondence course in commerce to gain a qualification.

Three participants were either studying or talking about wanting to study. One is a business student at university and hopes to work in an audit company before becoming a consultant. This person is convinced "the ACC money won't last". He told me that at present the ACC money is all right, but it will not last forever, because the country will not be able to continue to afford it. He thinks there are likely to be more people who will need funding as a result of a spinal cord injury. He told me that it is important for him to find a way to become financially independent in the future. Another participant is interested in social work but first has to study and pass examinations at high school level. The third participant wishes he could get a career from computing rather than "just playing games on it [his computer]". He also admitted that he had a long term problem with his motivation to learn, which was not related to his damaged body. He carefully explained to me that since his injury, it would be almost impossible for him to attend classes because of the problems of getting to class each day. He would have to get up early, he would have to ask his care-giver to come early, someone would have to be with him to help him in class, and he would have to do this for some time in order to gain a qualification. There is no doubt that quadriplegic people experience more difficulties in meeting daily schedules and the requirements of educational programmes because of their dependence on other people.

The other three participants told me of their desire to have a career. One of these spoke in terms of “wanting to return something back to the community”. She believed she had a lot to offer, in counselling or “knowing about life” but did not know where to begin to find a starting point. In a way, she deeply appreciated what she knew about living with quadriplegia and her struggles to live alone, and she thought she could provide information for others who were faced with similar difficulties. She was limited because of her lack of educational qualification and did not seem to have an appreciation for formal education. It was obvious to me, that her authority was her own experience, and this may not be sufficient to influence others. Her inability to find a way to share all she knows seemed to be a constant source of frustration to her and therefore added to her lack of independence. Finding a career for this participant would not be straight forward.

The two former tradesmen are clearly unable to perform their former occupation, because of their damaged bodies. However both had ideas about what they could do which was somewhat linked with their former work. Both told me that they needed more assistance to get started than was currently available to them. One wants to develop his computer skills so that he would be able to work within the family construction business, using his past experience. He was in need of a computer. The other spoke of either developing his woodwork interest into a business in which he would need appropriate equipment, or becoming an advocate for disabled people. He already does volunteer work as an advocate for others who are disabled and gains a great sense of accomplishment in seeing other people succeed. The conflict between the two potential interests, woodwork and advocacy, appeared to me to be something of a

dilemma for this man, given the diversity between the two occupations. I was unable to discover which was the more realistic as a future career, especially with regard to being financially rewarding.

### **Engaging in a rich and full social life**

The data show that in spite of the physical difficulties of living with a damaged body, the participants engage in a variety of activities which I have grouped within the category of 'engaging in a rich and full social life'. The data are alive with descriptive names for some activities. "Murder Ball" was the original nickname for Quad Rugby, which is played by people with quadriplegia using sporting wheelchairs on an indoor court. There are five people in each team and the aim is to get the rugby ball between posts, similar to the way tries are scored in rugby. The weekly practise sessions are the social highlight of every week for some of the participants. On one occasion during the data collection, I was told by a person who answered the phone at the home of one of the participants, that "after the game they sit around talking for ages so I do not know when he will be home".

The majority of the participants were involved in sport prior to their injury. The data reflect statements like "I lived for sport". It seems that as much as possible the participants are still involved with sport. "I still watch rugby, I still like it, I love all sports". He regretted that he could not play quad rugby. He told me that because he was strong in one arm and weak in the other he would just go round in circles. He said "I'm what they call, not a couch potato, I'm a wheel chair potato, I watch from the side-lines". For several participants quad rugby is an important occasion. The data indicate

that this is a highly competitive game and a social occasion particularly for the young men with a spinal cord injury. I was told that basketball is the team game for people who are paraplegic, (there are two distinct groups here - 'paras' and 'quads') and there was nothing for those with a high spinal cord lesion. This participant proudly said:

I actually saw it [quad rugby] when I was overseas ... and introduced the game to New Zealand ... we went to the world champ games .... and came away with the bronze medal. I just get so much fun out of quad rugby, its fantastic. We have a really good training routine now where the guys work bloody hard.... it was called murder ball.

Training is every Thursday night and Sunday morning for these fifteen or sixteen 'quads' and these are the people he "hangs out with". Another participant said that quad rugby was often number one in his life. He was very pleased to have travelled overseas with the team. In spite of living with quadriplegia, and the difficulties this involved, he loved the sport, the travel and the achievement. He said, "the classic example [of my achievement] was going to the world champs".

One participant described himself as a fanatical Bridge player and told me that he plays at least three times every week. I consider that Bridge has become a healthy outlet for his competitive nature, previously expressed in rugby football and other sports. He described the competition:

Mondays are pretty cut throat .... Friday is the best day we have a bit of a natter ... I like playing tournaments 10 to 5 o'clock, ... Long day. Some of the hardest players around are those women in their late 50's and 60's, they're vicious ... Lovely ladies, but show no mercy.

Through Bridge, he had been able to establish a whole social circle in which he has found meaning and competitive pleasure.

“Cruising About” was a phrase which was used to describe the early activities of one of the youngest people participating in this study. In my observation of young teenagers, considerable time is spent in ‘cruising about’ and for this age group it appears to be a rich and full social activity.

### **Travel and other things**

Several participants have travelled both in New Zealand and overseas. During the concluding minutes of my first interview with one participant, he told me, “I’m going to America next Wednesday”. He was going to see a friend and was also going to look at the latest equipment for quadriplegic people, so that he would be up to date with all that is available. When he was younger he had been a very courageous quadriplegic overseas traveller who had travelled alone. He told me of one occasion arriving in London by himself expecting to meet someone. I asked him what would have happened if the person had not there and he simply said, “I would have figured something out”. He told me, as an aside, “I took off overseas to Europe with a couple of girls .... and we yahooped around with a campervan ...”.

The data indicate that the participants engage in similar activities to other people.

They watch television, listen to music or read. Several participants told me that they do as they feel. Others do things such as going swimming or to the gymnasium for exercise or take the dog to the park to have a run. Activities with family members during one

participant's early years included pottering about, shopping with his mother or going to work with his father. Several participants told me about getting together with friends and family for dinner and picnics.

In many ways the data show that this group of people, who each live with a damaged body, demonstrate amazing independence and have found ways to enjoy a range of adventures and interesting activities.

### **Conclusion**

This chapter has discussed the challenges of seeking satisfaction in work and play. The chapter highlighted career hopes and development, their participating in a life of rich social and sports activities and the involvement that quadriplegic people have with family and friends in every day life. The adventures of travel were highlighted which indicate that independence occurs at least for some people who live with quadriplegia. Nelson (1990, p.132) concludes her final summary with the following words: "Successful reintegration assures the newly injured SCI patient returns to a viable occupation ... participates in a rich full social life ..." All of the participants in the present study spoke of their desire to have a viable occupation and the data indicate that they engage in a rich and full social life.

The next chapter, *Battling the Odds*, describes the difficulties experienced by people who are quadriplegic. The data indicate that the majority of these difficulties are socially constructed and bureaucratic in nature.

## Chapter 7

### BATTLING THE ODDS

“.... in a wheelchair they’re going to stare at you ....”

This chapter examines the data which refer to disability and society generally. It focuses on the experiences of the participants with people unknown to them, the systems which have been established to support those with a spinal cord injury and the means of securing financial and other assistance including care-givers.

The process of ‘Battling the odds’ was one of the subsidiary processes to emerge from the data. As a result the ‘battle’ is on-going for these people who seek to move from dependence toward independence. Their spinal cord injury which caused quadriplegia, instantly created physical dependence for the participants. ‘The odds’ is a ratio expressing the probability of an event or outcome. It is used especially in sports contests to indicate the chances of success. In this present study the term is used to imply that living with a damaged body, in a world which has been constructed for the able-bodied population, leaves little chance for the participants to move toward independence. Independence here signifies winning. The data show that physical dependence is constant, and while winning against the odds happens, ‘the battle’ to do so is ongoing. The odds include: the problems related to the damaged body; the influences of society which are not supportive of disability; financial and bureaucratic pressures; and the management of care-givers.

### **Being segregated**

One participant had just begun high school when he was injured. He found that he could not go back to his school because it was not wheelchair accessible. Instead he was sent to a high school which had a disabled unit. While he was there, he met other disabled people, learned a lot about their disabilities and “we had a lot of fun.” Initially, he was puzzled as to why some children needed electric chairs yet at the same time they could use their hands. He found the variety of disability ‘amazing’. Schooling for this boy was limited to places where his wheelchair could be accommodated and while he learned about other people’s disabilities, the able bodied high school population was not part of his educational community.

From the time of his injury, he was part of the disabled group for his schooling. Another participant spoke about her original family and then her disabled family which she described as “a second family”. These were friends she had made who also had a disability. Just as she seemed to have her two families, society also has two groups, disabled and non-disabled. This present study shows that segregation occurs between non-disabled people and people who live with a damaged body.

It is significant that this participant’s injury forced him to attend a different school. In a weekly paper for the education sector, Matheson (1996) reveals that a report has been ignored which contains evidence that many disabled students experience serious difficulties. These difficulties include the lack of specialised services, inadequate income support and weak systems to ensure institutions were complying with human rights law. Matheson strongly makes the point that nothing had been done since this issue was



raised in 1994. Segregation contributes to 'the odds' for people who live with a damaged body.

### **Being in the minority**

One of the participants told me about being a minority in the population. She said that people in general believe they understand what it is like to be a disabled person but they do not. We are treated differently. She made the point that even if people in wheelchairs are in the minority, "we're still there". She believed that although there is often a lot of talk about what needs to be done to make things easier for people in wheelchairs, somehow it does not get done. This has to do with the power of the dominant culture. It is a matter of what is taken for granted by the dominant group without realistic awareness of the position of the minority groups within society. For example, most able bodied people expect that there will be steps to enter a building, whereas for a quadriplegic person, steps create a barrier and enforce dependence.

The data contain many examples of people in wheelchairs being treated differently. Highlighted at the start of this chapter was an observation by one participant about how disabled people are treated. She told me a story about being in a bar with her friends and being stared at, by a stranger for a long period of time. After being stared at all evening she felt very angry and began to stare back at this person. Eventually, the stranger went red, and then she said to the person, "If you are going to stare at me all night, why not me stare at you?" She managed her anger by giving the stranger the same treatment as she had received. She told me her opinion - that more education about spinal cord injury

to all parts of society could “make people feel easier” and therefore some would be less likely to stare at people who use wheelchairs.

Some of the participants had found ways of dealing with being in the minority. They say when they are out at restaurants and bars and there are members of the public who act as though people in wheelchairs can not speak for themselves, they use their sense of humour, use being thick skinned so as not to be offended, or take over and lead the conversation. One participant told me that he just acts as he is in social situations and he sometimes knows that it is awkward for people, but “I have enough to think about”. Another participant said “ ... they look at her (his partner) and ask ....would he like to come over here ... and she always says, ‘You’d better ask him’. Its quite a laugh”.

Children are often more accepting of people in wheelchairs. A participant said, “I went to the zoo with my sister and a kid came up alongside us in a pushchair looked across at me and said, ‘my one’s a green one’”. He explained to me that the child was being friendly and saw his wheelchair in a similar way as her own pushchair.

### **Fighting Bureaucracy**

The majority of the participants qualified for finance and assistance from the ACC. New Zealand legislation in establishing the ACC defines ‘accident’ in the following way: “A specific event or series of events that involves the application of a force or resistance external to the human body and that results in personal injury ...” and later the section which applies to most of the participants -

(h) While the person is participating, other than at the person's place of employment, in a recreational activity provided by or at the expense of the employer or sponsored by the employer, or by or at the expense of the injured person where that person is not an employee" (Accident Rehabilitation and Compensation Insurance 1992, 4 - 6).

Despite its official purposes to assist those disabled in an accident, the data indicate the extreme dissatisfaction some of the participants have had with the ACC. The exact nature of this dissatisfaction was beyond the parameters of this study, however, there is a concern here because it is part of battling the odds. Participants entitled to ACC assistance often failed to get it.

It is important to describe some of the experiences the participants have had with the ACC which contributed to this category of battling the odds. The data indicate that at least some of the participants had become experts about their needs and the equipment which they had discovered they required for maximum mobility and independence. In response to my question about their experience with ACC, one participant spoke with graphic description, for example:

The hiccoughs they do are unbelievable, they dick you around something shocking, its not the person you're dealing with, it's the system and you know its tricky sometimes. I've got this wheelchair approved and then they say its all go and then they ring up and say 'oh no, we're not allowed to do it, it's only this amount limit you're allowed to have'. They don't realise.

Another participant responded to the same question with an equally confused story about his difficulty in being able to organise to purchase a hand controlled car through ACC.

He said that he could drive since his accident, because ACC had paid for \$2500 worth of driving lessons. He had also got ACC approval for \$15000 towards cost of the car. He had it all organised and "then when it came down to the crunch, to put in the hand controls so I could actually drive, ACC said, no." The reason he was given was, "it won't give you immediate employment". He is still battling with ACC to get hand controls for his car.

As has already been mentioned, several participants told me that they want to return to employment. But they needed assistance to get started. This is one of the purposes of ACC. One participant said that he needed a computer, and he was entitled to get it "out of ACC". He had been told by ACC that until he has his 'complex injury assessment' a computer can not be considered. He has been waiting over 18 months for this assessment. He described his situation this way :

I've been waiting for an assessment and I've put a written application in ... had two meetings with the manager and complained about what's happening, still haven't had any answers and I'm about to ring the manager again today or tomorrow and ask for more action. I've had 4 case managers, I've just had the run around so much, every time I've got to re-explain my situation, I'm told that they've got to read the file. I had a letter just a few weeks ago saying that if I'd like to go on CPI (complex personal injury) I need to write a letter, so they fired my case manager and got me a new case manager and she found my letter and she's actioning it now, she's going to be really good ... .

As well as battling the odds to get the equipment needed to move towards independence, this participant also was battling the odds because of bureaucracy and repeated changes in case workers and other ACC staff.

One participant had very clear ideas of how ACC could help. He told me that he knows people who just “breeze on day by day”. “The system gives them nothing, and they don’t ask for anything, because they don’t know about anything” [to do with what they are entitled to]. He was of the opinion that a Case Manager should come out and sit down and say to you this is what the system can do to help you and this is what’s available.

Another participant told me that she slept on a normal bed with three mattresses, to make the bed higher. I am of the opinion that this participant and her family would benefit from a special bed with electric controls. When I asked her about why she did not have an electric bed, she simply told me what bed she did have. She apparently did not know about the possibility of special beds to make life much easier for her, available with assistance from ACC.

### **Acquiring and Managing Money**

Money is major concern for quadriplegic people. Living in a damaged body is a more expensive way to live. Essential services and items cost more. One participant said “Money is very important”. The importance of money for most of the participants was centred on the fact that they need money to pay for the care that is essential. This participant estimated that about \$2000 per week would be sufficient “to do the job”. For this participant, ‘the job’ was staff who would do what he was unable to do. The actual amount which the state funds participants to pay care-givers and home helpers is

approximately \$10 per hour. Several participants said “at that rate it is impossible to get quality people who expect a higher rate of pay”. Others said that if they had a little more money, the quality of their lives would be a little more comfortable. Most of the participants are funded through ACC but a few receive an invalid’s benefit, and from either state financial source, the hourly rate is similar. A few of the participants find that they have to rely on some form of financial assistance from their family and they would prefer to be financially independent. One participant said that if she had more money it would be easier for her daughter to engage in activities to the same extent as her peers - more money would add to her own self confidence and the self confidence of her daughter.

One participant told me that he was grateful that he had “a bit extra”. He has always believed that money was important. He observed those quadriplegic people who had little or no money today, would probably have had a similar lifestyle had they not been injured. This, I think, is probably true. Several participants were actively working towards financial independence. Two expected to gain an income through mouth painting and another three were studying for a qualification. Worry about money was one reason why participants were keen to get paid employment.

There were other concerns about money. One participant said his opinion was that “ACC’s sole objective is to save money, that’s it”. He expressed serious concern about the employment and financial management of care-givers. He maintained that people who required assistance from a care-giver might not have the business skills which were needed to employ and pay this person. Specific questions he had were: Who is the

employer, who pays the tax and how does a newly injured person learn these kinds of things? He believes that ACC should handle the tax, so that neither the care-giver nor himself has that responsibility. This raises questions about business issues and these matters have not been investigated in the present study.

### **Finding, employing and managing care-givers.**

The desperation of constantly trying to find care-givers was described by several participants. For one, it was the dominating concern of her life. She lived alone and required assistance from employed care-givers several times every day. She told me of feelings of desperation over the constant need to find new care-givers. The enormity of this stress lead to occasional suicidal ideation which troubled her when sleepless in the very early hours of the morning.

The data suggest that there are two groups of care-givers, informal and formal. Firstly, the informal group, these are friends and family members who engage in care-giving activities (who may or may not be paid as discussed in chapter five) and secondly, the formal, these are care-givers who are employed and paid as staff.

Although everyone with quadriplegia, is dependent on others for the daily routines of living, there is not an organised system which manages care-giving. Several participants told me that they advertise in the local paper for a care-giver. Each participant does his or her own interviewing and managing the terms of employment. The job description of a care-giver includes doing those activities for the person whose damaged body, is unable to do. The work of a care-giver is of a highly personal nature. It entails hygiene



and toilet assistance, meeting mobility and exercise needs, attending to food and fluid requests, providing assistance with coughing, picking up items when they are dropped or out of reach, doing banking and many other duties and motor activities. The challenge of being a care-giver is doing this work in such a sensitive and unobtrusive way that it is acceptable to the person who is quadriplegic.

The participants appear to have a variety of experiences in the employing of care givers but since they are financially limited as to what they can pay, as described, in an earlier section of this chapter, there are some problems. Participants had a variety of ways of telling me about this concern. One said: "Care givers need to live so they need a decent wage. Love is not enough, people need money and I am dependent in having care givers to help me". Another said that organising care-giving is a "nightmare" because of the small amount of money he receives, and more particularly because of the difficulty of finding reliable and honest helpers.

Some participants who relied on paid employees said that they preferred women who were around forty years of age. For example, one said, "Most of the time I get the older women as they don't have kids to run home to if they get sick .... I have to come first. Older women are more reliable, not many ties". Another gave me her opinion that care-givers do not need previous training or experience. She said, "people who have worked in rest homes all their life need to stay in a rest home, they can't leave that [attitudes and work styles] behind. It comes down to individuals. The best people are housewives and mothers because they have not got any preconceived ideas". However, other participants told me that they had young "girls" working for them and some of these



“girls” were nurses. This area of this current study could have become the major project. It seems from the data that market forces and chance determine whether or not care-givers adequately provide the assistance which is essential to the participants.

The continuous management and timetabling of care-givers is a very complicated business. There is little room for error or mis-understanding between the parties because there are no structures for the provision of a replacement care-giver. One participant told me about her daily roster of care-givers:

I have three every day, one person to get me up, home help in the afternoon, and someone to put me to bed .... and these are not necessarily the same people as I had yesterday.

She said her choice would be to have three people sharing the evenings, three sharing the mornings and two for the afternoons. This pattern would allow for sickness and other problems. One participant referred to his care-givers as “ladies”. He carefully planned the roster for his “ladies” including one who “comes down to the Bridge Club in my van at about 10.45pm on Wednesday nights, picks me up, brings me back, cup of tea, and go to bed” and then she leaves. He says that he has been given the money to assist him with his life, and he likes to play Bridge, so he finds someone to work at the time he needs assistance. This man seems to have no difficulty in finding care-givers. He told me that he gets on well with most people and if he treats them well, they treat him well. One woman had been working for him for three years and he described her as “a real friend, she’s terrific”.

In some instances there was some blurring between the role of care-giver with the role of friend. Again, further research is necessary to fully understand the nature of the care-

giver relationship with those who require the assistance. There is a high level of individuality in these arrangements. One participant said "There is no way that I would ever have my family do my personal care - I would always hire my staff to do that sort of thing". Living with a damaged body means that in order to move towards independence, care-givers are an imperative in the life of the quadriplegic person. For some, there is a strong preference for the care-giver to be a family member, for others, the equally strong preference is to have hired staff.

### **Being on the receiving end of care-giving**

Participants rely on paid people to provide assistance they need as a result of their spinal cord lesion. The data provide a varied picture of the participants' experience with receiving care-giving. There were many examples of good will and generosity toward the participants from their care-givers. The participants also need to reciprocate and be flexible and considerate with their employed care-givers. To adequately research the nature of the quadriplegic employer / care-giver employee relationship, care-givers would need to be interviewed.

Corbin and Strauss (1992, p.19) in their work on the management of chronic illness, describe some care-giving activities as 'everyday life activities'. They discuss the term 'limitations management' to denote the alterations and adaptations which people have to make to carry out these everyday activities. As an example they make the following statement: "For a quadriplegic, managing limitations means arranging to have an attendant come each morning and at night to get him/her out of bed, dressed, prepared

for the day, then get back into bed at night.” This concept of limitations management accurately reflects the participants’ need to receive care-giving.

However, there is a serious philosophical weakness in Corbin and Strauss’s use of this example which reflects a commonly held attitude. By including quadriplegia as an example within a discussion focussed on chronic illness, Corbin and Strauss fall in to the perceptual trap of equating permanent disability with chronic illness thereby putting quadriplegia within the medical model. Compounding this mistaken perception is the fact that quadriplegia does result in increased medical complications. Nevertheless, quadriplegia is not an illness.

The participants’ experience reflects being on the receiving end of this misperception. Hence the opinion of one, based on lengthy experience, that ex-rest home workers are not good care-givers because they carry the medical model attitude of perceiving the quadriplegic person as a sick person. There is a very subtle but very important distinction between the quadriplegic person being seen as a person in constant need of care from others and the quadriplegic person being seen as a sick person in constant need of being treated. This is a disempowered, one down position. The illness framework is no longer acceptable when applied to disability, according to the Human Rights movement. This idea will be followed up in the next section.

### **Assuming that disability is a social problem**

The data reflect a strong awareness in the participants of not being accepted as equal members of society. The stories from participants provided evidence that living with a

damaged body is very difficult in comparison to living as an able bodied person. The 'battling' was ongoing in the lives of the participants and was necessary if they were to move towards independence. Oliver (1996, p.129) writes:

The hegemony of disability, as it is produced by capitalist society ... stems from the ontological assumptions it makes about the pathological and problem-oriented nature of disability. ... Hence the assumption is, in health terms, that disability is pathology and in welfare terms, that disability is a social problem.

Oliver continues and suggests that both able bodied and disabled people alike view disability as "having something wrong with you". The hegemony of disability in recent years has been under attack. The Disability Rights Movement and other writers are now of the view that "disability (is caused) by the failure of society to remove its disabling barriers and social restrictions." In other words, the existence of the idea of disability implies that there is something wrong with society (Oliver, 1996).

The data contain many statements from the participants in which they suggest that, society as a whole needs to support their cause. "... if they are going to keep us alive, then there is the responsibility to damn well do it properly and make sure it works" Other participants used the term "stigma" in relation to society. Another said that it was less than it was, but still existed. The participants used terms like "their problem not mine" and they took advantage of social situations to educate people about disability. Another participant described her situation as being powerless and said "the people who fund me run my life".

During the data collection participants did not relate any experience of violence directed towards them. However, Waxman (1991) discusses violence towards disabled people with strong conviction and evidence from literature. She is adamant that the medical model is responsible for the plight of many disabled people. Waxman embraces the socio-political paradigm of disability, which means that “the major problems of disabled individuals are found in a disabling social and physical environment rather than in any defects or deficiencies of disabled people themselves”(p.192).

Waxman’s (1991) article is disturbing. In discussing the vulnerability of disabled people, she indicates that vulnerability is too superficial to explain the disability-related violence statistics and writes (p.191)

Rather, hatred is the primary cause, and vulnerability only provides an opportunity for offenders to express their hatred. Indeed, people who are respected and considered an equal are not generally abused.

Waxman’s writing and the present study both confirm that disability is a social problem.

## **Conclusion**

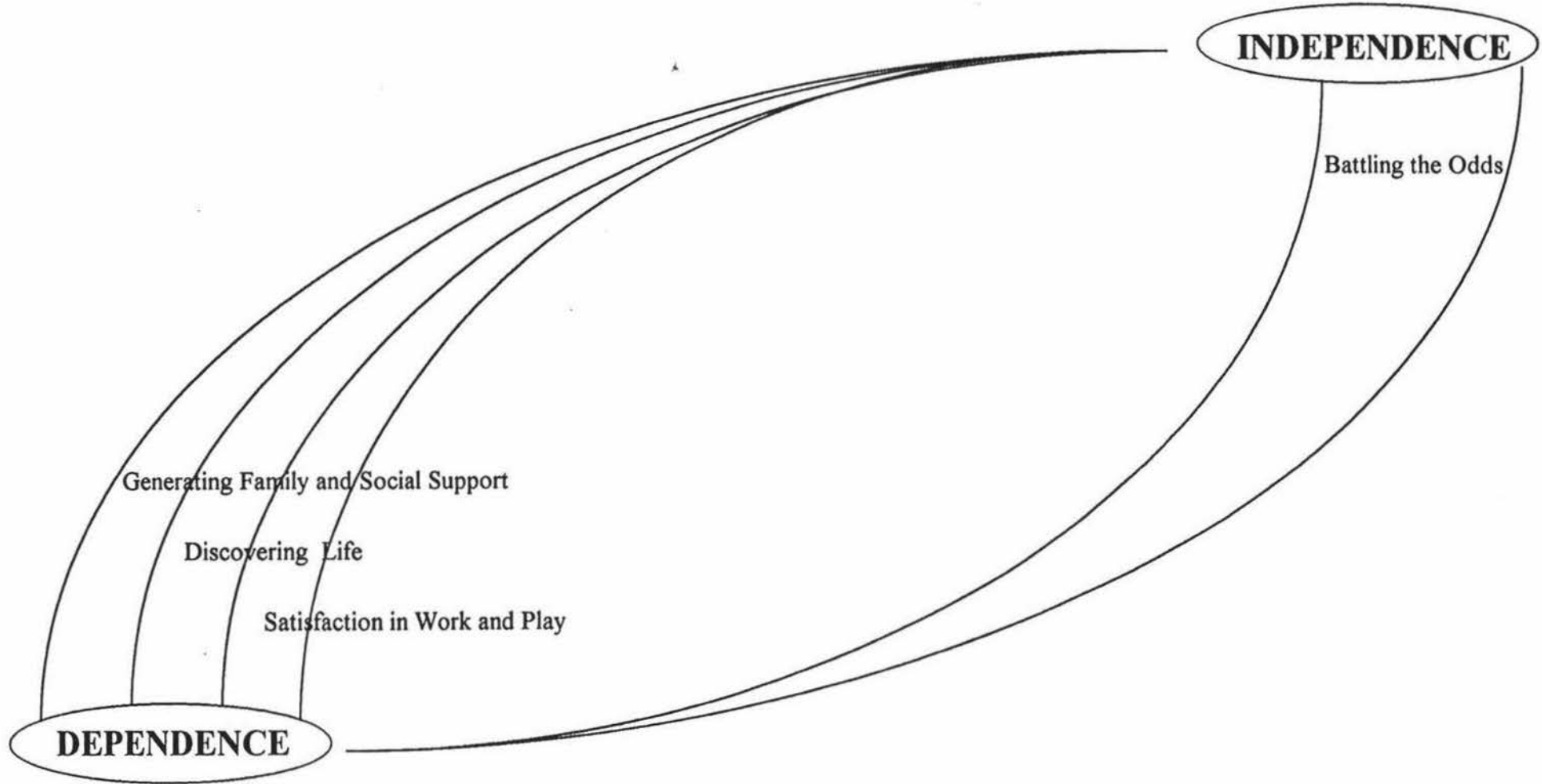
This chapter has described the experience of participants as a disadvantaged group in society and as such they must constantly battle the odds. The topics discussed have been financial acquisition and management; being segregated and in a minority; the finding, employing and management of care-givers; problems in equality and the battles with bureaucracy.

It is important to summarise that spinal cord injury which results in quadriplegia creates physical dependence. The participants in this study were quadriplegic and therefore lived

with a damaged body. Each individual wanted to become as independent as possible and was progressing towards this goal. Their physical disability forces them to be reliant on their family members, or on paid care-givers, for the assistance they require. The majority of these participants live active lives and enjoy what they do, whilst at the same time they battle the odds which are against them because of their damaged body. Finally this chapter introduced the powerful socio-political model of disability which comes from Waxman (1991) and her work on protecting disabled people from violence.

The following chapter explains the theoretical model which emerged from this study. The model is presented in diagram form and shows the findings in a to and fro pattern of the subsidiary processes between the states of dependence and independence. The core process is living with a damaged body as a consequence of quadriplegia following spinal cord injury.

## LIVING WITH A DAMAGED BODY



## Chapter 8

### DEPENDENCE AND INDEPENDENCE

#### The Model

The model which has been generated from the data in this study is depicted in the diagram on the previous page. The diagram indicates patterns of movement and change between the polarities of **dependence** and **independence**. The new way of being in the world following a spinal cord injury which results in quadriplegia is **Living with a Damaged Body**. This was the life-long situation for each of the nine participants as it emerged from the data of the study. At the time of this study there is no realistic possibility of this situation being reversed. The severity of cervical spinal cord injury is such that without emergency rescue and ongoing medical and nursing care the participants would have died. They were dependent on others for survival. As Morse and O'Brien (1995, p.889) write: "The injured are acutely aware that their life is in peril". These writers suggest that the injured are very involved in surviving - they strive not to lose consciousness and they attempt to remain active participants in saving themselves. Several participants gave their own examples which support Morse and O'Brien's conclusions.

Listening to the participants tell me of their experiences, I was struck by the degree of total dependency into which they were thrown at the time of their injury. In their study Morse and O'Brien (1995, p.889) report the process of patients having to relinquish control over their bodies and place themselves in the hands of care-givers ... one of their patients described the experience of having to totally rely on others as "a horrible



feeling”. One participant in the present study expressed the situation clearly, “Well at the beginning, when it happened, you hardly know what is happening. It’s like being very dependent again”.

Between childhood and later adulthood some degree of **independence** has been achieved by most people as the usual way of being in the world. The participants were all independent adolescents or young adults at the time of their accident which suddenly forced them to regress to being in total **dependence**. From this data, these polarities emerged for the model. The diagram indicates that there is ongoing movement, back and forth, between the polarities of **dependence** and **independence** for these people who live with a damaged body.

For the purposes of this model, it is essential that readers have a broad understanding of the terms **dependence** and **independence**. The category ‘living with a damaged body’ applies only to the physical body of a person. For all people, being human involves more than living in a body. These additional aspects of being human are still fully possible for a person who has quadriplegia. The model indicates that there were four categories which determine the on-going movement between **dependence** and **independence**. These four categories have been described in depth in the previous chapters of this thesis. These categories are:

- \* Discovering life
- \* Generating family and social support
- \* Seeking satisfaction in work and play
- \* Battling the odds

Participants spoke in the following ways about their intentions to move toward independence. Their words were:

“set your mind to it”

“make the best of what you have”

“work towards it”

“live as normally as I possibly can”

“I know my limitations and I try to do things for myself”

“balance for life, independence”

“getting back to driving and meeting people”.

One participant spoke, at some length, about sending his parents on holiday for a break as he wanted to test trying living alone. After passing this test, he looked forward to living his own life and to his parents being able to return to their own home and live their own lives. At the same time he recognised that “People are really important to help me live”.

One participant contributed to the data in a profound manner when he answered my last question concerning being independent this way:

..... support is the main thing you need, you have to have support, because there are things you can't do for yourself. Secondly, and just as important, you need encouragement, because the public impression is that you are disabled, that you can't achieve what you want to achieve, that's a load of crap because you can achieve what you want to do if you're given the right support and encouragement. Support is mental, financial, physical, emotional, everything. And thirdly, I think a practical example of what you can achieve, maybe that's

not just one person, you may need to see 3 or 4, because that person may not be on the same understanding, they may have a different mental understanding of life than you do.

Participants told me of significant life events which have happened since their injury. From this data, it is clear that life goes on as usual and the participants continue to experience the normal round of life events and to involve themselves in these events as fully as their damaged bodies will allow. Several examples: the death of her father meant taking on more responsibility in the family business where she was working; accompanying his mum and dad on a religious pilgrimage to an overseas city; discomfort while in a wheelchair at a tangi (funeral) because she could not go round to the coffin and kiss the body, as customary, and it was "a very awkward feeling". However, although these participants experienced some difficulty in these situations, within their limits they did engage fully in the activities with emotional and social independence despite their damaged bodies. These life events in the experience of these three participants serve to illustrate the processes which occur in the movement between dependence and independence in the model. In a sense these processes are the variables which intermix to contribute to the movement between dependence and independence.

The following chapter discusses the implications of this study for nursing and suggestions for further research.

## **Chapter 9**

### **DISCUSSION AND IMPLICATIONS OF THE STUDY**

The previous chapter explained the model which emerged from the data. The categories which influence the movement between dependence and independence for people who live with a damaged body, as a result of a spinal cord injury, were highlighted. The next step is to bring the findings together and consider how this study contributes to nursing and the care provided for quadriplegic people who live in the community.

This final chapter, firstly, discusses the implications for nursing as a profession including recommendations. Secondly, there are suggestions for further research, and thirdly, there is an evaluation of the study as a whole and boundaries of the study are mentioned.

#### **Implications and Recommendations for Nursing**

The findings of the study indicate that people who live with a damaged body because of quadriplegia continue to be physically dependent, to varying degrees, as they return to live in the community. Within these limits the aim for each of the participants was to strive towards maximum independence. The following discussion is organised according to the six categories which emerged from the data.

#### **Between Dependence and Independence.**

It is important to acknowledge that the model generated from the present study indicates that movement occurs to and fro between dependence and independence for quadriplegic

people. These terms, dependence and independence, are holistic concepts and therefore not limited to the physical domain. They refer to all aspects of human life, including body, mind and spirit, also culture and society.

In discussing dependence and independence Moore (1992) suggests that underlying these terms there are general assumptions, meaning dependence is bad and independence is good. Moore makes the point that total independence may create other difficulties for people, such as avoiding friendship and intimacy. Sometimes, I think, nursing may focus too strongly on assisting people towards independence, as if the profession is caught in the assumption that independence is good. For many nurses, as indeed for people in general, it is not easy to relate to and provide appropriate assistance for physically disabled people who are independent in all other ways. In our society, there is an expectation of a parallel between physical and non-physical dependency. We would be better off if healthy people could be understood as being both dependent and independent in different ways, and that neither polarity was considered good or bad. If society held this idea it would not be considered strange to observe a person with a damaged body who is professionally and financially independent. There are many examples of individuals who use a wheelchair for mobility being spoken to by strangers as if they were deaf or mentally defective.

People with quadriplegia may create difficulty for nurses, because as time moves forward from the moment of injury, their rate of increasing independence is much slower than is generally experienced with other patients. During the acute phase of spinal cord injury, or following recovery from a medical complication of living with a damaged body, there

are additional difficulties which are likely to occur. Lawler (1991) explains the management of recovery from surgery in terms of normal expectations, and suggests that it is difficult to generalise how nurses manage when patients do not follow the normal trajectory of recovery. Lawler (1991, p.183) writes "Recovery is essentially about becoming independent and regaining control over one's body functions and body care". The expectation is that the patient "progressively resumes responsibility" and that nurses are able to relinquish what they have done for the patient. In the case of spinal cord injury, physical dependence may continue for weeks or months before nurses can hand back any level of independence to the patient. It is my observation that quadriplegic people are often perceived as being 'difficult' by nurses when they are accommodated in busy medical-surgical hospitals, and this may be one explanation.

#### Living with a Damaged Body

Usually people who are quadriplegic are severely disabled permanently. In spite of the fact that there is likely to be a reduction of their life expectancy they probably have many years ahead of them (Rogers, 1986). While there is a philosophical error in linking disability with chronic illness, as described earlier, there are, I think, some useful comparisons to be made. The demands of nursing a person with a damaged body, such as quadriplegia, could be compared in some ways with the demands of nursing a terminally ill patient. Lawler (1991, p.186) describes the nursing of terminal patients as one of the most demanding types of nursing because it is time consuming, difficult and relies heavily on emotional labour and the patient will not recover. She suggests that the more demanding the work of the nurse is, the more it is likely to be unrecognised by society, in a way similar to the failure to recognise women's work. The present study

identified that most of the assistance provided to the participants was by women and, I suggest, the extent of this contribution is unlikely to be recognised by society. It is obvious to nurses, that living with a damaged body is not easy for either the person or for the care-giver providing the assistance.

The damaged body of a quadriplegic person will almost certainly have ongoing medical complications. People who are quadriplegic require assistance from nurses and other health professionals more frequently than do the majority of the population. The participants reported many experiences which indicated ignorance and arrogance from providers of health care. Disabled people should not be treated differently from nondisabled people when they are ill. It seems nurses are not good at distinguishing between disability and illness. The result is the possibility that when the disabled person is ill nurses will treat him or her as being ill in a double way. Shaw (1995, p.18) writes "Many people with disabilities ... believe that nurses have no place supporting those with disabilities. This view is based on the belief (and experience) that nurses are part of the medical model and therefore link disability with illness." (See participant's opinion in the care-giving section of Chapter Seven). Shaw (1995, p.18) goes on to suggest that if nurses work with people who are disabled they must work from an empowering base and "not assume they can work in this field as of right". People in the community, who live with a damaged body as in quadriplegia, have greater contact with nurses. Therefore, nurses must be aware of their own philosophical position and attitude towards disability.

To provide quality nursing care for people with quadriplegia requires adequate planning and provision by the health service, the practitioners and by educators. This is true for

newly injured people and for those living in the community who have a medical complication related to their spinal cord lesion. Nurses and their managers must have an understanding of the knowledge, skills and attitude which are necessary for patients who are living with a damaged body.

### Generating Family and Social Support

To live successfully in the community, quadriplegic people require assistance from other people. In order to fully survive the injury and the shock of becoming quadriplegic, people with a spinal cord injury must maintain a will to live. To do this they must first know that they are still valued. Rosenblatt (1996, p.45) provides an example in Christopher Reeve who said:

When they told me what my condition was I felt that I was no longer a human being ... Then Dana came into my room and knelt down to the level of my bed. We made eye contact. ...I said, 'Maybe this isn't worth it, maybe I should just check out.' And she was crying, and she said, 'But you're still *you*, and I love *you*.' **And that saved my life.** [emphasis mine]

Since human interaction is a two way process the newly injured person will benefit from initial love and support which is freely given as described above. This initial stage following injury is similar in some ways to the beginning of bonding between a parent and a new baby. At first the baby is dependent on love and caring coming from the other. In order for the injured person to begin to trust that life is worthwhile in their new state of being quadriplegic, a similar developmental pattern of first receiving family and social support is essential. After a period of time, the disabled person can begin to act for him or herself to generate social and family support. However, this may not be easy.



It is clear from this study that the participants perceive that people in general act from assumptions and expectations which demonstrate they have difficulty in accepting those with disability. In comparison, it is refreshing to read Moore (1992, p.19) who in discussing the sacredness of life, writes "all lives are important". Moore believes that this quality is at the very heart of every individual. This, I believe, is a core value of nursing and is a central focus in nursing practice, nursing research and nursing education.

Field (1996, p.26) describes the social experience of a successful businessman who had a stroke which "really whacked me". After months of therapy this man sings the praises of his therapists and his "fantastically supportive wife and family" and the few friends who have stuck by him. Field (1996, p.26) continues by writing that some former business acquaintances did not know what to say or where to look when this man had problems talking and "I would often see them crossing the street to avoid meeting me". There is a need for nurses and members of society generally to be educated on how to accept and to relate to those members of society who are disabled in any way and to support close family members who contribute to the independence of those people who have a severe illness or injury which results in a disability. Nurses could be major change agents in this societal situation.

In her article, "The alienation of the sufferer", Younger (1995) discusses the compounding of adversity as being the loss of community and the aloneness which follows serious illness or disability. According to Younger there are profound reasons for this state of alienation, which begin with the fact that "people who were previously

friendly become embarrassed and strained in their presence" (p.54). As nurses care for people who are facing adversity, such as following a spinal cord injury, it is recommended that nurses appreciate this human experience of alienation. Younger (p.67) writes:

What, then, does caring for the sufferer consist of? The expression of caring is well directed by Henderson's definition of nursing, which is to "do those things the patient would do unaided for himself if he had the necessary strength, will or knowledge; and to do this in such a way as to help him gain independence as rapidly as possible." In the specific case of suffering and its attendant threat of alienation, what patients would do for themselves if they could, is bear the burden, express the nature of their experience, help others relate to them, connect with others, and connect with universal forms of life that will survive after their death.

Nurses have much to contribute in the area of this category by assisting to generate family and social support. Younger (1995) includes practical suggestions for nurses and others who attempt to prevent alienation for a sufferer, such as a person with quadriplegia. These are: our presence, which Younger describes as being the "most fundamental experience of reality"; the dance of compassion, which includes silence; the actual dance of moving back and forth to the sufferer; and the voice of reconnection, that is, assisting the sufferer to express and identify the suffering. I believe that the role of nursing is not only with the sufferer, but also with the family. The data indicate that families were also effected by the quadriplegic person's injury. The family needs nursing care to recover from shock and devastation and to become a useful source of support for

the spinal cord injured sufferer. Both the family and the injured experience Younger's (1995) sense of alienation and her practical suggestions also apply to nursing the family.

### Discovering Life

The process categorised as discovering life is complex. To discover life means to find that one's existence can be enjoyable, purposeful, rewarding, ethical and contributive. Making this discovery is the existential task of all people. Because this quality of life is mediated through bodily sensation and movement, when these are damaged by spinal cord injury it can seem at first as though life itself is lost. The process of discovering life now that one is living within a damaged body is a crucial adjustment in the movement toward independence. Some whose bodies are damaged decide that life, in these circumstances, is not worth living and commit suicide. None of the participants in this study had this attitude. Although at different stages of achieving their life goals, they all had positive aspirations to live well. The process of discovering life again after the damage does not keep pace with the recovery and healing of the body and is clearly dependent on non-physical, psychosocial factors.

The notion of 'Discovering Life' as a newly disabled person must not be confused with the desire for cure and the hope of walking again. In the letters which were published following Rosenblatt's story on Christopher Reeve (Time, September 16, 1996) the focus for many was on the belief that Reeve will walk again. The hard fact is that with spinal cord damage, he may not. Hope is idiosyncratic and relative. Years ago, I met a man in a wheelchair who told me that if medical science could increase his quality of life, it would not be walking which would be his first priority, it would be to have a better sex

life. The priority of walking again may be the fantasy of the able bodied. For a quadriplegic person it may be the recovery of hand function.

The process of 'Discovering life' and the ability to live well, with a damaged body until death, is very demanding and requires the support of many resources. Nurses are part of the resources since we know about holistic care for patients and the instillation of hope for their future. In a study by Lindsay (1996) chronically ill and disabled people were asked to share their understanding of health. Although there is a problem in considering these two groups as one sample, the results are useful in this discussion. Lindsay (1996, p.465) found that her participants reported feeling healthy whilst living with a chronic condition. The six themes which contribute to this sense of health emerged as follows:

- |                           |                                       |
|---------------------------|---------------------------------------|
| 1. honouring the self     | 2. seeking and connecting with others |
| 3. creating opportunities | 4. celebrating life                   |
| 5. transcending the self  | 6. acquiring a state of grace.        |

Lindsay (1996, p.470) writes

Nurse educators and practitioners need to become sensitized to the phenomenon of health within illness. ...Medicine and nursing have traditionally focused on problem identification ... McKnight (1992) urges health professionals to abandon this problem orientation and to adopt an approach which focuses on people's capabilities.

This is true for people with a spinal cord injury which results in quadriplegia. The capabilities which the participants in this study had were variable, and individual assessment of them would be essential. If nurses were to assist these people through a

focus on their capabilities they could then be assisted in ways which were empowering and consequently move towards independence.

As discussed in Chapter Four, one participant had benefited from information gained from books and tapes. Nurses can contribute to people 'discovering life' through bibliotherapy.

This process of 'discovering life' involves an unresolved question which has relevance for nursing, how much of the grief process requires attention? There are opposing opinions in the literature and in the data from participants in the study. Price (1996) suggests that people need to work through the grief for their disability before they can refocus on other attributes. Nelson (1990) tends to support 'the taboo against depression and anger' during rehabilitative hospitalisation for spinal cord injury. Depression and anger are part of the grief process. One of my participants said that psychotherapy was an essential part of his adjustment and one other dismissed any suggestions that attending to psychological processes might be useful. Clearly more research focussed on grief is required. Until the results of this research are forthcoming, from my own nursing practice, life experience and observation, I favour giving attention to the grief process which involves the careful management of depression and anger.

#### Seeking Satisfaction in Work and Play

Opportunities for work and play provide a structure for time and give meaning to life. This was true for the participants and is true for all people. Without this structure time is

long and contains little purpose. In short, people need something to do. In a brief profile about Sione Hema (Royal Tongan Airlines Magazine) it is written:

I asked (a Catholic) sister to give me a brush and some water colours so I could start to do something. It was so funny. We started with paint brushes that we used to paint houses, the paper had been used to wrap food. But I enjoyed it.

He now has the proper equipment for painting and spends increasing amounts of time facing the easel. This man became paralysed from the neck down in a fall in 1990 and lives in Fatuoaga (a special needs facility) in Tonga. The idea of 'starting to do something' has lead on to computer skills for this man as well as selling his artwork and now he hopes to design a house for himself. Oliver (1996 p.138) writes:

The experience of spinal cord injury, therefore, cannot be understood in terms of purely internal psychological or interpersonal processes, but requires a whole range of other material factors such as housing, finance, employment, the built environment and family circumstances to be taken into account.

There are occupations which are suitable for people with quadriplegia and there are sports and activities for which quadriplegic people have capabilities. The participants in this present study knew their capabilities and their goals and they were realistic about their physical limitations. The challenge for nursing is to assist these people to achieve their capabilities and to do this effectively within the social context.

### Battling the Odds

The category of battling the odds is important for nursing. The data clearly indicate just how difficult the world is for people who are living in a damaged body. Wendell (1996)

discusses disability as being socially constructed. She suggests that there are many factors which have lead her to this conclusion including the availability and distribution of basic resources; the many forms of trauma which damage people's bodies; current medical practices; and the pace of life. Wendell (1996, p.36) writes:

I see disability as socially constructed in ways ranging from poor conditions that straight forwardly create illnesses, injuries and poor physical functioning, to subtle cultural factors which determine standards of normality and exclude those who do not meet them from full participation in their societies.

It is these standards of normality which contribute to the struggles, people who are living with a damaged body, have in their movement towards independence, categorised here as "Battling the Odds".

If disability is socially constructed then society is hostile towards those with a damaged body. In this case Nelson's (1990) "toughening up" phase in the process of reintegration she describes following spinal cord injury has a place. The newly injured quadriplegic person needs to be prepared for the hostile environment society presents. Nelson writes (p.122) "During the toughening up phase, the patient begins to see the 'big picture' of what life after a spinal cord injury entails." Toughening up included both physical and emotional dimensions so that the quadriplegic person could face the hurts they would meet out in the world. In my opinion some toughening up is necessary and changes in society are necessary to reduce the hostility and make the 'big picture' more welcoming for a newly disabled person. For those people who use wheelchairs there are still many barriers, such as public buildings which do not have easy access, while a motel advertised as being suitable for a wheelchair may mean that the door is wide enough for the



wheelchair, but the bathroom may not be appropriate at all. The participants told me many examples of architectural as well as bureaucratic barriers which made life more difficult for them on a daily basis. The accounts of bureaucratic management suggest that there are agencies which make it as difficult as possible for people who are living in a damaged body.

Nursing can make a difference for people who are living with a damaged body. The diagram of the theoretical model indicates that the three processes over which the quadriplegic person has most control, assist his/her movement towards independence. The process of battling the odds is one in which the quadriplegic person has least power and influence. Society creates the odds against the disabled whose only control is over how they do battle. The energy they can give to the process is largely determined by the constant background of having to live with a damaged body. Thus, this category of battling the odds is the one which persistently holds quadriplegic people back from attaining maximum independence. Nurses can be influential in reducing the odds against which the disabled are forced to do battle by using advocacy and nursing skills effectively.

Nursing education and nursing practitioners have a responsibility to be knowledgeable about the rights of disabled people and of the sociological dynamics which construct the social reality in which quadriplegic people have to live. This study finds that there is much to learn from people who experience an injury and become disabled and live with a damaged body for the remainder of their lives. The data demonstrate that nurses perhaps do reasonably well in the acute phase of injury but, like the rest of society, there are large



gaps in the acceptance of disability by nurses, and nursing is coloured by the dominant social construction of what is normal and abnormal. This is of serious concern. Nurses are in a perfect position to teach their patients and their family members about the sociological perspective of living with a damaged body. Nursing education, therefore, must prepare students to be able to handle the processes of what it means to live with a damaged body as, in the future, a large proportion of health care will be required to assist individuals and their families to live with the result of injury or illness. Lindsay (1996, p.470) confirms "People with chronic conditions are the prime health concern of this era, and will remain so for the foreseeable future".

### **Suggestions for Further Research**

The model, which is an outcome of this present study of spinal cord injured people, could be applied to the situations faced by nurses who care for other groups of patients who have a high degree of dependence resulting from other severe diseases or injuries, such as amputation, polio and severe burns.

The outcome of this study has been to demonstrate by research, that any situation where a person has to live with an irreversibly damaged body which forces him or her into a state of dependency on others, there are still possibilities for that person to move toward independence providing the four categories of processes are effectively managed.

here are several suggestions for further research.

1. A series of narrative case studies would extend our knowledge of the lives of quadriplegic people. Any one of the participants in this study would be a rich resource for an in-depth narrative case study. The knowledge obtained would greatly extend the understanding of nurses required to care for disabled people.

2. A study which explored the attitudes of nurses towards patients with quadriplegia would increase our baseline knowledge and would therefore indicate the extent of desired attitudinal change. Quadriplegic people require both in-depth and comprehensive nursing because of their degree of dependence but at the same time they require assistance and empowering to move towards independence.

3. Further research is required on the significant grief and depressive reactions of people who live with quadriplegia as a result of spinal cord injury. My study has shown a lack of clarity in this area of emotional management by people living with a damaged body. This area of emotional care is an important aspect of nursing practice. Nelson (1990, p.130) writes "Further research is needed in this area, related to the long term effects of depression and lack of depression during rehabilitation on the functioning of SCI patients postrehabilitation". It is my observation that little is known of the long term incidence and effects of depression in those living with quadriplegia.

4. Further research is needed to examine the provision of care-giving for a family member. In my study the majority of care-giving was provided by women who were

either employed or were a member of the family. Little is known about the long term effects on women who provide care for a family member.

5. According to earlier research, (Kreutzer, Marwitz & Kepler, 1992 Robinson & Steele, 1995) little is known about the effects on male family members or on families as a whole following a significant injury which damages the body. Research on the response of the family as a whole would be useful for nursing.

6. Pain is a major problem for people who live with a damaged body, yet it is very poorly understood or managed . More research in this area is a matter of urgency.

7. The world view of those who live with a damaged body is not well understood. Nursing understands little about the psychological or philosophical existential beliefs of persons who have a damaged body. Research to examine the beliefs of quadriplegic people hold about their paralysed body would be useful. For example:

- \* Do they live *in* or *with* their damaged body?
- \* Do they consider their paralysed areas to be dead or alive?
- \* How do they identify their sense of self with their paralysed body?

### **Evaluation of this Study**

The most significant evaluation of this study is contained in the information gained from a discussion of the findings with two people who have each had a spinal cord injury resulting in quadriplegia, within the last twelve years. However, before attending to their contributions there are additional aspects of evaluation to be considered, as follows:

### **Size of Sample**

Nine participants took part in the study. This is a small number of participants from which to generate any model or theory. Sandelowski (1995) discusses sample size. It appears that the sample size is a matter of judgment and depends on the purpose of the research. She writes:

A sample of 10 may be judged adequate for certain kinds of homogeneous or critical case sampling, too small to achieve maximum variation of a complex phenomenon or to develop theory, or too large for certain kinds of narrative analyses (p.179).

However, given the academic purpose of this study, the researcher believes that the sample size was appropriate for the time constraints and requirements in which to complete and manage this project. Time to complete this project is recognised as a boundary to this study. The present limited study is a beginning, and further investigation by other researchers would extend the current findings for the benefit of nursing practice.

### **Transcribing Process**

As was mentioned in chapter two the transcribing process was not as straight forward as was anticipated. The spoken word with the non-verbal cues of tone or voice, spaces and emphasis on the tape did not read the same once it was a typed transcription. This difficulty is discussed by Sandelowski (1994) who emphasises that the transcript is not an exact copy of speech in the way that a photograph is a duplication of a scene or an object. Secondly she writes "The transcription process obliges researchers to have a clear sense of the purposes for their studies and to recognise that there is 'theory' and an

ethic implicit in the process itself" (p.314). It is recognised that in this study the transcribing process created a limitation for absolute trustworthiness. Transcribing, especially by a person (no matter how thorough) other than the interviewer, adds a dimension of change and omission of detail between the tape and the transcript. For reason of desired trustworthiness of this study, I regret that time and ability did not permit me to transcribe the tapes following each interview. The benefit of transcribing the tapes myself would have added a more exact duplication in the process of data collection.

### **Scientific adequacy**

Sandelowski (1986, p.27) writes:

The criticisms of qualitative research are largely concerned with its scientific adequacy. Qualitative methods are frequently viewed as failing to achieve or to make explicit rules for achieving reliability, validity and objectivity - criteria of adequacy or rigour in scientific research.

Sandelowski (1986) suggests there are four reasons for these criticisms. First, qualitative methods include a wide range of inquiry of which grounded theory is one. Second, research methods are usually either qualitative or quantitative, but a few may be both. Third, qualitative methods tend to be judged against the criteria for quantitative methods and finally, there is some question whether qualitative inquiry belongs to the domain of science at all. She goes on to explore issues of internal and external validity as related to qualitative research. "In qualitative research, truth is a much more elusive goal" and

The truth value of a qualitative investigation generally resides in the discovery of human phenomena or experiences as they are lived and perceived by subjects, rather than in the verification of a priori conceptions of those experiences (p.30).

Sandelowski supports the notion that credibility be the criterion against which the true value of qualitative research is evaluated. In essence, faithful descriptions of the human experience create credibility.

External validity in qualitative research according to Sandelowski (1986) is most usefully understood as 'fittingness' or when the findings fit into contexts outside the study situation (p.32). It is important that when the findings are viewed by an audience they are meaningful and applicable to their own lives.

Generally, reliability refers to the notion that if the study were to be repeated the findings would be similar. Sandelowski (1986) supports the work of Lincoln and Guba (1985) who propose that auditability be the criterion of rigour or merit relating to the consistency of qualitative findings. She writes, "A study and its findings are auditable when another researcher can clearly follow the "decision trail" used by the investigator in the study" (p.33). According to the strategies outlined by Sandelowski (1986) this study meets the criteria of auditability, credibility and fittingness, as offered in the following explanation.

#### **Auditability, Credibility and Fittingness.**

The chapter on methodology includes evidence of the audit trail. Examples of coding and categories, and memos are included. The remaining data are available for audit.

With regard to credibility and fittingness, the findings of this study have been discussed with two people who are quadriplegic as a result of spinal cord injury and who were not participants in the research. Their comments are as follows.

*Person 1:*

After discussing the theoretical model, this woman said: "You have covered the areas". She also had other comments of interest. She suggested that the word 'play' in the category 'seeking satisfaction in work and play' might be more appropriately be 'leisure', and the category 'Discovering Life' might be called 'Reawakening to Life' or 'Adjusting to Quadriplegia or Disability'. I asked her why she thought she had done so well, and she made the following statements:

- \* I have good communication skills and people I can talk to.
- \* I have always had a positive outlook.
- \* Therapy has helped.
- \* I had a good foundation, with education and life experience around dependency.

*Person 2*

After discussing the theoretical model, this man said "The model is quite accurate".

He discussed several ideas which arose as he examined the model. They are as follows:

- \* There is a chasm in the system somewhere. Why do so few quadriplegic people gain employment? We discussed the government funding agencies and he told me that he is very grateful for the financial assistance he receives from ACC. He said, "As a society we should be singing the praises of ACC." Yet there are problems with the delivery of service in the minds and experience of many quadriplegic people. For some reason ACC

contributes to a disincentive to paid employment. This idea could become a future study.

\* There is confusion and apathy towards disabled people in New Zealand especially when compared to the United States. The informant thinks the impact of the Vietnam War and the size of the population has put the US ahead in this area. He finds in New Zealand there is a tendency to see quadriplegic people as ill and therefore they are managed within the medical model.

\* For him the reason he has been successful is family support, “especially my mother”. He told me: “At the time of the injury she focussed on what I could do and not on what I couldn’t do”.

The comments of these two people provide credibility for the theoretical model on the basis of their experience of each living with quadriplegia for approximately ten years.

On a personal note, the findings reflect what I expected through my experience with my daughter’s journey following her spinal cord injury in 1987. When I began this study I had in mind that the core process may be the notion of personal development prior to injury. However, while I still believe this fact is very influential in successful rehabilitation, it did not emerge in the study using grounded theory methodology.

## **Summary**

This chapter has included recommendations and implications for nursing, suggestions for further research and an overall evaluation of this study. The evaluation section included a summary of two conversations with non-participants who have quadriplegia following a spinal cord injury and who support the theoretical model.



## CONCLUSION

This study offers a theoretical model for nurses and other health workers who assist people who live with a damaged body to move towards independence. The model indicates that for quadriplegic people there is movement to and fro between dependence and independence. There are four variables which influence this movement and these are: discovering life; generating family and social support; seeking satisfaction from work and play and battling the odds. The theoretical model is confirmed by two quadriplegic people who were not participants in the study. Time did not allow for a response from the participants about the model.

This was a qualitative study using grounded theory methodology. There were nine participants who were interviewed in depth. The data were analysed using constant comparison and the model emerged from this process.

The study has important implications for nursing and for nursing education and several suggestions for further research have been included. Nurses are the group of health workers who are in the most strategic position to assist people who live with a damaged body to move from dependence towards independence. To be effective in doing this, nurses must understand the four processes which contribute to the movement to and from independence, and especially be aware of the odds society constructs against the disabled moving away from dependence.

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## Appendix A

### STUDY OF SPINAL CORD INJURED PEOPLE

### AS THEY RETURN TO LIVE WITH THEIR FAMILIES

### INFORMATION SHEET

My name is Isabelle Sherrard. I am a graduate student in the Department of Nursing and Midwifery at Massey University where I am enrolled in my Masters thesis. I am a Registered General and Obstetric Nurse and I have been employed in nursing education for the last 20 years.

This study has grown out of my interest in people with a spinal injury and the effect of this injury on their relationships with members of their families. My interest in this topic stems from my personal experience with my daughter who developed quadriplegia following a spinal cord injury in 1987. Nursing literature contains little information on this subject. Yet spinal injury survival is increasing and disabled people are returning to live with their families. My specific interest is to contribute to the theoretical understanding of the adjustment process which may assist spinal cord injured people and their families.

You are asked to consider being interviewed in depth, on a single occasion and in the English language. Interviews will be audio taped. Each will take approximately one hour. The tapes will be transcribed and then you will have the opportunity to read the transcript of your interview and have the opportunity to delete and to add material if you wish. If you request to add material a second and shorter interview will be arranged and again you will be offered the transcript to read and delete material. Information collected from the transcripts will then be analysed and a theory developed.

If you have any queries or concerns regarding your rights as a participant in this research you may contact the Health Advocates Trust, phone (09) 638 9638

If you take part in the study, you have the right to:

- \* refuse to answer any particular question, and to withdraw from the study at any time
- \* ask any further questions about the study that occur to you during your participation

- \* provide information on the understanding that it is completely confidential to the researcher, her supervisor and a transcribing typist who will sign a confidentiality agreement. All information transcribed from the tapes will only include pseudonyms of any names or institutions, and it will not be possible to identify you in any reports prepared from this study
- \* be given access to a summary of the findings from the study when it is concluded.

can be contacted at work: (09) 815-2928  
and at home: (09) 620-8863

Supervisor: Jo Walton, Department of Nursing and Midwifery, Palmerston North  
Phone (06) 350 4326

## Appendix B

STUDY OF SPINAL CORD INJURED PEOPLE AS THEY RETURN TO LIVE  
WITH THEIR FAMILIESCONSENT FORM

I have read the Information Sheet for this study and have had the details of the study explained to me. I have had time to consider giving consent for being a participant in the study. Any questions about the study which I had, have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree to have the interview audio-taped.

I have the right to request that the audio tape be turned off at any time.

I also understand that I am free to withdraw from the study at any time, and to decline to answer any particular questions in the study. I agree to provide information to the researcher on the understanding that it is completely confidential.

I agree to participate in this study under the conditions set out on the Information Sheet, of which I have a copy.

I agree/do not agree to the interview being taped.

Signed:

Name:

Signature of Witness:

Date: