

**WHEN MOBILITY DIFFICULTIES DO NOT DOMINATE:
A NARRATIVE-PASTORAL APPROACH**

by

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DISCLAIMER

I declare that: **WHEN MOBILITY DIFFICULTIES DO NOT DOMINATE: A NARRATIVE-PASTORAL APPROACH** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

Susan Eksteen:

Date:

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ABSTRACT

This qualitative study was interested in what needed to be heard from people who have difficulty in putting one foot in front of the other. The research aimed to expose some of the dominant discourses around mobility difficulties through exploring the relationship discourse has with power and to look for less talked about ways of resisting some of the harmful effects of dominant discourses. It also explored how participants used their spiritual beliefs to establish meaning in their mobility difficulty experiences. The exploring was done by employing discourse analysis as analysing tool to search for dominant and alternate meanings found in experiences of mobility difficulties. Theoretical frameworks included practical theology, pastoral care, narrative practices, postmodern ideas, discourse, social construction theory, deconstruction, qualitative research and action research. The researcher's own experience of mobility difficulties has been used as background where she was both an observer and participant.

KEY TERMS:

Action research, alternate meanings, discourse, discourse analysis, medical model, mobility difficulties, modernism, social constructions, spiritual beliefs, postmodern ideas, practical theology.

CHAPTER 1

Creating the skeleton of the research body

In this first chapter the ‘skeleton’ of the ‘research body’ is introduced. The literature study and the pilot conversations with the participants about their experiences of living with mobility difficulties have been woven into this chapter. This chapter further guides the reader through the research paradigm and process. The paradigms used were social construction theory, qualitative research and action research as well as discourse analysis, which is a process in investigating the social constructions of discourses. The participants and researcher have co-laboured throughout the research process. The background information provided relates to the personal story of the researcher in living with Mobility Difficulty¹ and the research interests regarding people living with such a condition.

1.1 BACKGROUND TO THE RESEARCH

As a background to this research project the researcher’s own experience of mobility difficulties will be mentioned as well as literature descriptions of mobility difficulties, resilience and disease and illness. Additionally the medical model’s view of illness will also be discussed. A framework for listening to illness stories will also be provided.

The researcher is both an observer as well as participant in this study and this is reflected in the language used. Therefore reference will be made to ‘I’ and ‘the researcher’ interchangeably.

1.1.1 Researcher’s own Experience and Mobility difficulties

I have walked with Mobility Difficulty all my life and became interested in what some of the practices might be that encouraged people to live well with such a condition. I was born with dislocated hips, have endured many operations and have a lasting limp, accompanied with osteoarthritis and pain. Visits to doctors and specialists have been a part of my routine and have left me with many questions concerning the meaning of Mobility Difficulty and its relationship to spiritual beliefs, medicine and living well.

¹ Mobility Difficulties will be externalized for the purposes of this study and is capitalized whenever it is externalized. See Chapter two 2.2.3.

I became curious to explore the stories of other people who live with mobility difficulties and started wondering what the helping professions and research community as well as other mobility difficulty sufferers and the people who care for them, might find helpful to hear about people who live well with such difficulties when these difficulties do not dominate.

My focus has been on visible, enduring (or pervasive) problems in putting one foot in front of the other, in other words problems in the actions of walking that I refer to as mobility difficulties.

Mobility difficulties include a wide range of health problems, for example: arthritis; osteoarthritis, rheumatoid-arthritis; musculo-skeletal disorders; multiple sclerosis; congenital abnormalities; amputations; gait disturbances, people experiencing minimal brain dysfunction, even disabled people in wheelchairs to name but a few. I was interested in practices that employ resilience with those who live with any of these forms of mobility difficulty. Additionally, I wanted to know how people living with mobility difficulties use their spiritual beliefs to establish meaning for their experiences.

1.1.2 Why Mobility Difficulties?

A research curiosity started to develop regarding whether there were certain factors or themes in difficulty sufferers' lives making some practices more resilient towards the effects of mobility difficulties than others, and what the church community and helping professions needed to hear about these factors or themes. I wanted to use my own experience to highlight sufferers' need for telling stories of the meaning of their unique experiences (spiritual and secular), concerning Mobility Difficulties.

Many people worldwide face coping with such difficulties from day to day, Taylor & Aspinwall (1990:7) said the prevalence of arthritis in its various forms afflicts 37 million Americans. Costa & VandenBos (1990:2) noted that the way people respond to illness was increasingly being researched. They went on to include questions about 'why some individuals were disabled by a condition when others were not, how personal and situational factors contributed to relapse and prevention, and how different individuals managed chronic illness and pain.'

Despite positive adaptive coping and attempts at making meaning of my experiences, there has been a dominant discourse in my life that tried to rob me of living well with Mobility Difficulty. When I reflected on this, I thought it could have something to do with an internalized state of

constantly comparing myself to people who walk with a perfect gait and to view myself as blemished and not 'up to standard'. This belief, or discourse, of me seeing my own Mobility Difficulty as a chronic state of being has, I think, in many ways tried to restrict me from alternate beliefs. It attempted, and sometimes succeeded! Thinking of oneself in 'impaired' terms can restrict you to being seen by yourself as impaired, inactive, unattractive and disfigured. Taylor and Aspinwall (1990) noted

the sequelae and impact of chronic illness can be pervasive, affecting physical and emotional well-being, work, sex and family life.... producing a variety of adverse outcomes, including pain and discomfort, fear and uncertainty about the future, and a variety of adverse emotional effects such as anxiety and depression.

(Taylor and Aspinwall 1990:22)

Parker and Wright (1997:377) also said 'beyond socioeconomic aspects arthritis also exacts a heavy psychological and emotional toll on many people who have one or more of the musculo-skeletal diseases.' Taylor and Aspinwall (1990:40) as well as Parker and Wright (1997:378) further said that 'research was necessary to understand the impact of chronic disease and its treatment on a patient's quality of life'. Parker and Wright (1997:378) said the manifestation of psychological and/or psychiatric problems in the arthrides was far from universal; they also quote De Vellis (1993) in this regard, having said: 'some people with arthritis cope extremely well and were able to avoid emotional and/or psychological problems'. Morse and Johnson (1991:1) quoted Conrad (1990) where he said: 'despite emerging bodies of literature the understanding of illness behaviour remains largely fragmented and in its infancy'.

Treloar (2002) further emphasises the necessity for gaining knowledge regarding meaning making in disabling experiences where she said:

People who effectively adapt to disability may choose to view difficulties associated with disability differently from those who do not share their experience. Accommodation to life's challenges may vary from the ideal situation or professional's recommendations. One cannot assume that professional perspectives for health and quality of life represent those of people affected by disability.

(Treloar 2002:601)

When experiences of mobility difficulties allow someone to view him/herself as different and devalued, this can create discourses of isolation, marginalisation and subjugation and opportunities for sharing of feelings associated with these events must be provided.

It is worth noting here that the voices of literature included in this study reflected Euro-American cultural perspectives. As researcher and participants live in South Africa, with its many cultural differences, it should be noted that they came from a Western cultural background and this is reflected in their stories. The difference between the available literature being Euro-American centred and the participants being South-African made this research even more important regarding hearing voices in this region of the world. A limitation, however, of this study is that it does not reflect the different population groups in the country and is restricted to a particular group of Afrikaans women living within a specific context. This was not deliberate, but the population group that responded to the research invitation happened to be female and white. This could have been avoided by inviting people from other population groups but due to the limited scope of this research it did not happen.

1.1.3 Describing Mobility Difficulties, Resilience, and Disease and Illness

1.1.3.1 Mobility Difficulties

For purposes of this research the researcher coined the term ‘mobility difficulty’ (MD/md) to refer to the difficulties people included in this study suffered from. ‘Mobility’ referred to actions of affected mobility of the lower limbs or legs, i.e. walking. Participants would thus have restrictions or difficulties in putting one foot in front of the other, due to the conditions mentioned under 1.1. Participants might have made use of aids such as crutches or wheelchairs, but the use of aids was not a qualification for participating in this research project.

Mobility difficulties affect the musculoskeletal system. Wikipedia (http://en.wikipedia.org/wiki/Musculoskeletal_disorders 2007) describes musculoskeletal disorders as affecting the body’s muscles, joints, tendons, ligaments and nerves. It can affect the back, neck, shoulders, upper limbs as well as the lower limbs. Wikipedia (<http://en.wikipedia.org/wiki/Arthritis> 2007) regards arthritis and osteoarthritis as a form of musculoskeletal disorder. ‘Arthritis and osteoarthritis is known as a degenerative joint disease and occurs following trauma to the joint, following infection of the joint or simply as a result of aging’ (wikipedia 2007). Hence, it may occur instantaneously due to an injury or the onset may be gradual as in osteoarthritis. Mobility difficulties can affect the very young as well as the old. Some forms of arthritis can be gender specific and could be found mainly in elderly woman, whereas other forms commonly affect young men. Arthritis patients are not systemically unwell, but pain, deformity, swelling, stiffness and limited movement characterize the difficulty. The

disadvantages of operations and immobilization interfere with quality of life, and could necessitate significant adaptations in lifestyle.

1.1.3.2 Resilience

Davidson, Seaton & Simpson (1994:846) explained resilience as the ability to bounce back, recoil or recover from a position elastically. Applying this to the participants, resilience could be seen as their ability to bounce back to their pre-illness state of well-being. Wessels (1999:6) quoted Collard, Eppenheimer and Saigin (1996) who defined resilience as ‘the ability to adapt to changing circumstances, even when the circumstances are discouraging and disruptive’.

Appelt (2002:100) quoted Hawley and de Haan (1996) who said ‘resilience’ was made up of several threads. It appeared in the face of hardship; it carried the property of buoyancy – the ability to bounce back and was associated with wellness rather than pathology. Appelt (2002) further referred to Walsh (1996) saying:

The paradox of ‘resilience’ is that some of our worst times can also be our best. Traumatic experiences sometimes make family relationships more precious and loving than they might otherwise have been. This kind of resilience does not imply bouncing back as if untouched, but involves a process of integrating the fullness of the experience into the fabric of individual and family identity and a way people go on to live their lives.

(Appelt 2002:100)

1.1.3.3 Disease and Illness

This research is situated at a time in history where mobility difficulties are very much defined in explicit medical terms. However, this research is working not so much with facts and figures as with meanings that people attach to experience. This is seen through a lens of postmodernism which is a time in history that challenges any one claim to reality or a meta-narrative. Stevenson (2005:285) says, ‘however postmodernism is defined, it’s a mistake to see it as a clean, sharp break from everything that has come before’. Keeping this in mind and speaking from a postmodern position, there are times when we are, in some ways, working with modern ideas. It has been the case in this research where the talk of the medical symptoms of the participants and the narrative nature of their stories overlap. Hence, terminology borrowed from the medical model has been used to describe the physical signs of the Mobility Difficulties while

participants' stories were viewed with postmodern narrative glasses. This overlap might have brought rich descriptions that helped in interpreting the text that emerged.

From the literature and subsequent research on mobility difficulty (Morse & Johnson 1991, Parker & Wright 1997, Taylor & Aspinwall 1990, Costa & VandenBos 1990), medical practitioners (coming from a Westernized model of medicine) and patients appeared to live in two different worlds and they have different interpretations of what illness means to them. The medical world would rather speak of illness as a disease and the patient would speak of it as 'illness-as-lived' (Toombs 1992:13). Toombs (1992) distinguishes between the medical doctor's and the patient's descriptions of illness:

The physician is trained to perceive illness essentially as a collection of physical signs and symptoms which define a particular disease state....the patient, however, focuses on a different reality. One does not 'see' one's own illness primarily as a disease process. Rather, one experiences it essentially in terms of its effects upon everyday life.... the scientific interpretation is quite distinct from other interpretations of 'reality'. In particular, it is quite different from the immediate experiencing of the 'reality' in the everyday world.

(Toombs 1992:11)

Frank (1991) expressed the difference between disease and illness as follows: ‘

If disease talk measures the body, illness talk tells of fear and frustration of being inside a body that is breaking down.... In illness talk there is no such thing as *the* body, only *my* body as I experience it.... What's happening to *me*? Not *it*, but *me*'.

(Frank 1991:12,13)

Morse and Johnson (1991:2), confirming the medical model's view of illness said pathology and the treatment thereof, rather than illness, has been the focus of medical practitioner's training for many years. The emphasis was on the cell and tissue rather than on the person.

1.1.4 The Medical Model and views of Illness

The medical model is very much linked to modernism's pursuit of finding 'the truth' in disabling conditions and viewing people in terms of their parts or as objects rather than seeing them as human beings behind those parts. Pathology is measured in objective, quantifiable terms focusing on parts of the body using a machine metaphor (Becvar & Becvar 2000:90) to describe

pathological health difficulties. This was also my experience during knee replacement surgery when I heard the doctor referring to me as “*the knee in bed three*”.

Disability scholars and advocates criticize a Western medical model that views disability as pathology in need of repair (Treloar 2002:595, Freedman & Combs 1996) and persons as unable to cope or participate effectively in self care related to the disabling condition. Centuries old beliefs involving stereotype, stigma and devaluation (Sue, Sue & Sue 1994:18) continue to influence public perceptions surrounding disability. Since Freud, within a Western medical model, the focus in pathology, psychodynamic theories, biologic psychiatry medicine and illness has been on mechanistic and controlling ways to treat the body and the mind (Truter 2002:20). People experience themselves as passive recipients of external wisdom. Freedman & Combs (1996:4) cites Hoffman (1981) who said: ‘The ill person is seen as a machine (subject) and the doctor or therapist is the (objective) repairperson’ who fixes the pathology. Dysfunction and pathology is seen as the focus of the medical model.

Contemporary perspectives (Treloar 2002:595, Truter 2002, Toombs 1992) suggest that the problem lies within the environment, rather than the person. Scholars like Engel (<http://www.ncbi.nlm.nih.gov/sites/entrez?cmd=Retrieve&db=pubmed&dopt=AbstractPlus2007>) suggested the ‘need for a new medical model’ that could give recognition to the socially constructed nature of disability as early as 1977 where he said

The dominant model of disease today is biomedical, and it leaves no room within this framework for the social, psychological, and behavioral dimensions of illness. A biopsychosocial model is proposed that provides a blueprint for research, a framework for teaching, and a design for action in the real world of health care.

(<http://www.ncbi.nlm.nih.gov/sites/entrez?cmd=Retrieve&db=pubmed&dopt=AbstractPlus2007>)

The biopsychosocial model (wikipedia 2007) is a general model or approach which posits that biological, psychological and social factors all play a significant role in human functioning in the context of disability and illness. This is in contrast to the traditional, reductionist medical model that suggests every disease process can be reduced or explained by an underlying process. The biopsychosocial paradigm is also a term for the concept of the mind-body connection, which addresses more philosophical arguments between biopsychosocial and medical models, rather

than their empirical exploration and clinical application
(<http://en.wikipedia.org/wiki/Biopsychosocial> 2007)

Despite these increased efforts to integrate holism into health, many health care professionals continue to practice from a pathology-based model of disability. This made me wonder whether having been reduced to parts and compared to a machine, how could people be viewed both as cells and tissue as well as human beings in need of making meaning of their illness experiences. I agree with Morse and Johnson (1991:2) when they said, 'Clearly, the reduction of persons to their physical parts does not ensure the humane and effective care of patients'.

This resonated with Felten (1993) who argued that:

it seems as if medicine is going more and more in the direction of high-tech for evaluation and diagnosis at a time when people are crying out for someone who cares for them, someone who will sit down and actually listen to them, and hear how their condition affects them in their social environment and with their family and friends. ...we should add more of a humane and personal touch to medicine.

(Felten 1993:218)

With this Felten didn't deny the value of expert medical knowledge, but sought an approach of care, listening and understanding of how illness affected patients.

Frank (1998) provides a framework for listening to and understanding how illness affects patients. Illness experiences can allow views of devaluation that can create discourses of isolation, marginalisation and subjugation, and opportunities for sharing of feelings associated with these events must be provided.

1.1.5 A Framework for Listening to Participant's Stories

Frank (1998: 197-212) offers a framework for listening to the stories of the 'deeply ill' where he suggests three narrative types in which 'the deeply ill' tell their stories: a restitution-, chaos- and quest narrative. These narratives intertwine, sometimes one narrative is foreground and the others background.

1.1.5.1 The Restitution Story

The narrative of illness that is currently preferred in western cultures tells of getting sick, suffering, being treated, and through treatment being restored to health (Frank 1998:200). These stories are expected and encouraged by most scientific versions of medical practice. Although this is so, in restitution stories, the clinicians – physicians, nurses, and therapists of all sorts – are the heroes, the active players in the illness story; they determine the cause of the action, and replace the ill person’s identity.

Since most illness conditions will end in the restoration of health, for most ill people the restitution story is adequate. Problems arise when the restitution narrative is no longer perceived as forthcoming. Because disease and dying is an enemy, the notion of talking about illness as a *meaningful experience* seems superfluous to biomedicine. Our culture is deficient in telling stories when the restitution narrative has run out. When people have no restitution story to tell, they can become isolated in their suffering, they cannot achieve distance from their pain. The deeply ill whose immediate reality does not include restitution, are further marginalised. ‘Those who have no story that society judges worth telling feel they have no place in society’ (Frank 1998:200).

1.1.5.2 The Chaos Story

According to Frank (1998:201) chaos stories are marked by increased disability and unremitting pain. Physicians don’t understand what is wrong or are unable to treat it successfully. Medical problems proliferate into social problems, e.g. job and income loss and people cannot fulfil responsibilities. Chaos stories elicit responses in listeners such as feeling sucked into a whirlpool of problem stories and they only want to get away from it. Chaos stories reflect life lived at the bottom of an ‘illness problem funnel’. Our western culture fears the chaos story and the multiplication of troubles as the illness symptoms increase. The chaos narrative tells of how awful life can get in serious illness. In hearing the chaos story people feel overwhelmed by the need to do something.

Frank (1998:202) says the first thing someone in the chaos story needs is someone who will ‘just listen’ without attempting to change anything. Too quick offers of help may show the listeners’ own dis-ease with what is being told; compassion means to literally *suffer with* the other. A

challenge then for our society is how to honour the suffering that the chaos story implies, without accepting the lack of care and pathologising that perpetuate this suffering.

1.1.5.3 The Quest Story

According to Frank (1998:203), quest stories are being told when the teller claims new qualities of self and believes illness has been responsible for these changes. Illness is lived as a condition from which something can be learned and where meaning can be made; where the illness experience can lead to new insights. Although suffering has meaning, in quest stories the chaos of illness is still recognized and respected. Finding meaning does not imply that there is something enabling rather than disabling in illness experiences. In making meaning you become a witness to your own suffering; and in being a witness you can authenticate that suffering.

Listeners find it hard to listen to quest stories because they want to believe in a restitution story; that every breakdown can be fixed, particularly within western discursive practices and beliefs. Physicians and patients alike reinforce each other's commitment to restitution as the only speakable eventuality. Quest stories carry the message that the restitution story might one day prove inadequate to what experience might have in store for many of us. Because physicians prefer to concentrate on cure and do not routinely find meaning in illness, they are often not disposed to listen to patient's attempts to reconstruct selves beyond restitution. Quest stories are about being forced to accept life unconditionally, a life that the previously healthy self would have considered unacceptable. In this, perhaps, those telling quest stories can show the healthy how they too could be living.

Weingarten (2002:45) might add to the above framework where she describes different witnessing positions in which a teller of illness stories can find themselves. These positions are generated when an individual witnessed with or without awareness. In such circumstances the witness is in an empowered or disempowered situation in relation to that which is being witnessed. The first position in which a witness can find herself in is an unaware and disempowered position; second you can find yourself aware but disempowered; then you can be empowered but unaware; and fourth you can witness your own story by being an empowered and aware witness.

My personal journey was from an aware but disempowered witness of my own condition to an aware and empowered position where I became the 'landlady' dictating the terms of my Mobility Difficulty.

This dissertation reports on the findings of a study of persons affected by mobility difficulties and it seeks out meanings - within a qualitative framework - that enable people to live well with illness and disability as they 'quest' to secure alternate meanings within their lived experiences. This brings an expectation that within this study ways can be found to include sufferers' stories rather than exclude them from the medical, pastoral and therapeutic fields. The study further explored how participants used their spiritual beliefs to establish meaning in their mobility difficulty experiences. This meaning making will be viewed through the paradigms of practical theology and pastoral care that are the disciplines under which this research project is being conducted.

1.2 PRACTICAL THEOLOGY

The South African context - particularly among the Afrikaans-speaking, Dutch Reformed population, which was the population group that this research was working with - had a long walk with religion and faith traditions. These traditions have been influenced by Reformed and Evangelical theology.

Practical theology was historically concerned with preparing clergy for the tasks of ministry; today practical theology's tasks have moved to a reflection on the practical character of theology as a whole. It is concerned with actions performed in the service of the gospel, in other words the encounter between man and God; it takes the practical situation seriously. For a discussion on practical theology see paragraphs 2.2 and 2.3 on pages 37 - 43.

1.2.1 Practical Theology's Relevance to the study

The focus in this study was not so much on the scientific value or 'the truth' of faith systems. The focus was rather on the effects and meanings of these knowledges, truths and beliefs on people in real life. In other words this research focused on the effects of discourse in participants' lives as suggested by Phillips and Hardy (2002) and discussed on page 55.

A question that was important in this research regarded what we needed to hear about the stories of the participants. Such a question became relevant in this field of enquiry; on the understanding, that practical theology is concerned with the correlation between God and man and how it gets acted out. This question also resonated with Furet (1974) cited by Heyns & Pieterse (1990:6), where he asked, 'What do we need to hear about the "encounter between God and humanity"?' This made me curious about the role this encounter has to play in the resilient stories people had to tell around Mobility Difficulty. Rossouw (1993) said the following regarding those on the receiving side of expert knowledge:

... those with expert knowledge are not the only ones to whom one should listen when decisions are made. Those who are affected by such decisions also have a valuable and indispensable contribution to make. ... Expertise must be enriched and informed by the experience of those on the receiving side of expert opinion.
(Rossouw 1993:902)

In congruence with the third aim (as will be discussed in paragraph 1.6 on page 23) of how participants use their spiritual beliefs to establish meaning in their illness experiences, communication on a spiritual level was explored and talk about participants' personal G/god and the meaning of their faith practices, crises and struggles were voiced. Treloar (2002: 596) said, 'little is known about how people use spiritual beliefs to establish meaning for and respond to life with disability. Even less is known about how people with a particular set of shared spiritual beliefs make meaning for lived experience with disability'. Treloar (2002) further said 'despite efforts to integrate holism into health care, many helping professions ignore spiritual issues surrounding disability'. Eiesland (1994), confirms this where she, inter alia, criticizes the church for its 'failure to provide clear or adequate teaching that address disability and associated issues'.

As thinking, feeling, spiritual beings, humans seek to understand the reason and purpose for disability (Treloar 2002:595). Spiritual questions could include private intrapersonal conversations with a personal G/god and bring into the open certain struggles of faith, like 'why me'? 'What did I do to deserve this?' 'How can a good God allow this to occur?' As a variety of religious and non-religious coping strategies may be utilized, the researcher was curious as to what might be learned if talk about G/god and the faith crises and struggles that we have, can come to an awareness in the interpersonal conversations around Mobility Difficulties. Through understanding faith within a context of the polarity between G/god and man, faith and not faith, this study engages with a more modernist perspective of a G/god who is 'out there'. This is

pertinent in this study as the faith community that this works with makes meaning of G/god in this way.

By listening to the stories on experiences of mobility difficulty as well as spiritual and faith issues, the participant's faith in God can be transformed as he/she reveals him-/herself in his/her relationship to human beings in their specific circumstances. Practical theology further encourages the practitioner/researcher to explain and translate his/her own interpretations and to critically reflect on the results found in the research project.

1.3 PASTORAL CARE

This research report was further written within the specialization field of pastoral care. Pastoral care presupposes a faith conviction as the starting point and a faith community as one of the contexts from which to do theology or from where counselling is offered.

The pastoral caregiver can be viewed as a representative of the Christian story and its tradition (Gerkin 1991:11). In a pastoral therapeutic dialogue, theological traditions can function as a 'participant in a dialogue' (Botha quoted by Grobbelaar 2001:175). This means that the story of God becomes a conversational partner in the bigger story of faith. Matching the third aim (1.6) the 'story of God' can be used as conversational partner in how participants use their spiritual beliefs to establish meaning in mobility difficulties, and in their responses to the challenges of a life with Mobility Difficulties.

With the growth of the social sciences, practical theologians have been encouraged by some of the insights offered by these fields of study; the work of pastoral care and counselling was therefore influenced by psychology and social work. Literature in the social sciences focused on matters of diagnosing and ways of providing psychologically informed care, it did not focus on issues of the theological reflection. As time moved on specialization in pastoral care fields became established.

Gerkin, (1991) in his narrative hermeneutic approach to pastoral care argues that experiences are made meaningful through the stories that we tell of our experiences. These stories can also include a relationship with God's story as it is acted out through metaphors found in the Bible.

In this way it links with Frank's (1998) description of a quest or a journey. The Bible has traditionally played this role as the major sacred text of the West. Interpreting and reflecting on these stories are important practices in pastoral care. During pastoral care encounters, the story of God, the stories of the counsellor and counselee should be interpreted through the contexts of language and social symbol. From this alternative life generating stories can emerge. Pastoral workers must be prepared to reflect on normative issues in the ordinary human language of relationship, image, metaphor and story.

Congruent with the participatory approach to pastoral care, this research project's focus was on the *doing* of pastoral care and to care *with* and not *for* the participants. Kotzé & Kotzé (2001:8) said when the pastoral caregiver participated *with* the care receiver to negotiate 'alternative ways of being and doing'; they could challenge oppressive and subjugating discourses. This allowed for 'negotiating ways of living in an ethical and ecological accountable way'. This resonated with Frank (1991) who said nobody could be allowed to categorize an ill person; rather we have the opportunity to understand his or her unique experiences. 'When the caregiver communicates to the ill person that she cares about uniqueness, she makes the person's life meaningful' (Frank 1991:48).

The curiosities as to how participants used their spiritual beliefs to establish meaning in their mobility difficulty experiences and how they responded to the challenges of their lived experience, led me to ask preliminary questions to two people behind the conditions of Mobility Difficulties. I undertook a pilot study interviewing two people with visible and enduring difficulties in their actions of walking. This became the pilot study for the research.

1.4 PILOT STUDY

In order to clarify and develop a research question around Mobility Difficulties the researcher conducted an informal pilot study in which two people have been 'interviewed'. A lady from the researcher's church cell group who walked with difficulty was asked to participate in a conversation regarding her mobility difficulty. She agreed. At the conclusion of the conversation her husband overheard me asking whether she knew anyone else whom the researcher could talk to who has similar mobility difficulties. He mentioned a man at the cripple

care association where he does voluntary work who, he thought, might also be willing to participate. The man was contacted and agreed to a conversation.

The lady was an elderly woman with visible difficulties in her walking actions due to a viral infection (similar to the polio virus), which she contracted during her first pregnancy 42 years ago. The man working at the cripple care association was thirty years old. He also had visible and enduring difficulties with walking, but his condition is due to a fall on his head from the first storey of an apartment building when he was one and a half years old. He suffers from cerebral palsy.

The purpose of the pilot study was to clarify a research question. 'Rough sketches' of the research curiosities needed clarity. The influence of mobility difficulties and their effect on body image and identity, experiences of medical personnel, preferred care from significant others and issues of spirituality regarding disability, needed exploring. It was interesting that although those were the areas that were tentatively enquired about, both participants spontaneously offered information on the subjects without being asked directly.

The pilot participants were firstly questioned on how their condition originated. They were also asked how the condition affected their view of themselves or self-esteem, as well as how it affected their body image. Further enquiries related to their experience of the medical personnel who treated them and also matters and difficulties regarding their family's involvement, or the lack thereof. The conversations also included matters on spirituality. The participants spontaneously introduced these matters when they were questioned on how they managed to live so well with the mobility difficulty and when asked what their message would be to a person who was a newcomer to the condition of Mobility Difficulty.

What also emerged from the conversations in the pilot study and in the literature (Taylor & Aspinwall; 1990 Parker & Wright 1997), were discourses different to the one that claims mobility difficulty to be restricting a person to functional impairment, inactivity and disfigurement, as I had believed it to be. These discourses spoke of such resilience in the lives of people living with mobility difficulty that the researcher had at the onset of this study wished to find. Costa & VandenBos (1990:2) said in this regard, 'research increasingly concerns itself

with questions such as why some individuals were disabled by a condition when others were not’.

1.5 RESEARCH QUESTION

The search for a meaningful question related to what it might mean to live well with Mobility Difficulty, and listening to the two people who partook in the pilot study, helped to formulate a question around the subjugated discourses and voices that talk of living well.

The research question then is:

What do we need to hear from people living with Mobility Difficulty when the Difficulty does not dominate their lives?

The importance of this question for the research is two-fold. Firstly, it implies that the participants and the researcher would ascertain the meaning of mobility difficulties regarding body image, self-esteem, medical relations and relations with family members as well as spiritual matters, and what it means to them to live well with it. I, as researcher, am aware that I could have assumed that they were living well with it, but it might be very different and they might struggle to come to terms with their difficulty.

Secondly, it is important to give the participants a voice through the telling of their stories, so that they could be heard and taken notice of. This works with an assumption in narrative therapy that life was multi-storied (Morgan 2000) and alternate stories await an audience in order to be brought to life. Regarding this, Weingarten (2001) writes:

The ill person who turns illness into a story transforms fate into experience, the disease that sets the body apart from others becomes, in the story, the common bond of suffering that joins bodies in their shared vulnerability.

(Weingarten 2001:120)

Thinking about stories’ ability to ‘transform fate into experience’, curiosities developed regarding how and if resilience could be co-constructed between the participants and researcher by exploring participants’ skills and knowledges about their resilience. Appelt (2002:100) reported that Engeland, Carlson and Sroufe (1993) proposed that the capacity for resilience

developed over time in the context of environmental support. The research was aimed at exploring the skills and practices of resilience, which could be expressed in the researcher-participant relationship, and how these were reflected in personal values, goals and dreams. 'Resilience' then becomes those 'day-to-day experiences that fit with self-care rather than self-abuse' (Appelt 2002:100). The counterplot of 'survival, resilience, protest and resistance' becomes more clearly articulated and 'thickened' and people can 'identify preferred accounts of their wants, tastes, desires, purposes, goals, hopes and so on' (White 1995:95).

1.6 RESEARCH AIMS

The first aim around mobility difficulty was to expose some of the dominant discourses as well as subjugated discourses. In other words, the research interest lies in the less talked about ways of resisting some of the harmful effects of dominant discourses in mobility difficulty sufferers' lives. An attempt was made to do the exposing through exploring some of Foucault's (Flaskas & Humphreys 1993) work on discourse and the relationship that dominant discourse has with power.

The second aim was to challenge some of the socially constructed discourses around mobility difficulty.

Thirdly, the aim was to explore how participants use their spiritual beliefs to establish meaning in mobility difficulties and how this could contribute to the ongoing conversations within the helping professions as well as religious institutions, around pastoral care with people suffering from mobility difficulties.

1.7 RESEARCH PROCESS

This part of the research concerns the study's design elements and methods of data gathering and analysis. It is where the worlds of the participants were entered and where the relevant conversations started.

Design elements in qualitative research are usually crafted during the course of the study. Rubin & Rubin (1995), cited in Mouton (2001), explained this as follows:

You cannot plan the entire design for a qualitative project in advance, because the design changes as you learn from the interviewing. But you can begin the work with a rough and tentative design, talk with potential interviewees, sort out initial ideas, refocus the research, and decide with whom else to talk and about what.

(Mouton 2001:195)

1.7.1 Selection of Participants

Five participants were recruited to take part in the research project. All of the participants were white females, with a high school or higher education. They lived in middle economic neighbourhoods in a metropolitan area in South Africa. Three of the participants reacted positively to an invitation placed in three local churches' announcement leaflets. The invitational leaflet assumed that Christians would respond as it was distributed in the Dutch Reformed Church. The fourth participant was recruited through a spontaneous conversation that went in the direction of her health difficulties. A family member referred a fifth participant after she had injured her knee.

The criteria for participation have been set out in 1.1.1. The focus has been on visible, enduring (or pervasive) problems in putting one foot in front of the other. As mentioned, mobility difficulties included a wide range of musculoskeletal problems ranging from arthritis to people in wheelchairs.

Although gender and cultural issues did not play a role in the selection of the participants it is worthy to note that only women responded to the invitations. While it is possible for women and men to use such research services, it is also probable that emotional matters concerning illness differ depending on gender. Although it is beyond the scope of this study to elaborate on gender issues, a short remark on gender issues will suffice. Altschuler and Dale (1999:26) refer to studies done by Bequaert Holmes and Purdey (1992), as well as Altshuler (1993) in this regard. They say:

The incapacity and vulnerability of being ill does not carry the same implication for masculine and feminine identity, and there are indications that the gender of the patient influences the responses evoked in others.

(Altshuler & Dale 1999:26)

The age spectrum was not a criterion for participation although with the people who partook the ages ranged from twenty-three to seventy-two years.

1.7.2 Data Collection Methods and Techniques

Preference was given to calling the meetings with the participants 'conversations' rather than interviews. In calling it a conversation it created more of a two-way communication than an interview, which might have implied that the researcher was merely extracting information from participants. A conversational style of communicating, rather than interviewing, gave participants more freedom of choice in what they preferred to share regarding their stories. It allowed participants to tell only that which they were comfortable with telling, because their stories could have been of a sensitive nature, and I as the researcher did not want to exploit such sensitivities.

Confirmation of participation was followed up by a letter of consent (Appendix 1) that allowed the use of the conversation to be audio taped by the researcher for research purposes. Copies of an information sheet with the aims of the study as well as the letter of consent for participating in the research were given to each participant; see (Appendixes 1 and 2).

After receiving the written consent from each participant, the conversations began and were audio-taped. These conversations were conducted using a narrative form of interviewing in which the problem was the problem, rather than the person being the problem (see the discussion on the aspects of externalization by Freedman and Combs (1996) on page 50). In conducting the conversations I let myself be informed by a 'not knowing position' (Anderson & Goolishian 1992). Through this way of working there were no predetermined sets of questions, but it was important to elicit 'shades of meaning' (Rubin & Rubin cited in Mouton 2001: 197), rather than zooming in on detailed questions. The questions were asked in relation to the participants' words that emerged in the conversations. In this way the research developed in directions the researcher was not fully in control of.

The audiotapes were available to the participants and supervisor. The conversations have been transcribed verbatim. A discourse analysis as suggested by Phillips and Hardy (2002) and discussed on page 54 and chapter 3, has been conducted on the transcribed texts where the researcher sought to expose the subjugating and dominant discourses that participants might have

regarding their Mobility Difficulties. The research interest also lay in the less talked about ways of resisting some of the harmful effects of dominant discourses in mobility difficulty sufferers' lives.

After participants' discourses had been analysed a letter, as summary, was written to each participant on the discourses found. This was where the researcher's voice and analysis became privileged in that it was the researcher that selected the texts that were included. The letters were, however, taken back to each participant for suggestions, corrections, feedback and comments, in order to represent the participants in a way that they would choose to be heard. However, considering the researcher's position of power within the research, this silences in many ways that which can and cannot be talked about. For this purpose a fill-out form entitled *Feedback from Participants* (see Appendix 3) was supplied. The form also allowed space for giving consent that the letter may be used in this research project.

If, in the conversations the need for therapy arose, participants were invited to an additional therapeutic conversation. This is in line with an ethical consideration that people are not taken advantage of for the purpose of research. Discussion of this however, falls outside the scope of this research.

1.7.3 Data Analysis and Discourse Analysis

Fieldwork culminated in the analysis and interpretation of participants' qualitative transcripts. Analysis involved 'breaking up' the data into manageable themes, patterns, trends and relationships. The aim of data analysis was to understand the elements of the data and to see whether themes, patterns or trends could be identified or isolated (Mouton 2001:108).

Discourse can be broadly defined or described as our social reality that we experience as solid and real. Discourse has the ability to produce our reality, our version of our social worlds and the different descriptions that accompany these realities. Discourse can also be described as that which holds our social worlds together. Discourse is expressed through language. Phillips & Hardy (2002:11) says 'Language is much more than a simple reflection of reality – it is constitutive of social reality.'

Phillips and Hardy (2002) further say that the things that make up our social worlds appear out of discourse.

Our talk and what we are are one and the same. We do not believe that individuals have the luxury of choosing their truth and their reality. We think our experience is largely written for us by the multitude of conflicting discourses of which we are a part. Our ability to act is strategically limited by the discourses that accompany our intervention and the complex processes of social construction that precede it.

(Phillips & Hardy 2002:2)

The transcribed texts have been analyzed using a process of discourse analysis. Mouton (2001:168) says 'Discourse analysis aims to study the meaning of words (but these words are within larger 'chunks' of text such as conversations) by interpreting and making sense of 'chunks' of discourse. Discourse analysis is sometimes defined as analysis of language 'beyond the sentence' (Mouton 2001:168). According to Breakwell Hammond & Fife-Schaw (1998:245) discourse analysis aims to 'closely inspect social texts to be able to better understand social life and interactions within spoken and written texts'.

Discourse Analysis, according to Phillips & Hardy (2002:iv) is an investigation into the processes of social construction. 'As a domain of study, discourse analysis concerns not only the selected texts but the history and context associated with these texts'. How such texts can be unpacked and understood as 'reality constructors' (Phillips & Hardy 2002:iv) is the purpose of discourse analysis.

Social analysis, including discourse analysis, according to Phillips & Hardy (2002:2), focuses on 'the processes whereby the social world is constructed and maintained'. With its emphasis on reflexivity it aims to remind readers that in using language, producing texts and drawing on discourses, researchers and the research community are part and parcel of the constructive effects of social discourse. For the purposes of reflexivity I have drawn on my own story as this impacted the way I understand the world.

Discourse analysis is thus a process in helping researchers to question and understand how social reality came into existence. It 'interrogates' (Phillips & Hardy 2002:6) the social meanings and how social ideas are created and maintained and tries to uncover how social ideas are produced. It is also interested in how language constructs our discourses about our social worlds.

Discourse analysis places accent on the research process rather than on the product, therefore it cannot be anticipated what the end product would be. My own hearing is filtered through the lens of my own discourses; therefore I cannot take a neutral position. I will find my way as the research progresses, attempting to question my own assumptions. This might be difficult, but it has an advantage in that it helps me as researcher to remain connected with the participants' stories. It also links back to doing research *with* participants and not *on* them.

1.8 RESEARCH APPROACH

Having worked with resilience and subjugated discourses in the lives of people living with mobility difficulties and the role I, as researcher, sought to play in co-constructing alternate stories within a narrative relational frame, this research worked within a qualitative paradigm, where meanings attached to experience and language were not assumed but explored. As Mouton (2001:150) said: 'a qualitative research approach seeks to gain understanding and insight into life worlds of research participants'.

1.8.1 Qualitative Research

This study utilized qualitative conversations to learn how mobility difficulty sufferers saw, understood and interpreted their worlds. Rubin and Rubin cited by Mouton (2001:196) said that 'qualitative interviewing emphasizes the relativism of culture, the active participation of the interviewer, and the importance of giving voice to the interviewee'.

Truter, (2002) discussing Denzin and Lincoln's (1994) description of qualitative research writes the following:

... the emphasis in qualitative research is on process and meaning and not on the rigorous measurement of quantity, amount, intensity and frequency. Qualitative researchers emphasize 'reality that is socially constructed', and also stress the importance of an 'intimate relationship between researcher and that which is being studied', as well as the 'situational constraints that shape the study'. Qualitative researchers look for answers to questions that stress how social experience is created and given meaning.

(Truter 2002:48)

A social construction epistemology has been used in which knowledge or the truth could not be discovered, but it was socially constructed between people (Burr 1995:4). Researcher and

participants became equal partners who created knowledge together, which was applicable and had value in our particular situations. As we constructed meaning together this in itself became an action. In this way this research was an action research project. The construction of meaning was an ongoing, active process; something was not being proven or discovered (Truter 2002:48), but meanings were explored. This might seem to have assumed that this research project was participatory. Although the researcher sought to co-create knowledge with the participants, a single one-on-one interview was planned and in some ways the researcher's voice became privileged in the analysis of the texts. As a result the research did not develop into a fully participatory approach. In other words, the texts that emerged have not been fully co-created, but were seen through particular lenses of discourse and language.

Qualitative research was done within a framework of values, in other words the researcher's values and belief systems played a major role in the interpretation of the findings; thus the researcher has not been completely able to separate her own beliefs from that which were being researched; because of this, qualitative research could not be value free.

According to the open-ended nature of qualitative research, the last word concerning research on Mobility Difficulty might not be spoken when the last word of this dissertation has been written, but conversations about it can become an ongoing meaning-constructing process.

1.8.2 Action Research

Uzzell (1998) describes the role of the researcher in action research as follows:

The researcher moves from the role of being...a chronicler...to that of an agent of social change. Doing the research is integral to taking action, because action is part of the research and research is part of the action: they are two sides of the same coin.

(Uzzell 1998:310)

Uzzell (1998:311) cited Zuber-Skerrit (1992), who described five characteristics of action research. Firstly, the research should have practical consequences for all the participants and not only lead to theoretical and disciplinary advances.

Secondly, it has to be emancipatory, liberating participants from the subjugating discourses and placing them in positions of influence both in respect of the research and their daily lives.

Thirdly, it should be interpretative whereby the perspectives and interpretations of all the participants should have validity. It was important for me to value each participant as an expert on his or her experience of Mobility Difficulty and as valuable to the research project. Zuber-Skerrit (1996:21-22) saw action research as research where every participant's opinion on the situation was valued and taken into account; not any single opinion was taken as the final understanding of what the other points of view really meant. The variety of difference between viewpoints made it a rich resource: 'To treat all viewpoints as a collaborative resource is thus to suspend the conventional status hierarchy which gives some members' viewpoints greater credibility than others' (Zuber-Skerrit 1996:22).

Fourthly, relationships formed in the course of research raised issues of power, influence, control, responsibility and accountability. Co-labouring attempted to overcome the power relations between researcher and researched. This made me wonder whether the way participants perceived me as the researcher and the position of power I held in the research could have influenced the kind of information they supplied. In being aware of my own position of power I wanted the participants to have a say in the way they want me to re-tell their stories of Mobility Difficulty. Consequently, I attempted to give them a say by going back to the participants with the written letters and gave them a chance to comment on the discourses found, and to change anything they did not agree with.

Finally, action research called for critical analysis, allowing participants to analyze their situations; consequently allowing for courses of action that might have led to change in their circumstances and in themselves. The participants had to be aware that the research had relevance for them, some things or ideas might change following the research and they could have gained something from it. In exploring the subjugating discourses, space could have opened up for alternate descriptions and social action.

The focus in action research shifted from questions about 'who' and 'why' to questions of 'how' and 'what'. Keeping the research aims in mind, I could ask: How did it come about that the doctors and medical personnel have so much power to diagnose you as pathological? I also asked, 'What does the participant know about his/her condition that the doctors don't know?' And, if the participants could ask for their preferred treatment, how would it differ from the treatment they received? I sought to be informed about what they thought other people might

need to hear about living with Mobility Difficulty. Such questions opened up conversations for new dialogues to develop.

1.8.3 Ethical Considerations

In this research project an attempt was made to convey an ethical position that does not view mobility difficulty sufferers as objects of inquiry, as in the medical model, but to open up an alternative way of viewing the people behind the illness.

In having done action research the researcher participated with the people who took part in this project. Heshusius (1996:131) referred to this as “the larger participatory consciousness or the ‘hermeneutics of connection’ where the self and the other are seen, not as separate entities, but as an ontological and epistemological entity”. My ongoing awareness of inclusion and participation left me with important moral implications. Regarding this, Heshusius (1996:133) says, ‘When the self and the other are seen belonging to the same consciousness, all living is moral’. Kotzé (2002:5) calls this ongoing consciousness the ‘ethics of awareness’. Heshusius (1994:17) further referred to the being in there together with the participants as ‘selfother’ relationships; I saw this as me doing research *with* the participants and not *on* them.

The intention with this research was not in an epistemology that is practiced in an objective, scientific way, but it is embedded in an epistemology in which knowledge is made in an ethical way. Kotzé, (2002) regarding this, says:

My focus is not so much on the scientific value of paradigms and bodies of knowledge....I choose to focus on the effects these knowledges, paradigms, truths, doctrines and beliefs have on people in real life.

(Kotzé 2002:11)

Having thought of my ethical accountability in this narrative pastoral research project, the following questions could be asked. Do I as a researcher and pastoral therapist have the moral authority and knowledge to ‘act as knower’ or do I focus on the healthy, authentic, appropriately developing person – ‘the kind of person one should be’? (Browning 1990:366). Having kept this in mind further questions could be: On whose behalf may I speak, or ask a question? Who may benefit by my talk? How would they benefit? And, how will I benefit?

Having asked these questions the researcher was then able to ask mobility difficulty sufferers questions such as: What were the effects of subjugating discourses on you? Who benefited by these discourses? Who were damaged by them? And, how could other mobility difficulty sufferers not participating, benefit from this research? The effect which knowledge might have had on participants could become ethical issues; not the 'how' and the 'what' of knowledge. In this research project, how I 'made knowledge' was thus an issue of 'ethical epistemology' (Kotzé 2002:12). Epistemology was in the service of ethics.

1.8.4 Limitations of the Study

Neither objective tools nor multiple measures were incorporated into the study. The qualitative objective of this research was to yield thick descriptions and rich detail. Therefore no claims can be made as to the generalisability of the study. According to Stringer (1991:11) the success of a research project can be measured in 'its ability to enhance lives of the people with whom it is engaged'.

1.9 RELEVANCE OF RESEARCH TO MYSELF AND THE WIDER COMMUNITY

This research project wrote to all Mobility Difficulty sufferers who may identify with the stories told in this study, giving voice to those fenced in by health difficulties. Being part of the community myself, the researcher's own personal journey of pain and being trapped in a "not fully functional" body might also reflect something of the larger group. It might also have benefited me in making sense of what subjugating discourses I was subscribing to, as well as challenging the 'disempowered' position that I found myself in.

I am writing to a therapeutic community and perhaps a church community where these issues of disability and disempowerment are part of our work and thoughts. I will include stories of sufferers where I feel what they say brings voice to this topic. I hope that this study may generate ideas on how to become communities of healing where our 'being human' will be more important than our 'broken bodies'.

1.10 CHAPTER OUTLINE

This first chapter started with the researcher's own experiences of Mobility Difficulty. In thinking of my own difficulties I reflected on giving voice to the voiceless and on the meaning that such a difficulty might have in one's well-being. A framework for listening to the stories of 'the ill' was provided as well as a discussion on practical theology and pastoral care which was the academic disciplines under which this dissertation was being written. Comments were made on the pilot study that was employed for the purpose of clarifying a research question. This chapter further reflected on the aims and approach, as well as the literature study and the proposed process and data gathering and –analysing methods, which were employed.

The following chapters will be a collection of the stories of people living with Mobility Difficulties.

Chapter two will put muscles and flesh on the research skeleton and it will introduce qualitative research and the theoretical underpinnings guiding this study. Sections on practical theology and pastoral care will be included. It will further contain postmodern ideas, social constructionism, the narrative shape of illness experience, action research, discourse analysis and deconstruction.

Chapter three will be the heart of the study as it will introduce the research participants, their conversations and the discourse analysis thereof. It will also contain the letters as summaries of the transcribed research conversations.

Chapter four will organize the organs of the research body and there will be discussions on the discourses found, according to the themes set out in the discourse analyzing process.

Chapter five will wrap the research body up in skin and will include a discussion on future possibilities for research and also include the limitations that have been encountered in the research. There will also be reflections on what might have been done better or differently and how it has affected me as a researcher, therapist and person.

CHAPTER 2

Muscles, joints and beliefs

If the first chapter built the research skeleton, this second chapter provides the muscles of the research body. This chapter contains discussions on qualitative research and the theories and beliefs guiding the study. Theories include postmodern ideas, social constructionism, narrative shape of illness experiences, action research, discourse analysis, mobility difficulty and discourse as well as deconstruction. Chapter two also introduces ideas from practical theology and pastoral care.

2.1 QUALITATIVE RESEARCH

2.1.1 From Quantitative to Qualitative

In more traditional quantitative research the assumptions guiding such research are that ‘truth’ is seen as something objective and identifiable, something that can be discovered ‘out there’. According to Heshusius & Ballard (1996:7), in quantitative research ‘reliable knowledge can... only be obtained through externalizing modes of knowing, through distancing, quantification, atomization, manipulation and experimentation’. Qualitative research, on the other hand, according to Denzin & Lincoln (1994:4), points to processes and meanings that are not rigidly examined and measured, but sees ‘truth’ as something that is socially constructed by a group of people in order to bring meaning to their experiences.

In this research project, qualitative research looked towards the meanings behind actions and words. It attempted this by looking beyond ‘facts’ towards understanding the nature of ‘realities’ that were socially constructed. By looking at meanings behind words and actions, qualitative research could help us find many other possibilities for identities to emerge (Treloar 2002:594). Rather than working deductively and reducing data, it opened texts of participants up to multiple readings of it. In this study a qualitative methodology was used to explore alternative identities of participants that could bring hope and enable them to escape the nets of dominant ideas and belief systems. This is not possible using quantitative methodologies of research because the purposes of quantitative and qualitative research are different and explore different territories. This does not mean that they are mutually incompatible, simply different.

In searching out meanings attached to experience, qualitative research, in this project, was interested in discourses, both dominant as well as subjugated. As mentioned in chapter one, (1.7.3), discourse is the beliefs, ideas and practices of the broader culture in which a person lives. Within a narrative study (White: 1995), and in working with discourse analysis (Phillips & Hardy 2002), there was a great interest in finding some of the ways that dominant discourses might have served and assisted problem stories. According to Morgan (2000:45) the beliefs and ideas that are assisting problems are often regarded as ‘taken-for-granted’, as ‘truths’ or as commonplace understandings. Qualitative research, through exploring meanings, fits with discourse analysis (Phillips & Hardy 2002), which was used as a way to research both dominant as well as alternate meanings found within any given discourse. In attempting to do discourse analysis on the conversations of the participants, the researcher was interested in the words of the participants that carried within them much assumed meaning. Even though every spoken and transcribed word was important, only certain parts of the conversations with the participants that fit the researcher’s understanding of their mobility difficulties were selected. Accordingly, no objective tools or multiple measures could have been included in the study. The qualitative objective of this research was to yield thick descriptions and rich detail of the analysed conversations.

Qualitative research was unpredictable and somewhat risky because there were so many meanings that could be attached to any given word, in that words have no meaning on their own. Therefore it couldn’t be envisaged how the participants and researcher would experience the development of this research. Both the participants and researcher might have risked changes in their ideas and identities. This posed a challenge, but at the same time the researcher had a responsibility towards fellow mobility difficulty sufferers to tell their stories. Frank (2002:123) says, regarding the responsibility of the ill: ‘It is to witness their own suffering and to express this experience so that the rest of us can learn from it’.

Due to the non-objective nature of qualitative research, it was done within a framework of values; in other words, the researcher’s values and belief systems played a major role in the interpretation of the findings, thus stressing the intimate relationship between the researcher and that which was being researched. Truter (2002) quotes Stringer (1991) in this regard where he says qualitative researchers are

... no longer experts capable of defining, describing and interpreting the 'facts' or 'truth'. The writer as scribe-for-the-other helps people give voice to their interpretations of events working with them to identify the key elements of their experience and shape them into a report.

(Truter 2002:49)

That was why the researcher has not been able to separate her own beliefs from that which was being researched and, because of this qualitative research could not be value-free. The researcher as 'scribe-for-the-other' (Truter 2002:49) was an equal partner in challenging oppressive discourses. This partnership became a journey into myself as researcher and into the worlds of others. Therefore the researcher had to return to the participants to check the trustworthiness of the analysis.

This has been done by writing letters as summaries to each participant and taking it back to them to check whether the descriptions fitted something of the understanding and meaning of their experiences. It is interesting to note here that although these letters were designed as a 'scribe-for-the-other' they were written from the researcher's prior experiences, as can be seen in chapter three and four. The letters were limited in their value and it is worth noting that the research participants did not change anything within them, perhaps indicating the researcher's power within the constitutive force of discourse.

2.1.2 Using Participants' own Stories

By using the participants' own stories, access could be gained to their local knowledges and meanings of their experiences of living with Mobility Difficulty. They could tell something of what it was like to live with such difficulties that the medical or therapeutic world did not know, and which we needed to hear. Ballard (quoted by Grobbelaar 2001: 172) said that telling stories was a valuable way of documenting research. 'Stories are important, relevant, meaningful and as generalisable as any other writing that is referred to as research'. Winslade & Smith (1997) says about the telling of our stories:

Stories from which we build our self-concepts are stories that have been told and retold in linguistic contexts of our social networks. If this is true for problem stories...it needs to be made true for new stories of competence... A good story needs an audience before it can be appreciated as a good story.

(Winslade & Smith 1997:188,189)

2.2 PRACTICAL THEOLOGY

Theology, simply defined, can be viewed as ‘talk about God’ or ‘words about God’ (Heyns & Pieterse 1990:3). Defined this way, every person of faith is in fact a theologian and any conversation about God is theological.

Practical theology, however, is concerned with the actions performed in the service of the gospel; in other words the encounter between God and man/woman. According to Cochrane, de Gruchy and Petersen (1991:2) practical theology is at the crossing point between theological theory and the way faith is worked out in practice. A more traditional way of viewing practical theology applies theory to the world, rather than allowing ‘praxis’ and lived experience to create theory (de Gruchy & Villa-Vicencio 1994:5).

There are different approaches to practical theology and these reflect different views of the relationship between the traditional theological disciplines and the social sciences. These approaches grew out of challenges facing the community of faith. These challenges included questions of how the community of faith is to relate to the world in general, including ethical and behavioural questions.

A further question regards whether society exists to serve the church, or does the church exist to serve society. This has been at the centre of recent moves in theology; away from top-down approaches towards more participatory approaches (Kotzé & Kotzé 2001:5). The emphasis is on interacting with a pluralistic and heterogeneous society and a participatory approach would support an openness to ‘the other’ by encouraging various viewpoints and voices. This approach no longer regards only ‘academic theologians’ or clergy as theologians. Practical theology is practiced/done by *all* people grappling with an understanding of the presence of the spiritual, holy, ‘other’ or God in our human circumstances. Bosch, (1991:427) refers in this context to ‘local theologies’, the theologies of the so-called ‘non theologians’. A participatory approach to practical theology would further encourage researchers to be increasingly aware and critical of their own perspectives and how they are influenced and challenged by the participation of others.

Linking the above postmodern move away from top-down approaches to this research project, in some ways it worked from a more traditional or modernist angle in that discourse analysis, which

has been birthed from theory, guided the interpretation of the texts that emerged. Although this is so, the research also worked within a postmodern context and participatory approach where meaning attributed to experience were explored and not 'discovered' or assumed. Having said this, the researcher - in an attempt to dissolve some of the assumptions concerning a more modernist approach to theology -, also had to work within them, thus finding it difficult to distil or separate it from the greater stream of theology informing this work.

This study was carried out within a Dutch Reformed Church context and faith community, in which all participants have been informed in their identities by their belief in God. Working with the participants' faith positions and the historically constructed broader culture in which they were formed, theology was used that fitted with their belief systems. Thus, theologies influencing this study were evangelical, reformed, contextual, feminist and postmodern theology.

The researcher's faith commitments, coming from a Dutch Reformed Church background, have been influenced by her understanding of Reformed and Evangelical theology. Because the participants came from a similar church background, the study was done through lenses of Reformed and Evangelical theology.

2.2.1 Reformed and Evangelical Theology

Evangelical theology is a very broad and diversified movement and provides an important identity to many Christians. According to König (1998:92) 'much of the theology and spirituality in the Afrikaans Reformed Church tradition would be deemed Evangelical'. De Gruchy (1978), cited by König (1998:92) also says that South African history has been largely shaped by Evangelical Christianity.

Evangelical Christians holds a high view of the Bible; they relate the Bible to personal life situations. They are also Christians with a personal experience of Jesus Christ. Christ has done all that was needed to achieve salvation, salvation should be accepted as a gift from God; faith produces good works. Emphasis is placed on sin and grace and salvation only through Christ. The cross is the symbol representing the willingness of God to share the burden of pain and brokenness to the point of death. The tragedy of the cross speaks to the struggles which humans, especially the marginalised face, thus Christ is viewed as the suffering servant. Evangelical theology takes scripture to be the revelation of God in the language of humans; the Bible is both

a divine and human book. Evangelism and the sharing of their faith with others are also important in Evangelical theology.

For me this is congruent with my own experience of God and Jesus Christ. The God I know invites surprise, and news of difference, and seeing people for the wonderful beings He/She created, which can increase possibilities and avoid traps of certainty. Griffith (1995) says:

If one is too certain of her specifications of God, she will miss God. A Rabbi told me that the Israelites could not wholly name God. They said “Yahweh” which meant, “I am who I am, and I will be who I will be”. Movement and mystery.

(Griffith 1995:137)

In the past, traditional, modern evangelical theology adopted an authoritative stance, speaking the ‘truth in love’ (Kotzé 2002) in ways which alienated many from the church because of perceived judgment and self-righteousness of proponents of these methods. Decisions were based on doctrinal and dogmatic truths; people affected by these decisions were never or seldom invited to participate and were not privileged to take part in arguing right or wrong – their voices were silenced. These can be referred to as patriarchal ways of shaping the truth, in this sense there are similarities in church and medicine. Effects of these truths include oppression, suffering, exploitation and marginalization of people at the receiving end.

2.2.2 Contextual and Feminist Theology

If theology is ‘God talk’ I would go on to suggest that all theology is contextual. Every distinct tradition or perspective in Christian theology can be understood in terms of the historical, social and economic contexts in which it developed. Kotzé and Kotzé (2001:5) say contextual theology is ‘affirming justice against oppression, shifting from the general to the local, co-constructing a variety of “local knowledges” and opposing Western theology claiming universal validity’. Maimela (1998) writes ‘What characterises this type of Liberation Theology is that it arises from the experience of one or other form of human oppression’ (1998:111).

According to Truter (2002:82) contextual theology’s roots lie in liberation and feminist theology. In reaction to the ‘objective truths of the Bible’ that churches in the pre-modern and modern contexts advocated, contextual and feminist theology ‘broke away’ from traditional theology. Both theologies start with experience (praxis) and then moves on to reflection; within this the

context is emphasized. Additionally, feminist theology revealed the dominance of patriarchy over almost every aspect of theology and church life over the past 2000 years. From liberation theology, feminist theology learned that we cannot do theology ‘as though we lived in some abstract realm or dead corner of history – we have to be involved in our world.... Injustice is not simply an act of fate; it is caused by people’s actions and therefore requires people’s actions to redress the balance’ (Isherwood & McEwan 1993:76).

Within the backdrop of this study where it concerns the ‘illness-as-lived’ (Toombs 1992:130) and the marginalised voices of the participants, it seems that a contextual approach to practical theology can best express what needs to be heard about participants’ Mobility Difficulty experiences. The reasons the researcher chose to listen to the voices of people living with mobility difficulties are, that theology starts with these people in their context. It also began with my own lived experience as a ‘moment of insertion’, as can be seen from the hermeneutic circle described in Cochrane et al (1991:17); thus my point of departure was both discourse as well as own lived experience. This connected with the aims (1.6) of this research in that it was searching by way of discourse analysis what dominant discourses might be overlooked in some of the assumptions that the participants made about their mobility difficulties. My hope is that this research will create a safe space for voices, that have been silenced by subjugating discourses, to be heard. Ackermann (1994:206) in this regard quotes Nelle Morton saying, ‘we become involved in creating space which will allow the victims to be “heard into speech” ’.

Kotzé and Kotzé (2001:5) further say that contextual theology must take sides and take a firm stand against every attempt at a non/under-contextualised approach. This necessitates self-other (Heshusius 1994:17) actions committed to “doing” care and pastoral therapy. Within this self-other context we do not come to knowledge by means of separation, but by way of care and love, by an attitude of openness and receptivity to create greater wholeness amongst all participants. According to Kotzé & Kotzé (2001:5) ‘the challenge is to maintain this manner of dialogue when realities of participants differ’. Such a contextual approach is seen as a theology from below and, ‘it grows from self-other participation and not from a position of knowing’ (Kotzé & Kotzé 2001:5).

2.2.3 Postmodern theology

Kotzé & Kotzé(2001) state that ‘from a postmodern position of scientists as participants we are left to participate in a world where there is social injustice, poverty, sickness and silence’. As a consequence, this research project holds forms of postmodern theology in relation to other theologies.

Heroldt (1998:215) defines postmodernism as ‘a serious effort to restore the loss of meaning that is attributed to modernism’. Postmodern theology influences this work in that the search for ‘truth’ that is associated with more empirical methods of theology is replaced with a sense of understanding our faith through the stories that we tell. Stories become selected over time and they represent our lived experience as well as our meaningful beliefs; these stories are expressed within language.

The experience of my own Mobility Difficulties persuaded me towards a scepticism regarding ‘an objective understanding of how it works’ (Webb 1996:156) and an affinity towards the stories of others and their views on experience. My own and the other participants’ stories of Mobility Difficulty tentatively informed me that I will never gain definitive answers concerning many of life’s questions. But, it also told me that those who claim certainty of ‘the truth’ should be challenged.

Certainties about ‘how it works’ may easily lead to thinking in binary opposites and good/bad splits. For example, sufferers are good and doctors are bad. We as sufferers and therapists need ways to challenge the fragmentation created by binary splits. If a both/and attitude of inclusivity is accepted, it opens up areas of accommodating differing viewpoints of sufferers as well as medical people, where ways of seeing one another are opened up and made flexible, and where we can have movement in understanding one another’s points of view. Having said this, creating multiple readings and accommodating a constant weaving of both/and, also becomes problematic when, as pastoral therapists, we do not challenge the abuse of power through the potential silencing of those who experience the effects of specialist knowledge in a way that diminishes their own voice. Dominant scientific and religious truths can marginalise other possible realities that tend to diverge from the dominant truths. Dominant power/knowledge is not innocent – they privilege those they serve and can oppress those who differ.

Although this research works with modern concepts, in a sense it moves beyond modernism towards postmodernism to provide new meaning. This cannot be accomplished by a denial of the valuable results offered by the scientific method (Heroldt 1998:218). In this research, participants' input is combined with reference to modernistic concepts to result in a balance between meaning making and 'possible extremes' or binary opposites. Thus, it has a multi-layered character in stead of a dualistic character. Participants' faith is fitted in a frame of how mobility difficulty is experienced on different levels.

2.3 PRACTICAL THEOLOGY AND PASTORAL CARE

This practical theology research report was written within the specialization field of pastoral care/therapy/counselling. Pastoral care presupposes a faith conviction as the starting point and a faith community as one of the contexts from which to do theology or from where counselling is offered. Knowledge of theological traditions can enrich the faith of the care giver as well as broaden their perspectives; it can also enable caring in a variety of ways, responding with greater understanding to the contexts of the persons they seek to care for.

The pastoral caregiver is a representative of the Christian story and its tradition (Gerkin 1991:11). Frank (1991:101) says regarding the overlapping of medical care and pastoral care: 'Physicians and nurses often forget that when treatment runs out, there can still be care. Simply recognizing suffering for what it is, regardless of whether it can be treated is care'. Pastoral care continues long after medical treatment has stopped due to a bad prognosis. Truter (2001) quoting Clinebell confirms this:

Health is much more than the absence of illness; it is the presence of 'high level wellness'.... High level wellness involves wholeness in all six interdependent dimensions of persons' lives – physical, psychological, interpersonal, environmental, institutional, and spiritual.

(Truter 2001:79)

In a pastoral therapeutic dialogue, theological traditions can function as a 'participant in a dialogue' (Botha quoted by Grobbelaar 2001:175). This means that the 'story of God' becomes a conversational partner, this also connects with Gerkin (1991:24,25) in the bigger story of faith.

This research attempted to open up conversations around the meanings of participants' spirituality and faith issues, by exploring the influence of traditional theological dialogues and connecting it to the participant's stories. It assumes a prior faith commitment (on the side of both researcher and participant) that must be open to inspection and allows for self-reflexivity and awareness as well as opening oneself up to questioning by others, this also connects to the ethical considerations of this study discussed in chapter one. Cochrane, de Gruchy & Petersen (1991) remark:

We should expect of all practical theologians that they become self-aware of their prior commitments, on what these commitments are based, and how they affect one's entire approach to practical theology. To make things explicit for oneself is to become not only self-aware, but also to allow for being self-critical, and to open oneself up to questioning by others.

(Cochrane, de Gruchy & Petersen 1991:16)

2.3.1 Approaches to Pastoral Care informing this study

With the growth of the social sciences, practical theologians have been encouraged by some of the insights offered by these fields of study; the work of pastoral care and counselling was therefore influenced by psychology and social work. The pastor or counsellor was encouraged to learn from the insights and skills of psychology.

The years after 1965 were years in which pastoral care teachers and practitioners sought to adopt a virtual plethora of methods that became available on the psychotherapeutic market. Most of the literature chose to focus on practical matters of diagnosing and ways of providing psychologically informed care and did not focus on issues of the theological grounding for pastoral care. As time moved on specialization in the fields of pastoral care was proceeding rapidly. Pastoral counselling became defined as a specialized service used by pastors and others as a means of ministering to persons whose needs lay beyond the competence and time limits of the parish pastor.

Heitink's (1993) bi-polar or hermeneutic approach encourages the pastoral worker to become an interpreter, able to interpret the message of God through the insight and assistance gained via psychological practice. According to Heitink (1993:265), an important question to be addressed in practical theology regards: '*how theological theory, taken as text, and modern society, taken as context, are related to each other*'. This approach reveals a tension between faith and life,

Gospel and context, theology and psychology (Louw 1998:31). Heitink's hermeneutic approach attempts to act as mediator between psychological and theological language. Within this research, I as researcher, was mindful of this tension and was very aware that many participants experienced this tension between God and their contexts.

Gerkin's Narrative Hermeneutic approach shifts away from diagnosis and analysis of a condition, toward an interpretation of life through the examination of stories, symbols, language and social interactions. How this subjective process of interpreting and meaning making takes place is the main question of hermeneutics.

According to Gerkin (1991:5) there are theological concerns (theory) on the one hand and practical concerns (the way our faith is worked out in practice) on the other hand. This research concerns 'the way our faith gets acted out' and is thus involved with how narrative-pastoral discourses are contributing to making meaning of mobility difficulty experiences.

Gerkin, (1991) refers to core values or narratives that are undergirding premises of Christian pastoral work. As much as this research attempted to make meaning out of people's core narratives it did not adhere fully to the idea that there can be a core narrative in that it was more informed by a postmodern theological paradigm. I go along with Gerkin's concept/idea of needing core stories and identities to live by in order to make connective meaning from our lives so that our stories are not chaotic. However, this research focused more on postmodern ideas.

Gerkin's reinterpretation of stories can be seen as a paradigm shift and is rooted in philosophical hermeneutics, mostly the works of Gadamer and Ricoeur. 'In the work of the pastor it is necessary to get beneath the cognitive level to the intuitive, emotional level and relations emerging from community living' (Gerkin 1991:13), in other words the taken-for-granted norms or discourses in which communities live must be broken open in pastoral work. Pastoral workers must be prepared to reflect on normative issues in the ordinary human language of relationship, image, metaphor and story. A rich variety of metaphors is necessary, and found in the Bible, to adequately convey the rich and varied meanings of the Christian understanding of God.

The Participatory Approach is committed to *doing* spirituality in a participatory way. This commitment brings about a need 'not to care *for* but to care *with* people who need care' (Kotzé & Kotzé 2001:7).

The pastoral caregiver becomes decentred and as a participator collaboratively negotiates alternative ways of being and doing (Kotzé & Kotzé 2001). Contrary to Western individualist thinking 'this is a participatory process in which therapists collaborate with people in challenging oppressive discourses and negotiating ways of living in an ethical and ecological accountable way' (Kotzé & Kotzé 2001:8). The pastoral worker is committed in this model to a relinquishment of power in favour of a relationship of mutual responsibility for care and growth. He/she becomes a participant with members of the community of faith as they together work out beneficial ways of living and relating. In this it moves beyond dualism and dichotomy by integrating various voices which together co-construct the reality in which people's lives are lived out.

This study will attempt to open up an understanding of the experiences of people suffering from Mobility Difficulties and fit them into the greater narrative of faith and pastoral care, giving rich 'pictures of their experiences' (Grobbelaar 2001:173). Stories told by the sufferers will present these 'pictures of their experience' and of the contexts that reflect their actual lived experiences, which are important to them.

2.4 THE SIGNIFICANCE OF A NARRATIVE-PASTORAL APPROACH

A narrative-pastoral approach has been used in working both with discourse analysis and alternate descriptions regarding meaning making in Mobility Difficulties. Recognition was given to the fact that a narrative approach is not necessarily pastoral. However, in the context of practical theology, contextual theology and pastoral care under which this research was written, a narrative-pastoral methodology suggested that the researcher was attuned to how, *inter alia*, participants used their spiritual beliefs to make meaning of their lived experience with mobility difficulty. The researcher was aware that her own voice could join these experiences regarding meaning making, as researcher and participants share a mutual church background. This could have created blind spots for the researcher in it being difficult to separate the participants' spirituality from her own. This need not necessarily be a bad thing, because within a study such

as this the boundary between researcher and researched becomes blurred. Additionally, it can become a way in which knowledge is made.

The 'narrative' side of this approach included narrative therapeutic practices that focused on the less listened-to stories and voices of people suffering with mobility difficulty. These were people whose voices have been silenced by subjugated discourses circulating in society. Drewery & Winslade (1997:32) say in this regard: 'Narrative therapy in practice is about doing therapy respectfully – that is, promoting the construction of a client's life without enfeebling her in the process'. As mentioned in chapter one, Western ways of talking about illness have tended to 'enfeeble patients' by pathologising them using a somewhat negative deficit model. Individual deficits and what's wrong with a person come under the spotlight when we have our health difficulties examined (Gergen cited in Drewery & Winslade 1997); our capabilities and resiliencies play second fiddle. Narrative ways of looking at Mobility Difficulties paid close attention to the way language was used to give meaning to experiences; 'what we say and how we say it matters' (Drewery & Winslade 1997:33,34).

Within this research, a narrative-pastoral approach further worked on the understanding that people live and understand their lives through the stories that they tell. In the telling of the stories they select certain experiences above other things so that the coherence of the storyline can be maintained (White & Epston 1990:12,13; Monk 1997:13). This fits with discourse analysis in that stories that are selected tend to be controlled through dominant discourses that work in any given society at any one time. In this way stories are not told in isolation of people's broader world they are living in. What is included or excluded is determined by the dominant discourses in which they live (Freedman & Combs 1996:38). Within this research, the narrative-pastoral manner in which the letters were written, invited participants to be active role players in the process of understanding the influence of these dominant discourses on their experiences of mobility difficulty. This understanding can enable participants to lift the veil from the discourses that restrict and hold them back from richer descriptions of their experiences. White & Epston (1990:15) says the following in this regard: 'Those aspects of lived experience that fall outside of the dominant story provide a rich and fertile source for the generation, or re-generation, of alternative stories'. Although this particular research was limited in the way it worked with the research participants as 'clients' (in a therapeutic sense), it nonetheless was

involved in working narratively through the questions that were asked of the participants concerning their Mobility Difficulty experiences.

By employing narrative practices the researcher attempted to enhance the problem solving skills the participants possessed, rather than focusing on problematic, pathological processes. Monk (1997) writes the following in this regard:

Narrative therapy requires an optimistic orientation. The main character in the plot is frequently positioned in the therapeutic conversation as the courageous victor rather than the pathologized victim, as a colorful individual who has vivid stories to recount rather than a hopeless individual leading a pathetic life.

(Monk 1997:4)

2.5 POSTMODERN IDEAS

2.5.1 Postmodernism and ways of thinking about Mobility Difficulties

Stevenson (2005) describes postmodernism in the following way,

.... however, Postmodernism is defined; it's a mistake to see it as a clean, sharp break from everything that has come before. In fact, a number of philosophers of the past often get pointed to as anticipating aspects of postmodern thought including Wittgenstein, Nietzsche and William James'.

(Stevenson 2005:285)

Rossouw (1993:895,903) also states that in the postmodern culture we cannot abolish the modern culture; he says that 'postmodernism is a critical companion and interlocutor of modernism and is a reaction to and a result of modernism'.

This study entered the field where modern medical concepts and descriptions of illness experiences overlapped with postmodern narrative ways of telling stories of those experiences. Consequently, a rich text could be offered in this study. Embracing postmodernism did not imply the rejection of modernism; each gave meaning to the other and had utility relative to a given context. Thus, modernity couldn't be dismissed in its entirety, because the labels it gave us to identify and name illness conditions helped us to move illness from the unknown to the known and also to alleviate anxiety about illness conditions. Weingarten (2001:112) writes in this regard:

Illness or, more accurately, our relationship to it, threatens the way we know ourselves and how others know us also. Anything that helps put illness in its place, that allows us to feel that we are who we are despite it, is welcome.

(Weingarten 2001:112)

Postmodernists hold the view that there are limits to the ability of human beings to measure and describe the world in which they live in any precise, absolute and universally applicable way (Freedman & Combs 1996:2). Therefore, I as a researcher in a postmodern paradigm could no longer stand back and observe 'objective truth' from the outside, but I became part of the research picture. Becvar & Becvar (2000:90) say that in challenging the modernistic belief lays 'the notion that our "reality" is inevitably subjective and that we do indeed dwell in a multiverse that is constructed through the act of observation'. There could be no privileged outside position from where I stood and observed the picture of truth in an unbiased fashion (Anderson & Goolishian 1992, Freedman & Combs 1996). Instead, Anderson and Goolishian (1988:378) suggest that we 'understand our world as we communicate and interact together in an ongoing conversation.'

Becvar and Becvar (2000: 91) went on to say that in postmodernism 'facts are being replaced by perspectives; with this shift came a challenge to the *power* [my emphasis] and privilege previously attributed to the possessors of "knowledge" '. According to Kotzé (2002:7), Foucault, in his book *The archaeology of knowledge* (1972) comments on the historical shaping of knowledge. He examines the interplay and interfaces between knowledge (*savoir*) and power (*pouvoir*); how people ended up becoming objects or bodies of knowledge by means of internalizing, allowing these knowledges to become a gaze subjugating their lives. Scientific knowledge has become an expression of the power/knowledge connection, since to know implies exercising the power of subjugation and domination.

Another writing of Foucault, *Discipline and Punish*, is also interesting in this regard (Fillingham 1993:111-130); he wrote that modernism has created a system of subject and object that claims to be more humane than the pre-modern era in which it was not about being 'good' or 'bad', but about having a god-given right to power. Foucault argued that although it appears as if individuals today have 'power' and 'rights', it could be that modern forms of power render power less exposed and obvious. In other words, people who live with disability are rendered powerless in more subtle ways, particularly through the lenses of normality and abnormality.

An ethical challenge in this study is to establish conditions that encourage us as researchers to critique our practices and the practices of those who exercise power or those whom we think of as powerful and knowledgeable. Questions such as ‘whose knowledges are these?’ and ‘for whose purpose and benefit are these knowledges?’ could be asked. Further questions might include ‘who is silenced or marginalized by these knowledges?’ and, ‘who suffers as a result of these knowledges?’.

Consequently, if we are to be consistent with the postmodern worldview, participants should be understood as possessing equally valid perspectives; there should be an awareness that there is no “transcendent criterion of the correct” (Gergen 1991:111). According to Freedman & Combs (1996:22-35) a postmodern view of reality suggests that realities are socially constructed; that they are constituted through language; that they are organized and maintained through narratives and that there are no essential truths.

2.5.2 Theories of Illness and the Social Constructions thereof

Social analysis focuses on ‘the processes whereby the social world is constructed and maintained’ (Phillips & Hardy 2002:2). With its emphasis on reflexivity, social analysis aims to remind readers that in using language, producing texts and drawing on discourses, researchers and the research community are part and parcel of the constructive effects of social discourse. According to Phillips and Hardy (2002:2) the things that make up the social world appear out of discourse. Regarding this they say:

Our talk and what we are are one and the same. We do not believe that individuals have the luxury of choosing their truth and their reality. We think our experience is largely written for us by the multitude of conflicting discourses of which we are a part. Our ability to act is strategically limited by the discourses that accompany our intervention and the complex processes of social construction that precede it.

(Phillips & Hardy 2002:2)

Discourse analysis, which will be the type of analysis of the conversations in this research study, is thus a process in helping researchers to question and understand how social reality came into existence. It ‘interrogates’ the social meanings and how social ideas are created and maintained and tries to uncover how social ideas are produced. It is also interested in how language constructs our discourses about our social worlds. This research is further interested in generating alternate discourses and finding ways of making meaning in experiences of physical disability. In this way it moves beyond discourse analysis in itself towards action research,

which seeks to change and challenge dominant discourses around disability. Discourse analysis will be further explored in more detail in paragraph 2.7.1 on page 55

Social constructionism, which is situated within the postmodern movement, is helpful in this research methodology in looking at some of the social realities and meanings attached to medical care. It is particularly helpful in challenging the relationship between so-called medical ‘experts’ and lay people. Through challenging some of the hierarchical assumptions about the expert and the patient, it deconstructs hierarchies of knowledge, with the results that the status of the ‘expert’ is put on par with the ideas and accounts of the non-expert (Harrington 2001:31 quoting Nettleton).

It is common practice that medical experts hold great power and authority concerning illness. Medical practitioners decide on names and categories, often leaving patients somewhat powerless in the decisions that need to be made concerning their Mobility Difficulties. Regarding this Nancy Eiesland (1994:25) says:

... the act of naming someone or something grants the namer power over the named... Thus ‘capable’ persons and experts are needed to define the experience of disabled individuals. Therefore there has been a scarcity of substantial, direct information concerning the feelings, goals, and self-definitions of disabled persons. However, there have come changes in the language used to describe disability and changes in who does the describing. Persons with disabilities have become the subjects of our own lives, identifying our own needs and ambitions, and naming ourselves ... So naming the experience of disability is no mere exercise in semantics or a matter of personal preference, it is part of the political work of empowerment.

(Eiesland 1994:25)

2.5.3 Externalising in Narrative Conversations

By using a narrative style of questioning in the conversations with the participants the person is separated from the problem. Thus, experiences of Mobility Difficulty are viewed as the problem and not the participant. This can be seen as in congruence with Weingarten, (2001) 2.5.1 where she said that ‘... anything that allows us to feel that we are who we are despite illness, is welcome’.

Therefore, to externalise a problem is to view the problem as the problem and to separate it from the person. Within this process shifts in the use of language happens and mobility difficulties would be referred to as ‘the Mobility Difficulty’. To distinguish times when participants’

disabilities are referred to in an externalised way the words ‘mobility’ and ‘difficulty’ will be capitalised whenever externalised.

Through externalization of Mobility Difficulty, the relationship it has with the participant can become challenged, creating a new relationship where the participant gains more power and influence over the experiences thereof. A participant may start to experience herself as separate from the problem. By using externalizing questions, internalized beliefs describing and defining the person can be objectified and separated from the person. This means that the lived experience and meanings attributed to experiences of Mobility Difficulty are given a chance to feature. The participants must be allowed the opportunity to describe their experiences as fully as possible, using their own words. The meanings attached to their words will not be assumed but explored so that their experience of Mobility Difficulty is not misinterpreted.

Freedman and Combs (1996) describe externalizing conversations in the following way:

Externalizing is a practice supported by the belief that the problem is something operating or impacting on or pervading a person’s life, something separate and different from the person.

(Freedman and Combs 1996:47)

2.6 ACTION RESEARCH

The writing of an action research report emerges from a set of collaborative and action oriented relationships, rather than authoritative observation oriented relationships. Webb (1996:147) gives us a definition of action research where he cites Kemmis & McTaggart (1998a) as follows:

Action research is a form of *collective* self-reflective enquiry undertaken by participants in social situations in order to improve the rationality and justice of their own social or educational practices, as well as their understanding of these practices and the situations in which these practices are carried out... The approach is only action research when it is *collaborative*, though it is important to realize that the action research of the group is achieved through the *critically examined action* of individual group members.

(Webb 1996:147)

A clear distinction between action research and participatory action research, is somewhat blurred. The difference might lie in the word ‘*collaborative*’. In action research the participants and researcher are *co-labouring* or working together towards an ‘emancipatory interest ... to

show how people are oppressed, how their interests have become repressed and what life will look like when they have confronted their oppressions' (Webb 1996:143). In participatory action research the key word, to me, is *co-creative*. The participants and researcher are co-creating in the research conversation, together with each other, in a 'narrative endeavour', alternative stories of the problem they are researching. Monk (1997) says of this:

The co-creative practices of narrative therapy require the researcher to see the participant as a partner with local expertise whose knowledge may, at the beginning of the research relationship be as hidden as the artefacts of a civilization buried in the soil for centuries.... This process is a deliberate yet respectful and reciprocal activity.

Monk (1997:24)

This research was a mixture of action research and participatory action research in that the participants and researcher aimed collaboratively at exposing the harmful effects of dominant discourses. It was also somewhat participatory in that the participants and researcher were working together at co-creatively constructing alternate narratives of subjugated discourses. It distinguishes itself, however, from a fully participatory approach and therapeutic endeavour in that the researcher's engagement with the participants have been limited to one audio-taped conversation and a follow-up discussion. Thus, this research project can not be seen as therapy.

In legitimating action research Mc Taggart (1997:2) says there has been a willingness on the side of participatory research movement 'to recognize the commonality of interest between participatory researchers and action researchers'. Without participation and taking part in participants' difficulty stories, there can be no action research; the one cannot exclude the other.

This research further aimed at listening, on equal footing, to the hierarchical power relations visible in the medical model that are in danger of silencing participants' alternate voices. According to Zuber-Skerrit (1996:5) action research seeks to privilege each participant on the understanding that each person's contribution is equally valuable. This connects to narrative ways of doing therapy and what Anderson and Goolishian (1992) call 'the client is the expert'. Such research could further have emancipatory properties, such as 'when it aims not only at better understanding along with transformation and change, but also at changing those conditions, which impede desired improvement (Zuber-Skerrit 1996:4).

In both participatory and action research the role of the researcher as possessing expertise comes into play. There are certain inequalities on which the entire research process rests, and the researcher can easily be viewed as ‘the possessor of knowledge’. In some ways this is true and it cannot be otherwise, because it is the researcher who decides ultimately what gets written and what is excluded. Within this power relationship, however, the researcher attempted to find ways of working that promoted the participants’ voices to be heard. The question: “What do you know about your Mobility Difficulty that others don’t?” was most helpful in reducing the expert role and lessening the power that such a role brought. By asking this question the participants’ knowledge their conditions came to the centre. They were respected for their local knowledge while the power of the researcher was limited.

Each participant’s view has been taken as a unique contribution to resources for understanding her situation, and no one’s point of view have been taken as

the final understanding of what all the other points of view really mean ... it is the variety of differences between viewpoints that makes them into a rich resource. It is by using this resource of difference that our analysis can begin to move from its inevitable personal starting point towards ideas that have been interpersonally negotiated.

(Winter 1996:221,22)

Having treated all viewpoints as a co-creative resource was to suspend the status hierarchy, which might have given some participants’ viewpoints greater credibility than others. Phillips and Hardy (2002) also make the point that ‘how we view our experiences are largely constructed by the dominant discourse in which we live’. This implies that the participants’ own unique experiences are filtered through their dominant discourses and limited by the same discourses in which they live through language.

In South Africa action research has been grounded in what Noffke and Stevenson (1995), cited in Walker (1998:240), describe as “becoming practically critical” – a commitment to better understandings of social action. Being practically critical challenges the idea of objective, value-free research and the neutral role of the researcher, thus holding an implication that the researcher can also be researched. The insider-researcher’s assumptions and values that have shaped the enquiry and become part of the argument must also be ‘interrogated’ in a self-reflexive way. Through involvement in action research researchers submit their own accounts of

the situation to critique (Winter 1996:23). We don't exempt ourselves from the process because 'we want to change, because we want to learn' (Winter 1996:23). The viewpoints we started out with we want to transcend and the new viewpoints that emerge we wish to support.

What is at stake, is the interrelationship of the personal with the social, and ways of 'thinking about subjectivity as it is expressed in specific social contexts, involving ways of thinking about the self, and changing the self, that are socially rather than individualistically located' (Walker 1998:243). In action research there is a cycle of steps of planning, acting, observing and reflecting on the changes effected by the action. Recurring reflection leads one to modify the action throughout the research study in a recursive rather than a linear research pattern. An increase in understanding can happen in the space between observation and reflection.

Concerning the risks involved in action research, Winter (1996:23) writes: 'the research process can be seen as a threat to all the taken-for-granted processes that we and our colleagues use to function and cope with in our difficult circumstances'. By investigating our taken-for-granted beliefs, possibilities for the exploration of transformation can occur. Transformation can happen in the provisional interpretations of the situation, which can become mere resources alongside those of others. The researcher's decisions as to the question at issue and what is and is not relevant, might change as well as his/her anticipations of the sequence of events through which the fieldwork will pass.

Action research, participatory action research as well as discourse analysis was employed in this project where it helped to move beyond the 'taken-for-granted'. It also assisted in interrogating experiences of mobility difficulties rather than romanticizing it by pushing against familiar discourses towards 'analytic coherence' (Walker 1998:246). Winter (1987), cited by Walker (1998:246) writes about a way this might happen:

Research disrupts the taken-for-granted of action. Action is enmeshed in a social system, whereas research is the process whereby the self-perpetuating processes of the social system might be interrupted. In this way action research can make alternative stories available.

(Walker 1998:246)

2.7 DISCOURSE AND DISCOURSE ANALYSIS

As mentioned in chapter one (1.7.3 on page 26), discourse can be broadly described as our social reality that we experience as solid and real, expressed through language. Discourse can further be viewed as an interrelated set of texts and practices showing how our social realities are produced, disseminated and received to bring an object into being (Phillips & Hardy 2002:3). Our social reality is made real through discourse, and social interactions cannot be fully understood without referring to discourse that gives the interactions meaning.

2.7.1 Discourse Analysis

The research interest was in how and why our social realities, or our discourses, have the meanings that they do. Discourse analysis focused the attention on the processes whereby the social world was constructed and maintained. It raised questions about what was perceived as real. Discourse analysis inspected how social realities were constructed; how they came about and became natural; and also how pre-suppositions influenced the way researcher and researched saw ourselves and the world around us. Consequently it required me as researcher to be reflexive as mentioned in paragraph 2.3 on page 42, because I was part and parcel of the effects of discourse.

Being reflexive requires sensitivity to the researcher's role in the construction of research categories, one needs to pay constant attention to the process of categorisation. You cannot take analytic categories for granted, but should remain interested in the socially constructed nature of research categories themselves. This is because researchers are both receivers of these knowledges and are in danger of reproducing the very things criticized within the text. The construction of research categories should present the research in a way that acknowledges the complex relations of researcher, participant, academic community and society.

For Altshuler & Dale (1999:25), discourse analysis places emphasis on the analyzing of written and verbal texts as a way of understanding human phenomena. Talking and how we use language has the power of shaping our experience and behaviour. In this research, the focus has been on the language used by the participants; it explored how participants' comments presented images of their living with Mobility Difficulty. This kind of enquiry into social processes can generate what Clifford Geertz (1973) calls 'thick descriptions'. It is a detailed and textured

account of ways in which realities are brought forward by language and maintained through social interaction (Parsons 2005:2).

The task of discourse analysis was to explore the relationship between discourse and the meanings participants made of their mobility difficulty experiences. This was done by using participants' own words. According to Phillips & Hardy (2002) texts are the material manifestations of discourse. Individually texts don't have meaning, but through interconnection with other texts and contexts they are made meaningful (Phillips & Hardy 2002:6). Phillips & Hardy (2002) further say that discourse analysis has a three-dimensional nature; it connects texts to discourses, locating them in historical and social contexts, while referring to actors, relationships and practices shaping the situation. This enables the studying of social phenomena.

Discourse analysis was further interested in the constructive effects of language, for this it had to be reflexive as well as interpretative. Thus there are certain assumptions about the constitutive effects of language. Discourse analysis assumes that language has a relationship to social processes, and it attempts to provide an interrogation of meanings of how social ideas were created in the first place and how these ideas are maintained and held in place.

Traditional methods of qualitative research attempt to understand social processes, but discourse analysis interrogates these processes. Discourse analysis examines how language constructs phenomena – how discourse constitutes our social world; discourse is not a route to the social world as in other qualitative methods of research. In discourse analysis the world cannot be known separately from discourse. Discourse analysis gives explicit attention to the construction of the broader social reality and it shows how social reality came into existence.

Certain challenges (Phillips & Hardy 2002:10) await one in doing Discourse Analysis: Researchers need to link text, context and discourse, while simultaneously incorporating a highly subjective and reflexive use of research methods. Researchers can study the texts for clues to the nature of the discourse because we can never find discourse in its entirety.

2.7.2 Writing letters as summaries

Following the transcribing, letters were written as a summary of the conversation to each participant, focusing on the socially constructed discourses found regarding their mobility

difficulty experiences. The focus was on the meaning of the dominant and subjugating discourses and the relationship that these have with power. An additional focus has been on how spiritual beliefs were used to establish meaning of mobility difficulty experiences, if that featured in the conversation.

White & Epston (1990) as well as Epston (1994) say that using letters, as a therapeutic tool in narrative therapy, is a powerful way of capturing lived experience through the written word. Morgan (2000:102) says when writing these letters one must be careful to use the language and words (of the participants) that were spoken during the conversation. By representing participants' stories using as much of their original language as possible, the participants will remain the owners of their words. Language is a way of being present with another person, a way of touching the other (Griffith 1995:131). I believe that such summaries in letter-form have been a respectful way of using participants' words. Epston (1994:31) says that 'words in a letter don't fade and disappear the way spoken words do'.

Questions have been used within the summary letters to check my understanding of participants' discourses and to open spaces for participants to give alternate descriptions of their understandings of the discourses. These summary letters are included in Chapter 3. The letters also served to expose fragments of discourse and to make discourses available to greater inspection and interrogation within the discourse analyzing process.

The analysis of the discourses that emerged was done through the researcher's interpretations of the conversations, using the research question (1.5 page 22) and aims (1.6 page 23) of the study as guide. White and Epston (1990:15) talk of unique outcomes where alternative descriptions and stories can emerge that do not trap people into dominant stories or labels of pathology making them anxious and overpowering them.

Alternative stories will be woven into chapter 4, pages 85 - 101.

2.8 DECONSTRUCTION

Derrida (Powell 1997:30) introduced and explored how words can convey many different meanings simultaneously. He suggested that a text must be read with the 'other' in mind, 'the

not yet said' always lurking in the shadows. Thinking about the 'not yet said' there can be dangers in looking at illness in modernistic and normative ways without other views in mind. The danger could lie in being caught up in dichotomies in order to give meaning to experiences, for example doctors are bad and sufferers are good. Such good – bad splits would be to rewrite Mobility Difficulty sufferers' stories in just another bias until we go around in circles. Derrida's (Powell 1997:8) deconstruction helps us to unpack discourses and get out of biases where we see 'us' and 'them' and the differences between the views as two different poles; it further aids to exit biases that exclude one view in favour of the other.

Applying Derrida's deconstruction to this research project, instead of coming from a decisive, expert, certain position, the researcher introduced a curious, collaborative angle to questioning as well as kept in mind 'what is not said'. This type of enquiry tolerated ambiguity and confusion and it moved slowly and carefully towards defining the problem. It favoured the native, natural knowledge and vocabulary of the participants and allowed them to be the experts on their condition (Anderson & Goolishian 1992:24-37).

Burr (1995:161) refers to this as the 'relational self' who is permitted multiple descriptions, creating depth and perspective of what is both absent and present, talked about and not talked about (Gergen 1991). Therefore, we must be careful in saying that the medical world's descriptions of illness are wrong and the sufferer's descriptions are right. A deconstructive enquiry opened up space where different realities and alternative meanings could be heard without one dominating the other. The objective was not to rid the medical world of the 'truth' and advances that modernity brought, but deconstructing cultural beliefs and ideas and taken-for-granted assumptions about the power can help both doctors and patients talk 'with' rather than 'to' each other.

This brings an expectation that within this study we can find ways to include sufferers' stories rather than exclude them from the medical, pastoral and therapeutic fields. This might enable some ways of deconstructing dominant beliefs and ideas regarding mobility difficulties and work towards a future of including the human behind the condition.

CHAPTER 3

Heart of the study

If lucky, we spend much of the time in the world of health, but everyone holds a passport to the world of illness as well.

Sontag 1979.

‘Indeed, health and illness can be seen as two countries. This dual citizenship defines our behaviour and the relationships to others; when healthy, the meanings we ascribe to illness and our attitudes to care are often influenced by attempts to distance ourselves from the possibility that we too can become ill’ (Altshuler & Dale 1999:25).

Having given muscle to the study in the previous chapter, the following chapter will contain the heart of the study. Themes from the participants’ voices will be combined and blended so that they can be interpreted within discourse analysis.

3.1 INTRODUCING THE PARTICIPANTS

This chapter draws on transcripts of single conversations carried out on a one-on-one basis with participants. Texts were selected from five women facing mobility difficulties, including two women with osteo-arthritis, (Joan and Nancy) two women in wheelchairs (Ansa and Angelique); the one suffering from diabetes and the other living with cerebral palsy. The other participant (Liana) is a young woman who injured her knee on the netball field. Participants chose to use their real names and the use of pseudonyms was not necessary. The conversations provided the opportunity to explore a wide range of mobility difficulties. Ages of the participants ranged from 23 to 72. Conversations were conducted in Afrikaans and the themes found in the transcriptions were translated to ensure access to more readers. As the participants were not drawn randomly from a medical treatment unit, they represent a particular group of people who see themselves as experiencing mobility difficulties.

All the telephone calls received from the prospective participants were calls from women with mobility difficulties, no men responded to the small advertisements in the announcement leaflets issued at the churches. While it is beyond the scope of this research to elaborate on gender

issues, it is however probable that emotional matters concerning illness differ depending on gender. See the mentioning of aspects of gender and illness by Altshuler and Dale (1999) as discussed on page 24.

3.2 RESEARCH THEMES

The quotations/pieces of text in '*italics*' included in the letters that will follow later in this chapter were selected on the basis of their clarity in illustrating the five themes that were considered. The themes were:

1. Discourses describing participants' identities
2. Some of the taken-for-granted assumptions participants and/or society might have about the descriptions of their identities
3. Themes around doctors', or other persons in authoritative positions' use of power, in working with people who experience mobility difficulty
4. Knowledge that participants have about their conditions that they wish the medical fraternity would notice
5. Participant's messages to people in similar situations

The idea is that these themes might help in exposing dominant and subjugated discourses around powerful positions in the medical fraternity; these themes might also aid in challenging socially constructed discourses around mobility difficulties as well as contribute to the ongoing conversations in the helping professions regarding mobility difficulties.

3.3 USING THE WRITTEN WORD IN LETTERS TO PARTICIPANTS

In the first two chapters recognition was given to using letters (White and Epston 1990; Epston 1994; Griffith 1995; Morgan 2000; Epston 1990) as a tool of empowerment and of bringing voice to lived experiences. The following letters were written as a testimony to the skills and resiliencies that the participants have employed to help them live with Mobility Difficulty. An attempt was made to insert the above themes into the letters using the themes as they emerged. This was more a participative approach than a straight discourse analysis as it invited the participants to become part of the written word. By making use of the written word, it became a witness to participants' experiences as well as opened up alternate descriptions of the meanings

of their illness. This then made possible the challenging of dominant discourses, which could have labelled and stripped them from the wisdom of their local knowledge. The written word does not fade as spoken words sometimes do, and it can grant participants re-entry from the margins to a place where their stories can help to celebrate their humanity. The stories of participants were filtered through the themes set out earlier, selecting words and phrases that resonated with the aims (1.6 page 23) of this study. There are five letters, one written to each of the participants. The letters helped interpret the transcribed interviews with the participants.

The ethical commitment to participants also invited this form of reflection in letterform, as it deconstructed something of the researcher's power position and made the research more transparent. The researcher wished to be respectful to the participants and not just gain information from them without looping it back to them, and writing letters appeared to be the most fitting way to do the feedback. It also gave greater accountability to the way the researcher worked and more opportunity for participants to respond if they felt misunderstood. Interestingly, none of the participants changed the text in any way. This, of course, could be for many reasons.

Morgan (2000) says:

... by paying attention to the unique outcomes, the therapist facilitates the placing of these events more in the foreground of people's awareness. Attributing meaning to them and linking them to other events in the past contributes powerfully to the co-authoring of a new story. This alternative story brings forth people's skills, abilities, capabilities and commitments. Identifying some of these capabilities may have been difficult when they were overshadowed by the dominant problem story and the act of bringing them forward assists people to reconnect with their preferences.

(Morgan 2000:59)

3.4 DISCOURSE ANALYSIS IN ACTION

Discourse analysis can be defined as an action that is used to show how specific discourses are employed to reach specific effects and beliefs in specific contexts (See the discussion on aspects of discourse analysis by Phillips and Hardy (2002) on page 55). To be able to do a discourse analysis requires of the researcher the difficult task of 'critically distancing oneself from, and questioning the everyday cultural discourses dominating your life' (Coyle 1998:244). This was

particularly difficult in this research as it was mixing discourse analysis with a narrative style, and giving feedback to the participants in letterform. This feedback contributed to the participants co-creating the text.

Discourse can be seen as the general systems of meaning explaining certain texts; texts in this case were the words (audio taped and transcribed) of the participants. However, this research was limited in the sense that the texts of the participants were constantly being negotiated and created with commas rather than full stops, in order to create greater transparency and movement. Yet another challenge within discourse analysis, or mixing these forms of methodology, was to render familiar discourses as foreign. Every utterance in familiar discourses was supported by multitudes of implicit meanings, from which, as can be seen in the letters, it was virtually impossible to become distanced, particularly as I myself am immersed within this process as both researcher and a co-traveller with Mobility Difficulty. The implicit meaningful content of the texts of participants was made explicit by discourse analysis (Parker 1992).

One of the frustrations of finding out exactly how discourse analysis was to be done was the vagueness, or the absence of guidelines and technical procedures of what discourse analysis entailed (Coyle 1998:247), which was why, in order to help, the researcher selected the above themes. A researcher such as myself cannot rely on a set of technical procedures or instruments illustrating a stepwise “how to do guide” in carrying out the analysis. A text on the move was never static enough with its multiple meanings, to be captured in a step-by-step guide. In this, I as researcher, was subjectively positioned within my own preference for certain categories and themes as well as my own lived experience. ‘We learn as we do the analysis, as we use the techniques and we interpret meanings as we go along’ (Phillips & Hardy 2002:10).

3.4.1 How the Discourse Analysis was done

After transcribing all the interviews, the researcher started the discourse analysis on Nancy’s text, and then wrote the letter to her. An A3 paper was divided into 5 columns. Each column was given a heading corresponding to the themes, e.g. the first column had the heading: *Discourses describing participants’ identities*; the second heading was: *Some of the taken-for-granted assumptions participants and/or society might have about the descriptions of their identities*, and so forth until each column had a heading. See table 3.1 which is the analysis of an

excerpt of the conversation with Nancy. Also see Appendix 4 for further excerpts of the conversations with the other participants.

The researcher then went back to the transcribed conversations and read and re-read each paragraph several times. I was on the lookout for discursive strategies or broader discourses that operated at a societal level. Phillips & Hardy's (2002:76) view is that discourse constructs objects and concepts; they say 'it is clear that we need to establish what the texts constructed and we need to examine how the constructions relate to the individuals'.

To make the implicit discursive meaning of the text explicit, the researcher asked two questions while reading each paragraph. Firstly, what was the text doing, or what was the text trying to tell me? And secondly, how was the text doing it, or how did it describe, what words did it use to describe or elaborate on what was found in the first question? In other words what was the function of this particular part of text? For example, in reading Nancy's words: "*Going to an old age home is a terrible step to take*", an answer to what the text was trying to tell me was, that Nancy might be worried about the possibility of one day going to an old age home and becoming dependent. In answering the second question of how the text was describing this worrisome experience I pondered her subsequent words: "*I was frightened and shocked by the circumstances under which some of them lived...This is where I decided for myself to stay independent for as long as I can and to take care of myself as long as I can.*" This could probably describe that Nancy might be worried about not being able to care for herself when she gets old and that she placed a high value on independence.

These questions of what the text was doing and how the text was doing what it does were helpful in taking apart the transcribed text and marking the themes in it, on the understanding that language is constitutive of our beliefs.

Text continues after table 3.1

EXCERPT FROM TRANSCRIBED TEXT - NANCY	DISCOURSES DESCRIBING PARTICIPANT IDENTITY	SOME OF THE TAKEN FOR GRANTED ASSUMPTIONS ABOUT PARTICIPANT'S IDENTITIES	DOCTOR'S OR OTHER AUTHORITATIVE PERSON'S USE OF POWER	KNOWLEDGE ABOUT MD THEY WISH MEDICAL FRATERNITY KNEW	MESSAGE TO PEOPLE IN SIMILAR SITUATION
<p><i>Going to the old age home is a terrible step to take. I was doing charity work at an old age home on Monday mornings, where I mainly had friendly conversations with the old people while the linen is being changed. I was frightened and shocked by the circumstances under which some of them lived. Many people are sharing a room with 7 others with no privacy at all. They told me that each of them has his/her own habits and it's hard for them to share a room with so many people. It's problematic! Each person even has his own place at the dining table and beware if you took his/her place! This is where I decided for myself to stay independent as long as I can and to take care of myself for as long as I can. I am really working at it. That is why I am so involved with any thing that I can take part in. You can ask me what are the things I am doing – This excites me very much!</i></p>	<p>Nancy is worried about going to an old age home.</p> <p>She has empowered herself with first hand knowledge about circumstances in a particular old age home.</p> <p>Worried about not being able to care for herself when she gets old – being dependent.</p> <p>Speaks of being shocked and frightened about living circumstances in the old age home.</p> <p>Nancy talks of how important it is to her to be independent. She is working on staying independent.</p> <p>She is very involved in community work and invites me to ask her about what she is doing to stay independent.</p> <p>Nancy tells of the pleasure she takes in being involved in community projects.</p>	<p>Knowledge is power – by getting first-hand information about old age home Nancy empowered herself towards independence. Knowledge is a tool towards independence.</p> <p>To Nancy it is common sense to stay independent as long as possible. Independence is a virtue.</p> <p>Old age can bring dependence. Dependence is not good.</p>	<p>No power issues of doctors apparent in this piece of transcribed text.</p>	<p>Nancy got first-hand knowledge from observing people in old age home of how she would not like to be concerning dependence. It is not a good feeling to be dependent, rather stay independent as long as you can.</p>	<p>Find out as much as you can about old age homes before you make it your home. Stay independent as long as you possibly can.</p>

Table 3.1

3.5 THE LETTERS

3.5.1 Nancy

The conversation with Nancy moved in a somewhat different direction than expected, due to a recent trauma she experienced. Working within a qualitative research methodology that did not enter with prescribed questions, allowed space for this unexpected insertion into the conversation. Nancy responded to the small advertisement in the announcement leaflet of the Krugersdorp-East, Dutch Reformed Church, by phoning the researcher. An appointment was set up to see her at home for the conversation around arthritis. After initially talking at length about knee and neck problems and operations concerning these, the conversation went in the direction of the brutal murder of her husband. The couple was sound asleep one night when two burglars entered the house and demanded money and firearms. Nancy's husband refused to give them anything and he was strangled while she was laying next to him in bed. Nancy courageously survived this terrible trauma, but tells of her disappointment in our legal system in letting one of the trespassers go free. She moved from the big house and now lives in a secure townhouse complex where she manages the communal gardens of the complex. She is a busy 72-year-old lady who takes part in various community activities and church projects.

3.5.1.1 Letter to Nancy

Dear Nancy,

Thank you for sharing your experiences of mobility difficulty and the experiences you went through these past years concerning the trauma of your husband's death.

From the conversation we had, it seemed that you were concerned for your own safety and the prospects of losing your independence, and having to go to an old age home in the future. It seemed to me that you value your independence and being able to take part in community and church activities. You talked with excitement about *'my involvement with any thing that I can take part in'* and spoke about people ten years younger than yourself who commented, *"you wouldn't believe the energy this woman has"*.

I realize it is difficult to talk about arthritis and its effects at a time when you have a need to talk about your husband and the circumstances surrounding his death, and I appreciate you making time for me. I hope that by talking about the effects of arthritis and your husband, we haven't made it any worse for you. We

discussed the arthritis in your joints, and the knee and neck operations you had, as well as the medications and its effects on you, you said, *'having arthritis is a setback for me, but it won't get the better of me, our family has a history of being strong in dealing with hardships and not surrendering to it'*. I wonder whether this 'being strong' is something you know yourself by?

I was further wondering if the depression you are currently experiencing surprises you when you think of yourself in terms of being such a strong woman. Might it be that the experience of yourself as having depression doesn't rhyme with the *'strong fighter'* who is ready to tackle any problem? Might it be that by keeping going, you thought it was one way you could preserve your own power and resist the powerlessness in the face of what happened to you? Your ability to keep busy, and being involved in community activities has had a powerful impact on me and it challenged me. To be able to keep going in spite of all you have experienced seems to be a very great and rare gift.

Although you mentioned negative experiences with some doctors, you would rather speak about the respect you have for the knowledge of the doctors and the recommendations your son-in-law made concerning your knee, *'because he is also medical'*. This made me wonder about the things that you know about the conditions of arthritis and depression that the medical people don't know.

In the history of your arthritis you also mentioned that arthritis robbed you of certain handicrafts. You said, *'Arthritis does not like delicate embroidery work'* and you had to give up knitting as well. But, you had a certain wisdom concerning the position of your body in space, you mentioned, *'You must not always sit on the same chair when watching television, or you must not do things in the same manner too often. You must introduce newness and try different ways and different vantage points when doing an activity'*. I was surprised by this 'local knowledge' of yours and although you had to give up certain activities due to arthritis, it also taught you creative and innovative ways and it gave you fresh views of looking at certain things. I was wondering how this knowledge of "new ways of looking at things" came about. And yet, your innovative ways of doing and thinking did not stop here for you said, *'After my husband died, when I had to sleep alone in the double bed, I put a pillow behind my back just to feel that something is close to me.'* Is this ability to think creatively something that runs through your family?

As you related the story of your husband's murder and what happened, I have to admit that I had no words for the awfulness of what had happened to you. As you said, *'dit was 'n verskriklike ding!'* (an exceedingly awful thing), I can't even begin to imagine how awful it must have been, to have your home invaded by two black men,

your husband murdered, your belongings robbed, being held with a knife at your throat and then having your hands and feet tied with electric wire and left with the corpse of your husband in your bed and you still in your nightgown... It is hard to imagine that after having committed murder and robbery, one of the men got off scot-free.

When you mentioned the forensic tape around your house when you drove past it and the sad and tragic feeling it gave you, it got me thinking about the effects of a legal system that can let a criminal go free. You talked about the judge who said, *'if you (the advocates) had done more and handled the case differently, the verdict could have been different and the second murderer could have been jailed.* You said that it saddened your children and made you feel bad, *'but what could I do? It is something that happens in your life.'* You also said, *'let me tell you once again that I am a **strong person**, and I knew that I had to go on; I must be here for my children.'* We talked about how difficult it was for you to be a witness in the court case, *'I also did it for my family and for the community, that's why I became a witness in the court case.'* I as a researcher, was profoundly affected by the way you used your witnessing in the court case to the good of your community and family, and I wonder how doing this influences the lives of other people and perhaps holds hope for them?

I am recounting this story, perhaps because I feel that it needs to be told, as a testimony to how courageous you are, and the effect of your courage and the ability to stay calm in the face of terrible crisis, on yourself and on me as a researcher. As you said, *'to give you an idea of how positive a person I am, after I realized that my husband was dead beside me in bed, they told me to get up and give them the things they demanded - It was as if a stream of oxygen was pumped into me, it was like the power of God that told me "give them what they demand". I said to myself, 'If other people can get out of this, I can also get out of this'.* With these words you seemed to mean that the power of God also gives us the strength to carry on despite difficult circumstances.

Perhaps by having told me this, you created a way to find a voice and to stand against the awfulness of what happened to you. This brutality seems to have had a profound effect on you, and it has certainly shaken me up. It makes me wonder what other strengths are locked up in you as a person and in our humanity in general?

I found the story you told of the depression and you not succumbing to suicidal thoughts, very powerful. *'Holding on for your children'* seems to be a theme through your life that kept you going. We also talked about God and how you

gained strength from staying in His presence and praying. You said, *'there are powers greater than ours that decide over life and death - it was God's will that I am still alive today - decisions about life and death are not in our hands; my children also agree that it was not the doing of God that my husband died that day'*. I wonder if the gifts and qualities you have developed would have been as apparent or as strong if it hadn't been for the hardships you had to endure.

For me it has been an exciting and powerful path to walk with you. I am challenged and enriched by your ability to carry on in spite of so much hardship. Thanks, Nancy, for sharing the way all these health and life issues have impacted your life. As I have written this, I can't help but think about qualities you have, such as creative thinking, being creatively busy, independence, resilience and an ability to find strength in the midst of pain and hardship. These thoughts are impacting my life and giving me courage to continue in my search for answers to questions on health difficulties.

With love,

Susan.

3.5.2 Ansa

Ansa also responded to the church information leaflet and an appointment was set up for the research conversation. In her wheelchair, Ansa met me at the front door and I was introduced to her ex-husband, Willem, with whom she still shares the house. Before the conversation started Ansa offered tea and muffins she baked earlier that morning. Ansa has known since the age of twelve that she had diabetes, and doctors and hospitals have been part of her routine since an early age. Her vision became problematic in her early twenties and currently Ansa has only five percent vision, she can read when the letter size is big and also uses a magnifying glass to read smaller fonts. The hearing in her right ear has been affected by strokes.

Because of Ansa's difficulty to see, the font size was set to 20 in the letter that was taken back to her for comments and suggestions.

Writing the letter to Ansa was difficult. Maybe this was so because the conversation seemed to become less about her alone and more about both her and my journeys. In this way it was difficult to separate her disability and meanings attached to it, particularly around spirituality,

from my own. This is not in itself a bad thing, because within a more participative research the boundary between the researcher and the researched becomes blurred.

As an aid in getting out of the difficulty of writing to Ansa, some ideas in narrative therapy were revisited. It included maps to help one organize one's thoughts through landscape of action and landscape of identity questions (Morgan 2000:60-72). These questions concern what happens/happened and secondly the meanings attached to the actions or facts. When questions were asked in this manner, it appeared to relieve me of the 'stuck-ness' and opened up possibilities to use more descriptive language in verbalising ideas about our conversation.

The researcher's ideas are, in a postmodern idiom, not separate from the person you are working with, and it appears that the closer your landscapes are to another's experience, the more confused you can become. Immediately after returning from our research conversation, I started writing field notes about the conversation and how deeply touched I was by her faith and spirituality. These field notes together with the landscape of action-and-identity questions helped in writing the letter to Ansa in the way that I did. Being profoundly affected by her words might have caused the researcher to miss some of the actual discourses present in her language, but the letter that has been written speaks of the surprises, which might (not purposefully) be stumbled upon in research.

The narrative style in which the conversation was conducted allowed the researcher to not experience a sense of burden and responsibility to solve Ansa's health difficulties, but rather to experience joy, warmth and genuine interest in her spirituality, creativity and ingenuity. (See appendix 4 for an excerpt of Ansa's transcribed conversation).

3.5.2.1 Letter to Ansa

Dear Ansa,

Thank you for sharing your experiences of Mobility Difficulty with me. It has been a profound experience to have had a conversation with you around your diabetes, blindness and subsequent inability to walk. I realize it is difficult to talk about diabetes and its effects, and I appreciate your making time for me. I have changed, and I am challenged as well as enriched by your ability to handle the health and mobility difficulties as well as sight problems that are part of your life.

You experienced diabetic symptoms from the early age of twelve years and even as such a young girl you did not shy away from testing and injecting yourself with insulin, while still being in boarding school. Even now, where you admit that it is difficult to live by the clock, you do not complain. You say '*I have to eat on time, test on time and inject on time' the clock rules my world... but it is something I have to live with*'. It seems to me that you recognise the chaos of your illness, but at the same time acknowledge how difficult it is to live with it, although the acknowledgement is not a complaint. This seems to have brought on a certain toughness. I was wondering how this toughness came about. Is this something that runs through your family, the ability to be tough and take responsibility for yourself? Is this something that you know yourself by, this strength in difficult times?

On your honeymoon you realized that your eyesight was becoming problematic and you had to cut the holiday short in order to have surgery for rectifying the problem. Then followed a history of treatments and operations for releasing the pressure behind the retinas of both eyes. Your eyesight was restored and you could see, drive and carry on with your life and also practice your favourite artwork that you enjoyed tremendously. You said, '*The Lord was wonderful to me, because after the surgery I could see again!*'. Gradually, your eyesight deteriorated again and cataracts obscured your vision where currently, you must cope with distinguishing between light and darkness and being able to recognize little movement. You told me about the red gel coating you treat your nails to but quickly added that, '*it is not out of vanity, but the doctor recommended it so that my splitting nails can be protected and that I can see where my nails are*'. Thinking about vanity I am challenged by what seems to be very creative thinking. To me being practical and not vain was a mechanism of coping with diabetes and blindness.

You told me about the foot operations and the coma you went into while being under sedation and how, for a month you had been in intensive care due to the coma. This has affected your kidneys and so the potassium and calcium balance in your body is out of synchronisation. You said '*I must watch carefully what I eat and my meals are not exactly what you can call "exciting". Kidney dialysis might be in store for me!*' The illness has even robbed you of your ability to walk, due to the coma the balance centre in your brain was compromised and walking became a problem. You said, '*I can stand but must hold on to something like my wheelchair and finding the balance to start walking is no longer there. It is as if the brain cannot tell the feet to move*'. And yet you keep going and are able to find joy in the little things life still has to offer, like taking care of your bulldog Griet and hearing and having her around you. Recognizing the meaning of the '*little things in life*' seems to be a very great and rare gift.

I have to admit to learning a great deal from you about your 'local knowledge' of the little things', and although you had to give up a lot of aspects of being well due to diabetes, it also taught you new and innovative ways of mobility. You said when you wake up in the morning, *'I have to take five steps to the bathroom which is very difficult for me, many a time I just crawl those steps because it is easier.'* I was wondering how this knowledge of "finding ways of moving about that does not include walking" came about. Is this something that you know yourself by?

As you told me the history of your diabetic experiences, I have to admit that I feel privileged to have been a witness to your suffering in my position as a researcher. I am recounting your story here as a testimony to how courageous a woman I feel you are, and I would like to comment on the effect that your relationship with God had on me and how this challenged me.

It seemed to me that your coping with the condition goes beyond living well with it; what I experienced while being with you goes beyond words and language. Although you find it hard and it saddens you at times to be living in a body that is not functioning properly, you seem to have a spiritual wisdom about living in this body and a knowledge that there is more to life than physical bodies that let us down. Your spirit seems to know something of what it is to live life that your body doesn't know. How did you come to such spiritual knowledge? It makes me think about the important spiritual knowledge of broken bodies and what would happen if books were written about such knowledge for able-bodied people to learn from. Do you need a broken body to come to such knowledge? I think I saw God revealing Him/Herself in your attitude towards the illness and the respect you have for your broken body. You seemed to possess an inner calmness and contentment, (although not 'satisfaction' with your condition) that goes beyond words, which seem to defy description. And yet I sensed a connectedness to the great "I AM" that you practiced in every breath and gesture. This connectedness goes beyond mind and embodied knowledge. I sensed something greater than human watching over you and taking care of you. To me it seemed that you knew something about well-being that other well people don't know.

Your body language, the way you touched your face, your facial gestures, hand movements, voice intonations, and covering your face with both hands at times as if to protect yourself against the happenings of the coma, revealed to me that there appears to be a knowledge in your body which is hard to find when you are not disabled. I am wondering whether you would have had the same "knowledge" if you did not endure the sufferings and hardships that you had to? And your eyesight - although you cannot see, I got the impression that you saw much further than I

can. I think God became more real to me in the moments I spent with you and I could see Him more clearly through your blind eyes than I could in a long time.

You mentioned how fond you are of people and how you enjoy others' company but how, nowadays, you are more alone and sometimes only have God as your companion and how your relationship to Him/Her grew out of this being lonesome. I find language limiting me in expressing the 'presence of God' in our conversation.

Might I have found in my conversation with you what I was looking for in this research? Have your words enabled me to give a new description to resilience? Is our ability to use language enough to describe spiritual experiences? It seems to me now that I have many more questions than answers. Perhaps by writing this letter to you it is also a way for me to find answers to questions I could not yet formulate within language. Maybe I have found, together with you, a voice and to stand against discourses of worthlessness concerning disability. Our conversation had a profound effect on me, and it makes me wonder what other strengths are locked up in you as a person and in our humanity in general.

Your message to people in similar situations was also very powerful. You said that if you are for example congratulating any person, disabled or not, on their birthday you want to tell them to completely immerse themselves in what they are doing and to enjoy it to the fullest. You also want to wish them health and wellness, exactly the things you don't have. It seemed to me that you have additional qualities of unselfishness and a great generosity of spirit.

I feel that you have opened a window for me to take a look at your world of courage, which I respectfully enjoyed. Your story will remain with me, and remind me, of a very caring, unselfish, and courageous woman who is making the best of the circumstances she was dealt.

Respectfully yours

Susan.

3.5.3 Angelique

Angelique was referred by a family member. A meeting was set up to conduct the research conversation. Angelique was prematurely born at four-and-a-half months gestation due to her mother experiencing placenta praevia. After the birth both Angelique and her mother fell victim to septicaemia and Angelique stayed in hospital for 3 months. Twenty-six years ago technology

was not as advanced as it is today and her mother could not touch Angelique for three months while lying in an incubator. The history of her disability will be worked into the ensuing letter. Angelique was recently married and lives with her husband, Tom.

In an effort to write a letter to Angelique the transcribed sentences and paragraphs were read and re-read several times. In the reading and re-reading of the text, a question regarding 'what was this particular part of the text *not* saying' started to develop. In a discourse analysis one pays attention to both what is said and not said but embedded within the discourses that are acted out. This question was helpful in gaining distance from the transcribed text and made it easier to search for the discourses Angelique used to describe herself and her condition. (See Appendix 4 for an excerpt of Angelique's transcribed conversation.)

3.5.3.1 Letter to Angelique

Dear Angelique,

Thanks so much for sharing your life and health difficulty story with me. I was captured by your telling of how, since you came into the world prematurely, you had to fight for survival and battle health hardships. I am writing this letter to you to honour your 'survival against the odds'.

I was particularly struck by your ability not to buy into the shameful and secretive discourses of the time that wanted to make your mother and you believe it is a shame to have a disabled child. I was left thinking what it might have been that enabled you to find your '*big personality*' in a way that acknowledges your disability, yet you are not defined by it. I am further wondering how is it that society can sometimes hold us responsible for our own conditions. I don't know if you also got that idea? What enabled you (and your mother) to take a stand against what society possibly wants to make us responsible for?

As a two year old you had to undergo intricate neuro surgery to relieve your spastic muscles and get coordinated movement. The physiotherapists who treated you back then also honoured your fighting spirit by making a video of your improvements and achievements. Even at such a young age you did not shy away from challenges. You mentioned that you were constantly '*on display*' - what was private to you was made public and the medical people used you as a model to demonstrate their advances in neuro surgery. With your '*big personality*' you helped them gain knowledge and they contributed to your personal growth with the attention you received in '*being a model*'.

You said that your mother '*took a huge step of faith*' in giving consent for the operation and '*that she did her homework*' before they operated on you. '*My mother wanted to know the stats on such operations but the professor had not yet done such an operation before. He told my mom that he had practiced on 100 cadavers and had done his homework well... She still took that huge step of faith and it paid off well. It exceeded their expectations - a lot of people were surprised at what I could do after the operation.*' It seems to me this stepping out in faith and accepting a challenge is something that runs through your family.

You also accepted the challenges towards independence. '*When they saw I could do things, they (the school and boarding school personnel) wanted me to become more independent. It was hard being pushed towards independence and at times when, for instance I fell out of my wheelchair they would leave me alone and crying and to my own resources to get back onto the chair. Eventually you realize that crying is not going to help and you must make a plan to get back into the wheelchair. These were hard lessons but now I am grateful and proud of the skills of independence that I won through hardship. You also said, 'People pushed so hard because they knew I could do it, but I didn't know.*' Even in times of self-doubt you are willing to accept a challenge. Is this something you know yourself by?

You also talked about how you never outgrew the Moro reflex, and how it made you the subject of immense teasing by fellow school children. Even so, you found innovative mechanisms of coping with the teasing and never allowing it to spoil your '*big personality*'. Yet I do wonder what lasting effects these cruel behaviours had on you. You further talked about the effect of the reflex and how difficult it is coping with loud un-anticipated noise, and how, in church, you sometimes have to sit with your fingers in your ears in order to test the noise levels.

Thinking about the assumptions we sometimes make about church, such as it being a safe place to exercise our faith, church has at times been, for you, a hostile place. Especially where you mentioned clergy trying to rid you of the demons of disability residing in you. They employed methods of demon-riding, which included loud noise. The very mechanism supposed to cure you, magnified the reflex, and their way of ridding you of the demon aggravated your symptoms. You also said, '*Maybe one or two times I might have missed out on a blessing because I have been too afraid (of the noises) to go to the front and get prayed for. But, I think, God understands, I think He would bless me in another way. I don't think He would force anyone to do anything you are not comfortable with.*' This makes me wonder whether the church, that we suppose (or take for granted) to be a safe place, paradoxically can be a harmful place and can contribute to holding us responsible

for our illnesses and in this way keeps us on the margins and prevents us from entering the "in" crowd.

You had similar experiences of marginalization when you went to hospital for check-ups on bladder and colon functions. You said, *'if you have a lackadaisical attitude towards emptying the colostomy bag and manually emptying the bladder it costs you dearly in terms of infections. I went in for a check-up and left two weeks later with bronchitis. The hospital staff members are not trained to look after a person who has a physical disability and it takes more effort on their side to take care of you. They even have to turn me every two hours, I cannot turn by myself. If you complain about treatment they are just terrible to you'*. When complaining you are silenced by their behaviour and this silencing takes you further away from the world of those who are able-bodied. This makes me wonder what you and other people experiencing disabilities can teach the medical world as to how to treat these health problems and the people behind their disabilities. We often take for granted that hospitals are places where we get treatment in order to get well, but sometimes those places of care can turn out to be the opposite.

Still, the marginalization did not stop here, for in your job as a secretary your boss abused her power and you were worked out of the company. I am assuming that losing your job was a direct consequence of her not seeing the human behind the condition. Despite being placed in such a disempowered position, you refuse to view yourself in negative terms. I wonder what 'having a big personality' has to do with this? And what do you know about power and using it that people in authority positions don't know? Angelique, it seems to me that you have found a way of redefining your identity so that it both acknowledges your disability, yet does not subsume yourself in the process.

You wanted to give a message to the able-bodied community and said that they should not be afraid to speak to disabled people: *'If there is something wrong with our legs, it does not mean there is something wrong with our heads as well - treat us as equals, not as aliens. We don't want special treatment... We have to work harder because we have to be so much more determined to prove ourselves and to prove that we are worth of being in a normal society.'* You also said that disabled people's voices could be strengthened by people such as myself doing research with the disabled community and it could aid you in empowering yourself.

Thanks, Angelique, for sharing the way all these issues have impacted your life. As I was writing this, I couldn't help but think about qualities such as you being a tough survivor, determined to face challenges and use your voice, resilient and finding creative ways of coping in the midst of health difficulties and the inability

to walk. These qualities make me want to celebrate our being human and they give me the courage to continue my search for life's possibilities.

Respectfully yours,

Susan.

3.5.4 Joan

Joan also responded to the church information leaflet's invitation and an appointment was set up. At the front door the homely smell of "beskuit" (rusks) baking in the oven greeted me as Joan bakes these to aid her pension income. Joan was walking with a walking stick and had a friendly welcoming smile. Her husband passed away a few years ago and she now lives by herself. At times she is extremely lonely and in need of human contact and conversation. I conducted this conversation, attempting to be sensitive to her loneliness and honouring her abilities of 'making the best of things as they were'.

At first glance the transcribed conversation with Joan seemed to include a lot of irrelevant information not related to mobility difficulties, but on closer inspection of the text a lot of descriptions were found where societal discourses could have had an influence on Joan's view of herself. The question on what the text was not saying was also very helpful in analysing Joan's conversation.

White (1995) says within a narrative study and in working with discourse analysis (2.4) there is a great interest in finding some of the ways in which dominant discourses may serve and assist problem stories. The beliefs and ideas that are assisting problems are often regarded as 'taken-for-granted', as 'truths' or as commonplace understandings (Morgan 2000:45) that are not expressed but implied. The researcher was interested in Joan's words that carried within them much assumed meaning, therefore the question on what the text was not saying was helpful. 'What is included or excluded and "not said" is determined by the dominant discourses in which participants live (Freedman & Combs 1996:38).

An excerpt of Joan's transcribed conversation can be found in appendix 4

3.5.4.1 Letter to Joan

Dear Joan,

Thanks for letting me into your world during the moments I spent with you while we had the research conversation. You made excuses that you didn't know whether your contribution could be used at all '*for I am a simple and plain person*', but isn't that where we find life's most precious moments, in the plain and simple day-to-day activities?

After being prematurely born at seven months, your mother died when you were only four days old, and you had to go through life in the care of others who were not your own blood relatives. Despite these obvious setbacks you seemed to show strength of character and a will to survive against the odds, and you didn't let circumstances get the better of you. You mentioned a letter that your mother wrote to your stepmother asking her to take care of you before she died. Thinking about your mother and the letter she had written and what careful thought and planning it must have taken, and how sad it must have been for her to have had thoughts of losing her life and giving away her baby, she still found the resilience to continue with planning your life and giving you a future. It makes me wonder what skills, including good planning you have inherited from her?

As our conversation progressed you mentioned how '*routine oriented*' you are and how you like to '*plan things and be prepared*', for example, you put aside petrol money in a separate tin for the month ahead. You also get up at five in the morning and plan your baking work, as well as plan your day when your granddaughter visits in the afternoons. Good planning and being prepared seems to have benefited you in a positive way.

You had bone and joint problems since an early age and had to walk with leg casts for nine months at the age of eleven, after which an operation followed to put pins in the leg. You seem to have mentioned it rather matter-of-factly, but I wonder what skills you possess that enabled you to get through such health hardships at a young age. Currently you are experiencing pain and discomfort as well as walking with difficulty and it is necessary to use a walking stick, of which you feel shy and self-conscious. You said, '*people say I am too young to have such mobility problems*'. But I think you know better, and I wonder what you know about mobility difficulty problems that other people don't know?

You mention that '*I have always been fat*' and it has influenced the way you view yourself and the world. Where did we get the idea that only thin people can be successful? And what does the media do to us regarding being thin? I wonder, if

we put aside the "fat glasses", what surprises we would find in seeing the Joan behind the fat. What about the 40 kg you lost in weight with the support of your slimming club? What does that say about you and your abilities? I think there is much more of a winner in you than you give yourself credit for.

I was thinking about that great loneliness you described; in the face of great loneliness you seemed to make the best of the circumstances you were dealt. You described having lost your job at the home industry as being a great setback for you and that you miss the people whom you interacted with tremendously, yet despite this you talk about making the best of your day. You creatively find ways where you can care for other people and the animals and birds you love so much, and you take care of your granddaughter. But I also wonder at what cost you are able to put on a cheerful face.

Your creativity does not stop here for you invent ways of stretching your money to be able to make ends meet. This is a skill that takes a lot of self-discipline and I wonder if this is something you know yourself by? Despite having a tight budget you always find time for other people and you will encourage a friendly joke and positive attitude.

Joan, thanks again for opening a window onto your world and allowing me a glimpse of what it is like to live in a body not allowing you to walk with ease. I enjoyed our conversation and will take with me your friendliness, openness and positive attitude towards life and people.

Respectfully yours,

Susan.

3.5.5 Liana

Liana (twenty-three years old) is a friend of the researcher's daughter and no stranger to the household. Her friendly, lively personality has always been appreciated and therefore it was found surprising when spoken to in the research conversation that Liana's state of mood appeared to be depressed. Liana injured her left knee on the action netball field when the ligaments keeping the kneecap in place gave way and tore. She was taken to hospital and had an operation to fix the torn ligaments. For six weeks Liana walked with crutches and a knee cast. A consequence of knee surgery is that the patient's knee swells and can become stiff if regular bending exercises are not frequently performed (some people even have to go back to surgery where the doctor bends the knee under anaesthetic, which was the case with Nancy). Due to the

stiffness and swelling it is very hard to “force” the knee to bend, which also causes pain and discomfort. It is a milestone when the knee can reach an angle of ninety degrees and this gives you a license to ‘take part in life’s activities (get back in from the margins)’ such as driving a car and walking without crutches. This ninety-degree bending is hard earned, and it was during this time, attempting to get to ninety degrees, that the research conversation was conducted.

Writing the letter to Liana was not easy, and a lot of thought went into it. Perhaps I found it hard because her words resonated so closely to the feelings I experienced when my mobility problems were at its worst. Here again, as with Ansa, the boundaries between researcher and researched might have become blurred. She expressed moods of sadness, which I could recall so well and the residue of it still resides in me. Perhaps this “closeness to home” made it difficult for me to write the letter to her, but analyzing her conversation opened a surprising angle to depression.

Liana’s depressed mood was similar to what I experienced during frequent hip operations and a knee replacement. Not being able to walk unaided brings with it a great degree of dependence, for instance someone must help you bath, wash your hair and put on your socks and drive you to places where you want to go. Liana’s feelings of not being able to fully participate in life’s activities, and life seemingly passing her by, while she was sitting on the margin and waiting to get in, were familiar experiences to me. It was a difficult place to be and I found it hard back then to uncover language in order to verbalize my feelings. During this time I was very aware of feeling sad, worthless and “down”.

The message received from society was related to issues of dependence versus independence. Our society, and especially the Afrikaans speaking society where Liana and I come from, places a high premium on independence. From a young age I was raised to ‘not look other people in the eye for anything I needed’, but to be independent, meet my own needs and be proud of it. The more independent one was the better for one.

By being dependent you could easily view yourself in binary opposites and good/bad splits. We have been scripted by our society into a position of independence as good and dependence as bad. Thus, adhering to societal views and discourses around dependence, a person experiencing mobility difficulty might view him/herself as bad which, in turn, might manifest in a depressed

state of mood. This also makes me think of modernism's pursuit of autonomy and individual independence, especially from a westernized perspective.

Transcribed excerpts available in Appendix 4.

3.5.5.1 Letter to Liana

Hello Liana,

After transcribing our conversation and thinking about it, I found so many 'workable' ideas playing in my head, making me think long and hard. Liana, I genuinely want to thank you for taking part in this research and for the thought provoking conversation I had with you.

The knee injury, operations and subsequent lengthy recuperating process came as a big surprise to you, due to the unexpected and sudden nature of the injury. You described wearing the leg brace and using crutches as having been difficult for you. During this time you lost a great deal of independence. You said, *'my mother helped me to bath, wash my hair and even to get dressed. It felt as if I couldn't do anything for myself. I am a very independent kind of person, so I would rather die than ask someone to help me with something! It was so hard at the beginning.'* It made me wonder what we are taught since early childhood about being independent and what assumed virtues lie in independence?

You also told me about feeling excluded when you and friends went on an evening out to watch a popular singer perform. Quite a number of people took part in a group dance, but you could not participate due to the knee injury. You spoke of how *'excluded from the dancing circle'*, you felt and that the mobility difficulty accentuated your inability to take part in such social activities. You sat on the margin, alone, and the happy dancing was going on without you being able to take part in it. Your feelings of marginalization and isolation were further aggravated by people staring at you when you walked with the crutches in a shopping centre. You said, *'the staring made me wish I could be invisible, I felt exposed'*. You described that you felt people who really cared for you, for example your boyfriend, also contributed to these feelings of not being able to participate in life, and not being good enough for society, when they constantly reminded you to do the exercises and to bend the leg. You remembered your boyfriend saying to you, *'we are not going out tonight if you have not done the exercises.'* *It was as if they were police-ing me.'*

These feelings of marginalization and isolation also brought on anger outbursts, and you told me about a time when you threw your cell phone against the wall because it wouldn't charge and the phone broke into a 'million pieces'. This made me wonder whether the anger could have been an expression of wanting to break free from dependence? It also made me wonder whether it is possible that your body expressed what your voice could not.

What really stood out to me in our conversation, were the issues of dependence and independence. The society in which we live places a high premium on independence and when you are independent you seem to be all right. Sickness and mobility difficulty as you experienced it brought with it the inevitable issues of dependence. Viewing ourselves according to society's standards, we see ourselves as being dependent, which is not a good thing. This "not being good" can affect our moods and might make us feel depressed.

I remarked that your mood seemed to me somewhat depressed and suggested you see a doctor for a prescription of antidepressant medication. You were worried about the side effects and about the stigma associated with depression. You said, *'I don't want other people to see that I am feeling sad, I would rather avoid people than having them say I am a real "sissy"; I'm afraid it will drive people away. On the other hand it takes so much energy to try and show a happy face when in reality I am feeling sad'*. When society expects of us to show a happy face despite feeling sad due to illness, it seems to have a powerful effect to isolate us and push us further to the margin, something you might not experience when well. This further made me wonder if society is not holding us responsible for illnesses that happen to us. I think you also remarked on it when you said, *'I did not choose this knee injury, if I could have changed it, I would have done so!'*

I find it hard to make individuals responsible for what illness has done to them. It got me thinking about the confusion that I sometimes experienced and how we can, when healthy, be on the right side of "life's happenings" and then, not by our own choice but when illness happens to us, we are on the wrong side of it. I wonder then how can we, when sick, avoid being in camps of goodies and baddies?

You mentioned how helpful it was to have been asked about this experience and to be able to express your feelings of sadness in the safe space of our conversation. The conversation seemed to have enabled you to find language and get clarity on your fragmented emotions and uncertainties. It made me wonder whether maybe having conversations as we had in this research, we can create safe spaces where we can comb out this confusion of goodies versus baddies and avoid the powerful effect this can have in marginalizing and isolating us. I further wonder if we can

bring into this safe space memories, expertise, skills and family traditions that will honour our way of dealing with mobility difficulties.

This illness story made a big difference to your life and you said you would like to write notes that can be distributed to people in similar situations so that they are prepared for what is awaiting them. I thought it a very creative, generous and resilient idea to grant other people the opportunity to information that you needed (but did not have) in the process of experiencing mobility difficulties. Included in these notes you would stress the surprising length of time it takes to get well and be able to use the knee as you knew it before. You said *'it takes time and people must be made aware that it takes such a long time, maybe then they will be able to cope better than I have coped.'* I wondered if these notes could be used as an antidote to depressive mood states and allow people to get a handle on their illness experiences? I am also wondering how such notes could influence other people's experiences of their difficulties and how such notes can create hope for them.

For me it has been an exciting and powerful path to walk with you. I am challenged and enriched by your ability to verbalize you feelings and experiences and also by the thought provoking conversation I could have with you. As I was writing this, I couldn't help but think about your remark that *'after this experience I have more appreciation of my own health and I will take better care of myself'*. I can just confirm this and say that after such an experience one's body and mind cannot remain unchanged. These thoughts are impacting my life too and giving me courage to continue in my search for answers to questions on mobility difficulties.

With love,

Susan.

3.6 CLOSING REMARKS

The order in which the letters were presented was not the order in which the conversations were conducted. Joan was the first person with whom the research conversations were done. What might have had an influence on the presented order was that when the researcher realized how lonely Joan was and how much she needed conversation, it "clouded the glasses" used to analyse the conversation. This clouded view might have prevented an 'interrogation' of the text as suggested by Phillips & Hardy (2002:6), clearer glasses were needed. In order for the clouds to lift, the order of the letters was changed.

I found Joan's loneliness troubling and wondered what it was about this loneliness that seemed to connect with me. In a way, as our conversation developed, I sensed a resonance in our mutual conversation that was perhaps both challenging her loneliness and contributing to the richness of my research journey. I also wondered how social discourses around loneliness could contribute to the disempowerment of people experiencing loneliness.

The letter to Nancy was written first, partly because it was the conversation that remained most powerfully in my mind. During the initial analysing stages much of the content of her conversation did not appear to fit the themes that have been selected. It seemed important not to screen out Nancy's voice but to participate with her and focus on the effects and meanings of her experiences. To be ethically accountable (discussed under 1.8.3 page 31) an attempt was made not to 'act as knower' but to focus on the person behind the condition. In this way knowledge was created in the unexpected moments and surprises of everyday living, the 'making of knowledge' was in the service of ethics.

How Ansa used her spiritual beliefs to establish meaning in her mobility difficulty experiences might have resonated with my own. The conversation with her provided spiritual thought provoking ideas and faith issues, which were greatly respected. As someone who belongs to a similar belief system, I found it difficult to distance myself from our assumed similar beliefs. It in many ways created blind spots for me because her 'taken-for-granted' knowledge about God agreed in many ways with my own and therefore it was more difficult to challenge it. This could be a way in which our 'truths' or discourses become established. I was touched by her faithful relationship to God, and in these moments of sharing this 'God space', I experienced something of a mutuality of faith that deeply affected me.

From the conversation with Angelique it seemed as if she enabled herself to live an independent life, despite her health difficulties. Although she described herself in disabled terms she was not fully defined by the disability. I was struck by her ability to resist the harmful effects of dominant discourses like for example; her refusal to believe that church is a blameless place. Even so, she did not equate the church with God, but see Him/Her as separate from the church and as her companion. In this way she used her spiritual beliefs to establish meaning in her disability. Congruent with narrative therapeutic practices the research conversation focused on the less listened-to story and voice of Angelique. In this way research was done respectfully

without enfeebling Angelique in the process. Her deficits were not under the spotlight, but her capabilities and resiliencies were given recognition.

The conversation with Liana resonated with the experiences the researcher had concerning mobility difficulties. Her story challenged me to find language for my own needs to break free from societal discourses around dependence/independence and depressive mood states connected to illness and mobility difficulties. I found it interesting that I was able in this letter, to both resonate with Liana and to also experience her isolation. It makes me wonder whether it is easier when both of us have experienced exclusion not to buy into the 'taken-for-granted knowledges, or whether to question it more?

The letters included questions as well as interpretative statements. The questions posed to the participants might sound similar because this research was looking for common and taken-for-granted societal discourses. The researcher realizes that some of the questions might have sounded a bit prescriptive; maybe there has been a lookout for subjugated discourses of ability, rather than disability.

In the attempts to analyse the discourses of the participants, the researcher was not able to keep a clinical distance from them as people. Through the questions that were asked in the conversations and the letters, the researcher partially entered into their life worlds and this gave the study a somewhat more participatory approach than a straight discourse analysis, and it invited the participants to become part of the written word. This is regarded as a respectful process.

These conversations challenged and changed me as researcher and I am excited by the new thoughts and ideas they awoke in me. Hence, I now continue with chapter four where I will link text, context and discourse while weaving the feedback and comments of the participants through my own reflections on their texts.

CHAPTER 4

Organising the organs

With the research 'body' developing, this fourth chapter is where work will be done on arranging the organs, which are the participants' stories and discourses. Within a social construction paradigm there are multiple places in which their words can fit, depending on the many meanings and discourses generated within the analysis. In order to find order it is necessary, in this chapter, to find a temporary resting place where the participants' words might sit in a way that is comfortable for them and that brings clarity to the analysing process so that the chapter can form a coherent whole. It resembles the pieces of an unusual puzzle where the pieces can be placed into both a dominant picture as well as crafted into alternate pictures. It is difficult in that some of the original words are in danger of losing their impact, and the researcher feels responsible for her interpretation and stewardship of the participants' stories. This cannot be avoided, as some words will be a focal point while other words will be waiting their turn to come into focus.

In doing the discourse analysis on the various transcribed conversations of the participants, the researcher attempted to be sensitive to the different ways in which the participants use language in how they have constructed their ideas and beliefs, regarding Mobility Difficulties.

This chapter will reflect on the various or alternative descriptions that the participants have given to their experiences of Mobility Difficulty. This works with an assumption in narrative therapy that life is multi-storied and alternate stories await an audience in order to be brought to life (Morgan 2000:69). In this way the context required me, as a researcher, to also engage with dominant discourses in my own life and allowed me to examine some of its ill effects.

4.1 THE CHALLENGES OF DISCOURSE ANALYSIS

A challenge in this research was to maintain an interrogation of the participant's texts while at the same time appreciating its difference to the researcher's own discourses of mobility difficulty. As mentioned earlier under paragraph 2.7 page 55, and as discussed by Phillips and Hardy (2002), such a challenge can help one grow from a position where the researcher assumes

that he/she would know what the participants' experiences were like for them, to a position of self-other participation where meanings attached to experience are not assumed but explored through language. Due to the researcher's own experiences, it might have been easy to assume that others would also interpret their mobility difficulties in a way similar to a 'blemished' view I had of myself. Therefore, the researcher had to be vigilant in the interrogation of the participants' texts.

As researchers, we step into another person's world out of the framework of our own 'understanding'; therefore you can never be neutral or absolute and objective. An attempt was made in the interrogation of the texts, albeit as an insider or fellow traveller, to understand the specific situation of the participant and to 'unpack' her discourses, many of which crossed with the researcher's own. Consequently, the researcher wasn't working with an objective understanding of participants' discourses – the researcher tried to make sense of the participants' discourses by a subjective understanding or interpretation of their experiences seen through the researcher's own life experiences of mobility difficulty. Their texts were studied for clues to the nature of their discourses, knowing that discourse can never be found in its entirety.

Another challenge was that participants had to remain at the centre of their stories. Therefore the interrogation of their texts had to be careful, yet deliberate; it also had to provide an acknowledgement of the ways in which the stories of the participants were linked to or differed from the stories of the researcher. This gave attention to transparency – being open about why the researcher was saying what she said and recognizing participants as the experts of their own lives (Morgan 2000:125). This could also have aided in reducing the powerful position of the researcher, as mentioned in the second chapter.

Discourse analysis further held a challenge, and perhaps an advantage, in that it did not attempt to explain social phenomena; rather it revealed the discourse behind the phenomena.

4.2 ZOOMING IN ON PARTICIPANTS' WORDS

This section has been organised according to the themes discussed in the previous chapter, which will again be mentioned briefly:

1. Discourses describing participants' identities
2. Some of the taken-for-granted assumptions participants and/or society might have about the descriptions of their identities
3. Themes around doctors', or other persons in authoritative positions' use of power, in working with people who experience mobility difficulty
4. Knowledge that participants have about their conditions that they wish the medical fraternity would notice
5. Participants' messages to people in similar situations.

The rest of this chapter will incorporate the above themes into the reflections on the participants' words. The researcher realized that the choice of these particular themes might have said more about herself than it says about the words of the participants, and that her assumptions, values and subjectivities as a fellow traveller, could have shaped the enquiry and become part of the argument.

4.2.1 Nancy

Under the first theme, *discourses describing participants' identities*, fits Nancy seeing her identity as a '*strong woman*' rather than viewing herself in disabled terms. In the transcribed conversation, her being a '*strong person*' came up about six times. Nancy mentioned that '*being strong*' was part of her family of origin. Although it was not taken up in the letter, she talked about her parents divorcing when she and her siblings were still young. She also mentioned that the divorce experience, and the "exclusion" they experienced as a result, back then, contributed to them, as a family, and her as an individual, becoming stronger.

Perhaps, having mulled over her transcribed words and interrogating her text over time, gave me greater opportunities of reflection. In hind sight, if I had to write a letter to her now, it could include a paragraph on the divorce of her parents and discourses regarding exclusion and perhaps, shame and how this might link with the challenges of mobility difficulty and exclusion. Responding to the participants as soon as possible after the conversation, without using too much time for reflecting and analysing was an ethical position the researcher wanted to adhere to.

Nancy mentioned that in her childhood days divorce was viewed as a shameful thing, and I wondered if '*being strong*' hadn't been developed, maybe solidified, as a counterweight to being

disempowered by shameful discourses. Nancy also mentioned a shared inherited strength of her family who were left behind by the divorce: *'I come from a family of strong people'*. Linking *'being strong'* to the here and now, strength could have re-emerged when Nancy's husband was murdered, and might be viewed as a counterweight to the disempowerment she experienced during the murder. *'Being a strong woman'* seems to currently guide Nancy's thoughts and actions. Seen through a post structuralist lens that critiques a deficit model which could be analysed as possibly defensive, it is perhaps interesting to understand it more as some of the abilities that have enabled her to live in a difficult world.

Thinking pastorally about this discourse of strength, I wondered how her pre-suppositions of a *'strong woman'* influenced the way she sees God. Her words - *'after my husband was dead beside me in bed, they told me to get up and give them what they demanded – It was as if a stream of oxygen was pumped into me, it was like the power of God that told me: "Give them what they want"'. I said to myself "If other people can get out of this, I can also get out of this"'* - led me to think that God could be her partner in *'being strong'*. The less powerful she was, the more she needed a miracle God, as a fellow traveller and deliverer, to rescue her in her hardships.

This may speak of discourses of faith in God that could be a vehicle of strength, when she was disempowered by circumstances and unable to rescue herself. Ideas about God as deliverer are particularly strong in the Dutch Reformed church where it also has an interesting history, for example the Israelites coming to the Promised Land after years of hardship in the desert. This is also true for Africans within a liberation theology and can be related to an Afrikaans history of powerlessness in the face of the British at the turn of the twentieth century during the Anglo-Boer war. This fits with Gerkin (1991) as discussed on page 43 (2.3.1) and his narrative hermeneutic approach to pastoral care, that takes seriously the biblical, Christian values expressed through images and metaphors, found in the Bible. This gives a core narrative and stability within a given community that offer both strength and meaning. According to Gerkin (1991) there is a dialogical relationship between the issues and problems that people encounter and the core metaphorical values and meanings of the Christian story. Thinking of myself, coming from a similar church background as Nancy, could help in knowing something of her context and the history of her strength. This strength however, is important to understand in relation to weakness, which may also underlie her story of mobility difficulty.

Looking for discourses to fit under the second theme - *some of the taken-for-granted assumptions participants and/or society might have about the descriptions of their identities* – the researcher held an assumption that people suffering with mobility difficulty tend to remain more static than others and therefore more caught into rigid patterns of behaviour and movement. Because of this I became curious as to why Nancy changed chairs and even switched beds often. It could have been for many reasons, for example to keep her joints supple or to exercise her muscles. On enquiry in the initial research conversation, Nancy said it was to enable her to ‘find different vantage points, and see things from a different angle’. A dominant societal discourse, which I too live within, takes it for granted that if you have trouble moving you should remain static and don’t need to move at all, or that you function best under familiar surroundings and circumstances whether you move with difficulty or not.

The new ‘vantage points’ seemed to enable alternate descriptions for Nancy in coping with mobility difficulties. Nancy extended these alternate descriptions when she mentioned that she had to adjust to the arthritis in her fingers that ‘*does not like delicate embroidery work*’. Although she took medication for the symptoms of arthritis, she had to adjust to the arthritis in her hands and had to find different ways of keeping her hands occupied.

Also fitting under the second theme and this might connect with the first theme of Nancy seeing her identity as a ‘*strong woman,*’ strength seemed to be linked to ‘*staying independent for as long as you can*’. In this, strength and independence were virtues that should be sought. Both these qualities however, when read deconstructively, could be seen as both a weakness and a strength. For a discussion on aspects of deconstruction see Powell (1997), Anderson and Goolishian (1992), Burr (1991) and Gergen (1991) on page 57. Strength and independence could feed into modernisms discourses of the self-sufficient individual and bring with it feelings of isolation. On the other hand it could also be understood as admirably challenging a disability discourse about weakness and dependence. Thus, taken-for-granted ideas can both provide resources to participants on which they can draw in difficult times but it can also lead to feelings of isolation. It can also be linked to the above part in seeing God as a ‘strong God’, which can be both disempowering as a patriarchal, controlling father figure, or empowering as a comrade who travels the road.

Themes about *doctor's use of power in working with people who experience Mobility Difficulty* did not specifically feature in Nancy's words, although I prompted her to talk about it. Her pre-suppositions about doctors did seem to influence the way she saw the power of medical people. She mentioned that her son-in-law is a specialist doctor and that he '*is also medical*'. It seemed as if Nancy had great respect for her son-in-law's knowledge and she seemingly blindly trusted his judgement. This could be for many reasons, one being the elevated status of medical power and authority. This seemingly blind belief in her son-in-law's knowledge could be something of the taken-for-granted assumptions that are so assumed that they lose the need to be languaged.

Any discourse involves power relationships (Flaskas & Humphreys 1993) and is sustained in social practices which are not easy to access because they are rarely talked about. To examine the *doctors' authority* discourse I would have wanted to know how their power came about and is sustained in Nancy's eyes. This did not happen in my conversation with Nancy and I found myself trapped into a collusion of silence concerning the unquestioned authority of a doctor and the disciplinary power relationship of what is allowed to be talked about. This could also fit with a more traditional power relationship in which 'patients must be seen and not heard' or, that people in authority positions should be respected and obeyed and not questioned or challenged. This then loops back into the history of Afrikaans, Dutch Reformed upbringing playing into the hands of patriarchy.

Discourses about the legal system featured and its assumed power disappointed Nancy by '*letting one of the two men who murdered her husband go free*'. Nancy said '*the judge believed that if the advocates had done a better job and handled the case differently the results of the case would have been different and both perpetrators would have been found guilty*'. She said that it saddened both her and her children and made them feel bad, '*but what could I do?*' These words of Nancy indicate that she had no power against the authority of the legal system, a powerlessness that has been internalized (Kotzé 2002) that could have let her resort to '*being a strong person*' which again plays into the hands of isolation or patriarchy. This made me think about ways in which systems of control demand a naïve respect and admiration for those who possess knowledge of 'the truth'. This feeds into a powerlessness of those who don't necessarily possess knowledge and judicial power; like Nancy. She probably had to cope with the paradox of believing in the right and righteousness of a judicial system on the one hand; and her disappointment in the justice system that didn't do justice, but let a murderer go free. Maybe her

'letting go' belongs to a far older order of power relationship than modern or pre-modern power makes obvious. It could be a power that chooses not to be in a relationship with 'rights' or 'entitlement'. It could belong to a different spiritual order of being strong in the face of injustice in this world.

The writings of Foucault (discussed on page 47) in *Discipline and Punish*, (Fillingham 1993) is interesting in this regard; concerning modernism's splitting of subject and object that claims to be more progressive and humane than the pre-modern era in which it was not about being 'good' or 'bad' but about having a god-given right to power. Foucault argued that although it appears as if individuals today, such as Nancy, have 'power' and 'rights', it could be that modern forms of power relationships render power less exposed and obvious. In other words, people who live with disability are rendered powerless in more subtle ways, particularly through the lenses of normality and abnormality.

Discourses that fit under the fourth theme – *knowledge that participants have they wish the medical fraternity would notice* – did not seem to me to be present in Nancy's conversation. As Nancy was among the initial persons I had the conversations with, ideas of the themes were not strongly established in my mind and I did not ask her specifically, as with the others, what she knew about her condition she wished the medical fraternity would know. I do not want to risk a guess at what her answer might have been, because to me, this would not be ethical behaviour and my voice would be privileged over her voice, and it will not contribute to doing research *with* the participants. In the following conversations the themes were kept in mind when the participants were questioned about their experiences of mobility difficulties.

Out of Nancy's transcribed conversation, discourses of positive attitude and faith that could fit under theme 5 – *message to people in similar situations*. could be gained. Her words, '*holding on for my children*' and, '*it was God's will that I am alive today*' points to her positive attitude and alternate descriptions towards life. Her positive attitude could have solidified her '*being a strong woman*'. Her pre-suppositions of positivity and strength could have influenced the way she judged herself and in turn influence the message she would like to convey to people in similar situations.

Nancy's above words about '*God's will*' might also be linked back to the second theme. Of interest in '*God's will*' could be an ability to see beyond man as the sole dispenser of justice; and understanding something of a more traditional power relationship where Nancy has an understanding that man is not as much in control of the world as people might think.

Nancy's feedback regarding the letter was that it was indeed a witness to her experiences and that the words on the letter are not as temporary as spoken words are. She said it was as if her strength re-emerged through the letter and if she compared herself with four years before she was currently more connected to her stronger side. However, on my reflection of what was left out in the letter, it could mean that a significant purpose of letters is not so much about their cleverness or accuracy, but more about an ethic of caring about another human being.

4.2.2 Ansa

The first theme – *discourses describing participants' identities* – fitted Ansa seeing herself as a patient requiring medical interventions on an ongoing basis. She also viewed herself as disabled due to the diabetes that left her with poor eyesight, limited mobility and dependent on a wheelchair. This view came about due to an early diagnosis of diabetes (since the age of 12) by medical people. Her identity as a patient had been formed and might still be shaped by the medical diagnosis of her symptoms, and this could be linked to theme three. The authority of diagnosing her as a patient lay in a medical view of her symptoms. This 'patient' and subsequent 'disabled' view guided her thoughts and actions. It might have been difficult for Ansa to choose another identity outside of patient-hood, because we are limited by our discourses and the social constructions of our identities (as discussed in 2.7 on page 55). Her pre-suppositions about the condition influenced the way she saw herself, and her social realities defined her as a disabled patient.

Under the second theme – *some of the taken-for-granted assumptions participants or society might have about the descriptions of their identities* - Ansa might have thought one is no longer part of the 'in-crowd' you are excluded from the 'normal' society and thus marginalised by your condition. This exclusion might not be a product of the individual's circumstances or physical symptoms, but because of what society takes-for-granted about health difficulties.

If you are enjoying good health you tend to think ‘thank God that it’s not happening to me’. Society is inclined to take-for-granted that you will get well after illness; if you go and see a doctor and he/she treats or operates on you, one will get well again. According to Frank’s (1998) restitution story, mentioned on page 15, society further wants to believe that what you have lost in a certain department of your life due to illness you can gain in another area. Maybe society would like to put a more ‘positive spin’ on illness stories because they want the reassurance that if they too become ill, they can find something good and enabling in illness. This ‘positive spin’ might embody every healthy person’s fear of illness without the possibility of recuperation. If a healthy person then does become ill it is far easier to imagine that every breakdown can be fixed. Doctors as well as society reinforce the ‘getting well’-discourse by speaking only of ways of getting better and fixing, not of dealing with not getting better. Under modern discourses of health ‘not getting better’ and even death is the great enemy, as it means man has lost control over his destiny.

Issues about Ansa’s spirituality might also fit under the second theme. Although nothing ‘intrinsically good’ (see the discussion an aspects of Frank’s (1998) quest narrative on page 16) came from Ansa’s diabetes and Mobility Difficulties there are certain areas of Ansa’s life she seemed to have reclaimed from the illness, for example her spirituality and discourses of faith in God. This resonated with my own taken-for-granted beliefs about God and could have created an assumed mutual understanding of our shared spirituality; therefore I found it difficult to challenge it. This might have created blind spots for me, as it was difficult to separate her spirituality from my own. This (as I said in the previous chapter) need not necessarily be a bad thing, because within a more participative research the boundary between researchers and researched is more blurred. Additionally, it might be a way in which our ‘truths’ become established.

Third theme - *doctors’, or other persons in authoritative positions, use of power in working with people who experience mobility difficulty.* Ansa realized that she wouldn’t have the quality of life she has if it hadn’t been for doctors’ knowledge about her diabetes. In this it becomes difficult to criticize or challenge the authority of the medical profession. As this research works in a space where modern and postmodern knowledges overlap, (as in medicine linked to narrative) I found it difficult to deconstruct ingrained beliefs of the ‘good’ power of medical people. It could also be that I found challenging the medical world difficult, for if it hadn’t been for the power that their knowledge brought, I would not have been able to walk today. It is,

however, also true that medical power has held an enormously privileged position and times where medicine has failed, or created greater problems, can be overlooked in such a dominant narrative.

Forms of modern power and its diagnostic tools, as discussed in theme one, are likely to have contributed to Ansa feeling isolated and lonely and her valuing the '*little things*'. Isolation and loneliness in an intrinsic power relationship could then contribute to her relationship with God. Isolation and disempowerment through illness conditions then invites God more as a fellow traveller and a miracle God to rescue us from our hardships (see Nancy).

The analysing of Ansa's conversation further exposed medicine's power relationship with disability. Within this power relationship which Foucault (see the discussion on aspects of power by Fillingham (1993) on page 47), described as never equal, Ansa's narrative perhaps displayed this inequity of power when she said '*the red gel coating on my nails is not out of vanity, but the doctor recommended it*'. Within this it might be assumed that the doctor or medicine even takes control over something as personal as your choice to have red nails, or not. This makes the doctor even more powerful and tips the scale on inequality of power to an extreme point. Hence, it might be difficult for Ansa to choose another identity outside of patient-hood, because power issues can limit our discourses and the social constructions of our identities.

Looking for discourses to fit under the fourth theme - *knowledge that participants have about their conditions that they wish the medical fraternity would notice*- I find the words: '*there is more to life than physical bodies that let us down*' and '*there appears to be a knowledge in your body which is hard to find when you are not disabled*' descriptive of what Ansa knew about her condition that the medical fraternity do not know. It seems as if she is certainly 'not glad' (Frank 1998) to have the conditions of diabetes and Mobility Difficulties, but it has given her the opportunity to understand endurance and more fully appreciate life and living. Diabetes and Mobility Difficulty in other words have made an aspect of her life visible to her that would not have been possible were it not for the health hardships she had to endure. She can now live a meaningful life, not because of what illness taught her, but in spite of its influence. Suffering now has certain meaning, including spiritual meaning that the medical fraternity most probably would not have had experience of.

Included in her illness narrative may also be her sense of recognising the chaos of illness that is hard to understand if you have not lived within it (see Frank's (1998) chaos narrative description on page 15). Her words '*I have to eat on time, test on time and inject on time*' and '*my meals are not exactly what you can call "exiting"*' as well as '*it is as if the brain cannot tell the feet to move*' and also '*I have to take five steps to the bathroom which is very difficult for me, many a time I just crawl those steps because it is easier for me*'. might reflect this. Having said this, Ansa seems to know that she will not get well, but simultaneously recognizes that her illness is chaotic; but despite of this illness metaphor she knows that illness could lead to new insights. This can be linked to aspects of Gerkin's (1991) core narrative, discussed on page 43, that helps to find some organization within chaos and can also provide strength and meaning. She can now live a meaningful life, not because of what illness taught her, but despite its influence. Within this her resistance to medicine's power (Fillingham 1993) might become visible. She refuses the 'restitution narrative' (see aspects of the restitution narrative by Frank (1998) discussed on page 15) by recognising the chaos of her illness, but simultaneously finding alternate meaning in it. Hence the remark in the letter '*there is more to life than physical bodies letting us down*'. The illness metaphor does not fully define her identity and the above words indicate a great ability to reclaim alternate identities and meanings of her life and how she can use what is left to benefit her. The above might illustrate how Ansa both belongs to certain medical discourses but is also in resistance to them.

Theme 5 – *Ansa's message to people in similar situations*. This theme connects to theme four. Her message connects to discourses of living a meaningful life not because of what illness taught her, but despite its influence (see the discussion on aspects of the quest story by Frank (1998) on page 16) In other words she might be grateful for what she gained from her condition, although she is not glad to have the condition. In making meaning of her illness, Ansa seems to know and accept that she will not 'get well' (Frank 1998). In this acceptance and meaning making the other side of the discourse coin becomes visible which could be a discourse of 'gratefulness' or 'unselfishness'. This might be seen in her message to others '*I wish other people health and wellness*' and '*they must immerse themselves in what they are doing and enjoy it to the fullest*'. These words resemble discourses of unselfishness.

4.2.3 Angelique

Theme one - *discourses describing participant's identity*. Disability seemed to greatly define Angelique's identity as could be seen in her words '*since I came into the world prematurely I had to fight for survival and battle hardships*'. In this she appeared to be sitting on the sideline, not actively participating in her life story. The power of her 'disabled' discourse might have produced or shaped her reality; her talk about it and the way she languaged it made her disability 'real'. Her ideas on disability might also have come about by the diagnostic power of modern medical discourses and its influence on her identity descriptions. Since birth medical people diagnosed and described her in disabled terms, thus limiting her choices of her own narrative. Deficit, deficient and broken, along with fixing, have been influenced by a medical model that places great importance on being defined in physical terms (for aspects of the medical model see the discussion on page 12). Any dominant discourse has an ability to both define and describe who we are. However, in this writing the interest was in the less talked about ways of resisting the harmful effects of dominant discourses in participants' lives .

Theme two - *some of the taken for granted assumptions participants or society might have about the descriptions of their identities* – can be viewed as connected to theme one. Some of the consequences of Angelique's talk about her identity can be that she takes certain things about her condition for granted. It seemed that others – her caregivers, the doctors, nurses, hostel personnel, physiotherapists, ambulance men, etc. have displaced her personal presence, creating something of what Frank (1998) might describe as a chaos narrative (see page 15). They were the active players in her life story and Angelique sat on the sideline or was absent. This could also have contributed to Angelique seeing herself as a model, constantly on display, and lacking an alternative description. Society took for granted that, in order for medicine to gather knowledge, and consequently, to have power in conquering our health difficulties, Angelique had to be a model and on display. This perhaps becomes a challenge in society today to find ways in which those who seem to be 'models' or 'puppets' can find ways of participating that do not silence them or put them on the margin. This also becomes an ethical concern. The extremity of this position may well have contributed to her voice finding its rage in slitting her wrists.

In our feedback conversation Angelique wanted to tell me, and gave me permission, to use the fact that she recently tried to '*slit her wrists*'. She said, "*I had to phone an ambulance to come*

and fetch me. The paramedic man knew me from a previous trip to the hospital due to an earlier illness and he was VERY, very, very concerned for me when he realized that I slit my wrists. What I got from his concern was that there are still people who care for me and who are worried about me. He was a virtual stranger and he was so upset and worried about me; that gave me reason to go on. I was so relieved that they could help me and that I didn't have to die, because I do not want to die. I think with the wrist slitting I just wanted someone to hear my voice and needed to know that my life was significant to someone ... At this stage I think what aggravated my problems is that I am living in a different place, far from my family and I feel isolated in my environment and I know I am prone to depression. It is far from anything familiar and I cannot see my family and the people who support me as often as I was used to, or as often as I need them. We also had to employ a maid who comes in every day because I need someone to help me around the house. It has financial implications that we cannot really afford”.

In a discourse analysis one pays attention to both what is said and not said but embedded within the discourses that are acted out. For example in her words *‘there are still people who care for me and who are worried about me’* she could be implying that society does not really worry about the disabled. This also feeds into an illness discourse, which says *‘I deserve attention when I am ill or needy’*. It could be easy to pathologise this, particularly within a discourse of the individual, independent, autonomous person. However, a more traditional reading of this might be that people need to feel connected and will go to desperate measures to connect and know they are worthy of attention. It could then be that Angelique was resisting marginalization and isolation with the wrist slitting.

Theme three - *Themes around doctors’, or other persons in authoritative positions’, use of power in working with people who experience mobility difficulty.* Theme one and two included words about doctors’ use of power, but in Angelique’s case the church was a particularly powerful contributing theme. The church that one assumes, or take-for-granted, would be a kind place to someone disabled, can be a hostile place. In Angelique’s case they wanted to rid her of demons of disability and introduced measures (through loud language) that actually contributed to her identity of being disabled (by aggravating the Morro reflex); it could even have contributed in holding her responsible for her own disability. Angelique resisted their power in creating an alternative story by using the constitutive force of language to search out ways in which her descriptions of herself could escape the nets of dominant power discourses (see a discussion on

practical theology's relevance to this study on page 17). Her words *'I think God understands, I think He would bless me in some other way. I don't think He would force anyone to do anything you are not comfortable with'* confirms this alternative description.

Connecting this to pastoral care, the words of Angelique about demon-ridding opened up conversation around spirituality and faith issues where we explored the influence of theological discourses and connected them to her story. This exploration allowed a postmodern position of researcher as scientist to participate in a world where local knowledge was taken seriously and where dominant, subjugating discourses, 'truths' and injustices could be suspiciously examined. This stays in touch with contextual theology that takes sides with the marginalized and isolated people. It also allows for examining the ill effects of dominant discourses and finding alternate descriptions that engage with pastoral care in a different way; where Angelique's faith could be understood through the stories she told.

Theme four - *knowledge that participants have about their conditions that they wish the medical fraternity would notice*. Although Angelique describes herself in disabled terms, she does not fully define herself as disabled. There are areas of her life that are not subsumed by disability, for example, her *'big personality'*. Angelique also has practical advice to the medical fraternity – she wishes that the medical personnel could be trained to be more sensitive to the needs of the disabled, for they need more 'intensive' care than the able-bodied. She also wanted to write a manual to mothers of babies who are disabled, in order to inform them of what they can expect in future. This fits in with narrative therapeutic practices in which a problem rarely fully defines a person and where a person who lives with a problem is the expert of this problem.

Theme five – *message to people in similar situations* - can be connected to theme two- *what could be taken for granted about MD*. In looking for discourses to fit under the fifth theme Angelique's words *'if something is wrong with our legs it does not mean something is wrong with our heads as well.... Treat us as equals, not as aliens'*, were helpful. It showed that society's pre-suppositions about disability can influence the way they treat the disabled. It also indicated that a dominant illness or chaos narrative (see a discussion on narrative types on pages 14 to 16) is never fully defining a person. In other words, humans are in a resistant power relationship with a dominant discourse. Ways in which people who live with disability are viewed are, however, very much influenced by the larger discourses within any given society.

Angelique exposes something of a Foucauldian ‘gaze’ that suggests the disabled are linked to the mad and are to be removed to asylums (Sue, Sue & Sue 1994:18). The greater discourse in this sense influences a church discourse which could suggest that the victim [of disability] can be held, at least partly, responsible for the misfortune. Or, that people who were disabled were supposedly influenced or possessed by Satan’. No matter how these ideas came about, they still seem to have an influence on how society can push the disabled to the margin.

Through Angelique’s words: *‘we have to work harder because we have to be so much more determined to prove that we are worth of being in a normal society’* a double burden that the disabled have to cope with might be visible. Not only can just being what they are marginalize them; they also have to compete with the able-bodied for space in the workplace. Thus, concepts of disability can be sustained by discourses about them in the able-bodied and disabled societies.

4.2.4 Joan

Theme 1 - *discourses describing Joan’s identity*. Joan described herself in discourses of being fat, lonely and a victim of arthritis. The combination of these descriptions leads to Joan moving with difficulty. The history of her being overweight can be traced to early childhood where the doctors said: *‘your bones are too soft for your big body’*. This very powerful discourse that relates to weight becomes a significant player in current discourses around health and beauty. It is as if she is gazed upon by society as something that is less than acceptable. Joan has internalized this belief, which was expressed by her, as *‘I have always been fat’*. She says her obesity problem contributes to the arthritis and joint mobility issues, which is currently her main health complaint. The medical fraternity with their expert knowledge is centred in her identity descriptions as the central role players in Joan’s illness story, while she has become an object of their knowledge. Joan in this case becomes decentred and on the margin, the person behind the condition is lost and only the patient object remains; a patient that is gazed upon and judged in medical terms, particularly in relation to her weight, leading her to isolation and experiences of disempowerment. Joan also described herself in discourses of extreme loneliness since she became a widow and since she lost her job at the home industry.

Theme two - *some of the taken for granted assumptions Joan or society might have about her identity descriptions*. Society might want to hold Joan responsible for her arthritis due to her being overweight. Discourses circulating in society that could bring a cure might be ‘If she can

get rid of the fat she would get rid of the arthritis'. This discourse of 'obesity leads to health problems' might reveal why she sees herself as overweight and experiencing mobility difficulties. Her '*fat*' identity is written for her by the social realities.

In trying to deconstruct the '*fat*' discourse I asked her in the feedback conversation what she thought about the media and its attempts to make us believe that you should only be satisfied with your body shape when you look like the models and manikins showing off clothes. She replied that she had recently watched a television program about weight loss, and it was the first time that she saw people mentioning the struggle to lose weight. She said '*the advertisements always tell you about the easy bits, but they never show the struggle. I felt validated by the program showing it is not easy to loose weight*'. Within this '*feeling validated*' she might be resisting the powerful dominant discourse of slimness and medicine's authority and power regarding weight issues. Her weariness in giving herself credit for the 40 kg that she lost might be linked back to Frank's (1998) 'chaos illness narrative' (page 15) where she recognizes the chaos and struggle of not loosing 'enough' weight. With this she might resist letting her own 'local' knowledge about weight-loss and health be tricked, masked or downplayed by powerful marginalising medical discourses about obesity. Joan might have become aware of how much discourses of fat/ thin have been able to define and diminish her as a person.

It is interesting that weight, contributing to 'health' has become such a powerful modern discourse. The overabundance of diet preparations that are available might be seen as giving both credit and restricting people in weight-loss endeavours. It could give support to the struggle of loosing weight where the preparations can confirm the difficulty in shedding the kilos; by this the million-dollar business becomes a witness to one's personal struggle and could strengthen Joan's voice. The other side of the coin may also be true where the plethora of preparations that are available may be strengthening discourses of perfect body sizes and feed into people judging themselves in terms of normalcy and abnormality. This may point to the instability of any given discourse.

Theme three - *power issues of doctors or influential people, in the lives of the participants*. Joan mentioned that she must make use of a cane when walking, even indoors. She feels embarrassed by this and wants to hide it, especially when she encounters, who are to her, important people, like her pastor. She told me about an incident when she made excuses for her walking with the

cane when the pastor was present and his response was that she should not see it as an ordinary cane, but it is a *'wandelstaf'* with *'wandel'* being a more sophisticated description for the mere action of walking about. The *'wandelstaf'* should then be seen as something grand that important people who don't necessarily have difficulties walk with. She mentioned that she felt better when she could re-interpret her cane as a *'wandelstaf'*. Maybe, the *'wandelstaf'* could be seen as a bridge between disability and being able-bodied. The pastor's authoritative position gave her permission to walk with it and reframed her necessity for using a cane, which made walking with it easier. This re-interpretation helped her to understand her reality or social constructions about canes, which could have been that she judged herself as unattractive for needing a cane. This discourse of unattractiveness can serve to make sense of her identity as overweight, experiencing mobility difficulties and loneliness. This also complicates a pastoral position in which the power discourse of the church is constitutive of identity in both positive and negative ways.

Theme four- *knowledge that Joan has about her condition that she wishes the medical fraternity would notice.* This fourth theme connects to the second theme. Joan wished the medical fraternity would notice that getting rid of obesity is not as easy as the media wants you to believe. Discourses of easily losing weight do not tell the genuine truth about the struggle or chaos in shedding the kilos. Neither does it refer to how concepts of slimness came into being and is maintained through discourse, or how slimness has a particular meaning today when centuries ago it had other meanings. Maybe, if discourses about the history of obesity/slimness could be unpacked and recognition of its past, synchronicity and future could be explored; maybe then, the process of slimming could be opened up to scrutiny, and its un/usefulness recognized.

Theme five – *message to people in similar situations.* Joan wanted to suggest to people as lonely as herself to keep pets or birds as company. She's got a lovebird that she is teaching to talk, and whose company she enjoys very much. Joan also advised that you must take one day at a time and try to see the positive in what you still have. In everything she can see the hand of God and when she needs material stuff the Lord provides. This can be seen as discourses of faith that is similar to Nancy's; when she might feel disempowered by material needs she requires God to be a fellow traveller and rescuer. This also connects to discourses of faith that influence her day-to-day experiences of mobility difficulties.

4.2.5 Liana

Theme one - *discourses describing participants' identities*. Liana described herself in discourses of dependency and isolation as a result of the knee injury. The knee injury contributed to her "patient" status and subsequent mobility difficulty. How did these discourses come about and how did her pre-suppositions about dependency influence this view of herself?

Theme two - *some of the taken-for-granted assumptions Liana or society might have as to how her descriptions of dependency and loneliness came about*. Our society places a high premium on independence. This view has led us to believe that the more independent you were, the better for you; especially when you view it from a westernized perspective. This could lead to viewing yourself in binary opposites of dependence as bad and independence as good. We have been scripted by our social realities which we experience as solid and real, that independence should be a sought-after virtue. Connecting it to Liana, after injury she found herself dependent and relying on other people to take care of her. It might not then come as a surprise that she displayed depressed states of mood.

Liana's feelings of isolation were aggravated when people in a shopping centre stared at her, she said: *'the staring made me wish I could be invisible, I felt exposed'*. She felt different from society's norms, which lead her to feeling isolated. She also said: *'I did not choose this injury; if I could have changed it I would have done so!'* By no choice of her was she required to 'use her passport to the world of illness' (Sontag 1979).

In our initial research conversation I shared my own feelings of isolation, after she had spoken about hers. In this way I reduced my position of power as a researcher as well as resonate with her experiences of isolation. These shared discussions might have contributed to me questioning my own taken-for-granted discourses and aided me in being the 'landlord' and the mobility difficulty the 'tenant' (see paragraph 4.3 following on page 104). This deconstruction of a power position connects with contextual theology and might have lead to the exploring of different experiences of mobility difficulty, which supported my 'not-knowing' position (Anderson & Goolishian 1992). Additionally, it could have empowered Liana to be more of an author of her own mobility difficulty story. When an experience becomes something of a mutual involvement, the teller gains some distance between what is being lived and what is being told. At this distance can interpretations be perceived as having alternatives (Frank 1998), and change is made possible.

Theme three - *themes around doctors', or other persons in authoritative positions', use of power in working with Liana.* Liana said she was scared and afraid of what the injury held for her. She felt that she hadn't been informed as to what could be expected after the operation and was very surprised, in a negative sense, to see such a long cut over the knee. Liana's discourses around doctors' use of power included discourses of uncertainty and fearfulness of what was going to happen to her knee in future. This uncertainty might have come from the doctor assuming that patients would know what their conditions are about, if they had been having an ailment for some length of time; but when something happened as suddenly as in Liana's case, information was what she was lacking.

Theme four - *knowledge that Liana has about her condition she wishes the medical fraternity would notice.* According to Liana doctors know a lot about the procedures they have to perform, but they don't know how the caring after the operations should be done to the person behind the condition. This seems to be a modernistic discourse of medicine's search for 'truth' and a separation of body parts not only from each other but also from the soul. In this search the human behind the condition is neglected. According to Liana not all areas of medical care had such a modernistic outlook. She said the physiotherapists knew more about aftercare and the human behind the condition and she trusted their opinion and treatment more than the doctor's. *'It is also much more difficult to bend the knee than they make you believe, and the recuperation period takes much longer than six weeks'*. She thought that if the doctor had had the same injury he would better understand what his patients went through. With these words she might be recognising the 'chaos' of her illness story and in this way resists the power of medicine (see discussion on aspects of the chaos narrative by Frank (1998) on page 15).

Theme five – *Liana's message to people in similar situations.* Discourses of coping day by day, don't look too far into or attempt to predict the future, were apparent. She said that you must know that the recuperation is a lengthy process; it will most probably take much longer than the six weeks you anticipated due to the severity of your injury and the scanty information supplied by the medical fraternity. It is natural and normal for recovery to take such a long time; it does not mean there is something wrong with you. Such an injury lets you realize that your health is important and that you have to look after it.

Liana's identity seemed to have been less dominated or controlled by the medical world. She was a patient for whom the return to good health applied, like Frank's (1998) restitution story (discussed on page 15). She experienced MD for a short while and found a cure through the knee operation, although the chaos of her injury was still recognized. I think what we need to hear from her voice relates to issues of dependence versus independence. While she had to depend on people for day-to-day personal care and other activities, it did not mean that she had to depend on others for decision-making, determining the direction of her life and for choices she made (Oulton & Denborough 2003:15). She could choose to be independent from disabling discourses (like depression) that might have constrained her life. Independence brought resources as well as isolation. She both belongs to discourses of dependence/independence but is simultaneously in resistance to them.

4.3 REFLECTIONS ON THE ANALYSIS

All the participants' stories both bore witness to my own story and taught me a great deal. As I progressed with the analysis I realized how very helpful it was to listen to participants' stories in the 're-writing' of my own Mobility Difficulty story into an alternative version. Their stories gave me the opportunity to challenge some of the dominant discourses in my own life that I had taken-for-granted within a dominant discourse of wellness. Initially I was living with my Difficulty as if the Difficulty was the 'landlord' and I, the 'tenant' (Oulton & Denborough 2003:13). The Mobility Difficulty determined the rules. It lived my life in different ways, even though I had partially managed it. I was complying with a dominant discourse of illness, so often aware of my own inadequacy, or explaining and apologizing for my limp. I was living with Mobility Difficulty as my 'landlady'.

Listening to the dominant themes of the other participants, I am made more aware of just how much it has been able to define me and diminish me as a person. In time (maybe also as a result of this research) I began to turn this around, I saw there was a lot I could still do to control my own life and independency. Now, my Mobility Difficulty lives differently with me as I negotiate with it to abide by some of my terms and conditions – not the other way around. I am more aware of attempting not to measure what I am able to do against what other 'normally walking' people can do. This awareness helps me to be gentle on myself and look at myself more kindly;

I do what I can and this is a comforting approach to life, I am more relaxed with myself and therefore with others.

In chapter 5 a retrospective view of the research project will be provided.

CHAPTER 5

Wrapping it up in skin

This last chapter wraps the research body up in skin and also provides a retrospective view of the research project. Firstly, there will be reflections on the analysed discourses found in the voices of the participants and these voices will be woven together. Secondly, there will be a retrospective view on the research process and approach. Thereafter comments shall be made on the possible benefits the participants and researcher gained from the research. Fourthly, reference will be made as to what could have been done differently; and lastly, a discussion will be found on some of the possibilities for further research and how that which has been achieved, could be put to further use.

5.1 REFLECTIONS ON ANALYSED DISCOURSES

Discourse analysis exposed some of the dominant discourses that have been present in the participants' words. The analysis was employed in an attempt to answer the research question which was: *'what might need to be heard about people living with Mobility Difficulty when the Difficulty does not dominate their lives?'* The usefulness of the analysis lay in the different ways in which language was used to construct the phenomena participants spoke about (for a discussion on data analysis and discourse analysis see page 26).

5.1.1 Ways of Surviving within a Dominant Discourse

Interesting and insightful discourses emerged as the voices of participants were woven together. Among the discourses of identity descriptions, (see the discussion on theme one in chapter 4, pages 86 – 102) there were various interpretations of patient-hood. The different descriptions and meanings participants gave to experiences of mobility difficulty, constituted through societal discourses, shaped the way they saw themselves. It seemed that the medical world informed most of the participants' identities, but they were rarely fully defined by it. This can be viewed in congruence with what Toombs (1992) said, in the discussion on disease and illness on page 12, that the patient's view of illness 'focus(es) on its effects upon everyday life' rather than on the scientific interpretation. Thus scientific interpretation became a hidden discourse that affected patients every day lives, but did not fully determine their identities.

As mentioned in 4.2.1, page 87/88, Nancy saw herself in ‘strong woman’ terms. The traumatic events of her husband’s murder shifted her consciousness away from ‘patient’ and helplessness discourses to discourses of ‘survival instincts’ and self-reliance. Perhaps in having greater degrees of ‘self-reliance’ she could resist ‘illness’ and ‘patient’ metaphors. Seen through a post structuralist lens that critiques deficit models, it is perhaps interesting to understand it more as abilities rather than deficits that enabled her to live in a difficult world.

The other four participants (Ansa, Angelique, Joan and Liana) appeared to see themselves more in patient terms. Ansa seemed to have made spiritual meaning from her suffering as a form of resistance to the chaotic status of the illness in which the medical model failed to cure her. Her suffering has found meaning, within this meaning she neither ‘accepted’, nor ‘welcomed’ her illness and subsequent failed cure, but she ‘lived her illness as a quest’ (see a discussion on aspects of Frank’s (1998) quest story on page 16), where ‘new qualities of self’ could be seen as being in resistance to dominant discourses of patient-hood. In this way, although more defined by her patient status, she also escaped the net of pathology through finding ways of resistance.

Angelique was not fully defined by her patient status either. On the researcher’s own interpretation, her voice seemed to say: ‘If you’ve lived disability, you know more about it than the medical people who have studied it; their knowledge and power in making you an object of scientific study is not always beneficial to the person behind the condition, and it can lead to marginalization and isolation’. By refusing to be fully defined by her patient status, Angelique resisted a dominant power relationship in which she was a passive receiver of expert medical knowledge.

Joan’s discourses have been deeply influenced by the medical world. She experienced herself as a patient that was gazed upon and judged in medical terms, particularly in relation to her weight. Joan might have resisted the patient metaphor in realizing that getting rid of obesity was not as easy as the media or medical fraternity would make you believe. She resisted by not letting her own ‘local’ knowledge about weight-loss and health be downplayed by powerful marginalising medical discourses about obesity. Thinking of the over abundance of diet preparations available, it can both be seen as strengthening Joan’s voice and supporting medicine’s gaze. In this way it can be feeding into the hands of normalcy and abnormalcy. This again, points to the instability of any given discourse.

Liana's identity seemed to have been less dominated by the medical world, probably due to her temporary patient status. She was a patient for whom the return to good health applied, like Frank's (1998) restitution story (page 15). What the research and medical community might need to hear from her, related to issues of dependence/independence. While she had to depend on people for day-to-day personal care and other activities, she resisted discourses of dependence by exercising her ability to choose; she chose to not be controlled by disabling discourses of dependence. In this way she might both belong to and simultaneously resist disabling discourses, which again, as above, points to the instability of any given discourse. As mentioned on page 47 where a discussion can be found on postmodernism and ways of thinking about mobility difficulties, this study entered a field where modern (medical) and postmodern (narrative discourses) overlapped. This probably brought a richness to this study that was visible in what Liana was experiencing when she criticized the medical fraternity but at the same time depended on it to get well.

5.1.2 The role of Spirituality in enabling Alternate Identities

Nancy, Ansa, Angelique and Joan used spiritual beliefs to establish meaning in their mobility difficulty experiences, consequently spiritual matters were woven through their discourses. Thinking of the Reformed and Evangelical tradition, as well as models of liberation theology where God led the Israelites to the promised land and was their rescuer and fellow traveller, and also thinking of the symbol of the cross representing the willingness of God to share the burden of pain and brokenness to the point of death; it seemed that the more disempowered some of the participants became because of subjugated and marginalising discourses, the more they needed God to be a witness and fellow traveller in their meaning making of the mobility difficulty experiences. In a pastoral therapeutic dialogue, theological traditions can function as a 'participant in dialogue' (see the discussion on pastoral care, page 43 - 45). This means that the 'story of God' becomes a conversational partner.

Ansa used her spiritual beliefs to provide meaning in her mobility difficulty experiences. Her spiritual beliefs seemed to have stabilised her life, her joy and thankfulness despite stresses associated with disability reflected her belief in God's greater purpose and plan for her; her spiritual beliefs provided assistance with coping. Ansa saw her life as serving a purpose despite difficulties associated with disability, congruent with Frank's (1998) quest narrative (page 16). Perhaps the most moving quest stories are those, like Ansa's, that are lived. In finding terms to

live with illness – not grateful for illness, but grateful for a life despite illness’s restrictions – those telling quest stories show the healthy how they too could be living.

The above relates more to narrative hermeneutic and participatory approaches to pastoral care where it shifts away from diagnosis and analysis of a condition, toward an interpretation of life through the examination of stories, symbols, language and social interactions. It concerns ‘the way our faith gets acted’ out and is thus involved with how narrative-pastoral discourses are contributing to making meaning of mobility difficulty experiences.

5.2 THE RESEARCH PROCESS AND APPROACH IN RETROSPECT

The research was started with the researcher’s own experience as a ‘moment of insertion’ (see Cochrane, de Gruchy & Peterson (1991) on page 39), which attempted to approach knowledge making from a postmodern, social constructionist and discourse analytic perspective. This approach is not new to research of this kind as can be seen from different researchers that placed emphasis on research that started with personal experience (Truter 2001; Frank 2002). This more postmodern research sought meaning within discourses that related to prior experience and in this way connected to contextual and feminist research that places emphasis on research that starts with personal and cultural experience (Reinhartz 1992; Ackerman 1994; Weingarten 2001; Treloar 2002)

The discourse analytic approach taken, (for a discussion on aspects of discourse analysis by Phillips and Hardy (1996) see page 55) placed accent on the research process rather than on the product. At the beginning it could not be anticipated what the end product would be. In this way uncertainties had to be coped with, and I let myself be informed by a ‘not knowing position’ (Anderson & Goolishian 1992). The conversations, analysis and letter writing were restricted through my own knowledge and experience as I too am immersed within discourses that I do not necessarily have control over. In this way the research evolved in directions I was not fully in command of. Being aware of this, it was a journey where I had to find my way as the research progressed, attempting to quieten my own assumptions. This made it difficult. I had to make peace with living with uncertainty. This uncertainty might not have been a bad thing for it helped in staying connected with the participants’ stories, and in this way learn from them. It contributed to doing research *with* the people, not *on* or *about* them (Kotzé and Kotzé 2001:7).

My own struggle with this also meant that I learnt as I went along. Reflecting on the letters I had written to the participants, I had made many assumptions that I also critique as I look back on the work. In this I would write differently with my own shifting understanding and my own journeying with uncertainty.

Stories of fellow mobility difficulty sufferers were captured in letters, not to 'fix' them but to honour them. With the letters in chapter 3 an effort was made to show how participants resisted and challenged the harmful effects of subjugated and dominant discourses; it also showed how participants used spiritual beliefs to make meaning of their mobility difficulty experiences. Meaning was not created in isolation but was socially created through communal interchange (Drewery & Winslade 1997). This was congruent with the aims set out in 1.6 as well as practical theology (discussed on page 37 – 45). Within this healing became a mutual process in which the researcher too benefited from the participants' knowledge. A further significant purpose of the letters was not so much about their cleverness or accuracy, but more about an ethic of care about another human being.

5.3 RESEARCH BENEFITS FOR RESEARCHER AND PARTICIPANTS

Nancy phoned a few days after she had received the letter. She said it improved her sense of control over difficult circumstances and it was a witness to her experiences. According to her, it was as if her strength re-emerged through the letter and if she compared herself with four years before she was currently more connected to her stronger side (see the analysis of Nancy's discourses on pages 87 - 92). She mentioned that she kept the letter close and re-read it several times. Nancy's phone call can probably be viewed in congruence with what Stringer (1999) said about the success of a research project that could be measured by 'its ability to enhance the lives of the people with whom it is engaged' (page 32 paragraph 1.8.4).

However, another way of viewing this phone call from Nancy concerns the inevitable power imbalance that the researcher held within this research. In this, knowledge became a power relationship and the researcher's own expertise in the participants' eyes fed back into a dominant power position where their knowledge and voices were subjugated in preference to the researcher's own knowledge.

Exchanging stories can become a way of fracturing power relationships. This was done when the researcher shared some of her own story with Liana. It was however done in response to Liana's story. The telling of her story received primary attention, the researcher shared in appreciation of Liana's story.

On the researcher's own interpretation on benefits for participants, and as discussed in chapter four, Ansa used her spiritual beliefs to make meaning of her disabling experiences. Angelique got an opportunity to employ her 'big personality' in creating alternative descriptions of her identity. New breath was blown into Joan's view on weight issues; and through the conversation with Liana certain areas of her life could be withheld from dependence the injury brought, for example, decision-making and determining the direction of her life.

Congruent with Winter (1996) I agree that the writing of this research report was indeed a learning experience where, *inter alia*, I wrote for myself so that I could find out what I have learned. Through the writing different facets of my own Mobility Difficulty presented itself and of this chosen bias I have attempted to be explicit and open on the understanding that my immersion within the process adds both depth and authenticity to this journey. This is a very different position to that of researcher as objective observer of the process.

As I journeyed towards this last chapter the prosthesis in my right hip came loose and the leg shortened considerably. It is accompanied by pain, discomfort and difficulty in putting one foot in front of the other (1.1.1). The result of this is another hip replacement operation waiting in the very near future. This brought with it enormous anxiety over the handing in of this dissertation, another challenge on a difficult journey, where I too had to find ways of quietening the voices of disability that threaten the deadlines of handing in this dissertation. Through inserting this into the text this hidden dominant discourse becomes languaged and challenged by my own journeying with it in a more transparent way.

Prior to this research I felt betrayed and angry at the medical fraternity when the hip gave up (as had happened many times before); I blamed the doctors for not fixing me. Having done this research report, I find myself in accordance with Weingarten (2002), in an empowered and aware position (as mentioned on page 16 paragraph 1.1.5). I went back to x-rays that had been taken before any replacements were done. As I revisited them a 'crack of light' (Frank 1998) shone

through the darkness and I came to see with exactly how little bone “I was made with” in the hip region. I realised that it was not helpful to blame the doctors in that they could not ‘fix’ me, but it was my genetic make-up that made the fixing difficult; they have done the best they could. This instantly changed my view of doctors as I realised the fault lay within my bones. This realisation enabled externalization of the hip where I could work with it and speak to it from an empowered and aware witnessing position. This happened, however, when I too became included in the medical knowledge and became not a passive receiver of medical prescriptions but an active player in the diagnosis seen and understood through the x-rays.

Where I find myself now is also congruent with the quest story of Frank (1998). I have made meaning of my mobility difficulty experiences in the sense that I am certainly not grateful for having the condition, but I am glad that through it I could gain a better understanding of myself and a better understanding of my bones and joints. It also allowed being more at peace with the doctors and being more gentle on myself without feeling betrayed. The ‘landlady’ (page 104 paragraph 4.3) became a gentle, meaning making person of service to herself and others.

5.4 EVENTS THAT REALISED DIFFERENTLY, LIMITATIONS AND FUTURE TOPICS

The questions posed in the letters did not generate many ideas and comments from the participants and exposed some of the limitations of language and the fragility of selecting certain texts over others. Maybe the participants were ‘helping me’ rather than us creating knowledge together. The only corrections were technical ones and their comments were mostly that the letters represented their words well. There could be a number of reasons for this, one being the inevitable power relationship as mentioned earlier in paragraph 5.3 on page 110. This could have been a shortcoming in the co-laborative approach taken. Had this research been carried out in a more ongoing therapeutic setting, some of these limitations may have been avoided.

The feedback conversation that took place with Nancy revealed relationship problems with her late husband. Although it cannot be documented due to the confidential nature of the conversation, mention can be made that it took place and that it would be difficult to integrate it with the themes of the study.

Letters are dialogic in character and it allowed participation with the participants' voices. As can be seen in chapter three, letters exposed limitations on the researcher's own interpretation of the discourses within participant's lives. In order to reduce this limitation it could have been more beneficial to work with letters in a reflecting group process (Carey & Russel 2003; White 1991); rather than with individuals. Such an approach might be helpful in a future study on this topic.

Such community focused research can be designed to form a wider support system for the disabled. It can inform, rather than challenge the power relationships and dominant discourses present in positions of power and their potential abuse. Through communities of care new possibilities for action can be found. Strength can emerge from working together and harnessing one another's wisdoms and knowledges as lives are storied.

Other topics regarding mobility difficulties that could be explored are relationships outside of illness, for example creative abilities and alternative meanings. In exploring ways people live well with mobile difficulty, greater attention could be paid in scaffolding relational possibilities that move people away from isolation towards sustaining relational discourses. In this it might be interesting in the future to create a more relational context where this kind of research is carried out in a group relational process.

Comparing participants' perceptions of spiritual experiences to others who do not hold religious or spiritual beliefs may provide an increased insight into the influence of spiritual beliefs in response to disability. This was beyond the scope of this particular research as it was conducted within a faith community.

Gender, and the way our roles as woman and men suffering from mobility difficulties, might deserve further attention. Maybe, there is a lot 'not said' that the voices of men can contribute to such a study.

This study did not reflect discourses of the different population groups in the country and is restricted to a particular group of white Afrikaans women living within a specific context. This was not deliberate, but the population group that responded to the research invitation happened to be female and white. This could have been avoided by inviting people from other population groups but due to the limited scope of this research it did not happen.

Another limitation of this study was that it was skewed towards the marginalized, thus excluding doctors and medical personnel. It would be interesting reading a study done through the eyes of a medical person and asking questions, for example, what identifies a participant as a patient.

Research focusing on doctor-patient relations might further be explored. From this research it is apparent that doctor-patient relations play an important part in improving or restricting the well-being of the participants. A study that specifically focuses on this topic can cast light on the doctor-patient relationship and can make a valuable contribution. It would also be significant to research more in a quantitative way in this field.

Change does not happen overnight, but dominant discourses like the biomedical discourse and western discourses about mobility difficulties and disability have become established over long times and cannot be eliminated in one single research project – it can, at most, contribute to the ongoing conversations in the church and medical fields. Change might occur long after the conversations are over.

5.5 A LAST WORD

When I began this research journey I used the metaphor of creating a body. The body has now been birthed and through the process different ways of viewing my own health difficulties became possible. I had to make use of my ‘passport to the world of illness’ (Sontag 1979) because I was handed some body parts I would not have chosen. However, I was free to not let my Mobility Difficulties dominate and I chose to become the ‘landlady’. To me this is congruent with what T.S Elliot said in ‘Gerontion’:

We shall not cease from exploration, and the end of all our exploring will be to arrive where we started and know the place for the first time.

(Elliot 1981)

Here at the end of my journey I arrived where I started and now seem to know the place for the first time.

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APPENDIXES

APPENDIX 1

WHEN MOBILITY DIFFICULTIES DO NOT DOMINATE.

A NARRATIVE-PASTORAL APPROACH

CONSENT FORM FOR PARTICIPANTS.

I have read the Information Sheet concerning the research project and I understand what the project entails. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.

I know that:

- 1) My participation in the project is entirely voluntary.
- 2) I am free to withdraw from the project at any time without any disadvantage.
- 3) I am aware that the conversation will be audio-taped.
- 4) I am aware of what will happen to my personal information including audiotape recordings at the conclusion of the project, that the data will be destroyed at the conclusion of the project but that any raw data the project depend on, will be retained in secure storage for six months, after which it will be destroyed.
- 5) I am aware that I may request further therapeutic conversations if necessary.
- 6) I will receive no payment or compensation for participating in the study.
- 7) All personal information supplied by me will remain confidential throughout the project.
- 8) I am aware of the researcher's supervisor reading the material.

I am willing to participate in this research project.

Signature of participant

Date

This project has been reviewed and approved by the Institution for Therapeutic Development

APPENDIX 2

WHEN MOBILITY DIFFICULTIES DO NOT DOMINATE.

A NARRATIVE-PASTORAL APPROACH

INFORMATION SHEET FOR PARTICIPANTS.

Thank you for your interest in this project about the stories of mobility difficulty sufferers. As a fellow sufferer I invite you to participate in this research project. Your participation in this project could lead to better understanding of the difficulties experienced, and better handling of difficulties by ourselves and other sufferers.

Please read this information sheet carefully before deciding whether or not to participate. If you decide to participate, I thank you. If you decide not to take part, there will be no disadvantage to you of any kind.

Aim of the project.

This project is being undertaken as part of the requirements for a Master degree in Practical Theology – with specialization in Pastoral Therapy at UNISA. The aims of the project are:

- (a) to explore the personal her-/his-story of the mobility disability
- (b) to explore the influence of medical experiences, societal and cultural ideas and practices regarding difficulties, influencing sufferer's lives and how these discourse have informed us.
- (c) to explore the effect of the disability on the sufferer's spiritual and emotional identity.
- (d) to co-construct with participants alternative stories, questioning medical, societal and cultural views that informed us, and to retell our preferred "wellness" stories.

Participants needed for the study.

The researcher will approach five mobility difficulty sufferers who will be included in the research project, telling their stories of how they experience their lives as sufferers. Sufferers, male or female between the ages of 25 and 65(or older), including any cultural orientation is welcome to join the research project.

What will be required of participants?

Should you agree to take part in this project, you will be asked to give consent for the audio-taped information obtained during the interviews to be used in the research project.

Should the need arise for additional therapeutic conversations regarding the difficulty and/or the interview, it could be arranged.

It is important to know that the research will be conducted in the qualitative action research method. You are a co-researcher in the project and your opinion and participation will be respected at all times.

Free participation.

Participation in the interviews is voluntarily and you are free to withdraw from the research at any time without any consequences to you.

Confidentiality.

The information gained during the interviews will be discussed with my supervisor and will be used in the project. With your prior consent the interview will be audio taped. Should you wish not to have the conversation on audiotape, I shall make notes during the interview.

The information collected during the research project will be securely stored in a locked filing cabinet and will be destroyed after conclusion of the project, but any raw data that the project will depend on will be retained in a locked filing cabinet for six months.

Results of the study.

Results of this project may be published. At your request, details (names and places) will be distorted to ensure anonymity. You will have the choice to use your own name or a pseudonym of your own choice.

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

Questions of participants.

Should you have any questions or concerns regarding the project, either now or in the future, please feel free to contact me:

Susan Eksteen

Tel: (011) 954 – 0987

Cell: 076 051 1455

Or, you can contact my supervisor Bridgid Hess at the Institute for Therapeutic development.

Tel: (012) 346-2092.

APPENDIX 3

WHEN MOBILITY DIFFICULTIES DO NOT DOMINATE.
A NARRATIVE-PASTORAL APPROACH

Feedback from participants and consent form

FEEDBACK FROM PARTICIPANTS

My suggestions, corrections and comments:

The things that stood out for me in the conversation were:

CONSENT FORM 2 FOR PARTICIPANTS

I read the summary of our conversation and I give consent that, after I have given my suggestions, corrections and comments that the summary may be included in the research project.

Signature

Date

This project has been reviewed and approved by the Institution for Therapeutic Development

APPENDIX 4

EXCERPT FROM TRANSCRIBED TEXT ANSA	DISCOURSES DESCRIBING PARTICIPANT'S IDENTITY	SOME OF THE TAKEN FOR GRANTED ASSUMPTIONS ABOUT PARTICIPANT'S IDENTITY	DOCTOR'S OR OTHER AUTHORITATIVE PERSON'S USE OF POWER	WHAT DO PARTICIPANTS KNOW THAT OTHERS DON'T KNOW
<p><i>Initially, since the age of 12 I tested my insulin levels with a few drops of bendix, which I added to my urine and heated it over a flame. Nowadays it is much easier to test with the aid of a glucometer. You prick your finger, put a few drops of blood on a testing strip and feed it into the machine, which gives you a reading of the insulin levels. I do this four times per day.</i></p> <p><i>My fingertips are "aware" of this testing procedure and feel sore. The doctor recommended that I put gel on my nails to protect them from splitting and tearing into the nailbed, and to make the nails stronger. I have done this for 9 years now.</i></p> <p><i>It is not for vanity. I do it in red so that I can see my nails...</i></p> <p><i>A consequence of the diabetes is that I gradually lost my eyesight and now I can distinguish between light and dark and I have 5% vision.</i></p>	<p>It is part of Ansa's routine to consult medical people and - advice and to test four times per day for the insulin levels.</p> <p>Ansa speaks of advancements in medical technology and how it makes the testing easier.</p> <p>Speaks of discomfort in doing the testing, but also of the doctor hearing her discomfort and recommending a coping strategy. The gel nails have been part of her for a long time – 9 years</p> <p>Ansa might be worried that I will view her as vain and explains why she has red gel nails. She explains and connects the red nails to her difficulty in seeing.</p>	<p>Ansa is NOT taking her health for granted. She respects her health and test to make sure she will be ok.</p>	<p>Doctors use power to inform and empower the patient, power used positively.</p> <p>Doctor's use of power was to respect and benefit the patient. He was creative in prescribing a way to deal with the sore fingers.</p>	<p>Ansa knows she must be diligent in her insulin testing as to give herself a good chance to health.</p> <p>Red nails do not necessarily mean you are vain. There are lost of reasons why your nails can be red.</p>

EXCERPT FROM TRANSCRIBED TEXT ANGELIQUE	DISCOURSES DESCRIBING PARTICIPANT	WHAT IS PARTICIPANT OR SOCIETY TAKING FOR GRANTED IN THIS EXCERPT	DOCTOR'S USE OF POWER	WHAT DO PARTICIPANTS KNOW THAT OTHERS DON'T KNOW	MESSAGE TO PEOPLE IN SIMILAR SITUATION
<p><i>I was a child with a 'big personality'. If they wanted to demonstrate something connected to the Rhizotomy they would use me as a model. A Rhizotomy is where they cut certain nerve endings on the spine to loosen up the muscles. I was very spastic and stiff and my head used to hang, my eyes were squint and I couldn't clap my hands. The operation helps with co-ordination and control. It helped me a lot.</i></p> <p><i>I was one of the 1st children they did the operation on. The professor apparently practiced on a 100 cadavers before he touched me. He did his homework well and was clued up because it is intricate work on the spine. If you make a mistake you cannot undo it.</i></p> <p><i>The expectation they had I think I exceeded. A lot of people were surprised at what I could do after the op. Later, when I was in the West Rand school the personnel pushed a lot harder towards independence.</i></p>	<p>Angelique describes her self in positive terms as having a 'Big Personality'</p> <p>She seemed to enjoy the attention that being a model, and her purpose of being the resource of information, brings.</p> <p>Angelique is grateful to the medical advancements in helping her to be less spastic.</p> <p>The prof respects Angelique and her disability by practicing on a 100 cadavers before touching her.</p> <p>Positive attitude and independence comes at a high price.</p>	<p>Society might sometimes assume that people who are disabled might view themselves in negative terms, because they cannot do what able-bodied people can do.</p> <p>Society might assume further that, due to their disabilities, disabled people cannot become models and therefore cannot receive positive attention from being in the spotlight.</p> <p>Angelique is not taking her independence for granted; it came at to high a price.</p>	<p>People in power put Angelique in the spotlight to her advantage and did not misuse their power.</p> <p>Doctor shows respect by first practicing on a 100 cadavers.</p>	<p>You don't need to be able bodied or have a perfectly functioning body to have a big personality.</p> <p>Sometimes you have to take a step of faith in order for something to succeed.</p> <p>I am precious enough for the doctor so that he goes to the trouble of practicing on a 100 cadavers.</p> <p>Society must not leave disabled to their own resources, but must help towards the push to independence.</p>	<p>Being a model empowered Angelique towards having a 'big personality'.</p> <p>If chances are not sometimes taken how can humanity benefit?</p> <p>Don't be afraid to talk to us about our condition and to ask us questions about it. If there is something wrong with our legs it does not mean something is wrong with our heads.</p>

EXCERPT FROM TRANSCRIBED TEXT JOAN	DISCOURSES DESCRIBING PARTICIPANT	WHAT IS PARTICIPANT OR SOCIETY TAKING FOR GRANTED IN THIS EXCERPT	DOCTOR'S USE OF POWER	WHAT DO PARTICIPANTS KNOW THAT OTHERS DON'T KNOW	MESSAGE TO PEOPLE IN SIMILAR SITUATION
<p><i>All my years I have been big and fat. I have done knitting and machine-knitted up to 16 jerseys per day. I have osteoarthritis and hip problems. When I was little I spent a lot of time in hospital. On one occasion I spent 3 months in hospital. The doctors told my (step)parents that the hip came out of the socket and they had to put the leg in plaster. They said that I was fat and my bones were too soft for my body. On photos I was always fat.</i></p> <p><i>I am a stepchild. My mother died when I was born. The doctor told my mother not to have children. I was born at 7 months and didn't even weigh five pounds. My own mother wrote a letter to my stepmother and asked her if she would raise me. I was in an incubator and was 4 days old when my mother died. Afterwards I stayed in hospital for 2 months. My stepmother's husband died but she didn't marry my biological father. When I was 3 years old she married another man whose surname was Elger. My own father's wife also died whilst under an operation. My stepmother was very good to me, like an own mother would have been.</i></p>	<p>Joan describes herself as always having been fat with health problems due to her being overweight. Despite being fat she is able to work hard – knitting up to 16 jerseys per day.</p> <p>She identifies herself as being a stepchild who never knew her own mother. She was a premature baby but survived even though technology was not as advanced as today. Her mother knew she would not be able to raise Joan and planned ahead to give Joan a chance at a good life. Her father although living, did not raise her</p>	<p>Society might assume that fat people cannot work hard and that fat people, just by being fat are responsible for their own health problems. This might aid in pushing them to the margins of society.</p> <p>Society (but not Joan) might be taking for granted that biological mothers would not die so soon and that they would raise their children, if mothers cannot do that society might expect the father to raise the child. Many a time it is otherwise.</p> <p>Assumptions might also be that stepmothers are not kind to stepchildren and that they are unhappy when raised by a stepmother.</p>	<p>It might be that the power of the doctors was not questioned and that the stepparents accepted that the doctors knew better. Doctors also blamed “the fat” for causing joint and mobility problems that could have lead to being marginalised.</p>	<p>Joan knows what it is like to have health difficulties; she got first hand knowledge from experiencing mobility problems, and being made responsible for it. This made her very receptive to the needs of other people with health difficulties. She goes to great lengths to help her friends when they are ill and cannot take care of themselves.</p>	<p>Take life one day at a time and try to see the positive side of things. Reach out to other people and keep a dog, cat or bird that you can take care of.</p>

EXCERPT FROM TRANSCRIBED TEXT LIANA	DISCOURSES DESCRIBING PARTICIPANT	WHAT IS PARTICIPANT OR SOCIETY TAKING FOR GRANTED IN THIS EXCERPT	DOCTOR'S USE OF POWER	WHAT DO PARTICIPANTS KNOW THAT OTHERS DON'T KNOW	MESSAGE TO PEOPLE IN SIMILAR SITUATION
<p><i>I don't like it to be dependent, and this knee injury caused me to be very dependent – I HATE IT! I can't even go to the shops by myself, for if I get tired the knee buckles and I might fall. My mother must help me to bath, wash my hair and even to get dressed. It feels as if I cannot do anything for myself. I am a very independent kind of person, so I would rather die than ask someone to help me with something! It was so hard at the beginning.</i></p> <p><i>I am not one to tell other people I cant cope, but I don't want to be amongst people for long times, because then you pretend to be OK and you are not, it feels uncomfortable.</i></p> <p><i>At a certain stage I cried a lot when I was with my boyfriend and I thought he will get tired of it, and that is not what I wanted. I don't want to frighten people away. I want people around me. I would rather have them around for a short time and then be alone and cry by myself, rather than them thinking I am a "pissy" and that I can't handle things.</i></p>	<p>The new degree of dependence that the injury brought is very uncomfortable to Liana.</p> <p>Liana must get help with personal care and her moving around is restricted. It affects her self image and the view she has of herself.</p> <p>Liana tells of things that previously gave her pleasure, e.g. the company of others, which is not pleasurable any more.</p> <p>Liana notices her mood changes and is worried about the effect it will have on other people.</p> <p>She is worried that other people will view her in negative terms because of the changes in her mood.</p>	<p>It is possible that the society in which we live places a high premium on independence and when you are independent you seem to be all right. Sickness and mobility difficulty as Liana experienced it, might bring with it issues of dependence. Viewing ourselves according to society's standards regarding dependence/independence, it is easy to see yourself as spoilt</p> <p>This "not being good" can affect our moods and might make one feel depressed.</p> <p>We are afraid that society will not accept us if we show a depressed mood state.</p>	<p>No power issues of doctors apparent in this piece of transcribed text.</p>	<p>It takes longer than anticipated to get to your pre-operative state.</p> <p>Doctors treat the knee but give no attention to the person behind the knee.</p> <p>She was uninformed about the recuperating process. People in similar situations should get as much information and detail as to what they can expect, as possible. You tend to think after 6 weeks you will be perfectly well – a big surprise awaits you. The knee will be stiff and it takes a long time to be able to bend it to 90 degrees.</p> <p>It is normal to be scared to start using the knee you're afraid something might go wrong again.</p> <p>Many a time you take your health for granted and it is only when you loose it that you really start to appreciate it.</p>	<p>Know that when something happens to your knee it can be a very painful experience. Take one day at a time and don't plan to many things ahead, accept that the recuperation is a long process. It won't take only six weeks, be prepared that it can take much longer. If people are prepared for the long tome it takes, they might cope better.</p>

