University of Southern Queensland

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A LIFE CHANGING EXPERIENCE

- A RURAL PERSPECTIVE ON LIVING WITH PHYSICAL DISABILITY

A dissertation submitted by

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ABSTRACT

The topic of disability permeates medical literature. Yet, while disability as a medical condition is a focus of research and discussion, this research and discussion occurs often in neglectful ignorance of the total life experience of the individual person.

This research is grounded in interpretive phenomenology. The philosophical grounding for the study draws on the works of Heidegger and Merleau-Ponty. The methodological structure of the research used van Manen's (1990) hermeneutic phenomenology to guide a deeper understanding of the human experiences surrounding physical disability. Nine men and women living in different rural communities participated in a series of audiotaped, in-depth, unstructured interviews. The study suggests that living with disability encompasses a complex multidimensional phenomenon to be found within the context of a person's life. Defined by physical and social barriers, living with disability denotes an interaction between impairment, activity limitation, and restricted participation. Four themes emerged that explicate the experience: (1) The Everyday Life of the Body; (2) Valuing a Rural Life; (3) Relationships in Life; and (4) Relating Time to Life. Disability was understood as a life-changing experience that entails complex time-consuming and energy-depleting processes and is defined by personal, family and social development. For the participants in this study, the lived experience of disability can be characterised by the expression: "life is not the same".

The understanding of the essential nature of this lived experience that emerged from this study has implications for health practice. The practice of disability intervention, based solely on impairment, may be inadequate to facilitate optimal health outcomes for rural people. Instead, physiotherapists can assist these people in discernment of priorities, maintaining existing relationships, advocation of rights, and finding the balance to encounter physical and societal adversity. Thus, the study suggests that health professionals need a broad conceptualisation of what constitutes legitimate knowledge for practice and a recognition that disability is an ongoing journey rather than a final destination.

CERTIFICATION OF DISSERTATION

I certify that the ideas, work, results, analyses, interpretations and conclusions reported in this dissertation are entirely my own effort, except where otherwise acknowledged.

I also certify that the work is original and has not been previously submitted for any other award, except where otherwise acknowledged.

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Signature of Candidate Date

ENDORSEMENT

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Signature of Supervisors Date

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CHAPTER 1: INTRODUCTION

I have only this one life
and it is sometimes a relief to express my complaints.
I keep asking questions,
even when no quick answer comes.
Still, I am grateful when I comprehend that, in spite of my pain,
there are elements of my life
that bring me fulfillment and surprise.

- Patricia Nielsen (1994)

1.0. Introduction

As a physiotherapist working with people with a physical disability, the question I am most frequently asked is 'What's so different about rural people with a disability?'. My response to this question, in relation to my study, is contained in the pages of this dissertation. If one can expand the focus and look at the whole picture - the person, the support system, his or her living environment, life circumstances and history - one will have a much better understanding of the rural person living with a disability and the way that that person is similar to and different from an urban person with a disability.

Most people who acquire disability later in life are oblivious to the physical, psychological, and social challenges that lie ahead. These challenges are aspects that influence the beginning of a journey, occasioned because people's lives have been and continue to be disrupted by changing circumstances. The rehabilitation process, including the adjustment and adaptation to a multitude of losses, is often difficult and, for many, unending. Despite this, it appears for these participants that ways can be found around such adversities. They carry on with life in spite of - or because of - the presence of disability. Thus my thesis is: *that, for people in this study, living with disability is facilitated by a determination to move on with their lives, finding support to do so from their rural environment, surrounded by loved ones, and valuing time for its therapeutic worth.*

This chapter introduces the overall study, by contextualising the issue, which gave impetus to the study. The chapter begins by outlining the aim and the background to the study. The research question is presented, followed by the research methodology and method. The phenomenon of interest is introduced and the potential significance of this study is discussed. The study setting, a rural part of Queensland, is then described. To add richness to the data, voices of participants have been incorporated in the text throughout in font 'Arial'. The chapter concludes by outlining the dissertation, chapter by chapter.

1.1. Aim of the Study

The presence of a permanent physical impairment and subsequent disability, acquired later in life, significantly alters a person's everyday life and gives rise to much uncertainty. Concerns arise such as: 'How will I manage work?'. 'How will I manage social activities?'. 'How will I manage the farm?'. 'How will I manage everyday life?'.

Despite my medical knowledge about disability, I became keenly aware of my limitations in addressing these concerns. I believed I could offer so little to facilitate a person's response to the disability experience. As a physiotherapist I had questions as well: 'How do people define and explain disability?'. 'How do they make sense of disability?'. 'How do they respond to bodily changes that interfere with their physical access to the world?'. 'How do they find meaning in everyday life?'.

These questions underpinned the aim of the study which was:

To explore the lived experience of rural people with a physical disability and examine the personal and situational influences that account for unique experiences.

1.2. The Research Question

The formal research question in this study is:

What is the experience of living with a physical disability in a rural setting and how do personal and situational influences shape the experience?

1.3. Impetus for the Study

My interest in the experience of living with disability first developed when I met Sandra. It is difficult to explain the initial feeling that I had for her. To say that I felt sorry for her seems so inadequate. I saw a woman with severe functional limitation caused by physical impairment. She could barely walk, as she had an ill-fitting and broken foot splint that was tied with only an elastic band wrapped around her leg. Yet, I saw also a woman who displayed incredible strength in a multitude of other ways.

Introducing Sandra

Sandra and her husband, Joe, live on a rural property approximately 90 kilometres from the nearest town. The town is so rural that everyone knows every other resident by name. Sandra and her husband had reached the stage in life when some of their dreams had become reality. Their four children had grown up, left home and had all become financially independent. Sandra and Joe had saved enough money and soon they would buy a new truck and catch up with friends in far-away places.

Then one day Sandra suffered a serious cerebrovascular accident (stroke). The stroke affected the left side of Sandra’s body. Half her face was paralysed; and she had hemianopia - a severe problem with vision and with half her visual field lost. Her trunk was weak and her left arm and leg were paralysed. Fortunately, Sandra was able to return home, after several weeks in hospital, with Joe as her ever-present caregiver.

In the years following, Sandra and Joe were very much on their own. Twice a month on ‘pension’ day, the couple made the two-hour round trip to town to buy groceries, pay bills and visit family or friends. They had neither input from health professionals nor did Sandra receive any rehabilitation services. When Sandra was asked about her feelings, she replied that she was somewhat frustrated about her slowness. Other times, she felt ‘lucky’, as she was still able to live at home. She felt lonely though, as her friends had stopped visiting her and she was often too tired to visit them. Sandra was worried about the future; she was concerned about her health getting worse and ending up in a nursing home. When I asked about moving closer to her children, she shook her head. The thing she wanted most was to stay on the farm, with Joe, until the day she died. The thought of ever having to leave the farm was too much for Sandra - ‘it’s something I don’t want to think about at the moment’.

Sandra and Joe had dealt with these and many other issues, without help, for a long time. When I suggested that she might like to talk to others, such as a medical practitioner, about her concerns, she explained that she didn’t see her General Practitioner much. In the past, he had said that ‘he realised that it wasn’t easy, but there wasn’t much that could be done’. He simply [illegible]d ‘you’ve just got to live with it’. Joe felt helpless because he too was worried about the future. His health had also declined with age. To compensate, he read everything he could find about stroke but it wasn’t enough. He believed that he lacked vital information that could help him to handle this complicated and challenging situation. Living with disability has changed the lives of Sandra and Joe - with many of their hopes, dreams and plans now changed.

For Sandra, living with disability and the accommodations made because of it were regarded as ordinary living arrangements, just as she regarded her life as an ordinary life. Despite her physical deficits, Sandra simply ‘carried on’. Each new achievement encouraged her to persevere with other challenging tasks. She was determined to get on with life. Sandra had her own life to live, not the life other people (including her General Practitioner) thought she should live.

Szalai (1980, p.18) puts it this way: 'the life of an individual is, of course, unique and incomparable in a certain sense. It is his [sic] irreplaceable property which he cannot exchange for anything else'. Referring to people with disability, Dovey and Graffam (1987) found that the experience of disability differs significantly from one person to the next, and that an individual's experience varies over time and across contexts. They also found that people with disabilities do not experience disability, per se, rather they experience life.

When I asked Sandra what it was like to live with a disability, she voiced words, which I will not easily forget. 'No one really understands what it is like to live with a physical disability. It's like (pause)…I've lost a lot, but there's no use worrying about that. It's just … moving on I suppose (pause) … carry on like normal and take each day as it comes'.

Angered at my own ignorance and uncertain what to say, I found myself asking her to tell me what it was like to live with disability. It was Sandra's account that made me realise the difference between the patient's experience of disability and the physiotherapist's attention to it. Her words gave me a poignant sense of what it was like: her words formed the impetus for this study.

1.4. The Research Methodology

To answer the research question, this study uses van Manen's (1990) conceptualisation of hermeneutic phenomenology, that is both a research methodology and a method. In the context of research methodology, hermeneutic phenomenology refers to a certain theoretical philosophical framework in 'pursuit of knowledge' (van Manen 1990, p.28). The methodological premise of van Manen practises the philosophical belief that human knowledge and understanding can be gained from analysing the pre-reflective descriptions of people who have lived the experience in question. In other words, the essence of the phenomenon (here the experience of disability) is uncovered by gathering text from those living it and then interpreting this text. The experience of being human and the meanings and understandings that people have about their world are always centred in 'the world of the natural attitude of everyday life' (van Manen 1990, p.7).

Although it may seem that the research question rather than the research methodology formed the important starting point of this study, this is only true to a certain extent. The reality is that the research conducted was very much guided by the methodology chosen. My interest in turning to the nature of lived experience developed from a deep interest in investigating how different people, in the context of particular individual and societal life circumstances, set out to make sense of certain aspect of human existence and the interpretations that are made of those experiences (Heidegger 1962).

Treating a person in their own home meant developing close dealings with that person and his or her family. This created a strong sense of intimacy, a sense of closeness that enriched my work as a physiotherapist. Hence, I choose a research methodology that mirrored this important aspect of closeness. As van Manen (1990, p.2) says 'it is important that the method one chooses ought to maintain a certain harmony with the deep interest that makes one an educator [therapist] in the first place'.

Far-reaching travels, lengthy home visits, in-depth conversations, and extensive journalising of notes and reflective practice were other central elements of the research method and my development as a qualitative researcher. It is a phenomenological study in which lived experience of the world of everyday life is the central focus, an idea that will be discussed extensively in the methodology chapter.

Disability will be explored by examining nine study participants, seven men and two women, everyday, taken-for-granted understanding of their world through expression of their thoughts, language, perceptions and the body (Merleau-Ponty 1962). In doing so, I follow van Manen's methodological research approach in which human situatedness is placed central, based on the belief that human beings and the meanings that they assign to their experiences can best be understood from the experiential reality of their lifeworlds (van Manen 1990). This means that the voices of participants are incorporated in the research to provide a description of disability as it frames their lives.

1.5. The Significance of the Research

Health research about impairment and disability is dominated by positivist theory. It focuses on searches for cures, means of reducing impairment or assessment of clinical interventions; and employs methods such as controlled trials, random statistical samples, and structured questionnaires. Whilst respecting the value of such 'objective' information, such data 'bypass entirely the ways that experience [of disability] is constructed, and the way in which it is made to matter (more or less) in the lives of those concerned' (Radley 1999, p.27). The needed recognition from health researchers is to acknowledge the crucial importance of learning from people's personal, physical, and, especially, the social experience, to enhance our understanding of disability.

Underpinning a phenomenological philosophy is a doctrine characterised by the belief that people create their own social world - rather than merely being shaped by external social processes. Access to their social world, however, cannot be grasped until people are given a 'right of voice' (French and Swain 1997, p.27). The purpose, then, is to transform their voice into a textual expression of essence, which serves to capture a true picture of the meaning and complexity of disability as understood within the context of the participants' lives. van Manen (1990, p.36) describes this effect of the text as '… at once a reflexive re-living and a reflective appropriation of something meaningful: a notion by which a reader is powerfully animated in his or her own lived experience'.

Whilst the first part of the research question related to seeking an understanding of the diversities of the lived experiences, the second part of the question seeks an understanding of the way in which their [rural] environment influences the experience. Little research has concerned itself with the disabling environment, more specifically the rural environment, and its impact on disability experience. Labelling people as 'rural' infers that they should be treated as a special group apart from the mainstream. It also indicates that rural is a homogeneous group, which it is not, as each rural community is different (Humphreys and Rolley 1991; Reid & Solomon 1992; Mathers 1994; Fragar, Gray, Franklin and Petrauskas 1997).

This 'rural' labelling has been a deliberate act by the researcher to highlight further the plight of rural people with a disability who experience many health disadvantages compared with their urban counterparts (Australian Institute of Health and Welfare 1998). Furthermore, rural people are a rather poorly understood and mythologised population (Coward and Lee 1985). Typically, rural people are depicted whilst horseback riding, battling bushfires or crossing flooded creeks. Alternatively, we can see images of dry and drought-stricken areas to illustrate one serious challenge that rural residents face. It is easily seen why rural people evoke expressive language, such as 'he or she is a tough bushy'. This representation, justified or not, can lead to the perception that, because rural people are accustomed to exposure to hardship, they are hardened and can cope with challenges and adjust to hardship as it presents.

This study does not suggest that rural people, as a group, hold either one set of beliefs and attitudes to disability or that rural people hold constant and consistent views. Nor does the study suggest that the experiences are typical, or that the participants are representative of a culture. Each person's experience is different from that of anyone else; their circumstances and situations may be comparable, yet their experiences may not. The aim is to explore the range of views held by rural people and uncover unique meanings, not generalities, and to tease out common themes and patterns about the phenomenon. The crucial tenet, however is to conduct research *with* people and invite them to participate in the development of knowledge about themselves.

Management of disability, including rehabilitation, is well-described in the medical literature. The literature highlights the dominance of the medical model of disability, whereby medical and rehabilitative professionals tend to conceive disability as an individual physiological condition requiring the afflicted individual to be given appropriate medical care (Imrie 1997). Analysis of the literature reveals that wider social and environmental influences surrounding a state of disability are not highlighted. It is my belief, however, that incorporating the perspectives, views, attitudes, preferences and experiences of people affected with an acquired disability will illuminate the subjective 'lived' experience and provide a focus on new metaphors - which could make a difference to the way our culture views people with a disability and how we as health professionals provide care.

Given that physiotherapists are more likely than most other health professionals to spend a good proportion of their time with such individuals, it is critical to note the significance of the disability experience. Paris-Spink (1999) and Yardley (1999) believe that this knowledge influences health practice and facilitates reflective practice. Reflective practice encourages physiotherapists to think and act broadly and flexibly, outside the medical model of illness and disability, and without inadvertently restricting and alienating the very people they are trying to assist (French, S. 1997). Ideas and wishes of people with a disability are sometimes deemed as 'unrealistic' or 'impossible', perhaps because we, the health professionals, rarely consult the people who *actually* experience disability. Hence French's (1993) advice is 'to become fully acquainted with disability from the perspective of the person as it helps us to adjust the social and physical world to accommodate them' (French 1993, p.23).

There are studies, with empirical data on rural communities, that confirm that rural people with disabilities experience significantly more serious physical, psychological and social problems compared with their urban counterparts (see for example Mathers 1994; AIHW 1998). I believe, however, that highlighting the experiences and perceptions of rural people living with disability may suggest a more thoughtful practice with regards to service and facility development for rural residents.

By understanding the subjective human experience of disability, research evidence can be developed and synthesised, bringing together the existing body of knowledge and the perspectives of the individuals living with disability. It is my intention to present these useful findings to the physiotherapy profession, to international, governmental and non-governmental organisations, as well as to those working towards social development, that is, researchers, planners, practitioners, and policy makers. In short, I will present the findings to those in favour of the advancement of meeting the needs of rural people in general.

1.6. The Phenomenon of Interest - Physical Disability

Disability, by definition, is not an illness; and equating it with illness has led to confused and often misleading, negative and biased descriptions. For example, a World Bank (1993) publication depicted disability as a part of the ‘global burden of disease’, measured through estimates of years of life ‘lost’ from disease and disability. I am not certain that participants consider the years of life with disability as ‘lost’ years! To avoid some blurring between chronic illness and disability, I emphasise that the participants in the study identified themselves as having a physical disability (see Appendix A); they are not ill or sick, according to the common use of the words. I recognise that not all individuals who are chronically ill are functionally disabled; and that many disabled persons do not require any significant amount of health care. Moreover, I do acknowledge that many people with physical disabilities are disabled by disease or as a consequence of an illness. Furthermore, I also recognise that the same illness may cause a different disability; and a different illness may cause the same disability. I am not disputing a conceptual distinction, rather emphasising a practical distinction similar to the view of the philosopher Amundson (1992 p. 108), when he says:

> Unlike ill people, people with a disability are not (typically) globally incapacitated except insofar as the environment helps to make them so. They don’t require extraordinary medical care. Nor are they globally incapacitated by their physical conditions, but by the social devaluation.

Much has been written on ‘disability’, particularly ‘physical disability’, since the post World War II era, highlighting the diversity of professions and interested groups involved in this field. Within this literature, numerous definitions of disability are offered. One example is the widely-used definition of disability, developed by the World Health Organisation (WHO 1980, p.143):

> Disability: In the context of health experience a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner, or within the range considered normal for a human being.

Disabilities according to this definition arise as a result of impairment with the focus on the functional performance of an activity of the individual in a manner normal for a human being. Although the WHO (1980) definition is widely accepted in the medical world, I am not convinced that this definition depicts disability as study participants see it. The notion of who is disabled or not was avoided by asking participants to identify themselves. Self-identification as a means of recruiting participants for the study was useful, as it avoided debate over a definition of physical disability. As Weinsheimer (1985, p.1) noted ‘through definition, a word becomes a term: rigid, predictable, and invulnerable to the twists and turns that a word receives in dialogue and in the history of the language in general’. With this in mind, an information sheet was devised which invited people ‘who have a physical disability’ to participate in the study (see Appendix A) without adding a definition of physical disability. People who volunteered to participate had a Stroke, Parkinson’s Disease, Multiple Sclerosis, Muscular Dystrophy, Spinal Cord Injury, and Brachial Plexus Injury. Each person identified himself or herself as having a physical disability because their body caused them great physical struggles. However, soon it became apparent that physical, social, and other barriers too defined disability.

It is not the intention to develop another definition of disability; instead, disability will be described through detailed interpretation of various experiences as it relates to disability for people living in rural environment. Thus, it is the intention to know the meaning of disability, not necessarily by only defining it, but also by experiencing it through the lives of those who live with disability.

A conscious decision has been made not to ignore the current definitions of disability for two reasons. First, defining disability is important if one is to understand how the power of definition is exercised and experienced. For example, questions in regard to who does the defining in practice, for what purposes, and with what consequences for those who are deemed to fit the definitions are important. Second, a definition can serve as an important reminder that many of the obstacles faced by people with disabilities are not necessary consequences of their physical conditions; hence further exploration of the literature describing the phenomenon will be discussed in the next chapter where the literature will be reviewed.

Finally, in line with Australian Policy and Service provision levels (Australian Parliament Office of Disability 1994), the term ‘people with disability’ is used in preference to the term ‘disabled people’. Furthermore, to refer to the study participants as rural people with a physical disability is logical, but long-winded. It should be noted, therefore, that all of the participants in this study are rural people with a physical disability and they shall be described merely as participants hereafter.

1.6.1. The Prevalence of Physical Disability

Disability studies often incorporate objective statistical information intended for different purposes, for example, to substantiate the size of the problem (Jette and Branche 1981), to ensure equitable access to services and correct distribution of skilled workforce (Roemer 1987), or to serve as an indicator of service needs in the area of disability support or rehabilitation services (AIHW 2000).

Available statistics on disability give a brief, narrow picture of the disability experience. For example, a 1999 report produced by the AIHW titled 'The definition and prevalence of physical disability in Australia', identified that 11.9%, or 2,099,600 Australians have a physical disability (AIHW 1999, p.35). These statistics were obtained through a survey that focussed on abilities to perform basic personal care, household management, and work activities. Whilst the value of such epidemiological data on disability is extremely valuable, such figures do not necessarily increase our understanding of the 'problem' nor do they highlight how care should be provided. Yardley (1999, p.31) alludes to the purpose of statistics.

> … statistics maximize the precision and objectivity of analysis whereby the aim is to obtain measures of objective, physical reality which are uncontaminated by subjective, mental processes - whether these are the investigator's or the research subject's 'biases' in perception or reporting (p.31).

An alternate view is that incorporating subjective views can complement the disability research. This will enable a detailed insightful interpretation of disability and consider explicitly the way in which the participants and the researcher have jointly contributed to the understanding acquired throughout the course of the study. Disability and the meaning of it cannot be isolated from perceptions and interpretations of individual meanings - hence the use of a qualitative research framework to yield more detailed and elaborate description complements the quantitative disability research.

1.7. The Researcher

Over the years, as a physiotherapist practising in rural communities, I became increasingly aware of a discrepancy between the perception of disability and its consequences, as held by health professionals and as held by those people living with disability. It was recognition of this discrepancy that formed the background from which this study evolved.

Before this study began, my understanding and knowledge about disability was mainly derived from textbooks. This type of knowledge was imperative for my understanding of physical disease and disease processes, but did little to advance my understanding of the human experience. Over many years of practice as a physiotherapist, I became increasingly eager to understand the wider issues that frame the context in which physiotherapists work and, from this understanding, eager to enhance my practice. In terms of everyday practice, I wanted to embrace reality and investigate rather than avoid concerns presented by those living with disability. It is as Bogdan (1996, p.35-36) terms it ‘to get behind the scenes and understand [the patient’s] place in the world as it is presently constructed’. A note on the use of the word, patient, is warranted here. In this dissertation, I use the words ‘patient’ and ‘person’ interchangeably. The latter conveys a more accurate sense of my point of view than the former, as I wish to place stress on the person as an active human being, rather than the patient as a passive being. In spite of this good reason, occasionally, it sounds excessively artificial to avoid the term ‘patient’, particularly if a participant designated him or herself as such. Consequently, either word is used with the same meaning, that is more person, less patient, as the ultimate aim was to develop knowledge based on ‘understanding’, rather than merely knowing.

My encounter with Sandra led me to experience a heartfelt, soulful interest in disability as a human experience. Influenced by Skelly (1996) who encourages physiotherapists to research actively, rather than merely to be aware of the influence of socio-economic and psychological factors, I further developed my profound desire to understand the meaning assigned to disability as a human experience.

Over the years, physiotherapy has transformed from the status of a craft to that of a technological science; a development that likely influenced the way health care approached illness and disability (French 1997). Perhaps this accounts for the way in which health professionals, including physiotherapists, regard disability as a disease, that is, a health problem. Needless to say that the treatment, therefore, seems to centre much around the disease - with little or no attention on the *person* with the disease. Lives, for that reason, are not discussed in terms of human experience, but rather in terms of 'problems' to be solved. After all, the physical status is a 'fait accompli' - an accomplished fact; the physical problem is irreversible, in spite of everything, the impairment is permanent. A typical response from health professionals, to people with disabilities is, 'I can't do anything. You have just got to live with it'. Unable to agree with this view, this study began as an attempt to alter the type of response.

Disability, from my perspective, is not a disease; hence the medical model is not appropriate. The central focus of the study is not on anatomy, physiology, or other medical information but on the person. In my view, disability is more of a social phenomenon, with social aspects. I am aware that people with disability, particularly those living in rural Australia, are socially marginalised. As a physiotherapist, I have a clear vision of what can be done to improve the health outcomes of rural Australians. This vision begins with helping to illuminate disability experiences! My aim is, as Minichiello, Aroni, Timewell and Alexander (1990) state, 'primarily geared to finding out the truth as the informant sees it to be, rather than the truth per se' (p128). Rather than asserting 'I can't do anything more for you' - which, incidentally, does not align itself with 'Best Practice'- I believe that we *can* do more… if only the attention was focused firstly on the *person* as a unique individual who has had to face the challenges associated with physical loss, rather than merely focusing on the disease.

I became attracted to phenomenology as a research methodology and method for investigation. To pre-empt misunderstandings: I am a physiotherapist, not a professional social scientist, philosopher or a nurse. I do not claim to possess a foundation in social science, philosophy, or nursing. However, readings of

Heidegger, Husserl, Merleau-Ponty and a more recent phenomenologist, Max van Manen, have increased my knowledge of phenomenology to such an extent that an effort has been made to apply thoughtfully these principles in a meld of philosophy, social science, and nursing.

Following Van Manen (1990), who proposes that health professionals must become more involved in the way that people experience and live with their problems in a different, sometimes deeply personal and unique manner, I became ‘immersed’ in the social setting. As a full-time clinician, I was able to focus on individuals interacting with their social context and I was able to consider the environmental factors. I explored the communities, stayed in the towns, got to know the service providers in the areas, and worked in the area. In essence, I became involved in a multitude of community activities.

This research is woven with assumptions that are common to qualitative research. First, it is important to acknowledge the belief in multiple realities. Lincoln and Guba (1985) foster the idea of multiple realities and support the position that there is more than one way to know something and that knowledge is context-bound. Similarly, van Manen (1990) also considered the thematic analysis of an experience to be one interpretation amongst many and is therefore at no time considered to be the absolute truth of the experience, nor exhaustive of the potential for further interpretations. In this study, acknowledging multiple realities was achieved by inviting nine different voices to inform the study, as there is not one single truth about living with a disability. Each individual provided a different perception of disability, which represents something different for each individual. The result, however, is a reflection of my commitment to the participants’ point of view.

In-depth interviews were used rather than a quantitative means of measurement, analysis or replication and enabled the generation of rich data. Without participants and without the employment of unique and specific interview contexts, much of the data that I was seeking would have remained hidden - out of sight and beyond reach.

So, with as little disturbance as possible, that is, with phenomenological interviewing conducted in people's own homes, I aimed to minimise the intrusion and maintain the natural context of the setting, allowing the participants' experiences to be captured in an environment in which they live.

I acknowledge my participation as a researcher in the research process. It was impossible for me to be completely removed (or neutral) from the study. My position as an observer, an interviewer, and an interpreter made me an active participant. To prevent bias associated with preconceived ideas, bracketing was used. In fact, bracketing was used before data collection began, as well as during data analysis. Practically speaking, this meant setting aside biases, prejudices, theories, philosophies, assumptions and understanding about disability. This included, for example, perceptions of resilience, perceptions of low use of rehabilitation services and perceptions of resourcefulness. To make these perceptions explicit, I recorded these in a journal to keep me conscious of any arising disparities. It is clearly most important for any researcher to identify their own theoretical assumptions and frameworks, to recognise them as an integral part of the research process, and to report them, in order to evaluate successful bracketing when analysing and interpreting data. As stated earlier in the chapter, participants' quotes and commentaries are presented in altered font 'Arial' to signify their voices to the reader.

As a final point, physiotherapy research principles are traditionally placed within the empirical paradigm. Although it is extremely useful for comparative analysis, it does little to increase understanding of human phenomena. Since such empiricism is not the basis of this study, the choice of literature covers a wider array of sciences, most notably social science and other health sciences, such as nursing, occupational therapy, psychology and medicine.

1.8. The Study Setting

In line with the methodology chosen for this study, it is appropriate to draw a picture of the milieu in which the study took place, as a description of the area may serve to locate and facilitate understanding of the participants' experience of disability.

The people who participated in this study live in the 'Darling Downs', an area that fans out westwards from the crossing of the Great Dividing Range at 'Cunninghams Gap', southwest of Brisbane (see Map 1.1). This area covers 91,645 square kilometres and forms approximately 5.2 % of the State of Queensland (Office of Economic and Statistical Research 2000).

Map 1.1: The Darling Downs and Queensland

Source: Office of Economic and Statistical Research (2000, p.5)

The estimated resident population of the 'Darling Downs' in 1999 was 201,446 persons, with around half of this population living in large regional cities, such as Toowoomba and Warwick (Office of Economic and Statistical Research 2000). The rest of the population is dispersed in small rural communities, with significant distances between them. It is from within these small communities that participants were recruited. Residents living in large regional cities such as Toowoomba were not included.

The ‘Darling Downs’ is an area of rich agricultural production, producing 20% of Queensland’s total primary production (Office of Economic and Statistical Research 2000). It is classified as ‘rural’ for reasons that will be further discussed in the next chapter. In this introductory chapter it is acceptable to say that it is rural for the following reasons. First, farming is the primary industry. Second, the populations of the towns are quite small compared to the capital cities and third, the distance to Brisbane is well over five hundred kilometres - a six or seven hour drive from the most northern town on the Darling Downs. The Darling Downs is a sprawling region where roads crisscross the land like arteries pumping blood into the country towns and farms. Further west, there is grazing country with sheep and cattle stations. There are many fruit orchards and plantations, unique little towns with a character all of their own. Life for most people on the Darling Downs has generally been comfortable, prosperous and secure. However, there are disconcerting factors; change in the economic climate, emigration of younger people and their families. Additionally, the loss of a range of health services, social welfare agencies, retail and other services from the small rural communities of the ‘Darling Downs’ have impacted negatively on the physical and mental well-being of people. At the time of the interviews, some participants expressed concern about the changes implemented by the Government, such as introduction of the Goods and Services Tax (GST) and changes to the dairy milk supply quota system. Although it is difficult to predict the final impact of policies of economic rationalism, prospects look grim for these rural and remote communities.

1.9. Overview of the dissertation

The structure of the dissertation is, of course, imposed at the conclusion of the research process to produce a logic which is now available to the reader but which was not there while the work was in progress. It is the methodology that imposed the order of the research activity. This activity included movement between the literature and the participants, as the data were analysed and knowledge emerged.

Chapter Two, ‘Literature Review’ is presented in three parts. The first part, ‘Approaches to Disability’, contextualises the discussion about disability and its current, contested definitions. Questions in regard to who does the defining in practice, for what purposes, and with what consequences for those who are deemed to fit the definitions will be explored. The second part, ‘Experiences of Disability’, uncovers more about the mostly unfamiliar world of people living with disability. The third part, ‘The Rural Context’, highlights some of the distinctive features associated with living in a rural environment.

In Chapter Three, I describe in detail how hermeneutic phenomenology fits this study when seeking the meaning of physical disability. I outline the theory behind the method by discussing the philosophical framework and the fundamental assumptions. I discuss how the central point of this dissertation is the "everyday lived experience" of human beings, as they find themselves in the world, and as they give active shape to their world. It will be demonstrated that through phenomenological thinking it is possible to understand such experiences better and therefore subsequently to act more effectively in our dealings with clients. I will detail the way in which the methodology, positioned within the interpretivist approach, was developed to draw out the intricacies and intimacies of the disability experience. I argue that health professionals need to be thoughtfully aware of how people think, feel, see things, or experience issues and how this requires, on the part of the health professional, an embodied form of knowing and of understanding. More specifically, I argue that, if health care professionals are to assist and support people to recover, they must have accurate and detailed knowledge of the daily concerns, values and habits of the people for whom they are caring.

Chapter Four outlines the research design and the methods conducted in this study, by detailing theoretical and practical procedures. It describes the data collection techniques of in-depth interviewing, journalising, reflective practice, and outlines van Manen's (1990) six-stage process of thematic analysis.

Chapter Five introduces the participants whose lives are central to this study and whose shared experiences of disability give it its foundation. Comparisons are made and similarities and differences highlighted. The chapter continues by providing a vignette of each person, focussing particularly on their unique experiences in the disability context.

Chapter Six, *'Life is Not the Same'*, provides an overview of the data analysis and interpretation and presents a brief introduction of the bodily, spatial, temporal and otherness themes underpinning the experience of disability. It is apparent that the participants view disability as part of an experience, connected to four related interactive themes. The first theme, '*The Body in Everyday Life'* describes the tasks of resuming a life whilst dealing with physical, emotional and social changes. The second theme, *Valuing a Rural Life',* describes how and why participants assign high quality to rural life, in spite of its harsh and (often) unfair inequality. The third theme, *'Relationships in Life'*, was defined by participants' personal, family, spiritual and social interaction with others. The fourth theme, '*Relating Time to Life'*, denotes how participants experienced a sense of progression, from one life into a new, albeit different, life.

A much more detailed discussion of each of these themes is provided in the Chapters Seven to Ten. More intimate personalised insights into the disability experience are included. The data indicate that disability is a process that takes place over time and through which people's perceptions and experiences are altered, as opposed to being a permanent identity or status that occurs as a result of a discrete event.

Chapter Eleven summarises the research findings, draws conclusions from those findings and indicates some of the implications of the findings. Limitations of the study and suggestions for further research in this field are considered.

1.10. Conclusion

In this introductory chapter I have introduced the aim of the study, outlined the impetus for the study, and discussed the thesis that underpins the study. Next, the research questions were introduced, followed by an introduction of the phenomenon 'physical disability'.

To explore disability, van Manen's phenomenology has been used. Through the art of writing and rewriting I aim to uncover the meaning and reveal the personal and situational influences that account for the participants' unique experiences. This should have implications for the way in which health professionals address concerns and needs, as they arise in the lives of those living with disability. Furthermore, it may influence the way health professionals assist those newly-diagnosed with physical impairment.

The chapter continues with an overview of my personal and physiotherapeutic background, which undeniably influenced the study. The study context, the Darling Downs, was introduced, followed by an overview of the dissertation.

In the next chapter, I present an overview of the literature as it relates to the study and the context in which it takes place. It allows for the contextualisation of the current state of knowledge about disability, rural health, and literature about personal experience within the literature.

CHAPTER 2: LITERATURE REVIEW

2.0. Introduction

This chapter is divided in three sections. It sets the context of the study with a review of issues in the literature on the concepts, ‘disability’, ‘experiences of disability’ and ‘rural context’, which informed this inquiry.

The first section, entitled ‘Approaches to Disability’, explores the perspectives of disability that currently compete for dominance in the context of Australian disability treatment programs and intervention. To determine the most appropriate basis for this study and to understand the phenomena of disability, three approaches to disability are examined. I contend that the different approaches are based on different theoretical frameworks, leading to different policies and practices for people with disabilities - not always in the best interests of those living with disability. Using ideas from Bickenbach (1993) and Oliver (1990) I argue that the social model is a valuable way of conceptualising disability.

In the second section, entitled ‘Experiences of Disability’, the research literature is explored to uncover more about the mostly unfamiliar world of people with disability. Much of the literature constructs disability as a personal problem, a physical problem, thus a bodily problem. I argue that such a construct is narrow, as disability is more than an individual physical problem. It is proposed that the interpretations, adapted from the work of Bury (1982; 1988; 1991), Charmaz (1983; 1987; 1991) and French, S. (1993; 1994; 1997) present a more complete view of disability, one that incorporates elements of the social model of disability.

The third and final section, entitled ‘The Rural Context’, reviews the mainly Australian literature on rural issues. The purpose of this section is to highlight some of the distinctive features associated with living in a rural environment.

2.1. Approaches to Disability

This section explores the disability context from which this study evolved. One of the key features of disability literature over recent years has been the emphasis on changing the definition of disability (Barnes 1991; French 1994; Oliver 1996a; 1996b). It might be argued that this emphasis is purely a matter of semantics and hence its importance may be overlooked. Different definitions have very different implications, however for what is viewed as the appropriate response to disability.

Contention about terminology further extends to the term ‘disabled person’; a term much preferred by disability activists, as they regard disability as an essential part of the self which cannot be separated from the person (Oliver 1990; Wendell 1996). Activists and authors use ‘disabled’ in the same way ‘black’ was used in the civil rights struggle of the Black Americans. Unlike the disability activists, I prefer to use the term ‘people with disability’. In doing so, I acknowledge that, in Australia, the latter definition is the most accepted as an expression of respect for people with disability. Furthermore, ‘people with disability’ is a way to acknowledge the primacy of the person over the disability (Zola 1991). To understand how I came to this usage requires a closer look at definitions of disability.

Definitions of disability have long been a matter of contention (Oliver and Zarb 1989; Oliver 1990; United Nations 1994; French 1997) so how important is it to find the correct definition: does it matter? I share French’s view (1993, p.22-24) when she outlines that ‘if we are not prepared to discuss all aspects of disability, there will be no possibility of finding creative ways of reducing it’. Even if nothing can be done to alleviate a disability it may be very important to the person concerned that others should know of its existence.

Attempts to change people’s attitudes to disability have not been particularly successful overall, however this does not mean that the attitudes of some people, including disabled people themselves, cannot be modified by an understanding of the complex experiences of people with impairments. It is time, I contend, to broaden and intensify the examination of disability and to develop and deepen our knowledge, for the benefit of all who define themselves as disabled.

The first attempt to define disability began two decades ago by the World Health Organisation (WHO 1980) publication, which was released to parallel the International Classification of Impairments, Disabilities and Handicaps (ICIDH). At that time, the ICIDH classification system was considered as the standard taxonomy in the areas of medicine and health statistics.

Three central concepts defined in the WHO (1980) publication are impairment, disability and handicap.

> **Impairment**: In the context of health experience an impairment is any loss or abnormality of psychological, physiological or anatomical structure or function (WHO 1980, p.47).
>
> **Disability**: In the context of health experience a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner, or within the range considered normal for a human being (WHO 1980, p.143).
>
> **Handicap**: In the context of health experience a handicap is a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual (WHO 1980, p.183).

The WHO (1980) also gives a functional limitation definition of disability with regard to ‘physical disability’, and breaks it down into several subgroups:

> Locomotor disability, which refers to ‘… an individual’s ability to execute distinctive activities associated with moving, both himself [sic] and objects, from place to place (WHO 1980, p.161).
>
> Body disposition disability, which refers to ‘… an individual’s ability to execute distinctive activities associated with the disposition of the parts of the body, and including derivative activities such as execution of tasks associated with the individual’s domicile (WHO 1980, p.183).
>
> Dexterity disability, which refers to ‘… adroitness and skill in bodily movements, including manipulation skills and the ability to regulate control mechanisms (WHO 1980, p.160).

The WHO definitions were criticised for a number of reasons by disability activists and other scientific researchers (Oliver 1990; Madden, Black and Shirlow 1993; Wendell 1996). The main issues raised were that:

- The underlying assumption is that the problems (and solutions) lie within people with disabilities rather than within society - thus ignoring social arrangements and expectations. The apprehension regarding individualising disability is that the effect of the environment upon the lives of people with a disability is *not* addressed (Oliver 1990; Madden et al. 1993).
- Disability is viewed in terms of a disease process, abnormality, and personal tragedy (Oliver 1990).
- Action becomes focused on seeking to enable disabled people to strive for 'normality' in a world that is designed for the non-disabled majority (Northway 1997).
- A value judgement is passed on the person to whom the label 'disabled' is applied, in that it suggests a 'falling away from normality' (Goodall 1995, p.324) since the individual is unable to perform within the range considered 'normal'.
- The notion of normality is narrow, as it is used as an able-bodied conception imposed on people with disabilities (Oliver 1990). It ignores cultural differences or age (Wendell 1996). According to this model, for example, older people can be disabled by the normal process of aging, but not be handicapped, unless they cannot fulfil roles that are normal 'for our age' (Wendell 1996, p. 18). There is an inference that after a certain (old) age, it is 'not normal' to fulfil certain roles.
- Scientific researchers (Verbrugge and Jette 1994) cited problems of conceptual clarity and internal consistency, and experienced difficulty using the definitions as a basis for hypothesis development and study design.

Criticism also arose from the 'Union of the Physically Impaired Against Segregation' (UPIAS 1976). Members of this organisation reiterated that disability is not about individual limitations as the cause of the problem, but about society's failure to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account in its social organisation (Oliver 1996a). In view of UPIAS' criticism, Finkelstein and French (1993 p.28) devised the following definitions:

> Impairment is the lack of part of or all of a limb, or having a defective limb, organ or mechanism of the body.
>
> Disability is the loss or limitation of opportunities that prevents people who have impairments from taking part in the normal life of the community on an equal level with others due to physical and social barriers.

Similarly, the WHO (1997) decided to incorporate new developments and criticisms of the original ICIDH; hence the revised framework ICIDH-2. In the revised framework (ICIDH-2), the term 'disablement' is introduced as an 'umbrella' term to encompass the universe of disability experience, including three basic dimensions: 'Impairment', 'Activity' and 'Participation'. The term 'Activity' and 'Participation' replacing 'Disability' and 'Handicap', respectively.

The proposed ICIDH-2 definitions of impairment, activity and participation are as follows:

> **Impairment**: In the context of health condition an impairment is a loss or abnormality in body structure or of a physiological or psychological function.
>
> **Activity**: In the context of health condition is the nature and extent of functioning at the level of the person. Activities may be limited in nature, duration and quality.
>
> **Participation**: In the context of health condition is the nature and extent of a person's involvement in life situations in relationship to impairments, activities, health conditions and contextual factors. Participation may be restricted in nature, duration and quality.

The ICIDH-2 definitions are considered to be an important way forward for people with a disability and likely to influence the debate centred on the important question, is disability seen as an individual tragedy, with the problem residing within the individual or is it a social problem, largely caused by oppressive barriers within the environment? (Oliver 1990; Bickenbach 1993; Finkelstein and French 1993; Madden et al. 1993; Swain, Finkelstein, French and Oliver 1993; Wendell 1996).

2.1.1. The Australian definition of disability

Within Australia, the debate of defining disability has occurred essentially since the International Year of Disabled Person (Madden et al. 1993). Currently, bodies such as the Australian Institute of Health and Welfare (AIHW) use the terms as outlined in the draft ICIDH-2 (see for example AIHW 1999). The report titled ‘The definition and prevalence of physical disability in Australia’ (AIHW 1999) shows extensive use of the ICIDH-2 draft definitions.

As the phenomenon of interest is ‘physical disability’ it is important to consider this within an Australian context. There is substantial variation in the definition and scope within the terms ‘physical impairment’ and ‘physical disability’ as used in some international documents (AIHW 1999, p.25). Prior to the release of the AIHW (1999) report, ‘physical impairment’ or ‘physical disability’ was not generally defined within Australia. However, in order to constitute a basis for prevalence estimations and tailoring of service provision, the AIHW devised the following approach based on the ICIDH-2 whereby people with a disability are defined as:

> People who report an activity limitation, or participation restriction as well as a physical impairment or disability condition, thus incorporating the different aspects of the disability experience (AIHW 1999, p.28).

It is impossible to generate one single definition that describes ‘the experience’ of all those who report disability, for I can see the truth in aspects of several definitions generated. The important principle is that existential being is the basis for understanding rather than abstract theories. For at this point, however, I would like to use the following hypothetical scenario in order to illustrate ‘disability’ through an interpretation of various experiences.

A 60-year-old male farmer rolls his tractor and sustains fractured lumbar vertebrae and permanent crush-injury of the spinal cord resulting in flaccid paralysis of the muscles of the lower limbs (physical impairment - paraplegia). As a result, he cannot walk or drive his tractor (activity limitation). Absence of public transport or taxis in his living environment to accommodate his wheelchair deprives him from working and other social and cultural activities (participation restriction). Subsequently he experiences a sense of social isolation accompanied by emotional distress (emotional impairment).

This scenario, although hypothetical, captures the usage of the term ‘disability’ in Australia (as it considers disability as a multidimensional phenomenon; a combination between physical and emotional impairment, activity limitation and participation restriction). It is in this context that disability will be used throughout the dissertation (unless specified otherwise).

Notwithstanding the major use of the term ‘disability’ throughout the dissertation, it is necessary to have an understanding of the implications of the three different approaches that form the basis for the lives of people living with disability.

2.1.2. Models of Disability

This section relates to the implications which three different disability approaches based on the concept of impairment, disability and handicap have for the lives of people with disabilities. Oliver (1990) and French (1993) have argued that within every society there are competing models of disability, some more dominant than others at different times. Although often in conflict, these different models gradually influence and modify each other - hence a presentation of the relationship between the various models is useful.

Oliver (1993), an acclaimed researcher in disability studies, maintains that previous researchers have failed to identify their theoretical assumptions and that they generally implicitly adopt the dominant (medical) model in their research aims, designs, and results. This, in turn, perpetuates a particular view of disability to the exclusion of competing approaches. Authors such as Oliver (1986) and Bickenbach (1993) have argued that understanding the assumptions behind notions of disability is a pre-requisite for developing theories and research designs, and in turn constructing social policies for people with disabilities.

Although it is not my intention to construct policy or develop theories in this inquiry, I believe that it is critical for me as a researcher to identify my theoretical assumptions and frameworks, to recognise them as an integral part of the research process, and to report them in order to enable comparisons with other works and approaches. In doing so, I draw on Bickenbach's (1993) three-fold framework of disability approaches and discuss these in the light of Australian context. The three models are the individual/medical model (based on impairment); the economic model (based on disability) and the social model (based on handicap).

2.1.3. The Individual/Medical Model

For many years an individualistic or medical model has prevailed, which suggests that, because an individual has some form of impairment, then he or she is unable to perform certain tasks or take part in certain activities (French 1994). Parsons (1951) considers other key elements of the medical model such as the importance of the doctor, as the expert authority, who maintains 'objectivity', treating symptoms of disease scientifically and impartially. The patient does not play an active role, except for complying with the doctor's prescriptions. Thus within this model the focus is on impairment, with precise descriptions of the varieties of disablement, and provides clear resolutions of the 'problem', for example, prevention, cure, containment and rehabilitation.

Essentially within this model, disability is conceptualised as an individual issue requiring individual, medicalised solutions (Oliver 1990, 1993; Bickenbach 1993; Swain et al. 1993). Consequently, under the influence of this model, the 'problem' of disability is located within the individual. Further, it sees the causes of this problem as stemming from the functional limitations or psychological losses which are assumed to arise from disability. These two points are underpinned by 'the personal tragedy theory of disability' which suggests that 'disability is some terrible chance event which occurs at random to unfortunate individuals' (Oliver 1993, p.32). Others such as Brechin and Liddiard (1981) also identified that the medical model has guided and dominated clinical practice, with the resulting assumptions that both problems and solutions lie within disabled people rather than within society. Hence the concern that by individualising disability the effect of the environment upon the lives of people with a disability is not addressed.

Further, the medical profession, because of its power and dominance, has spawned a whole range of what Oliver (1996b, p. 37) terms 'pseudo-professions'. Oliver (1996b) refers here to physiotherapy, occupational therapy, speech therapy and clinical psychology, all geared to the same aim - the restoration of normality. The reality is that the individual/medical model lies at the heart of clinical practice thus it may be difficult for health care professionals, including physiotherapists to consider 'changing their attitudes and behaviour' towards disability and people with disability (French 1997, p. 336-337). Thus, our professional education has the potential to provide clinicians with a narrowed insight of disability, which can easily give rise to conflict or ineffective communication with people with a disability. Fulcher (1989, p.44), for example, notes that a medical view is seen as 'scientific', therefore value-free and apolitical … 'the doctor knows best'.

Another criticism of this model relates to the fact that, under the influence of the individual/medical model, people with disabilities are viewed as individual victims with special needs. Therefore to qualify for medical services, social welfare entitlement or any other special services, deficiencies and limitations have to be emphasised (Bickenbach 1993).

As Australia's service provision for people with disabilities developed, so did the second approach to disability, the economic model.

2.1.4. The Economic Model

The second approach to disability, the economic model, was growing in parallel with the medical model. This model arose with the growth of the welfare state and notions of rehabilitation for returned war veterans (Bickenbach 1993; Madden et al. 1993). For the first time, disability was seen as a social problem that was not reducible to medical impairment but it required social solutions. Hence the introduction of educational, vocational, and community support for people with disabilities rather than seeing them as incapable of work or independence (Bickenbach 1993; Madden et al. 1993). This model has an emphasis on disability, describing the effects of impairments on an individual's repertoire of capabilities, and measures the cost-benefit ratio of work-based disability.

In Australia, after World War I, in 1919, vocational training schemes and other support services for ex-service men and women were set up. In the years that followed, ongoing support service development continued, providing employment and training for people with disabilities. Within this model patients became 'clients' and service approaches began to emphasise a more holistic approach (Bickenbach 1993). Criticism of this model relates to the following:

- Despite the proliferation of new rehabilitation professions (Bickenbach 1983) doctors were in charge of most rehabilitation facilities and medical issues tended to have first priority (Brechin and Liddiard 1981; Oliver 1990).
- Disability is reduced to a matter of economic efficiency. In Australia, for example, cash social services were offered as cheaper alternatives to institutionalisation or charity, as a means of addressing disadvantage (Madden et al. 1993). Stone (1984) has argued that with the introduction of invalid and age pensions (introduced by the Commonwealth in 1908), disability became an important administrative category for distributing income and other benefits - encouraging the perspective of disability as an economic problem, amenable to cost-benefit analysis (Bickenbach 1993).

Several authors have shown how this model, similar to the previous model, falls back on individual’s notions of disability which emphasise impairment, rather than maintain the interactive notion of disability as being a relationship between people with impairments and their environment (Oliver 1990; Bickenbach 1993). Consequently, the discussion centred - yet again- around the adaptation of people to the environment, rather than the reverse.

To redress the economic disadvantages experienced by people with disability, federal legislation such as the Disability Discrimination Act 1992 (Australian Parliament 1992) was introduced. As a result of this legislation, discrimination on the grounds of disability is now illegal in any areas of public life, including employment. Another initiative to redress the economic disadvantage was the introduction of the Disability Reform Package by the Department of Employment, Education and Training in 1992. This package provides a series of incentives for employers of persons with disability, including wage subsidies, allowances, and reimbursements for special equipment for employees with disabilities.

Initiatives such as the Disability Discrimination Act and the Disability Reform Package are evidence that governments acknowledge the importance of the economic barriers that people with disabilities encounter.

Despite the Australian government’s disability reforms, with a focus on employment and skill development, there was a general perception that the effects of the social environment in creating disability were ignored. To create social solutions and ameliorate the disadvantage another model in the disability field arose - the social model.

2.1.5. The Social Model

The social model of disability was introduced in 1976 by the Union of the Physically Impaired Against Segregation (Shakespeare and Watson 1997) and formalised and extended by Oliver (1990; 1993; 1996a; 1996b) and Finkelstein and French (1993). Two important issues underpin the social model:

1. Social injustice of stigmatising attitudes and discriminatory practice produce disability. Thus problems are seen, not within the individual disabled person, but within society. For example, a person who uses a wheelchair is not disabled by paraplegia but by building design, lack of lifts, rigid work practices, and the attitudes of others. Finkelstein (1991) has argued that non-disabled people would be equally disabled if the environment was not designed with their needs in mind.

2. People with disabilities have the right to be in charge of policy and decisions about their lives. They have a right to be independent and be active participants at all levels in society, rather than dependent recipients of services dominated by able-bodied interests and perspectives (Oliver 1990; Swain et al. 1993).

Criticism of this model relates to its failing to connect with the real experience of impairment, thus denying the physical and psychological pain of impairment (Goodall 1995). As a disabled person and a nurse teacher, Goodall (1995) suggests that the social model has a tendency to disregard any suggestion of medical diagnosis or pain and consequently may fail to represent accurately the experience of disabled people. Writers such as Bickenbach (1993) and Finkelstein (1993) have warned not to view disability as being entirely caused by the environment and to retain the notion of disability as a complex, multidimensional phenomena: an ‘unstable mixture’ (Bickenbach 1993) of impairment, disability and handicap. This is echoed by Goodall (1995, p. 327) who suggested that:

> Disability is neither a medical condition nor the built or attitudinal environment. Disability is a life experience of physically impaired people, an experience which is restrictive, oppressive and frustrating. Disability exists at the meeting point, the interface between person and environment. Disability may be lessened, therefore, by addressing both the person with his or her impairment related problems and the oppressive environment.

The essence of conceptualising disability, according to Bickenbach (1993), is to understand disability as an active notion, or a relationship between attributes of individuals and the social environment, instead as an intrinsic entity such as a thing, event or process, which can be located or identified.

Within the social model, disability:

- is a dimension of human difference (and not a defect);
- derives its meaning from society's response to individuals who deviate from cultural standards (and is not inherent in the individual);
- depends on the quality of the arrangement between the individual and society (and not on the severity of the disability);
- is part of the variety of human differences (and therefore does not need eradication because the individual's 'differentness' is not the primary problem);
- can be addressed through a range of options because disability problems issue from the complex interaction between the individual and society (and is not limited to options that address the individual), and involves many experts (eg. doctors, health professionals, consumers with disabilities, lawyers, and so on (Hahn 1985; 1988).

Within Australia, much of the Federal Government policy is based upon the social model with the introduction of the Disability Services Act 1992 (Australian Parliament 1992). This Act makes direct and indirect discrimination against people with disabilities in Australia unlawful. Two years later, the Commonwealth Disability Strategy was launched (Australian Parliament Office of Disability 1994). This Strategy proposed a ten-year plan of national equal opportunity goals for Australia to reach the United Nations Standard on the Equalisation of Opportunities for Persons with Disabilities (Australian Parliament Office of Disability 1994; United Nations 1994).

Whilst the importance of a multi-theoretical perspective is acknowledged, it is maintained in this dissertation that the experience of disability is conceptualised within the social/political model. It has been stated that a major contribution of the social approach to disability has been the criticism of the lack of voice of people with disabilities in policy making, as well as personal decision making. As a result, non-disabled people, so called ‘experts in the field’ (UPIAS 1976), have dominated how disability is represented, creating disabling images and categories such as ‘dependency’ or ‘special need’, terms which incorrectly represent those living with disability (Oliver 1990; 1993; Swain et al. 1993; Wendell 1996). In my study, disability is conceptualised as an issue of equality; hence the research design includes the perspectives of the people with disability as a central aspect in the evaluation of their everyday life experience.

2.2. Experiences of Disability

The status and progress of medicine
Ought always to be judged primarily from the
Point of view of the suffering patient,
And never from the point of view
Of one who has never been ill.

Kleinman (1988)

In recent years, people living with disability (Cameron 1993; Leaney 1999; Robillard 1999) have written books and articles about their personal experiences. Their writings, which move beyond the personal limitations that impaired individuals face, have transformed the understanding of the real nature of disability. In this section I examine literature on other personal and theoretical issues that shape the disability experience framework. I draw primarily on the thoughts of disability theorists, health and social scientists who argue that disability encompasses a complex multidimensional phenomenon to be found within the context of a person’s life. Here, disability is not a stable entity but an interaction between physical and emotional impairment, activity limitation and participation restriction - a combination of physical, emotional and social barriers.

Health and social scientists, such as Blaxter (1976; 1993), Bury (1982; 1988; 1991), Charmaz (1983; 1987; 1991), Strauss, Corbin, Fagerhaugh, Glaser, Maines, Suczek and Wiener (1984) and Robinson et al. (1995), have written extensively about how people deal with chronic illness and disability. Amongst these are those who tend to use the terms ‘chronic illness’ and ‘disability’ interchangeably. Although it is virtually impossible to make a firm distinction between these concepts, because they are so interrelated, for analytical purposes, in this study, these terms are differentiated to focus attention on the varying dimensions of response to the disability experience.

Chronic Illness is a generic term and covers a wide and diverse range of conditions. The salient features of chronic illness are that they are long-term, uncertain, and require palliation (especially because they are ‘incurable’), may be expensive, and may require a wide range of ancillary services (Strauss et al. 1984).

Disability is a generic term and covers a wide and diverse range of disability conditions. The salient features of disability are physical impairment, activity limitation and participation restriction (AIHW 1999, p.28).

Disability literature is prolific with contributions from various disciplines, each focusing on a particular aspect of disability. The majority of these studies are conducted within the traditional positivist paradigm, which discern the cause and effect of disability. In the mid-eighties, however, another trend emerged within the disability literature. Health professionals and social scientists developed an interest in the social and psychological dimensions of disability, hence the upsurge of studies conducted within the interpretive paradigm. Any of these writings are concerned with distinct experiences of disability; examples include *Living with a Stroke - The Challenge* by Sloane (1984) and *The Experience of*

Chronic Respiratory Illness by Williams (1993). At the same time, sufferers also began writing about their experiences. For example, *Oyster Grit - Experiences of Women with Disabilities*, published by the Victorian Women with Disabilities Network (2000), '*Stroke' could it be just a bad dream?* by Cameron (1993) and *Whose hand is this?* by Leaney (1999).

When Robillard (1999), an ethnomethodologist and Professor of Sociology with Motor Neuron Disease, realised he was a living laboratory for revealing the countless, taken-for-granted methods people use to weave their lives together, he wrote a book '*Meaning of a Disability - The Lived Experience of Paralysis'* about his experiences. Robillard used literature to convey feelings and emotions in a poignant way; his experience is powerful and emotive reading. Touching personal stories such as these provide a detailed understanding of what it means to confront the limits of the disabled person's social world and the unspoken assumptions about meaning interaction, as they struggle with the day-to-day challenges of everyday life. It can be argued, however, that such knowledge is partial, and as a result, readers may overlook the idea that there are some common shared experiences of people with physical disability. Furthermore, it may detract from the fact that people with physical disability form a large part of the population that experience serious consequences of disability including activity restriction and exclusion from participation in the mainstream of social activities (Oliver 1996). Hence it is to this issue that the next section now turns.

2.2.1. Impact of Disability

As already outlined, the term disability covers a wide and diverse range of disabling conditions with salient features of physical impairment, activity limitation, and participation restriction. Thus, disability in this context seems to begin with the afflicted person's awareness of significant physiological changes and awareness of a series of physical and social barriers. Robinson et al. (1995) noted that 'the everyday experiences of people with disabilities can be summarized in one word, *inaccessibility* - not only to elements in the environment (site or building) that do not allow approach, but also the social environment, an approach to people' (p.75 emphasis in original).

A permanent change in an individual's physical status is followed by a period Lubkin (1990, p.93) compares to:

> … a ride on a roller coaster: constantly challenged or angered by the uphill struggles, never knowing when another curve will come, and unable to stop the motion. Individuals have a sense of instability during this period of mixed and conflicting emotion, of bewilderment, of a sense of helplessness. It is a process that is mostly characterised by inconsistency, questioning, and uncertainty.

Uncertainty relates to the 'inability to determine the meaning of events' (Royer (1998, p.41) and occurs in a situation where the decision-maker is unable to assign definite values to objects and events and/or is unable to predict outcomes accurately.

In their discussion on uncertainty Strauss et al. (1984, p.64) coin the term 'illness trajectory', when they describe the physiological manifestations of a person's illness, his or her perception of the situation and his or her response to the perception. For some it is argued, the 'illness trajectory' is predictable, yet for others there is much more ambiguity. This is true for some of the participants, particularly those who live with a neurological condition. For example, Sandy who is diagnosed with Multiple Sclerosis faces a progressive condition with an uncertain outcome. As such, it hampers the formation of any plan of action and thus impedes effective coping (Shalitt 1977).

Human beings do not experience life solely in physical terms, but also in psychological and social terms. Consequently, it is likely that the impact of disability also affects one's sense of independence and productivity - and ultimately, one's sense of worth and social value. Decreased independence and productivity may involve coming to terms with loss. 'The concept of loss implies a relationship with something or someone whose removal or disappearance leaves a gap in the life of the individual concerned' (Mumma 2000, p.192). Participants in Mumma's study who were asked to describe losses experienced following a stroke identified five major losses (1) mobility; (2)

independence; (3) physical abilities; (4) shared activities; and (5) communication. Mumma's findings are consistent with an earlier study by Adams and Lindemann (1974) who described loss of self, loss of physical and mental function, loss of work, loss of relationships, loss of financial security, and loss of a sense of control over life as losses associated with disability. Independence, as the most frequently mentioned loss is not surprising. Self-reliance and independence are powerful values in the western society. Hence the fear of becoming more dependent and becoming a burden on loved ones haunts individuals, as they grow older. 'Becoming a burden' means that a person 'no longer fulfils the obligations implicit in past relationships' (Charmaz 1983, p.187). She maintains that the worst feelings of becoming a burden are that of uselessness and dependency. Robinson et al. (1995) raise an important issue with regard to dependency when they question the goal of rehabilitation personnel to encourage clients to become as physically independent as possible. They argue that independent functioning 'tends to be overglorified in our society' (p.75). Hence this advice:

> Professionals … should all recognise both the right of comfort and the right of choice. The final decision, of course, rests solely with the person with disability, who determines whether or when to use an outside helper or aid for maximum functioning ability. In truth, none of us is totally independent. We all depend on others (p. 74-75).

The impact of living with physical disability necessitates a change to many aspects of one's life, including a personal change to adjust to the environment (Abeles, Gift and Ory 1994). Others, such as Oliver (1993) find that such a focus on merely the individual is too narrow. He argues that changes within the environment, by removing personal and social barriers, are necessary to aid the disabled person. I argue that recognition of both is warranted to understand the meaning of disability, hence in this context both views will be explored further.

2.2.2. Dealing with Disability

> The psychological 'experience of physical disability' and deformity encompasses myriad emotional reactions, a 'call to arms' of one's coping repertoire and defences, and a journey of personal challenge through the caveats of despair and loss to the ultimate reclaiming of oneself'.

Turner and MacLean (1989, p. 225)

Loss, according to Robinson et al. (1995, p.17) '… represents a disruption of life so severe that it is likened to a kind of death to people when the loss is irreversible'. Hence, the most quoted work in the area of 'loss' has been the work of Elizabeth Kübler-Ross, '*Death and Dying'* (1969) where she focused on the feelings of patients with cancer. Kübler-Ross identified five stages through which terminally-ill people frequently pass comprising of denial; anger; bargaining; depression; and acceptance. Numerous other authors (Vash 1981; Wright 1983; Lazarus and Folkman 1984; Moos 1984) studying disability, have found similar parallels in the elements of the grieving process similar to those described by Kübler-Ross (1969). Their findings suggest that those who encounter disability experience similar stages to those who encounter terminal illness. Indeed, Robinson et al. (1995) note that those living with acquired disability have to deal with:

- Mourning the loss of the old way of functioning;
- Dealing with new definitions of independence and interdependence;
- Adapting to physical discomfort as well as loss; and
- Confronting the issue of being different, both to themselves and others.

Much of disability research indicates that emotional reaction such as denial, anger and mourning, precede acceptance. Such reactions, however, are normal; they do not emerge in set sequence; and they should not be viewed as problematic - hence they should be accepted as part of the process of adapting to chronic disability (Parsonson 1989). Krueger (1984) developed a five-stage process that an individual with disability proceeds through before achieving the final stage of 'adaptation'. He labelled this framework the 'adaptation to disability' theory. The five stages of the framework include shock, denial, and depressive reaction, reaction against independence and adaptation. All are of relevance to my dissertation, but adaptation, and the emergence of new potential provides an insight into the experience of the participants in this study.

Adaptation and coping are often treated as synonymous terms, but Royer (1998) points out that, although both concepts are interrelated, they are distinct from each other. 'Coping' refers '… to the special mobilisation of effort and the drawing upon unused resources or potentials, [and] always involves some type of stress' (Royer 1998 p.81). 'Adaptation' refers '… to a broader concept that includes routine or automised actions' (Royer 1998, p.82). 'Adaptation', in a psychological sense, refers to individual survival, as well as to the capacity to sustain a high quality of life and to function effectively on a social level (p.82). Royer's (1998) definitions suggest that coping consumes energy whereas adaptation conserves energy.

Moos (1984) makes a similar, albeit basic, differentiation. Daily life for people with a disability means performing: (1) *general tasks,* such as preserving relationships with family and friends, maintaining an emotional balance and adjusting to society's rigid norms and values, and preparing for an uncertain future and (2) *disability-related* tasks such as dealing with pain, incapacitation and limitations, adjusting to treatment and integrating with the non-disabled population. My preference for conceptualising the difference (in the context of disability) is as follows: 'adaptation' is what people have to do to function with routines that are predictable ('general tasks' in Moos' words), 'coping' is what people have to do to with the unpredictable routines (disability-related tasks in Moos' words). The basic difference for people living with disability is merely that they have additional challenges. They must learn to live their lives in the context of disability with its permanency and unpredictability; hence they have to adapt *and* cope. The practicality of both concepts will be outlined.

Authors have identified determinants that might be clustered with Royer's ideas on adaptation and coping. These include the concepts of (1) individual biographies (Bury 1982); (2) self-efficacy (Bandura 1986; 1991); and; (3) self-concepts (Charmaz 1987; 1991). A brief discussion of these concepts is now provided.

- Biographies relate to a background or life history that makes each individual unique from others (Wiener, Strauss, Fagerhaugh and Suczek 1979). Biographical accommodation is a term Corbin and Strauss (1987) use to describe the process of the ill person managing some degree of control over biographies, that is, their beliefs about the event. People who believe they can achieve control are likely to benefit more than those who do not so believe. In other words, people with a disability will benefit from belief in personal control over their illness, injury or disease (Taylor 1986).

- Bandura (1986) offers the most coherent statement on the way in which a person's beliefs about their abilities can influence actual performance. His theory proposes that the strength of a person's belief in his or her ability of so-called 'efficacy expectations' to perform certain actions or achieve a given level of proficiency, determines whether they will succeed or not. People with a strong inner locus of control believe that they can personally determine their own fate by making wise decisions - and act accordingly. It makes sense to assume that the opposite is also true. Hence, believing recovery is totally in the hands of others may hinder successful adaptation as it minimises the important role of the individual taking responsibility. In similar vein to the concept of 'self-efficacy', as influencing factor, is the concept of self.

- Taylor (1986) proposes that 'the extent to which a person's self-concept is altered by illness or injury may also be a factor in their adjustment' (p.219). Hence an individual's self-concept before the onset of disability will influence his or her thinking about self after the onset. Taylor (1986) proposes a number of components of 'self' to be considered in the adjustment process: the physical, achieving, social and personal selves. The *physical self* refers to the person's body image, which may be adversely affected by the disabling condition. The *achieving self* refers to satisfaction from achievement in tasks; a positive force in recovery. The *social self*

> concerns interactions with family and friends, whilst the *personal self* involves the person's wishes, goals and ambitions for the future.

Robinson et al. (1995) summarises Taylor's concept with two examples. An average-looking male college professor who takes pride from his intellectual accomplishments is disabled by an accident. If functional loss does not seriously interfere with his ability to perform professional tasks, he may be seriously inconvenienced, but his self-concept will not be shattered, as the disability would be peripheral to it. Conversely, an athlete who takes pride in strength would find an identical disability devastating, perceiving him or herself as 'less than normal'. To him or her any devaluating change in body image would be intolerable.

So, how does one deal with functional limitations and psychosocial experiences? Much has been written about how people manage to 'carry on' despite, or in spite of, their chronic disabling condition. Pacing and balancing, for example, are energy conserving tactics to protect individuals from experiencing the world as 'intolerably anarchic' (Royer 1998, p.125). Similarly, 'avoidance of potentially embarrassing situations', 'limiting contacts', and 'covering up' of disability symptoms, as social processes involving negotiation with others and self, allow people to perceive themselves as they would prefer to be perceived by others (Robinson et al. 1995; Royer 1998).

In striving for sense making, individuals may employ various strategies, such as downward comparisons, 'it could have been worse', which serve to highlight the individuals' fortitude, promoting commensurate experiences of positive meaning (Royer 1998). Studies in social psychological research have shown that people seek information to validate their personal experiences and then engage in favourable comparisons to similar others.

Another strategy is engaging in denial, that is, saying 'I don't want to think about it'. Lazarus (1983) points out that denial is no longer denounced as the primitive, even unsuccessful, defence it once was; instead, denial is increasingly recognised by clinicians and health psychologists. Denial is seen as a value that protects people against crises, both in the initial stages of threat and later on, when people must come to terms with information that is difficult to accept, such as the diagnosis and prognosis of a chronic condition. Likewise, suffering is considered as a purposeful and valuable life lesson in the process of making sense and helps individuals to reorder priorities and values and transform their experience (Dunn 1994).

In the early part of injury or disease onset, people are occupied with immediate responses to their diagnosis, undergoing treatment, and rehabilitation, whilst beginning to deal with new bodily experiences. Once rehabilitation is completed and individuals return home, they begin to face the impact of disability on their everyday lives. This includes issues such as: dealing with altered body experiences; adjusting behaviour in the social environment; learning to manage disabilities in everyday life; and dealing with the uncertainty of the future (Kottke and Lehmann 1990).

A particularly encouraging feature of disability studies is that, whilst the consequences of a physical disability are irreversible, many people report that they lead satisfying lives with a high quality of life. Examples can be found in Secrest and Thomas (1999) and Tham, Borell and Gustavsson (1999) who researched stroke survivors and found that, overall, they live very satisfying lives.

2.2.3. Research about Living with Disability

It is of crucial importance to understand meanings of disability and to learn how disabled people work through their experience (Oliver 1998). Working through the experience of disability means that the individual must evaluate the meaning behind the onset of disability, in search for control and a need to make sense of a world that in many ways makes ‘no sense’. Living with disability tends to force a person to eliminate the insignificant, to mature, and to find and savor the important and meaningful aspects of life (Robinson et al. 1995). Related to finding new strengths is the development of a variety of interests, some of which are compatible with a restrictive life-style. Those who seek a positive explanation relating to the event tend to demonstrate improved psychological adaptation (Thompson 1985; Livneh 1986a; Livneh 1986b; Dunn 1994).

An increasing number of researchers have turned to qualitative methods including phenomenological approaches to examine the disability experiences. I have selected three studies that focused on people, who live with Unilateral Neglect; Parkinson's Disease; and Rheumatoid Arthritis - all conditions commonly treated by physiotherapists. Each study described themes that capture how people journeyed through the lived experience.

Tham et al. (1999) studied individuals with right brain damage and unilateral neglect in order to expand the focus on living with disability following stroke. They employed a modified form of an empirical, phenomenological, psychological method based on the philosophy of Husserl and to a lesser extent, Heidegger (Karlsson 1993) to analyse data. The participants (four women), who had suffered a right cerebrovascular accident resulting in a left hemiparesis, were interviewed about their experiences of living with Unilateral Neglect in the context of performing everyday tasks. People with Unilateral Neglect are unable to orient their attention toward the left hemispace when performing everyday tasks, such as eating or reading, and often are not aware of the left half of their body when performing tasks such a grooming or dressing (Bisiach and Vallar (1988).

Themes describing their experiences included:

(1) *'experiencing the new and unfamiliar'*. This related to new, unfamiliar and unpleasant bodily experiences;

(2) *'comparing the new with the old'*. The participants experienced that they were not being able to do things they had previously done spontaneously and routinely.

(3) *'searching for explanation'*. The women expressed a need for understanding experiences of living in half of a bodily world.

(4) *'becoming more familiar with the new'*. Whilst a cognitive understanding of the consequences of the event occurred, compensatory strategies were explored to overcome their limitations.

(5) *'understanding the disabilities'*. The women began to understand that they had a limited ability to interact with the left half of the environment in everyday life. This understanding, it appeared, was an important prerequisite for being able to search for new strategies to handle the disabilities in daily life.

(6) *'learning to handle disabilities in daily life.* Understanding of disability enabled the women to incorporate strategies in their lifeworld.

The themes identified by Tham et al. (1999) demonstrate the importance of an awareness of disability before a person can consciously use compensatory strategies and incorporate them in daily life. They argue that the compensatory strategies must be built on the 'unique experiences and understanding of each person who has Unilateral Neglect' (Tham et al. 1999, p.405)

Using a phenomenological approach, Secrest and Thomas (1999) explored the experience of living with Parkinson's Disease. Themes describing living with Parkinson's Disease included:

(1) *'Impact of the disease'* which relates to acceptance of diagnosis, acceptance of personal loss (physical and social) and emotional loss.

(2) *'Dealing with the disease'* involved the use of strategies such as comparing with others worse off, carrying on as normal and having a positive outlook. Other strategies included modification and adjustment of lifestyle.

(3) *'Maintaining independence and normality'* refers to a desire and perseverance to strive for normality.

(4) *'Effort'* was a consistent theme, relating to the increased effort required to live with Parkinson's Disease.

Similar to the study by Tham et al. (1999), the employment of compensatory strategies was a necessary part of everyday life when living with disability.

Ryan (1996) used a phenomenological exploration to study living with Rheumatoid Arthritis (RA). Amongst seven participants, Ryan identified the following themes:

(1) *'alteration in self-esteem/role'*. Data revealed that all seven participants possessed a negative internal perception which, Ryan suggests, could be attributed to the physical limitations that arthritis has caused.

(2) *'relationships within the family network'* were altered. Absence of a positive response can impede self-care strategies. For example, it is possible that a strategy such as 'pacing' could be misinterpreted by family as 'lazy'.

(3) *'frustration at perceived limitations'*. Frustration arose out of limited functional ability, accompanied by guilt and a sense of being powerless.

(4) *'negative perceptions regarding the future'*. Concerns about the future hinder the coping ability.

(5) *'the doctor-patient relationship'* relates to the unsatisfactory communication between the parties.

Unlike the two previous studies, participants in the latter study portrayed a predominantly negative internal perception and the belief that the control of events was outside their domain. It is likely that the presence of chronic pain and the severity of pain, typical in rheumatoid arthritis, influenced the concept of self and the experience. Another explanation can be found in the fact that rheumatoid arthritis patients require frequent medical management, and so may experience a strong illness role and were maybe more pessimistic. Feelings of negative self-concept, according to Ryan (1996), together with feelings of powerlessness, are of paramount importance as such feelings have an effect on how individuals relate to each other and how they conduct their lives.

2.2.4. Disability and Social Barriers

More than two decades ago, Blaxter (1976) already began to draw attention to the importance of psychosocial aspects to understand the experience of disability. Feelings of guilt, fear of being-a-burden and feelings of uncertainty in the individual, she suggests, need to be acknowledged in order to understand the meaning of disability. Her findings are consistent with those of other authors studying the experience of chronic illness (Strauss et al. 1984; Conrad 1987; Lubkin 1990; Bury 1991). Oliver (1986; 1990) and French (1994; 1997), however, they offer a different point of view. It is argued that, although scales, test instruments and other inventories provide objective measurements, it adds little to increase understanding of disability. Instead, they maintain the stance that disability can best be understood by pointing out the disabling environment and social assumptions.

De Jong and Lifchez (1983) advocate that there is a multitude of other social and physical environmental factors, such as self-image, social isolation, attitudes and stigma, that impinge a great deal more on the individual than physical impairment; and it is to these factors that the next section now turns.

2.2.4.1. Self-Image

The Australian culture reflects its value orientation, social attitudes, and norms through role behaviours centering on wellness and work independence (Humphreys, Mathews-Cowey and Rolley 1996). Hence, when loss of bodily function occurs and work ability is impaired, a threat to the loss of self can occur; and the individual may experience diminished personal worth; and the image of self may be disrupted (Rubin 1968; Esberger 1978). The threat occurs as Esberger (1978) explains, '…because it [our body] serves as a standard or frame of reference that individuals use when relating to each other and the physical environment' (p.218). van Manen (1990) refers to the phenomenological fact that we are always bodily in the world and, in this sense, it means that if bodies are impaired, so is our way of connecting with the world. Seymour (1998) interviewed men and women with profound bodily paralysis and examined how people reconstitute their embodied self after major physical impairment. She found that even major impairment has not annihilated these people's experience of an embodied self. She noted that the damage had disturbed, but not destroyed, their embodied selves and argued that people still possess their bodies and that 'their bodies are still resources with which they may explore new possibilities and opportunities of re-embodiment' (Seymour 1998, p.178).

2.2.4.2. Social Isolation

A major consequence of living with disability is social isolation. Isolation can occur either when the affected individual withdraws from social contact, or when friends and relatives withdraw from visits. The latter kind of social isolation is '…aloneness, experienced by an individual and perceived as imposed by others and as a negative or threatened state' (Lubkin 1990, p.82). Aloneness can occur out of concern about other people's reactions or by unwittingly perpetuating one's own isolation because of a visible 'negative' trait. Fagerhaugh and Strauss (1977) note that due to the amount of potential embarrassment from the nature of the condition, individuals restrict life voluntarily. For example, a person afflicted with stroke and resultant speech impairment, resulting in embarrassment, may avoid encounters with others.

Physical limitations may inhibit the individual's involvement in social activities, restricting social contacts and friendship. Pain or fatigue may preclude endurance for a prolonged endeavour, forcing the person to abandon an activity or withhold from attending. Because of the emotional and physical stress associated with relating to others who have a negative or misinformed attitude, individuals may isolate themselves to avoid stigma. Royer (1998) identified that people with a disability are frequently unable to return support, hence reciprocity which is so important for balanced relationships, becomes impaired.

Social barriers impede an individual's quality of life in a broad sense. They include physiological, psychological, and social difficulties that limit individuals who experience physical disability. Societal attitudes are among the strongest and most difficult to eliminate.

2.2.4.3. Attitudes

Of all the barriers that people with a disability face, the strongest and most difficult to eliminate, are the societal attitudes (Kleinman 1988). One's feelings about oneself are often affected by the attitude of others. Laws, rules, and etiquette are governed by individual or group attitudes. Literature and the media influence attitudes toward disabilities. Robinson et al. (1995, p.36) report how historically, this influence has been primarily negative (children are depicted as pitiable but stoic 'cripples', such as '*Tiny Tim'*) whilst adults are portrayed as dangerous villains, such as '*Captain Hook'.* This tendency to stereotype has finally taken a positive turn as film scripts depict people with disabilities as attractive love interests ('*Coming Home', 'Children of a Lesser God'*).

Critics argued that attitudinal explanations, in themselves, are not sufficient to understand disability because they do not address the role of socio-economic structures in oppressing people with disabilities (Oliver 1990; Bickenbach 1993; Finkelstein and French 1993). Such critics have argued that there is little point focussing solely on attitude change or anti-discrimination laws, without addressing social marginalisation, which is the core of disabling practices and which led to unjustifiable social inequality.

2.2.4.4. Stigma

A reflection of societal attitudes can be found in stigma, which Webster's (1974) dictionary has defined as a mark of shame or discredit. According to Jennings, Callahan and Caplan (1988, p.6) '… disability is often stigmatising; intolerance, fear, and misunderstanding, at one extreme, and well-meaning but humiliating and patronising sympathy at the other'. Stigma has its origin in the work of Erving Goffman (1963) who suggested that the central feature of stigmatised individuals was a question of acceptance. Ainsley, Becker and Coleman (1986) disagree and argue that stigma is not linked to acceptance or non-acceptance, but linked to fear and inequality.

> The ultimate answers about why stigma persists may lie in an examination of why people fear difference, fear the future, fear the unknown and therefore stigmatise that which is different and unknown. An equally important issue to investigate is how stigmatisation may be linked to the fear of being different' (Ainsley et al. 1986, p.227).

Stigma is caused by a discrepancy between an expected, socially-defined norm and an actual attribute. This discrepancy attaches a value judgment to its owner; it becomes the stigma. The person is discredited and less valuable. Discrediting, according to Siddell (1995), can arise from interactions with others as well as from within the individual who is frustrated and disappointed with him/herself because of the inability to function in ways that she/he would like. Authors such as Kleinman (1988) remind us that whether people resist the stigmatising, discrediting identity, or accept it; either way, it means a radical alteration to his or her world. Lubkin (1990, p. 82) also reminds us of another important fact when she writes that '… discrediting and socially isolating effects of stigma transcend any limitations imposed by the actual disability'. To limit the impact of stigma, affected individuals expend much effort in self-presentational tactics and conceal their condition to counter and minimise the effects. Thus, people may feel shame, not because of their impairment, but rather in response to the reaction of family and others and consequently choose to minimise social interaction with others. Alternatively, the desire to maintain a positive evaluation of self and to continue prior relationships with others may prompt individuals to engage in self-presentational tactics that counteract stigma and adopt strategies, such as concealing symptoms. The role of health professionals in relation to stigma, according to Kleinman (1988. p.161) is to develop an 'acute sensibility' to stigma, which means to acquire a sharp awareness and to have a commitment and a willingness to help bear the burden and empower those who experience it.

2.2.5. Disability and Physical Barriers

Stairs, narrow doorways and kerbs are some obstacles that limit the quality of life of people with physical disability. The environment can restrict the opportunities, limit the choices available, and increase dependency. Finkelstein and French (1993) noted that people in wheelchairs encounter a multitude of physical barriers. For example, travelling can be difficult, as public transport is not usually wheelchair accessible. Seating arrangements in buses are rarely large enough for a wheelchair, nor do they provide room for storing a wheeled walker. Holiday outings are limited, as many hotels and motels have stairs and no lifts; and the bathrooms do not have sufficient wheelchair-accessible bathroom space. Such lack of opportunity for independent travel may lead to increased dependency, isolation, hopelessness and poor self-concept (Oliver 1993; 1996b).

Johnson's study (1995) showed that the inability to drive a car is one that is difficult to accept and limits an individual's participation in activities. 'Regret, loneliness, and immobility were the results of no longer being able to drive' (Johnson 1995, p.18) and in this regard, the inability to drive can affect social esteem and self-concept.

Physical barriers can also exist in the form of inaccessibility to employment due to limited vocational re-training or job opportunities, lack of financial assistance, inadequate housing, and lack of leisure activities (Swain et al. 1993).

In addition to the inaccessible physical environment, attitudinal and geographical issues, rural people with a disability are further disadvantaged with regards to inaccessibility of information (limited availability of mobile library services and Internet services). Furthermore, the economic and financial disadvantage (price of fuel and telephone), and accessibility/ availability of health services (distance from urban areas) add a significant dimension to the experience of isolation for people with a disability.

2.3. The Rural Context

Australia is very much an urban society, with more than 70% of its population living in metropolitan zones (Australian Bureau of Statistics 1996; 1998a), yet it is the life rural Australians live that captures our imagination. Indeed, some of the first images presented to the world at the Opening Ceremony of the 2000 Sydney Olympic Games were images of rural Australia. It began with a single horseman who entered the stadium to the tune of the Banjo's Patterson's 'Man from Snowy River', soon joined by a legion of 120 horsemen and women on stockhorses. Each rider carried an Olympic flag; each rider dressed in the traditional Australian bush outfit. The remarkable entrance of these Australian men and women at the 2000 Sydney Olympic Games 'Welcome' segment showed the world that the image of 'the bush' is portrayed as the 'real Australia'.

Whilst stories of the adversity and hardship faced by countrymen and women in this vast land have become legendary, many of these images are based on myth and legend (Australian Catholic Social Welfare Commission 1998). The legends, together with the popular image of the bush defined as the 'national' image but in reality the dominant masculine image (Lake 1992), have stressed mateship, laconic speech, anti-authoritarianism, pragmatism, and the general, low-key, good humour of the rural Australian (Whitlock and Carter 1992). This, they argue, is seen to breed a culture of self-reliance, scepticism of government (and urbanites in general) and close social ties balanced by strong independence of families and individuals.

Many new Australians, like myself, born and raised in crowded European cities, catching buses and trains to school and driving through fog and smog, take a keen note of all new experiences and appreciate Australia very much. Living in Toowoomba, a regional city approximately 150 kilometres west of Brisbane, has enabled me to learn about rural living and working. Solitude, space and the sensible pace of life, together with the vastness of the region, produce a deep contentment and connection with the land expressed so vividly by Dorothea Mackellar (1883 – 1968) when she described the colours that characterise the rural landscape.

The Colours of Light

This is not easy to understand
For you that come from a distant land
Where all the COLOURS are low in pitch -
Deep purples, emeralds deep and rich,
Where autumn's flaming and summer's green -
Here is a beauty you have not seen.
All is pitched in a higher key,
Lilac, topaz, and ivory,
Palest jade-green and pale clear blue
Like aquamarines that the sun shines through,
Golds and silvers, we have at will -
Silver and gold on each plain and hill,
Silver-green of the myall leaves,
Tawny gold of the garnered sheaves,
Silver rivers that silent slide,

Golden sands by the water-side,
Golden wattle, and golden broom,
Silver stars of the rosewood bloom;
Amber sunshine, and smoke-blue shade:
Opal colours that glow and fade;
On the gold of the upland grass
Blue cloud-shadows that swiftly pass;
Wood-smoke blown in an azure mist;
Hills of tenuous amethyst. . .
Oft the colours are pitched so high
The deepest note is the cobalt sky;
We have to wait till the sunset comes
For shades that feel like the beat of drums -
Or like organ notes in their rise and fall -
Purple and orange and cardinal,
Or the peacock-green that turns soft and slow
To peacock-blue as the great stars show . . .
Sugar-gum boles flushed to peach-blow pink;
Blue-gums, tall at the clearing's brink;
Ivory pillars, their smooth fine slope
Dappled with delicate heliotrope;
Grey of the twisted mulga-roots;
Golden-bronze of the budding shoots;
Tints of the lichens that cling and spread,
Nile-green, primrose, and palest red . . .
Sheen of the bronze-wing; blue of the crane;
Fawn and pearl of the lyrebird's train;
Cream of the plover; grey of the dove -
These are the hues of the land I love.

Dorothea Mackellar

Mackellar’s poem depicts rural Australia as a unique landscape, a vastness of the empty spaces, the spirit of the people who live and work in an often-harsh environment and the spirituality of the original inhabitants of the land; central elements of our nations’ collective identity.

2.3.1. The Darling Downs

To the description of the study’s physical setting given at Chapter 1.8, I would add these comments. The ‘Darling Downs’ region was, prior to European settlement in 1840, home to the Aboriginal people who had lived in this region for at least 15,000 years (French, M. 1997). European settlement of the Darling Downs began as follows:

> …squatters Patrick Leslie and Arthur Hodgson, finding no pastures for their sheep and cattle in an overcrowded New England, formed the vanguard of a squatter advance on the open forest plains between the western slopes of the Great Dividing Range and the Condamine River where the grasses grew as high as a horse's flanks' (French, M. 1997, p.1).

'Squatters' refers to a transient group of tough pioneering adventurers, who were, according to M. French (1997), forced out of Britain by lack of opportunities, seeking restored fortunes in the colonies, and hoping for a comfortable return 'Home'. They were, in essence, a group of gentlemen-adventurers for whom the colonies of the British Empire represented renewed hope through the fruitful investment of their patrimonies. These men soon recognised the potential of this well-watered region with its fertile green slopes and named it the 'Darling Downs', also described by Allan Cunningham, a famous explorer, as 'sumptuous pastoral country' (French, M. 1997, p.5). Many farms were established, the agriculture industry was thriving and in those times, the region was known as the 'Garden of Queensland' (French, M. 1997, p.3).

The vastness and size of the Darling Downs is reflected in the diversity of landscapes that poses difficulties. Offering health services for example, in the Darling Downs, is a costly exercise given transport costs and the generally higher cost of living in this area. Hence, there needs to be a recognition of the distance factor in the allocation of resources in relation to service provision to rural areas (Office of Economic and Statistical Research 2000).

Although prosperous times have declined over time, today, the Darling Downs is still a sprawling region where roads crisscross the land into the country towns and farms.

2.3.2. Rural … not Bush

Attempting to define rural is fraught with complexities and seems to depend largely on the purpose of definition and the theoretical background on which it is based. For some, 'rural' is synonymous with 'the bush', a term considered by

'John', a participant in the study, as a rather discourteous gesture towards rural and remote Australia. Aware of this sentiment, the word 'bush' as a synonym for rural, will not be used in this dissertation.

In the early history, the term 'rural' referred to areas of low population density, small absolute size, and relative isolation, where the major economic base was agricultural production and where the way of life of the people was reasonably homogenous and differentiated from that of other sectors of society, such as the city (Krout 1986; Neil Bull 1993; Coward and Krout 1998). 'Rural', then had three aspects: ecological, occupational and sociocultural. Thus to know where a person resided was to know what he or she did for a living, the pattern of his or her values and their normal interaction situations. This is no longer true! As Sher and Sher (1994) explain, 'rural and agricultural are no longer synonymous' (p.11). The rural picture is more diverse; in fact, less than twenty percent of rural Australians are in the farming business - with the mining industry, along with the tourist industry, making up the rest (Sher and Sher 1994). So if farming and rural are not necessarily related, the question is raised what does 'rural' mean, referring to Australia?

As Sher (1977) stated '… the simple fact is that rural people, rural communities, and rural conditions are so diverse that we can find evidence to support nearly any characterisation' (p1.). I share the view of Johnson-Webb, Baer and Gesler (1997) when it is suggested that researchers can employ any of a number of definitions to answer best the given research question. Hence, I have adopted Humphreys et al. (1996) stance; they note that '… the essential characteristics of rural areas include large distances, sparsely distributed populations, often harsh environments, a dominance of extensive land-uses (notably agriculture and forestry), and considerable geographical and social diversity' (p.1). These characteristics correctly fit the description of the rural environment in which the study participants, all rural Australians, live. Consequently I adopted this broad notion of 'rural' throughout the dissertation.

Many classifications have been developed to describe where rural Australians live. The most common classification used is based on the Rural, Remote and Metropolitan Areas (RRMA) classification, which was developed in 1994 by the Department of Primary Industries and Energy (DPIE 1994), and the then Department of Human Services and Health (see table 1.1). The RRMA classification has also been used by the AIHW (1998) in their first report describing the health of Australians living in rural and remote areas.

Table 1.1: Structure of the Rural, Remote and Metropolitan Areas (RRMA) classification

Zone	**Category**
Metropolitan Zone	Capital cities
	Other metropolitan centres (urban centre population ≥ 100,000)
Rural zone	Large rural centres (urban centre population 25,000-99,000)
	Small rural centres (urban centre population 10,000-24,999)
	Other rural areas (urban centre population < 10,000)
Remote zone	Remote centres (urban centre population ≥ 5,000)
	Other remote areas (urban centre population > 5,000)

Regardless of what classification or definition of rural is used, it is well documented that Australians living in rural and remote areas have disadvantages that urban counterparts do not experience (Humphreys and Rolley 1991; AIHW 1998). Particularly, the recognition of health problems (eg. higher levels of mortality, disease incidence and hospitalisation) amongst rural residents has gained considerable attention from the Commonwealth and State Departments with numerous policies and initiatives designed to improve rural health status.

2.3.3. Health Disadvantages

The AIHW (1998) noted that the following factors contribute to the rural health disadvantage:

- Geographic isolation and problems of access to care;
- Shortage of health care providers and health services;
- Socioeconomic disparities;
- Greater exposure to injury, in particular for persons employed in farming and mining;
- Lower road quality; small, sparsely-distributed populations; and
- Indigenous health needs.

It is important to note that the AIHW (1998) report points out that *rurality* is not the causative factor of health disadvantage, but associated factors such as poverty and less access to health services. Compounding factors are isolation, large distances and very little supply of public transport options (Humphreys et al. 1996). These authors further note that the issue of transport disadvantage, in particular, can have an adverse effect on health outcomes for vulnerable groups, such as older people or people with disabilities, and hamper adequate or timely access to health services.

Individual definitions of health and wellness are also issues that affect use of health care services. Humphreys and Rolley (1991) state that ‘the potential consumer’s willingness to seek care depends, in part, on an individual’s attitude towards health, knowledge about health care, learned definitions of illness (social and cultural), and perceptions of need for health care service’ (p.61). Statistics provided by Medicare (AIHW 1998) confirm that rural people seek fewer health services for similar conditions compared with people in metropolitan areas.

The urban-rural difference is well-noted in the literature. Gray (1994) for example, noted that rural Australia, in terms of culture and tradition, is identifiably different from urban society. Another difference, which can be added in this rural versus urban perspective, is the difference in attitudes towards the perception of health and well-being. Elliott-Schmidt and Strong (1997) explored the difference between urban and rural dwellers' attitudes to health and illness. They found that, whilst urban dwellers' response to illness or disability is linked to discomfort caused by pain or cosmetic attractiveness, rural dwellers' response is often related to the degree to which the illness or disability affects productivity. Often rural residents will postpone seeking medical or associated services until it is economically or socially convenient. Kelly's (1989) paper titled '*City folk, country folk: demographic and attitudinal differences'* suggests that health behaviour is sometimes seen in terms of conservatism but can also be seen in terms of a rural ideology, which involves belief in such personal attributes as self-reliance, willingness to work hard and independence. Her study finds that rural people tend to hold more traditional religious beliefs, are more prejudiced, and work-oriented. Traits such as these, along with the independence and self-reliance (Clarke 1990), may have an adverse effect on health care service utilisation.

Another rural 'trait', which also may have an adverse effect on health care utilisation, according to Gregory (1979 cited in Humphreys et al. 1996), is a 'culture of stoicism'. Gregory (1979) noted that there is ample evidence to suggest that farmers:

- are independent by nature. They tend to let sickness look after itself, and are reluctant to seek specialist help;
- treat illness philosophically, because they understand the power of nature;
- are used to hard work and will put up with illness rather than take a day off work;
- perceive their way of life as healthy, and may not be aware of health risks; and
- are conservative, and may be distrustful of experts, including those in the health field.

The presence of rural stoicism within Australia seems therefore not only associated with physical illness, but also with the acceptance of illness and injury, as a normal part of life (Clarke 1990). The evidence provided here suggests that the decision to seek medical help and to access health services or not is possibly shaped by a belief that the self-reliant, independent individual, accompanied by resourcefulness, will manage - regardless of the circumstances.

2.3.4. A Rural Outlook

The aim of the National Rural Health Strategy, endorsed in 1991, was 'to achieve optimal health for all people in rural and remote Australia' (Department of Community Services and Health 1991, p.1). Since then, a broad range of specific rural health policies and programs have been initiated and implemented by health authorities throughout all States and the Northern Territory (Australian Health Ministers Conference 1996). A point raised by Keleher (1999) is that 'the [rural] debate is so heavily politicised and dominated by the discourse of curative services that any coherent vision for the health and social futures of non-urban Australia is obscured' (p. 342).

The reality of living in rural and remote area of Australia however is that there is still a serious disadvantage (AIHW 1998). It was disheartening to read the information in the National Health Rural Alliance 2000-20001 Position Paper (National Health Rural Alliance 2001). In this paper, the National Health Rural Alliance outlined the health disadvantages of people in rural and remote areas which, despite the assurance given by State and Commonwealth Government to remedy the disadvantaged health status of rural and remote Australians, has made little progress. For example, people in rural communities receive, on average, only $92 per year in Medicare services compared with $145 in urban areas (p.2). Based on the 92:145 ration, rural people are $250M worse off in terms of Medicare rebates for General Practitioner (GP) services. Lack of access to a GP is the most significant factor explaining this difference (p.2).

People with a disability are slowly recognised as a group in real terms. Within Queensland for example, the Government has recently launched the *'The*

Disability Services Queensland Strategic Plan 2001 - 2005' (Disability Services Queensland 2000) in an attempt to better the lives of people with disability. Section 3.4 '*Challenges for Queensland'*, draws attention to the particular challenges for both government and community sectors to providing services for people with a disability in rural and remote areas where the population and service infrastructure is sparse. Particular reference is made to the physical environment, that is, lack of service infrastructure, service options, and transport difficulties. Consequently, the principal goal is to ensure access and supply of services to rural people who have traditionally historically experienced such a significant disadvantage. It is laudable that the strategy focus is upon planning services for rural and remote Australians and particularly encouraging, noting the Queensland Government's commitment to the development of initiatives to improve access to appropriate services for people living in rural and remote areas. The question of whether this initiative will achieve a good outcome for all residents living in rural and remote Australia is yet to be answered.

2.4. Conclusion

The body of literature about disability suggests that there is a melding of views, which have emerged from this debate. The resultant outcome is that disability is not solely a physical issue of the individual self. Rather, disability encompasses a complex multidimensional phenomenon to be found within the context of a person's life. It is an interaction between impairment, disability and handicap or in AIHW (1999) terms '…an interaction between impairment, activity and participation'.

It has been argued that the three different approaches to disability each have certain implications for people with a disability. The social model which views disability as largely created by physical and social barriers within the social environment appears for this study to be the most appropriate framework from which to understand the disability phenomenon. Within this model, people with disabilities have rights to be active participants in an environment of equality.

Many studies have been conducted in the area of disability, but comparatively few studies have examined the experience of disability in rural men and women. The literature is extensive in terms of numbers of studies examining the prevalence of disability, but this literature has focused on epidemiological data and definitions of disability, rather than recording the everyday life experiences of people who live with disability. Furthermore, the disability studies, using empirical and deductive methods, focus solely on disability as a physical problem. There is a clear need for research that allows men and women's experiences to be heard. Their experiences can inform physiotherapists and other health professionals in their quest to offer holistic care.

This lack is particularly true for rural men and women, since there has been insufficient published research to date that documents their unique experiences. Whilst the few studies which have been completed indicate that rural people experience a unique set of difficulties, related to their rural isolation, their culture of self-reliance, and reluctance to seek help, there is also evidence that initiatives are developing to remedy this.

This study will address these gaps within the literature by asking those from rural areas who acquired disability, to describe and interpret their experiences of living with disability. The results of this research will add to the disability knowledge - as it relates to those living in environments that present with a multitude of physical and social barriers.

The next chapter will explore the philosophical, theoretical and methodological bases for this study, to reveal the meaning of disability.

CHAPTER 3: METHODOLOGY

3.0. Introduction

This inquiry, which explores disability, is ‘human science’ research following van Manen (1990). It is ‘human’ because it studies ‘persons’, or beings that have ‘consciousness’ and that ‘act purposefully’ in and on the world by creating objects of ‘meaning’ that are ‘expressions’ of how beings exist in the world (van Manen 1990, p.3-4). It is ‘science’ (derived from Latin *scientia*: ‘to know’) because knowledge is developed by a means of a rigorous human science methodology. To understand disability as a human event, I have used van Manen’s hermeneutic phenomenology. This methodological research approach places human situatedness central, based on the belief that human beings can best be understood from the experiential reality of their lifeworlds (van Manen 1990).

This chapter is divided into three sections. The first section provides a brief overview of the pursuit of scientific health knowledge. The section continues by outlining how ‘Interpretivism’ is a useful theoretical perspective to address the research question. This section also relates the way human scientific knowledge is constructed and created.

The second section explains why phenomenology is useful to facilitate retrieval of lived experience in order to uncover the meaning of disability. This section incorporates principles of influential phenomenologists such as Edmund Husserl, Martin Heidegger and Maurice Merleau-Ponty. To understand these philosophers’ ideas, sections outlining phenomenon and hermeneutics will be incorporated. As hermeneutics and phenomenology are both human science approaches, rooted in philosophy, a discussion of their philosophic traditions will be presented.

The third section and central component to this section outlines van Manen's (1990) hermeneutic phenomenology as the specific methodology to address the research question. The theory behind the method will be presented by discussing the philosophic framework and the fundamental assumptions. van Manen's (1990) hermeneutic phenomenological approach to inquiry and thematic analysis will be discussed. This section also introduces the four lifeworld existentials: lived space, lived body, lived time, and lived other, accompanied by an explanation of how these existentials tap the unique nature of each human situations and how it is rooted in the 'everyday lived experience' of human beings.

Finally, by choosing to detach the design and procedures that are congruent with the methodology method, I have sought to avoid offering material that is too condensed in one chapter. Hence, Chapter Four is directly linked to this one and includes van Manen's research method.

3.1. A Fitting Model for Health Science

Traditionally, the positivist paradigm has provided a basis for the medical model and its grounding of knowledge within experimental research. Increasingly health professionals, including physiotherapists, are questioning whether the medical model and its underlying paradigm is a fitting model for the health sciences. Richardson (1995, p.542), for example, stated that research within a positivist paradigm 'supports a disease-oriented system of care with the implied ethos of care as a dispensation of treatment to an individual for illness which is regarded as a deviation from an agreed health status norm'. In addition, she argues that research within a positivist paradigm 'supports a system of health care in which expert professionals make pronouncements on the status of their patients, judging or predicting the level of deviation from an expected norm and prescribing treatment which aims to restore to a normality' (Richardson 1995, p.542).

Although positivism is not rejected, there is the concern that studies within a positivist research paradigm do not consider regard for the patients' description of illness (Parry 1997); undervalue the worth of the patients' perception (Sim 1990; 1995; Taylor 1993) and do not advance an understanding of individual needs (Robertson 1996). Consequently, there is a case for clinicians, including physiotherapists, to explore alternative research paradigms and generate knowledge that promotes the understanding of the individual's needs in the context of health care. Higgs and Titchen (1998) in *'The Nature, Generation and Verification of Knowledge'* discuss at some length that a health care discipline, such as Physiotherapy, is both a human science and a physical science discipline. Hence, there is value in and need for different types of knowledge, such as 'propositional knowledge', derived from research and scholarship; 'professional craft knowledge' derived from professional experience; and 'personal knowledge' which can be derived from personal experience (Higgs and Titchen 1998, p.526). These authors propose that individuals create unique constructions or interpretations of nature and of their own experiences, and that knowledge is the product of a dynamic and difficult process of knowing or striving to understand. In this sense, the individual's depth and certainty of knowledge grows.

Unique constructions or interpretations of experiences are in abundance in qualitative research. This emergence of qualitative research approaches within the health sciences has brought a 'welcome paradigmatic shift to the field' (Ritchie 1999, p. 255) with exposure of 'patient's beliefs, perceptions and opinions in a way that provides the humanistic dimension that is otherwise lacking when the research is only expert-driven'.

Research in this sense is not a matter of offering interpretations of reality, but offering interpretations that become reality, to the extent that they are agreed upon. As this study contends, inquiry in subjective meaning will bring patients and health professionals closer together and present in-depth knowledge that will guide practice and assist patients to better health. An approach situated in the interpretive paradigm allows for a systematic analysis of socially meaningful action and acknowledges that truth depends on shared values, ultimately determined by the interaction and the context.

3.1.1. Theoretical Perspective - Interpretivism

> … increasingly the health science professional is becoming aware that people require not only health care assistance, surgical intervention, or pharmaceutical treatment, but that the professional must be much more involved in the way that people experience and live with their problems in a different, sometimes deeply personal and unique manner (van Manen (1994, p.1)

There is a profound need to be thoughtfully aware of how people think, feel, see things, or experience difficulty. This requires on the part of the health professional an 'embodied form of knowing and of understanding patient-caring act - that enables instant caring and immediate judging when involved with patients' (van Manen 1994, p.1). The majority of published research in health journals, in Australia and overseas, show a preponderance of studies based firmly on methodologies within the positivist tradition of research. Although the contribution of this research needs to be appraised in light of the ongoing change in health care policy and practice, I would contend that scientists (including physiotherapists) who persist in clinging to some tenets of traditional science fail to inform health professionals in designing and evaluating programs of care, focused on the needs of the *individual* and service delivery in the community setting.

Proponents of interpretivism aim to understand the complex world of lived experience from the point of view of those who live it. It is an epistemological position conceived, as Schwandt (1994, p.125) puts it '… in reaction to the effort to develop a natural science of the social'. This aim, he clarifies, is spoken of as an abiding concern for the life world, for the emic (local) point of view, for understanding meaning and for grasping the individual's definition of a situation. The means or processes by which the inquirer arrives at this kind of interpretation of human action are called '*Verstehen'*. Translated from German, *Verstehen* refers to a notion of 'understanding', contrasting with the 'explaining' approach which seeks to identify features offering cause and explanation, hence control and predicability (Dilthey 1976; Crotty 1998). Unlike an explicative approach, the key issue in the interpretivist approach, (Crotty 1998, p.67 emphasis in original) is that it '… *looks for culturally derived and historically situated interpretations of the social life-world'*.

How do we know or in Crotty's words 'look for' human interpretation? What is the purpose of this 'looking for'? The purpose of this 'looking for' centres around the assumption that to understand an individual's world of meaning one must interpret it. The inquirer must elucidate the process of meaning construction and clarify from the individual's perspective what and how meanings are embodied in language and actions. Rather than studying and explaining human action entirely in terms of externally-perceived events, interpretivists study and interpret social action in terms of situations and meanings of those involved (Geertz 1973). The underlying assumption of interpretivism is the assertion that meaningful interpretations of human experiences can only come from those persons who have thoroughly immersed themselves in the phenomenon they wish to interpret and understand. From an interpretive perspective, the 'why' question is replaced by the 'how' question (see, for example Denzin and Lincoln 1994). Interpretive approaches include Symbolic Interaction, Phenomenology, and Ethnomethodology, among others. While there is debate in the literature about whether these perspectives are different and how they are different (see, for example Denzin 1989), there are shared assumptions according to Ryff (cited in Marshall and Rossman 1980). These are:

- interpretive approaches emphasise a person that is active and intentional. People construct their own meanings and identities; they exercise control over their lives and are guided by internal convictions and goals;

- the emphasis is not just on behaviour but the meaning of behaviour, or action, that the person themselves has portrayed or expressed;

- human conduct must be understood from the point of view of the person;

- The contextual and historical relativity of what we know is emphasised in … interpretive works. Knowledge about human experience and social structure is time and culture bound. Rather than searching for sweeping generalisations about human experience or social structure, we must content ourselves with the unending task of monitoring changing human experiences in changing social worlds; and

- There is a concern for studying the 'Lebenswelt', the life-world, to get away from empty word abstractions and into the world as it is actually experienced, it calls for understanding the world as it is actually lived.

Interpreting, as a means of understanding the actual world, is to accept a particular model of being-in-the-world or ways of life (Shapiro 1981). The significance of interpretive studies in relation to a way of being-in-the-world is noticeably evident when Rabinow and Sullivan (1987, p.6) write:

> For the human sciences both the object of investigation - the web of language, symbol, and institutions that constitutes signification - and the tools by which the investigation is carried out share inescapably the same pervasive context that is the human world.

Within this context, researcher and participants seek understandings to emerge from reflexive, interactive and open dialogic processes. As Schutz (1972) argued 'unlike the world of nature … social reality has a specific meaning and relevance structure for the human beings living, acting, and thinking within it …it is these thought objects of theirs which determine their behaviour by motivating it' (Schutz 1972, p.59). The experience of what human beings directly experience (termed by phenomenologists 'primordial phenomena'), that is, objects of our experience even before thinking about it, interpreting and attributing meaning to it, indicates the congruency between the theoretical perspective (interpretivism) and the methodology (phenomenology). As phenomenology has been selected as an appropriate methodology for this inquiry. I turn now to the discussion of phenomenology and begin with a brief introduction of its historical evolution.

3.2. Phenomenology

Phenomenology, a branch of philosophy, has a long tradition in the social sciences. According to Hinchman and Hinchman (1984), the renowned German philosopher, Immanuel Kant (1724 – 1804) first distinguished between noumenal reality, 'things in themselves' and phenomenal reality, the 'appearance of things as perceived' (Palmer 1994, p.196; Stumpf 1994, p.309). It is the 'phenomenal world', the world of appearances, which phenomenologists study, for the noumenal world is inaccessible. Kant's search for an opportunity to study phenomena of everyday life in a scientific way helped to set the stage for phenomenology. Phenomenology (Greek for *appearance*) refers to a thing or event as it 'appears' to human consciousness, as opposed to what it is essentially, apart from perception. Kant argued that our minds structure our experience of the world; we can never know the 'things-in-themselves', only the 'things-as-they-seem'; never 'noumena' only 'phenomena' (Kant cited in Jary and Jary 1991). In essence, phenomenology is a methodology to investigate and describe 'being in the world' (Smith 1998, p.75).

Whilst I will not attempt to review or recount in-depth theories of phenomenologists, I have chosen to provide a brief introduction of some of the main phenomenological thinkers for the following reasons. First, I regard it as necessary to clarify some theories, difficult as some are, in an effort to appropriate certain ideas. Second, it may show how phenomenologists might be placed in relation to each other and, third, it may assist to identify a certain historical flow to twentieth century phenomenology. Phenomenology's primary historian Herbert Spiegelberg (1982), used the word 'movement' to signify that phenomenology was not a stationary philosophy. Spiegelberg (1982) identified three phases (1) Preparatory phase; (2) German phase; and (3) French phase - with contribution from many philosophers. The preparatory phase, for example, provided philosophers such as Franz Brentano (1838-1917), who wrote about phenomenology as a method of inquiry and discussed the concept of ‘intentionality’, a concept that implies the inseparable connectedness of human beings to the world (van Manen 1990) and that all actions have meaning and purpose.

The German phase marked the modern phenomenological tradition, which began prior to World War I. Philosophers there began to search for a science that recognised the importance of context and the individual construction of perception and meaning in that context. They asserted that humans, their meaning making and actions could only be understood holistically within their world.

At the forefront of this search for the foundation of human knowledge was Edmund Husserl (1859-1938), generally regarded as the founder of the modern phenomenological movement (Stewart and Mickunas 1990). Husserl, originally educated as a mathematician, searched for a method that would elevate philosophy to the status of a rigorous science. His search evolved into the analysis of the logical structures of consciousness. Philosophy, he argued, was based upon presuppositions, hence his proposal that by ‘bracketing’ these traditional, naturalist facts of knowledge and looking at the essence of the phenomenon that remained, a ‘presuppositionless’ account of the phenomenon would emerge. For Husserl, this absolute, rigorous science ultimately was the explications of consciousness, returning to *Zu den sachen selbst* (back to the things themselves) (Spiegelberg 1970, p.21). The prime intent was to discover, to explore and to describe phenomena, as it appears to human consciousness, as opposed to what it is essentially. Underpinning this approach is the notion of *Leib*, of lived body, in opposition to *Körper*, the body under a strict physical description. Husserl, according to Spiegelberg (1970), has set the groundwork for the phenomenological approach to the issues of the body that it is characterised by beginnings in the ‘Life-World’ of *Lebenswelt*. Life-world here means 'the world of the natural attitude of everyday life, the original, prereflexive, pre-theoretical attitude' (Spiegelberg 1970, p.7). Taylor (1993, p.175) points out that phenomenology is interested in people's 'lived intersubjective experience in their world for the way in which they illuminate "being", that is, the basis of their existence'.

Martin Heidegger (1889-1976) a German philosopher and loyal follower of Husserl, is most often acknowledged as the most original 20th century philosopher. Heidegger wanted to develop phenomenology into an ontology, and a discipline that thought of itself as governed, not by the question of the relationship between subjectivity and world, but by the question of the being in the world (Spiegelberg 1970). The result was to replace the notion of subjectivity with that of Dasein, Heidegger's preferred term for human being (Crotty 1996). As a consequence, Heidegger turns from the question of the body to the question of embodiment, 'we do not 'have' a body; rather, we 'are bodily' (Heidegger 1979, p.99).

What Heidegger embarks upon is a phenomenology of human being, or *Dasein* (Being-there). Heidegger's *Dasein*, according to Gelven (1989, p.120) can be considered as a synthesis of 'Being-in-the-world', that is, '… state of mind, which manifests the ways in which one is'; 'Being-ahead-of-itself', that is '… understanding, which manifests the ways in which one can be; and 'Being-alongside', that is '… fallenness, which manifests the ways in which one hides behind the chatter, the curiosity, and the ambiguity of inauthentic existence' (Gelven 1989, p.120). Thus, Heidegger's philosophical approach focused largely on interpretations of the way we experience the world and the way we also construct our sense of Being-in-the-world.

Heidegger's notion of 'Being', can be understood as a fundamental entity with 'its own distinctive character' (Heidegger 1962, p.24). Heidegger sought to correct the tendency to think about humanity in the same way as we think about things. 'We think about things by defining them, that is, by listing their attributes or characteristics. But the essence of humanity cannot be accounted for by listing its attributes. Unlike the being of things, the being of humanity includes an awareness of being. Unlike a hammer, which is simply a kind of 'Being', a person, says Heidegger, "always has to be (ie. realize) his[sic] being as his own"- by which he means that one is aware of the possibility of being or not being one's own self (Stumpf 1994, p.504). This understanding, Heidegger suggests, may assist us when we are trying to explore 'the way human beings relate to things' (Heidegger 1962, p.51) in the world (ie in 'everydayness').

Like Husserl, Heidegger had a phenomenological method for an analysis of being-in-the-world. This method was that of hermeneutics (derived from Greek *hermeneuein*: 'to interpret'). For Heidegger, hermeneutics begins at home in an interpretation of the structure of everydayness. Unlike earlier philosophers who viewed hermeneutics as a rule for interpretation of texts, Heidegger's hermeneutics refers to a 'phenomenological explication of human existing itself' (Palmer 1969, p.42). In his most important and influential work *Being and Time* (Heidegger 1962, trans.), Heidegger was concerned with what he considered the essential philosophical (and human) question: What is it 'to be'? Hermeneutics, for Heidegger, thus begins with a phenomenological return to our being, which presents itself to us initially in an unformulated, undeveloped fashion, then seeks to unfold that pre-understanding, make explicit what is implicit, and grasps the meaning of Being itself. Unlike Husserl's phenomenology that is primarily interested in epistemological issues, Heidegger's philosophy focuses on ontological issues about what it means 'to be a person'. Lawler (1998, p.50) describes the notion that 'Heidegger's continuation with, but departure from Husserl's ideas, is in part related to Heideggers' shift in focus from *consciousness*, to *being*' (p.50 emphasis in original). Here, she alludes to the fact that Heidegger is not more concerned with human subjectivity (which is how his work is often used by researchers), but that he was more interested in what it is to *be.* Hermeneutics, for Heidegger, thus means an unveiling of Being. Heidegger's shift from the problems of epistemology to those of ontology - that is, of what it is to be a human being - radically altered modern debates on the nature of science and of knowing (Dreyfus 1987).

The French phase of the phenomenological movement involved Jean Paul Sartre and Maurice Merleau-Ponty. Merleau-Ponty further developed the concept of the body first proposed by Husserl (1970), using light from Heidegger's notion of being-in-the-world to dispel finally what remained of Descartes' theoretical approach. Descartes regarded mathematics as a language of truths about the world and applied this approach to the study of the human body (Stumpf 1994). He gave a purely mechanical explanation to several functions that were previously attributed to the soul (motion, digestion, circulation, etc.) and reduced the body to what is extended in time and space, and thereby what is measurable. This split the theory in two directions. The nature of the mind according to Descartes was such that it had an existence that is completely independent of the body (Stumpf 1994). Second, it was an attempt to reduce various types of human experience to the mechanical interactions of the body, ie. ultimately to physics. For Descartes, the whole range of human passions and moods as well as determinations of the will, is nothing more than effects of the mechanical interactions of the fluids and parts of the body (Stumpf 1994).

With the rise of phenomenology, the Cartesian dualism approach has been called into question with various philosophers, most notably Husserl, Heidegger, and Merleau-Ponty, challenging the treatment of the body and the mind, and our intentional cognition of the world (Crotty 1996). Merleau-Ponty (1962) began to sketch out a philosophical trajectory that confirmed the importance of lived experience in grasping the nature of language, perception, and the body. In the '*Phenomenology of Perception*', Merleau-Ponty (1962) confirms the influence of Husserl on his own philosophy. Like Husserl, Merleau-Ponty emphasises the importance of the phenomenological reduction in order to open access to 'essences'. Merleau-Ponty (1962) points out that rather than attempting to establish the things that build up the shape of the world, human beings need to recognise our experience 'as the source which stares us in the face and as the ultimate court of appeal in our knowledge of these things' (Merleau-Ponty 1962, p.23). For Merleau-Ponty, the phenomenological return to experience is philosophy. Not philosophy as a particular body of knowledge, but philosophy as a vigilance that never lets us forget the origin of all our knowledge.

Concepts apparent in Merleau-Ponty's work are embodiment, the importance of perception or the *primacy* of perception, and the need to focus on lived experience (Merleau-Ponty 1962). The importance of embodiment as described by Merleau-Ponty is twofold. First, although the body is both object (for others) and a lived reality (for the subject), it is never simply object nor simply subject. As Grosz (1994) pointed out:

> It [the body] is defined by its relations with objects and in turn defines these objects as such - it is 'sense bestowing' and 'form-giving', providing a structure, organisation, and ground within which objects are to be situated and against which the body-subject is positioned. The body is my being-to-the-world and as such is the instrument by which all information and knowledge is received and meaning is generated. It is through the body that the world of objects appears to me; it is in virtue of having and being a body that there are objects for me (Merleau-Ponty cited in Grosz 1994, p. 87).

Second, pitting himself directly against the abstractness and emptiness of the Cartesian cogito - 'I think, therefore I am' - Merleau-Ponty shows that to be a body is to be tied to a certain world. The statement that 'our body is a medium for having a world, one that places each human being in the world' could sum up his view (Merleau-Ponty 1962, p.243). It is suggested that humans, through consciousness, are aware of being-in-the-world, and through the body gain access to this world; human beings feel, think, taste, touch, smell, hear and thus are conscious through the opportunities that the body offers.

Another concept relates to the belief that human beings perceive the world through the body. Merleau-Ponty (1962) argues that 'perception is not simply the result of the impact of the external world on the body, but the very imbrication of the perceiving organism and its surroundings is what lies at the basis of perception' (Merleau-Ponty 1962, p.42-43). This means that there is no perception in general - a notion that would turn it into an abstract universal; there is only perception as it is lived in the world. It is precisely the 'lived' nature of perception and the body that makes phenomenological research viable and necessary. According to Merleau-Ponty (1962, p.42):

> Primacy of perception gives one access to experience of the world as it is given prior to any analysis of it. To perceive is to render oneself present to something throughout the body.

Merleau-Ponty (1962) maintains that perception provides access to the truth and also the original mode of consciousness. In this sense, it is argued that one's perception is a totally unique, individual experience that depends on both the context of the situation and the external stimuli being perceived and accounts why truth is individualistic and subjective.

Another concept relates to Merleau-Ponty's thought that provides a vision and direction for turning to the phenomena of lived experience. In the context of this study, it means 'relearning to look at the world by reawakening the basic experience of the world' (Merleau-Ponty 1962, p.viii). It is an important concept and as such will be further explored in the following section.

3.3. van Manen's Hermeneutic Phenomenology

How one orients to lived experience, van Manen (1994, p.7) suggests, is in a broad sense, a philosophy or *theory of the unique*; it is interested in what is essentially not replaceable (emphasis in original). van Manen, strongly influenced by Merleau-Ponty's philosophy, explains how phenomenology differs from almost every other science in that it attempts to gain insightful descriptions of the way we experience the world. van Manen (1990, pp.37-38) proposed that 'phenomenology does not offer us the possibility of effective theory with which we can now explain and/or control the world but rather it offers us the possibility of plausible insight which brings us in more direct contact with the world'. Rather than seeking a judgement about facts or reality, the aim of phenomenology is to gain people's understanding, opinions and expressions of feelings. In other words, rather than generating theories or general explanation, phenomenology aims to describe the experience as it exists. It is about expressing thoughts and perceptions of phenomena in the form of language in speech or writing (van Manen 1990). It is about describing the essence of the experience and a fuller understanding of the nature of the experience.

My acquaintance with phenomenology has come through the writings of Crotty (1996) who explained the idea of phenomenological research in clear language. ‘It is a study of phenomena ie. of the *objects* of human experience. It elucidates *what* people experience’ (Crotty 1996, p.3 emphasis in original). ‘Mainstream phenomenology … wants to elucidate, first and foremost, the phenomena to which people are attaching meaning. It pursues, not the sense people make of things, but what they are making sense of. In the context of this study, what is physical disability as a phenomenon that people [living with disability] experience before they make any sense of it? Thus, I deem hermeneutic phenomenology as a research methodology that offers insights that are presently scarce in much of the disability literature written for health professionals.

The research orientation based in van Manen’s phenomenology is known as ‘human science’ (derived from German *Geisteswissenschaften*: ‘human sciences’). I note van Manen’s (1990) comment in *Researching Lived Experience*, that ‘human science’ is often used interchangeably with the terms ‘phenomenology’ and ‘hermeneutics’ (p.2). Whilst he argued that this is not inconsistent with the hermeneutic phenomenological traditions, as found in Germany and the Netherlands, I have found this confusing at times. Particularly when I note that at times these terms collapse into one, such as a section titled ‘hermeneutic phenomenological human science’ (van Manen 1990, p.8). Hermeneutic phenomenology is, according to van Manen (1990, p.6), ‘a human science which studies persons’. It is interpretive (*hermeneutic*), because of its claim that there are no uninterpreted phenomena, and it is descriptive (*phenomenological*) because it wants to be attentive to how things appear and let things speak for themselves (van Manen 1990). In other words, the phenomenon both speaks for itself and is interpreted through the use of text to describe it. ‘To do hermeneutic phenomenology is to attempt to accomplish the impossible: to construct a full interpretive description of some aspect of the lifeworld, and yet to remain aware that life is always more complex than any explication of meaning can reveal' (van Manen, 1990, p. 18).

In *'Being and Time'* (Heidegger 1962) there is a section titled 'Understanding and Interpretation' (*Verstehen und Auslegen*) which is extremely influential for van Manen's hermeneutic phenomenology (pp.188-195). Here, Heidegger argues that understanding is always 'ahead of itself' (*sich vorweg*) because it projects expectations, that interpretation then makes explicit. In similar vein is van Manen's (1990) belief that anything that presents itself to consciousness is there, because, in a sense, we are already related to and aware of the world. van Manen (1990), like Heidegger, proposed that it is only possible to interpret something according to one's own lived experience. Underpinning this methodological premise is the philosophical belief that human knowledge and understanding can be gained from analysing the descriptions of people who have lived the experience in question. The emphasis in such inquiry, then, is placed on recollection and recognition of ordinary day-to-day experiences of life which Spiegelberg (1982, p.382) considers as 'illuminating some of the fundamental way in which we make sense of everyday life, calling for the researcher to see what is normally hidden and forgotten'. van Manen (1990, p.27) states 'a good phenomenological description is collected by lived experience and recollects lived experience - is validated by lived experience and it validates lived experience'. A good phenomenological description is an adequate elucidation of some aspect of the lifeworld- it resonates with our sense of lived life (van Manen 1990, p.27).

Based on the philosophical works of Heidegger, hermeneutic phenomenology, as outlined by van Manen (1990), is a process of exploring one's interests and understandings of a phenomenon, uncovering the essence of that phenomenon by gathering and interpreting 'raw data' from those living it, and offering implications for practice. The 'raw data' of a phenomenological study are personal experiences, often complemented with poetry, biography, art or literature. Hence the remark that hermeneutic phenomenology is 'both descriptive and interpretive' (van Manen, 1990, p. 180). This denotes the emphasis is placed on understanding the etymological roots of words and on the writing process as a source for understanding and the use of text to describe it. While there is no procedure of sequential steps that must be followed in such research, van Manen (1990, p.30-31) has identified a methodical structure of human science research, which gives it its vigour. Summarised, his structure begins by turning to a phenomenon of serious interest that will be investigated as lived, rather than as conceptualised. Reflection on essential themes that characterise the phenomenon will be followed by a description of the phenomenon through writing and rewriting. This needs to be accomplished by maintaining a strong and oriented relation to the phenomenon. The final step is to balance the research context by considering parts and whole.

This research design is critical for this inquiry, as mentioned elsewhere (see section 3.1); therefore an in-depth discussion will be provided in Chapter 4.

As pointed out in Chapter 1, this study was initiated by quiet reflection on disability as a human experience after Sandra's comment 'no one understands'. Phenomenology begins in silence (Spiegelberg 1970) and in this sense phenomenology begins with a 'phenomenological return to our being' Crotty (1998, p.97). This presents itself to us 'initially in a nebulous and underdeveloped fashion, and then seeks to unfold that pre-understanding, make explicit what is implicit, and grasp the meaning of "Being" itself' (Crotty 1998, p.97). Crotty's analysis reflects Heidegger and van Manen's phenomenological assumptions about human existence as a process whereby human beings are always outside of and beyond ourselves, as we direct ourselves toward the future. I have interpreted it that the phenomenologist borrows the descriptions of the participants' experience and reflects on them. The reflection then enables the researcher to 'an understanding of the deeper meaning or significance of an aspect of human experience in the context of the whole of human experience' (van Manen 1990, p.55). van Manen's research approach underpins the belief that human beings can best be understood from the reality of their lifeworlds. In the following section of this chapter, I will outline the four fundamental existentials that evidently belong to the existential ground by way of which ‘all human beings experience the world’ (van Manen 1990, p.102)

3.3.1. The Four Lifeworld Existentials

Increasingly, health professionals become aware of the importance of interpretive research models that place human situatedness central and are based on the belief that we can best understand human beings from the experiential reality of their lifeworlds (van Manen 1990). Within the phenomenological literature four lifeworld existentials (corporeality, spatiality, temporality and relationality) have been considered as belonging to the fundamental structure of the lifeworld (see, for example, Merleau-Ponty 1962).

van Manen (1990) considers the lifeworlds are ‘productive categories for the process of phenomenological question posing, reflecting and writing’ (p.102). The first fundamental existential refers to the lived body (corporeality). In the ‘*Phenomenology of Perception’* Merleau-Ponty (1962) identifies the *corps propre* or ‘lived body’, as the seat of all human relation to the world. ‘Lived body’ refers to the phenomenological fact that human beings are always bodily in the world and thus grasp the world via a bodily, sensorimotor, intentionality, pragmatic and ambiguous nature (Merleau-Ponty 1962).

This is of central importance to this study because it demonstrates a means of understanding or interpreting the texts generated by the participants who gave me accounts of their everyday experiences. Merleau-Ponty (1962) gives an excellent description of expertise and continues by explaining that the body is ‘essentially an expressive space’ (p. 146). He uses an example of a blind man who uses a cane, to illustrate the human ability to incorporate the world into our bodies. We are able to take an object like a cane and ‘transplant’ ourselves into it, that is, ‘incorporate it into the bulk of the body itself’ (Merleau-Ponty 1962, p.143) and employ it with the same ease we might employ our own limbs.

Like Merleau-Ponty, I support the notion that objects can be incorporated into our everyday world and become part of us, like we become part of them. Objects such as John's prosthesis, Henry's ankle foot orthosis, or Karl's walking stick became incorporated into their body. For these participants, motor habits such as walking could not be achieved by the body's natural means. Thus, human beings use 'an instrument' and, in doing so, project themselves around a cultural world (Merleau-Ponty 1962, p.146). This enables the body (at all levels) to perform the same function, that is to 'endow the instantaneous expressions of spontaneity' with 'a little renewable action and independent existence' (Merleau-Ponty 1962, p.146).

> It is the condition and context through which one is able to have a relation to objects. It is both immanent and transcendent. And therefore the body is our general medium for having a world. Insofar as I live the body, it is a phenomenon experienced by me and thus provides the very horizon and perspectival point which places me in the world and makes relations between me, other objects, and other subjects possible. Phenomenological reflection on the body reveals that I am not a subject separated from the world or from others, a mind somehow cut off from matter and space (Merleau-Ponty 1962).

The second lifeworld existential relates to the experience of the lived space (spatiality). van Manen describes 'lived space' as 'largely pre-verbal', in other words something that is more difficult to put into words since we do not ordinarily reflect on it. 'Lived space' can refer to the world or landscape in which human beings move and find themselves at home or elsewhere. 'Space is not the setting (real or logical) in which things are arranged, but the means whereby the positing of things becomes possible' (Merleau-Ponty 1962, p.243).

Exploring of space is of great importance as it is helpful to inquire into the nature of the 'lived space' that renders that particular experience its quality of meaning (van Manen 1990). Hence in this study where I want to understand the rural person, I ask about their [rural] world, their background, their place of birth and childhood and their interests. Exploration of space, for example, can also occur within the living environment. A person with poor balance can experience space differently from someone who can walk straight. At home, a walk from the toilet or the shower, for example, can seem like an endless journey with many hurdles along the way. In mathematical terms, the length may only be a few metres or so, but the objective distance may not at all accord with the felt distance between these two places for someone who can't walk straight. The important point is that 'felt' space could be quite different to objective space. It is how *lived space* is experienced which reveals what it *means* to people and therefore places some kind of value upon it. 'Lived space' appears to be a category for inquiring into the ways we experience the affairs of our day-to-day existence; in addition it helps us uncover more fundamental meaning dimensions of lived life (van Manen 1990 p.103).

The third concept relates to 'lived time' (temporality). 'Lived time' is subjective time as opposed to clock time or objective time (van Manen 1990, p.104). Lived time is the time that appears to speed up for a patient, when he/she is visited by a friend telling funny jokes, or slow down, when he/she is anxiously awaiting a visit from a doctor to tell the result of test. van Manen's conception of lived time is that it also 'our temporal way of being in the world' (1990, p.104). In this study it is the person who recollects the past, enables to act in the present and hopes for a future. 'The temporal dimensions of past, present, and future constitute the horizons of a person's temporal landscape' (van Manen 1990, p.104):

> Whatever I have encountered in my past now sticks to me as memories or as (near) forgotten experiences that somehow leave their traces on my being - the way I carry myself (hopeful or confident, defeated or worn-out), the gestures, I have adopted and made my own (from my mother, father, teacher, friend), the words I speak and the language that ties me to my past (family, school, ethnicity), and so forth. And yet, it is true too that the past changes under the pressures and influences of the present. As I make something of myself I may reinterpret who I once was or who I now am.

van Manen's (1990) phenomenological description of temporality elucidates the nature of subjectivity, and helps to expand one's time perspective. The experience of past, present and future (lived) time features particularly when humans note physical loss and further disability (Charmaz 1991). 'Sorrow for a past increases when people believe that they might not reclaim it' (Charmaz

1991, p.194). We are able to develop a deeper understanding of the lived time as it is for the participants, since 'yearning and nostalgia steadily colour one image of self after another, they become etched upon the self-concept' (Charmaz 1991, pp.194-195). Or in van Manen's (1990, p.104) words 'through hopes and expectations we have a perspective on life to come, or through desperation and lack of will to live we may have lost such perspective'.

The fourth existential relates to *lived other* (relationality). *'Lived other'* is the lived relation we maintain with others in the interpersonal space that we share with them (van Manen 1990, p.104). It also means to be-with-others. Others form a substantial part of the world into which we exist. We interact with others on a daily basis, but we are also part of a social and cultural ethos, which has developed over time. We must therefore, engage in activities in which others are involved, and live in the world alongside others (van Manen 1990). The meaning of disability for people living in rural areas is not an external phenomenon imposed on those affected - meaning emerges from interaction with the everyday world.

This section has introduced the four existentials of lived body, lived space, lived time, and lived relation to the other. Whilst they can be differentiated, they can not be separated (van Manen 1990, p.105). At the outset, this premise suggests that lifeworlds cannot be studied separately. Even so, van Manen proposed that in a research study we can temporarily study the existentials in their differentiated aspects, provided that we realise that 'one existential always calls forth the other aspects' (van Manen 1990, p.105).

3.4. Conclusion

In this chapter, I have defined this inquiry as human science research with an interpretive perspective, using van Manen's hermeneutic phenomenology. Phenomenology can challenge the assumptions concerning the meaning of disability, as this perspective is open to the meanings people give to their experience. I claim that phenomenological research can achieve the fulfilment of our human nature, that is, to become more fully who we are. As a physiotherapist, I regard this study as an attempt to understand the experiences of people living with a physical disability and the subsequent meanings that they make of these experiences. Finally, a phenomenological approach reflects much of my own sentiments regarding research inquiries and data analysis, ultimately aiming to understand the lives of rural people within their own unique context.

The particular methodology used in this study could be supported from epistemological and ontological values, which have consensus support within human science research. Hermeneutic phenomenological research according to van Manen (1990) is ‘to construct a possible interpretation of the nature of a certain human experience’ (van Manen 1990, p.41). It offers a method for conversations and observations to be analysed so that we come to a fuller grasp of what it means to be in the world as a rural man or woman living with disability. van Manen’s (1990) hermeneutic phenomenology takes into account the socio-cultural traditions that have given meaning to human ways of being in the world and it is to this method that the next chapter now turns.

CHAPTER 4: DESIGN AND METHODS

'... the method one chooses ought to maintain a
certain harmony with the deep interest
that makes one an educator [physiotherapist]
in the first place'.
van Manen 1990, p.2

4.0. Introduction

Following the philosophical stance, theoretical perspective and methodology discussed in the previous chapter, this chapter discusses the approach to the design and method of this study. It begins by detailing and describing the theory of method first conceptualised for this study. van Manen's (1990) theory of data analysis is presented with an explanation of how such theory became incorporated into the practical components of the research project itself. The chapter will outline the choices made and why they were made with regard to the design, participant sample, setting and rigour, thereby leaving a path of decision that can be trailed for auditing purposes. The chapter concludes with a discussion on the ethical issues of this research.

At the outset, I wish to clarify that this inquiry used a research design and method that illustrates a close collaboration between the inquirer as a co-researcher and those with first hand experience or knowledge. Although 'special' language, such as participant observation and informant in-depth interviewing, is used at base for design and methodological procedures, as an interpretive inquirer, in a way I 'simply' watched, listened, asked, and recorded - with a commitment to the research question at all times. Here, I am acutely aware of Schwandt's (1994) reflection that the interpretive researcher lives the question by a process of returning to the question or phenomenon until a sense of the nature of the topic being studied is felt.

Another fundamental assumption, in line with the interpretive inquiry, is the premise that the inquirer is not only an observer of behaviour, but also an interpreter of meaning to which the object of study has privileged access. This is an ontological position that the interpretive research framework adopts. Knowledge of the social world can only be gained in the same way that those who live it, access *their* social world (my emphasis). Hence, what I learned about the 'Lebenswelt', the life-world of people living with disability, is in simple terms, the reality of one individual; it is *their* access to the world, context dependent, and an interpretation of *their* experiences and actions. It is likely that a great variability exists in the way each person in this study experiences disability. Although interpretations may generate a 'uniquely' increased understanding, they are not 'generalisable'. As van Manen, clearly states 'phenomenology is a theory of the unique' (van Manen 1990, p.7).

van Manen's research method developed from German philosophy *Geisteswissenschaften*, 'human sciences'. His approach is deemed to be a major contribution to the development of methodology (Munhall 1994; Crotty 1996; 1998) with its effort to close the theory-practice gap. Hence it is recognised as an important approach in qualitative research (Crotty 1996; 1998).

4.1. Research Design

The methodological structure of human science research expounded by van Manen (1990) was employed to understand what disability is like for men and women living in a rural setting. van Manen (1990, pp.30-31) asserts that hermeneutic phenomenology is a dynamic interplay among six research activities:

1. turning to a phenomenon which seriously interests us and commits us to the world;
2. investigating experience as we live it rather than as we conceptualize it;
3. reflecting on the essential themes which characterize the phenomenon;
4. describing the phenomenon through the art of writing and rewriting;

5. maintaining a strong and oriented relation to the phenomenon; and
6. balancing the research context by considering [the] parts and [the] whole.

The purpose of these six steps is to assist a process in order to gain a deeper understanding of the nature of meaning of our everyday experiences. Each methodological step will now be described in more detail.

4.1.1. Turning to the Nature of Lived Experience

As a physiotherapist and clinician, my aim has always been to undertake my work in a spirit of reciprocity and reflexivity, which involves a (re)search for thoughtfulness. Research becomes then ‘a being-given-over to some quest, a true task, a deep questioning of something that restores an original sense of what it means to be a researcher’ (van Manen 1990 p. 31). As a researcher, I became involved with nine people who, in the context of particular individual life circumstances, were forced, to some extent, to make sense of a certain aspect of their human existence or lived experience.

> Lived experience is the starting point and endpoint of phenomenological research. The aim is to transform this experience into a textual expression of its essence - in such a way that the effect of the text is at once a reflexive re-living and a reflective appropriation of something meaningful: a notion by which a reader is powerfully animated in his or her own lived experience (van Manen 1990, p. 36).

The clinical dilemma that triggered the study arose from my clinical experience as a physiotherapist assisting those who experienced physical (permanent) impairment with disabling consequences. As I would spend time - often up to an hour a day with each person - I realised that the disability experience is far deeper and extended than at first appears, as it penetrates many valued domains of life. I became increasingly aware that living with disability had the potential to disrupt one’s life in a serious way. The clinical dilemma encountered was a discrepancy between the perception of living with disability as held by health care professionals, and that held by those people who actually live with disability.

True phenomenological question, according to van Manen (1990), is only possible until one has identified an interest in the nature of a human experience. Consequently, my desire to bring to the forefront the experience of disability as a phenomenon that human beings live through directed the question 'what is it really like to live with the disability? In doing so, it formed the starting point for the study.

4.1.2. Investigating Experience as We Live It

The source of phenomenological research is the lifeworld; hence this section will discuss the approach used to enter the lifeworld. As described in Chapter Three, the study was grounded in Interpretivism, which calls for a non-exploitative relationship between the researcher and the researched; one based on collaboration, cooperation, and mutual respect (Schwandt 1994). Furthermore, as an interpretive researcher, the aim was to create a dialogue between practical concerns and lived experience through engaged reasoning and imaginative dwelling in the immediacy of the participants' worlds (van Manen 1990). Therefore the study was conducted from the outset, within a context that enabled an interpretive understanding of the environment in which the participants were living and managing their lives.

Setting

The location of the field depends on what is to be investigated (Strauss and Corbin 1990). Given that I wanted to investigate the experiences of rural people, the setting for the study was a number of rural communities on the Darling Downs in SouthEast Queensland.

Due to the nature of my clinical role as a member of the Rural Allied Health Team (RAHT), I was able to access a number of rural communities within the geographical boundaries of the Darling Downs in SouthEast Queensland (see Map 1.1. in Chapter One).

Frequent travelling to rural communities on the Darling Downs enabled me to establish a good relationship with those who became involved in the study and to thoroughly examine people's everyday experiences in a rural and social context.

Coleman (1991) suggests that it is important to develop close affinity with people as they '… in part tell us what they want to say, in part what they think we want to hear' (p.135). As this was their experience, it was therefore up to them to tell it how they wished and how they experienced it, but as an interpretive researcher, it helped that I was familiar with the social context.

The concept of 'lived space' within the interview was also important, as it was essential that the participants did not feel constrained in their reminiscences. It was also important to ensure that if they wanted to conduct the interview within the presence of their partner, that this was not commented on or challenged.

Participants

In phenomenological inquiry, purposeful sampling is commonly used (Munhall 1994; Streubert and Carpenter 1995; Crotty 1996). This method of sampling selects individuals for study participation based on their particular knowledge of a phenomenon, for the purpose of sharing that knowledge. People were considered potential participants if they lived in a rural setting, were able to speak English, and were living with an acquired physical disability, which had existed for longer than 12 months. Although it is acknowledged that there are no 'hard and fast' time limits with regards to the duration of grief and loss issues associated with disability, there is consensus that many people experience an awareness and acceptance in the second year (Glassock and Gressor 1992; Cox 1995).

Recruitment of participants through the use of newspaper articles explaining the research was discarded as this potentially would have excluded those who cannot read, those with impaired vision or those who cannot afford a newspaper or even live too remotely to have one delivered. Instead, recruitment of participants occurred through a team of rural allied health professionals from the RAHT. As I had only recently joined this team, I explained that my research role was different from my therapist role. As a researcher, I wanted to conduct research with people not previously known to me, in order to avoid any possible bias from potential participants feeling pressured to participate or the possibility of ‘hidden agendas’, positive or negative, re-emerging. Consequently, I chose not to recruit participants personally. After explaining the aim of the study, the RAHT members were asked to approach potential participants and distribute an information sheet in order to determine people’s interest in participating in the study. Those who expressed an interest and/or willingness to participate in the study were given a consent form to release their name and contact details to the researcher. It is important to point out that participant selection was based on self-identification of having a physical disability, signed informed consent and a willingness to discuss personal life experiences. Participants were fully aware that if they choose not to participate this would not effect their health care.

A total of nine people participated in the study, their experience qualifying them as informed participants (Taylor and Bogdan 1984; Morse 1991). In phenomenological research, the number of participants is often limited because of the quantity and richness of data obtained, and the 'extent to which the phenomenon is explored in the interview’ (Drew 1989, p. 431). The ages of the participants ranged from 46 to 81 years at the time of the interviews. I have made a deliberate choice to include a brief profile of the seven men and two women in Chapter Five. This choice reflects a more sympathetic (read: personal) introduction that gives each person a deservingly proper introduction and an opportunity for the reader to meet each participant in their individual environment. It is sufficient to state here that all participants have a long-standing, often a lifetime, association with the towns they live in; towns, which are classified by the RRMA as a ‘rural zone’ (see p.69).

Data Saturation

Many qualitative researchers use the term ‘data saturation’ to suggest when enough data have been collected. Saturation is term that refers to the repetition of discovered information and confirmation of previously collected data (Morse 1994). I, like Morse, consider the notion of data saturation somewhat of a myth. If another group of individuals were interviewed at another point in time, new data may be revealed. Personal descriptions of lived experiences are numerous and thus are in effect inexhaustible, making saturation ‘endless’. However, for practical reasons, an inquirer does not involve an exhaustive number of participants, but is able to identify when the data has revealed itself to be rich, diverse and significant enough to illuminate for readers, an experience which leads to a deeper understanding of the phenomenon. Ultimately, as van Manen (1990) points out, ‘the phenomenologist knows that one's own experiences are also the possible experiences of others’ (van Manen 1990, p 54).

Data Collection

Interviews

As I have described elsewhere, my interest in the issue at the heart of this study began with what appeared to be a simple question: what is it like to live with a physical disability? (see Chapter One). In order to address this human science question, other people’s experiences and their reflections were ‘borrowed’ (van Manen 1990, p.62) through interviews. Interviewing, in hermeneutic phenomenological human science, serves two specific purposes. First it serves as a ‘means for exploring and gathering experiential narrative material that may serve as a resource for developing a richer and deeper understanding of a human phenomenon’ (van Manen 1990, p.66). Second it serves as a ‘vehicle to develop a conversational relation with a partner (interviewee) about the meaning of an experience (van Manen 1990, p.66). Both functions will be discussed in this section.

The interviews were conducted between June 1999 and October 2000. Participants, once they agreed to participate, were contacted by phone, so any preliminary questions they might have could be answered. If they were willing at that time, the participant and researcher would agree on a time to conduct the first interview.

During the first meeting, I would introduce myself and restate the purpose and my interest in the study. Rarely was I asked questions about the actual study; in fact, many of the questions addressed to me during the first visit were of somewhat ‘personal nature’. Questions about my lingual accent, the country of my birth and curiously enough ‘my experience of living in Australia’ were often asked.

My experience in talking as a clinician to many patients over the years, confirmed that involving people in broad conversations needed to be undertaken first as an open-ended conversation, in order to form a relationship of trust and disclosure, ensconced in privacy. Hence, the first moments of each interview were of rather ‘general nature’ and often included a discussion on the weather and a forecast of more rain or drought. Next, I would describe the process of interview recordings, transcriptions and explain that a transcript summary would be given to them (or posted to them) for them to read and that I would ask them if they agreed that the transcript was a true reflection of what they had told me at the interview/s.

Interviews were carried out in people's own home, except for ‘Shane’, whose first interview was conducted in the therapy room at a hospital, as he was ‘coming into town anyway’. A series of two face-to-face interviews was undertaken with eight of the participants. One participant was interviewed once, but this was a three-hour interview. In two cases, at the wish of the participant, the interviews were conducted with the spouse present. A third and final follow-up telephone interview was conducted with everyone. There were two reasons for this: to seek clarification if it was needed, and, secondly, to determine whether the story had reached its natural conclusion.

The first interview was undertaken as a guided but open-ended conversation, where participants were asked to reveal, in their own words, their experiences about living with disability. The introductory question usually was, 'what is it like for you to live with …?' [Stroke, MS etc.]. No fixed order of questioning and no fixed way of asking a question was used, instead questions were guided by the responses of the participants. This method of interviewing is in line with a hermeneutic interview. In an interview of this nature, van Manen (1990, p. 98) explains that '… the art of the researcher is to keep the question (of the meaning of the phenomenon) open; to keep him or herself and the interviewee oriented to the substance of the phenomena under investigation'. In this way there is an interaction between the researcher and the participants, with participants directing the flow of the interviews (Holstein and Gubrium 1994). Other questions were asked if amplification or clarification were necessary. For example, when 'Sandy' told me that she decided to 'come out' and tell others about her Multiple Sclerosis, I asked her '*how*' she announced it. In this way, the interviewee becomes the co-investigator of the study (Holstein and Gubrium 1994).

Interviews ranged in length from forty-five minutes to three hours, depending on the amount of information participants gave and/or participants' fatigue. After the interview, when I drove away in the car I would record my own comments, first impressions, and thoughts on the tape recorder. The recorder, a pocket-size with built-in microphone, was an enormous benefit as I easily drove the car whilst talking into the tape to describe the house, the yard and other observations such as non-verbal messages or gestures. In addition, a diary of notes and journals, for what van Manen (1990, p.73) identifies as further 'sources or lived experiences', was kept to record my thoughts, my reactions and my observations. The accounts in this study are based on the interviews and the copious amount of notes I have entered in the journals as the study progressed.

Each interview was tape-recorded and later transcribed into narrative, written form and imported onto the computer, using a software package Ethnograph v4.0

(Seidel, Friese and Leonard 1995) for the initial phase of data import and line numbering of each file. From then on, Microsoft Windows ™ was used to manage the data.

Transcripts

After the transcription process, I would listen to the audiotapes again whilst reading the typed transcript at the same time, attending to both words and non-verbal messages, for example, pauses, emphasis, irony and humour. I made notes, which enabled me to develop a sense of 'gaps' or 'clarifications', that in turn provided the framework for the second interview. Transcripts in this sense were viewed as a tool that traversed the gap between the stories told to me as the inquirer and the written narrative that is created for a personally unknown audience. Each time the transcripts were re-read, I could ‘literally’ recall the situational context. My observational skills, developed over the years whilst working as a physiotherapist, were extremely helpful. Often I would listen to the transcripts and recollect facial expression and other bodily movements. Reading and re-reading the transcripts kept the interviews at the forefront of my mind. Prior to the second interview, usually conducted a few weeks after the first one, I would have a summary prepared of each transcript, ready for the participant to read.

The purpose of the second interview was to establish validity by ascertaining whether the transcripts and the thematic themes were an adequate reflection of the participants' experience and represented reality (Field and Morse 1985, p. 139). Lincoln and Guba (1985) call this activity 'member checks' (p. 314) whereby those who have lived the described experience validate that the reported findings represent them.

In addition to validating the transcripts, the second interview also enabled the participant to re-state events, remember further details and elaborate on particular issues. Here, according to van Manen (1990, p.99) both the researcher and the interviewee weigh the appropriateness of each theme by asking: ‘is this what the experience is really like?'. In doing so, they 'self-reflectively orient themselves to the collective ground that brings the significance of the phenomenological question into view' (van Manen 1990, p.99). As Minichiello et al. (1990) point out 'the qualitative researcher is not primarily geared to finding out the truth per se but rather the truth as the informant sees it to be' (p. 128).

On reflection, this process seemed to work reasonably well and managed to meet the criteria I had set for myself; that the interviews would be interactive, sensitive and enabled much opportunity for listening (Minichello et al. 1990).

4.1.3. Hermeneutic Phenomenological Reflection

Thematic Analysis

As pointed out elsewhere, each interview, was in van Manen's (1990, p.99) words, a 'collaborative hermeneutic conversation' that was transcribed as soon as possible after each interview. This attending to both words and non-verbal messages in order to produce themes and insights eventually helped to create the textual analysis. The act of thematic analysis is more than a superficial reflection of the explicit meaning of the participant's descriptions; it is a method as a way of achieving a level of thoughtfulness that encourages the researcher to make a distinction between their first-hand impression of the participant's stories (the text) and the essence of the experience in question. In this sense, van Manen's thematic analysis is a form of reflective inquiry that guides the uncovering of the essence or `... a bringing into nearness that which tends to be obscured and illusive to the first-hand superficial reflection of an experience' (van Manen 1990, p. 31).

Analysis of the participant's descriptions created for me a potential to momentarily `open up' for the reader a window of opportunity for a greater understanding of the experience as lived by these people. Following van Manen's (1990) hermeneutic phenomenological reflection, transcripts were analysed for recurrent phrases and themes, which were subsequently listed. These themes are not considered to be merely objects or generalisations of a superficial analysis, but as van Manen (1990, p.90) states, more likened, metaphorically speaking to `... knots in the webs of our experience, around which certain lived experiences are spun and thus lived through as meaningful wholes'. The analysis of themes can be considered as an act of constructing thematic formulations, indeed a way of capturing the phenomenon one is trying to understand.

Also important is our understanding of how themes come to 'be'. According to van Manen (1990) 'the theme is the needfulness or desire to make sense, the sense we are able to make of something, the openness to do something, and finally, the process of insightful invention, discovery and disclosure' (van Manen 1990, p.88). In terms of how a theme relates to the notion of what is being studied, the theme is the means to get at the notion, gives shape to the shapeless, describes the content of the notion, and is always a reduction of a notion (van Manen 1990, p. 90). Through themes, we can attain a deeper, more comprehensive insight into the world of those who live with disability.

Uncovering the thematic statement

van Manen asserts that '… any lived experience description is an appropriate source for uncovering thematic aspects of the phenomenon it describes' (1990, p.92). Whilst conceding that some descriptions may be a richer source of information than others and that different people will contribute more to our understanding of life than others, it is assumed that, when a person shares with us a certain experience, there will always be something there for us to gather.

Similar to data collection, phenomenology has no fixed rules regarding thematic analysis. As a result, it is often unclear how researchers analyse data and gather themes, which left me, as a beginning researcher, floundering in the initial stages of the study.

van Manen (1990, p. 92-93) offers a number of approaches toward uncovering or isolating the thematic aspects of a phenomenon. In this study, I chose to employ the selective or highlighting approach, whereby the text is read several times and statement(s) or phrases(s) that seem particularly essential or revealing about the phenomenon or experience being described, are circled, underlined or highlighted. These individual units from each interview were coded using Ethnograph v4.0 with the purpose of identifying topical codes (Seidel et al. 1995). The process of coding continued until all data were classified. The codes were grouped into clusters of similar topics and recorded using interpretive codes. The interpretive codes were grouped to reflect themes and/or thematic statements, which, as the study progressed, were captured in more phenomenologically sensitive paragraphs. This, van Manen warns us, is not a mechanical procedure, rather it is a 'creative hermeneutic process' (1990, p. 96). The initial coding yielded 77 codes (eg. fatigue, pain). During further analysis, codes were renamed and clusters were formed where relationships between codes were identified. For example, 'fatigue' and 'pain' both were labelled under the cluster 'physical discomfort'. The analysis proceeded similarly and sub-themes were formed where relationships between clusters were formed. For example, 'physical comfort' was labelled under the sub theme of 'the constrained body' and later on labelled as the theme, 'the body in everyday life'. Each theme was fully described with attention to range and variation. A presentation of the main themes will be presented in Chapters Six to Ten.

4.1.4. Hermeneutic Phenomenological Writing

Writing is an integral part of hermeneutical interpretation (van Manen 1990, p.32) as is the process of noticing, collecting, and thinking about things that are interesting. As data analysis occurred concurrently with data collection, writing formed an integral part from the start of the research process. To be attuned to rural living, I wrote about my rural travels. As I was always accompanied by my journal, my tape recorder and audiotapes, after a long day of interviewing, I would always reflect on the content of each dialogue and tape-record the things that participants told me off the tape. This information was later transferred into my journal. van Manen says that 'much of real writing occurs in this way' (1990, p. 114).

Soon I discovered that, as I began to write, there were no great schema on which I could draw to assist me in the process. Within this process, it was my role, as an interpretive inquirer, to ensure that writings of the interpretation of the participants' experience, formed an adequate representation of their voices. Then I had to ensure that my writings would produce a text, which could readily be conveyed to readers. Goodfellow (1998, p.179) refers to the former as 'field texts' and the latter as 'research texts'. Often I would find that my field texts collected through interview transcripts and observation generated a number of questions, hence I would return to the participants to seek elucidations about their experience. Other times, writing had the effect that I could 'instantly' see something in a manner that enriched my understanding of experiences. To see, in this context, is not a cognitive affair, but a reference to the creation of a text that speaks to our cognitive and non-cognitive sensibilities (van Manen 1990).

In my writings, I have made an attempt to incorporate lived throughness, evocativeness, intensity, tone and epiphany, as qualities central to phenomenological writing (van Manen 1996).

Lived throughness means that the phenomenon is placed concretely in the lifeworld so that the reader of the text may experientially recognise it. The aim is to portray a phenomenon in such a way, that, as reader of the text, one may find continuity between portrayal of the phenomenon and the particulars of one's own life. In Chapter Five 'Dorothy' discusses the experience of osteoarthritis in the knee and describes the impact on her life. This experience may be recognised by readers and as such a link may be found between the text read and one's own experience of pain. According to van Manen (1996), a concrete portrayal of text can place the reader in the midst of lived reality and so, continuity can be initiated between the interpreted text and thus recognise the particulars of one's own life.

Evocation means that the experience is brought vividly into presence, so that we can phenomenologically reflect on it. In Chapters Five and Seven, 'Troy' gives a vivid description of his pain, an experience that everyone easily recognises. The challenge here is to produce writing that not only provides a concrete description, but also evokes vivid images and associations that prompt our thoughtful reflection.

Intensification refers to the use of poetry and art, for example, in order to produce certain poetic effects and understanding. In Chapter Nine, I have included a poem written by ‘Shane’. His words are an example of finding meaning of being in a wheelchair. The purpose was to give certain meanings their full value, so that phenomenological meaning became embedded in the text.

Tone refers to the ability to read the text with ‘meaning’. That means that intelligible experiences are made into a ‘feelingly understanding’ manner. The text of Chapters Seven to Ten aims to create and imagine for the reader, forms of being as a signification of humanness.

Epiphany means that the text must bring about a transformative effect, so that its deeper meaning makes an edifying appeal of the self of the reader, such like a sudden perception of the life meaning of something, so strong that it may stir us at the core of our being. I am hopeful that the text of the dissertation will reveal itself to be rich, diverse, pertinent and of significant quality to open the experience for the readers’ entry into a deeper understanding of the phenomena. Ultimately, the readers will decide whether this is achieved.

Journalling

From very early on in the study I wrote down notes in my journal. Initially it served the purpose of not wanting to lose a significant essence of an experience. As the study progressed, however, the pages of my journal became much more. They became my sounding board, my confidante, and indeed a trusted friend. In my journal, I recorded my initial thoughts, my beliefs and feelings that had captured me during each particular dialogue. In fact, I also became aware of a heightening attentiveness in me on the days that I conducted interviews, as if I was afraid of missing a part. Whilst listening and typing the texts, I continuously entered more words, phrases or sentences in my journal. These journal notes have subsequently been used in identifying steps taken in the data collection process, decisions that were made, the rationale behind such decisions, and reflections on the whole data gathering and interpretive process.

Many words and phrases were initially written in Dutch. As a person whose first language is Dutch, I sometimes struggled to find an ‘instant’ proper translation of a particular word into English. An example of this is when I experienced the impossibility of translating the Dutch word ‘lakoniek’ (freely translated: ‘casual’). After listening to ‘John’ who spoke in a ‘matter-of-fact’ way about his lower leg amputation, I wanted to capture this in a single word, but could only think of the Dutch word ‘lakoniek’. To be time-efficient and ensure that I would not lose my thoughts, I would quickly write it in Dutch and return to it later in the hope to find the fitting English translation. Fortunately, this was always the case. Also, I realised that at the time of writing, despite living in Australia for nearly a decade, Dutch remained my first language in thought and silent reflection. Admittedly, when I read my journalling notes produced in the latter half of the study, much less Dutch appeared in the writings. A likely explanation can be found in the fact that both my exhaustive readings from literature and participants’ texts caused an immersion-of-self within the English language.

Through written language, I have tried to link participants’ texts into a comprehensive unified whole, which Polkinghorne (1988, p.19) refers to as ‘a principle of best fit’. Best fit, comes after the researcher has moved back and forth through the data, carefully considering various possible interpretations and forming a way of providing an explanation for the phenomena under scrutiny.

4.1.5. Maintaining a Strong and Oriented Relation

A tendency for abstraction, or in van Manen's words, 'arm chair philosophizing' or 'abstract theorizing' can form a hazard if we do not focus on the real world of people with a disability. Hence I was extremely careful to remain sensitive to the question: what is like to live with disability? In the later stages of the inquiry when the themes seemed to provide some insight, I once again worked through each transcript to examine whether the data supported such a theory. Each transcript was re-read for comments and further notes and comments were made in the margins (see Appendix C), to enable 'thickly contextualised materials' (Denzin 1994, p.511) to be used throughout the various chapters.

Hermeneutic Phenomenology aims to produce texts that are oriented, strong, rich and deep (van Manen 1990). In my orientation as a physiotherapist, it was necessary to work creatively to present accurately the voices of participants and their interpretation of the phenomenon. My desire was to produce texts, which should not present an artificial separation of 'theory' versus 'life', but present textual themes in concert with the notion of the phenomenon.

Critical of the fact that despite much rural health research, access to a range of health-related services remains limited, I remained aware that much theorising would not bring about an immediate change for those living with a physical disability. With this frame of mind, I conducted my research not as merely a descriptive or interpretive methodology but also as 'a critical philosophy of action' (van Manen 1990, p.154). I am strongly persuaded by the need for such an imperative, hence my intent to present the individual experiences as realistically as possible, without any simplification. As pointed out elsewhere in this dissertation, disability is a complex, multidimensional phenomenon. Consequently, it is my principal desire that those who read my text will be able to connect with it as a legitimate experience. The text should be read as one that encompasses not only the experience of disability, but also the way in which it influences how a person relates to the world in a different way.

4.1.6. Balancing the Research Context

In order to organise the research text and present an organisational wholeness of the text consistent with a methodical emphasis of the research approach, I have selected a combination of three textual approaches: the analytical approach; a thematical approach; and an existential approach.

In the first four Chapters of this dissertation, an analytical approach is used to describe how scientific literature presently depicts disability. I show that the experience as presented by traditional science is ill-understood and that generally accepted conceptualisations ‘gloss over’ rather than ‘uncover’ a more thoughtful understanding of the nature of disability.

In the Chapters Six to Ten, a thematical approach is used. Here, the emerging themes are used as a generative guide for writing of the data analysis chapters. These Chapters elaborate on essential aspects of the phenomenon, with each Chapter heading articulating the theme that is being described.

An existential approach which incorporated the existentials of corporeality (lived body), spatiality (lived space), temporality (lived time) and relationality (lived relationship to others) is also used throughout Chapters Six to Ten as an interpretive guide in this human science study. Throughout these chapters there are many ‘thick descriptions’ (voices of participants) included to make explicit the understanding which emerged from the text. Mindful of van Manen’s (1990) advice that all textual approach in a phenomenological study should be decided by the question, I have made a serious attempt, together with the nine participants, to create hermeneutic text from ‘thick descriptions’, so that these can be understood as an answer to a real question. It is ‘the close relation between questioning [inquirer] and understanding [participant] that gives the hermeneutic experience its true dimension’ (Gadamer 1994, p.374). With this, I acknowledge the contribution of each participant as the evidence of what van Manen (1990) terms ‘balancing the research context’.

4.2. Rigour and Quality

The questions of rigour and quality in relation to qualitative work constantly arise with a number of authors (Lincoln and Guba 1985; Burns 1989; Guba and Lincoln 1989). Drawing on Lincoln and Guba (1985), Burns (1989) proposes a number of standards to achieve rigour in qualitative research. They are:

(1) descriptive vividness; (2) methodological congruence; (3) analytical preciseness; (4) theoretical connectedness; and (5) heuristic relevance. A brief discussion on each standard follows.

4.2.1. Descriptive Vividness

To achieve ‘descriptive vividness’, a description of the research site and some particularities of each of the nine participants will be provided in Chapter Five. In line with Glaser and Strauss (1965, p.9) the aim is ‘to describe the social world studied so that the reader can almost literally see and hear its people’.

4.2.2. Methodological Congruence

Methodological congruence has four dimensions: rigour in documentation, procedural rigour; ethical rigour, and auditability.

An exhaustive documentation of the many elements of this study is presented in various chapters of the dissertation (see for example: Introduction, Literature Review, Methodology and Design and Method chapters).

Rigour in relation to procedures means providing detailed information with regards to steps taken to ensure that data are accurately recorded and the data obtained are representative of the data as a whole (see for example: van Manen’s six step analysis described earlier in this chapter). A detailed section on rigour in relation to ethical issues will be presented later in this chapter.

The final dimension refers to auditability, which means to leave an audit trail, a recording of activities over time, which can be followed by another researcher (Lincoln and Guba 1985). This particular dimension can be problematic, as Burns (1988) pointed out that other researchers might not necessarily agree with conclusions developed by the original researcher. However, in this study, I include an example of the relationships of codes, cluster, subthemes and themes. Furthermore, Appendix C has been added to enable the reader to arrive at his or her own judgment.

4.2.3. Analytical Preciseness

Analytical preciseness refers to 'a series of transformations during which interview transcripts are transformed across several levels of abstractions' (Burns 1989, p.50). This process requires that the researcher makes intense efforts to identify and to record the decision-making processes through which transformations are made. To evaluate the truth-value of my data analysis, I returned to each participant with transcripts of the interviews to ensure a true and correct representation of their experience. Often, I would literally receive the 'phenomenological nod' (van Manen 1990) which refers to the moment when the participant concurs with that what is written or said about the reality of the phenomenon. At the conclusion of the reading there was general validation that the text represented what they had said in the original interviews: 'It's spot on', or 'that's exactly how it is'.

4.2.4. Theoretical Connectedness

Theoretical connectedness requires that the themes developed from the study be clearly expressed, logically consistent, reflective of the data, and compatible with the existing knowledge base. As discussed earlier in the van Manen's six-step analysis, the themes, which had developed from the study, have been presented with the fundamental research question foremost in mind. The proposed relationships between each theme have been validated by data and can be considered as an accurate expression of original values as held by participants (see Chapters Seven to Ten). The themes presented in these chapters yield a meaningful picture of the phenomena and a clear connection is made between the data and the existing disability knowledge.

4.2.5. Heuristic Relevance

Heuristic relevance refers to the reader's capacity to recognise the phenomenon, its theoretical significance, its applicability to practice situations, and its influence in future research activities. It is anticipated that readers, when presented with the themes derived from the data, will find meaning within their personal knowledge base and immediately recognise the phenomenon being described. The final chapter of the dissertation shows how the knowledge generated from this study is applicable to health care practice, including physiotherapy, through integration into the knowledge base of health care professionals. The findings should also contribute to theory development within the discipline and guide future development of studies.

4.3. Ethical Issues

The study was approved by the University of Southern Queensland's Human Research and Ethics Committee. The reference number H97STU26 has been assigned to this approval. The Toowoomba Health District Research Committee and the Toowoomba Health District Ethics Committee also approved the study.

Potential participants who are fully informed about the nature of the research are in a position to make a decision whether or not to participate in the study. The process of complete disclosure, discussion and answering of any questions that a potential participant might have about the intended processes of the research, acts in accordance with that person's ethical rights of respect and self-determination. Thus consent by a person to participate in the research is an informed one.

The potential participants were invited to ask me questions, which may have been for the purpose of clarification or additional information. Participants were given an information sheet outlining: the purpose of the study, the nature of the research method, the time commitment involved, the benefits and risks of the research and an explanation of confidentiality and of freedom to withdraw from the study at any time, without consequences (see Appendix A). A Consent Form and a Permission Slip (see Appendix B) separate from the information sheet (see Appendix A) were signed, so that both the participant and I had a copy. By signing the informed consent the participants indicated that they understood the nature of their participation and voluntarily agreed to participate.

Privacy is particularly important in this study, as the rural Darling Downs remains a relatively intimate place. Great care has been taken to present the truth and substance of the individual experience with real and accurate descriptions of the lives as lived. Nevertheless, every effort has been made to protect the privacy of the participants by changing names, places and detailed particulars of the individual stories as it is my moral duty to respect the privacy of persons and their families; and I have taken this charge very seriously.

The Ethical Guideline for Qualitative Research (National Health and Medical Research Council 1995) was used to ensure that ethical issues were addressed appropriately.

In addition to their recommendation that the data be held for a period of five years from the completion of the dissertation and then destroyed, the following step was taken. The original consent form, the audiotapes and transcriptions of the tapes and the personal record containing personal details of each participant and their pseudonym was kept in a locked filing cabinet in the researcher's office at home, accessible only to me.

Finally, I anticipated the possibility of circumstances whereby I would have felt ethically compelled to intervene. For example, if a participant appeared to present with symptoms of clinical depression, it would be unethical not to intervene in the form of a referral to a General Practitioner or another appropriate organisation. Fortunately these circumstances did not arise.

4.4. Conclusion

The research design and methods based on van Manen’s hermeneutic phenomenology, presented in this chapter, have been selected as a means of finding out ‘what it is like to live with disability’. The participants and I have shared this study, hence my interpretation is not mine alone, but one in interaction with the participants. However, the presence of me as a researcher in the data means that my interpretation may well be different from that of another investigator. Phenomenology, in spite of everything, depends heavily on the researcher’s use of self. It is so because, as Lipson (1991, p.74) notes, ‘researchers use themselves as both data elicitors and processors’.

CHAPTER 5: INTRODUCING PARTICIPANTS

5.0. Introduction

This chapter introduces the men and women whose lives are central to this study and whose shared experiences of disability give it its foundation. The first part of the chapter provides an outline of some of the important characteristics of the participants, whilst the second part describes the characteristics of the group of nine participants. The chapter provides a snapshot of each participant, focussing particularly on the unique occurrences in each person’s experience. Various issues, such as the impact on everyday life and their social relationships, will be threaded into their experiences. The purpose of this chapter is to provide an illustration of and insight into the participants in this study, rather than a representation of them. The analysis and interpretation of the data, using van Manen’s research methodology, will be presented in Chapters Six to Ten.

I present some of the experiences the nine study participants revealed during the interviews. These experiences are presented in a truncated vignette of each person’s situational context. Each vignette is arranged in the same order that the experiences were told in the interviews. I present an outline of the taken-for-granted methods that different people in this study have used to weave their lives together. No claim is made that the accounts presented are straightforwardly representational of one reality as truth because, as Crotty (1998, p.64) points out, ‘… different people may well inhabit quite different worlds and their different worlds constitute for them diverse ways of knowing, distinguishable sets of meanings and separate realities’.

At the very least, this means that each vignette is not a case of mirroring ‘what is there’ or merely a textbook rehearsal of anonymous experiences belonging to anonymous individuals. Instead, it means that the nine vignettes are merely an introduction, which serves to portray the context of each person's world - as they see it.

5.1. The Participants

Seven men and two women were interviewed. Two participants were born in the United Kingdom, one in rural New South Wales and all the others in rural Queensland. The people interviewed were between the ages of 46 and 81 years, and the age that is referred to in this study was the age of the participant at interview.

At the time of the interviews, eight participants were married and living with their spouses. One woman had been a widow for ten years. The participants all live on the Darling Downs and have done so for at least five years. No one had any definite plans for future relocation. It is important to note that, although each person has lived for most of, if not all their life in a rural environment, their experiences should not be considered typical of rural people elsewhere in rural Australia - though in many respects, as will be noted, they are similar.

Six participants live on a farm with large acreage, one participant lives on a five-acre block; the remaining two live in a rural town. All, except the latter two, live at least a 20 minutes drive away from the nearest shop, bank or General Practitioner (GP).

The people in this study had experienced what could be described as 'fairly hard lives', typically working in the rural industry or in the agricultural sector. Despite this, they all rated their health as 'reasonable', with only an occasional visit to the GP or Specialist for a health check-up or renewal of a prescription.

There is a range of family compositions amongst the participants with all, except 'John' having children. These eight participants have at least one child living in close proximity to them. In two instances, sons have taken over the management of the farm. In both cases however, the parents have remained living in the old farm house. The sons and their families had moved into newly-built homes on the same block of land. All participants, with the exception of Dorothy, who is living with her daughter, own the house in which they live.

An important and defining aspect to this study was that some participants experienced an acute onset, whilst others had a more slowly progressive onset. Participants included a (retired) butcher who had experienced a stroke; a former nurse who developed Multiple Sclerosis; a dairy farmer with facioscapulohumeral dystrophy; a sheepfarmer with a brachial plexus lesion; a graingrower with a leg amputation; the pig farmer with Parkinson's Disease; a housewife with Osteoarthritis; a stationhand with a spinal cord lesion, and a sawmill foreman who suffered a stroke.

All but two of the participants routinely use a mobility aid. For example, John, Karl and Henry use walking sticks. Sandy, Shane and Don are wheelchair-dependent. Glenn often opts not to use a mobility aid indoors. Instead he likes to ride a motorised scooter, ‘a gopher’, outdoors. Dorothy requires a hoist for all transfers. Troy does not need a mobility aid as he has full use of both legs. As a more detailed description may identify the participants in this study, it is sufficient to say that all live with resultant physical limitations.

The preceding discussion has been necessary to establish the diverse nature of the people involved in the study. Many studies require close compatibility between variables such as age, disease category, duration of the disability, age of onset and the extent of the disability: this study explicitly does not. All of the medical conditions discussed here are relatively common to some extent, except for the brachial plexus lesion and the facioscapulohumeral dystrophy, which are, mercifully, rare.

While the phenomenon investigated is 'disability' - as an encompassing phenomenon - if the participant refers to [their] stroke or arthritis, I do so also. Where appropriate, medical terminology will be used when discussing certain aspects of the disease or the injury. For readers' ease, I have incorporated participants' words throughout the text and used single quotation marks and font 'Arial' to identify their voice.

In order to exemplify the phenomenon and provide some context for the reader about the life of people with disability, for the following reasons I have chosen to begin the next section with Dorothy's experience of living with osteoarthritis Firstly, osteoarthritis is a condition frequently encountered by physiotherapists in clinical settings. Furthermore, Dorothy's experience of living with disability, in particular the detailed particularities presented by her life trajectory, exemplified for me a unique texture of meaning on what it is like to experience disability. The final reason to expand on Dorothy's experience initially is that osteoarthritis is very common amongst Australians and considered to be the leading cause of disability in Australia (AIHW 1999).

In line with the methodological structure of van Manen's (1990) human science inquiry as pursued in this study, a detailed context outlining Dorothy's life, 'the whole' (van Manen 1990, p.33), with her experiences, 'the parts' (van Manen 1990, p.33), is presented. In this sense, the text of her whole life has incorporated her experiences with health professionals and assimilates her wish of living at home, along with her conflict stemming from fears of passive dependence. The section includes Dorothy's reflection of her lived experience of disability.

To provide all of the nine participants with a similar voice would mean an excessively long dissertation - yet to exclude their voices from this section would devalue their experience. The truncated vignettes offered focus only on several aspects of living with disability, yet are intended to give the reader a superficial glimpse of the person living with disability. How disability experiences are created, shaped, and made meaningful will form part of the Chapters Six to Ten.

The participants are not presented in a specific order and like 'Dorothy', all names used are pseudonyms, with omission of some details in order to preserve confidentiality. For ease of understanding, some aetiological (medical) information has been incorporated in the texts (in Book Antiqua). Each person's vignette begins with a description (in *Italics*) of the research site and my observation of some of the particularities of each participant.

5.2. Dorothy

Dorothy spends her days sitting in a lounge chair in the living room of the house of her daughter with whom she lives. As the first interview takes place in the middle of winter, Dorothy is well-wrapped up in warm blankets. The combustion heater is on and the room is warm. Before I sat down, Dorothy warned me about her impaired hearing in the left ear and invites me to sit on her right side. Rae, Dorothy's daughter who cares for her mother, is busy in the kitchen, making coffee for Dorothy and myself.

Dorothy spends most days simply watching TV from her strategically-placed overstuffed chair to which she now is confined. At the age of 81, Dorothy is the oldest participant in this study. She volunteered to participate in the study after reading the information sheet handed out by an occupational therapist, a team member of the Rural Allied Health Team. The occupational therapist had visited Dorothy in the past when she experienced some difficulties with an hydraulic hoist that needed replacement. An hydraulic hoist is an absolute necessity for Dorothy, since she has lost the complete use of her legs after extensive orthopaedic surgery and ongoing infections in both legs (to be discussed later in the chapter). Because Dorothy can no longer bend her knees, both legs are resting in a fully-extended position on a soft leather stool. I later discover that both the chair and the matching stool are covered with lamb's wool. Rae has made a pocket of lamb's wool to fit a hotwater bottle near Dorothy's feet to ensure that her legs are kept warm. As Dorothy and I talk - the first visit lasted over two hours- we drank cups of coffee and ate a few homemade scones with cream and jam made by Rae. Rae did not participate in the interview. The microphone, which is quite small in appearance, rests on the table between us.

I'm careful to position the equally small tape recorder, so that the tiny red light, indicating an active microphone, is not distractive for either of us.

Dorothy was born in a small rural town in New South Wales in 1920. She was the fifth of nine children. Her parents owned a cane farm. Dorothy did not continue her schooling. She left at grade six, during the Depression years, to help her parents on the farm. At the age of twenty, Dorothy accepted a job as an assistant manager of a large hotel in New South Wales. The work was physically demanding, with many cleaning duties including scrubbing floor-surfaces, whilst kneeling on the concrete. At the age of 30, Dorothy married Greg, who was two years older and worked as a cableman. They had four children, three boys and one girl.

Dorothy clearly remembers when the first symptoms of knee pain appeared. She noticed an ache in her left knee, irritating at first, but not very painful. Then the ache became a pain and would stay with her for most of the day. Then the pain extended into the night-time. Over the years, Dorothy visited her General Practitioner numerous times and, although the prescribed drugs reduced the pain; it would always return. Gradually, Dorothy became more and more house-bound. In the end she could only walk short distances within her own home, before she was forced to sit down. An everyday activity, such as collecting the mail from the mailbox near the front gate, which was some yards away, was nearly impossible. Dorothy had to relinquish driving her car. During these years, Dorothy found her experience with the medical practitioner very frustrating. She believed that she wasn't taken very seriously. In the end she literally 'begged' him to send her to an orthopaedic surgeon and to have x-rays. The x-ray reported that Dorothy suffered from severe osteoarthritis.

> Osteoarthritis (OA), also known as degenerative joint disease, is a very common form of arthritis that generally afflicts people as they get older. There may be some swelling from fluid in the joint or from bone spurs, but there is usually little redness, warmth, or morning stiffness. OA results from a wearing down of the cartilage in the joint.

> When this cartilage is damaged, frayed, torn or absent, the joint does not move smoothly and pain results (Mc Carthy and Koopman 1993).

A total knee replacement soon followed and after an uneventful stay at the hospital Dorothy returned home. Three months later, Dorothy's husband died from a heart attack. Tears roll over Dorothy's cheek as she talks about this. After a brief silence, Dorothy continues 'life since then never came good'.

New medical problems emerged and throbbing pains and swelling in the same leg necessitated admission to hospital to remove the infected artificial kneejoint. The second hospital experience was much more eventful. Although the operation went as planned, two days later, nodules filled with pus, appeared on the skin around the operation site. The nodules became infected and Dorothy was told that she had 'golden staph' (hospital-acquired bacteria). Despite intra-venous antibiotics, Dorothy could not easily rid the bacteria. Moreover, the doctor informed her that a metal rod had to be inserted in her thighbone to enable her to walk again. After three months of rehabilitation, Dorothy went home with a leg that she could not bend. She had weak muscles and frail osteoporotic bones. Dorothy felt fairly confident that she would be able to cope with her condition as soon as she got home and back into her own routine. With grab-rails installed in the bathroom and a raised seat placed over the toilet, Dorothy regained a moderate level of independence with most everyday tasks. She could also rely on the help of Rae and her husband - who both lived on a farm nearby.

The infection returned and the rod was removed and again there was the wait for the infection to clear. Anxious about the prospect of yet a further long hospital stay, Dorothy asked questions, but received few or no explanations. 'I realised that perhaps I was never going to walk again. I was scared. I wanted to go home; I couldn't see any progress inside the hospital'. Dorothy found out that the hospital staff had told Rae, Dorothy's daughter, that her mother was 'disobedient', 'stubborn' and 'difficult'. Dorothy believed that, these beliefs were held about her because she challenged the decisions made by staff. The nurses said to Dorothy that she made her situation even more difficult for herself because she failed to accept the conditions presented. Rae decided to take Dorothy home to and to look after her for as long as was needed.

Confined to the house, Dorothy stated that 'she has accepted that this is now her life'. Although family surrounds her, she does experience bouts of loneliness. She spends her days watching television and doing needlework. The most difficult aspect for Dorothy relates to loss of independence. 'It has been difficult for me to accept, because I've always been a fairly independent sort of person and I like to do things for people, so I do feel very dependent on them now, a burden to them, and I do worry about that. I don't give the future much thought, no point in worrying about that now, I just take life as it comes'. At the time of the interview, Dorothy's house was for sale as she had decided to live permanently with Rae.

5.3. Don

When I first arrived at Don's property, I found myself knocking on the wrong door. His son pointed to a dark brick building, further down the road and said that his father lived in that house. The driveway was lined with trees, all bearing fruit. I recognised them as lemon trees. From the window of the car, I could see cows, the mix of two colours, black and white, made it easy to recognise the breed as 'Friesians'. I thought of 'Holland' then. Don's wife, Jane, stood near the front door to welcome me. She stopped me from taking my shoes off 'don't do that' and then proceeded to say 'but you can if you want'. After a quick glance at her bare feet, I decided to leave them off. Don, a 74-year-old man, was sitting in his wheelchair. His voice was soft, something I had already noticed when we spoke on the phone. My first impression of Don was that he was a vulnerable man. I noticed the eyelid drooping and the facial expression characteristic of Don's condition. Had I not known that he suffered from a form of facial muscular dystrophy, I would have easily mistaken it for 'anger'. This once-tall man (he was six feet seven inches in height) sat with slouched posture in his wheelchair. His thinning light brown hair somehow matched his soft voice and *perhaps it was this combination that gave the appearance of vulnerability; a sort of helplessness. He invited me to sit on a kitchen chair next to him. He had a bit of a chuckle when I explained that I had mistakenly knocked on his son's door .'It has happened many times before', he reassured me. After briefly explaining the study again, he said that he had no questions. I turned the tape recorder on, with the volume knob turned up on 'maximum'.*

Don was the youngest of five. Together with his four siblings, he grew up on a farm. Both Don's parents died within a time span of five months and, consequently, the children were sent to different family members. At the age of thirteen, Don moved in with his mother's sister and her husband. He decided to leave school and work on his uncle's banana farm. Two years later, Don noticed some weakness in the muscles of his face. He experienced difficulty in whistling or blowing up a balloon. It took some time for doctors to identify the cause of his weakness; a rare condition, facioscapulohumeral dystrophy (FSD).

> FSD is a type of muscular dystrophy that affects the upper body and is characterised by progressive muscle weakness and loss of muscle tissue, primarily affecting the face, shoulder, and upper arm muscles. It is an inherited disorder with an autosomal dominant inheritance pattern. FSD is extremely variable in the extent and severity of the symptoms and in the age when symptoms appear. Symptoms often do not appear until ages 10 to 26, but it is not uncommon for symptoms to appear much later. In some cases, symptoms never develop. Symptoms are usually mild and very slowly progressive. Facial muscle weakness is common. Shoulder muscle weakness causes deformities such as scapular winging and sloping shoulders. There is difficulty raising the arms because of shoulder and arm muscle weakness. Weakness of the lower legs is possible as the disorder progresses and can be severe enough to interfere with walking. Other body systems are usually not affected, and intellectual function is normal. Progressive disability occurs very slowly and the life span is usually not affected (Swash and Schwartz 1997).

When he learned that his symptoms had a 'medical term'; he was not overly worried. Except for weakness in his shoulders and some difficulty lifting his arms, he did not have 'serious trouble'. In the years that followed, Don married and had three sons. The young family saved a small deposit to buy a dairy farm. It was hard work, but Don mentioned that he learned a lot about managing this dairy farm, including the idea that 'hard work pays'. This, he believes, would later in life help him to manage his health problems. Although Don was able to perform most of the farming duties, he did notice a gradual weakness, most notably in tasks such as lifting and carrying. About half of those with FSD retain the ability to walk throughout their lives; Don belonged to the other half. At the age of sixty-two, Don experienced increasing difficulty with mobility, particularly walking, hence his decision to purchase an electrical scooter.

Around the same time, Don's eldest son and his wife took over the management of the farm. Despite his withdrawal from the physical aspects of farm management ('farmers never retire' according to Don), Don remains involved in farm-business decision making. Daily consultations with his son keep him informed and he continues to provide advice. He enjoys following the share market and buys and sells stocks nearly everyday. Reflecting on his life, Don nominates the period from the 1940s to the 60s as the time of most significant change for Australia: from advances in machinery to the introduction of milking machines and other technologies in farming. He is surprised that, despite all these technologies designed to save time, people still seem to have less time.

Every few minutes during the interview, Don grimaces, and stiffly moves his shoulders from side to side. Periodically, his eyes fill with tears, as he endures the pain of talking about the future. Watching him, you feel he is doing all he can to keep his voice straight. When I suggested that I turn the tape recorder off and allow for a break, he declined.

Don has gone through almost every available orthodox and alternative treatment to find a cure for his FSD. He has seen dozens of physicians and also visited members of many of the other health professions, including physiotherapists, chiropractors and acupuncturists. He has also employed a great variety of selftreatments and therapies - some 'self-invented', others recommended by a health food adviser, who suggested eating chicken and steamed vegetables only. Don describes himself as having been a strong and very independent person when he was younger and as having slowly, but surely, become dependent and weak. Don has always been quiet and reserved but argues that having FSD seemed to have changed this. 'My wife and I now talk a lot about different things'. When asked what aspects of his personality might have changed because of his condition, he notes that his trust in others, most notably friends and family, has changed. 'Why don't they visit more often?' he asks. He contends that he is happy, however the use of certain words seems to suggest other feelings as well; words such as 'frustrated' and 'disappointed'. Admittedly, these words were used predominantly to express his feelings about the time that he wanted to go on a holiday - and realised that it was nearly impossible to find nice, affordable, wheelchair-accessible accommodation. He confided in me once, that he worried a lot, particularly about the future, immediately adding that he was so 'lucky' compared with others and that he was 'determined' to make the best of it.

5.4. John

If Don's life was characterised by 'worry', John's life is close to completely the opposite: 'don't worry'. I clearly remember the first time I visited John. His farm is a large one, in a rather run-down condition. It was separated from the road by a large hill; cut off, hidden and somewhat isolated with no other farms nearby. I felt somewhat threatened by what I first saw - an enormous bull, walking freely around on the property. John was amused to hear that I was scared of getting out of the car, afraid that the bull would be attracted to my red jacket! John was tall and very thin, and he dressed in the same checked flannelette shirt and baggy brown pants during both interviews. His grin was a seemingly constant part of his expression. John asked if Jan could be present during the interview, to 'help him if he didn't know the answer'. I began to explain carefully the purpose of the interview, and soon the tape recorder was rolling.

John is a 78-year-old farmer who shares his life with Jan, his wife of forty years. John is a rare breed of Australian; he has never drunk alcohol, never placed a bet and never smoked a cigarette in his life. Most of his life is spent outdoors. His days are very simple. He describes it as follows 'I get up, shower, dress, climb in the tractor and work till dark'. John's wife, Jan, says that 'John simply cannot sit still'.

Twenty years ago, John suffered his first stroke, which caused a hemiparesis (paralysis of the right side of the body). He recovered to some extent from this stroke, however another two strokes in the last five years have further weakened him and left him with some speech impairment and swallowing difficulties. John also suffers from diabetes. He told me that, due to a gangrenous ulcer on his big toe, he required a below-the-knee amputation.

> Amputation is the removal of a limb or other appendage or outgrowth of the body. Bloodvessel disorders such as atherosclerosis, often secondary to Diabetes Mellitus, account for the greatest percentage of leg amputation (Miller-Keane 1992).

Before prosthetic training could begin, John discharged himself from hospital because he was very homesick. 'I missed my home and couldn't think of anything else.' Within a week of returning home, he climbed back into the tractor, only to discover that he couldn't operate the tractor with one leg. He asked his wife to get him an old table leg, which he remodelled to some extent, he attached it to the remaining part of his leg and now he was ready to drive the tractor! In the end, John got a prosthesis and soon learned to walk. At the time of the interview, he required a walking-stick; his gait is slow, but steady. He reported several falls, but 'I'm not worried'.

Like Don, John has no inclination of retiring. Despite having experienced a series of small strokes and an amputation John regards his health as good and thus, he continues with that what he knows best. 'Farming is really my sort of way… I have to continue to farm'. Owing to his prosthesis and numerous modifications to most of his farming equipment, John manages to do tractor work and other farming duties. Jan, however, since the strokes and amputation, has become much more involved in farmwork. I will discuss the role of partners in Chapter Ten.

Possibly one difficult aspect of John's life now is that he feels embarrassed about his drooling; a consequence of stroke. He tried hard to cover up his impairment but decided that it was much easier to avoid contact with others. 'Who would enjoy a meal whilst being in the company of such an embarrassment'? he asked me. I felt some sadness about John's life, so devoid of human contact. But I don't think John saw it that way. For him, it was simple. His feeling was not of sadness, but shame.

The future of the farm, which has been in John's family for over hundred years, is uncertain. John and Jan are childless. When asked about the future, John asked me 'Do you know the Lord?'. He believes that much strength comes from the Lord. He believes that he and his wife are able to manage quite well due to God's caring nature: 'God looks after those who are in need - now and in the future'.

Whilst looking through the window overlooking the century old farm he offers his advice to others: 'Don't worry', it doesn't do a thing for you'.
John is determined to continue with farming for as long as possible. Never in his life, has John lived in another place. 'I was born in this house and I'll die here too'.

5.5. Karl

My first visit to Karl took place in early winter on a day that was grey, cold and short. The hour was late and I was surprised to notice how dark it was around that time of the afternoon. The cottage where Karl and his wife were living appeared small from the outside, but was remarkably roomy inside. The lights inside the house were turned on, which made me realise that the beautiful *autumn weather we had had until then, was slowly giving way to winter. Karl was looking forward to this interview he told me over the phone. I wasn't surprised to hear this. Our first phone conversation had lasted a total of twenty minutes, mostly because of his willingness to share with me his experience of stroke. Before the interview started, I was offered some hot chocolate and home-made biscuits. Karl, like John, also asked if his wife could be present for the interview; and again I had no objection.*

Karl was 69 years old when he suffered the first stroke. It was on New Year's Eve three years earlier. Karl had woken up with an unusual feeling of weakness in his hand. As the morning went on, he experienced difficulty walking and got tangled up in the barbwire, something that had never happened before. His daughter drove him to the GP. He was assured that it was a 'flu-attack'. That evening, Karl lost further use of his arm and leg. Karl insisted that his wife should not ring the GP as it was New Year's Eve. The weakness increased and a visit to the doctor followed where symptoms were immediately recognised as those of 'stroke'.

> Stroke or cerebrovascular accident (CVA) is an abnormal condition of the blood vessels of the brain characterized by occlusion by an embolus or cerebrovascular haemorrhage resulting in ischemia of the brain tissues normally perfused by the damaged vessels. The sequelae of a cerebrovascular accident depend on the location and extent of ischemia. Paralysis, weakness, speech defect, aphasia, or death may occur (Mosby 1986).

After nine weeks in hospital, Karl returned to his farm. Repeatedly he told everyone including his physiotherapist 'I'll come good, I'll beat this'. Karl related to me that his stroke was due to longstanding hypertension in the family. Karl's father had died of a stroke.

During the interview, I noticed that Karl would rub his paralysed hand and forearm which were resting on the kitchen table. Occasionally, a grimace passed across his face - fleetingly, without sound or comment from him. When I asked about it, he informed me that he had a terrible shoulder pain. This is not an unusual phenomenon amongst those who have suffered a stroke. Because of his difficulty with balance, Karl requires the use of a walking stick. His main concern relates to his favourite pastimes ‘horseriding’ and ‘driving the car’. ‘Do you think that I can do those things again?’, he asked me during the interview.

Karl’s interview text is interspersed with comments such as ‘when I drive the ute again’ or ‘when I ride the horse again’ and he considers these activities as benchmarks of progress. Although he still has these goals, as time goes by, he thinks of himself as a ‘survivor’, trying to hold on without thinking too much about the future. There is the possibility that owing to financial constraints, which seem tighter each month, he could be forced into selling the farm. His view, however, is brutally frank. ‘I’m staying here for as long as I can’. Karl is disappointed that both his doctor and past physiotherapist have informed him that they could not offer more help. Karl’s mind is consumed with the physical tasks he cannot complete and worries either about his limitations or about what will happen next.

Eighteen months after the final interview, the Blue Nurses informed me that Karl had died three weeks earlier on Easter Sunday. He died after having a severe stroke. Not long before Easter, Karl was admitted to the local hospital, ‘only with a small stroke’, they explained to me. ‘Within a week he went home’. His third stroke, however, was severe. ‘The ambulance brought him in and he never regained consciousness’. ‘He died within one hour’. His wife was at his bedside when he died. I was saddened to hear this and immediately contacted Karl’s wife, Betty, to arrange for a visit. Her warm welcome reminded me of the times when I interviewed Karl. We talked about Karl, and about the study. She maintained that his interview should be included. ‘Karl always wanted to help’. ‘I’m sure that he wants you to continue to write [about him] as it may help others in the future’. Many times during the writing process, my thoughts turned *to Karl, who displayed a great sense of humour along with a passion for helping others.*

5.6. Glenn

It took me only forty-five minutes to drive to Glenn's farm, but nearly twice that that long to find Glenn. When I arrived on Glenn's doorstep, I knocked on the door but received no answer. All three dogs were barking, but no one seemed to hear them or attend to it. It was nearly 30 degrees Celsius outside and I worried that perhaps I had mixed up the dates. I felt relieved when, after some moments, I saw someone. I asked for Glenn and was directed to the piggery. My eyes needed some adjustment to the darkness inside the piggery. There were three men standing there, but I immediately recognised Glenn. He walked towards me with a slow, purposeful shuffle, typical of Parkinson's patients. He had elbow and knee guards around his joints, similar to the protection that kids wear when roller-skating. John looked much older than his actual age; he was 70, but could easily be mistaken for a man in his eighties. Together, we slowly walked back to the house. Inside the house, the lounge room was filled with every walking aid possible: walking-sticks, hopper frames, a manual wheelchair and an electric wheelchair - and the latest purchase, a Gopher (motorised scooter). Those walking aids told a story.

From Glenn's perspective, both the onset and the course of his disease could be attributed to an event which occurred when he was twenty-one. One day, shortly after he started a painting job, he experienced a terrible headache accompanied by severe weakness in his arms and legs. He rapidly developed a high fever and felt completely exhausted. Glenn could not remember the diagnosis. 'In those days, you would never ask the doctor any questions; that was a privilege only reserved for them'. He remembered though that the doctor prepared his parents for the worst-case scenario. Glenn, to the amazement of the doctor, recovered, although he never returned to his former state of health.

Despite having relatively good health, Glenn mentioned that he was physically not a very strong man. But ‘I did okay with farming’. However, in the last twenty to thirty years, Glenn had watched himself become more feeble and infirm. Glenn felt that he had become ‘an old man’.

At the age of sixty, Glenn decided to semi-retire, because his health had deteriorated to the extent that he could only work a couple of hours a day. The doctor diagnosed the weakness as a heart condition and subsequently prescribed heart tablets. It took several years before Glenn was diagnosed finally with Parkinson’s Disease.

> In Parkinsonism the facial muscles exhibit an unnatural immobility. The eyes have a somewhat staring appearance, and spontaneous ocular movements are infrequent. The attitude of the limbs and trunk is one of moderate flexion. Voluntary movement exhibits some impairment of power, but more striking is the slowness with which it is performed. In general the movements which are carried out by small muscles suffer most. Hence, the patients show weakness of the ocular movements, which are characteristically jerky, of the facial movement, characteristically associated with tremor of the eyelids on closure of the eyes, and of movements concerned in articulation. The speech in severe cases is slurred and monotonous. Movements of the muscles of the hands are also markedly affected with clumsiness and inability to perform fine movements. The person has increasing difficulty in writing and handwriting tends to be smaller. Swinging of the arms in walking is early diminished and later lost. Emotional movements of the face are reduced in amplitude, slow in developing and unduly protracted. There is no sensory loss in Parkinsonism, but many, in the later stages, complain of pain in the limbs and spine, and extreme restlessness is a common symptom. Flushing of the skin and excessive sweating are occasionally seen, and the excessive greasiness of the face, and salivation occur in encephalitic Parkinsonism. Parkinsonism is not necessarily associated with mental disturbances, though such may of course be an independent effect of the disorder causing Parkinsonism (Kottke and Lehmann 1990).

At the time of the interview, I noticed how pale his face was and the muscles of his face did not show much, not unlike a mask-like appearance. He walked with a stooped and unsteady gait. Linda, his wife, assist him at night when he wants to change his sleeping position in bed. Linda is anxious about leaving Glenn for any period of time, because of the high frequency of his falls.

Despite his physical deterioration, Glenn continues to work on the farm. His responsibility is to care for 140 sows and their piglets. He cuts teeth and tails of every newborn piglet. His involvement with the pigs is 'what keeps me going'. He walks around the farm with knee guards to protect his knees during the numerous falls. His sons tell him to give up work completely. But he refuses. He will not let anyone else care for the sows and their piglets.

Glenn rarely sees his physician. He does not engage in social activities, except for a monthly visit to a support group, although he clarifies that it is more ‘to please the social worker’. At the time of the third interview, some six months later, Glenn’s physical condition had deteriorated markedly, although he was not entirely immobile. Glenn's worries about his future but his hope is to stay on the farm and continue to welcome each new piglet that is born on his farm.

5.7. Troy

Of all the many different surroundings in which interviews were conducted, it was Troy’s farm, in particular, that I fondly remember - probably because the interview took place in such an unusual place ... his woolshed. There was a certain atmosphere in the woolshed, and I’m certain that, at one time, it was as if I could hear the sheep snivelling about the loss of their soft coat. Sitting on the firmly-stacked bales of wool, the interview began…

Troy is a 61-year-old sheepfarmer, born in what Troy describes as a working class family in the United Kingdom in the year the Second World War began. Troy’s mother encouraged him to undertake an agricultural study as she could foresee that the expansion of the world population would demand a large supply of food. Troy became an agricultural scientist.

A mid-life crisis at the age of forty brought Troy, his wife and their two young daughters to Australia. They bought a large sheep property in rural Queensland. Initially, they experienced growth and success, but gradually the low commodity prices of wool combined with high interest payments began to create a financially 'challenging time'. Troy describes this time as a period where he and his wife both worked so hard, that they were completely exhausted at the end of every single day. The hard work, the worry and the rushing of the jobs took its toll on the day that Troy sustained the accident. Troy recalls his accident with great accuracy, as he never lost his consciousness. The experience is explained with much detail. 'I turned on this machine'… 'my sleeve was caught'… 'my arm was pulled in the traction belt'…it looked okay, but I couldn't move it'. He drove himself to the homestead where his wife immediately called the ambulance. 'The ride to the hospital, the serious look on the doctor's face, it all seemed so unreal'. Soon Troy learned that he had suffered a 'Brachial Plexus Injury'.

> Brachial plexus injuries are caused by damage to nerves that conduct signals from the spine to the shoulder, arm, and hand. Symptoms may include a limp or paralysed arm, lack of muscle control in the arm, hand, or wrist, and lack of feeling or sensation in the arm or hand. There are different types of brachial plexus injuries with avulsion, the most severe type whereby the nerve is torn from the spine. The site and type of brachial plexus injury determine the prognosis, however for avulsion injuries there is no potential for recovery (Berkow 1992).

Due to the excessive force of the injury, the cervical and thoracic nerves were torn from the spinal cord. The avulsion of the nerves caused permanent nerve damage, which meant that Troy lost the complete use of his right arm. Returning home was painful and distressing. A difficult time followed, a time where important decisions had to be made. Troy and his family did not sell their farm. Instead, Troy has adjusted most of the equipment needed for sheep farming in order to continue farming. After the accident, Troy's wife, Diana, searched for and found full-time employment. As both interviews were held during the day, I regretted not having the opportunity to meet Diana.

Troy suffers from phantom pain, which ranges from a tingling sensation to a severe sharp, stabbing pain. The pain is continuous, with episodes of worsening; pain-free periods last at most an hour. Troy describes the pain as ‘pulsing’, ‘boring’, ‘sharp’, ‘hot’, ‘aching’, ‘tight’, ‘nagging’ and ‘punishing’. The pain is exquisitely sensitive to drafts, hence, despite the pleasant temperature on the day of the first interview, Troy wore a woollen glove over his hand. In the morning the pain is mild, but by mid-afternoon it is more severe. Because of the pain, Troy feels troubled and frightened about the future. ‘I really have no idea and that worries me to some extent’. Troy has lost a sense of pleasure and interest in things and after each day he feels completely exhausted.

Active membership of a Chronic Pain Support Group is helping. Troy remains hopeful that one-day technology, drugs, science and medicine will come together and produce something incredible, which can restore nerve function.

5.8. Henry

Unlike, the previous participants who live on a farm, Henry lives in a double storey ‘Queenslander’ at the outskirts of a small town with many historical buildings. The home, adjacent to a creek, is so picturesque with its large balcony with white lace. There were many coloured flowers in the garden, but they were overgrown with weeds. The centre of the front yard has a large gum tree, which provided a lovely shady area. It was under this tree that the two of us sat for each of the three interviews. The tape recorder and microphone were resting on a wooden table whilst we were sitting on benches. The crickets in the bushes and trees around the water of the creek occasionally interfered with the interview and sporadically I had to ask him to repeat his words because they were lost in the noise. Henry, who looks far older than his age, seemed unperturbed by the noisy insects. I presume that is so because he is so used to their presence. At the time of the first visit, the council workers were busy constructing a concrete walking track along the creek. This path would later play an important role in Henry's life. As soon as I entered the house for each interview, Helen, his wife, *would leave the house, always joking by saying: 'I am leaving now so Henry can say whatever he wants to say about me'. Before the interview, I arranged for my chair to be on the right side of Henry as he had a slight hearing impairment of the left ear.*

Henry's early life has been filled with parent neglect, abuse and isolation. He left school at the age of thirteen, and became a farmhand. At the age of twenty-two, he married his childhood sweetheart. They had saved some money and bought their first home. When his 30-year-old wife suddenly died Henry was left to care for his four children, the eldest aged nine and the youngest six months. Anxious to keep the family together, he sold their house and bought a smaller house closer to town.

Years later, Henry married Helen, his present wife. Around the time he remarried, Henry became the foreman of a sawmill. Then Henry suffered a stroke. Henry is bitter about the time of the stroke. 'I wasn't all that old when I had it [the stroke]'. 'My dreams, hopes, plans for the future, in fact my whole life changed'. Henry speaks with a soft voice and the wavering lip is quite obvious. With the back of his hand, he wipes off few tears rolling down his cheek. He remains silent for some time. Then, he says as he straightens his back, 'Yes, I have always been very hard on both others and myself but', he adds with a somewhat triumphant look in his eye 'it is this attitude that helped me to move on in life. I think this has helped me since I have had the stroke'.

This pragmatic insight however, whilst it may have helped him to recover following the stroke, has had an adverse effect on relationships between himself and his children. In similar vein, is the change in relationship between Henry and his wife. Henry, as the breadwinner, had always made all the important decisions. Since the stroke, the roles were reversed and Helen now organises everything. Henry acknowledges that every-day life has changed and wonders whether things will ever 'be the same'. Henry is worried that he is a ‘burden’ for his wife; a theme which will be discussed in the Chapter Nine.

A defining experience in Henry's life is his feeling that some [previous colleagues] believe that Henry deserved to get something like a stroke, as he would in the past 'boss them around' and 'make them work [hard]'. Henry is certain that 'being hard' has helped him to move on in life. ‘If I don't think something is right, I will stand up and I will tell them what I think’.

5.9. Shane

Unlike with the previous participants, our first meeting did not occur at a home. The first of a series of three interviews took place in a clinical setting. Within the hospital I had found an area that was not too clinical in appearance. It was a lounge with a coffee table on which to rest the tape recorder. Shane remained in his wheelchair. A few minutes after we shook hands, I suddenly remembered why I had this feeling that I had seen him before. There was a remarkable resemblance between Shane and a television personality who presents documentaries about reptiles. As it would turn out during the interview, like the TV personality, Shane knows a lot about reptiles; and his stories about his collection of venomous snakes, toads, and spiders sent a shiver down my spine. He asked me how long the interview would last. I explained that he, not I, would determine the length. He apologised for asking the question, but explained that he had to pick up his wife from the clinic at a certain time. I explained to him that he could terminate the interview at any time. Reassured by this remark, he indicated that he was ready.

The interview began with a history of Shane’s family. A sixth generation of Irish-Scottish descent, Shane is the scion of strongly independent settlers who settled on the Downs many years ago. During his younger years, Shane favoured nothing more that being outdoors. His father had wanted him to take over the farm, but Shane preferred to travel and so became a farmhand, completing odd jobs on different farms in the area. He married Sonia and together they had four children, two sons and two daughters. One day, during a simple job on the roof of a shed, Shane fell off and sustained a spinal cord injury at the level of L3 (the third vertebrae in the lumbar area) and became paralysed.

> In spinal cord injury, the destruction of nerve fibres that carry motor signals from the brain to the torso and limbs leads to muscle paralysis. Destruction of sensory nerve fibres can lead to loss of sensation such as touch, pressure, and temperature; it sometimes also causes pain. Other serious consequences can include exaggerated reflexes; loss of bladder and bowel control; sexual dysfunction; lost or decreased breathing capacity; impaired cough reflexes; and spasticity (abnormally strong muscle contractions). The types of disability associated with spinal cord injury vary greatly depending on the severity of the injury, the segment of the spinal cord at which the injury occurs, and which nerve fibres are damaged. Most people with spinal cord injury regain some functions between a week and six months after injury, but the likelihood of spontaneous recovery diminishes after six months (Kottke and Lehmann 1990).

‘The accident’, as Shane refers to it throughout the interview, changed his future forever. Initial thoughts of suicide were apparent, but when Shane discovered how therapeutic writing could be, the suicidal thoughts disappeared. Writing of poems had a positive effect on his general well-being. In Chapter Nine, I have reproduced one of Shane’s poems with his permission.

The second meeting occurred in Shane’s home, a brick house, right in the centre of a small rural town. He built the home with the payment he received as a result of his accident. Inside, the house, numerous trophies are on display; a testimony of his many fundraising activities for the *Cancer Fund*. During the interview, Shane pointed at a wall in the living room with two chrome rails at different heights and explained that he designed most of his therapeutic equipment.

One of the issues that Shane now focuses on is to share his knowledge and experience with others who have suffered a similar fate. He wants to produce a video on recreational activities, such as camping and fishing, for spinal-cord-injured people. Shane spends a lot of time with fundraising for Cancer and lobbying to make shops more accessible to wheelchair-dependent people. His many poems, stories and song lyrics also are an inspiration for others. Each usually portrays 'real-life situations', songs that express happiness or sadness, each with a message of hope and love.

When Shane is not 'on the road' in his wheelchair, raising money, he cares for his wife who is recovering from surgery, radiotherapy and chemotherapy following ovarian cancer. Six months after the second interview, the local newspaper wrote an article about Shane who works so tirelessly as a fundraiser. To ensure anonymity, I will not disclose the details of this event, except to say that it was a daring act that generated funds that exceeded $A30,000. Being in the wheelchair is not the biggest handicap. Not accepting it is, Shane says. ‘Even in a wheelchair, you can get ahead and take a small step each time.

5.10. Sandy

Sandy is a slender, 51-year-old woman. She lives on a small acreage together with her husband and her mother. Her property was eas[illegible] find by the stunning colours of her bougainvilleas framing the fence near the road. The property was well-guarded by her pets, whose loud barks were a ‘dead-giveaway’ of my arrival. Before I could lay my eyes on Sandy, I could hear the electric wheelchair arriving. Then I heard her voice; it was loud! She asked if I wanted to join her in the greenhouse, as she was just on her way to water the plants. Her love for gardening was unmistakable. There were plants everywhere, hanging, standing, climbing against the walls, everywhere I looked there were plants. She possessed a whimsical comic sense and made me laugh a lot. Each time I listened to the tapes, I remembered her sense of humour. Sandy’s first interview lasted three hours, which then seemed to have flown past…

Sandy was born in the United Kingdom but migrated to Australia in 1965 with her parents and a younger sister. Two years later, her father died of a heart attack. She decided to become a nurse, but left the profession when she got married at the age of 24. During the first fifteen years of her married life, Sandy had horrendous obstetrical experiences with a total of six stillbirths and four miscarriages. No medical reasons were ever identified. In the end, she adopted a six-month-old babygirl ‘Natasha’. Around the same time, Sandy noticed a weakness in her legs, difficulty walking and numbness in her feet. Her nursing knowledge forewarned her of something ‘serious’. When she spoke to her husband about this unusual feeling in her legs, he dismissed it as probably the ‘babyblues’. Over the course of two years, she visited her GP several times. She tried to describe the symptoms in her legs by using as many phrases as she could possibly thin of: ‘tired’, ‘weak’, ‘heavy’, ‘funny’, in order to capture the sensation, she experienced. She believed that her GP was frustrated because he could not make sense of the symptoms. He thought that her high-heeled shoes were likely to cause the problems in the legs, other times he diagnosed Sandy with ‘nerves’.

A visit to a well-known neurologist in the UK confirmed her worst fears: ‘you’ve got Multiple Sclerosis’.

> Multiple Sclerosis is one of the commonest nervous diseases. It is characterised by the widespread occurrence of patches of demyelisation followed by gliosis in the white matter of the nervous system. A striking feature is the tendency to remissions and relapses, so that the course of the disease may be prolonged for many years. The early symptoms are those of focal lesions of the nervous system, while the later clinical picture is one of progressive dissemination. The cause of the disorder is unknown. In most cases the disease begins with the symptoms of a single focal lesion, usually unilateral acute retrobulbar neuritis is often the first symptoms. Other symptoms include numbness of some part of the body, usually part of a limb or one side of the face or both lower limb, and double vision, or weakness of a limb particularly of a lower limb with dragging of the foot, or precipitancy or micturation. The other mode of onset is an insidious and slowly progressive weakness of one or both lower limbs.
>
> In the insidiously progressive type of case, the abnormal physical signs are usually predominantly spinal, consisting of spastic paraplegia with some degree of superficial sensory loss over the lower limbs and trunk, or impairment of postural sensibility and vibrations sense or sometimes of both combined, the patient

> exhibiting a spastic and ataxic gait. In such cases, it may be difficult to be sure that the symptoms are due to multiple sclerosis. In a typical advanced case, the patients will be bedridden with scanning or staccato speech and slurring of individual syllables, pallor of both optic discs, nystagmus, and a dissociation of conjugate lateral movement of the eyes, the abducting eye moving outwards further than the adducting eye move inwards. The upper limbs will be weak and grossly ataxic. There will be severe paraplegia, either in extension interrupted by flexor spasms, or in flexion. Cutaneous or deep sensory loss, or both may be present in upper and lower limbs, and there is likely to be incontinence of urine and faeces (Kottke and Lehmann 1990).

Sandy had difficulty believing the diagnosis and told others she had 'rheumatism'. One day she realised that she had to face the truth. She talked about the loss of some friends after she disclosed her disease. Others however were interested to find out more about her MS. She was able to explain her MS symptoms to others as she described it in an interview. 'It changes from one minute to the next. I mean, one minute you've got pins and needles running up and down your arm, the next minute you've got it in your head, the next minute down it's down in your toes'.

Sandy's husband found it difficult to accept MS in their lives and the couple subsequently divorced.

Years later, Sandy remarried and moved to another rural town. She now lives with her second husband, Jim, in a fairly modern three bedroom brick home, built on a small acreage. Sandy says that she is happy with her life. She believes that the reason for her happiness is the support and friendship she receives from her husband. Although Sandy strives for a maximum of independence and self-sufficiency, she acknowledged that she often needs the help of her husband. She believes that living with MS has changed the way she is. She says that she has accepted her MS, but is 'wild' that society has not [accepted it]. She now has, in her own words, 'a strong view' on basically anything, especially health and illness. 'I make sure I exercise twice a day - and I volunteer to help other people with MS, because it's so good for my own spirit. I am always thinking, 'what can I do to make the public more aware of MS?'. She recalls the first time she sat in an electric wheelchair. 'I was laughing, crying and grieving that I had to accept this new indignity in my life. Now looking back, my life has not only gone on, it is enriched'.

Whilst Sandy is adamant that MS will not stop her from doing anything, she believes that other MS sufferers 'give in' [to MS] too quickly. She is concerned that people too readily accept the advice that 'nothing can be done' or 'sorry, you just have to live with it'. Sandy advocates for MS sufferers and assists the MS Society, but feels that 'even they do not understand what it is like to have MS'.

Sandy is convinced that it helps to actively plan each day, rather than passively seeing 'life just passing by'. Her philosophy is that 'there are good days and bad days and everyone, knowing this, should plan life around that; it is a normal part of living with disability'.

5.11. Conclusion

This chapter has introduced the nine participants who volunteered to participate in the study. The data collection technique, that is, in-depth interviewing, provided the opportunity to obtain the participants' perspective of what it was like to live with a physical disability. Although each person's perspective is different, some commonalities and similarities are threaded throughout. Much of the disability research uses a positivist epistemology wherein disability is predefined (Oliver 1990; French 1994). Whilst much valuable work has arisen from this approach, it avoids capturing the different contexts that give rise to different interpretations of life with disability and to different ways of managing everyday life. This chapter has also begun to raise some issues concerning the disability experience and whilst some of the findings of this study may reflect previous disability research, there are expansions and some unique connections with other areas of study.

The next chapter introduces the themes of this study and is followed by four chapters that explain each theme in more detail.

CHAPTER 6: LIFE IS NOT THE SAME

If you suffer an injury or disease,
it is not just your body that changes.
It is your whole life that changes
as a result 'life is not the same'.
- Glenn

6.0. Introduction

This chapter introduces the themes that spell out the experiential and subjective dimensions of the meaning of disability. In doing so, the chapter orients the reader to the overall results of the analysis and interpretation of data. Analysis of the data in this context encompasses 'processes associated with data synthesis and configuration' (Goodfellow 1998, p.107), whilst interpretation is facilitated by 'processes of assembling data and viewing contrasting data, or data that did not appear to fit*'* (Goodfellow 1998, p.115). Schwandt (1997, p.4) explains it as:

> The activity of making sense of, interpreting, or theorising the data. It is both art and science, and it is undertaken by means of a variety of procedures that facilitate working back and forth between data and ideas. It includes the processes of organising, reducing, and describing the data, drawing conclusions or interpretations from the data, and warranting those interpretations. If data could speak for themselves, analysis would not be necessary.

Concurrent data analysis and interpretation, using van Manen's phenomenology, incorporated literature with the participants' interview data to provide further explanations of what it is like to live with physical disability. To enable the reader to follow such a process and give insight into how inferences are made, I have 'borrowed' (van Manen 1990, p.62) 'thickly contextualised materials' (Denzin 1994, p.511) from nine people. Their experiences and their reflections on their experiences are written in font style 'Arial' that will enable the reader to view the original data in context, and make the analytical and interpretive processes transparent. The original data is accompanied by my analyses and interpretations in font style 'Times New Roman'.

As discussed in Chapter Four, I have used a selective or highlighting approach (van Manen 1990 p. 94) to obtain a phenomenological textual description. This provides the opportunity to examine each interview carefully and identify textual sentences, part-sentences or phrases that could be thematic of the experience. A note on the use of participants' texts included in the data analysis and interpretation is in order. The text does not always capture pauses, changes in voice pitch and tone, or other speech sounds. It is acknowledged that 'readers should be given participants' text in the language, feelings, emotions, and actions of those studied' (Denzin 1994, p. 511) with every 'ah' and 'um' faithfully recorded. However, since my chief concern is the ease of reading the transcripts, I have chosen occasionally to remove such elements of speech from the transcriptions, except where they seemed important to the person's meaning. In order to present the data analysis and interpretation in a useful way, I have deliberately arranged the chapters thematically. This provides chapter by chapter access to the different perspectives on the experience of disability as it is for the participants in this study.

6.1. Life is not the same

The data revealed that for the participants, the lived experience of physical disability could be characterised by the expression: '*life is not the same'*. On further exploration, this expression referred to a complex view of life for people living with physical disability that can be described by bodily themes, spatial themes, relationship themes, and temporal themes.

Although the themes in this study are interrelated, they are briefly studied in their differentiated aspects, whilst acknowledging that one theme always calls forth the other. Thus, whilst these themes represent an artificial separation of the components of living with a disability, as perceived by the participants, they occur simultaneously and are separated purely to provide clarity for the reader. It is hoped that throughout the reading of the analysis the relevance of each theme for the other will become obvious, as they are all components of the one experience.

The themes and their relationships are depicted in a model of living with disability as it exists for the participants in this study (see Figure 6.1).

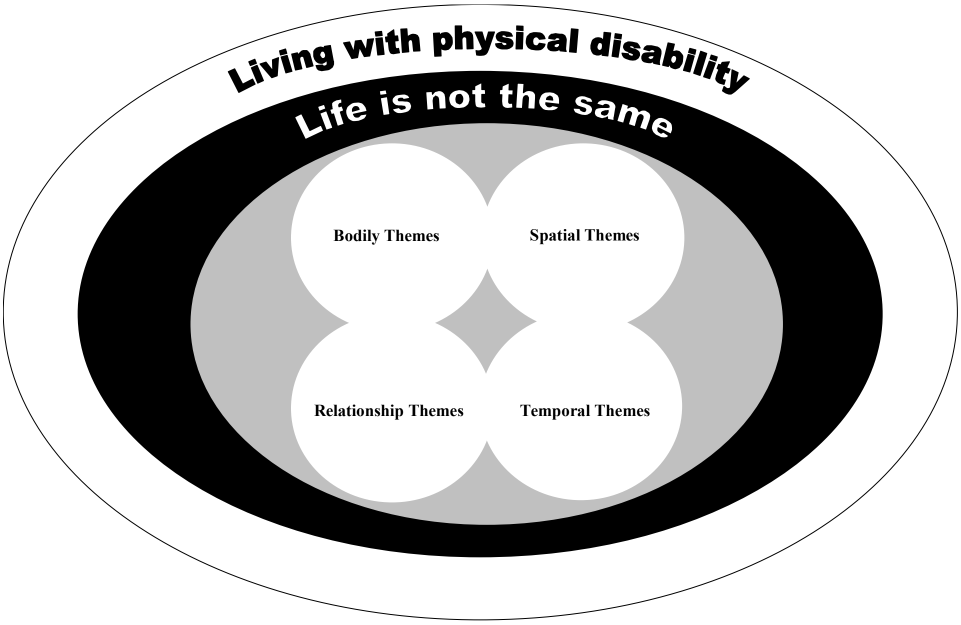

Figure 6.1 Participants' perceptions of living with a physical disability

For the participants, living with a physical disability means essentially, managing the body. Guided by Maurice Merleau-Ponty's classical work '*The Phenomenology of Perception'* (1962):

(a) **Bodily themes** explore the status of the body in relation to physical and emotional changes experienced by the participants;

(b) **Spatial themes** signify the value that participants attach to the space where they live. Spatial, in the context of this study, refers to a rural environment and to a place where participants feel they belong;

(c) **Relationship themes** indicate the relationship that participants have with others who form an intricate part of their everyday life world; and

(d) **Temporal themes** denote the concept of time, and relate to the 'past', 'present', and 'future' times in the lives of participants.

Together the themes form, in van Manen's words, 'an intricate unity' (van Manen 1990, p.105) that draws together the experience of living with disability. Although the identical size of each circle representing a theme suggests a uniformity amongst the themes, the data showed that life for the participants is not always carefully balanced. Different circles may dominate at different times, signifying that themes differ in importance at different times. For example, bodily themes may mark the start of the disability experience, whilst aspects of spatial themes may emerge when participants return to their homes. Eventually, all of the participants 'settled' into a pattern where the circles appear to be more or less uniform, without one being much more significant than another. The overlap of each circle shows that the themes coexist; they are interdependent and mutually supportive. Chapters Seven to Ten are dedicated to a detailed discussion of each of these four circles but, for now, the following is provided as an overview of those themes.

6.2. Bodily Themes

The participants described one aspect of living with disability in a number of ways. I have called it, with debt to Merleau-Ponty (1962), **'the body in everyday life'.**

First, there is recognition by the participants that disability begins when the '*body signals*'; the first subtheme. 'Body signals' refers to the earliest indication of bodily failure. This happened in distinctive ways. For some it was sudden, with no time to prepare; others had a much longer phase that allowed for planning and gradual time to adjust. Each person had their own account of how they experienced the onset of symptoms, seeking and receiving help from others, including health professionals. Different time spans exist from the time of onset till a diagnosis. For some it was instant and unmistakable, others experienced a much more ambiguous journey filled with obstacles. Eventually all participants learned of the diagnosis: 'you have …'(MS, Parkinson's Disease, Stroke etc.).

Second, participants repeatedly asserted that living with a physical disability meant that they no longer could perform certain everyday tasks due to bodily failure. For each person, everyday life is now experienced through a body that experienced impairment and feelings of discomfort, unsteadiness and so on. I have termed this the '*body constraints*'; the second subtheme. This theme relates to participants' experiences of physical and emotional constraint brought about by their physical bodies.

The *'body reconciles'*; the third subtheme relates to the different ways in which each of the participants face up to living with his or her physical and social limits.

6.3. Spatial Themes

This study is situated within a rural environment and as such rural living reserves a special experience for the participants. The connectedness between rural space and the participants' lives is woven throughout the data. I have termed this **'valuing a rural life'**.

First, the focus is on the 'lived space' and refers to the world or landscape in which human beings move and find themselves at home (van Manen 1990). In this study, participants emphasise the advantages of rural life, that is, the *'quality resides in rural living'*; the first subtheme. They repeatedly comment on the connection between themselves and their sense of belonging in their lived space. For them, rural life characterises quality-of-life.

Second, participants experience disadvantages associated with rural living. I have termed this '*inequality resides in rural living*'; the second subtheme. They comment on how the geographical disadvantage impacts on everyday life and refer, for example, to the cost of living or the distance to affordable, accessible health services.

The third subtheme, '*Rural Australians*', explores how participants' actions and behaviour are influenced by the unique setting of rural Australia (Marshall and Rossman 1980).

Despite the challenges associated with rural living, participants are not motivated to leave their place of residence. Instead, they expressed a strong desire to remain in their own homes and in their own community surrounded my members of that community. Participants discuss '*adapting lived space*'; the fourth subtheme. Here, they explain how they have organised their everyday life space and arranged their living areas to accommodate the impairments and the physical change associated with it.

6.4. Relationship Themes

For the participants, the experience of physical disability is not personal, but it is transactional, communicative and profoundly social. The data suggest that the experience of living with a physical disability is not only about one particular individual's experience. It is also very much about social networks, positive and negative social situations that together form a social reality with aspects of negotiation, sharing and support. I have termed this **'relationships in life'**.

Participants in this study conceptualised that living with disability leads to a disengagement with others. I have termed this *'disconnection'*; the first subtheme. This theme incorporates various aspects of the social reality that each of the participants encountered. Lessened and impaired social contact and a sense of social isolation were frequently mentioned. This happened in two ways. For some, it was of their own accord, forced by physical reasons, such as fatigue or mobility impairment. Others experienced avoidance, or even abandonment from friends and relatives.

According to the participants, signs and symptoms associated with musculoskeletal or neurological conditions are simply not accepted by many. *'Stigma'*; the second subtheme, is thrust on the participants in this study, due to the nature of their visible physical impairment. This subtheme, refers to what Williams (1993, p.111) terms an 'anathema to many of our contemporary codes of conduct', and 'our sense of what is deemed correct behaviour and good manners'. For example, John, who walks with a staggering gait and often displays uncontrollable movements of arms and legs in public, experienced negative comments and thus felt embarrassed to appear in public. This emotion was shared amongst the wheelchair-dependent participants, who confirmed that being in a wheelchair has little appeal to public sentiments.

'Accepting support'; the third subtheme, comes from personal networks and other social settings that together form an 'integral dimension of the lives lived together' (Kleinman 1988, p.186). The participants agreed that the main source of support tended to come from the family, particularly spouses and children. Support also comes from other sources, such as from support groups and health professionals. Apart from family support, participants felt reassured that they had their spirituality, a source from which strength was drawn, hope was based on and faith was given to.

'Communication'; the fourth subtheme relates to the importance of interaction between health professionals and the participants in this study. Many of the participants asserted that forms of communication with health professionals were deficient and often did not allow them to acquire knowledge of their status. Participants provided their own account of their efforts to counteract these experiences through adaptation to a changed life, coupled with a determination to get on with their lives. They did this in an effort to hold on to their lives in their own (rural) environment, so deeply valued.

6.5. Temporal Themes

Participants talked about their personal life history; their past, present and future which created an understanding of orientation to being-in-the-world, which van Manen (1990, p.104) terms 'the temporal landscape'. Over time, participants began to realise the impact of living with a physical disability in their lives, they began **'relating time to life'**.

Each person realised that an essential response to living with disability, is '*self in time'*: the first subtheme. Living with disability, means facing the reality of the situation, which began to take hold as soon as participants recognised and understood what had happened to them. Aware that they had to face adjustment of their life, participants made strategic decisions concerning the selective allocation of their (often-limited) resources to do the tasks they would like to do. This included a drastic change to what participants believed they could do in the present and the future. They were forced to reduce or modify their activities and thus structure and restructure time. They did this in mundane ways because their bodies dictated it. Participants asserted that the presence of a disabling condition had made lives uncertain and with that uncertainty came the enforced realisation of lost opportunities and prospects.

To focus on daily issues without being overcome by dashed hopes and unmet expectations, participants adopted '*one day at a time'*; the second theme. This theme, with debt to Charmaz (1991), was created by the participants' need to develop some guidance for everyday functioning, whilst at the same time, having some sense of control. By concentrating on the present, they also avoided, or at least minimised, their thinking about the future. Participants tried to pull their attention into the present whilst pushing the future further away.

Whilst participants realised that there was no cure available, they admitted that *'time heals'*; the third subtheme. They discussed how the initial period following diagnosis assaulted their sense of self and how it brought about a reorganised confrontation with the reality. However, as time went on, they began to adopt an expressive and cognitive approach solely intended to (re)gain a renewed perception of the self. On the one hand, they were realistic about their limitations within their current situation and expressed concern about not being able to participate in many of their valued activities and social roles. They accepted the reality of living with a disabling condition. On the other hand, mixed with this realistic position, was an optimistically positive construction of their situation accompanied by hope. Hope is tomorrow and beyond, a time period that relates to a continuation of everyday life activities in the usual way, time, and place. For all, the hope was to remain living in their own environment, surrounded by their loved ones.

6.6. Conclusion

Living with a disability, for the participants in this study, is defined as ‘life is not the same’. Data analysis, using van Manen’s (1990) hermeneutic phenomenological approach, has uncovered bodily, spatial, relationship and temporal themes and the relationships among them, which together provide some explanations of what the participants mean by ‘life is not the same’. A model depicting the themes relating to ‘life is not the same’ and their relationships with each other has been constructed. The significance of the model lies in the recognition that the themes are both interrelated and interdependent. The four interrelated themes feed into each other and are surrounded by a cast shadow. This shaded area represents a narrowing of territory, a reduction of activities, and a relinquishing of goals. A darker eclipse, that represents unwillingness and reluctance, surrounds the shaded area. The outer light circle represents a new beginning to define values, and, over time, the focus on priorities comes into sight.

The following four chapters discuss in detail the data from which the four themes and their relationships emerged.

CHAPTER 7: THE BODY IN EVERYDAY LIFE

It is painful to think of where I was and where I am
But I want people to know that it [stroke] doesn't mean the end of a life.
It just means a life that is very much changed.
-Henry

7.0. Introduction

This chapter focuses on the bodily themes present in the everyday life world of those living with disability. The main theme, *'the body in everyday life,* in the context of this study, relates to the meaning that participants attach to their own 'lived body' experiences. 'Lived body', a term coined by Merleau-Ponty (1962), works from the perspective that humans are in the world as embodied subjects with corporeal and sensory associations influencing body and mind. In this sense, the body is not merely a medical image but 'a medium through which human beings perceive and receive information of and from the world' (Crotty 1998, p.69), with each of us as a 'body-subject' situated in concrete lived experience.

As a physical phenomenon, the body consists of features such as skin, muscles, bones, ligaments, tendons and so on. The physical body also contains specific capacities, such as upright walking and speech, for example, that identify us as human beings. Over a lifetime however, physical features change. For example, as we get older our bones become brittle, our eyesight and hearing deteriorate, our skin starts to sag and our gait becomes slow. This transformation of the body relates to biological and physical dimensions of the body and appears to consider the body as a physical entity alone (Grosz 1994). Many writers, including Merleau-Ponty (1962) and Erving Goffman (1963), already note the inadequacy of the mind/body dualism. Their writings provide implicit focus on the ontology of the body. From their viewpoint, the mind is located within, and inextricably linked to the body. Grosz (1994) noted that everyday life is not independent of corporeal existence but based firmly in it. This finding is relevant to my concern with this study that focuses on how people experience their bodies as 'lived'. In examining the written transcripts 'the body in everyday life' is constructed around three bodily subthemes:

(1) **'Body Signals'**. This presents the participants' view of when, what, and how the body and its function first became physically damaged.
(2) **'Body Constraints'** presents a vast array of experiences encountered by the participants. Impaired mobility, pain, fatigue, together with feelings of frustration and incompetence produce the second subtheme of this chapter.
(3) **'Body Reconciles'** outlines how participants came to terms and learnt to live with their bodily loss.

Each of these aspects of corporeal changes in shown in the shaded area in the model in Figure 7.1

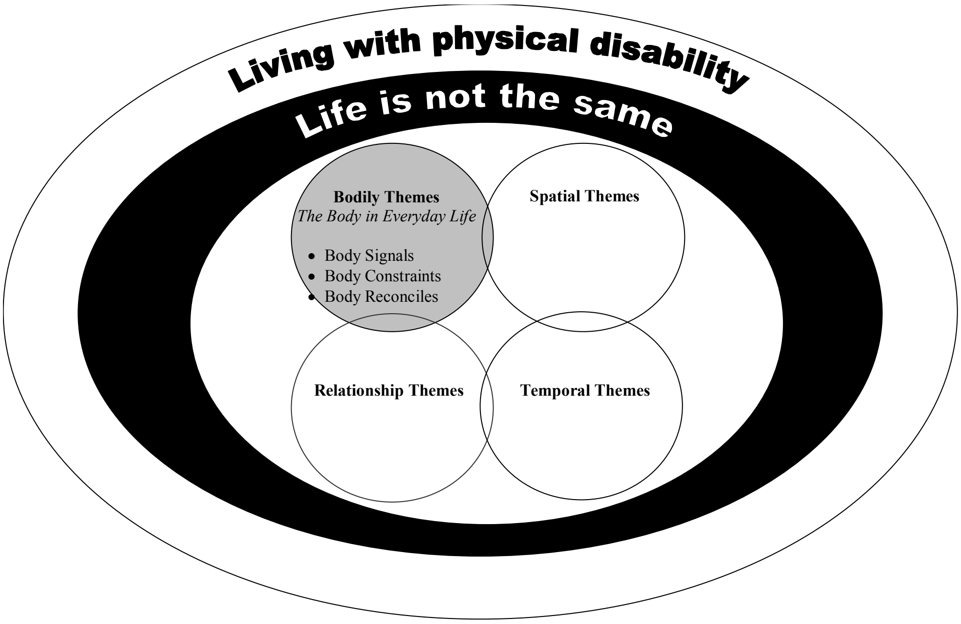

Figure 7.1 Bodily Themes - The Body in Everyday Life

7.1. Body Signals

Most of us go through life and everyday business, forgetful of our body. The nature of our body is often only discovered when something conspicuous is noted, upon which we begin to reflect. A weakness, loss of strength, a painful sensation or an ache were some of the conspicuous symptoms confronting the participants. The occurrence of bodily failure or presence of conspicuous bodily symptoms, were often signs, which I have termed 'body signals' that occasioned 'worry' in participants. Participants asserted that whilst the body signalled and integrity of the body was challenged, their lives became engulfed by uncertainty; the first subtheme. The permanent nature of injury or disease plunged each participant into a new situation - a crisis - such that they had never faced before.

It is, van Manen (1994) asserts, when the relation 'between something conspicuous and the function of the body' remains disturbed in a disquieting manner, that we exist in a protracted state of 'dis-ease', literally un-easiness. Body signals occurred in different ways - for some it was slow and vague, for others it was sudden with an acute onset of symptoms. Some participants (Sandy, Glenn and Don) noticed 'body signals' long before they received their diagnoses. For Sandy with MS, falls were the first signals of a failing body:

> I had problems for years, falling over and all the rest of it. Later, I couldn't keep up [with work]. I was getting slower … I was getting worse. I couldn't hold things and I kept dropping things…I collapsed on the stairs …until one day, I couldn't move from the waist down.

Gradual worsening pain in the knee was a reason for Dorothy to visit her GP.

> At first it was nothing, I just noticed a twinge of pain in my knee, every time I used the stairs. When it stopped me from doing my [house] work, I became worried.

The progressive loss associated with inflammatory arthritis may have seemed less dramatic for Dorothy in the initial phase, but when the continual deterioration of her kneejoints made it increasingly difficult to perform everyday life activities, Dorothy had reason to be more concerned.

Unlike Sandy and Dorothy, who experienced a vague slow onset symptomatology, acute onset also occurred. Shane was catapulted into acute body signals, after his farming accident caused a spinal lesion.

> I was on the roof of the shed to clean the gutter … I lost my footing and fell. It happened so quickly. Till today, I'm not sure what really happened.

Shane was lying on the ground, unable to move his legs: paralysis had occurred in less than two minutes. One minute, Shane was pursuing a simple activity which he had done many times before; the next minute, he could not move. The dramatic and highly visible nature of his accident led to a clear and unambiguous explanation of symptoms, namely, that of a spinal cord injury.

Body signals are not always immediately recognised. Karl, who suffered a stroke explains:

> One morning, I couldn't write a cheque…my daughter had to help me. I thought to myself, I've been working too hard lately, my hands have become weak. I had a job walking outside; I got tangled up in the damned [fence] wire. Next, I couldn't cut my meat with my right hand. I didn't know what to think.

Regardless of whether the onset was acute or slow, the body signals that persisted, legitimatised the understanding of the participants that something was wrong. Participants began to engage in a huge range of negotiations, interpretations, and choices before deciding what action, if any, might be the most appropriate to take. Sandy indicates how she felt at that time:

> I knew that there had to be something wrong with me, I went to see a doctor, who told me that my blood was good … nothing wrong with me. I wasn't convinced'. Something was not quite right.

Like Sandy, many of participants sought help by ‘going-to-the-doctor’ to find out more. Many had to undergo diagnostic processes in order to establish a diagnosis. The absence of local specialist diagnostic services made travel a necessity for many of the participants. Glenn for example, had to travel two hours for a stress test and angiogram, whilst Sandy had to travel four hours to undergo Magnetic Resonance Imaging (MRI).

For Troy and Shane, who both suffered a farm injury, the diagnosis was clear and unambiguous. The symptoms of paralysis were easily recognised. Troy received the diagnosis: ‘avulsion of brachial nerves’; for Shane it was ‘spinal cord lesion’. Dorothy’s symptoms helped her to recognise ‘osteoarthritis’, whilst the symptoms of Henry, John and Karl indicated the occurrence of a stroke. These participants received a diagnosis in a relatively short period of time, whereas for others the presenting signs and symptoms appeared less typical. Maddox and Glass (1989) refer to such atypical signs as ‘symptoms with ambiguous identity’ (Maddox and Glass 1989, p.475). Some of the participants said that, when their doctors could not come up with other possible explanations, they began to believe that it was something else, often a condition of a less serious nature.

> The doctor thought it was just nerves and so he sent me to a psychiatrist. The psychiatrist said it was nerves … so I began to believe that I had nerves. (Sandy)
>
> The doctor thought it was my heart. I had a stress test and an angiogram and after that he said that my arteries were clogged up. (Glenn)
>
> This doctor said, after he saw my [fat] tummy, ‘that tummy is in a bad way, that’s the first thing that you’ve got to do … get rid of that’. (Don)

Don's doctor misinterpreted the fat tummy - a telltale sign of muscle pseudohypertrophy - for obesity. The muscles looked big and bulky but really represent affected muscle infiltrated with fatty tissue, partly replaced by connective tissue (Lindemann 1981).

In addition to 'ambiguity' as an early aspect of living with a disabling condition, participants also frequently reported 'uncertainty' as a significant characteristic of life with disability.

7.1.1. Uncertainty

Authors such as Strauss et al. (1984) refer to the early part of a person's experience of illness, disease or impairment as the onset of an 'illness trajectory' (p.64). Other authors (Conrad 1987; Goodheart and Lansing 1997; Royer 1998) denote 'uncertainty' to typify the illness trajectory. First, there is the 'uncertainty of sensing' (Conrad 1987) or discovering that something unusual is going on with the body or a perception of feeling which led to a medical consultation. There is 'medical uncertainty'. This refers to a period of time (which in Glenn's case was up to 20 years) before diagnosticians could confirm a diagnosis. This uncertainty typically ended when the participants received a final diagnosis, eg., 'You have MS'.

Another type of uncertainty came from the diagnosis itself. While some of participants experienced a great relief, they also experienced a new set of uncertainties. 'Will my MS get worse' (Sandy), 'will I get another stroke' (Karl) and 'will I ever walk again' (Shane). These questions do not have simple answers and thus become a central part of the disability experience. Even with relatively predictable trajectories, symptoms do not appear and disappear in definite time patterns. For Troy, for example, the conferral of a diagnosis signalled the end of a period of vagueness, yet it also marked the beginning of a crisis related to the post-diagnostic period. He explains:

> The orthopaedic surgeon was sympathetic and told me what had happened to my arm. He said "go home and see how things develop."

> I had difficulty handling that. Losing an arm was a catastrophe, a crisis in my life, how was I going to manage at home?'

This matter of uncertainty with regards to the diagnosis and the resultant consequences is of utmost importance for participants, as for many it appeared to be linked closely with the ability to manage what Troy terms a 'crisis'.

The people in this study have had an overwhelming experience of bodily crisis. Crisis, in bodily terms, is the 'point in the course of a disease at which a decisive change occurs, leading either to recovery or to death' (Macquarie Dictionary 1996).

Each person had to contend with circumstances that involved a change of status. Seymour (1989, p.66) describes this change as 'the person becomes a patient'. It means that the person has a clinically ascribed diagnosis that legitimates the understanding that he or she is not well.

> The person becomes isolated in the world of the patient both practically because he or she is no longer a participating member of the everyday world, and conceptually by the way others see him or her' (Seymour 1989, pp.67-68)

The diagnosis for John, Karl, Henry, Shane, and Troy descended suddenly, necessitating immediate admission to an acute hospital setting. For Sandy, Glenn and Don, with diseases of a neurological nature, a sense of crisis could be experienced in relation to a trajectory uncertainty; in other words, the unpredictable nature of a condition. MS, for example, can present with remissions and exacerbations, whilst Muscular Dystrophy and Parkinson's Disease are likely to be progressive - though the rate of deterioration varies considerably (Bannister 1973).

Prepared to hold off the patient status Don felt health professionals had given him, when diagnosing him with Muscular Dystrophy, he immediately rejected this medical designation.

> The doctor suggested giving up work and applying for a disability pension. “No way,” I told him, “I will fight this and do whatever I can to find a cure”.

Despite the definitive medical certainty of his condition (confirmed through muscle biopsy), Don was not prepared to view himself as a ‘patient’; stating that he was going to find restoration to good health. Shane expressed a similar view:

> I was not convinced the doctors knew it all. They said that I would never walk again, I was going to prove them wrong.

Although denial was especially strong in Don and Shane, many of the participants seemed to use this response following the diagnosis and often denied that the diagnosis signified permanent loss. Denial is recognised as a ‘mechanism that protects people against crises, both in the initial and subsequent stages’ (Royer 1998, p.143) - when people must come to terms with information that is difficult to accept. Despite perseverance to hold off some aspects of symptoms, the ‘everyday crisis’ persists. I use this term to refer to the enormity of the disability under challenging conditions, which, for many of the participants, made a total rejection of reality very difficult. Notwithstanding the symptom onset and the duration of the diagnostic period before diagnosis, for the individual the meaning of ‘their condition’ emerged only when they realised the full extent of both the physical and social implications.

Whilst the conferral of a diagnosis, albeit serious, marked some closing stages about uncertainty and crisis, it also signalled the beginning of a life with a different body to that which participants had before. Living with a different body makes everyday life very challenging and is explained next.

7.2. Body Constraints

This section introduces the theme *'body constraints'* and describes how participants' physical body and mind together forms a medium to the world and shows how life is experienced now.

Once participants have had their body signals conferred upon them, they were placed in a realm allied with constraint. I use the term 'constraint' according to Giddens (1990), to denote that the body is a constraint which imposes 'strict limitations upon the capabilities of movement and perception of the human agent' (Giddens 1990, p.258). Malfunctions of the physical body resulted for participants in physical constraint and emotional constraints. Each will be discussed.

7.2.1. Physical Constraint and the Implications for Everyday Life

Physical constraints, in this context of this study, refer to physical incapacitation, discomfort, and symptoms of the physical impairment itself. Depending on the specific impairment, the limitations upon the capabilities included paralysis, decreased mobility and balance and pain.

Troy described how pain is an extremely negative physical constraint that occupies his life for 24 hours a day.

> I have a constant tingling pain in the hand. It is a constant drugging debilitating pain. It makes me tired. The hand is stinging, I have crushing pins and needles. You would think it was in a vice, being squeezed all the time. The pain is extreme, I wake up with it, and I go to sleep with it.

Troy's account illustrates quite graphically the pain and its potentially crippling effect, both physically and mentally. The pain holds Troy in a savage, demoralising grasp. Unlike acute pain that is usually short-lived, Troy has phantom pain caused by nerve damage. Troy's vivid descriptions showed that the experience and the emotion associated with his pain have implications beyond a perspective of pain, over and above that of sensory problems. He has tried various modalities including acupuncture, biofeedback and transcutaneous electrical nerve stimulation (TENS). These have been unsuccessful, except for one: self-hypnosis.

> I can hypnotise myself. I've learned to find the dial in my brain that controls the pain in my hand. When I find the dial, I slowly turn it down … it helps to be distracted.

Whilst Troy's experience of pain had a serious impact on everyday life, other participants' experiences related much more to the impact of impaired mobility.

One of the key challenges for people living with physical disability involves combating impaired mobility. This relates to the 'partial or total loss of movement of a limb or limbs as a result of muscle weakness, loss of strength or stamina, lack of muscle control, or paralysis' (Robinson et al. 1995, p.67). In a functional sense, it is a resulting movement issue involved with the limbs.

Although all of the participants in this study experienced a certain degree of impaired mobility, there are differences. For example, John, Karl, and Henry suffered a stroke and unlike some who fully recover, these three men all have hemiplegia. They are able to walk, but the stiffness of the affected lower limb and some spasticity of the calf muscles impede walking. Each man requires the use of a walking stick to 'get around'. Despite the use of walking aids, their gait remains unsteady at times and all three men have reported several falls within their own homes. Safe ambulation is a big hurdle. As Henry states:

> I can't walk very far. I need a walking stick to get around. I need help with going down the stairs to go out in the yard. It means that I have

> to spend much more time inside the house as I'm not feeling very safe outside on my own.

Similarly, Karl states:

> It bothers me that I have falls … at least one or two falls or stumbles a week. I turn too quickly and fall.

Glenn, who has Parkinson's Disease, does not have hemiplegia that affects his walking. Instead Glenn experiences a disturbance of motor function that is characterised mainly by slowing and enfeeblement of voluntary movements, muscular rigidity and tremor. His head makes small nodding movements and the tremor in his upper and lower limbs is easily visible. He cannot keep his arms and legs still. The muscular rigidity creates balance problems and often results in falls. Glenn's gait is slow, shuffling and composed of small steps. He exhibits a 'festinating gait' (Bannister 1973, p.250) which looks like he is hurrying with small steps in a bent attitude, as if he is trying to catch up with his centre of gravity. He has difficulty in starting to walk, or stopping when pushed forwards or backwards. He has difficulty maintaining his head in an upright position and that causes his head and shoulders to slump forward for most of the time. Glenn says:

> I have so many falls each day. I've broken my kneecaps several times. I can't use a walking frame, because I fall backwards and take the [walking] frame with me. It [Parkinson's Disease] is such a bother.

In his book '*A leg to Stand On'*: *Existential-phenomenological analysis*, Dr Oliver Sacks (1984) describes how there appears to be a simultaneous connection between participants' everyday dealings of bodily dysfunction and the emotions. This is demonstrated when Sacks recounts his experiences of becoming a patient with an injured leg.

> I tried to sleep - they had given me a sedative- but it was difficult to get my mind off the leg, especially since the least movement of the knee caused sudden intense pain (Sacks 1984, p.25).

Dr Sacks became engulfed in a new, uncommon and frightening world, which he terms a ‘no-land’ (Sacks 1984, p.78). Like Sacks, participants in this study also experienced the entrance into an uncommon and frightening world that brought about a different array of emotions. It is to this that the next section now turns.

7.2.2. Emotional Constraint and the Implications for Everyday Life

Influenced by Merleau-Ponty (1962), Seymour (1989), van Manen (1990), Robinson et al. (1995) and Royer (1998), an understanding was developed that the body and the emotions are interactive. More specifically, participants’ response to living with disability revealed that the way participants feel emotionally is related to the way they experience their body. Consequently, if the body is how participants experience life, the emotions are how they expressed their experiences of life. For example, Henry’s inability to dress shows an association with his feelings.

> I can’t do up the buttons of my shirt, it frustrates me.

Merleu-Ponty (1962) has noted that emotions appear to express the body’s experience of life (Merleau-Ponty 1962). Often when participants spoke of a range of activities lost due to bodily impairment, emotions were expressed, conveying the reality of the bodily assault. For example, many expressed annoyance and discontent related to the inability to walk freely in any given environment or to drive a car. Perhaps the most serious consequence for many of the participants was the inability to work. Time and again, the bereavement over lost capability to work triggered a whole host of emotional responses.

> Sometimes, when I think of the things I can no longer do, I feel miserable. (John)
>
> The fact that I will never walk or work again, makes me so sad. (Dorothy)

Everyday lives are dominated by the existence of our bodies. This means that bodily activities such as washing, dressing, sleeping, and working are major preoccupations of our lives (Pedretti 1990). The ability to perform these tasks, activities, and roles which together constitute an individual's daily life and social world has implications at both the practical and symbolic levels: what Bury (1988) has appositely termed 'meaning as consequence' and 'meaning as significance'. For many, vocational roles are a major source of value and identity. Consequently, the loss of work, coupled with the knowledge of one's inability ever to work again, may have implications for the individual at both the practical and symbolic levels. At the practical level, it means a loss of income; at the symbolical level however, it means much more. The symbolical meaning of everyday life for five of the participants (John, Glenn, Karl, Troy, and Don) is inextricably linked with farming. Prior to their accident or disease, all were earning a living in agricultural production. They find agricultural work productive and satisfying; in fact for them, work is not just a livelihood - it's a way of life. As John stated:

> I have been a farmer all my life. Despite my stroke, I was gonna keep on farming… I had to do it … I was going to do it: it's my way of life.

Glenn also expresses a desire to continue working on the piggery. Not being involved means losing a purpose in life. He says:

> I don't think I will ever leave the farm here. I don't think I can. My sons tell me to [give up farming] … but I need to know what's going on. If I can't … well, then I might as well not be here; the farm is my purpose. Seeing the farm growing is my goal.

Similarly John says:

> What am I going to do if I have to give it [farming] up? All I know is farming. I can't do without.

The issue for these men is that they possess a deep connection with *their* farm. They have strong views about this. Not only do they live there; it is also their business and their livelihood. Being able to work on the farm gives each of these men a purpose and more importantly, it adds meaning to their lives. The ability to work is an essential element of their past, their present, and their future. Many researchers (see for example, Anderson and Bury 1988 and Ortega, Metroka, Johnson 1993) have found high levels of depressed mood amongst individuals who could not continue to work, due to illness or physical disability. Like John, other participants also spoke of the profound moral, social, symbolic, and psychological effect that the loss of work had had upon them. Psychological effects such as a depressed mood, anger or feelings of frustration were recurrently expressed by some of the participants. 'Frustration' was the word Henry used to describe the psychological impact of not being able to work or perform other duties without help.

> It is so frustrating not being able to work due to my stroke. I don't like it that I'm no longer a worker. I can't do my work. That is so frustrating not being able to use two hands … so frustrating having to ask others for help.

Henry's feeling of frustration is not surprising, as the inability to translate personal desires into bodily capacity must lead to considerable distress. Participants often expressed that they were healthy, were feeling well, but lacked the physical strength and stamina. Don used expressions such as 'I get depressed that I can't do anything about it [disability]' or 'I get mad when I notice that I no longer can do certain things.'

The findings of the study match Charmaz' (1991) observations that people living with chronic conditions often experience a mix of emotions. They may feel simultaneously, 'fear about the prognosis, anger about incomplete information, self-pity for being ill, envy towards those who are not, inadequate for being dependent, and gratitude for receiving care' (Charmaz 1991, p.222).

Hence the change or loss of physical ability can create deep emotions of despair, particularly when life appears too difficult, too burdensome or too painful to endure. Henry, for example, recollects his suicidal thoughts following discharge from hospital.

> In the early days, I would lie in bed and cry from daylight to dark. I asked myself "what's the good of me living because I can't do anything, I'm absolutely useless". One day, I was on my own and I got so depressed that I went out to the kitchen and got these tablets. I thought, if I take these tablets, then I won't know a thing about it.

Prior to the stroke, Henry was a foreman on a sawmill where he had held a high position. Henry's feelings of uselessness could relate to the loss of work, loss of role, and loss of income; however, his feelings of 'uselessness' could also be based upon his feeling of incompetence that could stem from his dependency on others, most notably his wife. Two other participants (Don and Karl) mentioned being depressed at the onset of their illness and having to control negative emotions such as a sense of failure. Anxiety and apprehension caused by feelings of inadequacy are understandable. A study by Krach, Devaney, DeTurk and Zink (1996), for instance, showed a clear relationship between depression and disability in activities of daily living. Other studies show that one of the major risk factors associated with depression is suicide. Studies by Orford (1992), Krach et al. (1996), Guerrero-Berroa and Phillips (2001), for instance, identified that people in deep depression and despair often contemplate suicide. Fortunately, most medical studies show that 'suicide among the ill is relatively rare, even among those whose diseases are dreadful' (Robinson et al. 1995, p.141). Essentially two aspects of Henry's life dispelled his suicidal thoughts: strong religious beliefs, and family dishonour.

> As a Catholic, I knew suicide was wrong. I also thought of the shame it would bring on my family.

Henry now takes comfort in believing that living with stroke is not 'the end of the world'. Whilst Henry considered suicide in the initial phase of his impairment, Sandy considered suicide for 'the last phase' in the disability process. She painted a very stark, bleak, picture.

> The thought that my MS is definitely going to make me worse is frightening and frustrating. If it gets to that stage, I would kill myself… I know exactly what to take and I would do it.

Sandy mentioned suicide as an option when she talked about the future and the fear of having to move into institutional care. Her fear of going into a nursing home is expressed strongly when she talks about her plan for euthanasia that conveys a fairly chilling and disturbing picture. (This will be discussed in Chapter Nine).

From the data analysis, it became clear that the limitations imposed on participants by physical and emotional experiences sometimes led to depression, passivity, anxiety, and hopelessness. These psychological changes brought about by injury or disease are undesirable, cause a serious threat to each person's physical and mental functioning and as such should not be 'overlooked' (Streimer 2002). The inquiry showed that it is very important that these experiences are noticed and seen as providing the context for personal mood states and psychological reactions, rather than being seen as psychological reactions to impairment only. As the examples indicate, participants living with a physical disability experienced a wide array of emotions often related to the enforced passivity. Life as he or she once knew it was no longer familiar. Despite the overwhelming emotional experiences, participants have found ways of dealing with these emotions. They do this by incorporating changes and adjustments to personal values and lifestyles. They try to make sense of, cope with, manage and overcome the limitations imposed by their disabling conditions: they reconcile with the body.

7.3. Body Reconciles

Whilst the previous two sections of this chapter have described the experience of living with disability as a life filled with uncertainty and crisis and physical and emotional constraint, gradual recognition arose that in due course ‘life resumes’. Furthermore, recognition emerged among participants that they had to learn to ‘cope with limitations’. As a result, an acknowledgment occurred that the harmonic existence of the body has altered, and, step by step, a sense of reconciliation began to appear. ‘Reconcile’ according to Macquarie Dictionary (1996) means ‘to render, no longer opposed, bring to acquiescence’. For Karl and Shane, reconciliation began when energy was invested in the continuation of life.

> I expected it to be hard, but am prepared to give it my best. (Karl)
>
> I knew it wasn’t going to be easy, I may have lost power but not my courage. (Shane)

For these and other participants, realisation set in that energies would have to be directed to rebuilding their lives. Their preparedness to work hard on assimilation of the realities of loss and adjustment to the future, meant a focus on energies on the goal of what Seymour terms ‘remaking the body’ (1998). This is typical for the participants. The experience of physical disability means, first and foremost, dealing with physical barriers. This created a complex set of new issues, situations, and circumstances over which participants had little control - leaving them in a virtual state of tentative equilibrium, from which position they dealt with whatever life would bring. Despite many undesirable changes, participants were more or less forced to devise certain solutions and deal with the mundane tasks of everyday life. For them life had resumed.

7.3.1. Life Resumes

The different views that follow, show that resumption of life is not experienced in discrete categories but in a way that incorporates many different aspects. For some, it meant living with an altered mind-set, often preceded by acceptance. The following quotes from the participants illustrate various aspects of acceptance that precede resumption of life.

> I've accepted that I can no longer drive. When we go to town, Jan drives via the back roads. This gives me the time and the opportunity to see what others [farming neighbours] are doing. (John)

When Henry discussed acceptance, he had been living with stroke for five years.

> I have accepted the fact that there are certain things that I can do and other [things] that I can't. I've just got to live with it.

For Henry acceptance means an acknowledgment of the fact that he has made a decision to live with his stroke; he knows it won't go away and he has attempted to adjust to the circumstances. Shane on the other hand illustrated that the decision to accept lies within the person, not the circumstances.

> Being in the wheelchair is not the biggest handicap; being in a wheelchair and not accepting it is.

Although acceptance for participants may relate to the diagnosis of a disabling condition, by no means does it relate to the limitations of the injury or disease. As Henry explains:

> I can accept that I've had a stroke, people get strokes, it happens. But what I can't accept are the restrictions in my life.

'Acceptance' is frequently referred to as the final stage that a person reaches following a crisis (Kübler-Ross 1969). I would like to add that, whilst acceptance marks a final stage, the data showed that 'acceptance' also marks a beginning of a new phase, the time to move on with one's life. Of course, my data is not representative of all people living with a physical disability; I interviewed only people who voluntarily agreed to talk to me. It is possible, perhaps probable, that people unable to accept their life with disability did not volunteer to participate in this study. Ultimately, acceptance appeared to be much more than just another strategy within the process of adaptation that participants, consciously or subconsciously, use in order to get on with life.

Whilst the findings showed that physical demands in everyday life can drain participants and leave them with low energy levels for emotional work, it also showed that the emotional demands can form a 'tremendous challenge for the person with an acquired disability' (Price-Aadalen and Stroebel-Kahn 1989, p.187). The process of accommodating the impact of the bodily change into everyday personal life is not easy. Letting go of the bodily losses is overwhelming and often requires the individual to make a complete overhaul of their lifestyle. Some had to give up smoking, minimise alcohol intake, lose weight and incorporate physical exercise. Whilst many had reconciled to the plan of a healthier diet and had given up fatty meals such as 'bacon and eggs', much more difficulty arose when giving up an activity such as driving. The issue of driving will be further discussed in Chapter Eight.

7.3.2. A Lifetime of Coping with the Limitations

In the extracts derived from the participants, seven adaptive tasks designated by Moos and Schaefer (1984) were identified. Whether the onset of the disabling condition was chronic or acute, the individuals had to face the reality that their lives had changed and they had to cope with limitations. As a consequence they had to:

(1) deal with the discomfort, incapacitation and other symptoms of injury or disease. Whether it was pain, unsteadiness, incontinence or paralysis, participants had to learn to control their symptoms whenever possible. Participants have adopted major life style changes to accommodate the disconcerted bodily status and limitations related to mobility and dressing. For example, the mode of dress for some was altered so that clothing could easily be slipped on and off. Others, such as John and Karl, changed their food intake to avoid choking on larger food particles.

(2) deal with the hospital environment and special treatment procedures. All participants but one were hospitalised for their disabling condition. Separated from family and exposed to unfamiliar routines and procedures, understandably, hospitalisation was upsetting. A sense of alienation and isolation made it extremely difficult to feel in control of tasks they customarily performed. For example, others, most notably nursing staff now determined such matters as when to wake up, when to get out of bed or when to have a shower. The most common way people drift into feelings of incapacity is when they are removed from decision-making (Robinson et al. 1995). Indeed, there is considerable evidence from the data that lack of control created reactions of depression and helplessness and other emotions, that may have hindered the treatment and recovery process. In spite of this, the participants were prepared to undertake the task of convalescence, as it was one that was central to their rehabilitation.

(3) develop and maintain adequate relationships with health professionals. Although the experiences were mixed, most agreed that health professionals should try to establish more active roles for patients and their family members. For example, some of the participants mentioned that health professionals make decisions concerning them, without consultation. Often they had resigned themselves to the fact that health professionals were busy people and that this had an adverse effect on the relationship. Whatever the circumstances, people

have the right to ask questions or express emotional concerns to their health professionals. Participation and involvement in treatment and rehabilitation can easily be promoted by increased interaction, shared decision making and clear communication of information between health professionals, patients, and their carers.

(4) preserve a reasonable emotional balance. Whilst Moos and Shaeffer (1984) found that people with physical illness 'preserved' emotional balance, this was not always the case for the participants, who experienced emotional upset. Rather than preservation, participants' emotional balance was disrupted and had to be re-ordered. Maintaining hope did this, even when its scope was sharply limited by circumstances. This will be discussed in more depth in Chapter Ten.

(5) preserve a satisfactory self-image and maintain a sense of competence and mastery. The participants in this study have suffered injury or disease that affected their physical functioning, psychological well-being, social and occupational role and perhaps, most markedly, their body image. Amongst all the participants, there was evidence that supported my notion that many of the participants attributed their fate simply to chance, rather than to themselves. They compared themselves with others and seemed to think that, in general, they were better off than others in the same circumstances. Furthermore, I noted that participants had learned to rely on assistive devices such as walking sticks, walking frames and wheelchairs. By defining the limits of independence and balancing acceptance of help from others and taking an active part in controlling the direction and activities, participants were able to adjust expectations and goals - thus feeling in control.

(6) sustain relations with family and friends. The emotional support and reassurance which comes with a sharing of the burden can bring comfort at times when needed both now and in the future. To meet the long-term demands of living with disability, participants must learn to tap into other resources to augment their own.

(6) *prepare for an uncertain future.* This is the final task of adaptation to life with disability. Loss of function, dependency, and the chance of increasing infirmity over time can lie ahead for all of us; no one can control the future. The key to being prepared is the ability to redefine the situation in positive terms and preserve an optimistic outlook. Some choose to be prepared, unlike others who opt to wait and see. Whilst some participants fear the future, not all do, and thus are able to move onto hope which enables a valued future. This will be discussed in more depth in Chapter Ten.

Thus adaptive skills transform life from ‘constraint’ to ‘resume’ - with a vast array of coping skills. It is beyond the scope of this chapter to examine an in-depth overview of coping skills. Throughout the following chapters, however, participants describe the skills that they have found beneficial in their own situation. In spite of everything, participants made choices that earn respect and have to be respected.

7.4. Conclusion

Whether it was a simple twist of fate or a sudden serious accident, the accounts of the participants foreshadowed a lifetime of dealing with the limitations imposed by a physically disabling condition. In this chapter, nine participants discussed how they have faced the difficult task of resuming a life with restrictions whilst dealing with physical, emotional, and social changes.

As the analysis reveals, living with disability is a complex multidimensional combination of impairment, limitation, and restriction in the context of living with a ‘body in everyday life’ that requires effort and energy. In spite of this, participants were adamant that they would manage their physical changes as much as they could. The data also revealed that the body cannot be explained by physical factors only and that managing emotional change proved to be much more intricate. Participants experienced a diverse array of responses - including venting feelings of frustration and depression when they became aware that they could not do many of the things they had valued and enjoyed in the past. Determined to allay such feelings, participants took a positive attitude by redefining their lives. This was often accompanied by acceptance. By coming to terms with the situation, participants faced the reality that the current circumstances cannot be altered. Over time, they have become reconciled and have resumed their life.

For the participants, crises do not end with an obvious finish, but, as the data showed, participants have developed skills that have enabled them to move beyond a survival existence to a way of life that is ‘normal, although restricted’. For some the outcome of this process is the ability to carry on with life in spite of physical limitation. Others had no choice. They were forced to give up work and re-evaluate their body in everyday life. In many cases, participants have made great efforts to manage their roles as normally as possible, becoming skilled at functioning in everyday life despite their ever-present and often unpredictable bodies.

CHAPTER 8: VALUING A RURAL LIFE

Things just aren't the same anymore.
Everything is further away than it used to be.
It's twice as far to the corner now
And I've noticed they added a hill.
The worst though is that
they seem to make stairs steeper than in the olden days
Things just aren't the same anymore.

-Anon

8.0. Introduction

This chapter focuses on the spatial themes present in the everyday life world of those living with disability. The main theme, *'valuing a rural life'*, in the context of this study, relates to the meaning that participants attach to 'lived space'. It relates to the 'space in which human beings find themselves and the impact this space has on them' (van Manen 1990, p.103). 'Lived space' is a category for inquiring into the ways we experience 'the affairs of our day to day existence' (van Manen 1990, p.103). It helps uncover the more fundamental meaning dimensions of lived life.

Traditionally, 'space' has been regarded in mathematical terms, with the length, height and depth dimensions as common characteristics. In this chapter, however, space is conceived as 'Lived space' (spatiality) and relates to 'felt' space (van Manen 1990, p.102). 'Lived space' is difficult to put into words since the experience of 'lived space' is largely pre-verbal. This means that, whilst space is not something ordinarily reflected upon, we all know how the space in which we find ourselves can affect the way we feel. For example, the huge space of a hospital ward may make us feel small; or a person with a staggering gait, such as Glenn with Parkinson's Disease, can experience space in a different way again - everything is further away. For him, a short walk, such as from the toilet to the shower, feels like an endless journey, with many hurdles along the way. In mathematical terms, the length may be only a few metres, but the objective distance may not at all accord with the felt distance between these two places for someone who can’t walk straight. The distance may be geographically close and yet it feels further away for Glenn due to his balance problems. Merleau-Ponty (1962) attaches an important value to the way that the body constitutes space. ‘The possession of a body implies the ability to change levels and to ‘understand’ space, just as the possession of a voice implies the ability to change key’ (Merleau-Ponty 1962, p.251). In making the body central, Merleau-Ponty (1962) defined a fundamental category of human existence. Human existence, according to him, is uniquely characterised by its eccentric position. ‘In virtue of existing, the human being is a body; in virtue of having a point of view on that body, the human being has a body’ (Merleau-Ponty 1962, pp.243-298). In everyday life, the unity of the instrumental aspect of the body (being a body) and its experienced character (having a body) proceeds with little interruption. Yet this unity can be disrupted as is the case for the research participants. In the context of this study, it becomes understandable that participants’ bodily experience has affected the experience of space and confronted them with totally new and uncommon ‘lived space’ experiences. *How* space is experienced reveals what lived space *means* to people and therefore places some kind of value upon it. For example, a landscape environment can mean a sense of freedom, whilst a hospital environment can mean totally the opposite. In general, ‘we may say that we become the space we are in’ (van Manen 1990, p.102). The important point to make here is that 'felt' space is different from objective space (van Manen 1990, p.102-103).

The purpose of this chapter is to explore how lived space is experienced and to discover how this experience affects the lives of the participants. In other words, what is the meaning of ‘lived space’ for people with physical disability within a rural environment? This chapter also draws attention to the community in which participants live, not just the immediate physical surroundings. The chapter continues by revealing the meaning of lived space and the value participants attach to it.

For the participants, to live in a rural environment preserved an intimate space-experience - one that related to their fundamental sense of being. Living in a rural setting, created a strong sense of 'belonging'. 'Rural' is their 'home', a place of secure inner sanctuary - 'home is where we can *be* what we *are'* (van Manen 1990, p.102, italics in original).

According to van Manen (1990) 'lived space' is an existential theme that refers us to the world or landscape in which human beings move and find themselves at home. Van Manen (1990) believes that, generally speaking, humans become the space that they occupy; thus, when we want to understand a person, we ask about his or her world, profession, interests, background, place of birth, childhood, and other such matters. Thus to understand the nature of living with disability, it is helpful to inquire into the nature of the lived space that renders a particular experience its quality of meaning.

The meaning of 'valuing a rural life' for the participants in this study is constructed around four spatial themes:

(1) '**Quality resides in Rural Living'.** This section discusses the association with space that renders a certain qualitative dimension. It examines the space that participants believe they need around themselves to feel comfortable and content. Participants describe the rural environment in which they have lived for most, if not all, of their lives.

(2) '**Inequality resides in Rural Living'**: the second theme of this chapter presents an overview of participants' experiences that relate to the adverse effects of living with disability in a rural environment.

(3) '**Rural Australians'** profiles some of the characteristics present in the participants.

(4) **'Adapting Lived Space'** concerns the adaptive strategies that participants have used to negotiate space, that is, their own everyday living environment. Each of these aspects of spatial themes is shown in the shaded area in the model in Figure 8.1.

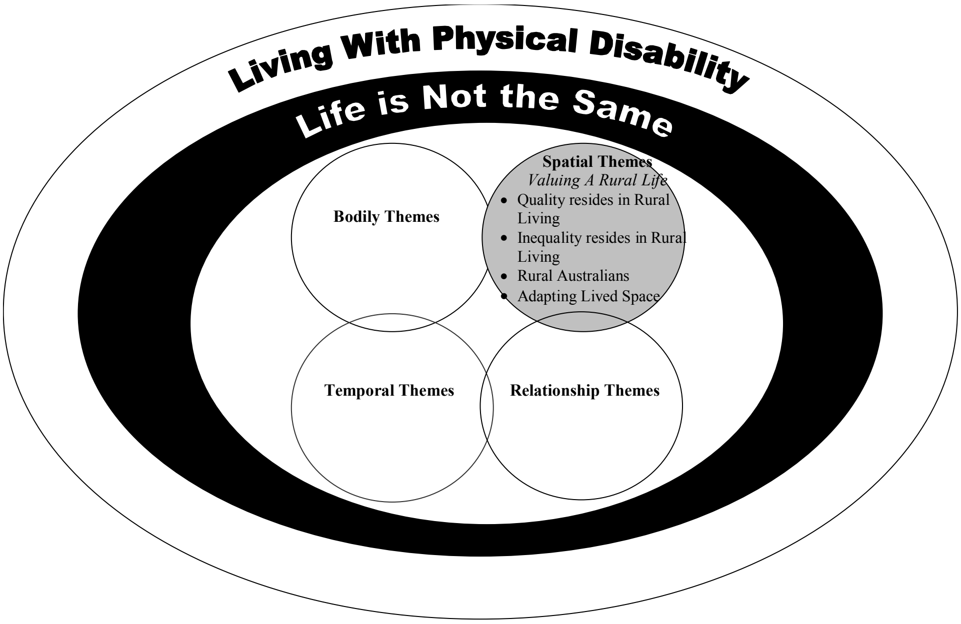

Figure 8.1 Spatial Themes - Valuing a Rural Life

8.1. Quality of Life resides in Rural Living

As mentioned in Chapter One, one of the aims of this study is to seek an understanding of the way in which rurality influences the experience of living with disability. To this extent, the focus is to explore the nature of *lived space* and expose that particular experience that gives it its quality of meaning to the study participants. 'Lived space' (van Manen 1990) for the participants was often associated with quality of life.

> I love living out here; it is a good quality of life. (Glenn)

For Glenn, the assumption of 'space' was associated with 'quality of life'. Even though an analysis of the data showed that no other participant used the phrase 'quality of life' in relation to space, many expressed values associated with it.

> Rural living is healthy. (Henry)
>
> I feel safe living here. (Karl)
>
> In this community we all know each other. (Shane)

The data showed that evaluation of 'lived space' added a certain quality dimension to the experience of space. 'Quality' in the data is expressed in two senses: as an essential feature of life and in a comparative or an evaluative sense (Meeberg 1993). It is useful to explain that participants tended not to use the word 'rural' explicitly during the interviews. Instead they used words such as 'out here' or 'the property' or 'the farm' to refer to their geographical location. In doing so, the participants influenced my interpretation of the descriptions of lived space: a place where they lived then, now and in the future or in Don's words 'a place of belonging', a place where he feels 'at home'. Belonging was also used in the context of the community that provided participants with a sense of belonging.

> I have never lived anywhere else, this is my place, I know all the people in the area, I belong here. (John)

Exploration of lived space provides insight into the way human beings experience the affairs of the day-to-day existence in their own space. When participants were asked the question 'what does it mean to live in a rural area?', their responses varied. Rural living for Henry means a sense of safety.

> I don't mind being a bit further out of town. It is quiet here, not much noise. I am not worried about being mobbed or being burgled. That can happen when you live in the city.

Rural living for Karl also relates to feeling secure. Assured that help is nearby, it feels 'good' for Karl to know that his neighbours are prepared to give help if needed.

> I know everyone in the area and they also know me. It is a good feeling to know that I can ask for their help and know that they would give it to me. The country spirit is very much alive here. When I had to

> go to the doctor but couldn't get in the car, my neighbours immediately came out and helped.

Another attraction of rural living is the image that nature provides. John relates rural living to experiencing happiness when he looks at his cattle.

> I love sitting here. It is so peaceful. This is my favourite spot. Nothing gives me more pleasure than looking out of this window …look at the trees and watch the cattle.

For Sandy, its attractiveness is its purity and cleanliness:

> It is good clean living out here. The air is so fresh …that is something I appreciate so much; it is pure living. No pollution of land, air or water.

Many Australian novels, poems, and paintings portray rural living as harsh, with the threat of a dry and barren land; gentle rural scenery is rare. The findings of this study indicate the opposite. Participants never described their environment as 'harsh' or 'threatening' instead they frequently used words such as 'pleasant' (Sandy) and 'peaceful' (Dorothy). Their appreciation of the environment was clear. Their statements confirmed that living in a rural environment was essential for the quality of their lives and, by comparing and contrasting rural living with living in other places, they were convinced that they had the better deal. Their evaluation of rural living was identifiable with peaceful, clean and safe living: it was pure, natural and unspoilt. They were aware also that rural living has some drawbacks or inequalities.

8.2. Inequality resides in Rural Living

Economic inequality seemed to be a major theme as it was frequently mentioned. Henry, for example, listed the restrictions imposed by the cost of petrol and long distance travel. Due to the increasing cost of petrol, Henry was forced to spend much more time at home.

> We are on a disability pension and with the current cost of petrol, we have to limit what we do and where we go. Life is expensive as it is, so we try to use the car in the most efficient way.

Another inequality in relation to cost relates to grocery home delivery. Whilst this service is not always available in rural communities, if offered, it comes at a cost.

> It cost nearly ten dollars to have the groceries delivered at home, I find that a lot. (Don)

Like city people, people from rural communities frequently lack accessible buildings. Some of the participants mentioned that their banking building has no ramp, whilst others could not get their wheelchairs into the public toilet designed for the disabled.

> The turning circle in the toilet is too narrow to accommodate a person and a wheelchair …it's obviously designed by someone who does not have a disability. (Shane)

Karl identified another physical barrier.

> There is a disability carpark in front of [name of shop], but the kerb is too high for me with my walking stick. I can't make it on my own.

'The presence of physical barriers continually impacts on the lives of people with significant impairments' (Finkelstein and French 1993, p.31). Lack of accessible buildings and entrances to shopping centres restrict access and therefore the opportunity to lead a full and interesting life. Physical barriers have the potential to affect adversely every aspect of the disabled person's development whether it is social or emotional.

> Because I can't use a wheelchair around the cattle yards at the sales, I haven't been for a long, long time. And that is what I find so hard … (long pause) … I used to go there every week, buying and selling …catch up with other people. Those days are gone. (Karl)

Another physical barrier relative to rural living is lack of a full range of appropriate and accessible health services, including alternative medicine. Troy would like to visit an acupuncturist to find relief for his debilitating pain.

> Apart from the doctor and the pharmacist, we don't have anyone else. The physiotherapist and the podiatrist sometimes come to town, but what I really wanted to try was the acupuncturist. I've heard about them. If you live in the city, you can find a whole range of alternative health professionals, but when you live out here, you have no choice. You either go to the doctor, or not. There is no easy way of getting alternative treatment out here.

The rural literature has identified a considerable number of inequalities in the delivery of services, including health-related services (see for example, Humphreys and Rolley 1991, 1993; AIHW 1998). Participants, like other Australians, stated that they would like easy access to a wide range of services, including health care services. Although participants asserted that they do not need much health care at present, it is likely that this may change if future health difficulties arise. Difficulties also extend to travel to health care services; it is inconvenient, timely and costly. 'Access difficulties due to distance, time, cost and transport availability in rural and remote zones can be compounded by shortages and uneven distributions of health facilities and health professionals' (AIHW 1998, p.77), including General Practitioners (GP). Access to a GP may be easier in town, but participants have strong feelings about relocating from farms located out of town. Karl anticipates that a move would hurry his death.

> My daughter says that I might live longer if I move to town. I disagree; moving to town would cut my life short. I would be so unhappy there now and probably worse as I got older … (pause). If things really get bad …(long pause), then maybe I'll think about it.

The trauma of relocation to 'town', in Karl's perception, could result in potentially devastating mental and physical consequences, including death, in spite of the possible benefits from the move. The additional demands necessary in adapting to a new place can be overwhelming. Despite being encouraged by others (most notably family members) to consider the health benefits, no one was prepared to consider this option - at least not at this stage in their life.

Whilst the geographical disadvantage was acknowledged by many, the benefits from living in a rural area were seen to override a number of considerations, including access to health services. And, although not all rural Australians experience inequity of access to health services (AIHW 1998, p.1), there is a large number of rural people who face a degree of difficulty accessing services highly desirable for rural living.

8.2.1. Jeopardy

Rather than using the word 'difficulty' when referring to matters inherent with rural living, rural literature uses the words 'double disadvantage' (Gething 1997, p.9) or 'double jeopardy' (Coward and Lee 1985, p.6).

> Double jeopardy refers to the supposition that older rural people, in general, face challenges and problems based both on age and other characteristics that are associated with older age, as well as disadvantages inherent in living in sparsely populated and geographically remote and rural areas with a lack of resources, opportunities, and services to meet those challenges.

An example of jeopardy can be found in Sandy's account. She found that the restrictions imposed by MS, a lack of energy, the large distance, the cost of petrol forced her to spend much more time at home.

> The MS support group goes to hydrotherapy twice a week. I would love to join them, but the drive to that pool is over 45 minutes. I simply don't have the energy to be in the car for all that time, nor can I catch a bus or a taxi. Then there is the cost of petrol. It all becomes too much and too tiring, so I had to cut down to once a fortnight. If they had a pool out here, I would go more often.

Whilst participants identified that life in the country is so 'peaceful' (John), 'safe' (Karl) and 'clean' (Sandy), the study findings showed that relative isolation from goods and services adds to the cost of living. Cost of food and cost of mobility aids were higher in comparison with city costs. The data also identified other inequalities, such as access to non-traditional Medicine, public transport options, limited ancillary services and inadequate access to public buildings. Coward and Lee (1985) arrived at the same conclusion, albeit by another route, when they concluded that 'the myth that people living in rural environments are healthier than their urban counterparts is clearly contrary to fact' (p.79). It is argued that on virtually every dimension of health, rural residents are disadvantaged, as they may be unable to travel great distances to seek the care that they need. Studies conducted by the AIHW (1998) also identified many health disadvantages experienced by people living in rural and remote areas. It is of interest to note that the AIHW (1998) identified that health disadvantages are caused by diminished access to health services, income and education differentials, standards of living, availability of quality health care, distance involved in access to health care and orientations toward health care systems - than rurality itself.

8.3. Rural Australians

Many of the participants had lived in the same area for many years. Their parents, grandparents and other ancestors had built their own homes, dug their own dams and established their own supplies of water, constructed the roads, and erected their own fences. Such hard work requires not only physical strength but also other forms of strength: sheer determination, being practical, and complete dedication. John's history is evidence of this. In the early 1900s, John's father built the house, the roads, and the dam and over the years he expanded the farms. He did everything himself. John refers to his father as a 'jack of all trades'. John's experience is not much different. He too, did much of the work alone, with help from some seasonal workers, but for most of the time, John did all the maintenance and repairs, as well as farming. Unlike some of the other participants, John has no children who work on the farm. Hence, his accounts are characterised by self-reliance which manifested itself in terms of self-assessment, self-diagnosis, self-medication and self-treatment.

> One day I woke up with a slight headache. I noticed that I could not cut the bread with my right hand (self-assessment). I had done a lot of fencing the previous day and so I figured that it was a bit of arthritis (self-diagnosis). I decided to take a Panadol (self-medication) and lie down (self-treatment).

Although there is no intention to stereotype John, or anyone else, I was reminded of the historian Russel Ward's (1958, pp.1-2) description of the Australian stereotype:

> …the 'typical Australian' is a practical man [sic], rough and ready in his manners and quick to decry an appearance of affectation in others. He is a great improviser, ever willing to 'have a go' at anything but willing to be content with a task done in a way that is 'near enough'. Though capable of great exertion in an emergency, he normally feels no impulse to work hard without good cause. He swears hard and consistently gambles heavily and often, and drinks deeply on occasion. Though he is the world's best confidence man, he is usually taciturn rather than talkative, one who endures

> stoically rather than one who acts busily. He is a 'hard case', sceptical about the value of religion and of intellectual and cultural pursuits generally. He believes that Jack is not only as good as his master but, [at least] in principle, probably a good deal better, and so he is a great 'knocker' of eminent people unless, as in the case of his sporting heroes, they are distinguished by physical prowess…'

Of course, Ward's account represents both an exaggeration and romanticisation of historical experience, however the point is that the stereotype is the main, if not the only contender, for a psychosocial identikit embodiment of Australia's distinctive national mystique. Whilst there are undoubtedly other 'types' to be found, it is likely that Ward's description is construed by others, such as the media, as distinctively Australian.

Another image of a rural Australian partly comes from a successful Australian film: Paul Hogan's '*Crocodile Dundee'*, released in 1986. 'Croc Dundee' is the archetypal improviser, a man of few words and understated wit, who sees through the illusions of urban sophistication, who embodies innocent 'chivalrous' values that millions of moviegoers easily recognised. Of course, many know that Australians are not like this bush-ideal and probably never have been. As Turner (1986, p.32) puts it:

> Given the basic inappropriateness of the bush legend and the iconography of the bush to contemporary Australian existential realities, the congruence of interest and focus on these pastoral myths requires explanation. The longevity of the pastoral ideal, surviving as it does in Australia's urbanisation and suburbanisation, suggests that its survival is due to its ideological and mythic function rather than its close relation to historical conditions at any point or series of points in Australian's past or present.

The rural Australian personality is part of a culture of independence and self-reliance (Stevens 1998). Such 'independence' and 'self-reliance' also appear in Karl's interpretation about living with stroke

> I'm not able to get up and go myself …ride the horse or go to the sale, drive the truck, go to the flats and check some heifers. I have to rely

> on other people. I like to be able to get up in the morning, have my breakfast and say well, I'm gonna do this today (independence). I'm gonna go out to the mountain, do my own work, check the cattle on the horse or I'm going to the flats and check the cattle. I'm absolutely useless now. I've never been one for asking others for help (self-reliant). It bugs me that I've gotta have someone with me, or else I can't go at all.

The data from this study found that many of the participants showed pragmatism, a 'matter-of-factness' and perceived their condition as an inevitable part of life, often associated with growing older.

> It's a jolly nuisance, but it's happened, there is nothing you can do about it. (John)
>
> No use complaining, nothing the doctor can do to fix it. (Don)
>
> Well, you can't turn back the clock, this [arthritis] happens when you get older. Doctors can't help; the best you can do is to get on with life. (Dorothy)

Whilst the statements appear adaptive, the assumptions that 'old age' and ill health are inevitable can also be problematic as it can result in failure to report health problems. Humphreys, Mathews-Cowey, Weinand. (1997) reported that many rural residents accept injury and illness as part of normal life and found that this attitude led many not to seek immediate help. This finding was confirmed by the AIHW (1998) when it was reported that despite the high incidence of chronic conditions amongst rural residents, many report few health problems.

Data from this study suggest that the strong influence of rural life experiences is likely to affect participants' decisions to report health problems. An example of this can be found in interview data from John and Shane who maintain that the attributes from their (rural) past still contribute to their present.

> I have always been able to deal with problems, so I can deal with this [stroke] as well. (John)

> My bush background has toughened me …I've always sorted out any troubles that came my way … that has helped me to cope with this [paraplegia]. (Shane)

Both men drew greatly on past experience of self-reliance and self-sufficiency. It is what they know, it is what's familiar: a recognisable experience that subsists within and thus has an effect on who they are. There seems little doubt that living in rural locations and the need to maintain the ability to perform one's role continue to play significant roles in their everyday life. My study confirms the findings from Elliott-Schmidt and Strong (1997). Their descriptions of the health of rural Australians include findings that 'they [rural Australians] are less likely to seek services and often delaying help-seeking until it is socially or economically convenient to do so' (Elliott-Schmidt and Strong 1997, pp59-63). The data I collected support my notion that many of the participants initially seemed rather philosophical about seeking help at the time of symptom onset. They often put off seeking proper medical attention - while engaging in a search for explanation and causation. John, a diabetic, recalled what happened prior to his leg amputation.

> 'It was only a tiny black spot (symptom) on my big toe (discounting symptoms). I thought I might have just knocked it, nothing serious (debating the significance). I just continued to go about my business, working and so (determined to carry on with activities) but when I saw blood, it realised it was more serious than I thought' (response to a serious symptom).

The study findings indicate that several participants did not recognise the seriousness of their symptoms and often attributed symptoms to minor ailments such as 'flu' (Sandy), 'fatigue' (Karl) or a 'knock' (John). Even when events were recognised as familiar, many, including John were filled with the belief 'it would go away'. According to Williams (1993, p.9) many people frequently 'explain away' symptoms and often do not seek immediate medical consultation until there is considerable interference with life and work. Similar to Williams' (1993) study, I found that participants often chose to ignore their symptoms and delayed seeking assistance whilst quietly hoping for symptoms to disappear. They were so intent on continuing with everyday life that they proceeded with activities and work - until their bodies gave in. The reality is that each participant can determine how and when to adapt, despite the physical and emotional limitations of living with disability. The following section shows how this has taken form in the life of the participants.

8.3.1. Self-determination

The essence of self-determination is the right to initiate activities with people of choice, at 'a time that suits and in a manner chosen' (Seymour 1998, p.79). To lose this represents a 'final threat to a person's identity' (Siddell 1995, p.66) in 'doing', 'being', and 'going'.

8.3.1.1. …doing my own thing

For John, self-determination means to continue working on the farm, paralysed by stroke or not. Self-determination means climbing in a tractor and spending all hours of the day there. Self-determination also means to remain active in making farming decisions. John's interpretation is expressed by the following:

> I may not have many years left in me, but until the day I die, I will continue to farm. As long I can do it, I will not give it away, despite advice from others. I like doing my own thing, farming is my life.

Sandy chooses to pursue activities of interest to her and does not allow MS to restrict her freedom. She values her life and all her efforts are directed to participating in life to the fullest extent possible.

> I will not to let MS stop me from living my life the way I want to do it. Yes, I know that I can't dance every Friday and Saturday night like I used to. But I am not going to sit at home and let my life slip by. I might be in a wheelchair, but that is not going to stop me from going places.

8.3.1.2. …being where I choose to be

For some of the participants, self-determination was about choosing one's own living situation. The fear of having to go into a 'home' because independent roles in everyday activities were decreasing was a serious assault on freedom.

> What I hope is that I can stay here. I don't want to go into a nursing home; I want to be where I choose to be.

The problem of admission to a nursing home is particularly serious for the participants who outlive their spouses. Haemmerlie and Montgomery (1987) believe that elderly people may choose institutional care because it offers them a safe environment in which to live, despite the likely negative effect on their health. My study shows that participants do not choose institutional care to guarantee a safe environment. Instead, they see it only as a last option; and would rather not consider it until adverse health forces a decision in the future.

8.3.1.3. …going wherever I want to go

Self-determination symbolises the ideal of personal independence: hence loss of self-determination means the loss of freedom. Freedom was often mentioned in relation to driving a car.

> I have always had a car. Having a car meant that I could go wherever I wanted to go. When you can't drive anymore, it means you're stuck at home. (John)

The people in this study consider mobility clearly a key to quality of life; and according to Kihl (1993) 'older [rural] residents equate mobility with the automobile' (p.84). Over the years, drivers' licences have helped participants to define a life-style built on expectations of continued mobility. For the most part, they have lived - and aged - in the one place; they remain in their own homes, on their own land, mostly because they prefer to stay there. Sadly, while they stay, some small home-towns decline. Grocery stores, for example, are generally only found in larger towns. Consequently, if participants are to buy their groceries at a slightly lower cost, they must 'typically travel considerable distances to the remaining service centers' (Kihl 1993, p.84). Another example relates to banking. Many small towns no longer have banks, hence participants are forced to travel to other towns for their banking business.

Whilst the experience of mobility impairment for many meant giving up driving a car, the experience of 'being stuck at home' is the worst aspect for John. Moreover, it means inconvenience and dependency on others. Unlike urban counterparts with a physical disability who can, for example, visit the doctor by ordering a taxi and using allocated taxi vouchers, rural residents are denied use of this alternative. For some, few options are left. John for example, had to surrender his driver's licence. He expressed concern when he said:

> The only thing that worries me is that I can't drive. I can drive, but I won't; if I have an accident, I would be in trouble. They probably would take the farm off me, you know I could be sued.

Whilst John weighed up the pros and cons, Henry fears for the loss of his own and other lives.

> What's the point of going [driving] in the car and end up smashing and killing myself and a couple of other people … Well, that's not worth it'.

Freedom is about taking risks. Unlike John and Henry who have given up their drivers' licence, Glenn has more difficulty. Although he is aware of the risks associated with his medication to control his Parkinsonian tremors, he says:

> I've always gone to church and I like to continue to go to church. I know that I shouldn't drive to church on Sunday but then again … it's quiet on the road.

Having a driver's licence and driving a car both symbolise freedom - freedom to initiate activities and the choice of how and when such activities would be done. Karl, who has limited use of his left arm and leg, for example, only uses his utility for relatively short-distance farm-related trips. He says:

> I shouldn't drive on the road but… every now and then I have to go and check the cattle. So…when there is no traffic on the road, I go and check on the heifers in the paddock further down [the road].

As the ability to drive has vanished, dependency on relatives, friends, and neighbours for assistance in securing medical services or to attend other social functions has increased. This situation is especially problematic but some participants have found methods to compensate. They ask their spouses to drive or have secured rides with other people. Some continued to drive, albeit it on the property or at least on private roads. In any case, for many of the participants, life with a physical disability was seen as an assault on their freedom to initiate activities of their choice in their own time and in their own space. Whilst they would continue to focus on seeking whatever freedom they could achieve, many have come to realise that loss of freedom is synonymous with loss of independence and loss of control.

8.3.2. Control

Whilst many of the participants related how much they appreciated self-determination, control as a subtheme also featured compellingly. Particularly, those with a strong inner locus of control believed they could personally choose their own fate by making wise decisions and acting accordingly. Sandy, for example, showed a strong desire to maintain health and well-being which prompted her to develop strategies for negotiating her position.

> My doctor once advised me not to go to hydrotherapy during an exacerbation of my MS. Worried that my muscles would further weaken, I did my exercises in bed. I kicked my arms and legs as if I was in the water. I felt really good about it. I wasn't ignoring my doctor's advice; I was just modifying it. My doctor may know what's good [for me], but I know best.

Many of the participants showed that in spite of their disabling conditions, they took control of their own lives to varying degrees. Some tried to learn as much as they could about their condition, while others learned how it could best be managed. Glenn for instance, has taken control by learning the latest pharmaceutical information in relation to Parkinson's Disease. He has gained knowledge through his support group peers. Empowered by this, he approached his physician.

> I was always afraid to question any [health-related] decisions made by my doctor and specialist. Through the support group, I've been encouraged to ask questions. Last time, I asked about some lighter tablet. The doctor said, "OK, we can try a lighter dosage". I felt good about it; it is about me … so I want to make decisions that concern my health.

Glenn already is the expert on Parkinson's Disease by having lived with it, but he feels reassured by obtaining additional information. Robinson et al. (1995) have found that people who feel they are in control feel empowered in life and can endure change better. By obtaining knowledge about the aetiology, diagnosis, treatment and many other aspects associated with disability, people can have many advantages and that is an obvious potential source of strength. Knowledge restores a sense of control through greater understanding, and provides answers, in the process, on how to control disability. Avoidance and minimisation of potentially stressful situations are a way to control Troy's pain.

> I know what things flare up the pain, so by avoiding them, I have the ability to more or less control the pain.

To be in control for some participants meant to be prepared mentally for certain outcomes. By being mentally aware that tasks and activities can take longer, Troy for example, has reached a state of preparedness in life.

> It is important to realise that a typical farmer can easily get ready in 10 minutes in the morning; showered, shaved and dressed. Now it takes double the time…that applies to every other task and you've got to be prepared and accept that it is going to take longer.

For some, the control of a lifestyle means living a life that is defined according to one's own needs. For others, control is about decision-making and determining for themselves exactly what they can or can't do. Control is about 'having-a-say' in life and in society. Although control in the context of this study often related to self-empowerment, more often it was about modifying lifestyles to enable maximal independence within one's own everyday lived space.

8.4. Adapting Lived Space

> As the time approached for leaving the hospital, I had very mixed feelings. I was, of course, delighted to be going home, but I would be returning to familiar surroundings in a different body. Would this different body cope in the environment? Would I be able to adapt? (Dorothy)

Living with a physical disability necessitates changes to accommodate the impairments and the physical changes. The individual has to adapt his or her environment or lived space. Adapting lived space for the purpose of this study means to be able to 'fit in' on physical, environmental and social levels with society at large. People with bodily deficits that impair the ability to participate and enjoy the same rights, privileges, and responsibilities as any other citizen are at risk of being left out. Consequently, special adaptation of lived space is needed to enable participants and all other human beings to live to their highest potential within a society that is challenging for everyone and particularly for them. Adaptive strategies are required to maximise safety and minimise dysfunction. This entailed assessment of a problem, recognising boundaries and identifying practical solutions, so those tasks could be performed without help from others. For instance, Henry wondered how he would go with his favourite pastime: fishing. For someone with paralysis of one arm, fishing or getting bait onto a hook is not easy. He preferred to go fishing on his own.

> I had this idea in my head and with a bit of help from a friend, I manufactured a chair with different attachments. What it means is that I can go fishing without needing any help. I can bait my own hook without help… all worked out by myself. (Henry)

With limited access to rehabilitation services, adaptation of lived space for Shane meant being inventive about the restoration of his body strength. With limited access to physiotherapy services, and limited funds to purchase rehabilitation equipment, he developed a standing frame.

> I have no therapy, so I designed a special frame that would enable me to strengthen my muscles and improve my balance. I anchored it in the wall of the garage. I like designing little odds and ends, I like helping myself and so I've combined the two. I do my own physiotherapy. (Shane)

Troy has a similar story. He has designed a three-wheeled wheelbarrow that could easily be pushed with one arm only. Troy, John and Shane contribute the success behind their self-designed devices to their 'bush-background' and maintain that rural living has equipped them with skills that 'city people don't have' (Shane).

Glenn has found a practical solution to avoid bone fractures when he falls.

> I wear kneeguards like skateboarders do.

Don has purchased a gopher (motorised scooter) which not only enables him to access a wide area in and around the farm, but also allows for mental distraction.

> I do get out in the yard on my gopher and do as much as I can. I like a challenge, and while I have this sort of thing on my mind, I don't think of my dystrophy.

When physical limitations hinder the performance of life-sustaining activities of daily living, it becomes necessary to turn to technology and adapted devices such as ramps and grabrails. These visible modifications make the living environment accessible for those with limited ability.

Shane sees adaptation of lived space in the broadest possible way.

> I talk to shopkeepers and advise them on how they could make their shop wheelchair-accessible.

The participants have found numerous ways of modifying, altering and adapting to the environment. They have shown an ability and determination to think of ways to perform activities or to enable them to stay in their own lived space. The research showed that not all strategies are intended to be strategies for learning to live with disability. On the contrary, many strategies are used to maintain a sense of normalcy and control by remaining involved with everyday business.

8.5. Conclusion

There are important facets and dimensions of physical disability that make the experience of 'lived space' substantially challenging. Geographical disadvantage, that is, those arising from isolated living, in addition to practical problems with impaired mobility, occurs almost simultaneously with the physical and emotional process of relinquishing self-determination, freedom, control and independence; elements that equate with and are highly valued in rural living. In their yearning to rise above these circumstances, participants adopted characteristics that enabled them to function as a separate entity - with control, autonomy and responsibility. They reminded me that most human beings are partial to exerting control over their own everyday affairs. Given the lack of easy access to health services, pressure is exerted by family members to relocate. For many, this is not an option. In fact, the fear of leaving an environment so much valued exceeds the fear of worsening health.

It is clear from the participants' experiences that the restricted physical activity affects everyday life in terms of the ability to maintain self-sufficiency and (ultimately) the freedom to live a chosen lifestyle. Most individuals engaged in minor and major life style modifications and adopted numerous strategies, including adaptation of the lived environment.

The data indicated that a surprising number of people saw their injury or disease as a challenge that could be conquered, probably because this perspective had worked in the past. And, although the evidence is far from conclusive, it is interesting to note that, without any exception, all of the participants assign value and quality to rural life, in spite of inequality and jeopardy (Coward and Krout 1990). Being in 'lived space' means an experience that adds value to life; 'lived space' for the people in this study, therefore means valued living.

CHAPTER 9: RELATIONSHIPS IN LIFE

9.0. Introduction

This chapter focuses on the relationship themes present in the everyday life world of those living with disability. The main theme *'relationships in life'*, in the context of this study, refers to the 'lived relation that human beings maintain with others in the shared interpersonal space' (van Manen 1990, p.104). It was Merleau-Ponty (1962) who prompted us to recognise the body itself as inherently expressive of one's existence and to identify its critical role in relation to the development and the maintenance of social relationships. The body's insertion into the world is the condition of 'interacting with other people' (Merleau-Ponty 1962, pp. 346-347). In his view, people and the world are linked in significant relationship; 'the human being is intentionally and dynamically involved in the world'.

In a similar vein, is van Manen's (1990, pp.104-106) notion that 'through our lived body human beings interact with others that form part of the world in which we live'. An excellent example is provided when van Manen (1990) says 'as we meet the other, we approach the other in a corporeal way: through a handshake for example or in another way that he or she is physically present to us' (p.105). What is illustrated here is the body's critical importance to both the development and maintenance of social interaction. As Merleau-Ponty (1962) and van Manen (1990) made evident, through the body, human beings are able to participate in social dealings with others.

This chapter demonstrates how participants in this study are embedded in social interactions which form the essence of everyday social life. From the written transcripts, it became clear that friendships, companionships, marriage, family and God were among the key elements that participants felt strongly about.

'Relationships in Life' emerged as a central theme to express the importance of relations with others - as they exist for participants. 'Relationships in Life' embodies interactions with families, friends, the community and God as facets that add richness and occasionally sadness, to daily routines. The meaning of 'Relationships in Life' is structured around four subthemes:

(1) **'Disconnection'** relates to the participants' state of loneliness and diminished participation in social relationships.

(2) **'Stigma'** focuses on the negative meaning that became evident when altered physical appearance or mobility was not acceptable.

(3) '**Accepting Support'** conveys the importance attached to the support received and accepted from family and friends. Support also comes from 'God' and from support groups.

(4) **'Communication'** signifies the value attached to interaction between human beings.

Each of these aspects of spatial themes is shown in the shaded area in the model in Figure 9.1.

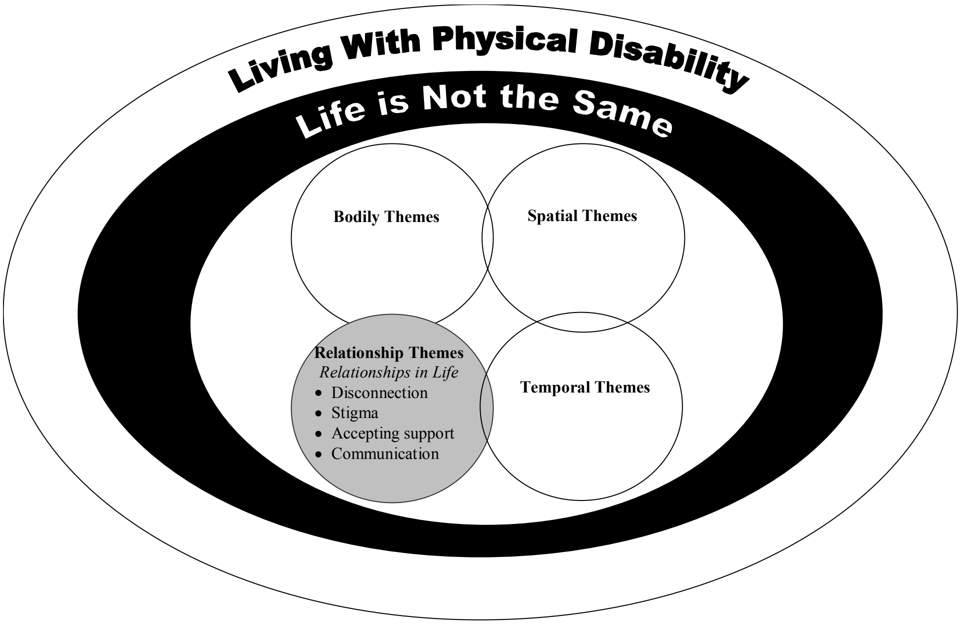

Figure 9.1 Relationship Themes - Relationships in Life

From the themes, it is apparent that relationships in life and the potential for disconnection with others are a source of concern for people with damaged bodies and the next section discusses this.

9.1. Disconnection

In her study of the meaning of disability, Blaxter (1976, pp.218-219) noted that ‘although the practical problems of work, money, and daily living seemed to be prominent … the social problems … were perhaps the most distressing’. The social problems that Blaxter (1976) alluded to include lack of occupation and recreation, fewer relationships, loneliness and isolation, in other words, a sense of ‘dissconnection’ with others. Similar to Blaxter’s (1976) study, participants also experienced lower levels of social activity and less involvement with others as a negative value that led to a feeling of ‘disconnection’.

Disconnection for Henry was associated with giving up dancing.

> Almost every Saturday, Helen and I would go to a dance. I took pride in being a good dancer and I enjoyed the company of friends but the stroke has taken that away from me. I take that very hard. Now, I stay home and feel absolutely useless.

Henry stated that the loss of the social side of dancing was one of the hardest things for him. Dancing and being with friends added value to his life and so, without this, he feels ‘useless’. A fundamental form of feeling useless, according to Charmaz (1983) and Bury (1991), is the loss of worth in people with disabling conditions who observe their former self-images crumbling away, without the simultaneous development of equally-valued new ones. Henry’s feelings of worthlessness are likely to relate to lost capabilities and being restricted from activities he was previously able to perform. Disconnection for some participants was typified as a feeling whereby they felt no longer part of the world. In this sense, disconnection relates to becoming detached from others. Many now are staying at home, with the resultant curtailment of social life and the inability to get out of the house. This generates a feeling of loneliness and isolation. As Dorothy said:

> Because I can't walk or use a wheelchair, I can't go anywhere. I haven't left the house for many years. I can't go to town, have holidays … nothing … I'm just sitting in this chair, mostly by myself. I feel like I'm no longer part of the world. That is my life.

For Karl, who was a 'mad horserider', the committal to isolation and not joining with others generates a profound sense of loss and a sense of separation from his friends.

> When I look outside through the window and see the boys going out on their horses, I wish I was going with them … can't do anything about it, but I do miss it.

The impact of disability on self and others is also reflected in the literature. Charmaz (1983) finds that disability impinges both on self and others and notes that the separation from others, in particular, is likely to be the most difficult to bear, adjust to, and cope with.

Occasionally, the effect of separation can generate a sense of resentment. Henry expresses the curtailment of a working life as follows:

> I miss my work … being with workmates … I wasn't even all that old when I had my stroke.

Similarly to Dorothy's experience, Troy's disconnection has resulted in less socialisation, which has created a sense of separation between himself and the outer world.

> You do become remote and tend to lose touch with the outside world. These days I don't go to town often, but if I do go and return home, I get the feeling that I've hopped off the world and am no longer on board.

Social withdrawal for John is based upon his symptoms associated with the stroke. In addition to his hemiparetic arm, John also experiences swallowing difficulties that cause considerable spoilage to interactions with others and have led to social withdrawal. John prefers to stay home, because he is self-conscious about his swallowing difficulties.

> I don't like folks staying here, I don't like eating out, I don't go out anymore … I am conscious and embarrassed about my choking, spluttering, dribbling and problems with swallowing. I'm happy to stay at home.

Such withdrawal from social interaction and social life, due to symptoms associated with one's condition, is what Strauss et al. (1984) have suggested as 'entirely understandable' (p.54). Understandable is also Glenn's comment:

> I'm very self-conscious about my Parkinson's Disease. I wear these knee guards around the house, but when I go to church, I don't [wear them]. I just hope that I don't fall in front of anybody. I don't go up [to the front of the church] to get communion … I don't like it when people stare at me.

As with social life, former occupational pursuits, hobbies and active pastimes may be curtailed or abandoned due to physical limitations. Shane, who grew up on a farm, had in the past pursued many sporting and other recreational activities. Together with his brothers, he was always ready for a game of cricket or 'footy' (football). He was a 'typical outdoor kid'. In adult life, he continued playing sport, camping, and fishing. His love for an active life style was reflected in his job as a farmhand. Mustering cattle, breaking-in horses and many other farming duties were part of Shane's everyday life until the day of the accident.

> I used to always be outdoors and played a lot of sport until I ended up in the wheelchair. If it wasn't for this [the accident], I would still do all those things. Age would never stop me, but then I had the accident. Now that I am in the wheelchair, I do different things. I am still active, but do more sedate things such as fundraising and talking to schoolkids to raise awareness about paraplegia.

For Henry, his social activities and his pastime of fishing had to be abandoned. His wife is very anxious. Henry explains:

> I used to go fishing as soon as I had the opportunity. Now I can't go because my wife is afraid that I would overbalance and fall in the water. She is worried that I would not be able to get up, I could drown and die.

Other social activities, such as holidays, may also prove to be problematic in the wake of a disabling condition:

> I went on a holiday … they said that the unit had disability access, well yes, it did at the front entrance, not anywhere else. The entrance door of the unit had a lip, and so had the bathroom. The 'Ag (agricultural) show' is the same, no access for wheelchair users. I wanted to go to the pavilion, down to the ring to see the judging of the cattle … couldn't get in. (Glenn)

Glenn's experience regarding inaccessibility to buildings is not unique. People who use wheelchairs are routinely blocked by curbs, steps, turnstiles, heavy doors and narrow doorways that prevent them from getting into many arenas, stadiums, theatres, and other public buildings. His account serves to highlight and reinforce the myriad dimensions of disadvantage and social isolation experienced by the participants.

Dorothy, too, talks about the restriction of social interaction and its impact on her world.

> My world has become very small, it is just within the boundaries of these four walls [of the living room]. I haven't left the house for years. It's terrible.

Dorothy's situation was further exacerbated by the fact that she cannot be transported in a car. She has learned that only those who require the ambulance for a medical reason are entitled to its use. Hence ambulance use for Dorothy's social outings is not allowed.

Whether living with disability means disconnection, social isolation or not, Johnson (1993) believes that 'anyone who no longer enjoys a place in mainstream society suffers a range of indignities and punishments' (p.264). Being excluded from social recognition or having no role in social relations certainly must be experienced as hurtful and damaging. Likewise is the loss of functional capacities that undoubtedly leads to a sense of confinement and infringement on one's sense of integrity. The findings of this study show that the inability to get out and about as much and as easily as before, together with a curtailment of social life, bring in its place a subjective feeling of disconnection: a social isolation and being cut off from the flux of everyday life outside the home. From the participants' own perspective, living with a physical disability imposes certain demands and constraints upon an already highly-compromised life style. Perhaps the most significant repercussions are a set of attitudes, sanctions and prohibitions that have the effect of 'dehumanising the individual and engendering depression and reduction of self-esteem' (Johnson 1993, p.264). Most of the concerns that characterise those who are subject to a dwindling of social interaction and social lives relate to acquired bodily damage: 'disabilities … attract penalties' (Johnson 1993, p.265). In fact, many of the accounts from the participants drew attention to negative circumstances that arose out of the visible disabilities. Participants commented on how their (visible) disabilities evoked a degree of embarrassment in or stigma from other people. We move on now to discuss certain problematic aspects of stigma.

9.2. Stigma

> Disability is often stigmatising with intolerance, fear and misunderstanding at one extreme, and well meaning but humiliating and patronising sympathy at the other. (Jennings, Callahan and Caplan 1988, p.6)

Whilst the main source of help and support concerning living with disability for the participants tended to come from the family, particularly spouses and daughters, it is nonetheless the case that participants and carers exist within wider social networks which may be more or less supportive. Indeed, the presence of a less-supportive environment may influence how individuals experience living with acquired disability. As stated in the introduction of this chapter, the body is critical to the development and maintenance of social routines and relationships. Authors such as Erving Goffman (1963) provided much insight into the centrality of the body in relation to the development and maintenance of social encounters and in mediating the relationship between one's self-identity and one's social identity. Although Goffman's book was published well over a quarter of a century ago, the influence of his scholarship on stigma remains alive today. Stigma originally referred to marks that publicly disgrace a person, but now stigma has come to refer more to the disgrace than to the actual bodily mark (Goffman 1963, p.2).

Many of the participants experienced directly the 'disgrace' (Goffman 1963, p.2) or stigma that physical impairment attracts. Friends often withdrew, which created a deep sense of sadness. Some participants raised the issue of stigma and societal attitudes that - in their opinion - arose from a foundation of ignorance about people in wheelchairs. This is evidenced by Don's testimony:

> People stare at me. I had this kid looking at me one day, I said to him "G'day Captain". The kid turned to his father and said "that man spoke to me". "Sshhh", said the father, "don't talk to him". I believe that this man was plain ignorant; he perceived me as a hopeless being in a wheelchair … so be it.

Negative or misguided attitudes and behaviour of others, together with their lack of knowledge about disability and impairment, can also create barriers. Henry presents his experiences as follows:

> One day, I felt really good and suggested to my wife to go to a dance in town. I felt safe [steady] that night and asked my wife for a dance. We got up, but people were staring, you know. They have never seen a person with a disability on the dance floor. You could feel their eyes going right through us. Helen got embarrassed and said that she felt uncomfortable and said "let's go and sit down". That is very hard to take.

A limping gait, which became obvious and ever so noticeable when Henry was dancing with his wife, drew staring looks from others. Embarrassed by the staring looks, the couple left the dance and returned home. 'If disabled people are denied access to normal social activities they will not only have different experiences from those of their able-bodied peers, but they will interpret, perceive, think, feel and talk about the world differently' (Finkelstein and French 1993, p.32). Approximately three decades earlier, authors such Goffman (1963) and Freidson (1965) identified that stigma, when attached to illness or impairment, could damage a person's identity. The term 'spoiled identity' (Goffman 1964, p.3) was coined and referred to internalisation of a feeling of being inferior, degraded, deviant, and shamefully different. In Henry's case, his experience of being stared at led him to feeling uncomfortable or embarrassed in normal social interaction, hence his decision to forego participation in future dances.

The stigmatising influence of disabling conditions often forced participants to withdraw socially. Glenn is well aware that there are many issues beyond the physical attributes of the tremors or an unsteady gait. He is frustrated about the fact that he is not able to drink coffee in public.

> You can't drink a cup of coffee without spilling and that's socially not very acceptable. I've heard people say when they saw me walking, "look that man is drunk".

For Glenn, the visibility of his damaged body has increased his vulnerability to the scrutiny and appraisal of others. The visibility of his bodily tremor enabled other people to make assumptions on the basis of the body that they saw. This left Glenn with little protection from the evaluations of others. Locker (1983) describes the 'stigma of disability' in terms of some diseases that are 'clean' and others that are 'polluting' (1983, pp.135-137). Heart disease, for instance, may be seen as 'clean' or acceptable, as it does not intrude on a person's interaction with others; while it could be extrapolated that less mobile people might attract a 'polluting' label. Locker's conception of labelling is closely related to Goffman's (1969) 'discrediting' that manifests itself in situations where people are in the eye of the public and thus become subject to public embarrassment. Disabled people, being part of society, frequently think of themselves in the same way as able-bodied people think of them and behave as others expect them to in their role as disabled people - 'the self-fulfilling prophecy' (Finkelstein and French 1993, p.32).

The participants' experiences confirmed Goffman's (1969) findings that the presentation of self, including the appearance of people, is instrumental in the way that others define or identify self. In similar vein, Seymour (1989) holds the view that ‘the exterior of the body is much more public space …a medium by which an individual represents him [self] or her [self] in public’ (Seymour 1989, p.12). For the participants, managing the bodily-appearance-of-self is difficult to overcome. It is practically impossible to hide a trait such as a tremor or a hemiplegic gait. With few resources to employ or few alternatives to pursue, participants had little means of protecting their bodies from the assumptions of others. Those who suffered pain, however, attempted to make an effort to present themselves in a way that kept their discomfort hidden. They describe the dilemmas experienced when keeping the symptoms ‘hidden’ from others.

> I make a huge effort to keep my pain invisible. It is an achievement, yet it’s also a burden.

Troy is hiding his pain from others, including his wife and daughters, as he doesn’t want to be seen as a ‘whinger’. He goes on to explain that this strategy has an unwanted effect, namely, that people do not realise that he is in pain, and therefore do not make allowances for it.

Presenting a positive image of self through smiling, was Sandy’s way to hide the pain out of love for her husband, her daughter and her mother.

> I am a hypocrite, an actress; I am two-faced. Inside, I cry from pain, outside I laugh to hide it. My pain would hurt the loved ones around me, I don’t want that.

For some of the participants, the visible bodily change and the impact of factors such as ‘staring’ or ‘covert comments’ has continued to perpetuate the disembodiment. For all participants, image management occurred to prevent stigmatisation (Conrad 1987; Wendell 1996) from their social world that had the effect of normalising (Strauss et al. 1984) their interactions with others.

From the analysis of the data from this inquiry, it is also evident that many of the participants - over time- found ways of living with disability that challenged this societal stigma. Except for John, all others were determined to carry on with communal life and not to 'hide' their bodies. As Sandy says:

> I no longer care if they stare at me in the streets; it's their problem. I refuse to stay at home; instead I want to live a normal life.

For the participants, the goals of their lives were to be 'normal', that is, not wanting to be considered different because of physical appearances. Being viewed as 'normal', also meant not feeling embarrassed or humiliated, but being accepted. The importance of acceptance by others and self to acknowledge what has happened prompted Shane to write the following poem:

I've been in this wheelchair for just over 3 years.
Outside I'm happy as Larry, but inside I hide my tears.
For there are things that I can't do and many more that I can.
And for those things I can do, I do as good as any other man
Like a smile or a word of cheer to help folks on their way
You know it doesn't cost a cent to say 'G'day stranger have a nice day'
And no matter what handicap you're saddled with, it's true
Just stop and realise that your biggest handicap is you
For you can laugh and you can smile, just the same as me
And if you share those thoughts with others, then pretty soon you'll agree
That it's a great giver, so give and give again
Give your love, give your smile, give whatever you can.

-Shane (reproduced with permission)

Thus, whilst this section focused on stigma and the lack of understanding of others towards those with visible and invisible physical presentation, the findings indicate that stigma involves the degree to which the participants are able to continue participation with the outside world and their links with wider social networks. Many participants, even those who lived in a small community, spoke of how their overall degree of social contact had considerably diminished since their physical deterioration first began. This was particularly the case concerning ‘friends’ as opposed to family. Although contacts with friends generally had decreased, support of family was evident in all of the interviews. Findings of this study suggest that living with physical loss and limitation was made possible due to the presence of sources of support. Indeed, all of the participants identified a number of social support networks that played a positive role in everyday life.

9.3. Accepting Support

Whilst the previous subtheme ‘stigma’ revealed the pain and suffering, many spoke of the consolation they received from family members who were so helpful and supportive since the onset of their disabling condition. Spouses were often singled out, commended and praised for providing such a great deal of support. Unable to achieve the tasks for health and comfort of the body independently, people in this study receive help from others, mostly family. Additional support also related to ‘spiritual support’ and support from ‘support groups’.

9.3.1. Family Support

Whilst some people were concerned about being dependent on others, most still felt that they could draw on the support provided by their friends and family members. Henry, for example, felt reassured that his wife would always be willing to continue to support him.

> I am dependent on my wife. Without her help, I would not be able to manage. She helps me with a lot of things. She looks after me, prepares the meals, helps with showers and helps me to get dressed. She drives me to the doctor and really in many ways I’m totally dependent on her for everything.

One of the notions closely associated with accepting support is ‘dependency’. Dependency in everyday life meant relying on others for transport from place to place, preparation of food, assistance with personal selfcare, grooming and other activities. Needing help with activities and reliance on others appeared to be viewed as one of the most serious drawbacks of living with disability. For Dorothy, dependency added strain and even tested the close relationship between herself and her daughter. The necessity to return to her daughter’s house after her failed surgery, for example, created in her view a great deal of ambivalence and resentment about the restrictions she was to put on her daughter’s life.

> My daughter has her own family to look after, but never complains about me. I’m sure she is putting on a brave face. I often tell her that I know that it is hard work [to provide care]. When she is tired and cranky, I say to her “tell me if you want to get rid of me, tell me if I’m a problem, I don’t want to be a burden on you”.

The Dutch psychologist Munnichs (1976) has highlighted the fallacy of the dichotomy between dependence and independency as ‘a problem’ when he writes that ‘dependency is always placed in contradiction to independency as if they exclude each other’ (Munnichs 1976, p.4). In the opinion of many Western policy makers dependency and independency are concepts used to denote the means by which existing measures are tested. Hence, when ‘measures promote independency it is all right, if not, dependency is the root of the problem and then measures need to be changed’ (Munnichs 1976 p.4). The question that accompanies this statement is who is independent in modern society (Jerrome 1993; Robinson et al. 1995)? Whose lifestyle would remain unchanged if those who support them withdrew? Wheelchair users who cannot do their own washing and ironing are labelled as ‘handicapped and ‘dependent’, but middle-aged bank managers who cannot do their own laundry are considered neither (Jerrome 1993, p.257). This example makes it clear that human beings live in an interdependent world. That means that there is no one who is in any proper sense independent. Instead, there is ‘interdependence for all who exist in human society' (Jerrome 1993, pp. 257-258). This seemingly simple truth has proved to be conceptually complex and difficult to accept for many, including Karl and Don. Both express sentiments that relate to the burdened feeling of dependency and subsequent support received, particularly from their loved ones. Both have used the word 'guilt' to describe their feelings about support received from their spouses.

> I feel guilty and keep asking my wife: "am I a burden"? I don't want to be a burden on you. (Karl)

> I do feel guilty about asking for help. Even though I think in my brain that she [wife] doesn't mind. Sometimes, though, she'll say "I'm getting older too you know". That's when the guilt kicks in. She is nearly eighty and instead of taking it easier, she has to work twice as hard. (Don)

Don's plight highlighted a concern not expressed by many others, namely, the spouse's ability to continue as a carer. A study by Havens and Kyle (1993) reported that changes in carer's ability to provide assistance relates to admission into a nursing home. Although the uncertainty around future abilities of the carer and the experience of caring was not frequently talked about, on one or two occasions it would arise. However, it is difficult to draw conclusions from participants' statements about feelings of guilt, dependency and 'being a burden' in relation to the significant others, as most of the interviews were held without the presence of the relevant spouse. It is evident that the participants are genuinely concerned about the impact of their physical limitations on others, most notably their spouse. A major premise of this section has been that acceptance of support versus dependency must be individually defined, based on functional need and comfort. It is a matter of personal preference whether one does something for oneself, engages help to save time or energy, or determines what level of help to use. People, including significant others *and* the people they assist should recognise both the right of comfort and the right of choice.

The final decision, of course, rests solely with the person living with a disability, who determines whether or when to use assistance for maximum functioning ability. 'The truth', according to Robinson et al. (1995, p.74) is 'that none of us is totally independent. We all depend on others' (Robinson et al 1995, p.74). The reality is that people with a disability have to learn to accept support from others. Thus, whilst independent functioning is a worthy goal for self-improvement, building self-esteem, and personal achievement, dependency and relying on someone else also need to be considered as an equally important value for balanced living.

Living with a disability also had positive features to it. One such example comes from Henry when he said: 'my wife tells me all the time that she gets a lot of comfort out of helping me'. Negative effects of caring might be counterbalanced for some carers by positive effects such as, 'a personal gratification from caring roles' (Rosenman, Broque and Carr 1994, p.444). Jerrome (1993, p.260) terms this 'altruistic giving' and points out that many carers do not have any expectations of charity, or hope for a reward or exchange benefit; for many caring is a given. In effect, many of the participants commented on their strengthened relationship with their spouse.

> My wife is my best friend. She knows how I feel, I don't have to explain or ask for anything. She knows. Since the accident, we have grown closer; we went through this whole thing together. Of course, things have changed; sex is one such thing. But we have found other ways of showing our love for each other. One thing is sure, the accident has made our relationship stronger; it will last forever. (Shane)

The study shows that living with a disability for the participants brought in its wake a quiet understanding between spouses and participants that the main responsibility and burden of care is often given willingly, in spite of its emotionally and physically demanding nature. More importantly, the renewed perception of life together with a reinterpretation of the situation appeared to have a positive effect on relationships between participants and their spouses. This reciprocal understanding appeared to be crucial to the acceptance of help and support, although it may not be crucial for some people.

Research suggests that embeddedness in a social network is vital for people with disability (Williams 1993; Robinson et al. 1995; Goodhert and Lansing 1997). The reassurance that one is not a burden helps to ease the transition into a life with a disability, and helps the emergence of the new self (Charmaz 1991). These findings confirmed the participants' accounts that a network with at least one, often more, confidant relationships can cushion damaging physical and psychological effects of disability. For the participants, a firm sense of knowing that unconditional caring will be provided now and in the future underpins living with disability.

The seemingly simple notion of accepting support has proven to be somewhat more complex that it appeared at the outset. From the moment participants experienced the onset of physical disability, family members assumed much of the responsibility for assistance in the form of emotional support, physical support, personal care, and transportation. Having supportive relatives made the difference between admission into nursing homes and 'staying at home'. Since the spouses were willing and able to provide assistance, a nursing home admission was avoided. Living with disability places a tremendous burden on family members; and many expressed concerns about the possibility that caring may become too taxing for the spouse. There was no obvious evidence of the latter in this inquiry. Although it was acknowledged that living with disability had touched on the aspect of marital life, spouse conflict generated by providing care, spouse's fatigue and increased dependency on the spouse were not mentioned. Most of the participants' families and friends were very supportive which was shown through compassionate caring, sympathetic understanding and accommodating attitudes towards physical limitations.

9.3.2. Spiritual support

Many of the participants explained how they found solace in knowing that there is a 'God', a source from which support and strength is drawn, in whom hope is based and in whom confidence is placed.

> 'The whole business goes back to one thing … I think you've got to have a lot of faith in the good Lord and then he will look over you and he will help you to overcome the difficulties'. (Henry)

Shane believes that there is a spiritual meaning in anything that happens.

> I'm not a real religious person, but my wife and I are both Christians. Having that sort of background helps. I believe that my accident is a test of my faith. I've done meditation and prayer and I believe that where there is faith, there is hope, healing and love'.

Shane is of the opinion that the accident and the time that followed can be considered as 'testing' by God. For Shane, believing is many things, including fervent prayer and thoughtful meditation. Shane's hope is that these actions will help heal and further increase learning and personal understanding.

Religious thinking constitutes one of the most prominent and successful ways older people control their emotional responses in difficult situations (Koenig 1993). However, religion can also be a great provider of meaning to life (Coleman 1993). Sandy, for instance, has wondered about the meaning of having MS and started out to seek an answer to the question: 'why me?'. She has found the answer and firmly believes that she has MS because 'God gives it to those who can cope'. 'The belief in a divine purpose or in the general beneficence of a divine spirit may serve as consolation or as encouragement to do one's best to deal with the difficulties one encounters' (Moos and Schaefer 1984, p.14). For Sandy it is the knowledge that she was 'given MS' because she was capable of dealing with it.

Spiritual support also meant a feeling of confidence that there is a higher being that nurtures people and whatever had happened or was going to happen, it would be something that fitted God's plan for that person's life. As Glenn said:

> No matter how hard life on earth sometimes can be, I know that I'm looked after now and in the future. That's why I am looking forward to going to Paradise when I die.

Many participants attributed their ability to living with the trials of a physical disability to God's help and constant presence in their lives. Their belief in the omnipotent, omniscient Lord is one that offers hope, faith and strength.

9.3.3. Support from others

In addition to family and spiritual support, participants received support from a very small community social network. Compared to the family's role, these services contributed only a small, but nevertheless significant amount of help to the people in this study. Support groups play an important role in the lives of some of the participants. Each person identified the support they receive.

> I go up just for a yarn. They also give me the latest information on treatment options. (Glenn)

> I don't go out much, but I look forward to our monthly meeting. I don't consider them as a group of stroke victims, more like a group of friends … we laugh a lot. (Karl)

> I go to a selfhelp group for chronic pain sufferers. We meet once a month and share advice on relaxation techniques. We encourage each other to think and act positively. (Troy)

> I go to meet others who are in the same position as me. Together we learn how to best fight the same battle (Sandy).

Attending support groups also led to situations where participants found themselves searching for the positives and comparing themselves with others who are in their view 'worse'.

> I look at the other stroke victims and think: well, I am better off than them. (Henry)
>
> There are other people worse off in the world than what I am. I am lucky that I can still walk around. (Karl)
>
> I look at some of the other people with MS in the group and think that I'm better off compared with them. (Sandy)

For the people who attended support groups, the group approach had significant advantages. It provided an opportunity to express fears and concerns in a mutually supportive and understanding atmosphere since their experiences and concerns were shared. This sharing of experiences and feelings also helped to reassure the spouses. The challenges that surround disability are not necessarily unique, but a common problem following onset of disability (Block, Boyer and Imes 1984). Wendell (1996) noted that people, including those with disability, are keen to compare themselves with others to confirm a belief that there are others who are worse off. Wendell (1996) argued that this way of minimising one's own difficulty helps to counteract frustration, grief or shame. For the participants, it could be a way of clinging to one's right to feel sorry for others and therefore to feel stronger, healthier and more normal than them. Support groups also served as a means of receiving support to deal with the adjustment process, encouragement to be practical about the eventual outcome and, most importantly, they serve as a channel of communication.

9.4. Communication

Robinson et al. (1995) suggest that communication is one of the most critical human needs because it is the primary means by which people interact with their world and relate to each other. This study has found that the ability to communicate effectively is especially important for the person with a disability who faces a series of lifestyle adjustments.

> It was pretty devastating stuff to be told that I had MS. I can remember sitting down in the chair in the doctor's surgery and praying 'please Lord let me not have anything serious'. But then he said those words, without any emotion "you have MS". It was just like a blow, pretty devastating. I remember staring at him and saying: "But doctor you could be wrong"! And he said with a tone that sounded so uncaring: "absolutely not." Then I asked "what should I do"? He replied: "go home." That's communication for you. (Sandy)

Sandy's physician may have been forthright about the diagnosis, but the way in which he communicated this made it difficult for Sandy to comprehend what the diagnosis 'MS' meant. Troy had a similar experience.

> This doctor came in and he was going 100 miles an hour with his mouth and it wasn't getting through my head and I thought what is this man saying. I said "excuse me…what did you say"? He stood over me, looked at me with some sort of a superior look and said with an even louder voice': "you have a brachial plexus lesion". He was so arrogant.

Instead of receiving the diagnosis and treatment decisions in a communicative manner that showed a caring nature, Sandy and Troy described their communication experiences with their respective health professionals as 'uncaring' and 'arrogant'. There are studies that suggest that health care professionals can be deficient in their ability to communicate (see for example, Fitzpatrick 1984) whilst other studies demonstrate that ineffective communication can significantly affect both the processes and outcomes of health care (Ellis and McClintock 1994; Ley and Llewelyn 1995). Whilst only a minority of people (John and Shane) were satisfied with the communication between them and their health professionals, more people were unsatisfied and stated that their dissatisfaction tended to occur around the communication of information. These participants asserted that they would have liked to talk more to their doctors, and would have preferred it if the doctor had listened. According to Gibbs, Waters and George (1990) there are substantial proportions of people who do not feel they have been adequately informed about their condition, with seventy per cent stating that they wanted more information than were given. It might however, as Henry suggested, be their manner to get over some devastating information as 'impersonally' as possible so they do not get too emotionally involved, rather than a disinclination to convey information. Knutson (1985) offers another reason for a display of emotional insensitivity in health professionals with regards to communication. She explains that medical personna are also 'human' and as such often experience difficulty with intricate situations and as a result, 'therapists and doctors may react with insensitivity or may withdraw because of frustration with the lack of a cure' (Knutson 1985, p.159).

Many expressed that words conveyed between a doctor and the patient were equally vital to their understanding of 'life with disability'. They wanted to know what was wrong and whether it could be fixed or not. Most people seem to want to know as much as possible about their illnesses (Ley 1988; Morris 1990) even if it was bad news.

The nature of the physiotherapy profession rarely requires conveyance of 'bad news'. Yet, it is important to recognise that 'the provision of physiotherapy is a form of communication and the whole process is one of communication between the client and the physiotherapist' (French 1997, p.247). During the interviews, many of the participants stated that they had experienced a trusting relationship with their physiotherapists during their rehabilitation. As Shane, who spent a long time in a rehabilitation unit, explains:

> I got a pretty good relationship with my physio. She had a good deal of knowledge about me as a person. She knew when I was happy or sad, so she would structure her therapy so and accommodate it to my mood. What I remember best, however, is her listening skills.

The importance of listening is heavily emphasised within the literature (see for example, Ellis and McKlintock 1994). French (1997) points out that listening is more than a skill or process in communication. She explains that, if people encounter someone who is truly understanding, someone who listens and acts on what is said, it changes their whole 'outlook' on the world (French 1997, p.255). The importance of listening as part of communication is also commented on by Henry.

> 'If you are mixing with other people, you hear their problems; you listen to them and take note of what they say. It takes my mind off other things that are worrying me'.

Henry has captured how listening can be regarded as an intense personal involvement with another person. What this research showed is that being considerate about the everyday experience of communication can do much to increase understanding of the meaning of disability. Locker (1983) emphasised the importance of communication as follows:

> It could be argued that the communication of information is even more important with respect to chronic illness since the patient not only has to manage a variety of distressing symptoms, but also has to learn to adapt to new and more limited lifestyles. Some would go as far as to claim that for many chronic illnesses the communication of information is the only form of treatment there is (Locker 1983, p. 53).

French (1997, p.259) deems communication as ‘meaning making’, rather than ‘information processing’. Communication in this way encompasses perception, description and understandings of the world (French 1997). Indeed, for the participants, communication is not only about expressing and listening to information. Rather it is an essential element that underpins the formation of mutual relationships and encourages self-confidence in those faced with disability.

9.5. Conclusion

Whilst it was remembered that disconnection with the outer world had occurred to a large extent, it was replaced by other positive things in their lives, such as the love, care and support from the people close to them. Conversely, just as the body is critical to social relationships, unsatisfactory relationships threaten embodiment. The relative visibility and stigma produced by physical symptoms and other bodily losses create unnecessary pain and suffering which is difficult to overcome.

Participants asserted that despite much uncertainty in their lives, there was certainty about increased family closeness, together with the comfort of knowing that they were loved and would continue to experience a sense of belonging. All participants reported that their supportive relationships, whether with partners, children, extended family or friends, were a source of strength for them. This strength had a positive effect on living with disability.

In this inquiry, there is also evidence that spiritual support offered a view that was both accepting of life’s challenges and comforting in times of difficulty - now and in the future. The importance of spiritual support was emphasised by those who have experienced adverse circumstances in their life. Whilst participants testified strongly that they were strengthened by their faith, they were also able to find meaning to their lives through the help received from support groups and other health professionals, including physiotherapists.

Communication and the importance of emotional sensitive health professionals featured strongly and, whilst not all of these experiences were encouraging or helpful most participants expressed satisfaction with the support they have received.

CHAPTER 10: RELATING TIME TO LIFE

10.0. Introduction

This chapter focuses on the temporal themes present in the everyday life world of people who experience disability. The main theme, *'relating time to life'*, in the context of this study, this refers to the relationship that has developed between the person living with physical disability and lived time. 'Lived time' or temporality is subjective time and could be interpreted as 'felt' time, similar to 'felt' space in the previous chapter. The French existentialist, Merleau-Ponty (1962) has given considerable thought to the importance of the body and its relation to time. 'Due to my body, there is a future and a past; a tomorrow when I will take my rest, and a yesterday when I prepared this writing and I was rather tired; due to my body I am in time' (Merleau-Ponty 1962). In this study I asked about 'lived time' and now explore the experience of time in relation to when the body fails. Here again, I asked participants about his or her personal life history and background and asked where they felt they were going. Questions such as these, according to van Manen provide insight and information about one's 'project in life' (van Manen 1990, p.104).

Merleau-Ponty (1962) wrote four decades ago in "*Phenomenology of Perception"* that lived time is our temporal way of being in the world. van Manen refers to it in a similar way when he writes 'that temporal dimensions of past, present, and future constitute the horizons of a person's temporal landscape (van Manen 1990, p. 104). In other words, how one experiences the present perspective of the world is tied to the past and the future. Lived time, in this sense, uncovers how people treat the past, present and future whilst showing their way of organising concepts of themselves (Charmaz (1991). To explore how people relate to time, how they think, do and feel about time becomes an 'implicit way of knowing and defining self' (Charmaz 1991, p.168).

Throughout the interviews, reference has continually been made to the crucial issue of time and the way it is managed. Time for the participants is a vital resource. The phenomenological interpretation from the data identified three temporal subthemes and the relationships among them, which together provide some explanations of what the participants mean by '*relating time to life'*. This theme is constructed around:

(1) **'Self in Time**' imparts the participants' views of the self in the past, present and the future - with the forced realisation that prospects for many are dim.

(2) **'One Day at a Time'** signifies the approach that participants adopt within everyday life. It is a life filled with uncertainty; not knowing quite what to expect, today, tomorrow, or in the future, yet by dividing life into days provides a way through which life becomes possible.

(3) **'Time Heals'** denotes the notion of hope and determination.

Each of these aspects of the temporal themes is shown in the shaded area in the model in Figure10.1.

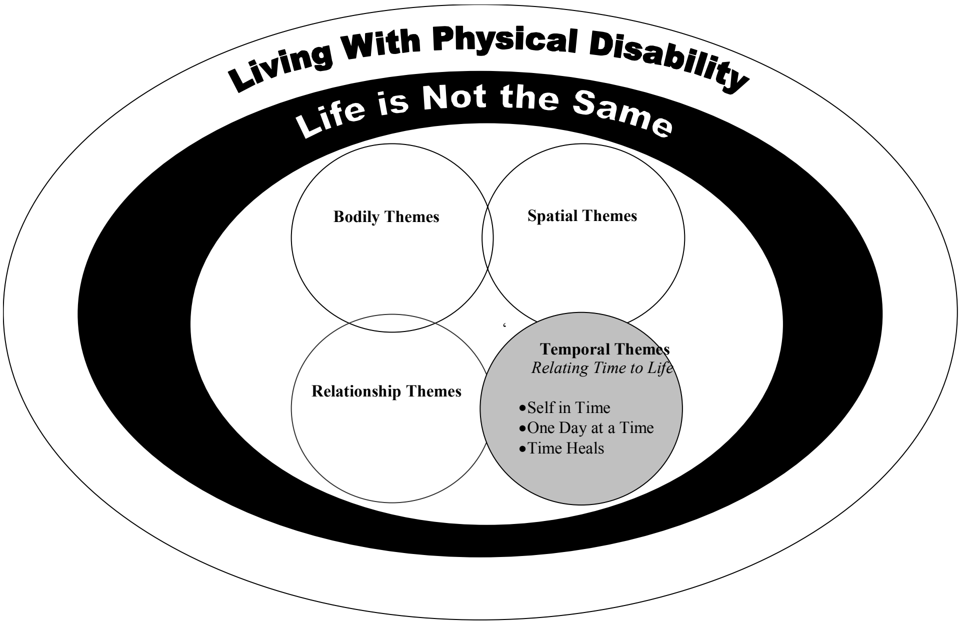

Figure 10.1 Temporal Themes - Relating Time to Life

10.1. Self in Time

During the interviews, participants talked about their lives and self in a distinct timeframe of ‘before [disease onset or accident] and after’. As Robert Murphy (1990) wrote in ‘*The Body Silent’*:

> My past is divided radically into two parts: pre-wheelchair and post-wheelchair. I think of the pre-illness years as a golden age and the recent period a time of bad auspices, gloomy auguries, and shattered expectations. My history is no longer smooth and linear, but bisected and polarised. My long-range future does not really exist. Time is running out. Most of my plans cover no more than a year. Beyond that, the future appears as a blank, impenetrable wall.

Murphy’s writings show that, although sense of self and time are barely separable, theories tend to tease these apart as if they are independent of each other. Guided by Bury (1982, 1988, 1991) and Charmaz (1991) this section will present interpretations that examine the self and time coupled to living with physical disability.

An injury or an illness can assault one’s taken-for-granted beliefs regarding the past, present, and future (Charmaz 1991) and calls for individuals to rethink time. Rethinking time for the participants in this study related to the making of strategic decisions concerning the selective allocation of their (often-limited) resources and to the doing of the tasks they would like to do. They were required to alter ‘time structure’ and to shift ‘time perspective’ (Charmaz 1991). ‘Time structure’ denotes how people ‘frame, organise and use time’ (Charmaz 1991, p.170), whilst ‘time perspective’ denotes ideas, beliefs, and views about the content, structure and experience of time (Charmaz 1991, p.170).

Many of the participants said that they had to narrow their territory, reduce their activities and relinquish goals, pursuits, and obligations. They did this unwillingly, reluctantly, certainly not voluntarily, but did so because their bodies forced them to it. Sandy had to revoke her previous allocation of time.

> I was always busy and never ran out of energy. Then the MS hit home. At first, I continued to be busy, but then realised how crazy that was. It was too hard.

Sandy's realisation 'it was too hard' prompted a shift in terms of time perspective. Conscious of the incongruence between time as it was played out in her daily organisation and everyday life, Sandy gradually realised that she had to curtail her perspective on life.

> After the diagnosis, I tried to live my life like before, but that wasn't living life… that was living hell. Now I organise each moment of every day of my life. I plan my periods of rest and my periods of activities. I never thought I could do it, but I have to … so that I don't spread myself too thin'.

The awareness of a trend, developed when time perspective is incompatible with time structure, is referred to as 'temporal incongruence' (Charmaz 1991, p.171). In contrast, temporal congruence is when change in time is accompanied by changed time perspective (Charmaz 1991). Troy's comment is another example of temporal congruence that shows an adjusted time perspective.

> For me it was a case of learning to live within my limitation … manage time properly and live life accordingly.

Because Sandy and Troy were both able to change time structure *and* time perspective, they both reached temporal congruence successfully. For Dorothy who spends all of her day in a chair, this was not so easy.

> In the morning, I do my crocheting, in the afternoon, I watch television. Then I just wait … and wait … and wait till nighttime comes around, so I can go to bed.

Dorothy tries to shorten the day by starting it as late as possible, breaks it into segments and ends it early. Whilst her time perspective has remained in the present, her time structure has led her to experience time as moving slowly.

Don, John, Karl and Glenn, who had lived very active lives before their disability onset, all continued to make serious attempts to create time structures that permitted them to be active and productive to a large extent. Each morning, after breakfast, each of these men would leave their house; they would go outside and begin the day with farm work. For Don it was a ride to the dairy; for John it was riding his tractor; for Glenn it was cleaning out the piggery; whilst each morning Karl would start his day by checking the heifers. However, over time, as the ability to handle workloads diminished, participants became aware of self and the time frames associated therein.

Although timeframes in participants' accounts were often mixed, for ease of clarity, I have presented distinctive timeframes: 'self in the past'; 'self in the present' and 'self in the future'.

10.1.1. Self in the Past

Participants would often locate themselves in events that formed the past as if to explain actions undertaken in the present. For Shane, the past appeared to serve as a time frame to contain certain events and to reflect on self.

> Like my dad, I come from a bushman's [sic] background. So when you're out in the bush, something happens to you, you haven't got anybody there to ask for help so you've got to be able to get help yourself. It's hard, but I've never minded it. It is all relying on self'.

Other participants also refer to the past as a time of hardship and tough experiences that may have helped to prepare for life with disability. Sandy, for example, believes that the premature death of her young father, six stillbirths within a period of ten years, a history of throat cancer and an unhappy marriage that ended in divorce have 'toughened' her up and made her better prepared for living with MS.

Not surprisingly, the past also referred to well-being and a familiar time that reverberated strength. As Don says:

> Oh yes, the good old days. I was a strong man. I could easily lift a bag of 50 kilo [grams] of wheat without any problems.

Many of the participants drew comparisons of past and present self and make the past self preferable. In the aftermath of his stroke Henry says:

> I was a foreman on the sawmill. I am proud to say that I was never sick. I was always working, never missed a day. That's why the stroke was so hard to take. I wish I could be like I once was.

Locating oneself in the past seemed, for Henry, to create a sense of familiarity with evoked memories of great vitality and vibrancy - with a strong body that managed incredibly hard work. For him, concepts of self in the past were based on action and productivity.

Others, such as Dorothy, feel trapped in an unfamiliar present with a self-concept that resides in a familiar past.

> I look at my hands now and think, "these hands have milked forty cows by hand, twice a day, for many years". Now, it is hard to take that the arthritis has made my hands so weak. I have lost all the strength I once had in these two hands, but that's the way it is'.

When Dorothy's disability presented with accumulated losses, the yearning for former strength-in-self became apparent. It is as (Charmaz 1991, p.233) suggested 'when the present marks a radical change, the past provides more than the security of familiarity, it offers a foundation for reconstructing an altered, if diminished, self-concept'.

Despite frequent reminiscing of the past and self, participants did not appear to situate themselves entirely in the past. They did not cling to the past, nor did they ruminate about lost chances. They were able to return to the present and accept their present status. Notwithstanding their isolation, dependency and frailty, talking about their past self brought them into the present. They valued their past and gained strength to handle their present circumstances. They tacitly came to form their present self-images from the past. Whilst the past may have represented strength and good health, it also signified hardship. Previous experiences of hardship had taught participants valuable skills, including that of recovery and survival. Others like Shane felt that they were able to draw upon strengths they had developed through years of rural living. They were strong and proficient and convinced that they owed this to rural living.

10.1.2. Self in the Present

At the outset of each interview, participants were asked to describe what it is like to live with a physical disability. I expected them to answer in terms of impairments, but they rarely did. Instead, they replied in terms of their self-concepts imbedded in a timeframe of the present.

> Well it is a rather boring existence. (Dorothy)
>
> It is slow-going and a nuisance as there are lots of things I can't do (Henry)

As a result of their physical impairment, Dorothy and Henry, like other participants, were more or less forced to live life at a slower pace. Not surprisingly, Dorothy used the word 'boring' to express her view, which may be explained in terms of the role that time has played in the shaping of her self and her present (see Chapter Five).

Situating one self in the present necessitates living in the present. Once the men and women in this study realised the permanency of their impaired bodies, they had to learn to deal with it - in the here and now. Some of the participants focused on the present by becoming involved in certain activities or interests. In doing so, they aimed to divert their attention to something more productive.

> First, I learned about the Internet, then I learned about shares. Now I do both each day. I find it a good distraction. (Don)

> I go to town to sell raffle tickets and do "para-awareness" (raising awareness about paraplegia). I enjoy talking to shopkeepers and advise them on how they could make their shop wheelchair-accessible. (Shane)

Others have developed hobbies to regain a feeling of accomplishment.

> I crochet dolls and coat hangers for charity. (Dorothy)
>
> I breed worms and joined a fishing club. (Henry)
>
> I love reading religious stuff. (John)
>
> I like to produce series of videos for people in wheelchairs. I am keen to show that it is possible to go camping, fishing and so on despite being in a wheelchair. (Shane)

Participants have found a multitude of ways to fill the here and now with a range of activities and this has made the present more meaningful and intense. Pursuing hobbies or interests also serves another purpose - that of avoidance of negative feelings of self.

> Knitting, concentrating on a pattern, learning the keyboard, those things stop you from sitting down and feeling sorry for yourself. (Sandy)

> I get out in the yard on my scooter and do as much as I can. I like a challenge, and while I have this sort of thing on my mind, I don't think of my dystrophy. (Don)

Another way of handling the present and self can be found in acceptance of their current status. Acceptance, according to Kübler-Ross (1969), represents a phase that is necessary to move onto with present everyday life. Kübler-Ross' work stresses the aspect of acceptance as a means of coming to terms with one's status despite or in spite of struggle and sorrow. Whilst Kübler-Ross' (1969) findings relate to death and dying, disability authors (see for example, Robinson et al. 1995) support her view.

The data analysis also showed that participants used the words 'struggle', 'sorrow' and 'anger' even if acceptance had occurred. This is evident in John's words when he describes how he came to terms with surrendering his driving licence.

> Time went on …I realised that driving was no longer an option. I cannot get used to it. I hate giving up driving [struggle]. It is terrible … like losing something so familiar [sorrow]. I am angry [anger] that through the stroke I had to part with it [car]. Anyhow, I have accepted it [acceptance] and now when we go to town, Jan drives via the back roads. This gives me the time to see what others [farming neighbours] are doing.

Accepting does not come easily, but when people come to accept, they feel they have more control over the present and more readily attach themselves to it.

Troy's experience of lived time is worth quoting, as he was able to define his interpretation of time and life in the present in a succinct way.

> Time is designed for new learning. Living with a disability gives you plenty of time to evaluate your situation. Over time, I learned to adapt activities. I asked myself, what can I do and what can't I do. If I couldn't do something, I would think around it. But if I had tried and still couldn't do it, I would just leave it. I was not prepared to waste time, because time will run out, it always does. The reality is that it is all about accepting what's happened, it is here to stay; there is no way back.

As noted in the previous chapter, acceptance, for the participants in this study, means an acknowledgment of the fact that they have made a decision to live with disability. Acceptance is also about the realisation that 'what has happened is here to stay'. Accepting also required a changed expectation of self and so each participant has thrown his or herself into selected pursuits that ranged from the grand to the mundane - from producing videos to crocheting coat hangers. In doing so, newfound activities became an important means to keep the self in the present and to move on to the future.

10.1.3. Self in the Future

> Imagine a man [sic] standing in the ocean, up to his waist, with a set of large waves coming in. He can see the waves and judge how big they are, how fast they are coming, and from what direction they will hit. With this knowledge, he can establish a method of coping with the force of the water that will keep him on his feet most of the time. Now imagine that man wearing a blindfold. He cannot see the waves, cannot tell how big they are, how fast they are coming, or from what direction they will hit. If the waves were regular, he could gain a sense of these things over time and adapt to cope with them. The problem is the waves are not regular; some will be large and some small

> and they may come from different directions. And so a technique that withstands one wave may not work for the next (Robinson et al. 1995, p. 139).

The analogy from Robinson et al. (1995) succinctly portrays one of the key aspects in the experience of living with disability: namely, the degree of uncertainty. As seen in the previous chapters, participants have experienced enforced realisation of a multitude of changes, losses, and restrictions. Over time, they acknowledged the lost past, recognised the inescapable present and accepted the unknowable future, all in the context of uncertainty. To live with disability is the epitome of this 'dealing with ocean wave' uncertainty. Like the man [sic] in the analogy (Robinson et al. 1995), who could not judge the waves, participants could not judge their future.

> I dread the future, I don't have a clue about what my body is going to do, neither has my doctor. We simply don't know enough and it's that simple. (Sandy)

Sandy's comment about the future is not atypical. Not a single participant had a clear idea of the future; in fact nobody is one hundred percent certain. This is not strange. No one, disabled or not, really knows what the future will hold. For those living with a disability however, the future is filled much more with uncertainty and unpredictability. This is evidenced by the questions participants frequently ask themselves 'will I stay the same?', 'will I get better?', or 'will I get worse?'. 'What will the future hold?'. These questions require an honest answer - which is not always easily available. Some participants, like Shane and Troy, feel assured that their condition is not likely to deteriorate. While paralysis is traumatic, once these men had returned home, they recognised that their disability did not constitute a threat to their future existence, as does cerebrovascular disease. Those with stroke (John, Karl and Henry) fear that the future may hold another stroke. Then there are those who keep in check with their bodies, note signs, and ponder whether they manifest further deterioration (Dorothy, Don, Glenn and Sandy).

Glenn is aware that his Parkinson's Disease is going to get worse; he just does not know how much worse. He is inclined to compare himself with the other members of the Parkinson's Support group with whom he meets once a month. He uses their status as an outcome measure. He says:

> Some of the people in the group are bad, I look at them and think that could be ahead of me, who knows.

The possibility of deterioration is a very real threat, particularly for those with neurological conditions. They remain alert and this consciousness adds a potentially threatening dimension to the experience of living with a disability. Henry gave the impression that they did not think about this a lot.

> Well the future is something that you have to put right out of your mind. At this point in time, all I think about is the two of us living here.

Thoughts about the future were not always easily disclosed. Sometimes long silences would precede a deep sigh. These discussions were not always easy; perhaps it was because participants did not always see themselves in the future. Other times, I acknowledged the difficulty that some of the men in particular had in talking about such a personal topic. In part this may have been a result of the sensitivity of the topic. It is also possible that some of the men in this study do not easily voice feelings and emotions, particularly in relation to sensitive information. As a sign of respect, I would never insist or exert pressure to continue the discussion of topics that created uneasiness.

The fear of drifting into total physical dependency often fed the uncertainty about the future. The dependency caused by impairment and its accompanying loss of physical ability brings fear of institutionalisation.

> I do sometimes think that, if my wife passed away, I'll have to go into a [nursing] home…that would be the worst. (John)

> I just hope that I don't end up in a nursing home and become absolutely useless. More importantly, I hope that, when the time comes to go [to die], I'll go [die] before Jan. I think about it, but try not to talk about it. (Don)

For many, such a change would simply represent an unacceptable degree of compromise with how they wish to live their life. Sandy stated that she would prefer to take the option of suicide rather than move into institutional care and join others who have lost their independence. Her account, an account concerning the uncertainty and unpredictability, together with the feelings and fears expressed about the future, conveys a fairly chilling and disturbing picture.

> If I went into a Nursing Home, I would die. Definitely! I will not live in it; I will kill myself … I know exactly what to take and I will do it because I will not go into a nursing home. I made my husband promise that he would never ever put me into a nursing home. As a nurse, I know what to take when the time comes. I have asked my husband "will you give it to me"? And he said "yes." He is an honest person and he'll do exactly what I want him to do.

De Vaus and Wolcott (1997, p.76) write that the emphasis on the nuclear family household and dependent children sometimes can lead to the assumptions that, as people grow older, they are 'dumped' into nursing homes or other institutional care. Whilst this picture is 'substantially inaccurate' (De Vaus and Wolcott 1997, p.76), many of the participants feared that this development is inevitable. At the time of the interviews, one participant (Dorothy) lived with her daughter, whilst the other participants lived with their spouses. The assistance they received embraced mobility, hygiene, meals, transport, and personal affairs.

Providing assistance for a person with limited physical ability can be satisfying as well stressful. Whilst it is clear that some of the participants displayed more confidence in the future, others expressed sadness about not having anything to look forward to by saying that it doesn't matter which way life goes; some day it will simply end. Although not everyone had clear future plans, many took the stance of continuing with life, just one day at a time; nothing more, nothing less.

10.2. One Day at a Time

Whilst the participants were not specifically asked about their views of self in relation to a lifelong time perspective, comments about their future often emerged during interviews, for example,

> I live one day at a time. I just do my work and see how things go. I am not thinking about retiring. (John)

Living this way, for John, means that he can pull his attention into the present and push the future further away. Shane - a strong lobbyist for disability issues - shares John's view.

> Life is too short to fill it with worry about the future. I care about the present much more than I care about the future. My motto is to take one day at the time.

Shane's present day is crammed with many activities that give him a purpose. He prioritises his life in such a manner as to enable him to find meaning. Hence, the focus is on getting the most out of each day.

Time is a vital, yet all too scarce, resource in the lives of the disabled (Williams 1993), yet paradoxically at the same time, the enforced limitations imposed by physical disability may mean there is too much time. It is in this sense that participants resort to re-ordering time and live 'one day at a time' (Charmaz 1991, p.178). In doing so, they hold future plans and ordinary pursuits in abeyance and thus tacitly acknowledge fragility. Furthermore, it helps to focus on a regime without being overcome by unmet expectations. It provides guidelines for functioning each day and confers some sense of control. By concentrating on the present, participants such as Don avoided or minimised thinking about further disability and death.

> Life today is far more interesting than life in the future. It certainly is more attractive. I prefer not to think about the future, too much doom and gloom.

The connection between ‘taking one day at a time’ and future with ‘doom and gloom’ meant that some of the participants had to relinquish certain goals. Dorothy’s goal once was to return to her own home as soon as she could walk again. Despite her early commitment to this vision, she realises now that such a goal will never be achieved. For Dorothy, a change in her time perspective constituted a radical shift. It meant changing her mindshift from looking forward to returning home to living one day at a time. Dorothy now lives her life on a day-to-day basis, a permanent accommodation to life.

Living with physical disability is plainly not easy. Yet, despite the uncertainty and the threat to the sense of self, many participants talked about having the opportunity to rejoice in their present life. Whether it is the appraisal of his or her situation that the body is not what it used to be, or the acceptance of reality, most of the participants seemed to adjust their priorities and values to correspond to their everyday life situations. Values and priorities are adjusted, as are attitudes on life in general.

> Since the stroke, I have come to appreciate the small things in life so much more; the smell of roses, the laughter of my grandchildren, the birds in the trees. Each morning when I wake up, I say to myself: “Henry, make every day count.”

The participants perceive life not in discrete categories which, when added together, equal quality, but in the interaction of everyday life situations. One element that forms the core of everyday life situations is the notion that 'time heals'.

10.3. Time Heals

Whether it is the re-ordering of time or the re-ordering of priorities or both, the notion that time heals added gains and not losses. The theme 'time heals' is made of two sub themes: (1) determination; and (2) hope. Although living with disability involved a certain amount of hard work, it appeared that, over time, with determination and hope, emotional pleasure and fulfilment could be attained despite overwhelming odds. Although ordeals are not behind them, some participants actually feel that they have a new possibility lying ahead of them. This is certainly the case for Henry who survived an endarterectomy after his stroke.

> After the stroke, I was sent to this hospital to have my [carotid] arteries stripped. It was a dangerous procedure and I could die. It didn't happen and I now feel that I have a second lease on life.

Similarly Troy stated:

> Whilst the accident has made my life more complicated, it also made it easier by forcing me to slow down. If I didn't have the accident, I probably would have died from a heart attack. I now focus much more on simple things, having a wine with my wife when she comes home from work or ringing my daughter to ask her how her day was. (Troy)

Both men have come to re-evaluate life and now savour the idea of having second prospects. Living with a disability tends to force individuals to 'eliminate the insignificant', and to 'find and savor the important and meaningful aspects of life' (Robinson et al. 1995, p. 146). Like Henry and Troy, other people in this study have also experienced a profound sense of temporal disruption: one in which time has to be completely and continually re-ordered which Strauss et al. (1984) terms 'temporal juggling'. Although temporal disruptions can add layers of disadvantage to the experience and challenge that living with disability on a daily basis posed, participants were determined to get on with life; expand the present and make a future possible. For them, determination turned into learning to adjust to diminished physical reserve, learning new ways of performing everyday tasks, and learning which tasks can - or can no longer - be done.

10.3.1. Determination

Participants' accounts often conveyed the sense of struggle which most were engaged in: namely, one of trying not to let such feelings drag them down still further. To combat such emotions, some of the individuals displayed great determination to get on with everyday life despite the challenging circumstances. Determination thus became a mindset when Shane tried not to let negative feelings get a hold or grip of him.

> I was not going to let this worry me … I got out of the spinal unit and I just never looked back … I haven't let it get me down. Determination has got me where I am today.
>
> and
>
> I am determined not to give up, I just steady down.

Like Shane, others also displayed a determination to get on with life. For many this was built on previous life experiences; some had battled droughts, others had battled floods or fires or other setbacks during their lives. Each time when they encountered such a disaster they were able to come back and contribute to the 'get on with life' mentality. They felt that those life experiences were helpful in their everyday life.

> I have lived a tough life with some hardship. My house has been flooded twice and burnt once. I was told to leave the place, but I was determined to stay there and rebuilt the house. And that is what I did.

> That is how I do things. I'm determined that this [stroke] is not going to get me. I am determined to make the best of it and just get on with life. (Karl)

Those who showed determination desire or expect their future selves to realise present potential, to expand understanding, and to fulfil their goals. This returns to my thesis statement: *that for people in this study living with disability is facilitated by a determination to move on with their lives, finding strength to do so from their rural environment, surrounded by loved ones and valuing time for its therapeutic worth.*

Determination, for the people in this study, has been a predominant feature that made it possible to find appreciation in everyday life. Whilst participants experience physical impairment, limited activity and restricted participation, many live a life that encourages prospect of a valued future; they are able to move on in hope.

10.3.2. Hope

'Hope is the spark of life' (Robinson et al. 1995, p.55) and 'without it no other life-enhancing action, thought or emotion is possible'. Hope embodies the sense that there is a possibility - no matter how remote - that things will somehow work out successfully.

> You never give up hope, any snippets on the news or science program about the sort of discovering the genes that unlock the pattern to grow arms and things like that. You think, well, possibly one day, they will use foetal cells. (Troy)

Troy is not the only participant who hoped for a cure. Glenn hopes that Michael J. Fox (a moviestar who disclosed publicly that he suffers Parkinson's Disease) may be able to use his celebrity status to generate more research funding for a cure. Shane made a similar comment when he discussed how the actor

‘Christopher Reeves’ who played the role of ‘Superman’ in movies, suffered a spinal cord injury following a fall from a horse. Shane expressed the hope that Reeves’ campaign for more funding into technology will benefit those with nerve damage.

Spiritual life played a most vital role in the area of hope for John.

> I am hoping for the coming of the Lord and when he comes back, I am putting all my faith in him. He will come before anything happens to my wife and I.

and for Henry:

> The whole business goes back to one thing … I think you’ve got to have a lot of faith in the good Lord and then he will look over you and he will help you to overcome problems.

Others expressed hope in relation to their future living situation. Don, for example, hoped to be spared undue suffering. He hopes that he will be adequately cared for by his wife until his death.

> I’m only hoping for one thing and that is that I die before my wife.

Don’s hope makes sense, considering his high dependency on his wife. He realised that he cannot live independently without her. The reality is that his sons cannot provide the care he requires and if Don survives his wife, his hope to remain in his valued environment may fade.

Hope provided the situation with some meaning from which the participants may gain strength to persevere in the face of fear. Moos and Schaefer (1984) consider hope as a significant emotion in relation to physical illness and emphasise that participants should never be left without hope ‘for when hope is absent fear may reign' (p.394). Accepting the participants' own interpretation, I have concluded that faith and hope played a potentially dynamic role in mastering a complex everyday life. Faith and hope seemed to alleviate fear and resistance to relinquishing independence; and fill the gaps between the present and the future.

10.4. Conclusion

All participants passed through a similar set of physical circumstances and situations, yet their experiences differ from one another and offer a varied insight into everyday life that may give valuable clues in understanding the phenomenon of living with a disability. In moving from one phase to the next, participants experienced a sense of progression, albeit it with some regret of leaving something behind: their former identity. This transition is not smooth and is compared to a struggle that is followed by an active decision to face reality and thus accept. By accepting and adjusting to time, participants are able to act in the present and foresee a future, whilst being submitted to a force that is beyond themselves. Resigning to the reality is not about 'giving in' or 'giving up'; rather it is a positive act, one that denotes strength, not weakness. The future, then, could be accepted only when participants were prepared to leave the old life behind them and disengage themselves from former familiar experiences. For some, disengagement was a liberating experience, and more easily accomplished by those with spiritual beliefs, as faith helped to give them inner strength. The task was always to balance hope and the future throughout personal crisis. Participants have much to fear: pain, suffering, mobility impairment, abandonment, social isolation, stigma, physical barriers, social barriers, uncertainty, dependency, deprivation, impending admission to a nursing home. These fears are balanced by hope - a hope for better … not worse. Whilst participants refrained from discussing detailed future prospects, they realised that the actual future is beyond anyone's control, although some control can be retained by hope and faith.

The next Chapter will provide a summary of the importance of this study to others living with disability, to the practice of physiotherapy and to other health professionals. Some recommendations for further research are included.

CHAPTER 11: CONCLUSIONS AND RECOMMENDATIONS

11.0. Introduction

Our understanding of disability has changed substantially over the past two decades. Revolutionary changes in medicine and technology now enable clinicians to understand and treat people with disabilities in ways undreamed of even a few years ago. However, arguably the most substantial change in the understanding of disability is not in the realm of clinical services, but in the growing body of research that finds that, while disability is universal, there is marked variation in how disability is interpreted. When this study commenced, there was an abundance of literature that based disability upon the assumption that the problems and difficulties disabled people experience are direct results of individual physical, sensory or intellectual impairments. This position is articulated most clearly in the medical model of disability. This model has led people to view disability in terms of disease process, abnormality, and personal tragedy. Clearly, the medical model with its individualistic approach has limitations for the way in which we provide care, as it is not broad enough to concern itself with disability from the disabled person's point of view - or the disabling effects of society itself. This model lies at the heart of clinical practice and, whilst it may be appropriate in the context of acute care, it does little to assist those attempting to make sense of their disability experience. Furthermore it may be difficult for health professionals, including physiotherapists, to consider changing their clinical practice, as their very existence is dependent on viewing disability in terms of the medical model, and the modalities which professionals have at their disposal serve to define and individualise problems.

This study returned to the person living with a physical disability and brought to the forefront their everyday life experiences in order to raise understanding and awareness of the meaning of disability. Literary descriptions of disability together with data and theoretical reflections have been incorporated to assist understanding of the phenomenon studied.

This chapter will consider the understandings that emerged from this study, by bringing together the wider meaning of disability and the prospective implications it might have for health professionals. A summary of conclusions and recommendations will be presented. The chapter concludes with the contribution to physiotherapy knowledge and recommendations for further research.

11.1. The Meaning of Physical Disability

The acquisition of disability is a serious assault on a person's health and well-being. Not only can disability sneak up slowly and attack a person's health; it can also rob a person of confidence and psychological well-being. Because disability can strike openly at the physical and emotional side of his or her being, a person can be left vulnerable, anxious, and insecure. People with a disability can overcome the physical loss of bodily function, but are defeated by the emotional 'loss of body'. Initially they feel shocked, depressed, and in despair; and imagine that life will never be the same again. Commonly they are bereft and are in a kind of mourning for their former selves. Following the state of shock and 'outcry' (Horowitz 1983) people mourn as they move through countless losses: loss of functional self, loss of independent self, loss of mobile self, loss of former self. A part of the physical body is lost and with that, a part of their life. Experience of the loss of a working life or the loss of a position on the farm is also considered to be a serious loss. Before the impact of disability, work, including farm work, was planned from a position of strength. Afterwards, there was a role reversal and mixed feelings emerged. In general, many people living with physical disability are concerned that they have lost their independence altogether; they feel useless and envisage that they will become burdens on others in society, most notably their families. Predictably, loss becomes the theme of his or her cognitive efforts (Seymour 1989) and there is a risk of becoming trapped in such despondency.

It is during these times that health professionals should be attentive and ascertain that men and women receive not only medical attention, but are given also emotional support. Good recovery will be jeopardised if this is ignored. People may sit and brood and become increasingly isolated. The unhappiness and inertia can become self-perpetuating; and people can slip into isolation with adverse effects on physical and psychological well-being.

Throughout the preceding Chapters, reference has been made to the four existentials. For the participants, living with a physical disability impacts on lived body, lived space, lived time and lived relationships. Second, living with a disability means finding strategies to manage the consequences associated with physical and emotional change.

A physical disability impacts on the level of mobility, defined by the WHO (1980) as ‘the individual’s ability to move about effectively in his [sic] surroundings’. The findings of the study showed that mobility was highly valued; it is an important element to independence of lifestyle. Losing upper or lower body mobility meant that an independent lifestyle was jeopardised in the home (through falls and through the requirement of help with ADLs) and in the environment outside the home. The latter includes such factors as restrictions in work, gardening, and negotiation of uneven surfaces. In wider community activity, participants experienced loss of independence when they had to relinquish their driver’s licence. Limited public transport access exacerbated the loss of independence. Inaccessibility of buildings or difficulty negotiating obstacles, kerbs, large crowds, and traversing different surfaces further restrict one’s lived space.

Social network and role changes can occur, including loss of social contacts due to mobility difficulties or sensory losses (AIHW 2000). All the participants relied on others to provide adequate and appropriate support - a reliance that potentially could jeopardise their relationship with others, particularly their spouses. Stigma and isolation, notably present in the lives of those who live with disability, leave extremely painful marks. The concern and ‘worry’ of being a burden creates sorrow and is ever-present.

The past is mourned; future goals and aspirations are destroyed; and ‘knowns’ about the present are challenged. The future is uninviting, as anxiety and despair mount in the face of unknown times of further physical decline, further dependency and further movement towards committal to a nursing home appear inevitable. Initially such portents are seen vaguely, later on they seem more clearly. Time drags on at a slow pace, with hours that are long and hard to fill; participants grieve for the past; yet tomorrow comes on so quickly.

Having a physical disability means a loss of the physical self, the vocational self, and the emotional self with the spirit of ‘independence’, ‘freedom’, and ‘control’. The self can never be the same again, as the impact of disability is permanent. It means, at times, experiencing varied feelings of fatigue and frustration, a sense of being locked into an unsatisfactory situation - in the circumstances of their lives and in their relationships with others. Experiences such as these are hurtful and damaging. **Thus I conclude that living with a physical disability means an assault on the lived body, lived space, lived time and lived relationship with others - with additional dimensions for those in a rural environment.**

However, out of the countless losses — loss of body parts, loss of embodied self, loss of self-image, loss of vocational self and loss of personal integrity, people, over time, began to draw some new valued meaning from the events. Self-concepts have become stained slightly, yet they are not disparaging at all. Hope and aspirations are not abandoned, but adjusted to some extent. Many are able to make transformational rearrangements (Seymour 1989) by incorporating physical disabilities into a ‘new and different, but for the person ongoing self-definition of health' (p. 109). Although the disturbances of bodily appearance, function and perception are quite inconsistent with the criteria a person would previously have used to evaluate his or her health, they come to terms, then accept and accommodate such inconsistencies. Although the physical disability persists, it is not an impossible barricade against the conception of a healthy self (Seymour 1989). How people will make a transformational rearrangement of self and adjust is difficult to predict. For people with a disability this means drawing from past experiences and knowledge and drawing from an understanding of his or her social context. The significance of understanding the social context returns us to Robinson et al. (1995) who argue that the roles of families, other social supports and the health care professionals are crucial in the sense-making process of people with a disability. **Thus I conclude that, whilst a person's concept of self becomes re-defined and most skills have to be re-mastered, over time feelings of competence and strength substitute the former sense of weakness and incompetence.**

This study showed that psychological recovery often accompanied physical recovery, despite instances whereby perpetuation of psychological symptoms remain - perhaps conditioned by the fact that full physical recovery is elusive. What is needed, first and foremost, is a redefinition of life (Bond, Coleman and Peace 1993; Robinson et al. 1995), beginning with the acceptance of physical limitation and the learning of new ways to achieve fulfilment. Many have learned to say 'yes' to help, and rediscover the quality of their relationships; many have grown closer to their spouse; all have come to revalue life. Their journey to find meaning led to enjoyable hobbies and other fulfilling activities. There is a need for homeostasis, with all body systems in balance and fully functional. Thus, when disability disturbed the balance, participants tended to develop a response that enabled them to find a balance between rest and work, and determine what they could and couldn't do. Their stoic attitude, combined with optimism and determination, is evident in the written interview scripts. Adaptational responses such as 'take one day at a time' and 'time heals' showed a sense of mastery. An attitude of determination 'I'll get through this' stimulates self-redefinition (Brooks and Matson 1987) and so, the participants begin to create a safe environment in and around the house and then simply get on with what they valued as a normal life.

To get on with life and find new valued meaning are critical elements, preceded by acceptance with an acknowledgment of essential permanent change (Charmaz 1991). From this acknowledgment comes the awareness of choices for applying acceptance to self. Next to the redefinition of self, this means shifting a negative mindset into a positive one.

Learning about the new self and new practical approaches to life in terms of time and energy means a comparison with others and an acknowledgement of 'how lucky I am'. There are others worse off. Pleasure is found in 'just little things'. A shift towards spirituality and lifestyle changes leads to intimacy - with an emphasis on finding social interaction which provides excellent opportunities to share and learn from others, further developing the participants fund of knowledge. With that, a formulation of strategies to combat the assault on the existential worlds begins. This complex active process within the person with a disability leads to developing strategies to contest the assault on the four existential worlds. Chapters Seven to Ten outline a broad range of strategies used to contest the assault on the existential life worlds. **Thus I conclude that, whilst the meaning of disability encompasses bodily, temporal, spatial and relationship changes, it also creates re-discovery of new capabilities and a re-interpretation of life.**

11.2. Implications for Physiotherapists

The way physiotherapists perceive disability is shaped by a multitude of factors including professional education, socialisation, and specialisation. The effect of this is often to produce a narrow perception of disability, which easily gives rise to conflict or ineffective communication with people with a disability (French 1994). People with a disability now demand that health professionals broaden their views on disability and start listening. Their 'expert' voices are instrumental in guiding our practice. Understanding that the successful work associated with a person with disability is dependent upon the recognition and meaning of its impact upon the individual will assist physiotherapists in their relationships with people living with disability. **Therefore I recommend that physiotherapists extend their viewpoint about disability beyond the 'disease-centred' medical model and expand their physiotherapeutic knowledge by paying attention to disability from a person-centred perspective.**

Whilst the following section will highlight important implications for the provision of physiotherapeutic care for people living with a physical disability and much of the discussion is directed towards physiotherapists specifically, it could relate to other health professionals as well. This study has demonstrated that a qualitative research approach has been an effective way of examining the meaning of disability. This has enabled me as a researcher to draw a holistic picture of disability. People noted that much of the disability impact does not relate merely to their physical bodies. Instead, disability is associated with social acceptance, a desire to stay in his or her own environment, and yearning to grow old in the midst of their loved ones. The results of this study show that there are gaps between such common expectations for most people and the reality for the people currently living with disability in rural areas.

Hence, the findings of this study imply that a more systematic policy at general level seems called for. One which extends far beyond medical care and involves a closer liaison with other service providers. Such interventions would aim to ensure that the general community, and services within it, accord the interests of people with disabilities, a place of importance and influence (Parsonson 1989). In practical terms, it means the following strategies: provide information, make available ongoing support and offer linkages to community resources for rural people with a disability. This should be initiated with the identification of appropriate supports for each person and his or her family, starting from the time of diagnosis. Emotional sensitivity is a vital aspect of any physical treatment.

The quality of good health care comes from the sensitivity of the health care professional. The provision of health care with emotional sensitivity should be a paramount consideration. The intention is not to focus only on issues that will provide immediate benefit, but to aid people in dealing with emotional and social consequences that will provide long-term benefit to the person. **I recommend that physiotherapists and other health care professionals who work with those who have a disability extend their perspective beyond the bounds of traditional clinical-based services and provide strategies with long-term benefits to make a meaningful difference in the lives of those they serve.**

It may appear that rural people with a disability manage quite well and need no assistance. Most disability management, however, takes place in and around the home, and consequently, a lot of the everyday life concerns faced by people living with disability and their families are invisible to health care providers. Indeed, the results of this study show that relatively few people were in frequent contact with primary care services. Further, no regular contact with secondary services was reported. Occasional contact with an Allied Health Professional had been available, although it tended to be episodic and there was no clear mechanism for re-establishing contact or monitoring progressive disabilities. After spending many hours with each participant, it appeared to me that many of the participants worried about their health. Their comments that locomotor problems increased their fear of falling - thus essentially forcing them to become more sedentary - is a concern. This finding showed a serious gap in the health service. Participants were not seeking social or health services input. Yet it is my firm belief that each person would have valued information about adaptations, equipment, living safely in the home, falls prevention and so on. Although health needs of people could be recognised by health professionals and service providers who are in a strong position to advise people with disabilities and refer to others if necessary, it did not appear to happen as often as might be possible. Health professionals, particularly physiotherapists, are in an excellent position to identify those who would benefit from rehabilitation. Since participants mentioned that they have annual checkups by their General Practitioner, **I recommend that yearly visits to General Practitioners be used as a means to refer those living with disability to a multi-disciplinary team in order to address each person's needs with as much breadth and depth as possible.**

Another result of this study showed that the relationship between disabled people and health professionals has not been easy. It is based on an unequal relationship - with the health professional holding most of the power. Traditionally, the health professional defined, planned, and delivered the health services, while the disabled person was a passive recipient with little if any opportunity to exert control. A shift in power relationships between health professionals and people with disabilities is needed so that they are in control of the decisions that affect their lives. It is crucial to take into consideration disabled people's experiences and their perceptions of the situation, together with that of the health professionals, to obtain a more realistic understanding of the total experience of living with disability. If people with disabilities were involved as partners in the planning, assessment, and decision-making process, they would have access to the same information that health professionals normally have access to. Such informed partnership of people with disabilities and health professionals would translate to jointly-developed, high-quality care plans in the early phase of the disability. These care plans would serve to inform families and rural health professionals, particularly the patient's General Practitioner, to ensure the best ongoing care. **I recommend the formation of a relationship reflecting shared care between health professionals and persons living with disability.**

The findings of this study suggest that the people interviewed were ill-equipped to deal with the exigencies facing them. Their potential vulnerability firstly related to work. The people in this study would have chosen not to end their working years, not out of concern for economic jeopardy, but because of the psychological effects of forsaking work. The second vulnerability relates to social supports. Until being struck by chronic disability, reciprocity, not dependency, dominated the relationships between participants and their families. Now dependency dominates and the fear of becoming too burdensome on informal carers is tremendous. Self-reliance, referred to in Chapter Eight, reinforces the belief that individuals and families are expected to take care of their own problems. If the de-institutionalisation of the long-term care system follows with health care reverting more to the home, the psychological and social impact on families and local communities will expand exponentially. **I recommend that physiotherapists and others, including health care professionals, policy makers and health planners, explore a multitude of scenarios that will enable each person with a disability to remain in their own home if that is their wish.**

The third vulnerability relates to health status and physical function. The people in this group are not prevalent users of the health care system - as yet! Although maintenance of independence was regarded as a top priority, there appears ‘passivity’ to restoration of function. That is, participants were not undertaking active exercise to maximise physical function. Without this, it is likely that the pattern of physical decline will continue. This ‘passivity’ in relation to physical function reflects poor advice - often from health professionals- that ‘nothing more can be done’. **I recommend that physiotherapists become proactive and advocate that people with disability receive rehabilitation services, if they so wish, to restore and/or maintain function.**

The final vulnerability relates to the future. The attitude of some health professionals, including physiotherapists, is that they often do not want to become involved with problems that may or may not arise in the future. This is reflected in a comment such as ‘go home and don’t think about it’. Many unhappy patient experiences began when a health professional uttered the infamous words ‘let’s wait and see’. The point is that this opportunity is actually a defining moment, as it may give rise to a successful (self) management of a lifelong condition. Pre-discussed plans, aimed at helping people to achieve a sense of mastery over future challenging situations and to gain a sense of personal control, is a useful process. The ultimate goal is to create enhanced feelings of competency, which may ease emotional distress. Future plans *can* be discussed; strategies *can* be put in place, even if the future is entirely uncertain. Having a 'blue print' of the future may encourage people to become active, rather than remain passive participants; more importantly it may boost the person's confidence in addressing problems as they arise in the future. **I recommend that physiotherapists and others health professionals turn their attention to identifying ways of preventing further health risks associated with disability by discussing future scenarios.**

Most people who face a permanent chronic condition, such as disability, experience many mental upsets such as anger, fear, grief, and depression. Traditional training of physiotherapists focuses largely on dealing with the 'physical' side. There is a trend emerging within physiotherapy training to incorporate curriculum on psychosocial issues - however it focuses merely on disability awareness, not necessary skill development in relation to providing support to the 'emotional' side. As a consequence, physiotherapists are generally not well equipped to recognise, understand, and assist people in relation to grief and loss issues. This is a disadvantage for the physiotherapist as they often do not possess in-depth knowledge of the work of counsellors, social workers or psychologists. Consequently, they may fail to recognise a situation in which referral to a psychologist or a counsellor may be beneficial. It also creates a disadvantage for the patient, as physiotherapists miss the opportunity to deal successfully with psychosocial issues. The situation is further disadvantaged if psychologists, counsellors and social workers are not available to deal with the psychosocial issues. Mental upsets associated with dealing with disability-caused loss pose major problems if these feelings remain unattended over a long time. Allowing for the fact that counsellors, social workers and psychologists are spread thinly across rural areas, physiotherapists need to be equipped with skills to ensure that holistic care is offered to anyone with a physical disability. Many physiotherapists would benefit by greater access to possibilities for counselling. By means of counselling skills, physiotherapists can explain carefully that the emotions people experience are a normal part of living with disability. I do not suggest that physiotherapists provide formal counselling; but **I recommend that the scope of physiotherapy widens to incorporate the use of counselling skills - relevant to the practice of physiotherapy- to reflect a holistic approach.**

Finally, as this study has revealed, concern about dependence and being a burden hinders the process of making sense of disability. Health care professionals, most notably physiotherapists, insist that 'independence' be generally considered to be something disabled people desire above all else. French (1993) argues that the notion of independence can be taken too far, restricting the lives of disabled people rather than enriching them. Henry's experience is recalled.

> I was made to struggle every morning to put my socks on which I eventually achieved some twenty minutes later. The physiotherapist in the hospital had said that "it is very important to be independent".

Important for whom is the question? Henry's wife had no dilemma in helping him with dressing. Henry, who dutifully put on the socks, admitted that he was exhausted for hours after dressing. Was it perhaps important for the physiotherapist who saw it as her responsibility to promote independence? Shearer (1981) and Sutherland (1981) argue that insistence on independence individualises disability rather than viewing it in social terms. The pressure to be independent can give rise to enormous inefficiency and stress. Using a medical model's viewpoint, it is the role of physiotherapists to help people to accept their physical limitation and then help them to adjust. It is thus expected that the *individual* should change. I believe that our responsibility extends further, namely, to change the environment to limit people's becoming dependent. Accessible buildings, removal of kerbs, cheap public transport to social outings are physical and social barriers in society which can clearly be addressed. If dependency is to gain a useful meaning - rather than being a negative label - it must be considered within both the local and national context. Much more attention needs to be given to the specific identification of barriers that inhibit independent function and then to the ameliorisation of these with effective measures. Physiotherapists can play an important role here in two ways (1) identify those factors that create functional disability and (2) seek environmental and therapeutic interventions to remediate these conditions. **I recommend that physiotherapists remove the negative connotation from the term 'dependency', that demands adjustment by the person with a disability, to a more positive one in which the environment is adjusted with effective social, medical, and financial support.**

11.3. Strengths and Limitations

Every research method has strengths and limitations. Several of these were the inevitable results of decisions about the design that were made early in the study; others form useful directions for future research.

A major strength of this study is the use of van Manen's hermeneutic phenomenology, which uses personal experience as a starting point. People's experiences are gathered 'allowing us to become more experienced ourselves' (van Manen 1990 p. 62). Lived experience material in this study was gathered and reflected upon by means of in-depth interviews with nine participants. The relationships formed with each person were intimate and trusting, adding a large degree of depth and richness to the data. The study group was small, and the quality of the information gathered was completely dependent upon forming trusting relationships with the participants. The words of Seidman (1991, p.103) summarise the strength of this type of research:

> In-depth interviewing's strength is that through it we can come to understand the detail of people's experience from their point of view. We can see how their individual experience interacts with powerful social and organisational forces that pervade the context in which they live and work, and we can discover the interconnections among people who live and work in a shared context.

Whilst it is not the type of study from which strong probabilistic generalisations can be made, and there is no wish (or need) to generalise any of the findings, it is possible that the views of the persons interviewed may correspond with views of other rural residents with disabilities in other rural locations.

People who are part of an ethnic or racial minority were absent in this study as no participants volunteered. The issues of ethnicity and race and how it impacts on everyday life are important and require further research and understanding.

The breadth of the study itself is also a limitation. For example, in the areas of disability and social relationships, it was frustrating not to have the scope to go into much more depth and interview the partners. The challenge now is to explore in separate detailed studies, some of the issues that this study has raised at a general level, such as the relationship between the spouse and the person with a physical disability.

Whilst inclusion and exclusion criteria have been devised, the study group encompassed a diverse combination of men and women. Gender differences and onset differences have been identified. It is possible that women have quite different experiences of disability compared with men, however this small sample could not confirm this. It is possible, perhaps probable, that people unable to accept their life with disability did not volunteer to participate in this study. It is also possible that the meaning of physical disability to people with rapid onset disability differs from those with slow onset disability experience, as the latter have the advantage of 'anticipation of events'. An age span existed among the participants. It is possible that older participants' experiences differ from those who are younger and who perhaps have more family and work responsibility and thus have more to lose. Clearly, further research is needed to explore the different issues for these groups of people, and explore how the experience of disability in these groups is affected by variables such gender, type of onset and age.

11.4. Summary of Conclusions and Recommendations

This study has revealed several findings that support the conclusions and recommendations made.

I conclude that a disability can involve countless losses, but such loss is not self-defining.

I conclude that disability engenders an assault on lived body, lived space, lived time, and relationship with others, but such assault is not self-defining.

I conclude that the positive experience of living with disability comes from a person's perceptions, rediscovery of new capability and a re-interpretation of the situation.

I conclude that, for people in this study, living with disability is facilitated by a determination to move on with their lives, finding support to do so from their rural environment, surrounded by loved ones, and valuing time for its therapeutic worth.

I therefore recommend that:

Physiotherapists extend their viewpoint about disability beyond the 'disease-centred' medical model and expand their physiotherapeutic knowledge by paying attention to disability from a person-centred perspective.

Yearly visits to General Practitioners be used to refer those living with disability to a multi-disciplinary team to identify health-care-related potential.

A relationship be formed to reflect shared care planning between health professionals and persons living with disability.

Physiotherapists and others, including health care professionals, policy makers and health planners, explore a multitude of scenarios that will enable each person with a disability to remain in their own home as long as possible, if that is their wish.

Physiotherapists become proactive and advocate that people with disability receive rehabilitation services, if they so wish, to restore and/or maintain function.

Physiotherapists and others health professionals turn their attention to identifying ways of preventing further health deterioration associated with physical dysfunction.

The scope of physiotherapy be widened to incorporate the use of counselling skills - relevant to the practice of physiotherapy- to reflect a holistic approach.

Health care professionals remove the negative connotation from the term ‘dependency’- that demands adjustment by the person - to a more positive one in which the environment is enriched with effective social, medical and financial support.

11.5. Recommendations for Further Research

This study has significantly contributed to the body of knowledge about the experience of living with a physical disability. However, as with any other study, it is not all-inclusive. This study indicates further research directions, which I pose as recommendations below.

- Having people with disabilities as equal partners in the research process, as well as discussing the results with them, which was achieved in this study, has been the ideal framework within which to conduct this study. However, qualitative methods alone do not generate demographic data or socioeconomic data, which could be beneficial for policy planners for determining the extent of disability and making comparisons across other rural communities. Future studies with rural disabled people, using combined qualitative and quantitative methodologies, are suggested.

- As this study has revealed, one set of major problems facing people with a disability is loneliness and/or deprived social relationships with others. I recommend that research attention be given to identifying ways that effectively break that isolation.

- The participants consisted of a small group of middle-aged and aged rural residents from white middle-class background. A further exploration using a larger group, including those from different socioeconomic and ethnic background, is warranted to determine what difference, in actuality, would be apparent in the experiences of people from different backgrounds.

- Given the grief associated with relinquishing a driver's licence, I recommend that transport options be explored.

- The final recommendation is concerned with interventions that can minimise the effects or reduce the impact of disability. I recommend the development of rural health education programs aimed at dealing with uncertainty, and promoting health and self-care in the face of chronic disability.

11.6. Conclusion

Interpretive research 'begins and ends with the biography and the self of the researcher' (Denzin 1994, p. 510). As a physiotherapist, who aims to provide a holistic care approach to people, I was seeking knowledge that would enrich my perceptiveness and contribute to my reflective understandings of the meaning and significance of people's everyday disability experience. The Greek philosopher, Plato, said that it is impossible to heal the body without knowing something about the soul or without knowing something about the nature of the whole (Gadamer 1994). 'Whole' refers to the unity of being itself; that is, to our place in the world and to the way we are in the world as this unity of being - which is at stake when humans concern themselves with illness and health (Gadamer 1994).

To explore the lived experience of physical disability and uncover how rural people make sense of their lives, van Manen’s hermeneutic phenomenology was used. This was inspired by my desire to draw knowledge from ‘experts’, which ultimately would inform health care practice - physiotherapy to be specific. There was the formal research question that guided the study ‘what is the experience of living with a physical disability in a rural setting and how do personal and situational influences shape the experience?

At the time the study commenced, I believed that being physically disabled was a personal tragedy. As a physiotherapist, my education and training reflected the dominant view of the medical model, which saw disability as a personal tragedy. In this model, the treatment strongly focuses on the ‘problem’, that is, the disease, the illness or the impairment, far less on the person. It was only by coming to know the people who actually live with disability that I began to understand that being physically disabled does not underpin the tragedy, rather it is their isolation, feelings of dependency and worry about an uncertain future. People with a disability have ordinary hopes, just like anybody else; they have hope for a positive future.

For the people in my study, the future is both certain and uncertain. They know what can happen - and fear that the most. They were limited in the things that they were able to do and to be; yet they would often find ways that would broaden their horizon.

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APPENDIX A

Information Sheet

Information Sheet

Experiences of Rural People Living With a Physical Disability

You are invited to participate in a research project about the experiences of people who have a physical disability as a result of an illness or injury. The aim of the project is to gain a better understanding of ways in which people manage their everyday lives and learn more about the overall impact on life.

Who will conduct the Research?

Ans Van Erp is a physiotherapist who has considerable experience working in the area of rehabilitation, as well as working with people in rural communities.

What is the Purpose of the project?

This study has been designed to find out 'what it means to live with physical disability' so an authentic picture can be built up from the perspective of the experiencing person.

This information will be put to practical use and can benefit people who have a physical disability. Although I cannot guarantee that you personally will gain any direct benefit from participating in this project, the information you give may help towards developing effective health care.

What is involved?

Should you agree to participate in this project, I will interview you in your own home. If you prefer, your carer or any other person may be present while being interviewed. I will ask questions such as :

- how do you feel about your situation ?
- what do you find easy or difficult ?
- how do you manage around the house?

The interview will last about one hour. It will not be difficult and it should not cause you any discomfort. You are free to not answer a question if you so choose.

Confidentiality

The project will be conducted in the strictest confidence and names will be changed in order to preserve anonymity. Final results of the research project may be published. Should you wish to, you may withdraw from the project at any time without affecting any services supplied by any organisation. No payment will be made to you for participating in this project.

APPENDIX B

Consent Form and Permission Slip

Consent Form

Experiences of Rural People Living with a Physical Disability

Investigator: Ansmarie Van Erp, Physiotherapist

1. The nature and purpose of the research project has been explained to me. I have read and I understand the Information Sheet and agree to take part in this project.

2. I understand that I may not directly benefit from taking part in the project.

3. I understand that, while information gained during the project may be published, I will not be identified, nor will any identifying data be published.

4. I understand that I can withdraw from the project at any stage and that this will not affect any treatment or services I am receiving.

5. I understand that I have the right to withdraw from the project at any time and - if I request it - information about me will destroyed and will not be used.

6. I have been given a copy of this consent form.

_____________________ _____________
(Name) (Date)

_____________________ _____________
(Witness) (Date)

I certify that I have explained the project to the participant and consider that he/she understands what is involved.

_____________________ _____________
(Researcher) (Date)

For any further information, please contact Ansmarie Van Erp on _______

Permission Slip

I, ____(Name)

____(Address)

____(Phone)

give permission to the **Rural Allied Health Team**

____

____

to give my name and phone number to Ansmarie Van Erp for further contact regarding the study.

______________________ ______________

(Name) (Date)

______________________ ______________

(Witness) (Date)

APPENDIX C

Example of a Transcript Page
(Thematic Analysis)

The following extract is taken from the first interview with Troy (TR1, ln 22-60) This example illustrates how ‘lived experience description’ (van Manen 1990, p.92) was analysed for recurrent phrases to uncover thematic aspects. Statements or phrases that seemed particularly essential or revealing were underlined and interpretive codes were written in the second colomn.

TR: I have a total loss of my arm. It is completely insensitive with constant pain. Initially I was protecting the arm, more or less favouring it and hoping that it would all come good.	Physical discomfort Hope
AV: What do you mean when you say ‘come good’.	
TR: Ah, well that my arm would get better and that I would be able to do everything with it again, just like before.	Hope Return to normal
AV: Was that your expectation?	
TR: Yes, I mean the doctor in the hospital had said that the damage to my arm was really bad, but when I asked how bad, he said that it would eventually improve. He said that he couldn’t do much for me at that time. He sent me home and told me to ‘wait and see’. I was annoyed, he wasn’t much help at all.	Communication Frustration
AV:What sort of help were you looking for?	
TR: Things like what to do when I got home. I had no strength or feeling in my right arm. Should I exercise it, how would I go about the pain. I was really down about the whole thing. When I was discharged from hospital, I didn’t get an appointment to see him again. My GP wouldn’t probably much of a help, I mean what if things didn’t work out? Jesus, my nerves of my arm were ripped off (pause).	Despair Depression Communication Fearful of future prospects
AV: What was it like to be having the use of one arm only?	
TR: I never realised how hard it was going to be. All the work that I do requires the use of two arms. I couldn’t use an axe. I had to modify my tools. And I can always ask my wife for help.Have you tried to shear a sheep with one arm? Well, I can tell you that it’s possible, but it took a long time. I had to start from scratch and work my way through till where I am today.	Effort Resourcefulness Family Support Time