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CONTEXT, CULTURE AND DISABILITY: A NARRATIVE INQUIRY INTO THE LIVED EXPERIENCES OF ADULTS WITH DISABILITIES LIVING IN A RURAL AREA

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A THESIS SUBMITTED TO THE FACULTY OF HUMANITIES, UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG, IN FULFILMENT OF THE REQUIREMENTS OF THE DEGREE OF DOCTOR OF PHILOSOPHY

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ABSTRACT

This thesis documents the everyday experiences of adults with disabilities living in a rural area of South Africa. Given South Africa's tumultuous history, characterised by human rights violations incurred through cultural, political and racial conflicts, and the country's current state of socio-economic and political turmoil, violence has come to represent a core feature in the lives of many South Africans. This, together with the impact of unemployment, food insecurity and unequal power distribution, has significantly affected the ways in which many people make sense of their life experiences. Despite the fact that exposure to unequal power dynamics, violence, marginalisation and exclusion are documented to dominate the life experiences of people with disabilities, little is understood about the ways in which these aspects manifest in the interpretation and reconstruction of experiences.

Previous research into the field of disability studies has depended primarily on quantitative measures, or on the reports of family members and caregivers as proxies, perpetuating the cycle of voicelessness and marginalization amongst adults with disabilities. Those studies which have adopted qualitative measures in order to explore the psychosocial experiences of disability have focussed largely on the limitations imposed by physical access, and have relied predominantly on the medical and social models of disability, or on the World Health Organisation's International Classification on Functioning, Disability and Health (WHO ICF, 2001). These models consider the psychosocial experience of disability to be universal, and do not adequately take into account the impact of cultural and contextual variables. This has negatively impacted on the establishment of a research repository upon which evidence-based practice could be developed.

This thesis aimed to explore and document the lived experiences of 30 adults with a variety of disabilities, living in 12 rural villages in the Mpumalanga Province of South Africa. A combination of narrative inquiry and participant observation was employed in order to examine the relationship between personal and social interpretations of experience. Data analysis was conducted using a combination of Clandinin and Connelly's (2000) Three Dimensional Narrative Inquiry Space, Harré's Positioning Theory (1990, 1993, & 2009), and Thematic Analysis (Braun & Clarke, 2006).

Results revealed that narratives were plurivocal in nature, giving rise to a complex relationship between personal and social interpretations of experience. The findings highlighted the impact of cultural norms, values and roles on making sense of experiences associated with disability. Four new types of narrative emerged, none of which conformed to the current interpretations of lived experience as reported in the literature. All of the narratives were pervaded by the embodied experience of violence, including evidence of structural, physical, psychological and sexual violence, as well as violence by means of deprivation. This gave rise to a sense of moral decay and highlighted the ways in which abuse of power has become woven into lived experience. In this way insight was gained into the complex interplay between impairment, exclusion, high mortality rates, violence, and poverty in rural areas.

Narrative inquiry proved to be a particularly useful tool for providing insight into disability as a socio-cultural construct, drawing attention to a variety of clinical, policy and theoretical implications. These gave rise to a number of broader philosophical questions pertaining to the role of memory, vulnerability and responsibility, and the ways in which all citizens have the potential to be complicit in denying the reality of lived experience amongst vulnerable members of society. These findings demand attention to the ways in which governments, communities and individuals conceive of what it means to be human, and consequently how the ethics of care is embraced within society.

Key Words: disability, context, culture, violence, narrative inquiry, responsibility

DECLARATION

I declare that this dissertation is my own unaided work. It has never been submitted for any degree or examination in any other university. All sources that I have used, made reference to or quoted have been indicated and acknowledged.

Joanne Frances Neille (neé Barratt)

August 2013

Signed _____

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Firstly, to the participants of this study, words cannot express my gratitude to you for opening my eyes to the reality of living with a disability in a rural area. Your stories shocked and horrified me, and I will do my best to ensure that these reports of human rights violations and violence do not remain stories. For too long, stories like this have been regarded as 'myths'. I promise to honour my privilege of being witness to your stories by making every attempt to address these issues.

To Lindiwe Thobela and Zelda Mubi, this research would never have happened if it were not for you. Thank you for your time, patience, guidance, friendship and sense of humour. You have allowed me a rare insight into the complex interplay between cultural and contextual issues and how these manifest in the lived experience of disability. I hope that this research will be used to inform policy, practice and teaching and in so doing, improve the quality of life for persons with disabilities.

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DEDICATION

This dissertation is dedicated to all of those who remain silenced, not only by nature of their disability, but also as a result of poverty, marginalisation, and violence, rendering their experiences too raw and painful to talk about.

To my participants, just as your pain cannot be transformed into words, neither can my gratitude. When I embarked on this study, I had no idea that my findings would reflect such horror. Your bravery and resilience is remarkable. In order to protect your identities, I have not mentioned any of your names in this dissertation, but if I could, I would shout them out loudly. Thank you to those of you who spent hours with me, welcoming me into your homes, sharing meals with me, talking to me about your experiences and sharing the stories and artefacts that in part, define who you are. Thank you, not only to those of you who 'spoke out loudly', but also to those who 'had no story to tell'. The contrast between your bravery and life experiences leaves me speechless.

Finally to Lindiwe, my friend, mentor, and research mediator, this research is dedicated to you. Your amazing work, which often goes unrecognized, has brought solace and comfort to so many people in your community. Despite the enormous challenges that you face, you are a source of power and strength to so many, always negotiating difficult situations with good humour and kindness.

"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."

T.S Eliot (1943)

NOTES ON TERMINOLOGY AND PRESENTATION

There are a number of terms and concepts that I have used throughout this study that require clarification. In terms of disability, I have included a description of the nature of the disability (e.g. physical, visual, communicative) and in some cases in have included a description of the nature of the diagnosis as was described to me during the interviews (e.g. stroke, epilepsy, cerebral palsy). I do not feel that classification according to type or degree of disability is particularly important in this study. However, by including these descriptions it emerges that neither nature nor degree of disability appear to be particularly significant, but that it is rather the interplay of personal and social interpretations of disability and the way in which these are mediated through context and culture that appear to be defining factors within the individual narratives.

Although at times I have used the terms 'story' and 'narrative' interchangeably, I feel that it is essential to highlight the subtle differences underlying these concepts. The term story is used to describe the act that the teller engages in as a means to recall an event or provide an experience with meaning (Clandinin & Connelly, 2000). The term 'narrative' has been used to suggest a structure underpinning the story, as defined by means of the temporal and spatial boundaries imposed, the actions, actors and event which inhabit the narrative, and the construction of a narrative plot (Clandinin & Connelly, 2000). Thus the action of 'narrative analysis' implies the structures that storytellers rely on but are not fully aware of (Frank, 2000).

There are times in the participants' narratives and in the excerpts included in this thesis where the terms 'illness' and 'disability' are used interchangeably. While both of these terms carry with them specific meanings, it must be acknowledged that in the rural villages in the Nkomazi East Municipality some people with disabilities refer to themselves as 'ill' or 'sick'. At times this is because their disabilities may have been acquired secondary to an illness (for example in the case of hearing loss as a result of meningitis, or stroke as a consequence of HIV), while at other times it would seem that both 'illness' and 'disability' are used as a form of identity. Thus the terms 'illness' and 'disability' are seen to be used as a way of reflecting

affiliations with the western explanations for illness and disability, or affiliations with other persons with disabilities as a form of 'group identity'.

At times it may come across as though I have made assumptions about the participants' feelings or responses to certain experiences. Given the nature of qualitative research, and the fact that I relied heavily on a reflective journal during the process of data collection, analysis and write up or results, I have made attempts to include my own responses to the data, while at the same time trying to allow the data to speak for itself. However, given my relationship with the participants and the research mediator, and the extended periods that I have spent in the community, it has been difficult to always keep these two separate.

Although the notions of place and context are fundamental to this study, as well as to the field of narrative inquiry, I have removed the names of all villages, schools, and hospitals in order to protect the participants' rights to confidentiality. Similarly, where reference was made to specific people, their names have been omitted and instead a description of the relationship of the participant to the person being spoken about has been included in brackets.

I have referred to the adults with disabilities who took part in this study as 'participants' and have referred to them as 'Participant 1, Participant 2', etc. While I acknowledge the APA guidelines that numbers 1 - 9 should be written as words, for consistency in terms of describing participants, as well as for the numbering of chapters, I have chosen to use numbers only.

When referring to clinical encounters and healthcare experiences, I have used the term 'patient' as opposed to 'client' or 'health service user' since this is the way in which participants refer to themselves in relation to accessing healthcare services.

GLOSSARY OF TERMINOLOGY

Baksakatsi	Witches
Bantustans	Alternative terminology used for ‘homelands’ which refers to the forced resettlement and restricted movement for black South Africans prior to and during the apartheid era.
Batho Pele	SeSotho term meaning ‘people first’. The Batho Pele initiative aims to enhance the quality and accessibility of government services by improving efficiency and accountability to the recipients of public goods and services.
Community Service	The South African government introduced a year of compulsory work in the government sector for medical professionals in 1998. By 2003 most allied medical professionals, including dentists, pharmacists, occupational therapists, physiotherapists, and speech and hearing therapists, among others were required to complete a year of community service, prior to being allowed to register with the Health Professionals Council of South Africa (HPCSA) in the category of ‘independent practice’.
Emadloti	Spirits
Gogo	SiSwati term for grandmother
Ingati	Blood
Inyanga	Medicine men
Lobola	African tradition whereby the bridegroom's family makes a payment in cattle or cash to the bride's family shortly before the marriage takes place.

Mieliemeal	Local term for ‘porridge’ which is produced by grinding maize and is the staple diet within the community
Mkulu	SiSwati term for grandfather
Muti	Medicine
Pass Book	Pass laws were introduced during the apartheid regime in order to control the movement of black citizens. All black South Africans over the age of 16 were required to carry a "pass book" containing personal information and employment history
Renamo	The civil war in Mozambique (1977-1992) took place between the Mozambican ruling party, Front for Liberation of Mozambique (FRELIMO), and the Rhodesian and South African funded Mozambique Resistance Movement (RENAMO). Soldiers are referred to by many of the participants in this thesis as ‘Renamo’.
Sangoma	Diviner who heals through the possession of spirits
Shebeen	Traditional name for a bar or liquor trading store
Sibongo	Clan praise name
Sichwala	Cripple (derogatory terms for person with a disability)
Sitfunti	Aura
Tokolose	Mythical ape-like creature, with the form of a man, but only measuring about half a meter in height that sexually entices women and then bewitches them.
Ubuntu	African philosophy which implies that the wellbeing of the individual and his/her interests are made possible through a communal web of relationships

Umtimba	Body
Umoya	Spirit
Umuti	In the case of disability, *'umuti'* refers to the onset of disability in situations where the family (usually the parents) have not heeded cultural norms and processes, such as planting crops or family obligations.
White Wedding	In many African cultures couples getting married will have both a 'traditional wedding' in which traditional rituals are performed and traditional clothing is worn, as well as a 'white wedding' which is more representative of a western celebration. During a 'white wedding' the bride wears a white wedding dress.

LIST OF ACRONYMS

AIDS	Autoimmune Deficiency Syndrome
ANC	African National Congress
CBR	Community-Based Rehabilitation
CBRW	Community-Based Rehabilitation Worker
DPSA	Disabled People of South Africa
GDP	Gross Domestic Product
HIV	Human Immunodeficiency Virus
HPCSA	Health Professions Council of South Africa
ICF	International Classification of Functioning, Disability and Health
TRC	Truth and Reconciliation Committee
WHO	World Health Organisation

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AREA MAPS

DETAILED MAP OF SOUTH AFRICA



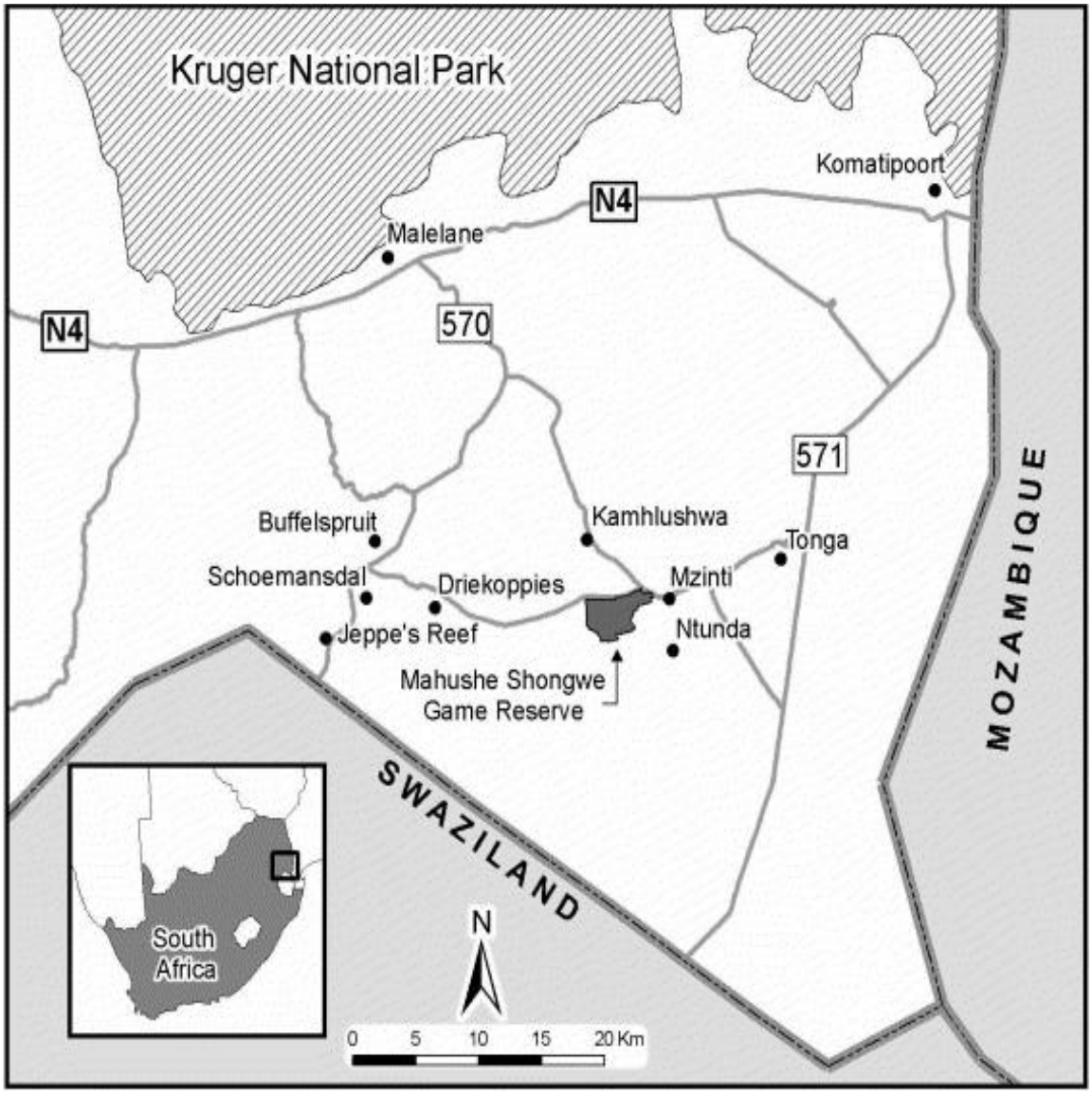
(Source: http://www.routes.co.za/map.html)

MAP OF THE MPUMALANGA PROVINCE



(Source: http://www.rainbownation.com/travel/maps/index.asp)

MAP OF THE NKOMAZI MUNICIPALITY



(Source: http://www.sciencedirect.org/maps)

CHAPTER 1

INTRODUCTION

'In the beginning was the story. Or rather: many stories, of many places, in many voices, pointing towards many ends'

(Cronon, 1992, p.1347)



Road leading up to a participant's home

This thesis is about the everyday experiences of adults with disabilities living in a rural area. By conducting a narrative inquiry, complemented by participant observation, I will provide a description of the participants based on their interpretations of experiences, desires, and fears. These are discussed in relation to their roles within the family and community, their networks of support, their help-seeking behaviours, and the cultural and contextual frameworks within which interpretations of experience are made. The findings of this study, however, extend beyond the individual and the family by providing insight into the larger structure of social relations. In this way I aim to contribute to the socio-cultural understanding of disability, specifically in relation to the way in which narrative can be used in order to make sense of experiences.

Since the millennium, there has been an increasing recognition of disability and its importance to international development (Mji, Maclachlan, Melling-Williams & Gcaza, 2009). Despite this, the field of disability studies remains vehemently contested, reflecting ambivalence in approach, and resisting definition and categorisation. Although explanations, responses and interventions differ according to contextual and cultural variables, the onset of disability frequently involves a sense of loss, including the loss of ability, loss of identity, and/or the loss of an envisioned future. Consequently, many people with disabilities become marginalised and as a result, other people make decisions on their behalf, causing a decreased sense of agency.

In recent years there has been a growth in the fields of health and human rights, and as a result, numerous policies and conventions have been developed, intended to protect the rights of people with disabilities. This study is aligned with a number of these initiatives, including the United Nations Millennium Declaration and the World Health Organisation (WHO) Action Plan 2006-2011, addressing five out of the eight identified key activities, including raising awareness about the magnitude and consequences of disability; facilitating data collection and analysing and disseminating disability-related information; supporting, promoting and strengthening health and rehabilitation services for people with disabilities and their families; promoting community based rehabilitation (CBR); and supporting the development, implementation, measurement and monitoring of policies designed to improve the rights and opportunities of people with disabilities (WHO, 2006). However, despite

increases in awareness and human rights imperatives, little is known about the lived experiences of people with disabilities.

To date, research into the cultural understandings of disability has been superficial, and as a result, evidence-based practice has remained based on a health beliefs model which views cultural and contextual variables as constant (Legg, 2010). Furthermore, limited attention has been paid to the ways in which class, race and gender impact on people with disabilities' interpretations of their experiences (Legg & Penn, 2013a). As a result, research into the field of disability studies has failed to adequately take into account the effect that the relationship between environmental constraints and social demands places on the physical and emotional spaces in which individuals live and act (Legg & Penn, 2013b). Thus, the enhancement of cultural knowledge on these factors has the ability to illuminate the disparities between policies and practices. This is particularly pertinent in the South African context where cultural and linguistic diversity has the potential to yield important theoretical insights into the psychosocial aspects of lived experience. Based on this imperative, this thesis will attempt to develop a theoretical understanding of the complex contextual variables which impact on disability, family structure, health-seeking behaviours, and cultural beliefs and practices in rural South Africa.

1.1 INTRODUCING THE RESEARCHER

I have approached this study, both as a speech-language therapist and as a researcher. The conceptualisation of this project has been guided by the challenges that I have encountered in attempting to provide a speech-language therapy service cross-linguistically and cross-culturally in a rural area. True to the nature of qualitative research, I feel that it is important to take into account my own history and biases, and the ways in which these may have influenced the conceptualisation and findings of the current study.

After finishing school, I registered for a BA Speech and Hearing Therapy degree, with my rationale being that 'I wanted to help people'. Naturally I was naïve about both the course

content and with the implications of working with people with communication impairments. Throughout the degree my passion increased for assisting those who had lost their ability to communicate to regain a sense of agency. By the end of my final year of study I was convinced that my future would involve working in an acute medical setting with people who had sustained head injuries. This plan, however, changed during my first year of work which coincided with the introduction of a year of compulsory community service for allied healthcare professionals. By default I was placed at Tonga Hospital – a rural hospital in the Nkomazi East Municipality of South Africa, situated south of the Kruger National Park and between the borders of Mozambique in the East, and Swaziland in the south.

The hospital staff consisted of me, two community service occupational therapists, a community service dietician, a permanent physiotherapist, two foreign doctors, and a few nurses. Working in Tonga was difficult, particularly in the beginning, partly due to the fact that I had such limited exposure to the interplay of factors such as disability, poverty, unemployment, malnutrition, lack of municipal services, and the effects of power and gender dynamics on individual experiences. This, coupled with an illiterate SiSwati-speaking population with whom I could barely communicate was challenging and it took me at least six months to understand my role in this rural hospital which had previously not had any rehabilitation services. Despite the challenges faced, my community service year was one of transformation, and it taught me many things, including how to be independent, how to draw on minimal resources and to be creative in my endeavours to deliver an appropriate speech therapy service in a cross-linguistic and cross-cultural setting without an interpreter.

Notwithstanding everything I learned during this year of rural work, I became increasingly unsettled for a number of reasons. I became acutely aware of the unequal distribution of wealth within South Africa and the consequent disparate access to services, particularly in rural areas; the impact of gender inequalities; and the relationship between poverty, disability and disempowerment. This sense of unease led me to question the literature that I had been exposed to as an undergraduate student as well as the methods used in creating a body of knowledge that I had been relying on as ‘evidence-based practice’. I felt that the literature was heavily biased towards the quantitative paradigm and the recommendations based on the experiences of persons with disabilities in developed contexts were not always appropriate in

the environment where I was working. This led me to read beyond the field of speech-language therapy, and I found myself becoming increasingly excited about some of methods used in the social sciences, particularly in sociology and anthropology.

My sense of unease regarding the complex social interactions that I was observing, together with a desire to explore the reality of lived experience led me to register for my Masters Degree which probed the experiences of mothers caring for children with cerebral palsy in Tonga (Barratt, 2007). While this study illuminated many aspects related to the way in which caring for a child with a disability is mediated by context and culture, I felt that my Masters dissertation left me with more questions than it could answer. These questions related to the relationship between disability, context and culture, the complex relationship between service providers and service consumers in the health and social welfare sectors, and the dominant voices which influence the interpretation of experiences amongst people with disabilities. These questions culminated in the conceptualisation of the current study.

Given the route that my career as a researcher and clinician has taken, this study transverses many disciplines, including bioethics, medicine, allied health sciences, law, philosophy, sociology and anthropology. In this way, this thesis is a reflection not only of the participants' experiences and viewpoints, but also of my own transformation, as a clinician and researcher. Despite my prior experience, I now look back and acknowledge my naiveté and vulnerability at the conceptualisation stage of this study, and am able to document how this changed over the period of data collection and analysis. By reflecting on the journal that I kept throughout the research process, I can see how I initially envisioned a neat intersection between disability, context and culture, yet the reality of lived experience is far more complicated, as will be revealed in the forthcoming chapters.

Over and above the challenges associated with the content that I encountered during this process, I was also faced with a number of ethical and moral dilemmas that I had not anticipated. These dilemmas could not be solved purely by relying on contextually irrelevant literature or on the guidance provided by ethics committees, but rather by confronting the

issues head-on and in so doing, evaluating my own role in maintaining or defying these predicaments.

1.2 THEORETICAL ORIENTATION OF THE STUDY

This thesis stems from the need to develop a contextually relevant socio-cultural concept of disability and, in so doing, to improve our understanding of the intersectionality between disability, race, class and gender, and the ways in which this impact on how individuals perceive themselves and how they think that society perceives them. In order to do this, I have drawn on a variety of methods from a range of different disciplines which allow for engagement in the life worlds of people with disabilities living in rural areas.

Previous research into the field of disability has relied heavily on quantitative measures (e.g Norman, Matzopoulos, Groenewald, & Bradshaw, 2007; Connor, Bryer, Meredith, Beukes, Dubb, & Fritz, 2005; Nattrass, 2006), focussing on the explanation of behaviours and experiences in relation to clinically normative standards. While this type of information is important in establishing the prevalence of disability and the need for policies and services, it is unable to describe lived experience and is unlikely to be able to provide explanations into the causal factors underlying health issues, which are frequently embedded within the social, behavioural, biological, economic and environmental characteristics of families (Kahn, Tollman, & Gear, 1999). In this way, research in clinical settings has resulted in the censorship of suffering (Frank, 2011), and is believed to have magnified the challenges experienced by people with disabilities.

More recently, a number of studies have been conducted which have used qualitative methods, such as semi-structured interviews and participant observation (e.g. Hundt, Stuttaford, & Ngoma, 2004; Schneider, Claassens, Kimmie, Morgan, Naiker, & Roberts, 1999; Parr, 2007; Worrall & Holland, 2003; Mattingly, 1994; Hinckley, 2006; Rohleder, Braathen, Swartz & Eide, 2009; Mji, Gcaza, MacLachlan & Hutton, 2011). These measures allow for insight into personal experiences, but do not allow the participant the freedom to

tell their own story, as the inquiry is framed by the researcher. Other studies have relied on interviews with disability activists and empowered members of disability forums only (Howell, Chalken, & Alberts, 2006). While this does provide a sense of the commitment and vision behind the disability rights movement, it does not take into account the experiences of those marginalized and disempowered not only by disability, but also by poverty, spread of disease, food insecurity; access to education, healthcare and information; stigma and cultural retribution. This has resulted in those who are most marginalized by their disabilities and living conditions remaining voiceless.

In addition to the limitations described above, the majority of research within the field of healthcare and rehabilitation describes the experience of disability in a matter of fact way or relies on anecdotal evidence (e.g Bakheit, Barret, & Wood, 2004; Code, Hemsley, & Hermann, 1999; Connor, Bryer, Meredith, Beukes, Dubb, & Fritz, 2005; Hundt, Stuttaford, & Ngoma, 2004; Kahn, Tollman, & Gear, 1999; Kilonzo, 2004; Parr, 2007). These studies are limited in that they do not provide a theoretical framework for understanding disability and the effects of the intricate and complex contextual and cultural variables on daily life, and therefore are unable to expose the social and biological processes underlying health inequality, disease, disability and death.

Internationally, limited research has been conducted by applying methodologies that have involved researchers working with people with disabilities in order to identify the most important research questions based on their needs and experiences (Tomlinson et al, 2009). This draws attention to the fact that historically, research has been conducted 'on' persons with disabilities, as opposed to 'with' them, and as a result, many people with disabilities are suspicious and hostile towards researchers (Mji et al, 2011). This highlights the need for improved research which can be translated into more accessible policies and practices as opposed to producing greater volumes of research that does not address the needs of persons with disabilities (Mji et al, 2009).

Based on the limitations of previous research discussed above, the question arose as to how best to design a study which explored the reality of lived experiences, while fostering a sense

of trust, empowerment and maximum participation between me and people with disabilities, as participants. In order to do this, I realised that I would need to search further afield for a method that would allow me to engage cross-culturally and cross-linguistically, while at the same time, allowing me to fully engage in the lived experiences of my participants. I came across the work of Arthur Frank, whose research into the ways in which people use stories to make sense out of experiences of illness resonated with my desire to understand the lived experience of disability. From this starting point I developed, what I argue is a rich interpretive framework for understanding lived experience. This is based on the works of Frank (1995, 2000, 2001, 2011, & 2012), Connelly and Clandinin (1990, 2000, & 2006) and Harré (1990, 1993, & 2009). These authors, among others have shown me the potential that qualitative research has in creating rich conceptual frameworks for understanding how individuals make sense out life experiences.

1.3 CORE THEMES IN THE CURRENT STUDY

This thesis is informed by three main conceptual domains – disability, context and culture, and narrative inquiry. Given the increasing prevalence of disability, both locally and internationally (WHO, 2011), calls have been made to raise awareness and develop policies that enhance the quality of life of people with disabilities (WHO, 2006). These calls necessitate social and attitudinal change, both of which are central to inclusive health (MacLachlan, Khasnabis & Mannan, 2012). This entails a rights-based perspective to healthcare, incorporating political, social, economic, scientific and cultural approaches to ensuring equitable healthcare for all (Sen, 2008). The right to health is not only about access to services, but includes numerous social factors which affect health, including gender equality, access to information and adequate nutrition, political stability, and inclusive understandings of diversity and culture (Tomlinson, Swartz, Officer, Chan, Rudan & Saxena, 2009). Thus, despite South Africa's relative wealth and its internationally acclaimed inclusive constitution, the possibilities for people with disabilities to achieve equal rights and meaningful community integration remain elusive (Mji et al, 2009).

While disability in South Africa has traditionally been regarded as a health and welfare issue (White Paper on an Integrated National Disability Strategy, 1997), increasing awareness has developed in relation to the ways in which culture and context shape the experiences of people with disabilities, creating an opportunity for dialogue regarding theoretical frameworks of disability, training and service provision.

1.3.1 Healthcare Provision in the South African Context

In order to understand the nature of disability and service provision in South Africa, it is important to take into account the country's socio-political history. Apartheid is acknowledged to have had a detrimental effect on service provision, including access to equitable information, education and healthcare. Thus, the experience of illness and disability is intricately linked to the country's environmental, socio-political and cultural phenomena (Legg & Penn, 2013a).

Since the end of apartheid in 1994, the government has made numerous attempts to redress the inequalities of the past, and to improve the healthcare status of its citizens. However, despite the redistribution of resources, and the introduction of free healthcare for children under the age of six years, pregnant women and pensioners (Coovadia, Jewkes, Barron, Sanders & McIntyre, 2009), South Africa's healthcare system continues to face challenges in service delivery. This is mainly related to limited resources, a shortage of healthcare professionals, the burden of communicable and non-communicable diseases, and increasing morbidity and mortality as a result of injury and violence (Coovadia et al, 2009). As a result, major inequities remain in the healthcare sector, with significant disparities between the services offered in the private and government settings. These inequities reflect inequalities of class, gender and race, highlighting a pervasive imbalance of political and economic power manifesting in the unmet needs of vulnerable citizens (Dréze & Sen, 2011).

Currently, state healthcare varies from basic primary healthcare clinics, to secondary and tertiary level hospitals where more complex cases are seen. In general, the more experienced healthcare professionals are based at tertiary level hospitals in urban settings, while new graduates completing their community service year are placed in the outlying areas. Most of

the state hospitals have long waiting lists, especially for surgical procedures and assistive devices, and the long waiting times, together with inefficient administration is frustrating for patients. Compounded with this is the fact that most of the clinical encounters take place within the confines of linguistic and cultural barriers as service providers seldom share a common language or culture with their patients.

In the Nkomazi East Municipality, where the current study took place, there are 27 day clinics, one 24-hour clinic and one hospital which can accommodate 150 in-patients. Out-patient services are also provided, including medical clinics, speech-language therapy, occupational therapy, physiotherapy, dietetics, radiology and pharmacy. However, capacity is limited, meaning that patients may wait long periods of time to make an appointment, and even when regular follow-ups are warranted, patients may wait for months in between appointments. Clinics, as well as the hospital are geographically inaccessible for many residents in the area, and this, together with high public transport costs make regular appointments challenging.

1.3.2 Disability in the South African Context

The promotion and protection of health and human rights for people with disabilities are inextricably linked. Human rights violations may have severe health consequences, and health policies and programmes have the potential to either protect or violate human rights in their design and implementation (MacLachlan, Amin, Mannan, El Tayeb, Bedri, Swartz, Munthali, Van Rooy & McVeigh, 2012). Consequently, international calls have been made for policy reform in order to ensure equitable access to healthcare for all (Mji et al, 2011; MacLachlan et al, 2012).

In South Africa, services for people with disabilities have traditionally been provided in line with the medical model of healthcare provision (White Paper on an Integrated National Disability Strategy, 1997). In recent years, as a result of an increased focus on equitable access to healthcare, service provision has shifted from the medical model to the social model, and more recently towards the World Health Organisation's International Classification on Funtioning, Disability and Health (WHO ICF, 2006). These models,

however, view contextual and cultural variables as universal (Legg & Penn, 2013b), and thus fail to adequately incoporate individual experiences and needs into service provision. Furthermore, these models rely predominantly on the proximal determinants of behaviour, such as behavioural norms and intentions as a means for explaining health-related issues (Tomlinson, Rohleder, Swartz, Drimie & Kagee, 2010), and in this way fail to take into account the impact that contextual variants have on the determinants of health. As a result, many people with disabilities continue to be overtly and covertly discriminated against, through impaired access to information and services, poor quality of healthcare, through cultural and linguistic barriers, and through negative attitudes, stigma and marginalisation. These forms of discrimination impact on the ability of people with disabilities to lead independent lives. Thus, despite the fact that international and local policies highlight the social fractures in society which predispose individuals to discrimination, including women, children, the elderly, the poor, people with illnesses and disabilities, the uneducated, and the illiterate, the perpetuation of socially embedded discrimination beyond physical limitations is poorly understood.

The perpetuation of vulnerabilities and socially embedded discrimination can be explained by Farmer (1999), who claims that medical and allied healthcare providers have historically positioned themselves on the periphery of human rights development. Article 25 of the Universal Declaration of Human Rights (1948) stipulates that "everyone has the right to a standard of living adequate for the health and well-being of himself and his family, including food, clothing, housing, medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age, or other lack of livelihood in circumstances beyond his control." Based on this declaration, it can be deduced that social and economic rights are as important as human rights. However, the upholding of these rights is challenging, particularly in developing countries such as South Africa, which is ravaged by the effects of poverty, unemployment, xenophobia, political instability, lack of access to services, and the uncontrolled spread of disease, all of which predispose individuals to illness and disability. This is supported by MacLachlan et al (2012) who claim that in order to promote equitable healthcare for all, an understanding of individual needs together with the influence of socio-economic context and culture is necessary. Thus, the wellbeing of people with disabilities cannot be achieved without taking into consideration the principles of non-

discrimination, autonomy, participation and social inclusion, respect for diversity, and equal opportunity (Tomlinson et al, 2009).

Based on the above, it emerges that the limited understanding of the lived experience of disability has significantly affected the body of literature upon which evidence-based practice is based, as well as models of healthcare provision and the implementation of policies intended to empower those with disabilities. In South Africa, the experience of disability is frequently linked with challenges imposed by poverty and access, together with the burden of uncontrollable spread of disease, malnutrition, dehydration, and stigma. The rural villages situated in the Nkomazi East Municipality, represent communities that are ravaged by these elements.

1.3.3 Narrative Inquiry as a Window into Lived Experience

Narrative inquiry is based on the premise that individuals organise and tell stories as a way of making sense of their lived experiences. In this way, experiences are assigned meaning, and through the construction of spatial and temporal boundaries, fragmented memories are reconstructed in order to form a coherent whole. A large body of literature exists on the value of narrative inquiry as a means for exploring lived experiences. Providing individuals with opportunities to tell stories of lived experience, implies an acknowledgement of the reality of experience and in so doing, the individual is provided with a sense of voice and agency. By placing value on diversity and individual voice, narrative inquiry has the potential to honour the ethics and values of therapeutic interventions (Hinckley, 2006), and in so doing, reflects the moral dimensions of clinical practice (Kleinman & Kleinman, 1991). For this reason, narrative inquiry has proven to be particularly useful in clinical encounters where individuals are confronted with an unexpected illness, acquired disability, or a traumatic event, since it allows for the reconstruction of events, by assigning relative meaning to experiences.

Penn (2000) suggests that in clinical encounters, the story of an illness is a vital point of intersection among many disciplines and provides an interesting range of perspectives on the condition as well as on diagnostic and therapeutic regimens. For this reason, narrative inquiry has the potential to be particularly useful in understanding how the experience of disability is

mediated by contextual variables and cultural beliefs and practices, or through power imbalances, both inside and outside of the consultation room. By employing narrative inquiry as a means for understanding lived experience, the interviewer and the respondent have the opportunity to become co-equals who engage in a conversation about mutually relevant, and often critical biographical issues. A central component of intervention and rehabilitation lies in understanding how people make sense of their disabilities. An effective way of doing this is by listening to the affected individuals' stories about daily life (Barrow, 2008). Penn (2004) asserts that the question "What does it feel like?" is important in acknowledging the impact of disability, since listening to individuals talk about the consequences of their impairment ultimately reveals how they construe disability as a whole, and more specifically how they make sense of '*their* disability' (emphasis added). Thus, learning to listen to the narratives of those affected by disability is vital since this reflects an intersection between personal and social beliefs, practices and societal influences (Barrow, 2008).

Narrative inquiry has been shown to be a useful tool in the South African context, particularly in its application for acknowledging the atrocities of the past and for facilitating healing during the Truth and Reconciliation Commission (TRC) Hearings (Moon, 2006; Fox, 2011). Narrative inquiry was adopted as an appropriate measure since it drew on the African philosophy of *"ubuntu"* which is defined as *"umuntu ngumuntu ngabantu"*, meaning "a person is a person through other persons" (Swanson, 2007, p.55). This philosophy links memory with storytelling and speaks to the very essence of what it means to be a human being (Fox, 2011) by embodying the notions of understanding acceptability, hospitality and a sense of community (Tutu, 2007).

Although narrative inquiry has the potential to be a powerful and ecologically valid tool which can transcend the barriers imposed by literacy and educational level, limited literature exists on the challenges and solutions to negotiating narrative construction cross-culturally and cross-linguistically, particularly in relation to the lived experience of illness and disability. Thus, its application for research purposes in the South African context has been somewhat cursory, and has limited our understanding of the construction of culturally acceptable plots, temporal norms, and culturally acceptable themes and characters. This has implications for understanding the ways in which people with disabilities make use of

narrative as a way of making sense of their lived experiences. For this reason, and taking into account the threats posed by uncertainty associated with poverty, illness, disability and death to memory and their combined threats to the African philosophy of *ubuntu* (Fottrell, Tollman, Byass, Golooba-Mutebi & Kahn, 2012), I shall use the forthcoming chapters to demonstrate the ways in which narrative inquiry can be used both as a means to strengthen our theoretical understanding of disability as a socio-cultural construct as well as a tool for improving service provision.

1.4 DESCRIPTION OF CHAPTERS

Chapter 1 has provided an overview of this thesis and has introduced some of the core concepts, including context, culture, and disability, as social constructs, embedded within society. It has also highlighted the impact of disability in the South African context, particularly in relation to the country's socio-political past and the implementation of policies and practices, drawing attention to the lack of culturally specific and contextually relevant research on the lived experience of disability in rural areas. This has contributed to the methodological justification for the study as highlighted in the theoretical orientation, which emphasizes the way in which previous methods of studying disability have influenced the development of evidence-based practice. As a result, a rationale is put forward for the use of narrative inquiry as a means for developing a contextually relevant and culturally safe understanding of the lived experience of disability.

Chapter 2 provides a description of the historical and current socio-political and economic situation in South Africa. Particular attention is paid to South Africa's history of cultural, political and racial conflicts with a discussion as to how these have resulted in a culture of violence. In addition, a description of South Africa's burden of disease is provided, with specific reference to the complexities imposed by HIV in relation to the country's health, economic and political situation. Chapter 2 concludes with a description of the historical, geographical, cultural and socio-political context of the Nkomazi East Municipality, where the study took place.

Chapter 3 attempts to contextualise and conceptualise disability. Attention is paid to the complexities associated with attempts to categorise and define disability as a static concept, and the increasing difficulties that this imposes on the development and implementation of policies. The nature of previous research is shown to have influenced the way in which society understands and responds to disability. Thus, particular attention is paid the various models of disability and the ways in which these are applied. The experience of disability in the context of poverty is highlighted as a human rights issue, yet the factors which maintain and perpetuate this relationship are poorly understood. Finally, a discussion on the impact of contextual and cultural beliefs regarding onset and management of disability is presented as part of the overriding psychosocial experiences of disability, focussing particularly on the impact of social role devaluation on the individual.

Chapter 4 provides an overview of narrative inquiry as a method for studying lived experience. This is discussed in relation to the embodiment of experiences, and how embodiment results in the need to tell stories. Particular attention is paid to the core concepts of narrative construction, including events and characters, and spatial and temporal orientation, and how these contribute to the construction of a coherent plot. Narrative inquiry is also discussed as a clinical tool which allows individuals to align with or reject cultural ideas and values. Despite the values associated with narrative inquiry as a clinical tool, its limitations in transforming the lived experience of trauma and suffering are also acknowledged. Finally, narrative inquiry is shown to be a particularly relevant tool in the South African context, given its cultural relevance and its previous application in the Truth and Reconciliation Committee hearings.

Chapter 5 describes the methodology used in this study. It highlights the specific aims and objectives, and shows how these were attained using qualitative methods. A detailed description of the way in which data were collected, managed and analysed using the principles of qualitative research is provided. It describes the sensitive way in which participants were accessed and discusses the fundamental role played by the research mediator, and consequently how information was shared cross-linguistically and cross-culturally. Significant attention is paid to the ethics of the study, specifically in relation to

conducting research with vulnerable populations. This leads into the results and discussion which is presented over the following three chapters.

Chapter 6 focuses on the reflexive interplay between personal and social interpretations of embodied knowledge, and aims to highlight how the individuals' perceptions about themselves combine with their interpretations of how others perceive them, and in so doing, forms the basis upon which their narratives are built. This is done by exploring the ways in which individuals position themselves as well as the ways in which other characters are positioned, and through this, how counter-narratives were developed.

Chapter 7 discusses the relationship between embodied knowledge, and the spatial and temporal dimensions of narrative construction, specifically in the context of social and emotional exclusion. The temporal dimensions of narrative inquiry focus on whether stories were told in the past or present tense and whether participants were able to shift between past, present and future orientations. These aspects are discussed in relation to the impact that they have on the construction of a narrative plot.

Chapter 8 begins with a description of the difficulties encountered in identifying coherent plots within the participants' narratives. This appears to be linked to the sustained experience of a variety of forms of violence within the community. Through the acknowledgement of violence as a fundamental aspect of lived experience, four new types of narrative emerge, which give rise to a number of policy, clinical and methodological implications as well as broader philosophical questions pertaining to the relationship between memory, vulnerability and responsibility.

Chapter 9 forms the conclusion of the study. Clinical, theoretical and policy recommendations are made and are discussed in terms of their relationship to future research. Although this thesis does highlight significant implications and recommendations, it also raises a number of philosophical questions pertaining to the concepts of vulnerability and responsibility, particularly in relation to how these manifest in Afro-centric environments.

These findings demand attention to the ways in citizens at all levels of society, including national, local and individual level conceive of what it means to be human, and consequently how the ethics of care are embraced within society.

CHAPTER 2

A DESCRIPTION OF SOUTH AFRICAN GEOGRAPHY, SOCIO-POLITICAL CONTEXT AND CULTURE



Illegal electricity connection at a participant's home

2.1 AN INTRODUCTION TO SOUTH AFRICAN CONTEXT AND CULTURE

South Africa is a diverse country, situated on the Southern tip of the African continent, spanning 1 219 090 km^2 (Burger, 2012). The country is divided into nine provinces, with 11 official languages, and a variety of cultures and religions. Recent estimates reflect a total of 51 770 560 persons living in the country, which accounts for approximately 0.73 per cent of the world's population (Statistics South Africa, 2012).

South Africa is one of the most unequal countries in the world (World Bank, 2012). Despite the fact that South Africa has been described as an upper-middle-income country, its distribution of wealth is uneven (Tregenna, 2012). This has been influenced by its history of inequality, deprivation and extreme spacialization of poverty, made possible by apartheid policies which divided communities by race and imposed a system of class (Stewart, Swartz & Ward, 2012). Currently South Africa has a two-tiered economy (Tregenna, 2012), where one tier is said to rival developed countries in terms of its industrialisation and productivity, while the second tier reflects an economy similar to other developing countries, given the large informal employment sector and the challenges imposed by poverty (Dréze & Sen, 2011).

Despite the fact that South Africa's Gross Domestic Product (GDP) has continued to increase since democracy in 1994 (Tregenna, 2012), and recent figures indicate that household income has doubled over the last ten years (Statistics South Africa, 2012), the country continues to face enormous challenges imposed by poverty, limited access to services, low literacy levels, and high levels of unemployment (Gradin, 2012). Furthermore, recent statistics reveal increases in unemployment rates (Statistics South Africa, 2012), which affect between 25% and 40% of the working-age population (Statistics South Africa, 2012; Gradin, 2012). This has resulted in a widening gap between the rich and the poor with many people continuing to live below the breadline (Tregenna, 2012; Gradin, 2012). Dréze and Sen (2011) point out that in order to recognise the impact of economic growth on living standards, it is important to take in account the nature of growth processes and public policies, since corruption, greed,

the unequal distribution of wealth, and inequitable policy implementation have the potential to threaten positive economic growth trends.

The influx of both legal and illegal immigrants into South Africa has impacted on the country's population growth and its socio-economic status. Engelbrecht (2012) suggests that the number of illegal immigrants living in South Africa ranges from two to eight million. The Limpopo and Mpumalanga Provinces are said to have the highest numbers of people entering the country, accounting for approximately 20% of migration figures (Statistics South Africa, 2012). The South African constitution protects the rights of both resident and non-resident citizens to dignity, equality, justice, basic education, basic healthcare and labour rights (Polzer, 2010). However, given the fact that many South African citizens live in conditions of poverty, the additional demands placed on housing, healthcare, education and employment have led to recent outbreaks of xenophobic violence in several urban and rural areas (Maloy, 2012).

Many of the challenges currently facing South Africa have been influenced by the country's history of cultural, political and racial conflicts. Consequently, many people live below the breadline, and rural areas, particularly, are plagued by high mortality rates, low levels of literacy, high rates of unemployment, and largely uncontrollable spread of disease (Coulson et al, 1998). Many communities still do not have access to running water, live in unsanitary conditions and experience high levels of stress related to poverty, affecting access to healthcare and contribute to disease exposure (Bhorat, Poswell, & Naidoo, 2006). In section 2.2, I shall provide a summary of South Africa's history and describe how this has influenced the current socio-economic and political climate.

2.2 A SUMMARY OF SOUTH AFRICA'S CULTURAL, POLITICAL AND RACIAL CONFLICTS

Moon (2006) defines South Africa's history as one of human rights violations, violence and trauma, with structural violence playing a central role in the establishment and maintenance of the apartheid era. Structural violence is a term that was coined by Johan Galtung during the 1960's in order to describe social structures that prevent individuals, groups and societies from reaching their full potential (Galtung, 1969; Galtung & Höivik, 1971). Farmer, Nizeye, Stulac, & Keshavjee (2006) add that structural violence is embedded within social structures and in this way becomes ingrained in everyday experiences, making it almost synonymous with social injustice and oppression. Although structural violence pertains largely to the development and implementation of policies and practices, it must be acknowledged that this takes place, directly or indirectly through human agency (Farmer, 1996). Farmer (2004) adds that while the poor are the primary victims of structural violence, a limited understanding exists with regard to the nature and distribution of this form of brutality.

In the South African context, colonialism and the subsequent establishment of the apartheid regime allowed for the reinforcement of structural violence where white citizens were viewed as supreme and were endowed with the authority to speak, while attempts were made to silence black citizens. Sections 2.2.1 - 2.2.3 below provide a description of South Africa's history of cultural, political and racial conflicts and their impact on the current socio-political context in the country.

2.2.1 South African History Pre-Apartheid: 1652 – 1948

South Africa has a colonial history, as described by Bundy (1986) and Warden (2012). Although the country had been inhabited for centuries by indigenous people, and served as a trading post for Portuguese explorers during the 1500's, it was formally "discovered" by the Dutch who settled in the Cape in 1652 (Bundy, 1986). Trade was initiated through the development of The Dutch East India Company which was established in order to provide supplies to passing ships (Bundy, 1986). As a result of growing trade and the colonists' demands for labour, slaves were imported from East Africa (Nasson, 1999). The colonists began to move inland, placing additional demands on land and resources (Penn, 2011),

resulting in local inhabitants being dispossessed and incorporated into the colonial economy as servants (Warden, 2012). During the early 1700's alliances developed along racial lines. This resulted in the evolution of a new social order based, which resulted in increased levels of conflict between the colonists and the local inhabitants (Warden, 2012).

The discovery of diamonds and gold in the late 1860's served as a turning point in South African history (Nasson, 1999). While these discoveries brought wealth and encouraged immigration, particularly from Europe, they also signalled the emergence of South Africa as an industrial state (Niehaus, 2012). The colonists' primary concern was ensuring a cheap labour supply which was provided by unskilled black[1] locals (Burger, 2012). The possibility of black competition in the mining industry was eradicated through the introduction of land dispossession and pass laws. According to these laws, black South Africans were forced to return to their 'homelands' or 'Bantustans' while migrant labourers were housed in compounds and paid minimal wages (Khan, 2006; Niehaus, 2012). These 'homelands' comprised 13% of arid rural land, yet they housed 75% of the population (Collinson, 2010). These barren lands constrained the possibilities of farming and harvesting crops and livestock, and thus the livelihoods of locals became entrenched in segregationist policies, resulting in a large migrant work force, in which working-age adults were forced to leave their families and relocate to urban areas in search of paid employment (Collinson, 2010). Through this process, skilled labour was reserved for whites, while black people provided unskilled labour, curtailing their livelihood opportunities (Warden, 2012).

The Union of South Africa was established in 1910 after the British defeated the Dutch in the Anglo Boer War (1899 - 1902) (Burger, 2012). Under the Union of South Africa, formalised segregationist policies were implemented in response to the increasing participation of black South Africans in the country's economy, resulting in an assertion of their political rights (Burger, 2012). This contributed to the formation of the African National Congress (ANC) in 1912 who challenged constitutional rights through the use of strikes and anti-pass campaigns,

[1] The terms 'black' and 'white' have been used here as racial categories, in line with the labels laid down in the South African law during this period (Burger, 2012)

leading to increased racial tensions and political conflict (Tutu, 2007). This resulted in the formalised institution of apartheid policies in 1948 (Tutu, 2007).

2.2.2 South African Rule under the Apartheid Regime: 1948 – 1994

The Nationalist Party came into power in 1948, and operated under the formalised apartheid regime. The increasingly repressive law of apartheid during the 1960's resulted in the forced removal of black people from their land, and in the development of vast slums in under-resourced areas outside of the main urban localities (Collinson, 2010; Warden, 2012).

Apartheid is proven to have had a detrimental influence on a number of South Africa's policies and practices (Dowdall, 1991; Warden, 2012). Services, including healthcare and education, were provided along racial lines (Chataika, McKenzie, Swart & Lyner-Cleophas 2012), with large well-equipped facilities available to white citizens, and under-funded, under-equipped and under-staffed facilities available to black citizens (Coulson, Goldstein, Ntuli & Usdin, 1998).

The Bantu Education Act (1953) formalised segregated education. Based on the implementation of this act, white children received superior education while black children were taught in overcrowded classrooms by under-qualified teachers (Chataika et al, 2012). The principles underlying the Bantu Education Act sought to prepare black citizens for unskilled labour only, while white citizens were prepared for higher education and skilled employment (Niehaus, 2000). During 1963 and 1965 respectively, the Coloured Persons Education Act and the Indian Education Act were introduced which served to create further racial division within the education sector (Kallaway, 2002). In addition, according to the homelands policy, school-age children were only eligible to attend schools in their respective homelands (Kallaway, 2002).

Concurrent with the introduction of the apartheid regime, was the ANC's rejection of white domination and the call for protests, strikes and other acts of resistance (Tutu, 2007). This resulted in a decade of turbulent mass action in opposition to segregation and oppression. In

1955, the Freedom Charter was drawn up which served as an important symbol in the struggle for equal human rights and non-racialism (Burger, 2012). However, mass action continued in the form of armed struggle, mass mobilisation, and international solidarity, making black townships virtually ungovernable (Warden, 2012). Consequently regional and national states of emergency were enforced during the mid-1980's, while international sanctions and boycotts against South Africa were instituted (Tutu, 2007). In response to the increasing local and international resistance against apartheid policies, President FW De Klerk announced the unbanning of liberation movements and the release of political prisoners at the opening of parliament in 1990. This marked the beginning of South Africa's newfound democracy (Tutu, 2007).

2.2.3 South Africa Post-Democracy: 1994 – Present

South Africa's first democratic election was held in April 1994, which the ANC won with a 62% majority (Burger, 2012). President Nelson Mandela was inaugurated as president and instigated a number of changes to overcome the country's history of division, exclusion and neglect and to improve the lives of all South Africans (Tutu, 2007). This was concretised in the development of South Africa's new constitution which evoked worldwide admiration. The new democratic government prioritised the provision of housing, piped water, electricity, education, healthcare, social welfare and safety for all (Tutu, 2007). In addition, the Truth and Reconciliation Commission (TRC) was established in 1995 in order to facilitate the healing of wounds inflicted on many South African citizens by gross human rights violations during apartheid (Truth and Reconciliation Report, 1998).

Based on the priorities identified by the new South African government, many national policies have changed and new ones have been implemented since the 1994 elections. For many South African citizens, 1994 symbolized the end of the apartheid regime and the end of an era of marginalization (Collinson, 2012). Today much emphasis is placed on establishing a culture of rights, and as a result the term 'community' is frequently recognised as a politically term (Kahn, Garenne, Collinson, & Tollman, 2007; Tutu, 2007).

However, despite South Africa's newfound freedom, political uncertainty was once again provoked as a result of civil unrest and service delivery protests in 2006 (Penn, 2011). This was followed by the recall of President Mbeki, successor to President Mandela, from his post as president in 2008 (Burger, 2012), resulting in a re-shuffling of cabinet, followed by the election of Jacob Zuma as president in 2009 (Burger, 2012). Currently, despite the introduction of a new constitution, and the presidency's prioritisation of basic education, safety and security, the eradication of poverty, and a healthy life for all, the South African political situation remains in a state of flux. Rates of poverty, crime, corruption and unemployment remain high, exacerbated by socio-economic inequality, xenophobia and political instability. These factors have contributed to the culture of violence seen in South African society today.

2.3 THE PERPETUATION OF 'A CULTURE OF VIOLENCE' IN SOUTH AFRICA

As described above, South Africa's socio-political history has been tumultuous in nature, which has contributed to the high levels of violence evident in society today (Truth and Reconciliation Report, 1998; Schönteich & Louw, 2001; Matzopoulos, Bowman, Butchart & Mercy, 2008). Moon (2006) states that while South African history is irreducible to a single plot, the TRC report reflects that violence has been the single most determining factor in the country's political history. This is supported by Niehaus (2000) who claims that one of the most consistent themes in South African history has been gender-based violence, with the silencing of women and the objectification of women's bodies by men. Although some areas have begun to report a decrease in crime levels, South Africa is still recorded to have among the highest levels of violence in the world (Matzopolous et al, 2008), with interpersonal violence a leading cause of death and the prevalence of homicide being seven times higher than the global average (Norman et al, 2007).

The term violence is frequently used to convey a message about the infliction of physical harm (Farmer, Nizeye, Stulac & Keshavjee, 2006), reflecting a narrow understanding of the pervasive nature of violence. Galtung (1969), thus proposes that the term 'violence' should be used to refer to "the avoidable impairment of fundamental human needs" (p.182). For the purpose of this study, the definition as adopted by the WHO (2012) has been used. According

to the WHO (2012), violence may be inflicted in four ways: physically, sexually, psychologically, or by means of deprivation. The term 'violence' thus refers to "the intentional use of physical force or power, threatened or actual, against oneself, another person, or against a group or community, that either results in or has a high likelihood of resulting in injury, death, psychological harm, mal-development, or deprivation" (WHO, 2012).

The risks of being a victim of violence in South Africa are shaped by context, socio-economic status, age and gender (Schönteich & Louw, 2001; Ward et al, 2012). Vulnerability is increased by the authority that the perpetrator has over the victim, poor social support structures, physical or cognitive impairment, lack of ability or opportunity to report on experiences of violence, financial or emotional dependence on the perpetrator, or repeated exposure to violence over the course of a lifetime (Plummer & Findley, 2012; Ward et al, 2012).

As described in section 2.2 above, apartheid is proven to have had a significant impact on the escalation of violence levels in South Africa. The liberation movement's strategy of ungovernability which targeted the principles underlying apartheid (Schönteich & Louw, 2001; Niehaus, 2002) resulted in the police using brutal force in attempts to maintain order (Cawthra, 1993). This resulted in a number of destructive effects including "…destabilising black local government, leading violent campaigns against black policemen, and urging a people's war which involved the youth in particular resulting in massive violence in black communities which bred a culture of violent lawlessness and a distrust in authority" (Schönteich & Louw, 2001, p.20). Once South Africa entered into a democracy, the right to engage in public demonstrations was liberalised, and the use of force among the police was discouraged (Shearing & Foster, 2007). However, more recently, service delivery protests have increased, resulting in an increased use of force among the police, most significantly supported by President Jacob Zuma's amendment to Section 49 of the Criminal Procedure Act which supports a 'shoot to kill' strategy to be used by the police in an "attempt to win the war against crime" (Marks & Wood, 2010, p.313).

Based on the above, South Africa has been described as a deeply divided society, struggling to overcome a heritage of collective violence and severe human rights violations (Cooper & Ward, 2012). In a number of areas, violence is deemed legitimate by higher status individuals against lower status individuals (Ward et al, 2012), and as a result, society has been observed to accept violence as a justifiable way of dealing with conflict (Schönteich & Louw, 2001; Ward et al, 2012). Violence is proven to be perpetuated by the breakdown of the nuclear family (Ward et al, 2012), the poor state of the education system (Chisholm, 2004), high levels of gang-related violence and peer pressure (Cooper & Ward, 2012), poverty (Schönteich & Louw, 2001), and the values placed on sexism and materialism as perpetuated by the media (Jiwani, 2006). These high levels of violence have significant implications for the economy, specifically in relation to the provision of healthcare and counselling services, as well as for the psychological well-being of individuals and communities (Matzopoulos et al, 2008).

2.4 SOUTH AFRICA'S BURDEN OF DISEASE

Africa is reported to have the greatest burden of disease of any continent, with some of the most poorly resourced health services in the world (WHO, 2008). In South Africa, burden of disease has increased since the initiation of the healthcare transition post the 1994 elections, with statistics reflecting that the burden of communicable, non-communicable, perinatal, maternal and injury-related disorders to have quadrupled (Mayosi, Flisher, Lalloo, Sitas, Tollman & Bradshaw, 2009).

Mayosi et al (2009) report that in the last two decades there has been a rapid increase in the number of persons diagnosed with cardiovascular disease, type 2 diabetes, cancer, chronic lung disease and depression, particularly in the developing world. The effect of these diseases is said to increase over the next few decades if measures are not put in place to address this concern (Abegunde, Mathers, Adam, Ortegon, & Strong 2007). According to the World Health Organisation's disability-adjusted life years, non-communicable disease accounts for 28% of the total burden of disease, while 72% is accounted for by communicable diseases.

These statistics are up to three times higher than those in developed countries, and are increasing at a rapid rate in rural communities (Mayosi et al., 2009).

In South Africa, life expectancy at birth is 52 years for males and 56 years for females (Statistics South Africa, 2011), compared to an estimated global average of 68 years (World Health Organisation, 2011). This low life expectancy has been influenced by the spread of communicable diseases, such as HIV and tuberculosis accounting for 79% of deaths, increases in non-communicable diseases, such as diabetes and hypertension accounting for 15% of deaths, and injuries and violence accounting for 6% of deaths (World Health Organisation, 2011).

In the Statistics South Africa report on Mortality and Causes of Death in South Africa (2008), it is reported that 91.1% of deaths were as a result of natural causes, and 8.9% were attributed to non-natural causes. Despite the fact that mortality has decreased since 2007 (Statistics South Africa, 2008), the country continues to battle against the ravaging effects of communicable diseases and the management of chronic conditions. This is shown in Table 1, reflecting the 10 most common causes of death as per death notification:

Table 1: Top 10 Causes of Death in South Africa (adapted from Statistics South Africa, 2008, Table 4.5)

Rank of Cause of Death	Cause of Death	Percentage (%)
1	Tuberculosis	12.6
2	Influenza and Pneumonia	7.7
3	Intestinal and Infectious Diseases	6.6
4	Other forms of heart disease	4.4
5	Cerebrovascular Diseases	4.1
6	Diabetes Mellitus	3.3
7	Human Immunodeficieny Virus (HIV)	2.5
8	Certain Diseases Involving the Immune Mechanism	2.5
9	Chronic Lower Respiratory Diseases	2.4
10	Hypertensive Diseases	2.4

While challenges exist in the accurate recording of statistics, and therefore findings are interpreted with caution, it is significant to note that in the Statistics South Africa (2008) report, death notifications contained as many as five different causes of death. Thus, conditions listed as the primary cause of death may not reflect the true underlying cause.

Collinson (2010) describes the most common causes of death in a rural area of South Africa, according to age group (Table 2). This highlights the significant impact of communicable diseases on rural communities.

Table 2: Causes of Death according to Age Group in the Agincourt Sub-District 2002 – 2005 (Collinson, 2010)

	Age ranges				
Causes of Death	**0-5 years**	**5-14 years**	**15-49 years**	**50-64 years**	**65 years +**
	HIV/TB	Accidental injuries	HIV/TB (accounting for 48% of deaths)	HIV/TB	Vascular disease
	Diarrhoea	HIV/TB	Assault	Vascular disease	Other cardiac disorders
	Respiratory Infections	Road traffic accidents	Road traffic accidents	Other cardiac disorders	Neoplasms

Traditionally the medical model of healthcare has been used for explaining cause of illness, and for dictating appropriate treatment and intervention methods (Posel, Kahn, & Walker, 2007). As a consequence, the ascription to the medical model of understanding has suppressed insight into other causal models recognized by communities, particularly those in developing contexts. The absence of local knowledge regarding models of causality, and contextually-appropriate models of intervention have affected the efficacy of attempts to minimise the effects that the burden of disease has on lifestyle, behavioural patterns, and coping mechanisms. This is supported by Posel, Kahn and Walker (2007) who suggest the need for "ethnographically dense renditions of local knowledge" (p.140) in respect of the pain, anguish and suffering that disease and death have on local communities in the attempt to develop effective public healthcare intervention.

2.4.1 HIV/AIDS and its Complexities in Relation to Health, the Economy and Politics

South Africa continues to have the largest number of people living with HIV in the world. HIV infection in the world. Current statistics reflect that there are approximately five and a half million people living with HIV in South Africa (Statistics South Africa, 2011), giving rise to an overall prevalence in the country of 10.6% (Statistics South Africa, 2011). The highest rate of infection in the age group 15 – 49 years (Joint United Nations Programme on HIV/AIDS, 2009), with appropximately 316 900 new infections in this age group during 2012 (Statistics South Africa, 2012). Research shows that to date there have been over three million deaths due to AIDS, and over two million children have been orphaned as a result of the pandemic (Statistics South Africa, 2011). Despite the vast coverage that HIV has received, the impact of the disease is believed to be much deeper than that of other conditions since "these merely kill" (Thornton, 2008, p.32), while HIV challenges the fundamental values of individuals and society (Thornton, 2008).

HIV is known to disproportionately affect vulnerable groups, with risk factors for infection including economic and social disadvantage (Whiteside, 2002), poverty (Emerson, 2004), lack of education (Soudien & Baxter, 2006), poor access to information (de Andrade & Baloyi, 2011), sexual abuse (Mall & Swartz, 2012), limited access to healthcare (Anderson & Kitchin, 2000), gender inequality (Matzopolous et al, 2008), gender-based violence (Ward et al, 2012), and disempowerment and social isolation (Braathen & Ingstad, 2006). Despite this acknowledgement, and the fact that both disability and HIV have similar physical and psychosocial dimensions reflecting exclusion from mainstream activities, little is known about the prevalence and impact of HIV among people with disabilities (Groce, 2005; Rohleder, Braathen, Swartz & Eide, 2009). The few studies that have explored HIV among people with disabilities have focussed heavily on the knowledge, attitudes and perceptions of those affected and those at risk (e.g De Andrade & Baloyi, 2011; Groce, Yousafzai & van der Maas, 2007; Wazakili, Mpofu & Devlieger, 2006; Yousafzai, Edwards, D'Allesandro & Lindstrom, 2005). Consequently, a paucity of knowledge has been exposed regarding the combined effects of living with a disability, the negotiation of safe sex, and the effects of HIV on the interpretation of lived experience.

HIV and AIDS are known to have far reaching effects on family structure. These effects include financial and emotional strain (Mayosi et al, 2009), increased burden of care (Fortson, 2011) and stigma (Niehaus, 2007; Thornton, 2008. In addition, Fortson (2011) reports that living in an area where there is a high prevalence of HIV is associated with lower levels of completed schooling, and slower progress through school, even among children who have not been orphaned by the pandemic. Furthermore, Mayosi et al (2009) point out that as a consequence of the HIV pandemic on working-age adults, those who are most prone to non-communicable diseases (e.g. grandparents or older people) are centrally involved in caring for and financially supporting children who have been orphaned, increasing the burden on the elderly population.

South Africa has a turbulent history in its approach to the etiology and management of HIV/AIDS, which has led to uncertainty, confusion and conflict regarding the effects of the disease (Posel, 2005). This highlights the pervasive failure of the government and of kinship networks to render effective care to those suffering from AIDS-related illnesses (Niehaus, 2007). Given the South African government's history of denialism and scepticism regarding the causes and treatment of HIV (Fassin, 2007), it is not surprising the illness is surrounded by uncertainty, confusion and conflict (Posel, Kahn & Walker, 2007). The conflict surrounding approaches to HIV has attracted international attention with Fassin (2007) describing HIV as "an epidemic of disputes" (p.64). Thus, while politicians debated the merits of antiretrovirals versus natural alternatives during the 1990's and early 2000's, thousands of people in both rural and urban areas bore witness to the prevalence of death as a consequence of AIDS (Posel, Kahn, & Walker, 2007). The relationship between political debates regarding HIV and the overwhelming effects of the disease became apparent as South Africa entered its new era of democracy (Kahn et al, 2007). As a result, promises of freedom and socio-economic change were countered with the overwhelming burden that the pandemic placed on the country (Kahn, Garenne, Collinson, & Tollman, 2007).

Political debate, initiated during President Mbeki's regime, regarding the causes and treatment of HIV attracted much attention (Booysen & Summerton, 2002; Thornton, 2008). President Mbeki publicly denied the causal link between HIV and AIDS at the opening ceremony of the 2000 International AIDS Conference in Durban, South Africa (Mbali, 2004),

supported by many of his cabinet, including the Minister of Health at the time, Manto Tshabalala-Msimang. Central to these denialist claims were the beliefs that "not everything could be blamed on a single virus" and that "poverty kills more people around the world than AIDS" (Mbeki, 2000, as cited in Mbali, 2004, p.109). While denialism was hotly contested, research does show that poverty increases vulnerability to HIV infection, as a consequence of food unsecurity, lack of knowledge, lack of access to protection, inability to negotiate condom use with partners, and entrenched gender roles and power relations (Booysen & Summerton, 2002; Campbell & Gibbs, 2010; Murrain & Barker, 2010).

The initial discourses surrounding the transmission and management of HIV/AIDS were predominantly embedded in the biomedical and public health models (Jones, 2011). Consequently, awareness and prevention efforts centred around campaigns on safe sex (Booysen & Summerton, 2002; Jones, 2011), without taking into account the social and cultural contexts in which they needed to be implemented (Posel, Kahn & Walker, 2007). In this way, prevention programmes failed to take into account larger-scale social structures and the cultural aspects of sex which are embedded within social relations (Thornton, 2009b). As a result, the biomedical appoach to intervention has been criticised for being too simplistic and not addressing the social realities of people and communities affected and infected by the disease (Mann, 1999; Jones, 2011). Thus the need to identify prevention strategies that address inequitable gender relations, lack of employment opportunities, and cultural meanings underpinning sexual exchange need to be considered and incorporated into prevention and management campaigns (Kalipeni, Craddock, & Ghosh, 2004; Jones, 2011).

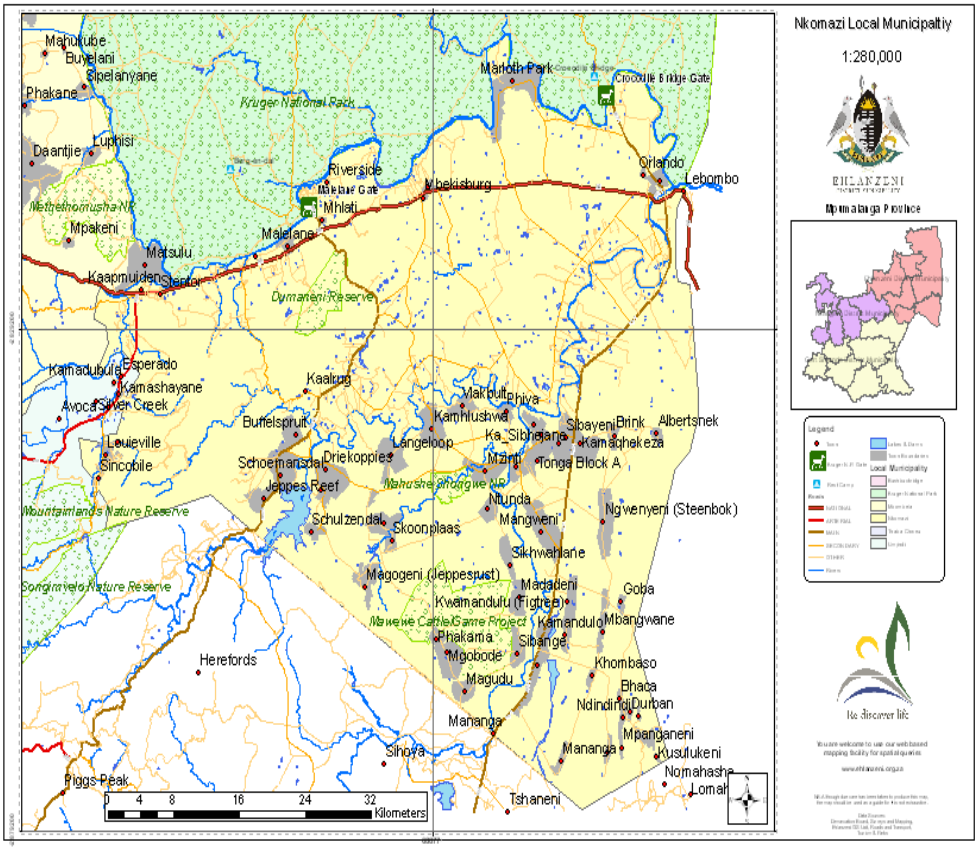
Given the fact that many South Africans live in the context of poverty and inequality, the manifestations of structural violence in relation to human rights has been noted in the accessibility to antiretroviral treatment (Thornton, 2008). The rollout of antiretrovirals (ARV's) in South Africa occurred in 2005 (Jones, 2011). While this was significant, not only towards providing treatment to those infected with the virus, but also in extending life expectancy, it also highlighted numerous problems related to food security and economic sustainability necessary for effective management of the disease for individuals and communities (Jones, 2011). This has been further impacted on by inequitable access to resources, unemployment and financial hardship, poor healthcare, and inadequate educational

systems. Thus, for many people living with HIV in South Africa, the experience of the illness is closely linked with that of financial strain (Cloete et al, 2010; Jones, 2011). The majority of persons infected with HIV in South Africa live in poverty-stricken conditions, are unemployed and financially suppported solely by social security grants (e.g. child support grants, old age pensions, care dependency grants, and disability grants). Thus Jones (2011) describes how, in the context of HIV in South Africa, many people are forced to choose between economic stability and health security. This is most commonly seen in among poor communities where people who are HIV positive receive disability grants when they are rendered too ill to work or be considered employable (often in the absence of other income) (UNAIDS, 2009; Jones, 2011). However, should their CD4 count rise again as a result of ARV's, rendering them employable, the disability grant is stopped, leaving them with no source of income, unable to care for their families, and with minimal access to the dietary requirements necessary for the effective absorbtion of medication into their bodies (Jones, 2011). Thus, the presence of illness may also be seen as a pathway to economic stability, and for this reason there is documented evidence that despite having knowledge regarding the importance of ARV's, individuals in poor communities may choose access to financial support over taking medication which ensures health (Jones, 2011).

Over and above structural barriers to effectively managing the disease, HIV and AIDS continue to be highly stigmatised conditions, which contribute to individual decisions to be tested for the virus, as well as decisions regarding treatment. This stigma has resulted in many people conceptualizing HIV as "social and physical death" (Meursing & Sibindi, 2000, p.19). This is expanded on by Ashforth (2005) and Niehaus (2007) who suggest that denial, silence, fear and fatalism in response to the HIV pandemic have all stemmed from people with HIV being treated as "dead before dying" (Niehaus, 2007, p.845). In this way, HIV may be considered to be not only an infection of the individual, but an infection of society, social structures and of culture itself (Thornton, 2008). Living with HIV is often accompanied by feelings of anxiety, healthcare discrimination, social discrimination, and marital violence and abandonment (Kimani-Murage et al, 2010). Furthermore, decisions to take care of HIV infected family and community members may be influenced by stigmatisation, financial limitations and emotional strain (Kimani-Murage, Manderson, Norris, & Kahn, 2010; Cloete, Strebel, Simbayi, van Wyk, Henda, & Nqeketo, 2010). Over and above the social isolation that results from stigma, it has also been found to prevent community members from

accessing emotional support, as well as other forms of support, such as food parcels (Kimani-Murage et al, 2010). In this way, stigma, stress and poverty associated with HIV has resulted in significant changes in family structure and places marginalised individuals at greater risk for exposure to violence (Thornton, 2008). This highlights the difficulties in translating human suffering into bio-medical categories (Kleinman, 1988).

2.5 CONTEXT OF THE STUDY



Detailed map of the villages within the Nkomazi Municipality

(Source: http://cgta.mpg.gov.za/IDP/Ehlanzeni2011-12/Nkomazi2011-12.pdf

The current study took place within the Nkomazi East Municipality of the Mpumalanga Province. Mpumalanga is the second smallest province in South Africa (Statistics South Africa, 2012), and is situated south of the Kruger National Park and Limpopo, north of Swaziland, and between the borders of Gauteng in the east, and Mozambique in the west. The Nkomazi Municipality is located within the Southern Lowveld area of Mpumalanga, spanning an area of 3240km^2, and spatially accounting for 4% of the province (Nkomazi

Integrated Development Plan, 2011/2012). The municipality is located approximately 350km east of Johannesburg. The closest towns are Malelane, which lies 45km northwest of Tonga, and Komatipoort, which lies 60km northeast of Tonga.

The name 'Mpumalanga' means 'place of the rising sun' in the SiSwati language (Mpumalanga Provincial Government, 2012). The area abounds a variety of wildlife, birdlife and plants, and San art which serves as confirmation of the early existence of hunters and gathers in the area (Delius, 2007). The fertile lands, as well as the discovery of iron and copper in the 1400's resulted in the migration of the Nguni people from the plains of Kenya (Delius, 2007), who today include the IsiZulu, IsiXhosa and SiSwati people residing in the Lowveld area of Mpumalanga (Thornton, 2009a). The Nguni initially settled near Maputo in Mozambique, but then moved west towards KwaZulu Natal and settled in what is now known as Swaziland, under King Sobhuza initially, followed by King Mswati I (Delius, 2007). King Mswati I was said to be feared by many (Delius, 2007). In an attempt to enlarge his empire his army attacked inhabitants living north of Swaziland within the borders of South Africa, but was defeated by the local inhabitants (Delius, 2007). Many of the Swazis who survived the attack are said to have fled the country in fear of King Mswati I and settled just north of its borders (Delius, 2007). Thus today, the Swazi culture is dominant in the Nkomazi East Municipality of South Africa, where both the culture and language are termed 'SiSwati' (Delius, 2007; Mpumalanga Provincial Government, 2012).

2.5.2 Clanship and Kinship in SiSwati Culture

Although published 50 years ago, Kuper (1963) provides a detailed description of Swazi cultures and traditions based on her anthropological studies conducted in Swaziland, many of which are observed to still be in existence today. Kuper (1963) reports that in the early 20th century a number of clans in the vicinity of Swaziland merged into a centralized state and political unit by conquering the Nguni aristocracy. The clan is the most distant extension of kinship, and is made explicit the first time two Swazi's meet as they will introduce themselves with reference to their *"sibongo"* or clan praise name (Kuper, 1963; Delius, 2007). Clan names are acquired by birth, whereby the newborn is given his/her father's clan name, even if his mother is not legally married to the father, and her child is cared for by the mother's family. Women retain their paternal clan name on marriage but may never transmit

it to their children (Kuper, 1963). Clan names are important since they determine behaviour in a number of situations, such as where and with whom a person lives, their range of friends and enemies, whom they may or may not marry, and the positions to which they are entitled (Kuper, 1963).

Kin are classified according to a limited number of broad categories which refer to all relatives. Thus the term 'father' is extended from one's biological father to his brothers, half-brothers, and sons of his father's brothers (Maverick, 1966). However, the use of a single term does not mean that a particular key relationship is unimportant, and within the category there are usually accurate descriptions of degrees of closeness (Kuper, 1963). Kuper (1963) describes that the first relative to be considered is always the father. As head of the family he is to be respected and feared, since he is the link between the living and the ancestors. In addition, the father's brothers are feared and respected in the same way that the father is, and are always consulted in family matters (Maverick, 1966). In addition, one of the father's brothers may become guardian of the wife and children should the father pass away (Maverick, 1966). Implicit in the system of terminology is the assumption that kinsmen covered by a single term share a common identity and, in some situations can serve adequately as substitutes for each other (Kuper, 1963), This reflects that greater significance is attached to the kinship group as opposed to the individual (Kuper, 1963).

2.5.3 Marriage and Child-Bearing as Important Traditions in SiSwati Culture

Within SiSwati culture, marriage is conceptualised as the linking of two families rather than of two people (Kuper, 1963; Niehaus, 2002b). The bearing of children is the essential consummation of wifehood, and since this is essential to the fulfilment of the woman's part of the contract, should she prove barren her family must either return the *lobola*[2] cattle that were paid for her, or provide her with a female relative, preferably a younger sister to bear children (Kuper, 1963). Niehaus (2002b), however, reports that since the 1990's conjugal bonds between men and women have become increasingly fragile, with women deserting

[2] The term 'lobola' originates from the Nguni term *ukulobola*, which means 'to set the bride price' (Shope, 2006), and refers to the African tradition whereby the bridegroom's family makes a payment in cattle or cash to the bride's family shortly before the marriage takes place (Kuper, 1963).

their husbands on the basis of unemployment and men separating from wives who failed to bear children or to keep the house properly. The act of sexual intercourse is intimately related to the act of childbearing, and has been found to be fundamental to male masculinity in the Lowveld region (Niehaus, 2002a). Sexual intercourse is believed to ensure a balanced supply of blood within the body, essential to the maintenance of good health, while prolonged periods of celibacy result in poorly regulated bodily fluids, short temper, recklessness and the inability to think clearly (Niehaus, 2002a). This is supported by Thornton (2009b) who claims that sexual relationships involve a complex combination of emotions, social roles, attitudes, actions and economic exchanges, all of which are embedded within complex social relationships and identities. Thus, in order to understand the complexities associated with sexual relationships and the act of childbearing, it is essential to take into account the complexities of social and cultural structures (Thornton, 2009b).

SiSwati culture stresses the physiological link between father and offspring (Delius, 2007). The biological tie between father and child must be confirmed by law and ritual, for the physiological father (genitor) is not automatically the sociological father (pater) (Kuper, 1963). Where a SiSwati man has fathered children, his relationship with them is defined by his legal authority over them, whereas the mother's relationship with her children is more indulgent. Rights of fatherhood are acquired through *lobola*. If no *lobola* has been paid, the child remains with the mother's family, while she herself may be separated and given in marriage to another man (Niehaus, 2002b). The child will, however, retain the clan name of the genitor (Maverick, 1966; Niehaus, 2002b).

The homestead is fundamental to the SiSwati family, and it is here that roles are played out in dynamic interpersonal relationships (Maverick, 1966). In control of the homestead is the patriarchal headman whose prestige is enhanced by the size of his family and his number of dependents (Kuper, 1963; Delius, 2007). Traditionally, polygamy is regarded as a social ideal rather than a sexual extravagance, and is considered a sign of wealth given that *lobola* must be paid for each wife (Kuper, 1963).

Each homestead is governed by a variety of functions. These include economic functions pertaining to the management of the home, fields and cattle, and educational functions which the women in the homestead take responsibility for initially (Niehaus, 2002b). However, once the children reach adolescence, the girls are taught culturally and gender specific skills by their mothers, while fathers take responsibility for teaching the boys how to take on male responsibilities (Kuper, 1963).

2.5.4 Traditional Approaches to Health and Illness

According to Thornton (2007) every South African village and town has a multitude of prophets and auditors who regulate the faithful and saved, the sceptical, the criminal and the damned. These prophets and auditors take a variety of forms, including medical doctors, traditional herbalists and faith healers, among others who dispense information, management options and advice according to a temporal process (Thornton, 2007). As with the vast majority of the South African population (Mpofu & Harley, 2002; Thornton, 2009; Mpofu et al, 2011), residents in the Nkomazi East Municipality exhibit plurality regarding approaches to health and illness by using a combination of traditional and western approaches for the management of illness and disability. In research conducted by Fottrell, Tollman, Byass, Golooba-Mutebi and Kahn (2012) in the Mpumalanga province, it was found that attributions of witchcraft in relation to death caused by illness was linked to the age and sex of the affected individual, level of education, duration of illness and types of treatment sought. Significantly, deaths of children and women of child-bearing age, and those who died following acute illnesses were most likely to be attributed to witchcraft (Fottrell et al, 2012).

In typical African communities, the occurrence of inexplicable instances of misfortune, such as illness and disease are believed to originate outside the body of the affected individual, usually in response to the malevolent actions of people or spirits, or as a result of acts of witchcraft (Niehaus, 1995; Sabuni, 2007; Thornton, 2008). This is particularly true for illnesses that have an insidious or inexplicable onset (Sabuni, 2007). However, the same reasoning is also used in the case of occupational hazards or motor vehicle accidents which are believed to be caused by spirits which set the stage for the accident to occur (Mpofu, Peltzer & Bojuwoye, 2011).

Within SiSwati culture, it is believed that the spirit (or 'breath') has an existence distinct from the flesh and therefore when a person dies, both flesh and spirit must be correctly treated to safeguard the living (Kuper, 1963). At the end of the mourning period, the spirit of the deceased is ritually 'brought back' to the family, and continues to influence members of the community, manifesting in illness or good fortune (Knox, 2008). It may be seen in a variety of omens, or it may materialize in the form of an animal such as a snake or cat (Kuper, 1963; Niehaus, 1995). Thus illness and other misfortunes are frequently attributed to the ancestors, although within SiSwati culture the *emadloti* (spirits) are not believed to inflict suffering through malice or wanton cruelty. In instances where an illness becomes fatal, it is believed to be the result of the intervention of *baksakatsi* (witches) who have taken advantage of the individual's weak resistance (Kuper, 1963). Fottrell et al (2012) state that these examples of traditional attributions of illness provide a moral agency framework that allows individuals to make sense of seemingly random events in space and time, and thus provide them with the ability to influence choices regarding treatment.

An underlying principle of traditional healing in the African context is the lack of division between mind and body, since physical and cognitive conditions are believed to co-exist (Mpofu, Peltzer & Bojuwoye, 2011; Lopez Levers, May & Vogel, 2011), and thus traditional healing methods are used to ameliorate a combination of physical, psychosocial and psychosomatic symptoms (Mpofu, Peltzer & Bojuwoye, 2011). In so doing, an attempt is made to provide the affected individual with a means of reorganising chaotic experiences (Levi-Strauss, 1963). Indigenous healers therefore help patients to understand the socio-cultural basis of their health conditions, and in this way, provide locally available and culturally acceptable methods of alleviating physical and social suffering (Mpofu, Peltzer and Bojuwoye (2011).

In the South African context, indigenous healing practices are strongly linked with a religious response to healing (Mpofu, Peltzer & Bojuwoye, 2011). This is supported by Edwards and Edwards (2009) who claim that indigenous healing is deeply rooted in the physical, emotional and spiritual aspects of being and is inextricably linked to individual belief systems. This implies that when a patient adheres to the protocol prescribed by the traditional healer, it is done under the belief that the spiritual or ancestral powers with which the

medication has been endowed will work to overcome the condition from which the patient is suffering (Mpofu, Peltzer & Bojuwoye, 2011).

Traditional healers consulted within SiSwati culture include *inyanga* (medicine men) and *sangoma* (diviners) (Kuper, 1963; Thornton, 2009a). According to Thornton (2008), *sangomas* heal through the possession of spirits which enable them to dream and to perceive illness in clients, while the *inyanga* use knowledge of the indigenous medicines in order to restore health. Both types of healers preserve African traditional philosophies and medical knowledge and elaborate on them (Thornton, 2008). In contrast, the *baksakatsi* (witches), may masquerade as traditional healers, but rely on poisons and violence for the deliberate destruction of property or people, manifesting in inexplicable misfortunes (Kuper, 1963). This may be directed specifically towards the generative capabilities of families and lineages, resulting in illness frequently being afflicted towards people of child-bearing age (Fottrell, 2012).

Traditional intervention involves manipulation of the spirit (*umoya*), body (*umtimba*), blood (*ingati*) and/or the individual's aura (*sitfunti*) (Thornton, 2008). Misfortune can enter the body in a variety of ways, including through food, clothing, or bodily fluids (Thornton, 2008), each of which is treated differently. The body and blood are usually treated with herbs that are drunk or rubbed into small cuts, while the spirit and aura are treated through herbal cleansing, steaming and sweat baths or by the inhalation of smoke or fumes (Thornton, 2008).

Indigenous healing practices are typically holistic in their attempts to ameliorate suffering. This holistic treatment relates to the underlying belief that ill health manifests its way across various levels of the community, and that physical impairments can manifest in psychological and spiritual dysfunction, and vice versa (Levers, 2006; Mpofu, Peltzer & Bojuwoye, 2011). In this way, illness is not individualised, but interpreted in relation to the social system, kinship and cultural norms and values (Levers, 2006). By diversifying the nature of the impairment across various levels of the community, the individual is removed from any form of responsibility in relation to the way in which the condition was acquired, as well as the

course which the condition will follow (Mpofu, Peltzer & Bojuwoye, 2011). The healer then investigates the beliefs held by the affected individual as well as those of significant others, in order to determine the course of treatment (Mpofu, 2003). Treatment methods typically involve the management of physical activity and the interpersonal relationships, the use of symbolism and enactment, the use of naming the person or spirit believed to be causing the suffering, dream interpretation, cleansing rituals, and the carrying out of culturally relevant sacrifices (Mpofu, Peltzer & Bojuwoye, 2011).

2.5.5 Current Socio-Political Status of the Nkomazi East Municipality

The Nkomazi East Municipality is predominantly rural in nature. In addition to the urban towns of Malelane and Komatipoort, the municipality is made up of 43 villages which are governed by eight tribal authorities. Thus, governance is provided by the ANC local government, as well as a number of local chiefdoms and traditional authorities (Delius, 2007).

Approximately 340 000 people live in the area (Comprehensive Rural Development Programme, 2012), the majority of whom are black SiSwati speaking residents, with the highest portion of the population falling within the age range of 5-19 years (Nkomazi Integrated Development Plan, 2011/2012), implying a high dependency ratio. Population growth has in recent years slowed significantly for a number of reasons, including increasing mortality rates, decreasing birth rates, and increases in the working-age population migrating to urban areas in search of work (Nkomazi Integrated Development Plan, 2011/2012). Currently, no published data exists on the numbers of persons living with disabilities in the Nkomazi East Municipality.

Current statistics reveal that the Nkomazi Municipality has an HIV prevalence rate of 47.3% (Comprehensive Rural Development Programme, 2012), with 10% of children living in the municipality recorded as being orphaned (Statistics South Africa, 2012). Furthermore, despite the relatively small size of the province, it has the third highest mortality rate out of all provinces in South Africa (Statistics South Africa, 2012).

Table 3 provides a summary of the community profile for the Nkomazi municipality as determined by the (Nkomazi Spatial Development Framework, 2011-2012; Comprehensive Rural Development Programme, 2012):

Table 3: Community Profile of the Nkomazi East Municipality (adapted from the Nkomazi Integrated Development Plan 2011/2012)

Employment	55% of the population fall into the economically active population. However, many of these persons are immigrants from Mozambique and Swaziland and do not have the documents required for formal employment. Thus, 40% of the economically active population are unemployed 80% of the employed population work in the informal sector
Dependency Ratio[3]	1:8
Household Density	6 persons per household
Population Distribution	47% population under 19 years old
Water Provision	14.9% of the population have piped water supply inside their homes 44.4% of the population have piped water within the perimeters of their property 31.4% of the population access piped water at a community tap. 9.3% of the population collect water from rivers, damns and rainwater tanks.
Sanitation	5.6% of the population have flush toilets connected to a sewerage system 1.9% of the population have a flush toilet with a septic tank 39.1% of the population have a chemical toilet 35.8% of the population have a pit latrine with ventilation 17.4% of the population have no sanitation facilities.
Waste Management	No organised waste management or disposal sites outside of the urban towns.
Electricity	44.1% of the population have electrification in their homes 2% of the population use gas

[3] Number of people per household that have some form of income in relation to those who have no form of income

	6.1% of the population use paraffin 41.2% of the population use wood 6.4% of the population use coal 0.1% of the population use solar energy 0.2% of the population burn animal dung for energy purposes.
Roads	80.9% of roads are gravel/sand tracks 40% of villages are roads almost inaccessible by car
Health	2 x 24-hour hospitals functioning at a primary healthcare level 1 x 24-hour clinic 27 x day clinics Numerous informal home-based care initiatives
Education	25% of the population have no formal education 35% of the population have a primary school education 17% of the population have a grade 10 education 16% of the population have a matric 1% of the population obtain matric results which enable university entrance 4% of the population have a post-matric diploma 0.8% of the population have a university degree 0.3% of the population have a postgraduate degree
Literacy Levels	49% of the population are illiterate
Cemeteries	No formal cemeteries but numerous informal cemeteries
Community/ Social Facilities	2 Libraries Numerous informal soccer fields

The Nkomazi East Municipality continues to be one of the poorest municipalities in the Mpumalanga Province (Comprehensive Rural Development Programme, 2012). The economic growth rate was 0.3% for the period 1996-2011, and is forecast to increase to only 2.5% by 2016 (Comprehensive Rural Development Programme, 2012). Provision of adequate housing remains a challenge for a number of reasons, including funding and access to land where housing can be developed (Nkomazi Integrated Development Plan, 2011/2012). Most of the land in the area is owned either by tribal authorities or by farmers. Furthermore, the

lack of enforcement of land controls has led to the uncontrolled growth of informal settlements, and the high dependency ratio and limited number of tax-paying residents, makes the funding of adequate municipal services difficult (Nkomazi Integrated Development Plan, 2011/2012).

Despite the challenges described above, the Nkomazi East Municipality has prioritised the improvement of basic service delivery, local economic development, municipal financial management, and governance and public participation in a bid to improve the infrastructure (Nkomazi Integrated Development Plan, 2011/2012). Furthermore, the improvement of health and social welfare services have been recognised as vital to sustainable development within the community (Nkomazi Integrated Development Plan, 2011/2012).

2.6 SUMMARY AND CONCLUSION OF CHAPTER 2

This chapter has provided an overview of the South African context in order to describe the physical, geographical, socio-political and economic background in which the current study took place. Specific emphasis was placed on the challenges faced by South Africa with regard to poverty, unemployment and disparate access to healthcare, education and information.

As described in section 2.2, provision of equitable services in South Africa has been significantly affected by the country's history of cultural, political, and racial conflicts. While these disputes are almost as old as the country itself, the formalisation of the apartheid regime between 1948 – 1994 is proven to have had a detrimental effect on the country. As a result of the implementation of the apartheid regime and the consequent forced removal of black South Africans from their land, violent protests were used to challenge the notion of 'white supremacy'.

Despite the unbanning of apartheid in 1990, and the subsequent introduction of new policies and practices, high levels of poverty and unemployment, together with the perpetuation of a

culture of violence, continues to threaten the South Africa's democracy. This is further complicated by the country's high burden of disease, specifically communicable diseases such as tuberculosis and HIV, since the effects of these conditions have been shown to significantly impact on the health and productivity of the country's citizens, thus impacting on its economic and political stability. As a result, the South African political situation remains in a state of flux, impacted on by the effects of poverty, xenophobia, unemployment, high levels of crime, socio-economic inequality, and lack of political leadership (Maree & Du Toit, 2011).

Rural areas have been shown to be disproportionately affected by the effects of poverty, spread of disease, and limited access to education and healthcare (Collinson, 2010; Posel, Kahn & Walker, 2007; Kahn et al, 2007). An example of a rural area that has been affected by the inequalities of the past, together with the current lack of service provision is the Nkomazi East Municipality in the Mpumalanga province, where the current study took place. The Nkomazi East Municipality is characterised by numerous settlements on arid land, making sustainable farming difficult. This, together with a high dependency ration and limited employment opportunities has resulted in extreme poverty (Nkomazi Integrated Development Plan, 2011/2012). These psychosocial inequalities have the potential to negatively affect kinship within the SiSwati culture, threatening the foundations of society.

Disability is known to affect vulnerable populations disproportionately (WHO, 2011), and therefore, persons living in rural areas are at significant risk for acquiring a disability. Despite this fact, little is known about the lived experiences of persons with disabilities in rural areas. Chapter 3 will provide a description of the historical and current perspectives on disability, with specific reference to the current focus on the various models for explaining and responding to disability, and thus, the emergence of disability as a human rights issue.

CHAPTER 3

CONCEPTUALISING AND CONTEXTUALISING DISABILITY

"The civility of a country is judged by how it treats its children, its persons with disabilities, and its poor and elderly citizens."

(Albrecht, 1997, p.45)



Wife of a participant helping the research mediator to access a home

Disability is a complex, dynamic and multidimensional concept which remains vehemently contested (WHO, 2011). Definitions of disability vary from context to context, depending on the prevalence of disability, the perceived impact that disability has on social systems, and the provision of, and access to interventions which enable and empower those affected by disability (Mpofu, Ukasoanya, Mupawose, Harley, Charema & Ntinda, 2011). In this way both conceptualisations and definitions of disability are dependent on the core assumptions held by society regarding the inherent meaning of disability and the obligations and responsibilities of both individuals and society at large (Burger & Burger, 2010). However, despite varying definitions and approaches to disability, international research shows that people with disabilities have numerous unmet health and rehabilitation needs, face barriers in accessing healthcare services, and consequently have poor health (Tomlinson et al, 2009).

Based on the complexities associated with definitions and models, the appropriateness of associated language used to describe disability remains disputed (WHO, 2011; Shakespeare, 2006). For the purpose of this study, the definition of disability adopted by the United Nations Convention on the Rights of Persons with Disabilities (2006) has been used. This definition describes people with disabilities as "…those who have long-term physical, mental, intellectual, or sensory impairments which, interacting with various barriers may hinder full and active participation in society."

3.1.1 Prevalence and Causes of Disability

It is estimated that 15% of the world's population suffer from some type of disability (WHO, 2011). This equates to over one billion people currently living with disabilities, 110-190 million have profound impairments and experience significant difficulties in everyday activities (WHO, 2011). These numbers are said to increase rapidly in the future as a result of ageing, advancements in medical technology, and increases in burdens of disease (WHO, 2011).

The prevalence of disabilities in Sub-Saharan Africa is estimated to be among the highest in the world partially due to under-developed and under-resourced healthcare facilities, low literacy levels implying barriers to information, and elevated levels of poverty and disease

(Lopez Levers, Magweva & Mpofu, 2007; Mpofu et al, 2011; MacLachlan & Swartz, 2009). This is significant since disability is known to affect vulnerable populations disproportionately (WHO, 2011). Recent estimates of the prevalence of disability in South Africa suggests that 13% of the total population are disabled, 5% of whom are severely disabled (Statistics South Africa, 2012). The incidence of disability is reported to be highest amongst the African population, and lowest among the Indian/Asian population, with women having a higher prevalence of disability than men (Statistics South Africa, 2012). Significantly, disability is found to be most prevalent amongst those who have no education. The highest prevalence of disability is seen within the category of people aged 40-49 years, with visual disability being the most prevalent (32%), followed by physical disability (30%), hearing disability (20%), emotional disability (16%), intellectual disability (12%), and communication disability (7%) (Statistics South Africa, 2012). However, it must be noted that the available statistics appear biased towards individuals with '*obvious'* physical and medical disabilities, and in this way exclude those with *'hidden'* disabilities, such as learning problems and psychiatric conditions (White Paper on an Integrated National Disability Strategy, 1997; Norman, Matzopoulos, Groenewald, & Bradshaw, 2007).

Narrow definitions of disability together with the absence of consistent applications of definition, and the use of disparate demographic methods appear to result in under-estimations and under-reporting of the prevalence of disability (White Paper on an Integrated National Disability Strategy, 1997). Thus the estimates of prevalence of disability are believed to be conservative. Despite this, the World Health Organisation (2006) reports that increases in prevalence of disability can be attributed to population growth, ageing, and medical advances that preserve and prolong life. The most common causes of disability are reported to be as a consequence of chronic diseases, such as diabetes, cardiovascular disease, and cancer; injuries resulting from road accidents, conflicts, falls, landmines; mental impairments, birth defects, malnutrition, HIV/AIDS, and other communicable diseases (World Health Organisation, 2006). These causes are supported by the findings for illness, injury and disability in South Africa (Kahn, Tollman & Gear 1999; Norman et al, 2007).

3.1.2 Contextual Beliefs Regarding Causes of Disability

Livneh (2001) reports that in order to understand disability, it is important to take into account the implicit and explict beliefs surrounding causality. Gilbert, Selikow and Walker (2002) report that within any society there are numerous groups or individuals who can offer ways of explaining, diagnosing and treating ill health, while Reis (1992) points out that causality beliefs determine the ways in which both lay and professional people explain, treat and handle disability and consequently how their explanatory models and beliefs develop. In many cases, historical, cultural and beliefs and practices relating to disability influence when, how and for what reason people seek out treatment for illness and disability.

In South Africa, traditional healers frequently attribute the onset of disability to evil spirits, witchcraft or disharmony among the ancestors (Ross & Deverell, 2004; Ashworth, 2005; Mpofu et al, 2011). For example, Niehaus (1995) describes how people believe that the *tokolose*[4], has the capability to make women give birth to deformed or disabled babies. Alternatively, disability may be viewed as punishment for a social transgression by the individual or family (Mpofu et al, 2011). The notion of family responsibility for disability is documented in Kuper's (1963) anthropological work on the Swazi culture. She describes how, when a woman is in labour the women assisting her ask for the name of the baby's father. If the mother knows that the father of the child is not her legal husband she is required to confess otherwise it is believed that the birth will be hard and may prove fatal since "the child belongs by blood to the clan of the genitor, but by law to the man who gave the marriage cattle" (Kuper, 1963, p.46).

3.1.3 The Relationship between Poverty and Disability

According to Mji et al (2009) disability is now considered to be both a cause and a consequence of poverty. This is further complicated by the interactions between disability, caste, gender, age, socio-economic and political status which interact with each other, impoverishing people and keeping them poor (Mji et al, 2009). The European Commission's Guidance Note on Disability and Development for European Union Delegations and Services

[4] Mythical ape-like creature, with the form of a man, but only measuring about half a meter in height that sexually entices women and then bewitches them.

(2004) claims that the goals of poverty alleviation reflected in the United Nation's Millennium Development Goals cannot be achieved without considering the needs of people with disabilities. Marmot (2012), however, suggests that the inequities observed in the health sector result from inequities in power, socio-economic status, access to resources, poor implementation of policies and practices, and bad governance. Marmot (2012) therefore calls for a shift in research focus towards developing an understanding as to why these inequities exist in the first place.

Despite the fact that the concepts of 'poverty' and 'disability' vary according to context (Whyte & Ingstad, 1995), the United Nations (2008) estimates that up to two thirds of people with disabilities live in poor conditions, limiting them not only in terms of their socio-economic status but also in their access to basic services and human rights, and their ability to make independent choices (Loeb, Eide, Jelsma, ka Toni & Maart, 2008; Van Rooy, Amadhila, Mufune, Swartz, Mannan & MacLachlan, 2012). Furthermore, poverty and social exclusion are documented to increase the severity of impairments, and in this way increase the individual's risk of developing mental illness (Shakespeare, 2008). This is expanded on by Sen (2000) who claims that social exclusion pertains to the inability to appear in public without shame and consequently the inability to take part in the life of the community. In this way, financial poverty is compounded by the lack of freedom to contribute in a recognised way to society (Sen, 2000).

Poverty has been shown to increase an individual's risk for acquiring a disability (WHO, 2008; Loeb et al, 2008), yet few studies reflect these inequities. Given that low socio-economic status is known to have a negative effect on health status, psychological well-being, food security and personal safety (Lustig & Strauser, 2007), poverty has in recent years, received a lot of attention. This is particularly noticeable given its position in the first of the eight United Nations Millennium Development Goals (2000) which aims to eradicate extreme hunger and poverty.

Despite the acknowledgement of the relationship between poverty and disability (e.g. Yeo, 2005; Grut & Ingstad, 2005; World Bank, 2006; Lustig & Strauser, 2007; Scullion, 2010) little is known about the factors which maintain and perpetuate it. Lustig and Strauser (2007) propose the Poverty Disability Model as a means for understanding this relationship. According to this model, poverty is associated with social role devaluation, environmental risk factors, negative group influences, and a weakened sense of coherence which renders the environment unpredictable and meaningless (Lustig & Strauser, 2007). Based on these negative effects, poverty predisposes the poor to an increased risk for acquiring a disability. Furthermore, the lack of predictability of both the individual's body and their environment increases the risks for psychological distress (Lustig & Strauser, 2007). While this model does provide insight into the correlational links between poverty and disability, it is presented in a somewhat linear and top-down way, and therefore does not take into account the impact that individual experiences have in creating barriers to social, psychological and physical wellbeing. Thus, this model remains limited since it is only able to provide superficial insight into the nature and causes of disability, and does not necessarily evoke changes in policy and social action (Sen, 2000).

Given the socio-economic profile of South Africa, for many people, the experience of living with a disability is associated with challenges imposed by poverty and access, together with the burdens imposed by other diseases and by profoundly restricted choices (Barratt & Penn, 2009). The relationship between poverty and disempowerment is a complex concept (White Paper on an Integrated National Disability Strategy, 1997), contributing to the relationship between poverty, disability and social exclusion. For this reason it is necessary to consider the significant levels of disempowerment found among people with disabilities, and the impact that this has on their interpretation of everyday experiences.

In order to redress some of the financial inequities experienced by persons with disabilities, the South African government initiated the distribution of disability grants to South African citizens over the age of 18 years (Social Assistance Act, 2004). In order to apply for disability grants, individuals undergo a means test and are then assessed in terms of their levels of functioning by a medical doctor who decides whether a disability grant is warranted or not, and if so whether the individual requires a permanent or temporary disability grant (Social

Assistance Act, 2004). The Social Assistance Act (2004) stipulates that only persons who are unfit to engage in any form of employment may qualify for a disability grant. Individuals who do qualify for disability grants are then referred to the Department of Social Welfare to process the application. During 2012 the disability grant was valued at R1200 per month (roughly $140).

Although social security grants do serve as a financial safety net for persons with disabilities, inequitable access to education and employment exacerbate poverty and perpetuate their sense of dependency on others. In this way, people with disabilities are forced to become reliant on the state, perpetuating pejorative attitudes towards the dependent (White & Tronto, 2004). This is further complicated by the fact where people with disabilities are recipients of social support programmes they are often viewed as incompetent because they are dependant (Tronto, 2010). The provision of disability grants has therefore led to a widespread belief that people with disabilities should be content to live off social welfare, thus limiting their opportunities and resulting in a sense of learned helplessness (Surender, Noble, Wright & Ntshongwana, 2010). In this way, social support grants may be viewed as a piecemeal approach to solving problems that in reality require large-scale social, political and economic reformulations (Tomlinson et al, 2010).

3.2 PREVIOUS RESEARCH ON DISABILITY

Disability has traditionally been viewed as a medical condition, and has thus been documented and described in terms of deviation from biological and social norms (Scullion, 2010). Much research has focussed on the functional restrictions imposed by disability (e.g. Gill et al, 2006; Murphy et al, 2007), the measurement of co-existing impairments (e.g. Cabrero-Garcia & Lopez-Pina, 2008), and factors affecting the success of rehabilitation (e.g. Murphy et al, 2009). Historically, research into the causes, types and incidence of disability has been prioritised, while studies into personal experiences of living with a disability have been largely omitted.

Based on the priority assigned to information pertaining to causes and prevalence of disability, together with the measurement of functional limitations, the majority of disability-related research has relied on quantitative measures, such as surveys (e.g Jelsma et al, 2002; Norman, Matzopoulos, Groenewald, & Bradshaw, 2007; Connor, Bryer, Meredith, Beukes, Dubb, & Fritz, 2005; Nattrass, 2006; Statistics South Africa, 2012). While this type of information is important in establishing the incidence and prevalence of disability and consequently the need for policies and services to support people with disabilities, it is unable to describe the unique lived experience of disability. Thus these studies are unlikely to be able to provide explanations into the causal factors underlying health issues, which are frequently embedded within the social, behavioural, biological, economic and environmental characteristics of families (Kahn, Tollman, & Gear, 1999). Studies that have used alternative methodologies to explore the challenges associated with living with a disability have frequently relied on semi-structured interviews and have seldom engaged in cross-linguistic research (e.g. Van Rooy et al, 2012; Hundt, Stuttaford, & Ngoma, 2004; Schneider, Claassens, Kimmie, Morgan, Naiker, & Roberts, 1999; Parr, 2007; Worrall & Holland, 2003). In addition, numerous studies (e.g. Mattingly, 1994; Hinckley, 2006; Ulatowska, Reyes, Santos & Worle, 2011) have excluded participants who are poor, marginalised, uneducated or those who present with cognitive-linguistic or psychiatric impairments.

These methodologies, together with the medicalisation of disability, have resulted in a biased view of disability. Significantly, the voices of people living in developing contexts, have been largely excluded from research (Chataika et al, 2012), and consequently policies and practices have remained based on western principles. This has impacted on the development of evidence-based practice, particularly within the fields of healthcare and rehabilitation, since many studies have relied on anecdotal evidence in order to describe the experience and effects of disability (e.g. Bakheit, Barret, & Wood, 2004; Code, Hemsley, & Hermann, 1999; Connor, Bryer, Meredith, Beukes, Dubb, & Fritz, 2005; Hundt, Stuttaford, & Ngoma, 2004; Kahn, Tollman, & Gear, 1999; Kilonzo, 2004; Parr, 2007). This has resulted in the absence of a theoretical framework for understanding disability and the ways in which contextual and cultural variables impact on daily life. This has negatively impacted on the conceptualisation and exposition of social and biological processes contributing to health inequality, disease, disability and death (Krieger, 2001).

3.3 DISABILITY AS A HUMAN RIGHTS ISSUE

Nussbaum (2011) states that human capabilities are closely related to human rights. Thus, given the fact that many people with disabilities have limited abilities to live up to gender and culturally appropriate roles and responsibilities, their human rights are often vulnerable to abuse. These rights include political and civil liberties (Nussbaum, 2011), economic and social rights (Nussbaum, 2011), and rights to bodily integrity and freedom from violence (Nussbaum, 1997). These rights are affected by government policies and processes, since the act of determining needs amongst vulnerable populations is one of the principal political struggles in any attempt to establish a caring environment (Tronto, 2010).

By investigating barriers and facilitators to human rights, the question arises as to what constitutes a life worthy of human dignity (Nussbaum, 2005). Nussbaum (2011) believes that the mere fact that an individual is born as a human being with a degree of agency or capacity for activity implies the right to human dignity. However, this notion is complicated by those who believe that people with disabilities do not possess agency or the right to make independent decisions (Nussbaum, 2005). This has been noted historically through the barriers faced by people with disabilities in their attempts to exert control over their lives and make independent decisions.

Despite the specific needs that people with disabilities have, 'needs-talk' has historically not been taken as seriously as 'rights-talk' (Tronto, 2010). Consequently policies relating to disability have been introduced as human rights issues, and as a result, a number of national and international initiatives have been entered into in order to address the needs of persons with disabilities. These include the World Programme of Action Concerning Disabled People (1982), the United Nations Rules on the Equalisation of Opportunities of Persons with Disabilities (1993), and the United Nations Convention on the Rights of Persons with Disabilities (2006). These policies recognise the importance of respect, non-discrimination, inclusion, accessibility and equal opportunities for people with disabilities.

In South Africa, the development of disability rights is still relatively new, and has been influenced by a variety of people, forces and organizations, significantly impacted on by the legacy of apartheid. In an attempt to redress the inequalities faced by persons with disabilities, the Disabled People of South Africa (DPSA) organization was formed in the 1980's (Howell, Chalken, & Alberts, 2006). By the early 1990's DPSA had made good progress despite practising under the apartheid rule, and had challenged the fundamental assumptions held by the apartheid government (Howell, Chalken, & Alberts, 2006). As DPSA became known within communities, people began approaching them with issues of discrimination. In response to this, the Disability Rights Charter was adopted in 1992 (Howell, Chalken, & Alberts, 2006). This formed the basis for the recognition of disability as a human rights and development issue which recognizes the fundamental needs of all people and their right to dignity, freedom, a healthy lifestyle, education, housing, and the opportunity to work and participate in all aspects of society, as reflected in the South African Constitution (pp.6-25). As such, disability activists stress that people with disabilities should be comfortable in their bodies and that 'difference' should not be equitable with 'inferiority' (Nussbaum, 2011).

In addition to the existence of powerful policies, all governments have an obligation to ensure that their citizens receive what they are entitled to by virtue of their humanity (Nussbaum, 2011). Sen (1979), however, warns that while a variety of needs may be considered to be universal, including the need for self-respect, economic opportunities and social freedom, these needs depend on a variety of personal, contextual and environmental factors. For this reason, it is important that policies which address the rights of persons with disabilities take individual variation into consideration.

The incorporation of disability-related policies into the South African Constitution (1996) reflects a broader incorporation of human rights issues into policy development. Disability legislation, together with strong advocacy towards the disability rights movement has led to the development of rehabilitation services and disability counselling services (Mpofu et al, 2011). These include the Disability Directorate which was established out of the Office of the Vice President in 1996, and the development of the White Paper on the Integrated National Disability Strategy (1997). These advances have outlined strategies for equalizing

opportunities and for developing a sustainable support network for persons with disabilities. Other disability policies adopted by the South African government for the protection of citizens with disabilities include the African Charter on Human Rights, the Patient Rights Charter (2005), the Batho Pele Principles (1997) the United Nations Convention of the Rights of Persons with Disabilities (2006), the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (1993), and the United Nations Millennium Development Goals (2000). However, the inclusion of these policies into the government sector is only the first step to ensuring that people with disabilities have access to their rights, since policies are open to judicial interpretation as well as the work of administrative agencies whose responsibilities it is to put policies into practice (Nussbaum, 2011). Furthermore, it is acknowledged that the implementation of many of these policies is challenging, particularly in poorer countries (Mji et al, 2009), yet little direction is provided in terms of how to address the barriers to policy implementation.

While the policies described above are comprehensive and theoretically sound, the implementation of these has at times been problematic (Mpofu et al, 2011). Sen (2004) states that rights may be understood in a variety of different ways and that the theoretical underpinnings of human rights may be obscured through the use of 'rights language' which may falsely indicate agreement where there is deep philosophical disagreement regarding attitudes towards disability. Evidence of this is seen in the South African context where, despite the prioritization of healthcare for all, increases in child mortality and the burden of communicable diseases, together with a lack of accountability towards the expenditure of healthcare budgets has resulted in inequitable service delivery (Democratic Alliance Health Review, 2011). In this way, practical, theoretical and philosophical differences, together with stark contextual differences in the settings where policies are implemented have contributed to the overt and covert discrimination and marginalisation of people with disabilities (Anderson & Phohole, 2003; Barratt, 2007; Hundt, Stuttaford, & Ngoma, 2004; Kalipeni, 2000; Makiwane, Schneider, & Gopane, 2004; Loeb et al, 2008). Consequently, South African service providers, particularly those working in the public sector, continue to face the challenge of transforming the human, economic and social rights reflected in the constitution into tools of empowerment.

Despite these challenges, the emergence of the disability rights movement has been accompanied by a slow cultural shift towards the acknowledgement that disability is a socially constructed concept. This implies recognition of the pervasive nature and extent of disability-related oppression and offers new insights into the diversity of disability (Onken & Slaten, 2000). The disability rights movement has given rise to the development of a 'disability culture' which came into being as a result of the combined efforts of disability activists in challenging the views held by society (Shakespeare, 1996). Shakespeare (1996) however, cautions that in some instances the values of the disability movement, such as independence, autonomy and choice, reflect western values, with limited focus on the role of family and community solidarity. This is reflected on by Ingstad (1999) who reports that during the 1980's there was a tendency to implement ready-made models such as those devised by the World Health Organisation or the International Labour Organisation's community-based rehabilitation models in developing countries. More recently, however, there has been an acknowledgement that policies and practices need to be contextually adapted, reflecting the shift from the medical understanding of disability towards a social understanding (WHO, 2011).

3.4 MODELS FOR UNDERSTANDING AND RESPONDING TO DISABILITY

Models of disability are used to define causal relationships, responsibilities, attributions, and to influence professional practice and guide legislation (Smart, 2009). In this way, the rights of people with disabilities; their access to education, information and to healthcare' their employment opportunities and their socialisation is determined through models of disability.

Over the years a number of different models and approaches to disability have been suggested. Although the ideas underlying these approaches have differed, each approach has faced a variety of moral and political issues in terms of how to best include and support people with disabilities (WHO, 2011). The various models of disability, most specifically the medical and social models are often viewed as dichotomous. However, in reality these models are often found to be on a continuum (Smart & Smart, 2006), reflecting changes in social and political ideologies and prerogatives. The primary models of disability are presented and discussed in sections 3.4.1 – 3.4.5 below.

3.4.1 The Medical Model of Disability

Prior to the 1980's, the mainstream narrative surrounding disability was delineated by the World Health Organisation which simply advocated that 'impairment causes disability', reflecting the Medical (or Bio-Medical) Model of Disability (WHO, 1980 as cited in Barrow, 2008.p.32). This model is strongly rooted in the scientific tradition, where disability is viewed in terms of deviance from the norm (Forhan, 2009). As a consequence, disability is viewed in terms of inferiority, malfunction and pathology (McCarthy, 1993). These ideologies resulted in people with disabilities becoming a devalued group (Burger & Burger, 2010).

Within the Medical Model, disability is viewed as a health and welfare problem, with most interventions focussing on the impairment itself, and minimal attention given to the structural barriers and power issues within society. The focus of this model is on identifying appropriate treatment or intervention in order to 'rehabilitate' or 'correct' the disability, and in this way, focuses on minimising or 'hiding' the impairment (Burger & Burger, 2010). Disability is thus viewed as 'problematic' and both the 'problem' and the 'treatment' are believed to be confined within the individual (Buntinx & Schalock, 2010). The nature of treatment offered to people with disabilities is, however, standardised regardless of differences in individual needs or resources. In this way disabilities are viewed as objective and universal conditions which foster a sense of dependency on welfare and healthcare providers (Burger & Burger, 2010). This in turn, creates a sense of disempowerment which serves to isolate people with disabilities from mainstream society, preventing them from accessing fundamental social, political, and economic rights (Crow, 1996; Smart & Smart, 2006).

Within the medical model, healthcare and educational professionals define disabilities and the experiences available to affected individuals, thus limiting rights to self-definition and self-determination (Smart & Smart, 2006). In this way, the 'disabled role' is determined by people who do not have disabilities and therefore have no experience in understanding the day-to-day challenges associated with disability (Buntinx & Schalock, 2010). Based on this, historical solutions have involved segregating people with disabilities from the rest of society through the provision of special schools and residential facilities (WHO, 2011). These

philosophies have since changed, with policies focusing on inclusion, while medical interventions have incorporated the notion that environmental factors may be as disabling as the physical condition itself (WHO, 2011). These shifts in perspective were largely prompted by the mobilisation of groups of persons with disabilities, themselves (WHO, 2011), and reflect an acknowledgement that in the past, people with disabilities have been underestimated with those in positions of power exerting authority over them (Mall & Swartz, 2012).

The strength of the medical model lies in its strong explanatory power (Buntinx & Schalock, 2010). Given that this model defines disability in the language of medicine it has traditionally been given more scientific credibility (Smart & Smart, 2006). Further, as a result of the medicalisation of disability, the medical model does not take issues such as individuality or social justice into account. However, the medical model is unable to incorporate or respond to variations in contextual, cultural, racial, or linguistic differences amongst individuals with disabilities. This model raises important questions regarding the responsibility of society towards people with disabilities, since responsibility is placed solely on service providers in order to minimise the effects of disability (Forhan, 2009). Furthermore, the medical model is based on the western dichotomy between the mind and the body (Shakespeare, 1996) and is not necessarily applicable in developing contexts.

3.4.2 The Social Model of Disability

In opposition to the medical model, an international disability rights movement proposed viewing disability as a construct that society imposes on individuals. This proposal implied that society should adapt to individuals with impairments, rather than expecting individuals with disabilities to 'fit into society', with less focus on disparities between what is considered 'normal' versus 'abnormal' (White Paper on an Integrated National Disability Strategy, 1997). This movement preceded the development of the social model of disability which recognises the cultural, societal, psychosocial, emotional, and physical effects of the impairment as fundamental to the individual's experience and perceptions of disability (White Paper on an Integrated National Disability Strategy, 1997).

The social model suggests that disability is a socially created phenomenon and that it is not an attribute of the individual (Burger & Burger, 2010), but that the collective disadvantage of people with disabilities is due to complex forms of institutional discrimination, fundamental to society (Crow, 1996). The social model is based on the belief that the positions of people with disabilities and the discrimination that they face is socially created and has little to do with the impairment itself. The social model therefore places emphasis on the shortcomings of society in accepting people with disabilities (Crow, 1996), and in this way shifts responsibility away from the individual, towards society. However, research into the experiences of persons with disabilities reflects that the nature of the impairment is often considered to be central in the structuring of experience (Shakespeare, 2008), and therefore this model has the potential to deny the impact of disability on the individual.

While both McClimens (2003) and Shakespeare (2006) acknowledge that the social model has politicized and empowered many people with disabilities, and in this way has highlighted obstacles to effective participation in society, this model is believed to represent a simplification of the reality of lived experience (Scullion, 2010). To suggest that the challenges faced by people with disabilities are purely as a result of environmental barriers serves to deny the personal experience of physical and psychological suffering (Morris, 1991). This raises concerns regarding the validity of the social model and the concern that the model may be accepted in theory but have little impact in real-life settings (Scullion, 2010).

3.4.3 The Functional Model of Disability

The functional model of disability, also referred to as the ecological model is considered to be an interactional model, since it takes into account the relationship between the individual, the disability and the roles which the individual is expected to fulfil (Gill, Kewman & Brannon, 2003). Within this model, "disability is defined in relation to the individual's skills, abilities and achievements as well as in relation to biological factors" (Smart & Smart, 2006, p.32). In this way, disability may be viewed as 'role failure' if, as a result of the disability, the individual is unable to perform gender and culturally specific roles that they otherwise would have been expected to fulfil (Buntinx & Schalock, 2010). Given this definition, the focus of the model is on the adaptation of functions, rather than on the rehabilitation of the individual.

However, Smart (2009) states that role adaptation is not easily accepted by society, reflecting society's resistance to responsibility.

Gill, Kewman and Brannon (2003) state that although the functional model of disability suggests that society mediates the experiences of persons with disabilities, the differences which individuals exhibit, and their inabilities to adequately or independently fulfil roles are considered to be aberrant or deviant. As a result, this model has been criticised for creating the perception that people with disabilities are burdens on society (Hahn, 1997; Smart, 2009).

3.4.4 The Socio-Political Model of Disability

The socio-political model of disability is also referred to as the Minority Model (Kleinfeld, 1979; Hahn, 1997; Smart & Smart, 2006). According to this model, disability is defined in terms of political or legislative documents (Forhan, 2009). Smart and Smart (2006) state that according to the socio-political model, disability is defined as "a social construction in that the limitations and disadvantages experienced by persons with disabilities have nothing to do with the disability, but are only social constructions and therefore unwarranted" (p.34).

The socio-political model maintains that policy makers, legislators and professional service providers form the 'problem' that people with disabilities are faced with, and thus a collective response is necessary in addressing the challenges imposed by disability (Smart, 2009). In a similar way to the social model, the socio-political model states that societal attitudes towards disability are the biggest barriers which individuals face since these result in affected individuals feeling embarrassed, insecure, uncomfortable or dependent (Weisgerber, 1991).

The strength of the socio-political model lies in its ability to explain and describe the day-to-day experiences of people with disabilities (Smart & Smart, 2006). Furthermore, this model provides individuals with the tools necessary to challenge prejudice and discrimination and the opportunities to speak out about these experiences. In this way, the socio-political model has the ability to mobilize groups of people with disabilities in order to facilitate change.

By maintaining that there is nothing related to the individual or to the disability that warrants change, the socio-political model places responsibility on society in order to adapt attitudes and laws.

3.4.5 The International Classification of Functioning, Disability and Health and the Bio-Psycho-Social Model of Disability

At present The International Classification of Functioning, Disability and Health (ICF: WHO, 2001) is the gold standard for defining and responding to disability. This model has been widely endorsed in a number of countries, including South Africa. The ICF proposes a bio-psycho-social model of disability, which also acknowledges that disability is more than 'something which a person has', but rather something that occurs outside of the person resulting in a functional limitation. This implies that disability is something which occurs in the interaction between a person, their ability, and the environment, including the physical, social, communicative, information, and policy environments (World Health Organisation, 2006). In this way, the ICF framework reflects a compromise between the medical and social models of disability.

As a consequence of the ICF framework, the World Health Organisation has broadened its definition of health to mean more than an absence of illness, but an incorporation of physical, mental and social well-being (World Health Organisation, 2006). This has led to the notion that the mind and body are inexorably linked, and together determine individual conceptions of health, illness and disability (Taylor, 2003), reflecting a rejection of a western dichotomy that is not necessarily applicable in other contexts (Shakespeare, 1996).

Within the ICF framework, disability refers to "the outcome or result of a complex relationship between the individual's health condition and personal factors, and of external factors that represent the circumstances in which the individual lives" (WHO, 2001, p.17). The ICF, thus, uses the term 'disability' as an umbrella concept to refer to impairments, activity limitations and participation restrictions resulting from any physical or cognitive condition (WHO, 2011). Significantly, the ICF strives to take environmental and contextual factors into account in the classification of restrictions to participation. In this way, the ICF

views impairments as physical manifestations of dysfunction in the body, affecting the individual's ability to perform major life activities including walking, seeing, communicating and eating (WHO, 2001, p.11). In this sense, disability reflects a complex relationship between the individual, society and bodily-related aspects of impairments, activity limitations, and participation restrictions in the socio-cultural environment. This concept of disability is reflected in the Convention on the Rights of Persons with Disabilities (2006) which describes disability as an "evolving concept" that is affected by attitudinal and environmental barriers which hinder active participation in society.

The ICF recognises a combination of environmental and personal factors which may serve as either facilitators or barriers to participation (WHO, 2001). The environmental factors include the built environment, services, systems, policies, support and technology; while personal factors include aspects such as motivation and self-esteem and view these in terms of an individual's capabilities and actual performance in the real world. However, despite acknowledgements that negative stereotypes persist for people with disabilities, very little attention is paid to the effects of 'hidden' or 'subtle' barriers, including the experience of stigma, discrimination and violence, and as a result these types of barriers continue to be perpetuated. In this way, the layering of cultural and contextual influences on the lives of people with disabilities are not adequately taken into account (Legg & Penn, 2013a), with policies and practices focussing more on environmental determinants of health rather than the interplay and effects of interpersonal issues.

3.4.6 Summary of Models of Disability

Each model of disability described above, attempts to provide a definition of disability and in this way, to answer the question "What is a disability?" Scullion (2010) claims that the history of models of disability can be traced by their focus of attribution or responsibility and the consequent formulation of policies and practices. Models of disability provide insight into societal attitudes relating to disability and in this way reveal how society provides or limits access to information, education, employment, service delivery and social interactions to people with disabilities. Models of disability therefore, provide a basis upon which government and society can meet the needs of people with disabilities (Scullion, 2010). However, the definitions of disability which models adopt frequently limit the concept to a

single dimension, implying that people with disabilities perceive their lives and align themselves with theoretical models. In this way, models become reductionistic, unidimensional and incomplete by emphasizing some aspects of lived experience while ignoring others (Smart, 2009). Furthermore, models of disability are bound in terms of both time and culture (Smart & Smart, 2006) and may not be applicable is all socio-cultural contexts. In this way individuals are deprived of their individuality and consequently the reality of their lived experiences are denied.

Caution must be exercised when applying models of disability for explanatory purposes since all models are a reflection of the values and needs of the defining group (Smart, 2009). As a result no model can be interpreted as value-free or morally neutral (Forhan, 2009). Consequently, explanatory models have a pervasive impact on the lives of people with disabilities, yet the nature of this impact is rarely acknowledged (Smart, 2009).

Models of disability are perpetuated through the media, as well as through healthcare and educational systems, and as a result the perceptions and beliefs underlying these models become an accepted and integral part of the social environment (Smart & Smart, 2006). Given that individuals make sense out of their experiences through the use of culturally acceptable narratives (Shafer, 1992; McAdams, 2001, Riessman, 2008), it follows that the dominant models of disability within a given society have the potential to shape and mould the way in which individuals interpret their experiences. It is acknowledged that the terminology used within the various models of disability may be unfamiliar to people with disabilities, particularly in rural contexts where there is limited access to education and services, yet the nature of society's responses to disability can usually be traced back to one or more explanatory models. This is particularly evident where people with disabilities are required to define themselves using stereotyped or medicalised terminology in order to be eligible for social and healthcare services. In societies where disabilities are stigmatised, those affected may become disempowered, and as a result may be viewed as inferior or dependent. In these contexts, explanatory models may only have limited ability to address the needs of persons with disabilities, which are pervaded not only by social and political attitudes towards disability, but also by approaches towards gender and racial and cultural equality.

3.5 PSYCHOSOCIAL EXPERIENCES OF PERSONS WITH DISABILITIES

The term '*psychosocial'* refers to a grounding of emotional experience within a social context (Code, Hemsley, & Hermann, 1999). Although not always reflected in explanatory models, it is acknowledged that the lived experience of disability is diverse (WHO, 2011). This implies that each person's account of their disability and the effect that it has on their life is unique and dependant on a number of variables which are mediated through context and culture. Research reflects that some people experience the onset of a disability as a personal tragedy (Oliver & Sapey, 1998) while others incorporate it into their life, viewing the experience as an opportunity to tell the story of how life challenges have resulted in change and growth (Frank, 1995).

While the psychosocial aspects of disability have been fairly well researched in developed countries (e.g. Code, Hemsley, & Hermann, 1999; Bakheit, Barret, & Wood, 2004; Parr, 2007), the focus on the psychological effects of disability in Afro-centric contexts is still relatively new (Lopez Levers, May & Vogel, 2011).

3.5.1 The Impact of Disability on the Individual

Historically, the life experiences of people with disabilities have been studied in relation to the spheres of education, employment and health (Pfeiffer, 2003; Scullion, 2010), and have been characterised by the impact of discrimination and social stigma. These aspects are further mediated by the individual's self-esteem, identity and relationships with family and friends (Parr, 2007). Commonly reported effects of disability include a change in self-esteem (Parr, 2007; Code, 1999), and a change in the sense of self which may be linked to the challenge of accepting a new identity (Parr, 2007). Previous research has raised the following psychosocial issues and effects as consequences of disability: depression (LaPointe, 1999; Code, Hemsley, & Hermann, 1999); social, physical and familial changes (Ross & Deverell, 2004); reduced self-esteem, sense of worth and self-confidence (Code, Hemsley, & Hermann, 1999; Bakheit, Barret, & Wood, 2004), and changes in spirituality (LaPointe, 1999). In addition, the inability to carry out daily activities due to decreased mobility or changes in communicative abilities, as well as 'visual reminders' of the disability, such as assistive

devices, may impact on the individual's body image and ultimately on their sense of identity and self-esteem (LaPointe, 1999). Contextually, the challenges associated with poverty, accessibility, and language barriers have also been found to influence the ways in which individuals make sense of their experiences (Van Rooy et al, 2012).

The experiences described above have been documented to result in social isolation (LaFond, Ponzio, DeGiovani, Sarno, & Joanette, 1993). These experiences may be bi-directional, whereby the individual may withdraw from social situations, while at the same time family and friends may display negative responses to the disability, resulting in insecurity regarding how to relate to the individual with a disability (Parr, 2007).

3.5.2 The Effects of Disability on Identity Construction

The concept of identity is a complex notion that transverses many disciplines, and encompasses aspects related to development, personality, context, resilience and coping mechanisms. This provides an ethical framework which serves as the scaffolding from which moral choices take shape (Tronto, 2012). In recent years the concept of identity has become so fluid that it defies coherent definition (MacInnes, 2004; Watson, 2002). In addition, both Tronto (2012) and Cameron and Kulick (2003) refer to the instability of identity in relation to the changeable nature of identity. These challenges make 'identity' a difficult notion to confine within specific parameters, resulting in the concept often appearing to be vacuous (Tronto, 2012). For this reason, caution must be exercised when conceptualising individual traits, behaviours and responses in terms of 'identity' since this has become an all-encompassing term of reference.

The notion of 'identity' is also problematic since it has been linked with both responsibility and morality (Lukes, 1972; Freud, 1920; MacInnes, 2004; Cerulo, 1997; Israelite, Ower, & Goldstein, 2002). This implies that where an individual's identity does not conform to societal norms, there are moral implications. In addition, the literature reflects a relationship between identity and intelligence (Mead, 1971; Neisser, 1988; Skinner, 1965; Bandura, 2002; Marrowlin, 2007; Pals, 2006), as well as identity and language proficiency (Gone, Miller, & Rappaport, 1999; Woodward, 2002), all of which imply that persons with cognitive and

communicative disabilities face impairments in identity construction. Thus the notion of 'identity' is used with caution in this thesis, yet the core concepts of affiliation, coherence, and stability over time are considered in the interpretation of experiences of disability.

Although a number of authors state that the onset of a disability may result in a crisis of the self (Shadden, 2005; Hinckley, 2006), Smart and Smart (2006) caution that disability is seldom the single defining feature of an individual's identity, but rather that disability is one of several important aspects on self-identity. Thus, while disability is a powerful identity which has the potential to transcend age, gender and culture (Shakespeare, 1996), major obstacles exist in relation to developing a strong and positive sense of self for people with disabilities (Shakespeare, 1996). This is largely linked to the nature of marginalisation, discrimination and oppression which people with disabilities face, including segregated education, parental guilt and shame, absence of positive role models, and isolation which inhibits collective support and strength (Shakespeare, 1996). This is expanded on by (Morris, 1991, p. 28) who claims that disabled people have limited access to ideals which place positive value on bodies with impairments, and consequently on the lives of persons with disabilities. This implies that self image may be dominated by non-disabled society's reactions (Morris, 1991).

Cerulo (1997) states that the development of group affiliation, such as disability identity, is enacted in a moral space, and in this way, the group defines their existence as right and good. This is influenced by the way in which the group members' perceptions of history, social structures and cultural arrangements constrain or enhance the interpretive process (Cerulo, 1997). While Hinckley (2006) suggests that successful identity renegotiation post onset of a disability is possible, it depends on a strong basis of social support which allows for an adaptation to a new sense of self, the ability to set new goals for the future, as well as the importance of taking responsibility for continued rehabilitation. Woodward (1997), however, states that identity amongst persons with disabilities is most clearly defined by difference, since it is constructed by "the marking of inclusion or exclusion – insiders or outsiders, 'us' and 'them'" (Woodward, 1997, pp. 1-2). This is related to the concept of the 'other' – a post-modern construct frequently referred to in the disability literature (e.g. Wendell, 1996; Thomas, 1999; Shakespeare, 2006). The notion of the 'other' is based on difference coupled

with issues of power. Through the process of 'othering', people in the dominant group marginalize those whom they view as different (Israelite, Ower & Goldstein, 2002). This can be viewed as a form of social oppression.

3.5.3 Disability and Social Role Devaluation

Wolfensberger (2000) states that an individual's psychological welfare depends on the social roles which they occupy. Social roles relate to a "combination of behaviours, functions, relationships, privileges, duties, and responsibilities that are socially defined, widely understood, and recognised within society" (Wolfensberger, 2000, p.106). Harré, Moghaddam, Cairnie, Rothbart & Sabat (2009) choose to use the term 'position' rather than 'role' since they maintain that positions are flexible and changeable, whereas roles are more formally defined and longer lasting. According to Harré et al (2009, p.9) positions are "clusters of beliefs about how rights and duties are distributed in the course of an episode of personal interaction." Furthermore, positions are believed to be embedded within the everyday practices of groups of people (Harré et al, 2009). However, much of the literature reflects the interchangeable use of the terms 'roles' and 'positions'.

Based on the definitions provided above, positions/roles bear inherent powers and abilities, or vulnerabilities and incapacitations which either allow or prohibit individuals from being ascribed certain positions (Harré et al, 2009). In this way, individuals who are able to fill socially and gender appropriate roles are positively valued by others within the same community, whereas those who are unable to are typically treated badly (Wolfensberger, 2000). This is particularly true for individuals who fall into more than one vulnerable category, for example being poor and disabled (Ingstad, 1999).

Ingstad (1999) states that in many cultures impairment does not necessarily determine an individual's status, but it is rather their ability to perform useful tasks in a socially acceptable manner which determines their inclusion into society. Thus, given the perception that an individual's well-being and social positioning may be determined by the social roles which they inhabit and their contributions to society (Devlieger, 1998; Lustig & Strauser, 2007), it can be assumed that disability can significantly affect an individual's social roles and their

perceived value in society (Mpofu et al, 2011). People with disabilities may be viewed as lazy or dependent and other community members may believe that they are deliberately failing to perform socially and gender specific roles (Lustig & Strauser, 2007). In the African context, the experiences of people with disabilities are documented to be characterised by numerous rejections and stigmatisation (Lustig & Strauser, 2007). This may lead to socio-cultural disadvantage as a result of limited access to resources, resulting in decreased community participation (Mpofu et al, 2011). Thus, the experience of social role devaluation results in a reduced sense of control over an individual's environment (Lustig & Strauser, 2007).

3.5.4 Disability, Sexual Freedom and Parenthood

As part of the medical response to disability, the majority of people with disabilities have historically been denied rights to sexual freedom and parenthood. Instead they were viewed as either 'eternal children'; innocent and asexual, or sexually rampant and unable to control their sexual desires (Mall & Swartz, 2012). As a way of enforcing these ideologies, forced sterilisations and abortions were used in order to limit or prevent sexual freedom and the right to parenthood amongst persons with disabilities (Kijak, 2011; Jones, Binger, McKenzie, Ramcharan, and Nankervis, 2010). In this way, stigma, myths and misconceptions preclude persons with disabilities from engaging in sexual relationships (Kijak, 2011), and as a result, many people with disabilities continue to have their rights to sexual freedom denied (South African National AIDS Council, 2008).

The types of philosophies described above have affected the appropriate implementation of programmes which facilitate safe sex, and have limited the implementation of HIV/AIDS programmes for persons with disabilities (Groce, 2006). Furthermore, failure to address the sexual needs of people with disabilities has increased their vulnerability to sexual abuse and sexually transmitted diseases (Fuller-Thomson & Brennenstuhl, 2012). This has significant implications for role devaluation within African communities since bearing of children is an essential role of a woman (Kuper, 1963; Knox, 2008; Thornton, 2008) while a man's prosperity and importance in the community is measured by his number of dependents (Kuper, 1963). In this way, people with disabilities continue to be excluded from active community participation.

3.5.5 Psychosocial Effects of Disability on the Family

The onset of a disability has been shown to affect the entire family dynamic and can be explained in terms of family systems theory where an impact on one family member disturbs the balance of homeostasis within the family unit (Ross & Deverell, 2004; Hinckley, 2006). This is important to consider since the affected individual's emotions are mediated through the family, and this can lead to increased levels of stress among family members (Möller & Blomstrand, 2001). Cognisance must be taken of this, since Mayhew (2003) emphasizes the importance of family systems as 'informal' support networks, even in first world countries. These findings concur with those found locally (Barratt, 2007; Anderson & Phohole, 2003; Kilonzo, 2004; Thejane, 1997). In South Africa many family structures differ from those in western communities, whereby family units do not only comprise of the traditional nuclear family, but may also include grandparents, aunts, uncles, cousins, neighbours and friends and new family forms. Gender roles vary amongst and within communities, and have a significant impact on the experience of caring for a family member with a disability.

Women are known to bear the brunt of care-giving activities (Cancian & Oliker, 1998). In developing countries such as South Africa, women in rural areas spend in excess of five hours each day collecting water and firewood, cleaning the home, preparing meals, and caring for the children (UNAIDS, 2004). This highlights the effect of context and culture on care-giving and emphasises that in situations where poverty is rife, the experience of supporting and/or caring for a person with a disability places immeasurable strain on the family system. Furthermore, in many African communities, disability is interpreted as a physical sign of misfortune or impaired social relationships, pertaining to both the affected individual as well as the family (Ingstad, 1999), resulting in stigmatisation and marginalisation.

3.5.6 Summary of Psychosocial Effects of Disability

The discrimination and marginalization described above results in people with disabilities facing violations of their civil, cultural, economic, political and social rights (United Nations, 2008), which in turn create barriers to participation in society. The United Nations (2008) refers to this as the 'silent crisis' and acknowledges that this does not only affect people with disabilities and their households, but also the economic and social development of entire

societies. This implies that while in theory the social model of disability is ideal, its implementation is challenging and subject to both individual and community perceptions and beliefs surrounding disability (Mayhew, 2003).

Both the Convention on the Rights of Persons with Disabilities (2006) and the World Disability Report (2011) suggest that progress on improving social participation can be made by addressing the barriers which hinder active social participation. However, the barriers identified and addressed in these documents reflect mainly physical barriers and do not take issues such as the inherent discrimination which exists in society into account. Thus both the focus and responsibility shifts from the individual to wider society.

3.6 SUMMARY AND CONCLUSION OF CHAPTER 3

Chapter 3 has provided an overview of disability as an evolving concept, and has highlighted the challenges associated with conceptualising and defining it as a static entity. In recent years, disability has received an increasing amount of attention, and is currently acknowledged as a human rights entity. This has resulted in a growing interest into the impact that context and culture have on the individual, and consequently, a number of policies and practices have been developed to protect the rights of people with disabilities. However, as can be seen from the discussion above, contextual and cultural issues are not always adequately reflected in models of disability.

Current models of disability rely predominantly on the standpoints provided by the medical and social perspectives, and more recently from those put forward by the ICF framework, which consider the psychosocial impact of disability as universal. Thus while these models do acknowledge that disability is a multi-layered phenomenon which has the potential to affect psychological well-being and social interactions, they fail to adequately take into account the impact of contextual variation and cultural norms on the lived experience of the individual (Legg & Penn, 2013a).

The core issues exposed by models of disability involve the freedom that individuals have in making independent decisions and engaging meaningfully in social interactions (Sen, 2000). However, the current models do not adequately take into account the extent to which people with disabilities' social and emotional engagements are rendered invisible. The explanatory models presented in this chapter appear to have a limited ability to engage meaningfully with their underlying social and political assumptions. This raises the question as to how explanatory models and conditions of care can be entered into in a non-exploitative way, opening a dialogue regarding ethics of care (Tronto, 1995) as opposed to politics of care (Swartz, 2012).

Given the complexities resulting from South Africa's turbulent history, together with the challenges imposed by service delivery and cross-linguistic and cross-cultural consultations (as discussed in Chapter 2), the extant models of disability are limited in terms of their ability to address the needs of persons with disabilities. The silences which pervade issues relating to shared responsibility, equity and equal opportunity seem to reflect a resistance to acknowledging the reality of what it means to live with a disability, and consequently reflect a resistance to change. Thus it is clear that only a limited number of narrative themes are currently available to people with disabilitites. However, by providing people with disabilities the opportunity to tell stories about their lived experiences, we are exposed to an emergence of new themes which are not always reflected within theoretical models of explanation. In this way, people with disabilities have begun to create their own stories rather than relying on traditional narratives as prescribed by biomedical intervention or political policies. This is reaffirmed by Shakespeare (1996) who claims that

> "Disability identity is about stories, having the space to tell them, and an audience which will listen. It is also about recognising differences, and isolating the significant attributes and experiences which constitute disability. Some we might choose to change, others to recuperate or celebrate. Theory has a part to play in the process but it all starts with having a voice" (p.111).

Chapter 4 will provide an overview of narrative inquiry as a means for understanding the lived experience of disability. More specifically, it will focus on the individual's need to tell stories in order to make sense of life experiences. This will be shown to be relevant in the South African context.

CHAPTER 4

EMBODIED EXPERIENCE AND THE NEED TO TELL STORIES

"Stories aren't just entertainment, don't be fooled. They are all we have to fight off illness and death. You don't have anything if you don't have stories."

(King, 2003, p.92)



A participant sitting outside her home, waiting to be interviewed

The process underlying narrative inquiry suggests that people live storied lives (Shafer, 1992), and that it is their agency as individuals that allows them to tell and live these stories (White, 1984). McAdams (1993) asserts that people construct stories in order to make sense of things that happen to them, to integrate disparate roles, values and skills, and in this way to organize the past, present and future into a meaningful pattern.

Riessman and Quinney (2005) describe the study of narrative as a 20th century development, that has been increasingly utilised as a method for studying lived experience, traversing the disciplines of literary studies, history, anthropology, sociology, psychology, sociolinguistics, medicine, law, and the therapeutic sciences, as well as being applied at macro-level within organisations and social movements. Although the study of narrative is reported to have its roots in phenomenology (Ricoeur, 1990), its application now extends beyond lived experience towards the interactions that occur within human relationships (Riessman & Quinney, 2005). These relationships are dependent on social interactions, and therefore, the relationship between the speakers determines what can and cannot be said, how things are expressed, what can be taken for granted, and what needs explaining (Riessman & Quinney, 2005).

Because narrative inquiry is used by researchers from multiple paradigms, including, realism, post-modernism, and constructionism, little agreement exists regarding a precise definition as to what actually constitutes a narrative (Riessman, 1993). Riessman and Quinney (2005), claim that as a result of the extensive application of narrative in a variety of fields, the term 'narrative' has come to be used as a metaphor for 'telling one's own story'. Thus, definitions of narrative vary according to discipline, and may refer to extended accounts of life histories, such as in anthropology (Myerhoff, 1992), or discrete units of discourse, such as in socio-linguistics (Labov, 1982). For the purpose of this study, Mattingly and Lawlor's (2000) definition, drawn from the fields of psychology and sociology has been applied. These authors define narrative as follows:

> "…. event-centred and historically particular, located in a specific time and place. Stories concern action, more specifically human action, and particularly human interaction. Stories have plots. They

> have a beginning, middle and an end, so that while they unfold in time, the order is more than mere sequence, but reveals a sense of the whole. Stories show how human actors do things in the world, how their actions shape events and instigate responses in other actors, changing the world (and often changing the actors themselves) in some way. Stories also reveal the way events and other actors act upon someone, shaping their possibilities, the way they view themselves and their worlds. Whether hinted at or baldly stated, stories explore the complex motives that drive individuals to act in some ways rather than in others and they also reveal the constraints of the environment, of the body, and of social contexts that delimit a person's possibilities for action." (p.6)

Based on this definition, narratives have the ability to endow experiences with meaning (Hinckley, 2006). McAdams (1993) argues that it is impossible to know a person without knowing their life story, and states that "if you want to know me then you must know my story, for my story defines who I am. And if I want to know myself, to gain insight into the meaning of my own life, then I, too must come to know my own story" (p.1). Narratives are by their very nature flexible and fluid concepts which may change over time (Connelly & Clandinin, 2004). In addition, they are plurivocal, in which a number of voices may be heard, either in unison or in conflict with each other (Riessman, 2004). Narratives are also said to be co-constructed, since they are not created in isolation or only for the purpose of the self, but are rather developed collaboratively between the speaker and the listener (Connelly & Clandinin, 1990). Thus the response of the listener is implicated in the construction of the narrative (Riessman, 2004).

Given the assumption that human beings are both biological organisms and social beings (Krieger, 2005) and that their stories have the potential to illuminate aspects of the individual that would be difficult to observe using other methods, it follows that theories of embodiment complement the narrative inquiry method. This is supported by Fox (2011) who describes the ways in which intractable traces of the past are felt on people's bodies and perceived through the moral fabric of their social relations. Scheper-Hughes and Lock (1987) describe

embodiment as a multilevel phenomenon that entails the interplay between bodies, components of bodies and the context in which life is lived. Given this definition, embodied experiences have the potential to influence the trajectories of biological and social development. Underlying the premises of embodiment theory are the assumptions that bodies cannot be separated from the conditions in which they exist, that existential conditions have the ability to influence the stories that people tell about their lives, and that bodies are able to carry and convey meaning about lived experience that cannot be transformed into words (Krieger, 2005). In relation to the current study, the experience of living with a disability in the context of food insecurity, inadequate sanitation, economic and social deprivation, and exposure to violence has the potential to leave marks on the body, and consequently on the ways in which stories are lived and told.

Embodiment invites the listener to consider the ways in which stories are recounted or withheld, in comparison to those that the body tells (Krieger, 2005). Embodiment of experiences occurs as a process since it involves the temporal transformation of biological characteristics into conscious and sub-conscious forms of social engagement (Krieger, 2005). By means of listening to the stories that people tell and observing how these experiences are embodied, the inequitable distribution of power in society may be observed, highlighting diverse forms of social inequality. Thus by paying attention to the ways in which bodies covey meaning, we are reminded that failure to take embodiment seriously can lead to research inadvertently increasing social suffering (Fox, 2011).

Given the interactive engagements involved in storytelling, narrative inquiry as a method may be considered to be participatory, since participants are provided with an opportunity to tell their own story, from their own perspective, using their own words. In this way, a research context may be created where previously muted voices can be heard (Riessman & Quinney, 2005). The concept of voice is a complex one, which is often absent amongst marginalised communities, yet is a vital in the empowerment of individuals and communities. This complex concept is described by Britzman (1991), who claims that

> "Voice is meaning that resides inside the individual and enables the individual to participate within a community…The struggle for

> voice begins when a person attempts to communicate meaning to someone else. Finding the words, speaking for oneself, and feeling heard by others are all part of the process…Voice suggests relationships: the individual's relationship to the meaning of her/his experience and hence, to language, and the individual's relationship to the other, since understanding is a social process." (p.127)

4.2 CORE ASPECTS OF NARRATIVE INQUIRY

Central to the notion of narrative inquiry is the sequencing of events and the consequent development of a plot (Mattingly, 1994; Clandinin & Connely, 2000; Riessman, 2008; Holstein & Gubrium, 2012). Further central aspects are related to the development of characters and their relationship to the narrator of the story (Frank, 1995; Clandinin & Connelly, 2000; Bamberg, 2012), the construction of events deemed as significant to the speaker (Frank, 1995; Clandinin & Connelly, 2000; Clandinin & Rosiek, 2007), the relationship between temporal and spatial domains of narrative construction (Clandinin & Connelly, 2000; Clandinin & Rosiek; Holstein & Gubrium, 2012) and their consequent effect on the creation of a narrative context (Mattingly, 1994; Riessman, 2008). The relationship between these features gives rise to the development of narrative sequence and consequence, which leads to the development of a narrative plot (Ricoeur, 1980; Frank, 1995; Holstein & Gubrium, 2012).

Fundamental to the analysis of narrative is an interrogation of the purposes and decisions underlying the story's construction (Mattingly, 1994). Riessman and Quinney (2005) claim that it is important to consider for whom the story is intended and for what purpose it was constructed, the cultural resources that it draws on and those which it takes for granted, and the presence of inconsistencies or disjunctures which hint towards alternative counter-narratives. Furthermore, it is vital to consider that narrative inquiry occurs in the midst of living and telling of stories, and therefore the inquiry can only end within the midst of reliving and retelling stories, and in so doing, shapes the way in which life is lived (Clandinin & Connelly, 2006).

The interrogation of the concepts described above provides insight into how and why stories are sequenced in a particular way, for whom the story is intended, the cultural resources the story draws on, and the presence of inconsistencies that suggest counter-narratives (Riessman & Quinney, 2005). Sections 4.2.1 – 4.4.4 below provide additional insight into the core aspects of narrative construction.

4.2.1 Events and Characters

Events and characters, also referred to in the literature as actions and actors (e.g. Mattingly, 1994; Hinckley, 2006; Bamberg, 2012), serve as the substance which holds narratives together (Clandinin & Rosiek, 2007). Characters and events are ascribed meaning by belonging to and contributing to the narrative (Mattingly, 1994). In this way, narratives are made whole, and serve to provide a moral or purpose of the story (Mattingly, 1994). In this way, the positioning of characters within narratives provides insight into the nature of social support to which the individual has access (Hinckley, 2006).

In addition, narratives situate characters and events within a particular socio-political context, such that all actions are directed towards the closure of the narrative where the meaning or value is depicted (Moon, 2006). In reality, sequences of events do not end, but rather in narrative form, the ending represents a constructed transition from one physical, temporal or social space to another (White, 1984).

4.2.2 Temporal Domains of Narrative Construction

According to Ricoeur (1980) temporality and narrativity are intimately related whereby time creates the structure for existence and narrative provides a language structure for organising and making sense of life experiences. In this way, narrative structure is said to pervade our experience of time and social existence (Carr, 1986). Through narrative construction, chronological time or ‘life in time’ is endowed with meaning by assimilating the narrative into a structure which has a clear beginning, middle and ending (White, 1984).

Different types of narratives lend themselves to different temporal orientations. For example, autobiographies are predominantly located in the past, interviewing is usually located in the present, and letter writing and journalling tend to be located in the future (Connelly & Clandinin, 1990). However, regardless of the nature or purpose of the narrative, Carr (1986) states that the past is used to convey significance, the present conveys value, and the future conveys intention. These three dimensions are used in the construction of meaning and for explanatory purposes. In this way, narratives acquire relevance by locating the present between the past and the future as opposed to an endless succession of 'nows' (Mattingly, 1994; Frank, 1995). In this way the present contains meaning because it is intimately related to a past that can be reflected upon and a future which is anticipated (Mattingly, 1994).

Although narratives are most commonly told in temporal terms, representing a western and linear concept of time (Riessman & Quinney, 2005; Riessman, 2008), it is also possible for them to be told thematically or episodically (Riessman, 1987; Gee, 1991; Cazden, 2001). However, regardless of whether narratives are constructed temporally or episodically, they can be distinguished from other forms of discourse through the analysis of sequence and consequence (Riessman & Quinney, 2005). Mattingly (1994) introduces the notion of 'human time' as opposed to distinguishing between 'western' and 'non-western' concepts of time, stating that human time is shaped by motive and intention. This implies that through narrative, a range of possibilities exist (Mattingly, 1994; Frank, 1995). In this way, narrative construction reveals the possibility that both the story and the life itself may have been lived differently (Frank, 1995).

Mattingly (1994) distinguishes 'life in time' from 'narrative time' by stating that our lived existence lacks the coherence of a unity with a beginning, middle and end. While narratives are told as an unfolding temporal whole, in reality, life events disrupt the coherence that narrative sanctifies because 'life in time' does not yield itself as a story but is rather transformed into a narrative through reflection (Kermode, 2000). Thus, once experience is converted into a narrative format, temporality creates a sense of authenticity which endows a sense of reality among events (Moon, 2006). In this way, episodic events are transformed into

a linear and causal structure that provides experience with coherence and meaning (Moon, 2006).

4.3.3 Spatial Domains of Narrative Construction

The spatial domains of narrative construction refer to the place where the action occurs, where characters live out their stories, and where cultural and social norms act as constraining or enabling variables within the narrative (Connelly & Clandinin, 1990). In this way, context is created which works together with the characters and the physical setting in order to create the place in which narratives are lived and told (Mattingly, 1994; Clandinin & Connelly, 2000).

According to Foucault (1973), context provides insight into the unspoken and unconscious perspectives of the individual. Given the relationship between time and space, it is important to consider the mutual relationship between the two dimensions and to understand the limitations that spatial dimensions place on the temporal dimensions of the narrative and vice versa. In the past, 'space' was considered to a rigid concept (Taylor & Spicer, 2007), with Foucault (1980) describing the concept of 'space' as "the dead, the fixed, the undialectical and the immobile" (p.70). More recently, however, space has become viewed as a more dynamic and changeable concept which may exert influence on the way in which individuals make sense of their experiences (Taylor & Spicer, 2007). Taylor and Spicer (2007) add that space is interpreted in relation to our individual experiences, and thus it is our perceptions of space that give it meaning. This implies that space is a flexible concept, and that different experiences give rise to vastly different interpretations of space.

4.4.4 Plot

According to Ricoeur (1980), a narrative plot may be described as a process that synthesizes experiences within a narrative. Thus, the plot may be viewed as the organizing theme of a narrative, which weaves together a complex set of events into a single story (Ricoeur, 1980). In this way, episodic events are given unity (Miller, 2000). Many authors claim that the plot is the essence of what holds a narrative together. Based on this, the plot is more than a theme within the narrative or a significant episodic event, but rather a combination of temporal and

spatial boundaries which facilitate a narrative pattern (Clandinin & Connelly, 2000; Mattingly & Lawlor, 2000; Riessman, 2008). The plot reveals an intersection of social actions and interaction, and spatial and temporal domains within which events are described (Mattingly, 1994). In this way, the narrative plot differs from the story line since it involves creating a whole out of a succession of episodic events, while the story line represents a chronological recall of events (Ricoeur, 1980).

According to Connelly and Clandinin (1990), time is essential to the plot, which implies the relationship of a beginning, middle and ending in the development of a narrative pattern. This allows for narrative data sources to be classified according to their relative emphasis on temporality. While it is important to be cognisant of the differences between western and non-western perceptions of time, the core features that distinguish the narrative construction of a plot, from other types of discourses are sequence and consequence (Riessman, 2005).

Propp (1968) states that plots develop around a desire which needs to be addressed. This desire may emerge as a result of an "insufficiency" or as a result of the action of a "villain who disturbs the peace" (p.42). This notion is supported by Mattingly (1994) who adds that conflict is always present in narrative plots. Through narrative construction, stories are told about enemies, risks, and difficult or frightening situations (Mattingly, 1994). While conflict dominates most narratives, desire usually emerges as a form of opposition which challenges danger in the attainment of goals (Mattingly, 1994). In this way, desire represents a readiness to suffer, since it allows individuals to take risks which may result in suffering (Mattingly, 1994). In this way, desire emerges in the aspiration for certain objects or actions, as well as in the listener's need to hear certain stories or conclusions and to fear or reject others (Mattingly, 1994; Frank, 1995).

As a consequence of the conflict that emerges within stories, different points of view materialize, which highlight the pluralistic nature of stories (Riessman, 2004). This implies that narratives, specifically, narrative plots, are fundamentally a reflection of social interactions (Mattingly, 1994) and the interplay between personal and social interpretations of experience (Clandinin & Connelly, 2000).

4.5 CLINICAL APPLICATIONS OF NARRATIVE INQUIRY

Mattingly (1994) asserts that as human beings we construct and convey stories of our lives through social interactions (Clandinin & Connelly, 2006). In this way, the world is interpreted and made personally relevant (Clandinin & Connelly, 2006; Radomsky, Hassane, Hoy-Watkins & Bandawe, 2011). Gone, Miller and Rappaport (1990) claim that people come to appropriate, inhabit or own cultural ideas and values through practices such as narrative, allowing them an opportunity to represent themselves through the construction of meaning. This is supported by Somers (1994) who claims that "it is through narrativity that we come to know, understand, and make sense of the social world, and it is through narratives and narrativity that we constitute our social identity. All of us come to be who we are by being located or locating ourselves in social narratives, rarely of our own making" (p.606). In addition, McAdams (1993) asserts that people construct stories in order to make sense of things that happen to them, and in this way are able to integrate disparate roles, values and skills, as well as organize the past, present and future into a meaningful pattern. These interpretive acts render individual life experiences meaningful (Radomsky et al, 2011). Ezzy (1998) adds that personal narratives provide a sense of continuity since they symbolically integrate the events of lived experience in the coherent plot of the story which a person tells about their life. This implies that the constitution of a robust sense of self is derived through role-taking which allows for a coherent view of the past, present and future (Mead, 1934).

Narratives have been shown to have clinical value in assisting individuals with making sense of negative life experiences (Mattingly, 1994; Greenhalgh & Collard, 2003; Hinckley, 2006; Moon, 2006; Maree & Du Toit, 2011). Greenhalgh and Collard (2003) argue that narratives are particularly useful in addressing patients holistically since they provide insight into their physical, psychological, social and economic situations and therefore into the illness itself and the impact that illness has on the individual, family and community. Narratives can be used not only as retrospective accounts of past events but also as a means for structuring clinical goals (Mattingly, 1994). In this way, clinical encounters are incorporated into the larger narrative structures of the individual's life story (Greenhalgh & Collard, 2003).

Maree and Du Toit (2011) suggest that narratives can be used in clinical encounters in which the therapist assists the patient in reconstructing their life experiences using a narrative format, and in so doing maximises their strengths in order to deal with their weaknesses. The act of storytelling can also be used to assist individuals in making major life decisions since stories act as a form of persuasion which impacts on both the nature and success of intervention (Hinckley, 2006). Thus by understanding not only what has happened in an individual's life, but also why it is believed to have happened, the form of rehabilitation believed to be justified, and how the individual made sense of the situation is paramount to intervention (Greenhalgh & Collard, 2003). In this way, clinicians can gain insight into the type of support that patients require (Hinckley, 2006).

Hinckley (2006) reports that the act of telling and retelling stories of the experience of stroke in a meaningful and coherent way assisted individuals in taking responsibility for their social environments as well as for rehabilitation. Ochberg (1996) adds that the stories of people with disabilities represent a way in which individuals can reclaim their sense of agency. Thus, despite the physical and emotional challenges associated with disability, individuals are able to take responsibility and exert agency over the way in which their story is told, thus defying a sense of passivity (Ochberg, 1996).

The clinical value of narrative has the potential to be particularly relevant in the South African context, given that counselling has traditionally been positivist and diagnostic in nature (Maree & Du Toit, 2011). This highlights the need to develop innovative methods and structures for effective and appropriate counselling services, and calls for culturally and contextually relevant and safe methods which *"enable rather than fit"* (Savickas, 1993, p.211).

Based on the above, storytelling has a number of functions, including contextual grounding, bonding with others, validating and affirming experiences, catharsis and resisting oppression, and educating others (Banks-Wallace, 1998). Contextual grounding is particularly important since it provides the foundation upon which our understanding of the world and our place in it is built (Banks-Wallace, 1998). In sections 4.5.1 and 4.5.2 below I will discuss more of the

clinical applications of narrative inquiry that relate specifically to making sense out of experiences associated with disability.

4.5.1 Narrative Inquiry as a Tool for Understanding Identity Construction

Riessman and Quinney (2005) suggest that part of the 'narrative turn' within the humanities can be attributed towards contemporary preoccupations with identity. Based on this, much focus has been placed on the narrative construction of identity. McAdams (2001) claims that narrative identity is made up of memories of emotionally significant experiences that are interpreted to reveal self-defining meaning and are integrated into the broader themes and patterns that comprise the life story as a whole. He expands on this by explaining that some memories fit neatly into the existing story line that has already been constructed, thus providing identity continuity, whereas others challenge the story line and invite identity questioning and transformation (McAdams, 2001).

Much literature focuses on the development of identity in childhood and identity crises in adolescence (Erikson, 1980; Israelite, Ower, & Goldstein, 2002; Fraiberg, 1959; Josselson, 1994), yet there is relatively little literature on re-establishing identity in later life, secondary to a life-changing event. Israelite, Ower and Goldstein (2002) state that identity challenges in later years call for a re-negotiation of the self, re-evaluating one's values and morals and re-establishing a place for oneself in society. Pals (2006) adds that identity in adulthood takes the shape of a coherent narrative or life story that integrates interpretations of the past with the present, thus providing life with meaning and purpose. However, significant life changes or traumatic events may trigger corresponding changes in patterns of thinking, feeling and behaving over time (Pals, 2006).

Goffman (1961) states that through identity construction and re-construction, individuals' behaviours and roles are brought into alignment with societal values. This implies that society's basic values influence the construction of the narrative, which is seen through the adoption of culturally acceptable plots for narrative construction (Goffman, 1961). Moreover, Ricoeur (1980) reports that narrative identities are always in-process and unfinished, continuously made and re-made as episodes happen. Goffman (1961) adds that where an

individual can show favourable qualities in the past and a favourable future awaiting him, their story is considered a success story. However, where the experiences of the past and present are bleak, the best the person can do is to show that he is not responsible for what has become of him and the term 'sad tale' is appropriate.

Baumeister and Wilson (1996) describe four needs for meaning in life, and propose that people who satisfy all four of these needs, generally regard their lives purposeful, whereas those who are unable to satisfy one or more of these needs tend to show distress, emptiness, or a life devoid of meaning. These four needs include purpose, value and justification, efficacy, and self-worth, all of which are central to the moral dimension of the life story. McAdams (1993) supports the notion of purpose and suggests that people who are 'highly generative' or easily able to transform their experiences into stories, tend to link misfortunes to subsequent positive outcomes, while less generative people tell life stories in which positive events lead to subsequent negative outcomes. Thus, when one's actions cannot be transformed from bad into good, a moral dilemma arises, since life events cannot be integrated into meaningful unity. McAdams (1993) proposes that this can be dealt with by acknowledging blame and guilt for them in the past, and in this way, life stories may take the form of redemptive sequences, vividly depicting the self as bad up to a certain point, but emphasizing a transformation that frees the present self from the moral onus of previous actions. Antonovsky (1987) postulates that factors such as financial well-being, religious and emotional support, personal safety and food security provide individuals with predictable life experiences that are characterised by consistency and can be used to derive order and sense out of chaos, making the world comprehensible and manageable. However, the experience of living in the context of poverty renders experiences inconsistent and unreliable (Lustig & Strauser, 2007). Thus, the sense of self-continuity in narrative identity construction is the product of consistency and coherence through life's changes (McAdams, 1993; 2001). In this way, narratives allow the individual to represent the temporal nature of unfolding human experience and its resultant capacity to capture the continuous yet evolving sense of self (Gone, Miller & Rappaport, 1990).

4.5.2 Narrative as a Tool for Understanding the Lived Experience of Disability

Given that many disabilities occur as a result of medical conditions, and that people with disabilities have traditionally received treatment in line with the biomedical model of intervention, the emergence of illness and disability narratives in the social sciences are discussed together. The World Health Organisation (2011) states that generalisations about 'disability' or 'people with disabilities' can be misleading, and as a result they are often perceived as a group with the same experiences, challenges and aspirations, as opposed to being viewed as individuals. Thus, Riessman (2004) states that historically, very little attention has been paid to the presentational features of illness narratives, and the intersections between identity, illness, and health that can be observed but are not always verbalised.

Hyden (1997) claims that illness narratives emerged in response to biomedicine's focus on disease rather than the personal account of illness, with the consequent neglect of human experience. Hyden (1997, p.49) adds that illness narratives give voice to human suffering in a way that lies ouside of the domain of the biomedical voice. As opposed to biomedicne, narrative inquiry acknowledges subjectivity in the adaptation to chronic conditions in terms of how the condition is perceived, enacted, and responded to by the affected individual and by others (Riessman, 2004). Despite an emerging field of narrative medicine, McCrum (1999) states that a vast unarticulated story of unendurable pain and desperation exists, which receive no publicity, highlighting the fact that many voices continue to be muted resulting in the experience of illness and disability being denied.

Chronic illness, disability and suffering have been documented to generate narrative loss (Mattingly, 1994; Frank, 1995). This may manifest in a sense of physical, emotional or psychological distress (Frank, 1995). The biographic disruption inherent in illness, disability and suffering create fractures within life stories, and through this process the affected individuals are forced to restructure their physical lives, as well as their narrative structures which are used to make sense of experiences in order to accommodate their disabled bodies (Mattingly, 1994).

Frank (1995) proposed three types of narratives which people experiencing illness use as frameworks for making sense of their life expereinces. These include restitution narratives, chaos narratives, and quest narratives. Restitution narratives are characterised by an attempt to narrate and live a normal life in spite of illness (Frank, 1995, p. 77), chaos narratives are characterised by their lack of narrative order, with no sequence or discernible causality, and where the teller never imagines life getting better (Frank, 1995, p. 97), and quest narratives refer to narratives that meet suffering head on, accepting it and seeking to use it, thus affording the teller a voice to tell their own story (Frank, 1995, p. 115). Frank (1995) states that the quest narrative is the most culturally acceptable form of narrative, while the chaos narrative is the least culturally acceptable form. This is supported by Mattingly (1994), Hinckley (2006), and Ulatowska et al (2011) who all report the need for listeners to hear stories that end well. In situations where the conclusion is negative, listeners tend to reject or fear the story and thus try to guide the speaker towards a more positive ending (Frank, 1995; Hinckley, 2006).

Mattingly (1994) suggests that even in the event of serious illness or disability, constrained by an altered body and events largely out of control of the individual, a narrative emerges in relation to how the individual and other people in their surroundings respond to the physical, cognitive, communicative or psychological changes inherent in illness and disability. Through the construction of a personal narrative in the presence of illness or disability, narrative time opposes biomedical time because it is constructed by the affected individual as opposed to the condition (Sacks, 1987). This is relevant in the South African context, where the experience of living with a disability, particularly in rural areas, is impacted on by a number of factors, not least of all myth and stigma (Barratt & Penn, 2009; Mall & Swartz, 2012). The relationship between myth and the experience of disability is a further reason why narrative inquiry is an appropriate tool for the study of the lived experience of disability, since Dorson (1976) notes that myths are the storied structures which stand behind folklore and oral history.

4.6 CLINICAL CHALLENGES ASSOCIATED WITH NARRATIVE INQUIRY

Despite the advantages of the narrative inquiry method highlighted above, a number of challenges may be encountered, specifically in relation to the construction of the life story after the experience of a traumatic event. The onset of a chronic illness or disability may be considered to be a major life changing event (Frank, 1995), and has been shown to evoke a change in the individual's sense of self and consequently in their life story (e.g. Frank, 1995; McAdams, 2001; Hinckley, 2006; Bernsten & Rubin, 2006, Ulatowska et al, 2011). Frank (1995) states that illness represents a crisis of the self, and that it is through reflection on the past, and attempts to re-narrate the life story, that the individual's interpretation of him/herself may be observed.

Bernsten and Rubin (2007) define a traumatic event as "a very shocking event that violates schema-driven expectations", which may result in "enhanced, schema incongruent material" (p.421). Moments of rupture are defined by multiple situation-bound ways of defining a non-coherent sense of being (Märtsin, 2010), and may also be considered as turning points in life narratives. Pillemer (1998, p.76) defines a turning point as "a specific episode or series of events that appear to alter or redirect the ongoing flow of the life course" (p.76). Thus, a turning point may be considered a causal agent in the life story which provides explanations of subsequent choices, acts and values, and may be seen as the end of one chapter and the beginning of another (Pillemer, 1998; Bernsten & Rubin, 2007; McAdams, 2001). Thus, the experience of a traumatic event has the potential to violate shared cultural norms which typically provide the basis of the content of the life story, and has been shown to have negative effects on mental health (Bernsten & Rubin, 2007).

Conway (2005) claims that the self-systems response to trauma is to lower the accessibility of memories of events or to even distort these memories. This suggests that over time consistency of the self may need to be maintained by alteration of the self-concept, which may lead to the development of the self-identity which is centred on being a victim of trauma (Bernsten & Rubin, 2007) or emphasizing self-change since the event (Frank, 1995). Märtsin (2010) adds that if something has become deeply embedded in an individual's functioning and sense-making, it becomes difficult to put it into words. Consequently, it forms the

background to the narratives which the individual tells, regulating the their way of being and interpretation of new experiences.

McAdams (2001) claims that trauma has the potential to contaminate positive events experienced prior to the disturbance, since these events may be reinterpreted and associated with the negative emotions connected to the trauma. Preoccupation with the traumatic event may result in a multiplicity of meaning (Robinson, 1996). Bernsten and Rubin (2006) report that because a traumatic memory may cause profound changes in an individual's outlook, it remains highly accessible for years and may come to mind in response to internal or external cues. It may thus be perceived as a turning point in the individual's life story, with the individual focussing on aspects of their current life which they explain in relation to the trauma and ignoring aspects which defy these causal relationships (Bernsten & Rubin, 2006). Stressful events may thus serve as reference points and are likely to generate 'a sense of serious current threat' (Ehlers & Clark, 2000). Pillemer (1998, p.74) refers to these memories as "anchoring events" which he describes as a "lasting reminder of the way things are". These 'anchoring events' are used by the individual to validate current beliefs and feelings and to guide thoughts and behaviours (Pillemer, 1998).

McAdams (2001) claims that since identity takes the form of a story, in situations where a traumatic memory is seen as a central turning point in the individual's life story, it is also likely to be regarded as a central aspect of the their identity. This relates to the social role of being a trauma victim or a trauma survivor and these roles impact on the individual's self-concept. Bernsten and Rubin (2007) add that having a traumatic event as central to identity may be seen as a symbol for persistent themes in the individual's life story, and in this way the trauma is seen as a stable characteristic of the self that can be sustained across a variety of situations. Thus the reconstruction of a personal narrative from the perspective of a person who has experienced trauma has the potential to render the traumatic memory as central to their understanding of the past, the current self, and the expected future.

Some authors (e.g. Bernsten & Rubin, 2006; Conway, 2005) propose a role for culture in the maintenance of a 'trauma identity' through social sanctions, expectations of trauma-related

identity, as well as the setting and attainment of goals. It has been proposed that in situations where the nature of the trauma is not culturally sanctioned (e.g. rape and incest), the individual may receive less acknowledgement, tolerance or discussion, which may result in them being forced to suppress their trauma-related experiences (Evans & Maines, 1995; Jobson & O'Kearney, 2008).

It has been suggested that coping with traumatic events is closely associated with the capacity to narrate difficult life experiences in a coherent way (Pals, 2006; Tugade & Fredrickson, 2004). However, it must be taken into account that an individual's psychological state at the time of producing the narrative affects the way in which he or she recalls the events which define that narrative (Pals, 2006). This is further explained by Pals (2006) and McAdams (2001) who claim that the narrative construction of traumatic events involves firstly exploring the meaning of the experience, and seondly constructing a coherent and positive conclusion.

4.7 NARRATIVE INQUIRY AS AN APPROPRIATE TOOL IN THE SOUTH AFRICAN CONTEXT

Chinweizu (1988) states that storytelling has been the most valuable way of preserving history and culture, for resisting oppression, teaching values, and strengthening family and community bonds in Africa. Stories form an integral part of South Africa's past, present and future, and are used in the transference of norms and values from one generation to the next. In this way, African oral traditions have served to preserve and perpetuate the "spiritual, ethical, cultural and moral wisdom of the community" (Maree & Du Toit, 2011, p.23).

Researchers often assume that values, perspectives and goals that are developed in western contexts are applicable to other populations too (Banks-Wallace, 1998). However, where this principle is applied, the realities of persons outside of these groups may be denied or devalued. Narrative research, however, has been a valuable tool when conducting research with people from a variety of different cultural, racial, ethnic, and social backgrounds (Mattingly & Lawlor, 2000). This is supported by Bessareb and Ng'andu (2010) who state that narrative inquiry represents a culturally safe indigenous method of research, and through

the process of eliciting stories, our understanding of participants' points of view and backgrounds are strengthened.

4.7.1 Trauma, Violence and Segregation as Dominant Plots in the South African Context

Given South Africa's history of violence, conflict, and segregation as described in sections 2.1 - 2.3, a number of narrative plots have developed around these topics (Graham, 2003; Moon, 2006; Maree & Du Toit, 2011). Despite the inherent difficulties of narrating coherent accounts of traumatic events, the narrative perspective was explicitly employed during the TRC Hearings (1995 – 1997) in order to facilitate South Africa's transition from apartheid to democracy, given the cathartic value of narrative and the fact that it does not rely on educational level or literacy (Moon, 2006). The TRC represented a culturally safe environment for storytelling, and in so doing created possibilities for individual and community healing. Victims were allowed the opportunity to remember and describe the historical and cultural crimes committed during apartheid and to express the human rights violations which they had experienced (Moon, 2006; Fox, 2011). In this way, the hearings served as an official acknowledgement of the abuses endured, and in this way helped to restore the dignity of those affected (Chapman & Ball, 2001). These hearings served to validate and acknowledge the gross human maltreatment which occurred during the apartheid era, and served as safe spaces for victims to have their accounts of the past made official (Graham, 2003).

Significantly, the TRC did not distinguish between factual truth and psychological or personal truth but rather sought to provide those affected with a sense of agency in terms of their ability to recount events as they had been experienced (Moon, 2006). By challenging the powerful conspiracy of silence which had dominated South Africa's past, the TRC hearings represented deeply political acts which resisted the dominant powers by documenting and publicising abuses of human rights (Graham, 2003). This represented a restoration of narrative in the South African context, and through this process individuals were given the opportunity to reinvent themselves (Ndebele, 1998).

Many of the experiences which individuals recounted during the TRC hearings were plagued by paradoxes that eluded all attempts at representation, highlighting the fragmented experience of the trauma survivors (Graham, 2003). Caruth (1995, p.5-6) states that this "unspeakability of trauma" constituted a "pathology of history" and a "crisis of the truth". Through the process of telling and retelling of traumatic experiences, new types of narrative and new ways of dealing with questions of agency emerged (Graham, 2003). However, similar to the need for listeners to hear positive stories expressed by Frank (1995) and Hinckley (2006), the trauma narratives that emerged during the TRC hearings were not culturally acceptable in either form or content and thus do not seem to have been readily applied in other settings.

Based on the above, narrative inquiry and the act of storytelling have played a significant role in South Africa's history. However, despite the progress that has been made in acknowledging the atrocities of the past and in attempting to provide all citizens with equal opportunities for their voices to be heard, many people continue to exist on the margins of society, silenced by the effects of poverty, disempowerment, poor education, and illness and disability. This relates to Frank's (1995) description of how ill people are not only wounded in body, but also in voice, and describes how they need to become storytellers in order to recover the voices that marginalisation and disempowerment take away. This, however requires firstly the opportunity to tell their stories, and secondly, the risk of opening themselves to the vulnerability and trauma of reliving the violations of the past.

4.8 SUMMARY AND CONCLUSION OF CHAPTER 4

Chapter 4 has provided an overview of narrative inquiry as a means for studying lived experience. A number of limitations exist in adopting an interpretivist approach, including challenges with generalisability and causal effects (Polkinghorne, 2007) which are often relied on in policy documents and position statements. However, this method is believed to have particular value for the current study, given the notion that we live 'storied lives' (Schafer, 1992) and that we tell stories in order to make sense of our life experiences (McAdams, 1993). In so doing, experiences are endowed with meaning and are reconstructed by applying temporal and spatial boundaries in an attempt to transform fragmented episodic

events into a coherent whole. By providing individuals with an opportunity to talk about their embodied experiences implies providing a sense of voice (Riessman, 2008). This has the potential to be a particularly powerful tool when used with populations who have previously been denied the opportunity to tell their stories (Riessman, 2008).

The act of locating oneself within an intelligible story is believed to be imperative to our sense that life is meaningful (Hinckley, 2006; Shadden, 2006; Riessman, 2008). Goffman (1974) states that through the construction of coherent stories we are able to make sense of our life experiences. Narrative has thus been described as a way of representing lived experiences in a coherent and meaningful way (Traugott & Pratt, 1980). Based on this, the underlying assumption is that stories are expected to have some sort of point or conclusion (Levstik, 1995). Geertz (1983, p.87) suggests that human thought is a "collective product, culturally coded and historically constructed" and thus narrative can be used as a means of representing cultural forms. This notion is shared by White (1984, p.6) who suggests that narrative is a means for transmitting cultural messages about a shared reality, and in this way is able to transform 'knowing' into 'telling'. In this way, narrative has the potential to shape events and lives by embedding them culturally and contextually (Levstik, 1995).

Mattingly (1994) suggests that narrative inquiry may be a particularly useful intervention in situations where the narrators themselves seem lost, where the narrator's voice is muted or conflicts with competing narratives, or where the purpose underlying their actions is unclear. However, despite growing literature in this field, a paucity of information exists locally on the lived and embodied experiences of persons who by nature of poverty, limited access to education, illness and disability, and cultural and linguistic barriers have been denied the opportunity to tell their stories. Thus, despite the evidence that narrative inquiry represents a potentially powerful and ecologically valid tool, limited literature exists on the challenges and solutions to negotiating narrative construction cross-culturally and cross-linguistically. This has specific relevance to the construction of culturally acceptable plots, themes and characters, and temporal norms, and has implications for our understanding of the ways in which people with disabilities use narrative as a way of making sense of their lived experiences.

The challenges described above are in part as a result of the methods of elicitation and analysis applied in understanding the ways in which individuals recount their lived experiences. While the pluralistic and flexible nature of narrative inquiry challenges the more rigid and absolute frameworks of enquiry that were used in the past (Riessman, 2004), it is important to consider that the ways in which narratives are elicited has the potential to fundamentally alter the content and structure of the story. The use of structured or semi-structured formats limits the content of the narrative to themes which in some way are predetermined by the researcher (e.g. Stewart, Swartz & Ward, 2012; Stoebenou et al, 2011; Surender et al, 2010; and Stein, Lewin & Fairall, 2007), and in this way, limits insight into the impact that certain experiences and events have on the individual.

Similarly, the methods of analysis used to make sense of results may also significantly impact on the emergent findings. While the placement of characters and events, as well as the spatial and temporal boundaries are proven to be fundamental to understanding how people make sense of their lived experiences, few studies, particularly in the fields of healthcare and disability have focussed on the impact of spatial and temporal dimensions of narrative construction. For example Mattingly (1994), Frank (1995), McAdams (1993; 2001); Hinckley (2006) and Ulatowska et al (2011) have all used narrative as a means to explore the presentational features of illness and disability and its effect on the individual, yet the focus of these studies has been on the emergent content as opposed to the effects that the temporal and spatial dimensions of narrative construction have on the development of a plot. Though not without some value, this type of data presents with numerous limitations, making it inadequate as a basis for the development or evaluation of policies and programmes. Furthermore, these methods of elicitation and analysis have the potential to perpetuate traditional biomedical approaches to illness and disability by providing only partial understandings of appropriate management with diverse caseloads. This is particularly relevant in instances where the experience of disability is entangled in a complex web of social and cultural constructs and structures, and highlights the need to explore the relationship between content and temporality in order to develop an understanding of how these aspects relate to each other and their consequent impact on the development of a plot.

Based on the above, in the following chapters I will demonstrate the applicability of narrative inquiry as a tool for providing voice and consequently for cross-culturally and cross-linguistically exploring the lived experience of disability among people living in a rural area. In so doing I shall attempt to reveal how the act of telling stories of lived experience has the potential to reveal not only the impact of bodily changes, but also the influence of personal and social interpretations of experience, the role of institutional structures and government policies and practices, and the impact that cultural beliefs and practices have on the construction of a coherent and meaningful narrative.

CHAPTER 5

METHODOLOGY

"Everyone has a story to tell which shapes and defines who they are or how they came to be who they are."

Wingard & Lester (2001)



Road leading to a participant's home

5.1 RESEARCH QUESTION, AIM AND OBJECTIVES

5.1.1 Research Questions

- How do context and culture affect the everyday life experiences of adults living with disabilities in a rural South African community?
- How do people with disabilities make sense out of their lived experiences and how are these articulated through narrative construction?

5.1.2 Research Aim

To use narrative inquiry as a means to explore the aspects which shape and define lived experience among adults with disabilities living in a rural area.

5.1.3 Research Objectives

- To identify the persons and events that define lived experience among adults with disabilities in a rural community.
- To explore the most prominent psychosocial aspects of disability which define lived experience.
- To identify unique and recurring themes within the narratives of adults with disabilities in order to provide a comprehensive understanding of the socio-cultural processes associated with disability in a rural area.
- To recognize the dominant aspects of context and culture that shape individuals' interpretations of disability as reflected in their narratives.
- To identify barriers to effective policy implementation amongst marginalised groups within a rural area.
- To develop a theoretical understanding of the psychosocial and socio-cultural aspects of disability through the use of culturally appropriate techniques.

5.2 RESEARCH DESIGN

The design of this study comprised of a combination of both 'basic research' and 'applied research' (Patton, 2002) in that I aimed to contribute to fundamental knowledge and theory, as well as illuminate a societal concern. Thus, this study employed both an interpretivist and inductive approach using qualitative methods in order to develop a holistic understanding of the experience of living with a disability in a rural area. Gray (2009) defines the interpretivist approach as a "philosophical position which is concerned with understanding the way that we, as humans make sense of the world around us" (p.156). This was complemented by an inductive approach (Gray, 2009, p.167-173) in order to help the researcher gain an understanding of the meanings that humans attach to events. A core concept of inductive research is that it provides the researcher with the flexibility to modify the research design as data are collected (Smith, Becker & Cheater, 2011). In this way, the methods of data collection and analysis are directed by the data, ensuring accurate and credible representation (Smith, Becker & Cheater, 2011).

Based on the above, a flexible design (Flick, 2009) underpinned by narrative inquiry and participant observation was used in order to develop an understanding of the socio-cultural constructs associated with disability. Given the depth and detail offered by qualitative approaches, the combination of narrative inquiry and naturalistic observation were viewed as appropriate tools to address the complexities associated with living with a disability in a rural area. Given that the qualitative paradigm is suitable for exploring the social inequalities underlying health conditions (Smith, Becker & Cheater, 2011) and for guiding the appropriate development of health and social welfare policy (Swift & Tischler, 2010), these methods were used in order to place an emphasis on understanding individuals' life experiences by closely examining their words and actions (Crowe, Cresswell, Robertson, Huby, Avery & Sheikh, 2011).

5.3 ACCESS TO SETTING AND PARTICIPANTS

Over the period 1 January – 31 December 2003, I was employed at Tonga Hospital as a Community Service Speech-Language Therapist and Audiologist. My job description included providing an in- and out- patient speech and hearing therapy service at the hospital, at outreach clinics in the surrounding area, and doing home visits for patients who were unable to access the clinics or hospital. This enabled a first-hand experience of the community, its culture, belief systems, and practices, and exposed me to many of the frustrations that the local community face, including lack of provision of municipal services, poor conditions of the roads and limited access between the hospital and many of the homes in the community, as well as the frustration of travelling long distances in order to acquire basic products. Considerable time was spent with the local leaders and elders in order to gain access to the community and in order to develop an understanding of the needs of the community so as to deliver a basic rehabilitation service. This experience provided a degree of understanding of the way of life within the community, the beliefs and cultural practices, as well as the support structures and roles of various members of the community.

In 2006 and 2007 I returned to Tonga in order to gather material for my Masters Degree on caregivers' experiences of parenting children with cerebral palsy. This study relied on qualitative methods, including semi-structured interviews and participant observation, and enabled a profoundly powerful snapshot of the link between disability and daily life, the interface between historical, social and demographic factors, and the relationship between the individual and the community (Barratt & Penn, 2009). Consequently a number of issues were highlighted that required further investigation, in order to develop a better understanding of the lived experience of disability and the needs of people with disabilities in rural areas. These issues formed the rationale for the current study.

5.4 SAMPLE SIZE AND SAMPLING STRATEGY

Participants were sampled from within 12 villages in the Nkomazi East Municipality using snowball sampling. Snowball sampling is an approach for locating information-rich informants by asking members of the community who they recommend the researcher should speak to (Patton, 2002). Although these informants were considered to be 'information rich', they were not unusual in their community involvement or experiences. This sampling

approach was implemented by initially interviewing individuals through the recommendations of the research mediator, with subsequent interviews being based on the recommendations of participants who had already participated in the interviews, as well as through the recommendations of other community members and contacts that I made through my interactions with the community.

Consistent with the nature of qualitative research, specifically narrative inquiry, the sample size was limited (Riessman, 2008), but not determined prior to the onset of data collection. Over the period of data collection, 30 participants were interviewed. After the initial data collection visit, interviews had been transcribed and translated into English, I began data analysis, which guided further data collection at subsequent visits. This allowed for data to be collected until such time as saturation was reached in terms of the emergence of new information and themes (Leininger, 1994; Patton, 2002).

5.5 PARTICIPANTS

Participants included adults living in rural villages in the Nkomazi East Municipality. Participants fulfilled the following criteria:

- All participants were over the age of 18 years. Persons under the age of 18 years are considered minors and are unable to give informed consent, and were therefore excluded from the study.
- Although participants with a variety of psychiatric, cognitive and linguistic disabilities were included in the sample, all participants had the ability to produce a personal narrative and were capable of providing informed consent (as discussed in section 5.7). This was measured by their ability to engage in and maintain a conversation of mutual interest with a conversational partner.

No measures were put in place to control for factors such as length of time since onset of disability, cause of disability, and gender. No additional criteria were set regarding type/nature of disability. Table 4 provides a description of the demographics of participants.

Table 4: Demographics of Participants with regard to Age, Gender, Nature of Disability and Access to Basic Service Provision

P. No	Age	M/ F	Type of Disability	Description of Disability	Length of time since onset of disability	Disability grant recipient	Distance of home from tar road	Water Provision	Electricity Provision
1	50 years	M	Physical	Paralysis of lower limbs and bedridden since the age of 10 years as a result of an infection	40 years	Yes	10km	2km away from home	No
2	45 years	M	Visual	Progressive degeneration of vision from the age of two years	Since birth	Yes	8km	1.5km away from home	No
3	53 years	F	Physical	Paraplegia secondary to being stabbed in the back repeatedly in Mozambique	25years	Yes	4km	1km away from home; water reservoir on property	Yes
4	29 years	M	Physical, Cognitive, & Communicative	Head injury secondary to assault after receiving wages on a farm near Komatipoort	4 years	Yes	6km	2km away from home	No
5	54 years	F	Physical Cognitive Communication (also has a 13 year old daughter with a physical, cognitive, and communicative disability)	Left cerebro-vascular accident resulting in hemiparesis and word finding and memory problems. Able to walk with pronounced limp	Unknown	Yes	7km	3km	No
6	33 years	F	Physical	Right cerebro-vascular accident resulting in left-sided hemiparesis. Able to walk with a mild limp	3 years	No	1km	Yes	Yes
7	35 years	F	Psychiatric	Psychiatric impairment since childhood	Unknown	Yes	On tar road	1km	No
8	30 years	F	Cognitive	Cognitive impairment secondary to epilepsy	23 years	No	500m	Yes	Yes
9	52 years	M	Physical	Bilateral amputation of lower limbs secondary to mining accident	19 years	No	4km	1km	No
10	38 years	F	Physical and cognitive	Right cerebro-vascular accident resulting in participant being confined to a wheelchair. Subtle cognitive impairment	3 years	Yes	5km	3km from home, water reservoir on property	Yes
11	40 years	F	Physical	Paraplegia as a result of gunshot injury during a political protest resulting in participant being confined to a wheelchair	23 years	Yes	4km	100m away, on neighbour's property	Yes
12	36 years	M	Physical	Right leg amputated post motor vehicle accident. Walks with crutches	15 years	Yes	5km	7km from home (at Nkomazi river)	Yes (illegal connection)
13	30	M	Physical and	Right leg amputated (has prosthetic leg) and	1 year	No	5km	7km from	Yes

	years		Communicative	tracheostomy post motor vehicle accident.				home (at Nkomazi river)	
14	38 years	M	Physical and Communicative	Congenital impairment resulting in hemiparesis and articulation impairment	Since birth	No	1km	Yes	Yes
15	47 years	M	Physical and Communicative	Left cerebrovascular accident resulting in speech and language impairment and participant confined to wheelchair	5 months	No	3km	2km from home, water reservoir on property	Yes
16	81 years	F	Physical	Clinical it appears that participant has Parkinson's disease and osteoporosis	Progressive over the last 10 years	Old age pension	4km	Yes	Yes
17	27 years	M	Physical	Paraplegia secondary to gunshot injury during a hijacking. Participant confined to a wheelchair	7 years	Yes	1km	Yes	Yes
18	19 years	M	Physical and Communicative	Athetoid cerebral palsy resulting in spastic dysarthria and participant confined to wheelchair	Since birth	Yes	2km	1km	No
19	45 years	F	Psychiatric and Communicative	Communication impairment secondary to psychiatric illness. Mother of two young boys with muscular dystrophy and confined to wheelchairs	Unknown	Yes	1km	3km	No
20	28 years	M	Physical	Congenital foot abnormality. Participant able to walk without assistance but has a pronounced limp.	Since birth	Yes	8km	Yes	No
21	28 years	M	Physical	Congenital bilateral lower limb abnormality. Participant walks with crutches.	Since birth	Yes	8km	300m	Yes
22	54 years	M	Physical	Bilateral deformity of both lower legs and feet as a result of a mining accident	9 years	Yes	2km	Yes	No
23	39 years	M	Physical	Physical congenital deformity of right leg.	Since birth	No	3km	Yes	Yes
24	57 years	F	Physical	Physical disability as a result of illness	50 years	Yes	500m	Yes	No
25	28 years	F	Physical	Congenital absence of upper and lower limbs	Since birth	Yes	4km	1km	No
26	42 years	M	Physical and Visual	Completely blind and right leg amputated secondary to a landmine explosion in Mozambique	27 years	No	1km	200m	No
27	49 years	F	Visual	Completely blind as a result of illness	2 years	Yes	2km	500m	Yes
28	50 years	F	Physical	Right leg amputated secondary to cancer	Unknown (after birth of 3rd child)	Yes	500m	Yes	Yes
29	83 years	F	Physical and Communication	Language impairment and paraplegia as a result of a cerebrovascular accident	4 years	Yes	4km	Yes	No
30	44 years	F	Physical	Paraplegia as a result of polio at the age of 8 years	36 years	Yes	1.5km	Yes	Yes

Based on the information in Table 4, it can be seen that the sample comprised of 30 participants (15 male and 15 female, with ages ranging from 19 to 83 years). Seven of the participants had congenital disabilities, while 23 had acquired disabilities, ranging from five months to 43 years from time of onset. Twenty-two of the participants were receiving disability grants, while eight were not. Of the eight participants who were not receiving disability grants, one was receiving an old-age pension. Only one participant's home was located on a tar road, while the other remaining 29 participants lived between 100m and 10km off the tar road. Twelve participants had a tap with running water on their property, while the remaining 18 participants walked distances of between 100 metres and 8km to collect water. Of those participants who did not have water supplied to their properties, three had water reservoirs on their property for collecting rain water. Sixteen out of the thirty participants had electricity provided to their homes, while only seven had both water and electricity provided to their homes. As described in Table 4, the sample was heterogenous in nature, and many of the participants' identities traversed the intersections of disability, race, class and gender, impacting on the way in which they were positioned within their communities and the ways in which they positioned themselves within their narratives. While the diversity of the sample created significant challenges in managing the learning from such diversity, it was also considered to be a strength of the study in that input was obtained from individuals who are frequently excluded from research (i.e. those with cognitive, communicative and psychiatric disabilities), reflecting the experiences of persons with disabilities as a group.

Based on the demographics presented above, the participants' living conditions are consistent with those described in section 2.5.5 of the literature review, highlighting the lack of service provision in the Nkomazi East Municipality. Given the lack of service provision, the challenges associated with access to information, education and healthcare, as well as the lack of consistency associated with the provision of disability grants, highlights the relationship between poverty and disability. These challenges are known to have a negative impact on health status, psychological well-being, food security and personal safety (Lustig & Strauser, 2007), and consequently affect the individual's ability to make independent choices (Loeb et al, 2008) resulting in a sense of disempowerment (Whyte & Ingstad, 1995). The combination of these effects is believed to weaken the individual's sense of coherence in

terms of their ability to make sense of their experiences, thus rendering the environment unpredictable and meaningless (Lustig & Strauser, 2007).

5.6 WORKING IN A CROSS-LINGUISTICALLY AND CROSS-CULTURALLY

Considering the nature of this study, and the context where it took place, it is impossible to ignore the challenges imposed by cultural and linguistic barriers. While it is preferable for research to be conducted by a first-language speaker (Squires, 2008), this is not always practical. Furthermore, Temple and Young (2004) caution against the avoidance of cross-linguistic research, since this would result in narrowing the research field and continue to disadvantage previously neglected cultural-linguistic groups. This is supported by Squires (2008) who stresses that linguistic barriers should not inhibit the development of knowledge in the arenas of health and culture.

Taking the above into account, yet acknowledging the fact that data are likely to be richer when collected in the participant's first language (Squires, 2008; Bessareb & Ng'andu, 2010), the decision was made to employ a research mediator in order collect the narratives and negotiate the nuances underlying the participants' choice of words. The term 'research mediator' was chosen above the term 'research assistant' given the fact that the research mediator was able to put me into contact with a variety of contextual issues that I would not otherwise have been able to engage in (Angrosino & Rosenberg, 2011). Given the fact that I only possess a basic command of SiSwati, I heeded Temple and Young's (2004) warning that language does not only serve to transfer meaning, but contributes to the co-construction of meaning. Furthermore, given that the nature of this research was culturally and socially grounded, and that the stories which people consider most expressive of their lives often remain told within that community only (Frank, 2012), the research mediator also served as a cultural broker, negotiating between linguistic, cultural and contextual barriers.

The research mediator for this study was the Community-Based Rehabilitation Worker (CBRW) who is a local woman confined to a wheelchair. During the time that I worked at Tonga Hospital, the CBRW and I worked closely together and formed a trusting friendship. Furthermore, during my Masters study, the CBRW was employed as a research mediator.

Thus, our long-lasting relationship, together with the CBRW's relationship with the community and her previous experience in qualitative research made her an obvious choice as a research mediator for the current study.

While limitations exist in working with a mediator who is employed in the rehabilitation sector, given its relationship to western medicine, it was still felt that the CBRW was an appropriate mediator, for the following reasons:

- The mediator is a local woman who shares a common language and culture with the members of the community. In addition, she is a disabled woman, confined to a wheelchair as a result of an acquired disability. She therefore has an intimate understanding of disability and the challenges it poses in a rural area.
- The mediator and I already had an established relationship based on mutual trust and respect which developed when we worked together and was strengthened during the previous study in which the CBRW also took on the role of mediator.
- The mediator has a vested interest in disability and improving the lives of persons living with disabilities.
- The mediator has received formal training on disability and counselling, provided by the Mpumalanga Department of Health, DPSA and the Department of Community-Based Rehabilitation.
- The mediator has earned a position of trust and respect within the community through her continuous involvement in community upliftment.

Based on the above, the mediator took on the following role:

- Acting as a cultural and linguistic broker
- Identifying possible participants within the community
- Accompanying me to the homes of the participants
- Conducting narrative interviews with the participants
- Providing insight and contextual information into my interpretation of observed events and narrative interviews
- Reflecting on her experiences and responses to both the elicitation and content of the narratives and discussing these in relation to my reflections.

The research mediator was reimbursed for her time on a daily basis, based on the University of the Witwatersrand guidelines for paying research assistants. Furthermore, the mediator was required to sign an agreement with me prior to the onset of training and data collection (appendices 4 and 5).

5.6.1 Training of Research Mediator

Attention was paid to the fact that the elicitation of narratives involves specific training and skills. Although the research mediator had already received some training in conducting narrative interviews during the data collection for my Masters Degree, additional training and opportunities to elicit narratives were provided prior to the onset of data collection. Intensive training took place between Monday 12 October and Wednesday 14 October 2009. Important aspects of eliciting information using narrative interviews were recapped at subsequent visits. Training took place as follows:

- During the initial visit the rationale, nature, and proposed methodology of the research was discussed. Feedback was obtained from the mediator in terms of the need for this type of research within the community, the appropriateness of the proposed methodology, culturally acceptable terminology, and personal accounts based on the mediator's engagement with the community that may have impacted on the study, including timing of interviews, locations where interviews would take place, and number of times that each participant would be interviewed. Particular attention was paid to ethical issues, including confidentiality of information obtained during interviews, sourcing participants in such a way that they would not feel obliged to participate, obtaining true informed consent, and ensuring the ethical principles of non-maleficence and autonomy for participants who agreed to take part in the study. The mediator also provided input in terms of what types of tokens of appreciation were considered appropriate within the community.
- Thereafter, a discussion of potential participants who would be appropriate to contact took place. An effort was made to include participants of both genders, with a range of ages and disabilities. A draft timetable was put together so that the mediator could arrange for days and times when potential participants could be visited. The principles underlying narrative interviews were

discussed in detail, as well as the type of information that narrative interviews are able to yield in comparison to other types of interviews. This was demonstrated to the mediator in a simulated interview where I posed the same question to her using both a narrative and a semi-structured interview format, and highlighted the differences in the type of information yielded using the two different approaches. I then discussed the single question to be posed to participants, and highlighted some of the aspects that the mediator could expand on if they were to come up during the course of the interview (appendix 2).

- Subsequently, the research mediator and I set up a mock interview, where I interviewed the mediator using the proposed format. Thereafter the mediator interviewed me, while I took on the role of both a person who was forthcoming with information, as well as a person who was reserved so that the mediator had the opportunity to negotiate a narrative interview with both types of participants. These interviews were video-recorded, after which the research mediator and I watched and analysed them, identifying features of good interviewing skills as well as poor interviewing skills, as well interactional patterns that were conducive to obtaining information as well as those that were not. The notion of self-review appeared to work well, and the research mediator responded well to this method of preparation.
- Finally the research mediator had an opportunity to approach someone of her choice in the community and conduct a narrative interview with them. This 'participant' was informed of the purpose of the interview and was given the option to decline. The individual was informed that the purpose was purely for training and their interviews would not be listened to by anyone other than the research mediator and the researcher. For purposes of confidentiality, this interview was not recorded. After the interview, the research mediator once again conducted a self-review on the outcome of the interview, and was given the opportunity to provide input on the aspects that had gone well, as well as those they would go back and change, and how this would impact on the interviews she would conduct in future, specifically in relation to the study.

5.7 ETHICS

Permission to conduct this study was granted unconditionally through the University of the Witwatersrand Non-Medical Ethics Committee (protocol number H090612) (appendix 1).

This research was guided from an ethical point of view by the World Medical Association Declaration of Helsinki (2008), The South African Constitution Bill of Rights (1996), and the Medical Research Council (MRC) of South Africa's Guidelines on Ethics for Medical Research, as well as by taking into account local and international literature on the complexities associated with ethical research among vulnerable populations (e.g. Luck & Rose, 2007; Penn, Frankel, Watermeyer, & Müller, 2009; Marshall & Rossman, 2011). These documents were used in order to shape the processes and decisions made during the research process, as discussed below:

5.7.1 The Responsibilities of the Researcher

As researcher, I took full responsibility for the participants' safety and emotional well-being during the period of data collection as recommended by the MRC (2003). In this way I attempted to uphold the principles of non-maleficence and autonomy by protecting the participants' rights to "health, dignity, integrity, self-determination, privacy, and confidentiality of personal information" (World Medical Association Declaration of Helsinki, 2008, p.2).

Cognisance was taken of the fact that the participants' narratives were of a very personal nature and relied on their individual subjective experiences. For this reason, I took into account the possibility that through the process of eliciting narratives, an emotional reaction may be evoked. Contact was made with the social worker at the local hospital (appendix 10) and a referral system was set up. Although the narratives often contained recounts of traumatic experiences, none of the participants responded in such a way that warranted post interview counselling. However, all participants were followed up by me and the research mediator a minimum of once after the interviews. A number of participants commented that although their stories were *"painful"* they *"felt free"* after telling them. This highlights the potentially cathartic nature of narrative research (Kannai, 2012).

5.7.2 Researching Vulnerable Populations

The Medical Research Council of South Africa (2003) defines vulnerable populations as persons who are at risk for being taken advantage of or harmed during the research process. This definition is expanded on by MacLachlan et al (2012) who state that vulnerable populations include those who have limited resources and are consequently at high risk for morbidity and premature mortality, including those who are marginalised as a result of disability, ethnicity, gender, age, class, caste, socio-economic status, religion, sexual orientation, geographical location, and immigrant/refugee status, among others. In this study, the participants were viewed as a vulnerable population as a result of their disabilities, their dependency on others, their socio-economic status, and their limited understanding regarding their rights in participating in research. As a result they were considered to be at risk for being coerced into participating in the research project.

The MRC (2003) and the World Medical Association Declaration of Helsinki (2008) strongly suggest that measures be put in place in order to protect participants from physical, social or mental harm, and to ensure true voluntary participation, ensuring that non-maleficence and autonomy are upheld as principles of paramount importance. Therefore, where participants were known to have cognitive-linguistic or psychiatric impairments, adaptations were made to the process of informed consent in line with the recommendations provided by Penn et al (2009). This included a detailed verbal explanation by the research mediator in the participants' home language, augmented by the principles of supported conversation, repetition of significant points, the adaptation of questioning styles whereby closed-ended questions were posed, and by requesting recall and feedback from the participant on the nature of the study and what their involvement would entail. In addition, permission to include participants with cognitive-linguistic and psychiatric impairments was obtained from family members and caregivers, in addition to obtaining consent from the participants themselves, in order to protect them from potential violation during the research process (appendices 15, 16 and 17). In this way, a shared decision making process was implemented to obtain informed consent by engaging with the individual, the family and where necessary, members of the community.

Marshall and Rossman (2011, p.113) suggest that gestures of reciprocity and the provision of feedback to the study population should serve as measures to enact beneficence. These authors define reciprocity as the act of presenting participants with a token of appreciation for participating in research projects. However, researchers are cautioned against using this as a form of coercing vulnerable participants to participate (Marshall & Rossman, 2011, p.113-115). For this reason, participants were not paid for their participation in the study as this would have constituted coercion, especially given their socioeconomic vulnerability. Instead, at each visit to the participant's homes, biscuits and two litres of cold drink were taken as a token of appreciation. Furthermore, food parcels and clothing parcels were donated to the hospital, churches and the CBRW to distribute to participants who were destitute.

5.7.3 Voluntary and Informed Consent

Voluntary consent is based on the principle of allowing participants the autonomy to freely decide if they want to participate in a study (Marshall & Rossman, 2011; MRC, 2003), and to the end of distributive justice, all persons meeting the inclusion criteria for the study should be given equal opportunities to participate in research (MRC, 2003). However, measures for obtaining voluntary consent need to take into account the potential participants' social, family and cultural environment into account (MRC, 2003). In the afro-centric tradition, this often implies communal decision-making by involving the family members and significant others into the decision-making process. However, the ultimate decision to participate should still lie with the individual (MRC, 2003). Furthermore, Marshall and Rossman (2011, p.120) state that in order to ensure the comprehensive upholding of ethical principles, consent should not only be voluntary, but that participants need to be provided with detailed knowledge as to what participation entails. This should include the aims and methods of the study, the possible risks and benefits of participation, and the demands that the research will place on the participant (MRC, 2003).

Prior to the first site visit, signed consent to conduct the study was obtained from Ms Emily Ntuli, Director of the Mpumalanga branch of Disabled People of South African (appendices 6 and 7), Ms Mamsy Mashele, coordinator of Mpumalanga Community-Based Rehabilitation Services (appendices 8 and 9), as well as from Ms Lindiwe Thobela to act as research mediator in the study (appendices 4 and 5). Special attention to issues surrounding

confidentiality of data are reflected in both the information letter for the research mediator and the contract. This was reinforced verbally prior to all data collection sessions. In addition, during the first site visit, and prior to recruiting participants, local leaders within the community were approached in order to explain the nature of the study, and verbal assent was granted (appendices 18 and 19).

During the period when participants were recruited, a number of strategies were implemented in order to ensure that the principles of voluntary and informed consent were upheld. All participants were provided with information letters and consent forms explaining the study, and inviting them to participate (appendices 12, 13 and 14). Information letters and consent forms were also made available in SiSwati for participants who were literate. Two consent forms were provided. The information letter and first consent form (appendices 12 and 13) served as an agreement between the participant and the researcher to participate in the research, as an acknowledgement that the participant understood the nature of the study and what their role in the research entailed. The second consent form allowed the participants to provide the researcher with permission to audio-record the interviews (appendix 14).

The MRC (2003) suggests that consent may only be provided by individuals who are legally and factually capable of doing so, in the absence of illness of cognitive impairment. Given the nature of the current study, it was acknowledged that by virtue of their disabilities and limited access to formal education, many of the participants were unable to read and fully comprehend the information letters. Furthermore, some were unable to provide a signature as a symbol of informed consent. The MRC (2003), does, however, suggest that verbal consent is acceptable (and in terms of protecting participants' privacy may be considered preferable) provided that consent be formally documented and witnessed (World Medical Association Declaration of Helsinki, 2008). In seven instances participants were unable or unwilling to provide a signature or a thumb print as a symbol of informed consent, yet insisted that they wanted to participate. In these cases, the research mediator discussed each point on the information letter and consent forms and requested that participants summarise the main points in order to gauge their understanding. In addition, information was presented using a variety of modalities, including written and spoken language, and supported conversation (Penn et al, 2009), and questioning styles were modified in order to ensure understanding of

the content of the information letter (Luck & Rose, 2007; Penn et al, 2009). Participants were given time to think about whether they wanted to participate in the study or not, and were contacted two to three days after being provided with information relating to the study, in order to find out if they were willing to participate. Where participants did indicate their willingness to participate, a follow-up appointment was scheduled in order to conduct the initial interview. However, prior to conducting the interview, participants were asked to recount the purpose of the interview and to once again indicate their willingness to participate. In addition, the information sheet was reviewed at each visit prior to data collection.

The MRC (2003) cautions that particular attention should be paid to ensuring the validity of voluntary consent when potential participants are drawn from vulnerable populations since they may feel coerced to participate for the reasons described above. The MRC (2003) suggests that in order to ensure voluntary participation, participants should be reassured that they will not suffer any adverse consequences should they choose not to participate. Furthermore, potential participants need to be reassured that they are free to withdraw from the study at any time without suffering any negative consequences. In order to ensure this, participants were informed they were welcome to turn the audio-recorder off at any point during the interview, and should they wish to withdraw from the study at any point, they were free to do so without any negative consequences. However, no participants withdrew from the study, and almost a quarter of participants approached the researcher, wanting to participate in the study.

5.7.4 Protecting the Participants' Rights to Privacy

Maintaining a culture of confidentiality and implementing precautions to ensure the anonymity of data are paramount to the protection of participants' privacy (Marshall & Rossman, 2011; MRC, 2003). In this way, ensuring confidentiality of information requires that all personal and potentially sensitive material be adequately guarded against public scrutiny (Marshall & Rossman, 2011, p.141).

In accordance with these recommendations, all consent forms ensured confidentiality of the personal details of the participants and their families. Only the researcher and the research mediator had access to identifying details. The translators had access to the participants' names and any personal information that they disclosed during the interview, yet other identifying material such as the participants' addresses and contact details were withheld from the translators. All identifying details were omitted from the raw data post data collection, and these were not shared with the research assistant who was involved in determining trustworthiness of findings. Direct quotes have been used in the reporting of findings in order to highlight specific aspects of living with a disability in a rural area, however, all identifying details have been omitted. All data were stored on my computer and backed up on an external hard drive, both of which were password protected.

5.8 METHODS OF DATA COLLECTION

In order to establish a valid understanding of the individual experiences of living with a disability, a triangulation of methods was employed (Patton, 2002; Crowe et al, 2011), including narrative interviews, participant observation and researcher and research mediator reflections. These are discussed in detail below:

5.8.1 Narrative Inquiry

Given that conversation is a natural form of engagement and that it is considered a familiar and culturally safe tool among most populations (Bessareb & Ng'andu, 2010), an oral narrative approach was thought to be the most ecologically valid tool for investigating the lived experiences of adults with disabilities. This is significant since Smith (1999) claims that historically, indigenous people have been over-researched with little attention paid to whether the methods of engagement are culturally safe or appropriate. Bessareb and Ng'andu (2010) suggest using yarning as a culturally acceptable tool for engaging a variety of indigenous people in research. Yarning is similar to narrative inquiry in that it takes the form of an informal and relaxed discussion through which both the researcher and participant "journey together visiting places and topics of interest relevant to the research study" (Bessareb & Ng'andu, 2010, p.40). Given that the principles underlying yarning are the same as those underlying narrative inquiry (Bessareb & Ng'andu, 2010), for the purpose of this study, the methodological tool used is referred to as 'narrative inquiry'.

The narrative approach was used to define how, why and in what way the individual was affected by the disability. Penn (2000) states that the study of narrative offers a possibility of developing an understanding that cannot be arrived at by any other means, since it connects the listener and the teller in a unique exchange which transcends the barriers of culture. This approach calls for attention to be paid to the cultural influences that impact on daily life and ultimately necessitates an acknowledgement of the cultural and psychosocial issues that impact on individuals' perceptions and emotional reactions to life events. In this way, narratives support the individual's interpretation of the self and support the link between mind and body (Bell, 2002; Mpofu et al, 2011).

Implicit in narrative inquiry is the focus on the spatial and temporal dimensions of human self-understanding (Charmaz, 1991; Mattingly, 1994; Clandinin & Connely, 2000; Riessman, 2008; Holstein & Gubrium, 2012). For this reason, the temporal and spatial positioning of characters within the narrative was explored in order to develop an understanding of how the experience of living with a disability shapes the individuals' narratives. This implied a focus on the interplay between the way in which individuals with disabilities interpreted their experiences and the way in which they believed that others perceived and responded to them, highlighting the interplay between personal and social interpretations of experience (Clandinin & Connelly, 2000).

Through the use of narrative inquiry, participants engaged in conversations with the researcher and research mediator about their experiences of living with a disability. The relationship between the participants and the research mediator was pivotal, since the trust that develops during narrative engagements determines which stories are told and which are withheld (Bessareb & Ng'andu, 2010). It is through this relationship that the process of narrative becomes reciprocal and mutual, and as a result, narratives become co-constructed between the researcher and the participant. A rigid geometric structure of questions was not used for fear of overlooking the narrative and thus misinterpreting the individual's personal experience. Instead, a single question (*"Can you tell me your story?"*) was used. Based on the information provided by the participant, Flick's (2009, p.83) approach to "guiding questions" was employed (Appendix 2). By using this approach, I was able to obtain

information relating to everyday life experiences of adults with disabilities, as well as the perceived community responses to disability.

Participants were visited a minimum of twice in naturalistic settings (e.g. at home, and at the stimulation centres) over the period of data collection. At the initial visit, narratives were elicited as far as the participants were able and willing to describe. At follow-up visits the main points from the previous interviews were verified, and significant points made by the participants were probed and followed up on.

5.8.2 Participant Observation

The purpose of observation in this study was to develop an understanding of what daily life is like for people with disabilities living in rural areas. Based on this understanding, observations were conducted in order to establish how the individual interacts with his/her environment and how other people in the environment interact with the person with a disability. This assisted in identifying enabling and disabling factors to participation in everyday life activities. In an attempt to develop this understanding, I took on a position that ranged between passive participation and moderate participation (Spradley, 1980). In this way I attempted to maintain a balance between being an insider and an outsider, and therefore between participation and observation.

Henning, Van Rensburg and Smit (2004, p. 81) explain that the focus of participant observation is to observe "the way of life of an identifiable group of people" in order to see how human life in action happens. The underlying belief is that the astute observer may discover the essentials of human behaviour in a way that cannot be captured through narration. In an attempt to facilitate this understanding I kept field notes, as well as tape recordings, photographs of the setting, and diagrammatic pictures which reflected the social situation. Furthermore, while the research mediator conducted the narrative interviews, I attempted to absorb the events in the field. My familiarity with the context in which the data collection was conducted contributed towards developing an understanding of the actions, actors and events in the field. Having said this, I was cautious to heed the warning given by Henning et al (2004, p. 84) who state that a researcher cannot simply enter a group and hope

to see the world through their eyes. More realistically, I was only able to capture what was available to my observation, with the knowledge that what was observed was impacted on by my existing knowledge and understanding of the semiotics of the field.

5.8.3 Reflections of Researcher and Research Mediator

In an attempt to account for aspects related to researcher and research mediator subjectivity and bias, I kept a reflexive journal to document my own reactions as an outsider to the events in the field. In addition, reflexive conversations were held between me and the research mediator in order to discuss our responses to the events in the field. This served to enhance the quality of the research through its ability to extend my own understanding of how our positions and interests affected all stages of the research process (Crepeau, 1997). Primeau (2003) describes the process of reflexivity as a qualitative research strategy that addresses our subjectivity as researchers related to people and events that we encounter in the field. Through the process of reflexivity, we are able to demonstrate our awareness of our own biographies, assumptions and personal values, and in so doing, provide a context in which our analysis and interpretation of data can be understood. In this way the researcher is able to display multiple levels of consciousness (Crepeau, 1997). My reflexive journal contained a record of experiences, ideas, fears, mistakes, confusions, breakthroughs, and problems that arose during fieldwork, as well as my reactions and responses to informants. Ahern (1999) states that reflexive accounts are valuable since they can be used to make sense of and validate observations and events taking place in the field. This is significant since the nature of qualitative research implies that the researcher becomes an important research instrument and once the researcher starts writing up the study, the journal becomes an important source of data (Spradley, 1980). Thus, keeping an introspective record of fieldwork enables an understanding of personal biases and feelings which ultimately influence the research.

5.9 DATA COLLECTION SCHEDULE

Data were collected over a period of four site visits, spanning a time period of three months. During the site visits, I spent part of the time staying with friends living in the community, as well as in a local bed and breakfast. The site visits were scheduled as described in Table 5:

Table 5: Data Collection Schedule

DATE	PURPOSE OF VISIT
11-17 October 2009	- Training of research mediator - Identification and recruitment of initial participants
15 November – 12 December 2009	- Data collection in the form of initial narrative interviews and participant observation - Ongoing recruitment of participants
11 January – 5 February 2010	- Data collection in the form of initial narrative interviews and participant observation - Follow-up interviews with participants and member-checks
28 March – 3 April 2010	- Follow-up interviews with participants and member-checks - Initial feedback to community stakeholders

5.10 RECORDING AND MANAGEMENT OF DATA

5.10.1 Recording and Management of Narratives

Narratives were recorded using a digital audio-recorder. Following Patton's (2002) recommendation, this was done in order to increase the accuracy of data collected and to allow the interviewer to be fully attentive to the interviewee instead of attempting to produce verbatim transcripts during the interview. In this way an attempt was made to establish a natural conversational environment.

Once narratives had been collected they were transcribed and translated into English to allow for preliminary analysis and to identify points requiring verification, clarification and further probing at subsequent site visits. Particular attention was paid to the challenges associated with the translation of interviews from SiSwati into English, given that the final product represented an inventory of cultural capital (Drennan, Levett & Swartz, 1991) and provided insight into the historical and cultural processes which had contributed to the social constructions of disability within this particular community. Particular attention was paid to issues of power during the translation process, given the unequal power relationship between the participants and the researcher, as well as the political history of English language dominance during the apartheid era (Kilian, Swartz & Joska, 2010). This is of utmost importance, since the relationship between the participant and the researcher has the potential to provide insight into the ways in which power pervades everyday interactions, and may also highlight evidence of resistance to power (Foucault, 1973; Drennan et al, 1991).

The research assistant employed to translate the interviews was a local resident from one of the villages in the Nkomazi Municipality who was a first language SiSwati speaker, had studied English First Language at a Grade 12 level, and had a diploma from an English University. Given that translation is fundamentally an interpersonal process (Drennan et al, 1991), I felt that it was important to work with a translator with whom I had a good relationship and who understood the extent to which I was familiar with linguistic and contextual nuances. Thus I adopted a hermeneutic approach to translation (Drennan et al, 1991). The translator employed was a previous colleague of mine, with whom I had worked while I employed in the area, and with whom I had a longstanding friendship.

Although the translator was required to directly translate interviews from SiSwati into English, it was acknowledged that terms and concepts would arise that could not be translated directly into English. In these situations the translator was required to leave the original wording in the transcripts, but to provide the closest translation or explanation of the phrase so as to maintain the integrity of the participants' message that they were trying to convey. Given the constructionist paradigm, the translator also served as a cultural broker by providing a culturally informed interpretation of the contextual relevance of what was said (Squires, 2008).

While translating the data from SiSwati to English, the data were made vulnerable to the possibility of losing its richness (Drennan et al, 1991; Temple & Young, 2004; Müller, 2007). Given that the preservation of meaning is both an ethical requirement and a reflexive component of qualitative research (Müller, 2007); a number of steps were taken in an attempt to maintain the integrity of the data. This was done, following Müller's (2007) guidelines and involved the following:

- Regular inclusion of the source language (SiSwati) alongside the closest form of translation into the target language (English). This principle was specifically targeted (as demonstrated in the results and discussion chapters) for linguistic constructions that were difficult to translate and for those with particular cultural and linguistic relevance. In addition, the inclusion of SiSwati phrases and concepts served to address the power differential between

English and SiSwati, which has the potential to render the source language invisible (Temple & Young, 2004; Müller, 2007).

- The equivalence of translations was confirmed by an independent translator in order to ensure their trustworthiness. While back-translation has previously been considered to be the gold standard in ensuring trustworthiness of translation (Brislin, 1986), Squires (2008) suggests that this is in line with the positivist notion that translation can be performed objectively, and thus recommends that translations are rather critically reviewed by a suitable individual for conceptual equivalence. A third of the interviews were critically evaluated and compared to the original manuscripts in order to determine accuracy of translation by a first-language SiSwati-speaking Speech and Hearing Therapy student. Consistent with other cross-cultural and cross-linguistic studies conducted in the South African context (e.g. Kilian et al, 2010; Drennan et al, 1991) a few differences in translation were noted, for example, *"bath"* compared to *"clean"*, *"I would have to buy"* compared to *"bought"*, and *"it was paining me"* compared to *"it was so difficult"* or *"my heart was painful"*. This is likely to be due to the fact that there is no direct translation for these terms and thus, when translated, additional or substitute words are added in order to convey the closest and most relevant meaning (Kilian et al, 2010). In this study, however, none of differences detected through the process of critical evaluation and comparison appeared to change the meaning of the narratives. In a few instances, some inaccuracies in translation were noted, but these pertained mainly to the omission of redundant words.
- The limitations of translation are acknowledged in the results and discussion chapters, particularly in relation to the difficulties encountered in drawing conclusions based on translated material, as well as in relation to the lack of literature pertaining to the norms of narrative construction in SiSwati language and culture.

Both translators were reimbursed for their time in accordance with the University of the Witwatersrand's guidelines for paying research assistants. Furthermore, both translators were

required to adhere to the ethical principles outlined in section 5.7, with particular emphasis on maintaining confidentiality of all participants (Squires, 2008).

5.10.2 Recording and Management of Observations

Flick (2009, p.54) refers to field notes as the classic medium of documentation in participant observation since observations become results by their documentation in text. Thus field notes were recorded as recommended by Spradley (1980), Henning et al (2004), and Flick (2009).

Field notes were used to document observations in the field and included information such as where the interviews took place, the persons who were present, and non-verbal cues such as body language and facial expressions, as well as the occurrence of daily actions and events. Condensed accounts were recorded during observations to represent a summarised version of what actually occurred, while expanded accounts were written up directly after the field session to fill in details and recall aspects that were not recorded during the observation (Spradley, 1980, p.67-69). Once the expanded accounts had been written up, observations were analysed thematically (Spradley, 1980).

5.10.3 Recording of Researcher and Research Mediator Reflections

Reflections were recorded by the researcher in the form of a written reflexive journal as recommended by Spradley (1980), Crepeau (1997), Ahern (1999), and Primeau (2003). Given the fact that the research mediator only had a primary school education and was not confident in writing, her reflections were elicited by means of conversation, primarily obtained during journeys to and from participants' homes over the course of data collection. These were audio-recorded and later transcribed for analysis. Reflections were typically elicited by asking the research mediator how she felt after an interview, and what emotions were evoked by the stories which the participants had told. Depending on her responses, these were probed, or discussed in relation to other interviews or observations which had taken place over the course of data collection. Periodically, the research mediator was asked to reflect on interviews conducted thus far and to provide a sense of emergent themes.

5.11 DATA ANALYSIS

Data analysis focussed on the first-hand accounts provided by participants. These were supported by my field notes and reflections as a means to triangulate the findings. Although I acknowledge that narratives by their very nature are co-constructed, I chose not to focus on the role of the interviewer in the construction of the meaning in relation to non-verbal aspects of communication. In the results and discussion chapters, I do, however, refer to some aspects of her role in both the community and in the interviews, and the ways in which this influenced the participants' narratives.

Frank (2000) warns that through the process of narrative analysis, researchers run the risk of misunderstanding the relevance of the story if they attempt to rapidly transform the narrative into a text for analysis. For this reason, I heeded Corbin and Strauss's (2008) recommendation to dwell with the data and to apply a variety of methods in the analysis of findings, including a combination of thematic and narrative analysis (Holstein & Gubrium, 2012; Sparkes & Smith, 2012; Riessman, 2008). In this way, thematic analysis focussed on the content of narratives, while narrative analysis focussed on the ways in which stories were told and the form that they took (Riessman, 2008). According to Holstein and Gubrium (2012) the combination of narrative and thematic analysis is used to document "the whats and hows of narrative production, featuring the way stories and storytelling both reflect and refract the narrative actions and the conditions of narrativity*"* (p.8). The decision to use a combined approach was based on the concern that using a single approach only could be misleading (Riessman, 2008). While thematic analysis allows for a rich description of themes across the data set (Riessman, 2008; Braun & Clarke, 2006), this could lead to ambiguities and ignoring the 'unspoken' (Riessman, 2005).

The notion of 'ignoring the unspoken' during the process of narrative analysis was an important concept, given the numerous disjunctures which emerged within the narratives, as discussed in chapters 6, 7 and 8. Thus, the narrative approach, in combination with thematic analysis was used in an attempt to retain the complexity of personal narratives (Holstein & Gubrium, 2012). Furthermore, by transforming lived experience from the spoken word into a transcribed and translated transcript, meant that the data were altered from a fluid and unbounded form, into a static structure (Riessman, 2001). In this way, linguistic markers,

intonation, and the use of gestures and facial expression to emphasize language were lost. In addition, through the process of translating the data from SiSwati into English, meaning was inherently lost as certain words and cultural concepts were altered when translated into English. Thus, the use of a variety of data collection techniques, and the application of a combined method of analysis served to strengthen the credibility of the findings, and ultimately to provide a window into the way in which space and time are incorporated into both the personal and social aspects of living with a disability in a rural area.

5.11.1 Working within the Qualitative Paradigm

Based on the research question for this study, a qualitative approach was adopted in order to determine how meanings are formed in relation to context and culture (Corbin and Strauss, 2008, p.12) amongst adults with living with disabilities in a rural area. Due to the very nature of qualitative research, as researcher, I was intimately involved with the study from conceptualisation to data collection, and extending to my interpretation of the results. Thus my own background, knowledge, biases, and identity became woven into all aspects of the research process (Guba and Lincoln, 1998, p.124).

Frank (2000, p.160) warns that it is difficult to engage in the analysis of narratives in a systematic way, and suggests a more personal engagement. Thus, as I collected data in the field and compiled field notes and reflections, I began to develop concepts that varied in both significance and abstraction, and used a variety of different methods of analysis to make sense of these findings. Towards the end of the analysis phase, the data were viewed as a collective, instead of as individual case studies in order to theorise about the impact of context and culture on the experience of living with a disability in a rural area.

Data analysis proceeded according to the four cognitive processes described by Morse (1994, p.73-81). These included comprehending, synthesizing, theorising, and re-contextualising the data. Once data had been collected, transcribed, translated, and validated for accuracy of translation, a significant amount of time was spent dwelling on the data, reading and re-reading transcripts, field notes, and research reflections. Corbin and Strauss (2008, p.32-41) stress the importance of sensitivity during the process of being immersed in the data, since

"sensitivity allows the researcher to grasp meaning and respond intellectually and emotionally to what is being said in the data and later to arrive at concepts that are grounded in the data" (p.41). During this period, notes, memos and journal reflections were kept relating to my own thoughts and responses to the data in order to develop analytic thinking which was later used to explore and explain the underlying patterns and processes within the data (Rapley, 2011; Corbin & Strauss, 2008). These were discussed in consultation with other qualitative researchers, including the research supervisor in order to ensure authenticity (Creswell, 2012).

According to Strauss and Corbin (2008, p.45) "analysis involves examining a substance and its components in order to determine their properties and functions, then using the acquired knowledge to make inferences about the whole." Significantly, these authors stress the notion of 'feeling right' which implies that after being immersed in the data for some time, the researcher believes the findings derived through reflective analysis convey the true nature of what the participants are trying to express. This step in the analytic procedure preceded coding of data, where codes were developed by means of interacting with the data such that concepts could be developed to represent it, prior to developing the concepts in terms of its properties and dimensions (Corbin and Strauss, 2008). However, despite following a sequential process in data analysis, I found that a number of different approaches needed to be employed at various stages in order to provide a comprehensive and convincing description of the experience of living with a disability in a rural area. Figure 1 provides a visual description of the processes followed in data analyses. Although the steps followed in the analytic process were sequential, they were also cyclical in nature whereby findings based on one form of analysis influenced and required revisiting of earlier findings. This is followed by a detailed description of these processes.

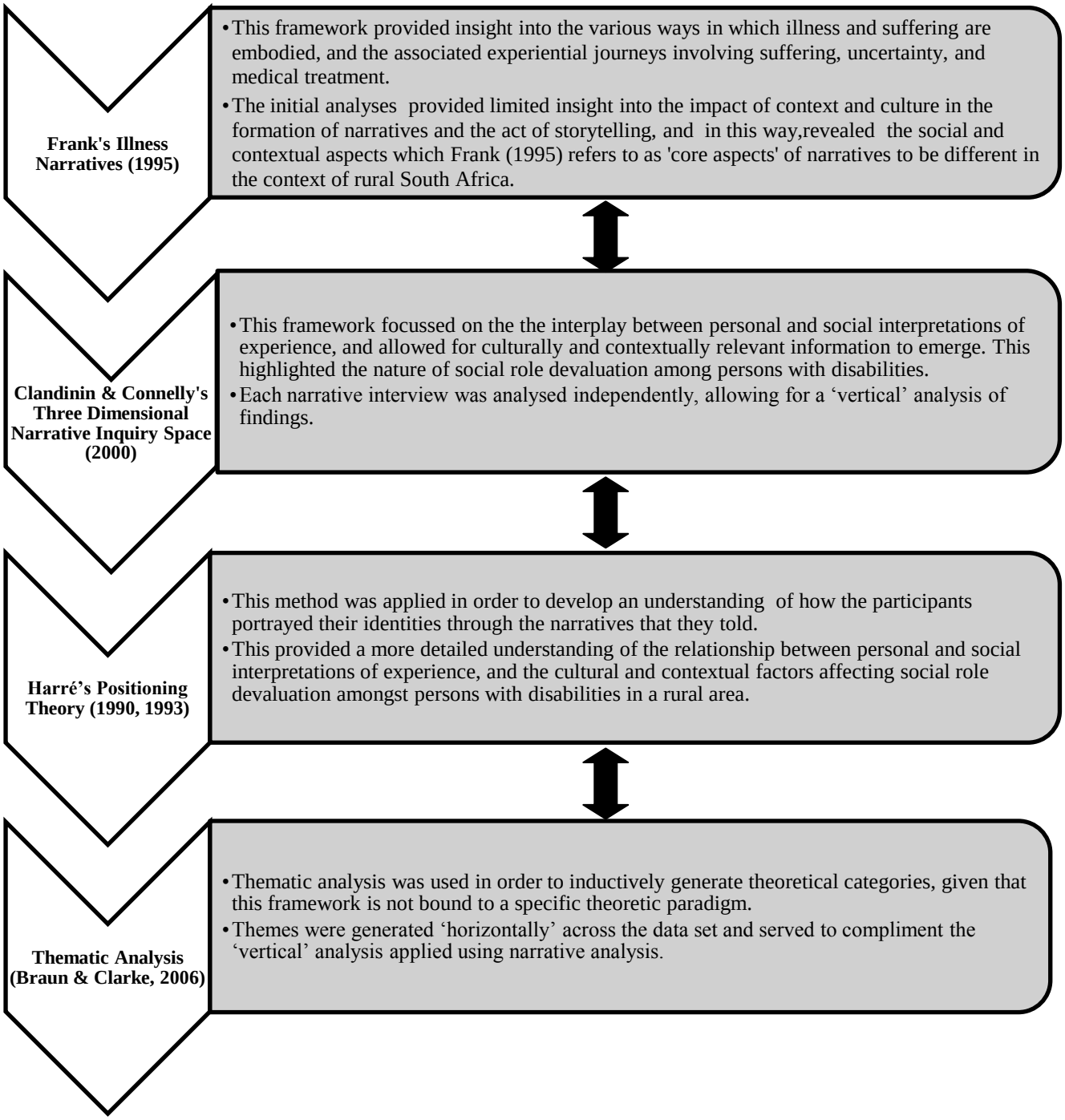


Figure 1: Description of Processes Followed During Data Analysis

It is important to acknowledge that a variety of stories can be told through analysing the data (Riessman, 2008), and thus, identifying the key concepts and determining how they fit together can involve many different attempts until the researcher believes that final story 'feels right' (Corbin and Strauss, 2008, p.47). Since qualitative analysis is both an art and a science (Patton, 2002), it was important for me as the researcher to remain both flexible and

creative in my approach to working with the data (Corbin & Strauss, 2008). By actively engaging in the process, I was able to reach the stage of interpretation, which was heavily influenced by my own understanding of the events in the field (Blumer, 1969).

5.11.2 Description of the Processes followed in Narrative Analysis

As described in Chapter 1, Arthur Frank (1995) suggests three types of narrative (restitution, chaos and quest narratives) which are used by persons suffering from a variety of illness in order to make sense of their lived experiences. Frank's (1995) work is based on the lived experience of illness, the various ways in which illness and suffering are embodied, and the associated experiential journeys involving suffering, uncertainty, and medical treatment. In this way, Frank (1995) attempts to shift the cultural perceptions of illness as a passive experience to an active transformation of the self. This framework has been predominantly applied in western contexts, specifically contemporary America, with middle-to-upper class citizens (Frank, 1995).

Given that Frank's illness narratives (1995) have been applied in a number of studies exploring the lived experience of disability (e.g. Hinckley, 2006; Sparkes & Smith, 2005; Ulatowska et al, 2011), the process of telling an illness story has been found to be empowering (Hinckley, 2006) and the framework for analysis is reported to be flexible in nature (Smith & Sparkes, 2005), I initially thought that this framework would serve as a valid means for providing insight into the lived experiences of persons with disabilities living in a rural area. However, although the core concepts of suffering and uncertainty may be applicable across a wide range of populations and contexts, as I attempted to apply this framework, I became aware that the social and contextual aspects which Frank (1995) refers to as core aspects of narratives seemed to be very different in the context of rural South Africa. This pertained specifically to the disempowered nature of the participants in my study, the fact that by nature of their disabilities and living conditions few had ever been afforded the opportunity to tell their own stories, the impaired access that they had to education, information and healthcare services, as well as the interplay between western and traditional models of healthseeking behaviours. Thus, while this approach was useful in examining coherence within the narratives, I began to question the application of Frank's (1995) narrative framework to my own data set, taking into account the impact of context and

culture in the formation of narratives and the act of storytelling (Goffman, 1961; Evans & Maines, 1995; Bochner, 1997). Given that within the SiSwati language and culture, a paucity of literature exists in relation to the culturally preferred principles of narrative formation, I felt that by forcing the narratives into Frank's (1995) typology I would prevent the 'true' interplay between personal and social factors from emerging. In addition, by applying a distinctly western approach could result in perpetuating the already existing inequalities experienced by marginalised populations (Riessman, 2008), and would thus have prevented the emergence of new themes and new narratives.

Based on the above, the decision was made to focus more generally on how stories were assembled and what content defined the narratives, using a combined approach (Holstein & Gubrium, 2012, p.3). This involved analysing the following aspects of 'storied content': characters (Frank, 1995; Clandinin & Connelly, 2000; Ollerenshaw & Cresswell, 2002; Holstein & Gubrium, 2012; Bamberg, 2012), space and context (Ricoeur, 1980; Clandinin & Connelly, 2000; Riessman, 2008), temporality (Clandinin & Rosiek, 2007; Clandinin & Connelly, 2000; Frank, 1995) plot (Ricoeur, 1980; Frank, 1995; Holstein & Gubrium, 2012; Bamberg, 2012), and emergent themes (Holstein & Gubrium, 2012; Frank, 1995; Riessman, 2005). Thus, by employing an eclectic approach towards data analysis, involving both narrative analysis (Clandinin & Connelly, 2000), and thematic analysis (Braun & Clarke, 2006), allowed for a 'vertical' analysis through individual accounts, as well as a 'horizontal' analysis across the entire data set. In this way, the narratives revealed a sense of continuity or contradiction across individual accounts (Riessman, 1993), while thematic analysis allowed for a rich description of the data by identifying, analysing, and reporting of themes which emerged across the data set (Braun & Clarke, 2006).

By attempting to understand the narrative form as well as its content allowed for insight into the tensions associated with developing culturally appropriate narratives amongst adults with disabilities in rural contexts, as will be discussed in Chapters 6, 7 and 8. These tensions highlight the need to investigate not only the spoken narratives, but also the silences which framed them, and called for an analysis of the reflexive interplay between the content of narratives and the way in which the stories were told (Holstein & Gubrium, 2012). The framework chosen to best identify these relationships was Clandinin and Connelly's (2000)

three dimensional narrative inquiry space, since it provided an opportunity to conduct a detailed investigation into the tensions and ambiguities between personal and social experiences of disability in the context of time and space.

5.11.2.1 Application of the Three Dimensional Narrative Inquiry Space (Clandinin & Connelly, 2000)

While narrative-based practice is not new to the profession of speech-language pathology (Hinckley, 2008; Shadden, 2005), this method of collecting and analysing data has remained somewhat limited. The majority of literature reflects that researchers continue to take the view points of proxies as opposed to providing persons with communication impairments with a voice, and few, if any, researchers, engage in this type of research cross-linguistically and cross-culturally.

Based on the need for detailed insight into the impact of context and culture in the formation of narratives and the acts of storytelling, Clandinin and Connelly's (2000) three dimensional inquiry space was adopted. As educationists, Clandinin and Connelly (2000) describe how their work has been influenced by the contributions of John Dewey (e.g. 1916, 1934, 1938), Johnson and Lakoff's (1980) work on embodied metaphors, MacIntyre's (1981) work on narrative unity, and the fields of anthropology (e.g. Geertz, 1995; Bateson, 1994), and psychology (Polkinghorne, 1988; Coles, 1989). Thus, this framework provided a unique opportunity to investigate the relationship between personal and social interpretations of experience.

Clandinin and Connelly's (2000) three dimensional model is based on the premise that in order to study lived experience, one must be able to ask questions from both an inward and outward perspective. This implies investigating aspects related to internal conditions, such as hopes, feelings, moral dispositions, and social aspects pertaining to external conditions and the environment, as well as taking into account the temporal nature of both narratives and lived experience. These dimensions are underpinned by spatial contexts, as well as the influence of other people's thoughts and actions (Clandinin & Connelly, 2000). Table 6 provides a visual representation of the various dimensions of the model.

Table 6: Visual Representation of Clandinin & Connelly's Three Dimensional Narrative Inquiry Space (as depicted in Ollerenshaw & Cresswell, 2002, p.331)

Interaction		Continuity			
Personal	**Social**	**Past**	**Present**	**Future**	**Situation/Place**
Look inward to internal conditions, feelings, hopes, aesthetic reactions, moral dispositions	Look outward to existential conditions in the environment with other people and their intentions, purposes, assumptions and points of view	Look backward to remembered experiences, feelings, and stories from earlier times	Look at current experiences, feelings, and stories relating to actions of an event	Look forward to implied and possible experiences and plot lines	Look at context, time and place situated in a physical landscape or setting with topographical and spatial boundaries with characters' intentions, purposes and different points of view.

According to Clandinin and Connell (2000), their 'model' is metaphorical in nature and, for this reason, it is discussed in terms of dimensions. The first dimension considers the relationship between individual and social interpretations of experience by examining the relationship between inward dispositions (such as morals, feelings, hopes, and reactions), and outward dispositions (such as the individuals' perceptions of other people's intentions, assumptions and points of view). The second dimension is that of temporality, and considers how the individual makes sense of their lived experience, based on their sense of continuity and coherence. This is dependent on the individual's ability to move between past, present and future within their narrative, and allows for understanding of how stories are lived and told over time and in particular places or series of places. Finally, the notion of context or place is taken into account by attending to the specific concrete, physical and topographical boundaries within the inquiry landscape.

Clandinin and Connelly (2000) caution that any framework of analysis places unnatural and constraining boundaries on the inquiry into lived experience, "since living, itself, is unbounded" (p.89). Therefore, the authors acknowledge that fixed analytic structures may constrain the interpretation of lives, or may prevent alternative possibilities from emerging. Thus, by providing this framework, the authors "hope that the three dimensional space will open up imaginative possibilities for inquirers, possibilities that might not as easily have been seen without this idea" (p.89).

Clandinin and Connelly's (2000) three dimensional narrative inquiry space served as a useful tool for delving into the relationship between personal and social interpretations of experience since it allowed for a detailed investigation into the effect that the interaction between personal and social interpretations of experience has on the individual and their ability to construct a coherent sense of self. This is important, since Frank (2000) states that the personal and social aspects of a narrative standpoint each recursively calls the other into being. Furthermore, Clandinin and Connelly's (2000) three dimensional narrative inquiry space allowed me, as the researcher, to engage in relational research alongside the participants, and, therefore, to attend to both my own and the participants' experiences and reflections. This allowed for a better understanding of the ways in which personal experiences are shaped by individual, social, cultural and institutional narratives.

5.11.2.2 Application of Harré's Positioning Theory

Given the relationship between disability and social role devaluation described in section 3.5.3, it was vital to analyse the way in which persons with disabilities positioned themselves and other characters within in their narratives. Thus, once Clandinin and Connelly's three dimensional narrative inquiry space had been used to make sense of the narratives, Harré's (1990; 1993) positioning theory was applied as a method of understanding how the participants portrayed their identities through the narratives that they told. Frank (2000) states that standpoints are neither static nor optional, and thus by analysing the way in which the participants position themselves and other characters in the stories creates a more detailed understanding of the relationship between personal and social interpretations of experience. Harré et al (2009) state that positioning theory focuses on the 'normative frames' within which people carry out their lives. This implies that positioning choices and interpretations regarding other people's responses and reactions are interpreted against contextually and culturally specific "standards of correctness" (Harré et al, 2009, p.8).

For the purpose of this study, a 'position' was considered to be "a cluster of beliefs about how rights and duties are distributed in the course of an episode of personal interaction and the taken-for-granted practices in which most of these beliefs are concretely realised" (Harré et al, 2009.p.9). Harré et al (2009) adds that positions are normally reflected in the everyday practices of a particular group of people. Moreover, they reflect features of a contextual

moral landscape in which individuals are assigned positions based on their personal characteristics.

Positioning theory maintains that the significance of events is context-specific and relates to the distribution of rights and duties within a given community (Harré et al, 2009). Furthermore, the ability to make sense of human interaction is confined within the boundaries imposed by our abilities to think and talk in narrative forms (Harré et al, 2009). In this way, the approach focuses on the explicit and implicit patterns of reasoning that are realised in the ways in which people act towards each other (Harré et al, 2009). For this reason, this approach seemed to be applicable to the current study, given the belief that individuals perform their preferred identities through the stories that they tell, implying that identities are situated and accomplished within social interactions (Riessman, 2001; 2008).

Analysis of the positions that participants inhabited involved identifying words and phrases which were used as a means to locate themselves within their narratives, the way in which participants related to the interviewers (audience) during the process of storytelling, the roles assigned to other characters, and the nature of identity claims made (Riessman, 2001). This was done by taking into account the contextual "standards of correctness" (Harré, 2009, p.13) as determined through culturally appropriate roles, particularly gendered roles.

Positioning Theory (Harré, 1990; 1993) was thus used to develop an understanding of the explicit and implicit patterns of reasoning that are realised in the ways in which people act towards each other (Harré et al, 2009) as revealed through their narratives. This was relevant, given that positioning is a reflection of rights and responsibilities (Harré et al, 2009). Thus, by acknowledging that life unfolds as a narrative (Harré et al, 2009), the significance of individuals' actions is influenced by both the positioning of the narrator and the characters. These are further influenced by the rights and responsibilities that are assigned, ascribed, claimed or assumed by the narrator (Harré et al, 2009). Therefore, given that positioning theory has emerged as a tool which is useful for understanding personal relationships (Sabat, 2009), it served as a powerful tool for understanding the interplay between personal and social interpretations of experience.

5.11.3 Thematic Analysis

Thematic analysis was adopted in line with the guidelines prescribed by Braun and Clarke (2006) in order to inductively generate theoretical categories (Riessman, 2011). Whereas other methods of qualitative analysis are strongly linked to theoretical dispositions, thematic analysis is not bound to a specific theoretical paradigm (Braun & Clarke, 2006), and was therefore considered to be an appropriate method of analysis to complement narrative analysis, as well as to analyse field notes and researcher and research mediator reflections. The purpose of applying thematic analysis was to perform a 'horizontal analysis' across all of the narratives within the sample, and in this way, to generate inductively a set of concepts that could be used to theorise across the data set.

Braun and Clarke (2006) highlight the fact that themes do not emerge passively from the data, but rather that it is an active process through which the researcher identifies interesting patterns within the data and reports them to the reader. In this study, the identification of themes related to the constructionist paradigm (Burr, 1995) which was chosen as a means to theorise about the way in which socio-cultural contexts and structural conditions impact on the lived experience of disability.

The procedures used were recursive in nature (Braun & Clarke, 2006). These involved familiarizing myself with the data set, generating initial codes across the data set, searching for themes by collating similar codes into potential themes, searching for unique and recurring themes, and refining the these by looking for linkages across themes and associations between themes. By labelling and categorising emergent themes, the data were reduced to a manageable entity, and verbatim quotes that highlighted the various themes were preserved in order to maintain the voices of the participants (Rapley, 2011) (appendix 21). Initially themes were identified at a semantic/explicit level, however, as data analysis progressed, these semantic themes merged into latent themes, which were more interpretive in nature (Braun & Clarke, 2006).

According to Braun and Clarke (2006), the purpose of the analysis is to provide a rich description of the entire data set, in order to highlight prominent themes. For this reason, the

themes identified are representative of the entire data set. While it is acknowledged that some complexity of data may be lost in this way (Braun & Clarke, 2006), this was chosen as the best way to represent the data since a paucity of information exists in relation to the lived experience of disability, particularly in rural areas.

5.12 TRUSTWORTHINESS OF FINDINGS

Particular care was taken to ensure trustworthiness of findings in this study. The term 'trustworthiness' was adopted in order to ensure that the findings were truly representative of the participants' and researchers' experience of the phenomena under investigation (Corbin & Strauss, 2008). In order to do this, the principles of trustworthiness as described by Leininger (1994, p.105 -107) were applied.

5.12.1 Credibility

According to Leininger (1994), credibility refers to the "truth, value or believability of the findings" and can be described as "the truth as known, experienced or deeply felt by the people being studied" (p.105). Credibility was ensured by my own prolonged presence in the field over a number of years, in the form of a service provider within the community, as well as my involvement in previous studies conducted within the same context. In addition, this was ensured through the contact that I had with various members of the community in various contexts, including visiting them in their homes, at stimulation centres, and at various other places within the community, including the shops, and during activities of daily living, such as collecting water and firewood. The nature of this contact allowed me to use the combination of observation of lived experiences together with participant reports of their experiences in order to broaden my understanding of what it means to live with a disability in a rural area.

Verbatim quotes have been used in the results and discussion chapters (chapters six, seven, and eight) in order to highlight significant points or experiences as described by the participants. Thus, the participants and research mediator's emic perspectives (Geertz, 1974; Creswell, 2012) on various experiences of living with a disability were used, together with my own etic perspectives (Geertz, 1974; Creswell, 2012) in order to develop a credible

understanding of the lived experience of disability in a rural area. Examples of how the data were analysed and how results were arrived at are included in appendices 20 and 21.

Once data had been analysed, an independent researcher working within the qualitative paradigm was employed to analyse a third of the transcripts. Although this research assistant was at a disadvantage, given that he was unfamiliar with context in which data were collected, the close agreement between his findings and my own, served to reinforce the notion of credibility of findings (Woods, Priest, Roberts & 2002). In addition, this process allowed for discussion over the thought-provoking emergent themes.

5.12.2 Confirmability

Confirmability refers to the repeated and documented evidence obtained from a variety of sources (Leininger, 1994). In order to ensure confirmability of findings, observations and interviews were conducted over a period of three months, with participants being visited a minimum of twice in naturalistic settings (Woods, Priest & Twycross, 2002). In addition, a variety of data collection methods were employed, including participant interviews, field notes and reflective journaling on the part of the researcher and research mediator in order to triangulate the findings (Flick, 2009).

As described in section 5.8 above, data were documented using a variety of methods, including the audio recording of interviews with participants, field notes and photographs documenting the context within which data were collected. Furthermore, during follow-up visits with participants, member checks (Flick, 2009) were conducted, whereby the researcher and research mediator discussed the main themes that had arisen in the previous interviews and their interpretation of these, and asked the participants to give feedback on the credibility of these interpretations. In this way I was able to ensure that the research mediator's understanding and recording of the narrative closely mirrored the participant's own description thereof (Woods, Priest, & Twycross, 2002).

In addition, audit trails (Corbin & Strauss, 2008) in the form of reflective journaling on the part of the researcher (Spradley, 1980), audio-recorded reflective conversations between the researcher and research mediator, and memos of decisions made during the process of data collection and data analysis (Corbin & Strauss, 2008) were kept and reflected on during the analysis and write up of this project. These also served as discussion points between the researcher and research mediator, as comments made by participants and emergent themes were debated, prior to member checking with participants.

5.12.3 Recurrent Patterning

Leininger (1994) describes recurrent patterning as the "repeated instances, sequence of events, or experiences that tend to be patterned and occur over time in designated ways in different or similar contexts" (p.106). As the researcher, I was cautious in my application of this principle, given that I did not want to omit narratives or experiences that were reflected by only a single participant, as this would have meant "denying this participant's reality" (Frank, 1995, p.109). However, by applying the principles of qualitative research, and dwelling with my data over time (Corbin & Strauss, 2008), I found that patterns emerged within the data. These are discussed in chapters 6, 7 and 8.

5.12.4 Saturation

A further criterion to be considered in ensuring the trustworthiness of qualitative research is the notion of 'saturation'. Leininger (1994) describes saturation as "the full immersion into phenomena in order to know them as comprehensibly as possible" (p.107). Initially, it was difficult to determine when saturation had been reached, given the different narrative content and form provided by each participant. The data obtained were dense in nature, reflecting emergent themes that were rich in information. Thus, by immersing myself within the data and performing a variety of different forms of analysis, saturation was reached in terms of redundancy of the emergence of new themes as well as in terms of information provided by participants.

5.13 SUMMARY AND CONCLUSION OF CHAPTER 5

This chapter has provided a discussion on the methodologies used in order to provide an ecologically valid understanding of the lived experience of disability in a rural area. Specific attention was paid to the implementation of tools that were considered as 'culturally safe' (Bessareb & Ng'andu, 2010) by the participants.

In addition to highlighting the tools used in data collection and the complexities associated with conducting research cross-linguistically and cross-culturally, this chapter has demonstrated some of the complexities associated with data analysis when working within the qualitative paradigm. This was particularly true for conducting a narrative analysis and relates to Frank's (2011, p.34) notion of the "difficulty in ending an analysis that rejects last words". The notion of working with data which "rejects last words" is demonstrated in the forthcoming results and discussion chapters (Chapters 6, 7 and 8).

Chapter 6 focuses on the reflexive interplay between personal and social interpretations of embodied knowledge (Scheper-Hughes & Lock, 1987; Krieger, 2005), and aims to highlight how the individuals' perceptions about themselves combine with their interpretations of how others perceive them, and in so doing, form the basis upon which their narratives are built. Chapter 7 discusses the relationship between embodied knowledge, and the spatial and temporal dimensions of narrative construction, specifically in the context of social and emotional exclusion. These aspects are discussed in relation to the impact that they have on the construction of a narrative plot. Chapter 8 follows with an acknowledgement and description of the various forms of violence that people with disabilities living in a rural area are exposed to and the impact that these manifestations have on narrative coherence. Through the acknowledgement of violence as a fundamental aspect of lived experiences, four new types of narrative emerge, which give rise to a number of policy, clinical and methodological implications as well as broader philosophical questions pertaining to the relationship between memory, vulnerability and responsibility. These are discussed in Chapter 9.

In order to highlight the findings of this study, a combination of visual representations in the form of figures, and verbatim quotations from participants are used in order to demonstrate the participants' emic perspectives (Geertz, 1974; Creswell, 2012), given Smith's (1999) recommendation that theory should be used in order to highlight the significance of particular events in order to support and sustain the author's argument. Following this, the combination of quotations embedded within an academic argument, together with my own perspectives and interpretations as a researcher were used to develop a socio-cultural understanding of the lived experience of disability in a rural area. Significant care was taken in this process so as not to fragment the participants' accounts, or to represent them in such a way that they could feel disrespected. Figure 2 provides an overview of the presentation of results.

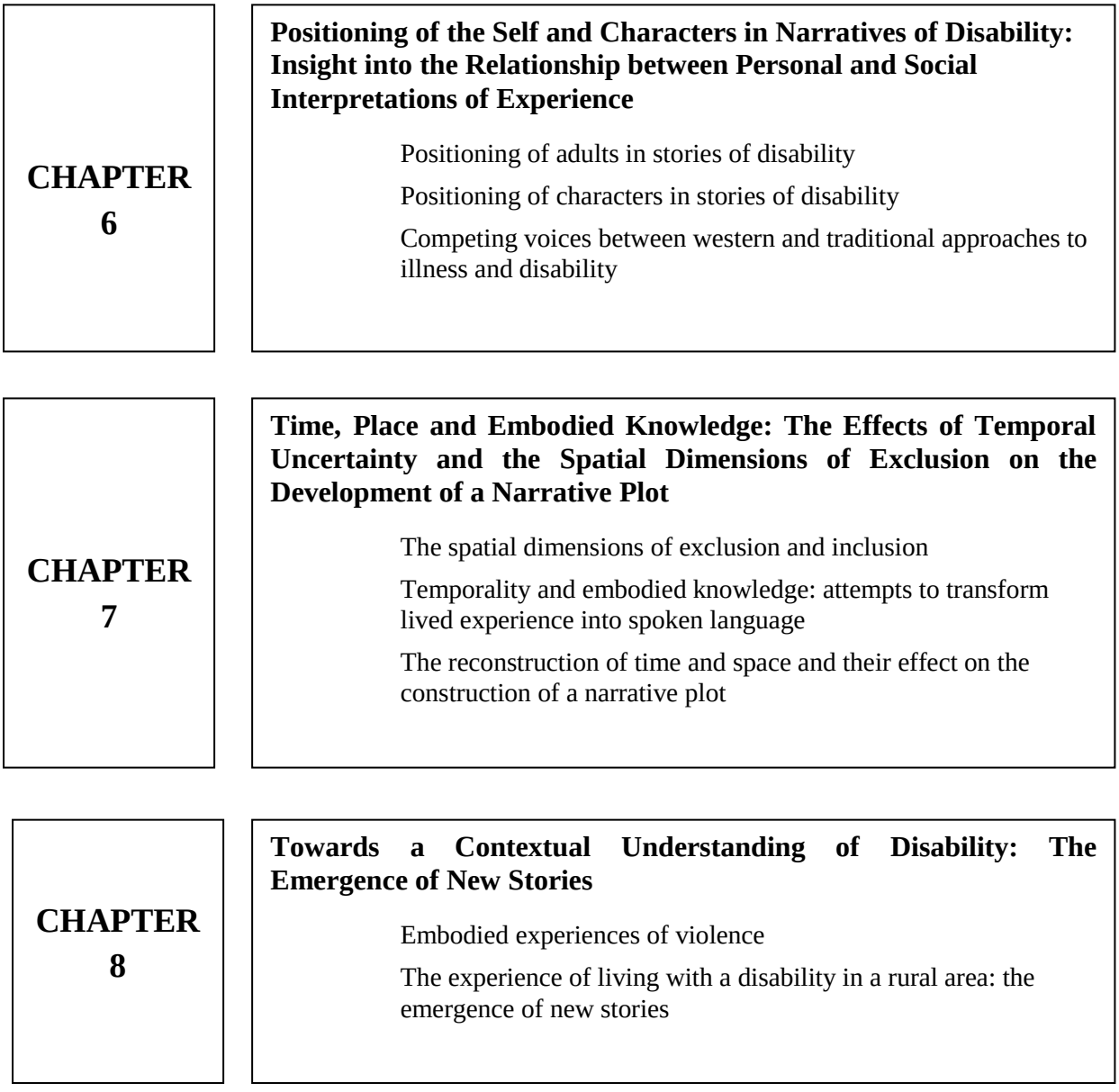


Figure 2: Overview of Presentation of Results

The results and discussion of findings is divided into three chapters. Chapter 6 focuses on the positioning of the individual and characters within the narratives, and in this way provides insight into the relationship between personal and social interpretations of embodied knowledge. This is followed by Chapter 7 which focuses of the temporal and spatial dimensions of narrative construction amongst adults with disabilities, specifically focussing on the dimensions of exclusion and inclusion and how this affects the construction of a coherent narrative plot. Chapter 8 reviews the various forms of violence to which adults with disabilities are exposed to, detailing how the impact of this on narrative construction prevents the construction of culturally acceptable plotlines for narrative of disability. This gives rise to what I will term 'new narratives' on disability, and provides insight into a contextual understanding of the lived experience of disability in a rural area.

CHAPTER 6

POSITIONING OF THE SELF AND OTHERS IN NARRATIVES OF DISABILITY

"Events of massive public suffering defy quantitative analysis. Do numbers really reveal the agony, the interruption, the questions that these victims put to the meaning and nature of their individual lives as a whole?"

(Chopp, 1986, p.2)



Mother carrying a baby on her back, firewood on her head and shopping in her hands

6.1 INSIGHT INTO THE RELATIONSHIP BETWEEN PERSONAL AND SOCIAL INTERPRETATIONS OF EXPERIENCE

According to Frank (2012) every individual's sense of selfhood is constrained by the resources that are made available to them in order to tell their stories, as well as by the stories that are told about other people with similar characteristics. This implies that narratives are constrained by the types of stories, characters and culturally acceptable genres and plots that exist within communities (Goffman, 1961), as well as the perceptions of others in the community. In terms of disability, this translates into the existing models and frameworks for explaining and responding to disability which create a narrative framework for individuals to affiliate with and in so doing create a narrative which reflects their interpretations of experiences.

Within the narrative construction of identity, it is impossible to separate the personal from the social (Bamberg, 2012), making it impossible to delineate where the personal ends and the social begins. By attending to the ways in which people use narratives to negotiate their social relationships provides insight into situations that result in incoherent understandings of experience (Shuman, 2012). Furthermore, by examining the relationship between individual and social interpretations of experience, and the positioning of the narrator in relation to other characters, it is possible to develop deeper insight into the way in which individuals negotiate ownership of experiences. Sacks (1992) claims that our experiences are just about the only things that we truly own, yet we are not always in the best position to know or talk about what has happened to us. This seems particularly true for vulnerable persons who by nature of their gender, economic status, citizenship, or (dis)ability are rendered voiceless and their stories and life experiences remain unacknowledged.

Bamberg (2012) states that when speakers relay events that occurred in the past, they reveal aspects of who they are, and in this way are able to make identity claims. Bamberg (2012) also states that one of the core features of narrative identity is the ability to maintain some form of continuity and constancy over time, and in this way, identity is established in relation to a notion of 'sameness' or 'difference'. Through the creation of boundaries and identity categories, the narrator positions him/herself proximally or distally in relation to other

characters, and in so doing, creates boundaries around him/her self and others. This results in the establishment of individual and group identities (Bamberg, 2012).

In section 6.1.1 below, I will discuss the way in which the participants positioned themselves within their narratives. This is followed by section 6.1.2 where I will discuss the ways in which participants positioned other characters in relation to themselves, and in so doing, created either a sense of proximity and affiliation, or a sense of distance and 'difference'. This is discussed in relation to the impact that positioning has on the development of a coherent sense of self. Finally, in section 6.1.3 I will highlight the most prominent competing voices that emerged within the narratives, and discuss the effect that this had on narrative identity construction.

Figure 3 provides a visual representation of the intersecting positioning of the self and others within the narratives, highlighting the ways in which these overlap and combine in the construction of embodied knowledge. Each of these aspects will be discussed in detail below.

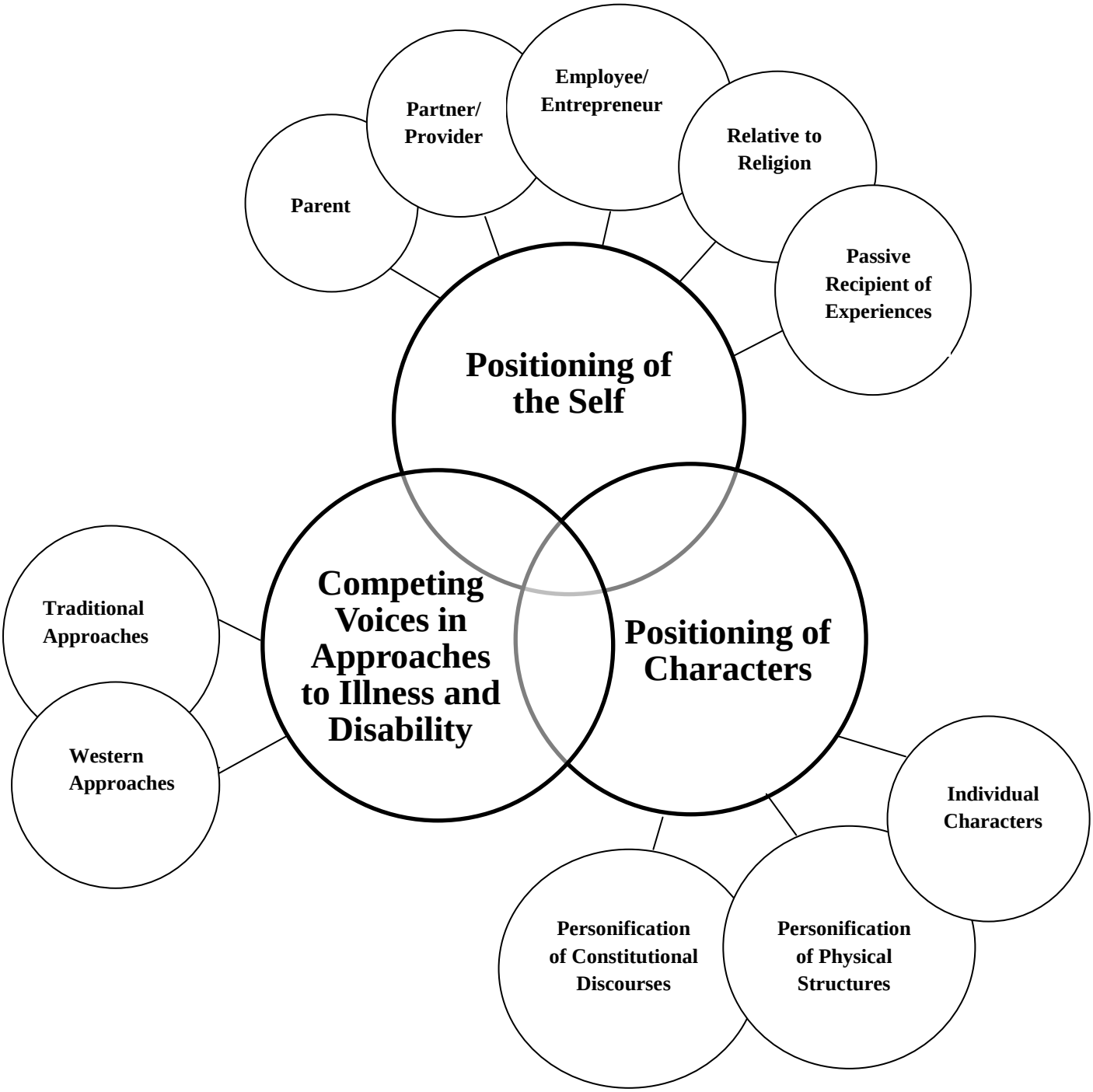


Figure 3: Intersecting Relationship between Personal and Social Interpretations of Embodied Knowledge

6.1.1 POSITIONING OF THE SELF IN STORIES OF DISABILITY

Harré et al (2009) explain that positioning is usually based on a number of implicit or explicit practices which either imply powers, status, and abilities; or vulnerabilities, incapacitations and social deficits. By telling one's story, an individual provides insight into what and who they are. This representation of the self depends on how the individual is positioned and what rights and responsibilities are available to them. As seen in Figure 4 below, the most common ways in which participants positioned themselves was in relation to whether or not they were parents, partners or providers, and their ability to produce an income, independent from state subsidy. Where participants could identify themselves in at least one of these positions, they were able to develop a degree of positive self-representation. However, where participants were unable to identify themselves as being an independent or productive member of society, they were more vulnerable to the effects of stigma and exclusion, resulting in self-representations of dependency and victimisation. While it is acknowledged that it may be misleading to present data pertaining to specific representations of the self, since representations of identity are usually multifaceted and plurivocal (Riessman, 2008), I specifically chose to do so, in order to highlight the contradictions experienced by adults with disabilities in their attempts to create a coherent sense of self, and how this affects the ability to develop a coherent narrative.

Consistent with Kuper's (1963) and Delius's (2007) reports of the importance of kinship and clanship, all interviews began with an orientation to the participant's clan name, the names of their parents, and in some cases the names of their neighbours. This concurs with Kuper's (1963) claims that clan names form a major form of identification, and serve to regulate both marital affiliations and political status.

Given that the stories obtained from the participants took the form of biographical interviews, it is assumed that by telling their story, each participant needed to manage a variety of positions within their narrative, including being the narrator of events and a character within these events, as well as positioning themselves as individuals in relation to other characters within the narratives. This relates to the dynamic chorus of styles and voices which manifest

in the variety of social and ideological positions represented in storytelling (Bruner & Gorfain, 1984). However, as can be seen in the examples below, the individual voices often lacked conviction and were subject to both competing voices and overwhelming silences within the narratives. In some cases, participants' voices were almost totally muted by the extent of poverty, food insecurity and suffering to which they were exposed.

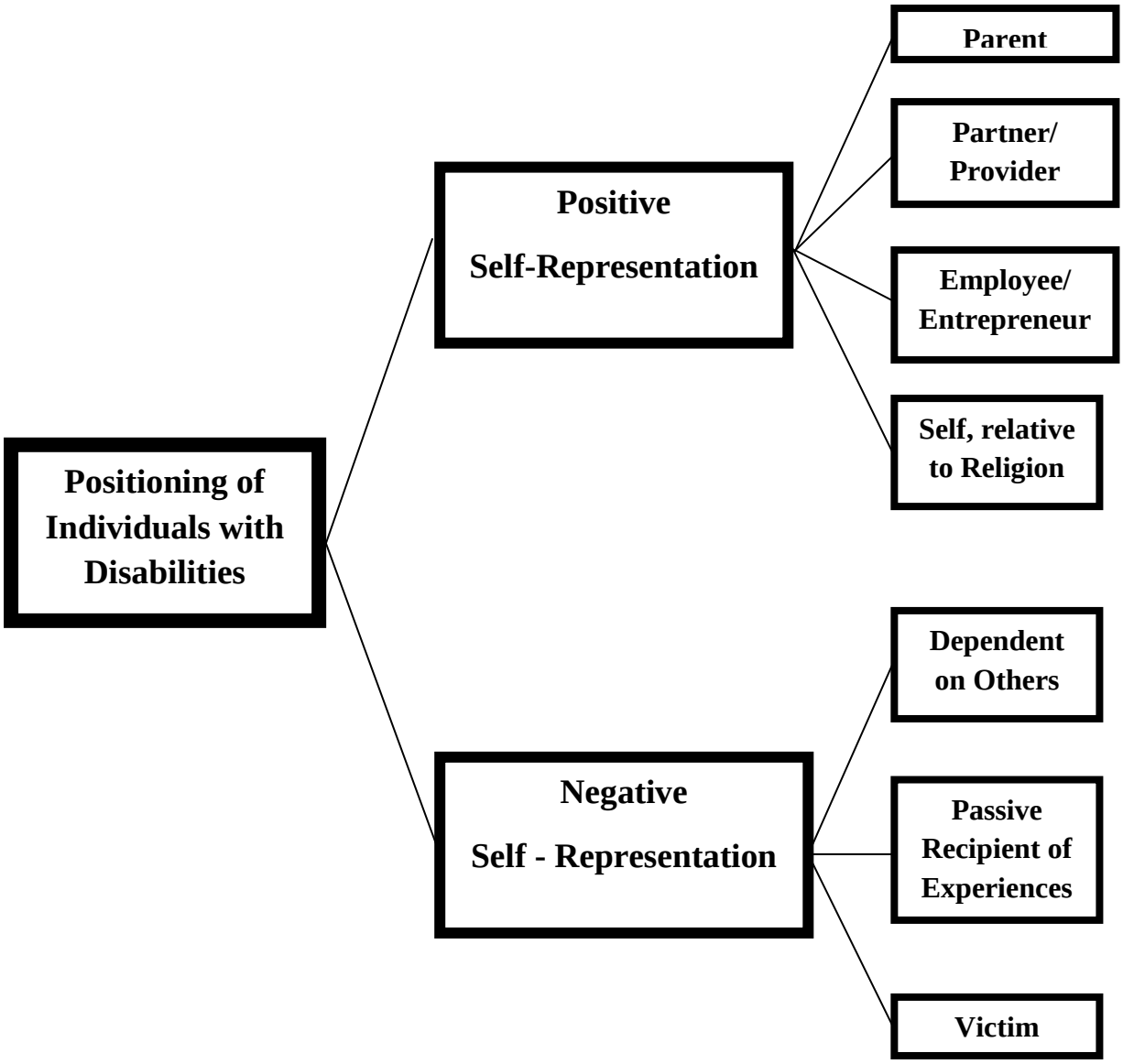


Figure 4: Narrative Positioning of Adults with Disabilities

6.1.1.1 Positioning as a Parent

Many of the participants in the sample positioned themselves according to whether or not they were parents. Given that the majority of the sample fell within the child-bearing age range, this is not surprising and is consistent with the culturally expected norms for the community,

(Kuper, 1963; Knox 2008; Thornton, 2008). Kuper (1963) states that within the Swazi culture, bearing of children is essential to the consummation of wifehood, and should a married woman be unable to bear children, her family may be requested to return the cattle which were paid for her hand in marriage. However, bearing of children is not only a core aspect of identity for women, but also for men, since a man's prosperity and importance in the community is measured by his number of dependents (Kuper, 1963). Similarly, both Caldwell and Caldwell (1996) and Thornton (2008) describe the significance that fertility carries within African cultures in relation to kinship, property regimes and the exchanges in networks and relations. This is expanded on by Knox (2008, p.175), who states that, particularly within the Afro-centric worldview, the prospect of being unable to bear children is a source of great distress, raising the question as to who will remember the individual after their death. This leads to the shame of "cosmological insignificance" given the potential of not having a future in the next life (Knox, 2008, p.175). In addition to this, Niehaus (2007) found that bachelors living in the Lowveld area of Mpumalanga were considered suspiciously, with prolonged celibacy being considered to be abnormal, distrustful and linked to witchcraft. Thus, the lack of opportunity to bear children has the potential to impact significantly on the ways in which family and community members respond to individuals, and consequently on the individual's interpretation of experiences.

The positioning of the self in relation to parenthood was thus, a prominent theme among both male and female participants. An example of positioning of the self as a parent was observed in the narrative of Participant 30, who contracted polio at the age of eight years. She introduced herself by stating *"I am a single parent of three children – two boys and a girl."* In a similar way, Participant 5, a 47 year old woman with a physical and cognitive-linguistic disability as a result of a stroke reported "*I gave birth to them, and then I grew them, little by little, until they became old."* This demonstrates that being a parent is fundamental to the identity that these participants have constructed for themselves. These identity constructions are important because they not only reflect a sense of agency and independence, but also a sense of kinship. Similarly, in each of these quotations the notion of cultural and gendered norms of child-bearing and child-rearing is reflected.

Many of the female participants reported that their family and neighbours were upset or angry when they found out that they (the participants) were pregnant. Consequently, they had experienced negative reactions from the community during pregnancy, yet their narrative positioning as mothers and caregivers provides evidence of defying the community's definitions and responses to disability. Internationally and locally, the issue of childbearing amongst women with disabilities is fraught with negative connotations associated with disability and sexuality. As a result, the Declaration of Sexual Rights (WHO, 2002) was drawn up, which stipulates that persons with disabilities should be given equal rights to engage in intimate relationships. Furthermore, a number of studies have highlighted the negative perceptions of family and community members in response to the sexual practices of persons with disabilities (Healy, McGuire, Evans, & Carley 2009; Jones, Binger, McKenzie, Ramcharan, & Nankervis, 2010; Kijak, 2011; Mall & Swartz, 2012).

These perceptions are further confounded by the cultural associations with childbearing. Knox (2008) explains that in African culture, sexual relationships are valued as an expression of kinship, while child-bearing signifies the bonding of both visible and invisible worlds. However, taking into account notions of causality, Thornton (2008) explains how sexuality relates both towards the cultural representation of the body and the flow of substance as gifts between partners during sexual intercourse. This implies that individuals are permeable to both physical and spiritual substances of other persons, and suggests that the biological boundaries of the individual are rooted in the cultural concepts of the body (Thornton, 2008). Given the traditional African beliefs regarding the onset of disability as a consequence of *umuti*[5], it is possible that family and community members may be concerned about the transmission of evil spirits or misfortune through sexual encounters.

Despite negative reactions of family and community members, it is important to note not only the cultural value, but also the individual value assigned to childbearing. Both acquired disability and stigmatisation during pregnancy may be considered a 'biographical disruption',

[5] In the case of disability, *'umuti'* refers to the onset of disability in cases where the family (usually the parents) have not heeded cultural norms and processes, such as planting crops or family obligations, or in cases where the male head of the household has more than one wife.

and it is noteworthy that although most of the narratives contained significant elements of biographical disruption, reports of parenthood were portrayed as biographical reinforcement. This is in line with the findings of both Wilson (2007) and Damar and du Plessis (2010), implying that although identities may be threatened by disability, the experience of childbearing can also form a reason for continuity of identity and a source of self-worth. This is expanded on by Woodward (1997, p.12), who claims that 'essentialist identities' such as motherhood may be particularly attractive to marginalised individuals.

Masculinity was also defined in terms of whether male participants had children or not, which implies that taking on the role of a parent is not only a priority for females. For example, Participant 2 who has been blind since birth defines himself by saying *"I am a father of four children, and I have supported them up until now,"* while Participant 23, a 39 year old man with a physical disability, who is married to a woman with a hearing impairment, reported "*My wife had four children from before, and we have three children together, so all together we have seven children. My wife's family were not happy when we had children, but I will not allow them to rule my life. I am supporting all the children – even those from another man."* This highlights the importance assigned to being able to portray oneself as a provider and a parent.

As can be seen from the discussion above, parenthood serves as a marker of success and contribution among the participants in this sample. Following this, it can also be understood that the inability to form intimate relationships, and limited opportunities to bear children has the potential to affect the participants' sense of self. This is reflected on by Shakespeare (2012) who reports that despite the fact that many people with disabilities are able to access sexual relationships, the majority are excluded from intimacy. This is evident in the narrative of Participant 1, a 50 year old man who has been bedridden and confined to a small room for 40 years after he sustained a physical disability as a result of an illness. His narrative was dominated by his desire for an intimate relationship and to have children, as evident where he says *"I want to have children, because that is the will of God."* His narrative reflects a contrast between the senses of desire and despair. The sense of desire is underpinned by a longing for an intimate relationship and a desire for *"children and things that belong to me"*, while at the same time contrasted by a sense of despair relating to the nature of the disability,

dependence on others, and a lack of social support. This can be explained by Thornton (2008) who reports that sexual relationships embed individuals in dense social networks of duties, expectations and obligations. Thus, the experience of living with a disability in the context of poverty not only places significant physical and emotional demands on the individual, but questions the individual's identity in relation to basic human elements such as the value placed on sex and childbearing.

6.1.1.2 Positioning as a Partner and Provider

In a similar way to the manner in which participants defined themselves in terms of whether or not they were parents, they also defined themselves in terms of being partners and providers.

Many of the participants with acquired disabilities exhibited a sense of surprise and relief when they were able to say that their partners had not left them after the onset of the disability. This is evident where Participant 13, who had sustained a physical and communicative disability as a result of a motor vehicle accident said, *"My wife did not try to run away from me,"* and where Participant 17, who had sustained a spinal cord injury as a consequence of being shot during a hijacking, said *"My wife still loves me and I love her. People tried to convince her to leave me when I became disabled, but they failed, we are still together."* In addition, Participant 16, an 81 year old woman, who has a progressive physical disability reported *"I thank God for giving me a good husband. He helps me with everything. He never left me."*

While some participants defined themselves in terms of being partners or providers, others defined themselves in terms of not being able to establish intimate relationships, or having been abandoned by their partner post onset of their disability, where, for example, Participant 21 laments on the his wife's family's perception of him, recalling *"They are always saying 'what can I do for her, being a disabled person, what can I give her?" So they are always telling her she must rather find someone who is not disabled."* On the whole, male participants reported more difficulty in establishing intimate relationships with women. This is apparent where Participant 1 reflects *"It is difficult for me to find a wife. I think the ladies*

are always asking themselves 'will I be able to nurse him? Will I be able to have sex with him, or will I nurse him only?'"

Many of the other participants reported being abandoned post onset of the disability. For example, Participant 3, a 50 year old woman who sustained paraplegia after being stabbed in the back during the war in Mozambique, reported *"I was married, then I got injured, then my husband left me. We separated because I was disabled,"* while Participant 4, a 29 year old male who sustained a cognitive-linguistic and physical disability as a result of an attack reported that after his injury, his partner and the mother of his child phoned him and said *"'Since your injury, I don't think I will still be coming to visit you.'"* Similarly, Participant 9, a 52 year old male reported that after he sustained a bilateral amputation, he was unable to work and as a result his wife left him for another man, while Participant 22, a 54 year old man who also sustained an amputation after a car accident, reported *"At home they accepted my condition, but my wife left me. I was still in hospital when she left."*

These excerpts indicate that persons with disabilities, especially those with acquired disabilities, seem to anticipate that they will be abandoned by their partners. This is reflected not only in the element of surprise exhibited where participants overtly state that they have not been abandoned as a result of their disability, but also in the manner in which participants who have been abandoned describe their experience – briefly and to the point, devoid of all emotion. This anticipation of abandonment is further complicated by reports of community members encouraging individuals to leave their spouses after the onset of a disability, as seen in Participant 17's narrative, where he states *"People tried to convince her to leave me when I got injured, but they failed."* The effect of perceptions that people with disabilities are unworthy of love is well articulated by Participant 30 who contracted polio at the age of eight years. She reported, *"I was always thinking that it was just for normal people to love each other."*

6.1.1.3 Positioning as an Employee or Entrepreneur

According to Kuper (1963), traditionally, labour is divided according to age, sex and pedigree, with all men being expected to be able to build, plough, milk cattle, and sew skins;

and all women being able to hoe, thatch, plait ropes, and weave baskets, mats and beer strainers. While these traditional obligations may have changed somewhat, it is acknowledged that the inability to engage in culturally acceptable activities and gender roles threatens the individuals' sense of identity and agency. Thus, many of the participants portrayed employment as a core aspect of their identities and defined themselves either in terms of having a form of income (other than the disability grant) or being reliant purely on the disability grant or on others. Participants who were employed or showed some form of entrepreneurial skill displayed a greater sense of agency within their narratives. This is evident, for example, where Participant 30 says, *"I applied and I got the job. Now I am happy."* In addition, this participant defines herself in the initial part of her introduction to the researcher as *"...I am a single parent and I am working for an NGO"* which highlights the fact that her employment is central to her identity and contributes towards a positive self-representation. Participant 12, who sustained a physical disability after being involved in a car accident, describes his financial difficulties of trying to provide for his family and trying to access treatment at the hospital, while having no income and not receiving a disability grant. He reports, *"So I decided to become a shoe maker. That was my job from long ago; it was just that I was not serious about it."* He goes on to describe how the money he made from shoe-making went towards waterproofing his home and putting a door on the home, as well as funding the education of a neighbour's child.

Despite the fact that participants indicated a preference for earning their own money as opposed to being dependent on state subsidy, it is acknowledged that disability grants have the potential to transform the identity of the person with a disability from one of dependence to being empowered and independent. For example, Participant 10, a 38 year old woman who sustained a physical disability as a result of a stroke, reports *"There is one woman that I employ with money from my grant."* This indicates the participant's agency and attempts to be independent, yet this is countered by her reports of dependence where she says, "*It is difficult because I always have to rely on someone else's assistance. Like in the night, if I want to go to the toilet, I cannot get there. I have to wait until my helper arrives in the morning so that she can take me."*

A number of the participants defined themselves in terms of their disabilities, thus aligning with the medical model of disability. This was observed specifically in relation to unemployment and financial insecurity, since many of the participants believed that they were unemployable as a result of their disabilities, and those who received disability grants were forced to foreground the role of disability in their life in order to qualify for the grant. An example of this is seen where Participant 21, a 28 year old man with a physical deformity of both feet, says *"The biggest problem is that I am not working. You see, a person like me with a disability, where can I work?"* Furthermore, Participant 20, a 28 year old man with a congenital deformity of the feet reported that because he does not have an identity document, he cannot apply for a disability grant, so he attempted to start his own business by selling fruit on the side of the road. However, he recalls *"People were chasing me. They were saying 'why am I selling fruit if I am disabled?' I am taking their work, so I must rather get the grant and leave the work for them."* This reflects how the participant was caught between not being eligible for social support, and being discouraged from finding a way to produce his own income.

In cases such as those described above, the International Classification on Functioning, Disability and Health Framework (WHO 2001) provides a compelling argument for understanding the limitations to participation imposed by disability. However, in the absence of cultural information pertaining to the roles which men and women are expected to fulfil within the community together with contextual information regarding the limited educational opportunities for people with disabilities, and the high levels of unemployment, it is difficult to identify the root of the problem and consequently to identify measures that can be put in place to address these barriers.

6.1.1.4 Positioning of the Self Relative to Religion

Agrimson and Taft (2009) claim that in order to find meaning in life, one's spiritual needs must be met. Spiritual needs can be conceptualised quite broadly into cognitive, behavioural and emotional components (Agrimson & Taft, 2009) and include the need for love, the need to find meaning and purpose in life, the need to find hope for the future, the need for forgiveness, creativity and continuity with the past, and the need to serve a higher power (McEwen, 2005 as cited in Agrimson & Taft, 2009). This view is shared by Galek, Flannell,

Vane and Galek, (2005) who define spiritual needs in accordance with belonging, meaning, hope, the sacred, morality, beauty, and acceptance of dying.

Despite the hardships that many of the participants had endured, the majority of them revealed some form of positive self-representation in relation to having a religious affiliation, which appeared to be used in order to create a sense of belonging and a sense of meaning. This was particularly significant amongst participants who had consulted with traditional healers, since the act of healing, specifically indigenous healing is typically a religious act (Mpofu, Peltzer & Bojuwoye, 2011). Interestingly most religious affiliations emerged spontaneously within the narratives (without any prompting from the interviewer), and occurred mostly towards the ends of the narratives. For example, Participant 1, who has been bedridden and confined to a small room for over 40 years says *"I can say that I am the person who is saved. I believe in God and love Him so much."* Similarly, two of the other participants (one of whom was born blind and the other had a psychiatric disability) claimed that "*if it were not for God, I do not believe that I would be alive."* In addition, Participant 3, who sustained paraplegia after being stabbed in the spine during the war in Mozambique, said *"I know that God loves me,"* while Participant 7, a 35 year old woman with a psychiatric disability said "*So for me the answer is to kneel and pray always."*

The use of religious metaphors in dealing with chronic conditions have been reported by Stein, Lewin and Fairall (2007) and Leydon, Boulton, Moynihan, Jones, Mossman, and Boudioni (2000). This relates to Boswell, Knight and Hamer's (2001) findings which suggested a reciprocal relationship between disability and spirituality which involves an on-going and recurring personal process, culminating in a revision of the individual's beliefs. This is expanded on by Knox (2008) who explains that religious healing rituals place the affected individual at the centre of a concerned social circle, including family, kin and healers. This social circle and social approach to healing forestalls the social death of isolation and stigma associated with disability, and in this way the individual is able to maintain a sense of self within the community. Thus, by providing the individual with a process in which they can trust helps to alleviate despair and instils a sense of hope.

In addition to the explanation provided above, Prince, Denis and van Dijk (2010) highlight the value that churches have added, specifically in under-developed communities to the management of the HIV/AIDS pandemic, including addressing the needs of those who were infected and affected by the virus. Given that church communities frequently cater towards those who are marginalised, it would seem that persons with disabilities, who have difficulty in establishing meaningful roles in other sectors of the community are able to develop a sense of belonging within church communities. This is seen where Participant 7 says *"It is only in the church were they treat me well,"* and where Particiant 30 says "*For me, I only feel comfortable when I am at church.*"

Another possible explanation for the emergence of religious affiliations within the narratives pertained to the shift of responsibility, possibly for both the onset of the disability and for subsequent actions from the individual. This is explained by Sabuni (2007) who claims that in African culture, the origins of ill health are believed to originate outside of the body of the affected individual, in relation to acts of malevolence or witchcraft, and in this way the individual is absolved from responsibility of the aetiology and treatment of the impairment. Furthermore, Frank (1995) claims that to experience an illness, it is necessary to imagine, and that "imagination is consciousness struggling to gain sovereignty over experience." (p.70). Acknowledging that one's imagination knows that the story could have been told differently, the question arises as to whether the life should have been lived differently? This is a particularly important question given guilt and stigma associated with many models of causality regarding the onset of disability (Crow, 1996; Shakespeare, 2006; Smart, 2009; Scullion, 2010). An example of this type of shift in responsibility which results in the a reduced sense of agency within the narrative is provided by Participant 18, a 19 year old man with athetoid cerebral palsy, who described his experiences of being taunted by the neighbours for the way in which he moves. When asked what his reaction to the experience was, he said *"I told my mother. She said, 'Let it pass. Let Jesus be the one to judge them.'"* Similarly, Participant 16, an 81 year old woman who suffers from a progressive physical disability also spoke of her dependence on others and claims *"That is why God gave me a good husband,*" while Participant 14, a 38 year old man with a physical and linguistic impairment as a result of cerebral palsy reported *"It was difficult for me, but I accepted my condition. I believe this is what God has given me."* In this way these participants absolve themselves of responsibility, believing that God has intervened on their behalf.

In contrast, Participant 20, who has a congenital physical disability as a result of a bilateral deformity of his feet, claims *"I believe that one day God will be with me. One day God will answer me and I will get the grant."* This implies that he does not believe that God is currently with him, since despite all of his attempts to apply for a disability grant have been rejected, and his attempts to produce an income by selling fruit on the side of the road were thwarted by able-bodied persons. This response could imply that the participant's spiritual needs are not being met. This is described by Agrimson and Taft (2009) as a spiritual crisis which is defined by a fragmentation of the self, while Knox (2008) and Ncube (2011) describe this experience as 'desolation', implying that a sense of protection has been withdrawn, leading to the feeling of alienation and despair regarding one's future.

6.1.1.5 Positioning of the Self as a Passive Recipient of Experiences

While the majority of participants made attempts to define themselves relative to culturally acceptable roles and whether or not they were able to fulfil them, other participants' primary form of narrative representation was as a victim or as a passive recipient of experiences. It was unclear whether this related to the participants 'protecting' the listener from the harsh reality of their lived experiences, or whether the limited agency reflected in these narratives served as a protective mechanism such that the participants were not forced to confront the responsibility associated with memory in terms of altering their life trajectories (Frank, 1995). Frank (1995, p.84) does, however acknowledge the need to retain control over experiences which may be threatened through the act of narrative construction is a stage in the embodiment process that every 'body' passes through. Another reason underlying this lack of articulation of experiences is that silences or 'gaps' in the narratives may be used as a powerful means for acknowledging the impact of trauma on the individual (Hoffman, 2004). However, the use of silence is dependent on shared knowledge (Danieli, 1998) and potentially reflects the shared knowledge and shared experiences between the participants and research mediator, such that an understanding is created in the absence of speech. This is referred to by Danieli (1998, p.4) as a "conspiracy of silence" and serves as a marker of the transmission of trauma and traumatic memory between two individuals with shared contextual knowledge.

An example of this passive positioning with limited agency is evident where Participant 3, who was stabbed in the spine during the war in Mozambique, and was subsequently exposed

to various forms of violence, acknowledges *"So I became a victim."* Furthermore, other participants revealed difficulty in developing a coherent sense of self, and as a result their self-representations lacked conviction, marked by their ascription to passive positions within their narratives. This is evident where Participant 7, a 35 year old woman with a psychiatric disability was asked about her disability, and she responded saying, *"I don't know. I know nothing."* Similarly, when asked to tell their stories, Participant 21, who was born with a bilateral deformity of both feet, said *"I am disabled,"* and Participant 25 who had been born without arms or legs responded by saying *"I was born like this."* These responses create an impenetrable distance between the interviewer and the interviewee, as it is difficult to ask relevant, open-ended questions based on these types of responses. In this way it is possible that the participants were attempting to prevent their lack of coherent self from being revealed, either consciously or unconsciously. It is also possible, at least in some of the participants' cases that their isolation and exclusion have prevented them from engaging in typical interactions (such as with friends, in schools, and within families) resulting in limited options for choosing the type of role which they would like to portray.

6.1.1.6 Summary of Positioning among Adults with Disabilities

Based on the various descriptions above, it is apparent that the participants' narratives were plurivocal (Riessman, 2008) in nature and that they positioned themselves in relation to a variety of culturally acceptable roles. Although the various roles are presented independently from each other in the discussion above, most of the participants positioned themselves in a variety of different roles within their narratives, depending on the event being described, concurring with the multifaceted nature of narrative identity construction (Riessman, 2008; Bamberg, 2012).

Most of the participants appeared to position themselves in defiance of mainstream disability identities. This is seen where participants describe having intimate relationships and bearing children despite the reactions of the community, attempts to find work or start businesses, and beliefs that despite their disability and existing narratives regarding disability that God has saved them. This type of positioning appeared to develop in relation to societal attitudes towards people with disabilities, reflecting a range of understandings and opinions. Although literature exists on the stereotyping and marginalisation of people with disabilities, public

discussions pertaining to the reasons why these exist is narrow. This is expanded on by Kulick (2012) who states that society identifies certain types of attitudes and practices ad being desirable and right, and therefore in instances where individuals 'deviate from the norm' they are discriminated against, mocked, ridiculed or punished. Thus, the evidence that emerged of positioning in defiance of mainstream disability identities is significant as it challenges the extant narratives and roles which exist in relation to the lived experience of disability.

6.1.2 POSITIONING OF CHARACTERS WITHIN STORIES OF DISABILITY

Frank (2012) claims that stories are driven by the characters that inhabit them, and that it is the characters' dispositions that cause actions to occur, rather than fate. Thus, narrators position themselves in alignment with or in contrast to other characters. The positioning of the self and others creates the space and context where actions and events take place.

Bamberg (2003) states that positioning involves the interplay of self-reflection, self-criticism, and agency. It is therefore important to consider how characters are positioned with one another within reported events, and in relation to the speaker, in order to understand narrative positioning. The positioning of a speaker and characters within a narrative are not static conventions, but rather concepts that are fluid and subject to change (Shuman, 2012; Bamberg, 2003). Thus, as the individual constructs and reconstructs their narrative, they negotiate the intersections between tellability, positioning and agency (Shuman, 2012).

Figure 5 provides a visual representation of the primary characters which dominated the participants' narratives, each of which is discussed in detail in sections 6.1.2.1 - 6.1.2.4 below. These characters included individuals (e.g. family, friends, community members), physical structures (e.g. stimulation centres, healthcare facilities, schools, and churches), and constitutional discourses (e.g. government policies and practices, constitutional rights, and health and social service providers). Although distinct characters could be identified, characters overlapped, with, for example, individual characters being reflected in both constitutional discourses and stories about physical structures. Both structures and

constitutional discourses were personified by the participants and in this way, these abstract entities were endowed with human qualities.

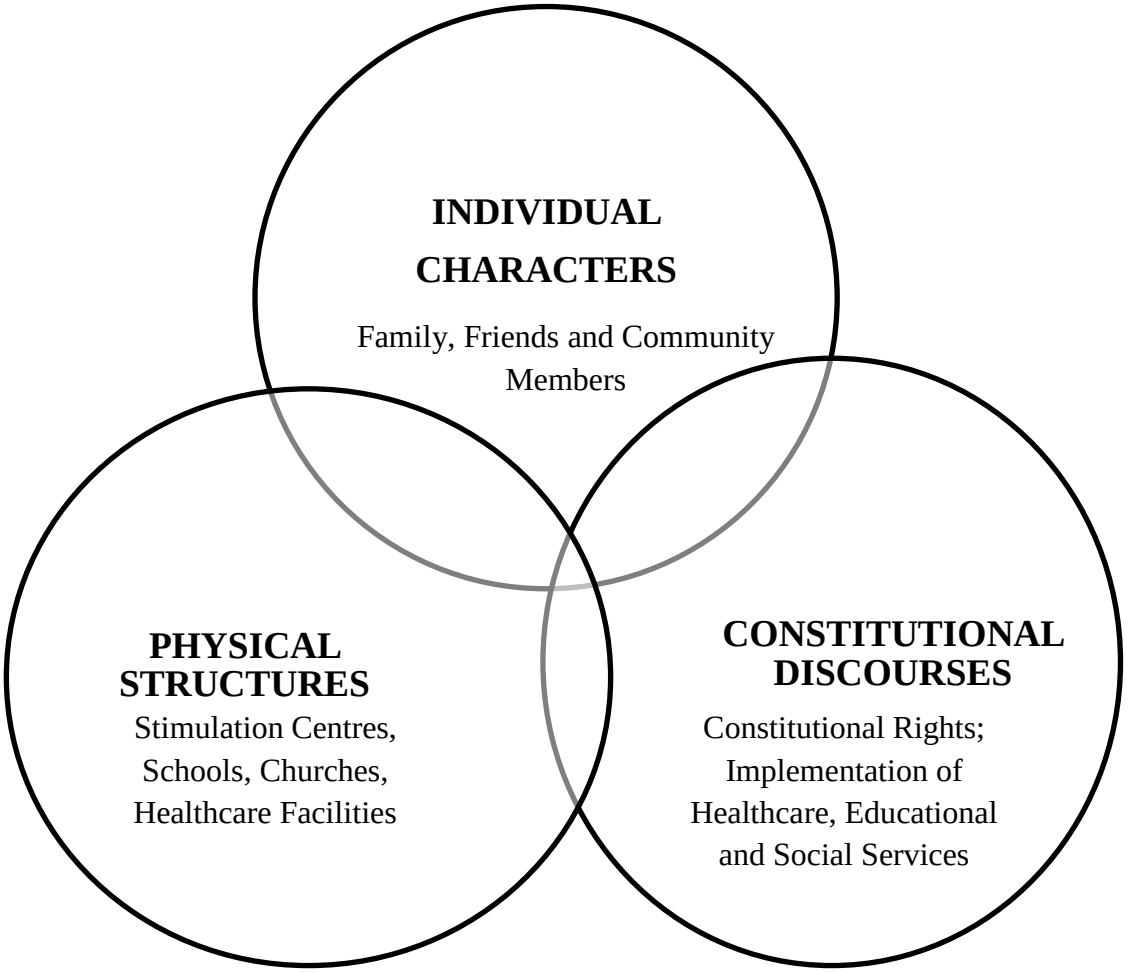


Figure 5: Visual Representation of Characters Dominating the Narratives of Adults with Disabilities

Characters were represented both positively and negatively, depending on individual experiences. Characters that were represented positively seemed to contribute in a positive way to individual interpretation of experience and consequently strengthened the participants' abilities to construct a coherent sense of self. However, characters that were represented negatively appeared to weaken the individuals' resilience, leading to narrative incoherence. This in turn seemed to affect the participants' ability to align themselves with socially and culturally acceptable roles, leading to isolation, marginalisation, and insecurity, and detracting from the ability to reveal a sense of independence within the community. Negative reactions

on the part of family and community members appeared to be directly related to stigma associated with disability.

6.1.2.1 The Positioning of Individual Characters within Stories of Disability

Consistent with other research into the effect that disability has on the individual (e.g. Clarke & Black, 2005; Albrecht & Devlieger, 1999) this study revealed that individuals' life experiences are significantly impacted on by their engagement with the social world. Depending on the nature of the family's and community's responses to disability and the type of support received, participants either aligned themselves with the characters inhabiting the narratives or positioned them distally.

A number of authors (e.g. Ridgway, 2001; Clarke & Black, 2005) report that support and resources in the individual's environment are of paramount importance, especially where the individual is dealing with both an altered body, altered abilities and consequently an altered identity. Thus, access to health and social services as well as socio-emotional support provided by family members and friends were found to have a profoundly positive impact on the individual with a disability.

Positive support provided by family members was evident where Participant 25, a 28 year old woman who was born without arms or legs, reported *"I grew up with good manners because my parents had a lot of love for me. They do not have a problem with me being like this."* Similarly, Participant 13, a 30 year old male who sustained a physical and communicative impairment as a result of a motor vehicle accident, reported, *"My parents were very supportive. Even now, they are still supportive."* Other participants reported support obtained from other family members, including, husbands, fathers, brothers and sisters, and cousins. Participant 4, a 29 year old man who had been physically attacked and left on a railway line, resulting in a head injury, with concomitant physical and cognitive-linguistic disabilities reported, *"My father said 'I won't throw you away. You are my child and I will help you.'"* These extracts highlight the nature of care and positive support received from family members, to the point where participants likened their family members to God. This is seen where Participant 11, a 40 year old woman who sustained paraplegia after being shot during a

protest march said *"My brother is so good to me. The way he is, I don't know what to say. He is my brother, my mother, my father, even my God, the way he is treating me."*

On the whole mothers were portrayed positively as caregivers and support structures. This is evident where Participant 2, a 45 year old man with a visual impairment reported *"I am a man because of my mother. She did not kill me,"* while another participant reported *"when I think about all of the things that have happened in my life, I know that if it were not for my mother, I would not be alive now."*

Other examples of positive support emanated from within the community. Participant 27, a 49 year old woman with a visual impairment reported*, "My neighbours give me the support I need,"* while Participant 25 said, *"My neighbours are too much supportive of me. They are even visiting me and taking me to church."* Participant 13 also reported positive community support, saying *"my friends were so supportive. When I was in hospital, and even now, they are buying bus tickets for my wife."*

These references to positive support received from family members and community members reinforce the notion of a positive identity as a parent or caregiver. Thus it can be assumed that in cases where the individual had a positive role model, especially in the form of a parent or partner, significant value is placed on these roles and the individual ascribed to being able to fill these roles. Furthermore, in situations where participants reported positive family support, they appeared to have positive self-esteem and exhibited more confidence and agency in their ability to tell their story than those who experienced a lack of family support. This was reflected on by the research mediator when she said *"It is important, as a disabled person to learn to communicate with other people and to learn to love. If you have family at home, you must live like this so that they learn to respect you, because if your family doesn't respect you, then people outside also won't."* However, it must be noted that although some participants reported support within the home, other experiences, including the community's responses to disability, or negative experiences in terms of applying for disability grants or in seeking employment, tainted their overall self-representation in their narratives.

It was noteworthy that participants who had acquired disabilities, specifically as a consequence of motor vehicle accidents or as a result of violence, appeared to have a greater degree of support than those who had congenital disabilities or disabilities as a result of illness. It would appear, that within this community, disability as a result of violence or as a result of a car accident was viewed as 'accidental' in nature, and something over which the participant and their family would not have had any control. However, disability as a result of an illness or a seemingly idiopathic cause, was regarded with suspicion relating to the malicious intentions of others, bewitchment, or concepts relating to *'umuti'.* This concurs with the findings of both Niehaus (1995) and Fottrell et al (2012) whose research into the beliefs surrounding causation of death in the Lowveld area of Mpumalanga, revealed that assigning blame to witchcraft may be a mechanism for dealing with the incomprehensibility of illness and the consequent effects that is has on the family and community. Furthermore, Crawford (1994) demonstrates how the societal beliefs of a community affect the ways in which the members of that community construct beliefs about who becomes ill and who remains healthy and how this serves to ostracize an already marginalized community. In turn, Crawford (1994) demonstrates how the language of health has come to signify those who were responsible from those who were irresponsible, those who were respectful from those who were disreputable, those who were safe from those who were not, and ultimately those who have the right to rule from those who need supervision and guidance. This gives rise to a social distancing from the 'unhealthy', a further stereotyping of an already stigmatized group. In this way, people with disabilities are not only made responsible for their condition, but they are also made to feel different.

Numerous examples of negative reactions of family members were reported. For example, Participant 21, a 28 year old male who was born with deformities of the feet said *"At home my parents were not treating us as equals. They were treating those who were able better than they were treating me,"* while Participant 20, another 28 year old man who also presents with a congenital foot abnormality reported that *"when I ask my parents or my in-laws for help, they are always complaining, saying to my wife 'why did she marry me? I am disabled so what can I do for her?'"* Of concern were reports of physical abuse as a result of disability. An example of this occurs where Participant 27, a 49 year old woman with a visual impairment as a result of an illness reports *"My father beat me because I was disabled. He said I was bewitched and he beat me and tried to cut me with a knife."*

Within the community, many of the participants provided descriptions of negative experiences and stigma related to disability. For example, one participant who had undergone a bilateral amputation reported that when he asks for assistance, members of the community respond, by saying *"aaahh…this one. It is not us who said he must be disabled. Now we are tired of him,"* while Participant 10, a 38 year old woman who had had a stroke said, *"If I need help with something, people are saying 'These disabled people are a problem.'"* Additional examples of more overt discrimination emerged. Participant 28, a 50 year old woman whose leg had been amputated as a result of cancer reported, *"The problem I have is that when I am walking in the streets, people are speaking about me and pointing fingers at me,"* while Participant 18, a 19 year old man with athetoid cerebral palsy reported, *"They (neighbours) are always laughing and pointing at me."*

Women with disabilities appeared to have faced significant forms of overt discrimination during their pregnancies. Participant 11 reported, *"I had my first child when I was 24 years old. People in my area were not happy about it. They were saying someone was abusing me and that it was a sin to be sleeping with a disabled person."* This is similar to the experience of Participant 30, who claimed that *"People are thinking that if you have a boyfriend, then you are a prostitute,"* while Participant 3 reported *"at the clinic the nurses were telling me to stop having children."* These barriers are in direct defiance of Chapter 2 (section nine) of the South African Bill of Rights (Constitution of the Republic of South Africa, 1996) which ensures the right to freedom from discrimination, including discrimination on the grounds of pregnancy and disability. While some international studies have identified similar barriers faced by persons with disabilities (e.g. World Health Organisation & United Nations Population Fund, 2009; Kijak, 2011, Jones, et al., 2010), confounded by myths pertaining to the sexuality of persons with disabilities (Brodwin & Frederick, 2010; Mall & Swartz, 2012), there is limited local knowledge on the effects that these barriers have on the individual's attempts to create a coherent sense of self.

6.1.2.2 Positioning of Physical Structures as Characters within Stories of Disability

The personification of stimulation centres, healthcare facilities, and schools served to endow structural facilities with human qualities. In this way, the participants referred to structures such that they took on the attributes of characters within the narratives.

The most commonly referred to structures were stimulation centres. Stimulation centres have been set up in a number of the larger villages over the years by individuals with disabilities, as well as by therapists employed within the area in order to provide a support base for people with disabilities. While no formal stimulation is provided here, people with disabilities appear to benefit from the peer support that they receive and the opportunities afforded to them to engage with others in similar predicaments. Initially, when I was introduced to these stimulation centres, I scathingly thought *'stimulation centre' – what a misnomer!*, because all that I could see was an empty shell of a building, with no seating provided for attendees, and no evidence of any form of stimulation. However, based on my observations and my discussions with the participants in this study, other people with disabilities, and the research mediator, I came to view these centres in a completely different light. Over the period of time that I spent in the stimulation centres, I came to view them as a representation of safety, and a place which provided a sense of meaning and belonging to people with disabilities, who, otherwise would have remained in their homes, behind closed doors, isolated and hidden from society.

The value of the support obtained at the stimulation centres is evident in many of the narratives. An example of this is articulated by Participant 4, a 29 year old male with physical and cognitive-communicative disabilities as a result of a physical attack. He said, *"At home most people say they do not want to stay with a disabled person, but here at the centre we sit together and we share ideas."* This notion of support is shared by Participant 24, a 57 year old woman with a visual and physical disability sustained as a result of an illness. She reported *"The meetings at the stimulation centre have changed my life."* In a similar way, Participant 3, a 53 year old woman with paraplegia described the benefit that she receives from the stimulation centre by saying, *"The centre built a lot of things in our minds, and now we are able to help other people like us."* This highlights the powerful relationship between mind and body, which is facilitated by peer support. The notion of the relationship between

mind and body is explained by Scheper-Hughes and Lock (1987) who explain that the body is both physical and symbolic, both naturally and culturally produced, and always representative of the history which the individual has lived. Thus, considering the notion of both disability and embodied knowledge, the relationship between mind and body is a particularly powerful construct in narrative construction.

Stimulation centres also appeared to represent a form of mobilisation amongst people with disabilities. This was evident in a conversation between the research mediator and Participant 3, where the participant said *"So your encouragement helped us. Like you said, disabled people must be helped by the government, but the government cannot visit house to house. We need to be together in a group so they know we are here and that there are many of us, then the government will come and assist us. So it worked, because the social workers came and are trying to help us to get identity documents and grants."* This extract not only highlights the notion of a common identity that is shared amongst the attendees at the stimulation centre, but significantly, the participant transforms the government from an abstract entity, to one which is personified, and to which responsibility is allocated. This is discussed in greater detail in section 6.1.2.3, in relation to the constitutional discourses that emerged within the narratives.

This notion of peer support is important and highlights the importance of finding meaning in the negotiation of acceptance of disability and the responses of others. In this way, individuals are able to find focus and renegotiate their priorities and expectations (Clarke & Black, 2005; Hinckley, 2006; Parr, 2007). The peer support offered at the stimulation centres appeared to create an opportunity for the development of group identity, and highlights the way in which finding common ground and support is extended from the sharing of life experiences to long-term social survival. Many of the participants referred to 'disabled people' as a group within their narratives, highlighting the development of a group identity. Thus, despite the numerous barriers referred to in the development of a coherent sense of self, all of the participants chose to identify themselves as 'disabled' and took on the group identity of 'disability' which in turn appeared to strengthen their sense of self. Some of the participants compared their abilities to those of others with disabilities, and in this way developed a form of positive self-representation. For example, Participant 30 reported that only once she started meeting other

people with disabilities did she realise that many of them were completely dependent on others and did not consider the fact that they could be independent. She describes how this led to a new revelation, saying *"And then I realised that I was the same, and it made me realise that if there are things that I want in life, then I can make them happen."* This is significant as it not only signals identification with other people with disabilities, but also a reflection on her own identity as a person with a disability. This highlights the value of a group identity, and reveals a shift in agency based on a positive representation of the self.

In contrast to the support received at stimulation centres, the education sector was discussed in many of the narratives, with the participants reporting consistently negative experiences. An example of this is provided by Participant 21, a 28 year old male with a congenital bilateral foot deformity and epilepsy. He reported, *"In the classroom it was bad because when the teacher was asking questions, and I failed to know the answer, he would say 'You Sichwala*[6]*, I taught you yesterday but now you forgot!' Then the students would laugh at me and I felt embarrassed."* Another participant recalls the barriers she faced in accessing education. She reported, *"The school was saying they could not admit me because that was the school for normal people. Another time they were saying, 'No, they could not admit me because I didn't have a wheelchair,'...you know, always a different story."* In this way, the participants positioned the educational sector as a barrier to educational success. While it would appear that the educational sector is fraught with challenges for people with disabilities, by placing the blame on 'the school' or 'the Department of Education' serves to absolve individuals from responsibility by shifting accountability towards the societal implementation of policies and practices.

Another example of a physical structure which was portrayed as a character was the local hospital. The most significant example of this was provided by Participant 6, a 33 year old woman who had suffered a stroke. Her narrative was dominated by psychosocial inequalities and family conflict. During a description of conflict with her mother, she reported *"I told her that I told the hospital about our relationship and the way she is treating me. I told her the*

[6] The closest translation of the term 'Sichwala' equates to 'cripple'.

social worker will come to see what she is doing to me." While it is positive to note that the participant is aware of her rights and the facilities available to her where these rights can be addressed, it is also significant to note that the hospital is provided with human qualities and is used in an attempt to conjure fear of negative consequence. By endowing the hospital with human qualities, the participant creates the notion of power and authority in an attempt to realise and assert her own human rights.

From the above, it is clear that the participants positioned physical structures in such a way as to provide them with human qualities, and in so doing, endowed their positions with power and authority. In some instances structures were positioned positively, so as to mobilise disability rights and responsibilities, as is seen in the positioning of stimulation centres and the local hospital in participants' narratives. Paradoxically, structures such as schools were positioned negatively reflecting barriers to equal rights and opportunities. As a consequence of the positioning of rights and responsibilities in relation to physical structures, constitutional discourses emerged within the narratives.

6.1.2.3 The Positioning of Constitutional Discourses in within Stories of Disability

According to Harré et al (2009) it is important to acknowledge the emergent constitutional discourses within narratives since these reflect both the historical and social situations of what people are saying and doing. Shuman (2012) adds that telling stories is a cultural resource for negotiating meaning across cultural, historical and social contexts, in which individual narratives may form part of a larger political context. Based on the above, it was pleasing to note that constitutional discourses emerged in a number of the narratives, reflecting social, political and historical shifts. This implies that information on rights and social movement programmes are infiltrating rural areas and reaching those who have previously been marginalised not only by means of their disability or geographical location, but also in terms of their access to information.

An example of shifts in government policies and practices was provided by Participant 1, a 50 year old man who has been bedridden and confined to a small room for over 40 years, when he asked *"How far have we come with our rights? Like in terms of education for people with*

disabilities?" This participant goes on to say *"It is just that I need the constitution. I need to know what it says so that I can tell other people, even my family. Then people will know, hmmm, (name of participant) knows the laws, and they will show me love and care."* While it is important that knowledge regarding rights has infiltrated the community, it is worrying to note that this participant feels that he will only be shown love and care – such basic human rights – if he has access to the South African Constitution which stipulates that all people, including those with disabilities, have rights to them (South African Constitution, 1996).

Other examples of constitutional discourses in the narratives related to laws regarding employment. Participant 2, a 45 year old man with a congenital visual impairment said *"As you know, in South Africa, we are oppressed a lot. They say we are supposed to be appointed in all offices, but then they don't appoint us."* This quotation can be explained by Harré et al (2009) who explain that by attending to the features, constraints and opportunities imposed by local context, highlights the availability of certain practices, which are determined by both, the individual's levels of competence as well as through rights and duties. Thus, it is interesting to note how the concept of oppression has infiltrated the ways in which marginalised communities make sense of their life experiences. His comment signifies his ability to distance himself and reflect on equality of rights, and limited job opportunities for people with disabilities, despite legal obligations to employ suitably qualified persons (Employment Equity Act, 1998). Furthermore, it is noteworthy that this participant refers to the third person 'they' in a vague way since it would seem that the participants do not know who 'they' are and how, as individuals, to take these issues forward.

Another example of constitutional discourse in relation to social support and employment was obtained from Participant 20, a 28 year old man with a congenital foot abnormality. He tells his story as follows: *"My story is like this. Before, I was trying to sell fruit on the side of the road. Then I met people who were chasing me, saying 'Why am I selling fruit if I am disabled? I must get the disability grant and leave the work for them.' But the problem was that every time I applied for the grant it failed. I don't know what to do anymore, because it is difficult for me to get the grant."* This highlights the fact that in some cases, social grants can be disempowering, as they create the perception that people with disabilities should live off disability grants and should not even consider finding work. This concurs with the findings of

Surender et al (2010) who also claim that high value is placed on paid employment in contrast to social security. Furthermore, the authors report defiance of the notion of learnt dependency but claim that social grant recipients ascribe to mainstream values and aspirations in terms of employment (Surender et al, 2010). The perception that people with disabilities should be content to live of disability grants is strengthened in the context of poverty where there is much competition for only a few employment opportunities, and thus, where a person with a disability endeavours to create their own employment, this is discouraged by able-bodied people.

In contrast, Participant 3, a 53 year old woman with paraplegia secondary to being stabbed in the spine during the war in Mozambique describes the freedom she obtained when she started receiving a disability grant. She reveals how she has become empowered by obtaining a disability grant, by saying, *"I told myself I have a man, and that man is the Government. He is looking after me, so why should I worry?"* Of particular interest was the way in which this participant personifies the government such that it takes on human qualities. In this instance, the government is personified in the form of a provider and protector, and this has allowed the participant to move away from abusive relationships to the point where she can be independent.

Numerous discourses regarding barriers to obtaining identity documents and disability grants emerged. Participant 9, a 52 year old man who sustained a physical disability as a result of a bilateral amputation described his anguish related to repeated unsuccessful attempts to apply for a disability grant, and went so far as to say, *"I think the government is throwing me away because they don't want me to have the ID."* In addition, many other examples of barriers to accessing disability grants emerged. These included stories about how the grant had been stopped, and the participant didn't understand why, as evidenced in this extract from Participant 8, a 30 year old woman with a cognitive-communicative disability as a result of epilepsy: *"The problem is that the grant stopped last year. It is difficult because when I go to the social work offices, they will say it failed and I will have to start again, filling the forms*

and then last time they said the problem is in Pretoria, so they told me I must go to Pretoria[7] *to appeal."* In addition, Participant 7, a 35 year old woman with a psychiatric disability displayed her angst at not receiving the disability grant, yet not being able to work as a consequence of her disability, by saying, *"The problem is that I don't receive the grant. I go to the doctors, they fill the forms, but when I go back to the social work offices to check they say 'sorry, it failed.' It hurts me a lot because if I were not sick, you wouldn't find me here. I would be working."*

The positioning of constitutional discourses within the narratives serves a number of functions. Firstly it highlights the value assigned to social, political and historical shifts as they play out in the participants' everyday lives. The most significant constitutional discourses that arose were those associated with human rights and employment and it is pleasing to see that this information has filtered down to those for whom these policies were intended – the most vulnerable in society. Social grants, specifically the 'disability grant' formed central features within many of the narratives. These were represented in both positive and negative lights, with social grants having the potential to provide people with disabilities with economic freedom and independence, but also the possibility of creating feelings of disempowerment, especially in the absence of employment opportunities. Unfortunately, in the majority of narratives, constitutional discourses emerged as having limited power, specifically in relation to the withholding of basic rights from persons with disabilities, including the right to education, employment and access to basic human rights. Significantly, the reports of barriers to accessing identity documents for South African citizens represents a gross violation of human rights and raises the question of the difficulties associated with identity development, while at the same time, being denied an official identity by the Government. This notion is discussed in further detail in Chapter 8 where I will be discussing the various types of violence to which people with disabilities are exposed.

[7] Pretoria is the administrative capital of South Africa

6.1.2.4 Summary of the Positioning of Characters within Stories of Disability

As can be seen in the discussion above, the characters that enact the participants' narratives include individual family members and community members, as well as the personification of physical structures within the community, and governmental policies and practices in the form of constitutional discourses. Furthermore, the section highlights the way in which participants negotiate their own positions as both a narrator and a main character within the narratives. These representations of the individual in relation to society serve to highlight significant differences and discrepancies between the individuals' interpretations of experience and the consequent positioning of the self within the narrative, relative to the way in which they make sense of society's responses to disability. These are shown to affect the individual's ability to present a coherent sense of self and will be discussed in more detail in relation to the spatial and temporal dimensions of narrative construction in Chapter 7.

6.1.3 COMPETING VOICES BETWEEN WESTERN AND TRADITIONAL APPROACHES TO ILLNESS AND DISABILITY

Not only were the narratives plurivocal in nature (Riessman, 2008), but many of them provided evidence of competing voices, which threatened the coherence of self-representation. This is consistent with the findings of Legg and Penn (2013a) who found that adults with aphasia living in a peri-urban township in South Africa entertained multiple explanations of causation pertaining to the onset of disability, including supernatural powers, biomedical causes and social determinants of health. One of the primary examples of competing voices that emerged in the current study related to conflicting approaches to medical and traditional African attitudes to health and illness. This is particularly pertinent in the field of disability studies, taking into account the impact that context has on beliefs regarding causation, access to treatment, and models of help-seeking behaviour. Thus, the competing narratives which emerged also appeared to be a reflection of differences in inter-generational priorities and ways of dealing with illness and disability.

Positioning theory (Harré, 1990; 1993; Harré et al, 2009) was particularly useful here, since it facilitated the understanding of causation and attitudes towards illness and health by looking at the meaning couched between and within opposing narratives instead of seeking to create a

static understanding of beliefs and responses to disability related to causal law. In this way, both temporal and causal beliefs regarding causality emerged reflecting a search for answers regarding the reasons why a certain individual had been affected by disability, why the onset of the disability had occurred within a specific time frame, and who the instigator was behind the onset of disability. According to Legg and Penn (2013a) the need to answer these temporal and causal aspects of impairment are central to the African conception of illness.

The majority of the participants produced evidence of traditional Afro-centric approaches to illness in the form of visiting traditional healers. However, these were countered with stories of seeking assistance from clinics and hospitals, reflecting a western approach to illness and disability. This type of discourse is evident in the story told by Participant 24, a 57 year old woman who acquired a physical disability in childhood as a consequence of what seemed to be an illness. She reported *"My parents took me to (name of town) hospital where I was admitted. When my grandmother heard that I was admitted she told my mother to make a plan so I could be discharged. My grandmother took me to stay with one traditional healer, but he failed to help me. From there I went to stay at another traditional healer. He cut my whole body and taught me to walk with a stick. That stick helped me to become better and strong, until you see me as I am today."*

Some of the participants reflected traditional African beliefs relating to attribution, while at the same time being treated from a western medical perspective. These perspectives are significant, given the fact that beliefs surrounding causality determine the way both lay people and professionals explain, treat and handle disability, impacting on their explanatory models and illness beliefs (Reis, 1992). For example, Participant 22, a 54 year old man with a bilateral physical deformity of his legs and feet as a result of a car accident, reported *"After the accident, while I was in hospital, my family were fighting with my wife. They said she is a witch and she caused me to be injured."* This was seen as the underlying cause of the disability, which resulted in the participant being hospitalised for two years. Similarly, Participant 9 reported *"I was sick because of witchcraft here at (name of village), so I went to (name of hospital) where they decided to cut off my feet,"* once again reflecting an intersection between traditional African and western beliefs.

While some participants aligned themselves clearly with the traditional African approach to intervention despite competing voices of western medicine, others reflected a move towards western approaches to dealing with disability. A clear example of this was produced by Participant 30. She reported *"It started when I was eight years old. So it was the polio, but in my culture we did not know about polio, so people were saying that it was umuti."* She goes on to report that *umuti* can only be treated by a *sangoma*[8] and describes her experience as follows: *"So they took me to the sangoma, and the sangoma treated it by using, you know roots and herbs to make me better and to make me stand up again….but…ah, they can't do that."* This reflects a difference in the family's approach to intervention and that of the participant. Similarly, Participant 27, a 49 year old woman who became ill in 2007 and lost the ability to walk and see, reported *"I got an illness that caused me to be like this, but my father said it was because I was bewitched."* Other participants also reported having sought intervention from traditional healers, but when no change in their condition was noted, they either terminated all attempts at intervention or sought western medical intervention. Participant 23, who has a physical congenital impairment of the right leg said *"My parents thought that it was umuti. I went to Mozambique to see traditional healers, but it didn't work, so I decided to just join the stimulation centre where I am keeping myself busy,"* while Participant 6, who had sustained a physical and communicative disability as a result of a stroke reported, *"At home, my family tried to take me to traditional healers, but it didn't work. I went to hospital where I got assistance of a walking stick and pills, so that is where I am going now to get treatment."*

These shifts from traditional African to western approaches are perhaps not unexpected, and as far back as the 1960's, Kuper (1963) reported conflict in Swazi communities between hereditary chiefs and newer forms of administration, each of which represents different values. These shifting approaches can potentially be explained by Participant 2, who reported *"In our generation we do not talk about umuti, but the older people in the past generation, they talk about umuti."* Changes in generational attitudes to help-seeking behaviours concur with the findings of Barratt (2007), Barratt and Penn (2009), and Legg and Penn (2013a; 2013b). Despite the high prevalence of disability, these varied ascriptions to the causes

[8] The term 'sangoma' refers to a diviner who diagnoses the cause of the illness/disability as opposed to directing a cure, and rely on spirit possession for their insight (Kuper, 1963).

underlying disability, particularly in the context of poverty and generalised social suffering, raise the issue of trust among community members, given the often insidious onset of disability. This issue becomes of increasing concern given the burden of care placed on able-bodied community members, not only in the context of disability, but also in the context of HIV and HIV-related deaths. Thus, not only does the individual and family have to deal with the implications of disability, but also with decreasing levels of informal social support.

While the implications of competing voices is significant since they have the potential to lower the individuals' resilience and their ability to construct a coherent narrative, caution must be heeded in seeing the world neatly divided into the western world and the non-western world (Swartz, 1998). The value of categorising individuals according to western and non-western perceptions and practices is limited since it does not reflect the diversity of beliefs that people hold, nor the commonalities that exist across different groups of people (Swartz, 1998). Thus, beliefs and practices cannot be generalized as there is much individual variation. Furthermore, Reis (1992) heeds that causality beliefs are not a static thought system, but a dynamic process which reflect changes in society. This implies that stigma in relation to disability is neither a result of traditional African or western approaches to health, illness and disability, but rather a result of deeply embedded social responses to the notion of 'difference'.

6.1.4 SUMMARY AND CONCLUSION OF CHAPTER 6

This chapter has relied on the use of Clandinin and Connelly's (2000) three dimensional narrative inquiry space and well as Harré's (1990; 1993; Harré et al., 2009) positioning theory in order to reflect on the interplay between personal and social interpretations of experience. This has highlighted the plurivocal nature of the participants' narratives, the emergence of counter-narratives, and some of the challenges associated with managing a variety of positions.

Characters within the narratives took the form of individuals, physical structures and the personification of constitutional discourses; and were positioned in a variety of ways

dependant on the participants' life experiences. Thus those who were positioned positively appeared to contribute meaningfully to the individuals' interpretations of experience and consequently had a positive effect on their sense of self. Conversely, characters that were represented negatively appeared to weaken the individuals' sense of self, leading to an inability to fulfil socially and culturally acceptable roles, resulting in narrative incoherence.

Finally, the notion of competing voices between traditional and western approaches to health was discussed. These appeared to reflect inter-generational differences of dealing with illness and disability, and provided insight into the associated cultural and personal meanings associated with help-seeking behaviours that lie between the different discourses.

The effects of stigma and isolation resulted in participants positioning themselves distally in relation to other characters within the narratives. This created a sense of difference and distance. This is significant, since it defies Kuper's (1963, p.25) notion of a "shared common identity" in the Swazi culture, between persons of similar age and sex, "to the extent that individuals can adequately serve as substitutes for one another in cases of need." In this way, the experience of disability appeared to contribute to the isolation and exclusion which adults with disabilities experienced, and also created a power differential between persons with disabilities and other members in the community. This power differential appeared to have a significant impact on the positioning of characters within the narratives, and also highlighted asymmetries relating to the geographical 'safe spaces' for persons with disabilities, as well as the impact that marginalisation, disempowerment, exclusion and social suffering have on the emotional spaces in which persons with disabilities are able to construct their narratives.

Given the fact that biographical narratives are inherently linked to time and place (Koven, 2012), Chapter 7 will delve into the effects that the temporal nature of uncertainty has on narrative construction, as well as the spatial dimensions of exclusion and inclusion, and the effects that these have on narrative coherence.

CHAPTER 7

The Effects of Temporal Uncertainty and the Spatial Dimensions of Exclusion on the Development of a Narrative Plot

'Dialogue begins in bodies before it is expressed in symbols,
and it returns to bodies once those symbols are expressed.'

(Frank, 2012, p.40.)



A home of one of the participants

This chapter focuses on the relationship between embodied knowledge, and the spatial and temporal dimensions of narrative construction, specifically in the context of social and emotional exclusion. As discussed previously, the way in which individuals position themselves within narratives develops from the sense of an embodied self within a given time and place (Hermans, 2001). This notion of the embodied self is based on the assumption that "space is not simply outside the self but also within the self" (Hermans, 2001, p.259). With this in mind, the temporal and spatial dimensions of the participants' narratives are discussed in relation to the impact that these have on the construction of a narrative plot.

As discussed in Chapter 4, the relationship between time and space are well documented as important features of narrative construction (Ricoeur, 1980; Connelly & Clandinin, 1990; Clandinin & Connelly, 2000; Riessman, 2008, Holstein & Gubrium, 2012), since they create the confines within which the story is created and told. Connelly and Clandinin (1990) stress the importance of this relationship by saying that "Time and space are not, in themselves, interpretive, nor conceptual. Nor do they represent narrative criticism. They are the thing, itself" (p.8). However, despite relatively rich literature on this topic little attention has been paid to the ways in which these constructs are developed in the life narratives of persons with disabilities, particularly those living in impoverished environments.

Given that this study took place in a rural area, factors such as poverty, poor service delivery, malnutrition, dehydration, and limited access to information are believed to have impacted on the content and structure of the participants' stories. Over and above these features of living in a rural area (Collinson, Gerritsen, Clark, Kahn & Tollman, 2007; Barratt & Penn, 2009; Collinson, 2010), the research context was dominated by high mortality rates as a result of the HIV pandemic, the rampant spread of communicable diseases, poor management of chronic conditions, limited access to healthcare services, and the effects of poverty. Thus, not only were boundaries created in terms of the challenges imposed by living with a disability in a rural area, but they were compounded by both social death related to HIV-related stigma (Meursing & Sibindi, 2000) and the temporal uncertainty of "living in a time of death".

The notion of living in the context of death became overtly clear to me during my second site visit. Over this period, I visited 18 homes, and every one of these households had experienced a death in the three days leading up to the interview. At times, interviews were set up, but days later when we arrived, the participant had died, while in other instances locations of interviews had to be changed as a consequence of a death in the family. Although Khan (2006) has extensively described the changing population patterns in rural areas and the consequent changes in mortality patterns, I was shocked and upset by the pervasive presence of death within the community and I found myself questioning how I could go on with data collection in the midst of such pain and suffering. However, despite this, the participants themselves were still keen to be interviewed and were the ones to suggest changes in times and/or venues. Thus, data collection took place under the imminent presence of death, which although only spoken about in passing, seemed to pervade the narratives. Although the participants made reference to the death of loved ones, none of them discussed the effect that this was having on the community as a whole. It is, however, likely that the presence of death may have influenced their ability to envisage themselves in the future. While attempting to deal with the presence of death within the community, and the effects that this had on the participants' narratives, I became acutely aware of the limited insight that we as researchers and as health professionals have on the ways in which the presence of death affects the communities in which we work. This concurs with the findings of Posel, Kahn and Walker (2007).

Based on the above, the notion of 'uncertainty' emerged as a prominent theme. Uncertainty has been identified as a common theme post onset of illness (e.g. Posel, Kahn & Walker, 2007) and disability (e.g. Becker & Kaufman, 1995; Parr 2001; Legg, 2010; Legg & Penn, 2013a). For many people with disabilities, especially those with acquired disabilities, the notion of 'time' and 'temporal ordering' appear to be unreliable constructs, given that the onset of disability is usually unexpected. This implies that both bodies and lives may be changed without warning, and thus the temporal ordering and the socially and culturally anticipated stages of life can neither be anticipated nor relied upon. Furthermore, living in a community that is dominated by high mortality rates also creates a feeling of uncertainty and the notion that time is unpredictable. In a study conducted locally by Posel, Kahn and Walker (2007), into community beliefs regarding increasing mortality rates it was found that community members ascribed this to social and cultural causes of death, such as poverty,

generational conflict, emotional strain, moral disorder and not adhering to social and cultural norms, rather than to biological or medical causes. Consequently, many participants displayed anxiety and uncertainty regarding the increasing presence of death within the community, as well as mistrust of fellow community members and govenrment healthcare facilities (Posel, Kahn, & Walker, 2007). This suggests that the experience of disability in the South African context may evoke a heightened sense of uncertainty pertaining to contradictory perspectives on healthseeking behaviours, disintegration of the extended family, and the failure of biomedicine to overcome structural and language barriers in healthcare consultations (Legg & Penn, 2013a).

Over and above the experience of uncertainty pertaining to living with a disability, reports of persons with disabilities being confined to their homes, with extremely limited access to assistive devices, education, information and healthcare, create spatial dimensions of exclusion. This implies that persons with disabilities have limited access to places where they felt safe to live out their stories, strengthening the relationship between disability and disempowerment. Section 7.1 below will delve into the spatial confines imposed on the narratives of persons with disabilities, as well as the spatial dimensions created where persons with disabilities felt safe to tell their stories.

7.1 THE SPATIAL DIMENSIONS OF EXCLUSION AND INCLUSION

Although it is widely acknowledged that persons with disabilities are subject to exclusion from mainstream activities (e.g. Code, Hemsley, & Hermann, 1999; Hall, 2004; Parr, 2007, van Rooy et al, 2012), little is known about the way in which the physical and emotional dimensions of exclusion limit the construction and telling of stories. Literature reflects that physical access to buildings and public transport, limited opportunities within the employment sector, and access to education and information act as barriers to inclusion (Hall, 2004; Loeb et al, 2008; Sloane & Jones, 2012, van Rooy et al, 2012). While these barriers are acknowledged, local reports of persons with disabilities being confined to their homes and hidden from society highlight the extent of exclusion (Ingstad, 1999; Loeb, et al, 2008). This highlights the fact that exclusion may be both active and passive (Sen, 2000) and in this way,

the notion of exclusion is extended beyond the physical domains to also include the impact that emotional and psychosocial barriers have on individuals' interpretations of experiences.

Social exclusion is described by Madanipour, Cars and Allen (1998) as,

> "A multi-dimensional process in which various forms of exclusion are combined: participation in decision-making and political processes, access to employment and material resources, and integration into common cultural processes. When combined, they create acute forms of exclusion that find a spatial manifestation in particular areas." (p.22)

Based on the definition above, the relationship between poverty, disability and social exclusion has the potential to lead to impoverished lives (Sen, 2000). Impoverishment as a result of social exclusion is especially prominent in rural and under-developed areas, particularly in the context of poverty (Barratt & Penn, 2009). This is expanded on by Sen (2000) who claims that social exclusion pertains to the inability to appear in public without shame, and claims that the consequences of exclusion may limit the individuals' opportunities to take part in the life of the community. In addition, given that rural areas are characterised by a lack of service provision, poor roads, and generally poor infrastructure (Collinson et al, 2007), inclusion into mainstream activities is difficult for persons with disabilities, further implying significant barriers to accessing assistive devices and support groups. This in turn creates a deepened sense of isolation and thus strengthens the relationship between disability and disempowerment.

Section 7.1.1 will focus on the physical and emotional dimensions of exclusion which emerged within the participants' stories. This is followed by section 7.1.2 which discusses the contexts where participants felt safe to both live and tell their stories.

7.1.1 The Physical and Socio-Emotional Dimensions of Exclusion

Within this study a variety of factors impacting on the physical dimensions of exclusion emerged. These included the effects of reduced mobility, as well as the ways in which limited access to assistive devices impacted on individuals' access to support, education, healthcare, and social support grants. A number of the participants, specifically those with physical disabilities were confined to their homes. While these participants were not necessarily purposefully 'hidden' from the community, the nature of their disability, together with limited access to assistive devices meant that they were restricted to their homes and isolated from mainstream society. An example of this was seen with Participant 1, a 50 year old man who has been bedridden for over 40 years after a slow, progressive onset of a physical disability. This participant lives in a small village approximately 60km from the local hospital. As a result of the nature of his disability, as well as his distance from the hospital, he did not have any type of assistive devices, and thus remains confined to his bed and dependent on his sister for help with activities of daily living. The emotional effects of these constraints were apparent where the participant stated *"it is difficult for me, especially when I am thinking that I am not walking, not going outside, always in the house like a dead person."* Furthermore, the effects of these restrictions become evident where the participant expresses his desires, including *"I still have hope that you will help me to be exposed to people"* and *"For me, I would like to be educated, like to learn how to read newspapers. As long as you are in this world you need to be educated, but my problem is that I can't sit."* The impact of exclusion culminates where the participant states *"For me, I can say that I have never received the help that I need"* and where he laments *"difficulties in life can make you unhappy, sometimes thinking that you must rather die."* In this way the participant's embodied knowledge regarding his physical constraints, are transformed into severe psychosocial and emotional forms of exclusion. In a similar way, Participant 18 describes how he remains confined within his home because the neighbours *"laugh and point"* at the way he moves. He reveals his lack of agency in dealing with the situation where he describes how he spoke to his mother and she said *"Let Jesus be the one to judge them."*

Government facilities, specifically the offices where identity documents and disability grants are applied for and issued, were commonly discussed as physical arenas in which people with disabilities were excluded from mainstream society. Many participants reported applying numerous times for identity documents, or reported experiencing long waiting periods before

receiving them. This does not only serve as a barrier to constitutional rights (South African Constitution, 1996), but it also serves as a barrier to identity construction for persons with disabilities. It is widely acknowledged that persons with disabilities, specifically those with acquired disabilities, face a renegotiation of identity construction (LaPointe, 1999; Code, Hemsley, & Hermann, 1999; Hinckley, 2006; Parr, 2007), and thus, the withholding of an identity document from a South African citizen serves to challenge the interpretation of their value to society.

In a similar way, barriers were faced in relation to accessing disability grants. An example of this is seen where Participant 8 describes how her grant was suddenly terminated. She says *"It is difficult. I went to the social work offices and they said 'sorry, it failed.' So then they said I must apply again. Then another time they said I need to go to Pretoria to appeal."* Similarly, Participant 7 reports *"I don't receive the grant. I go to the doctors, they fill the forms, but when I go to the social work offices to check, they say 'sorry, it failed.' They don't explain to me what is happening."* Both of these examples highlight how exclusion occurs within the spatial dimensions of the social welfare offices, and how the emotional effects of this type of exclusion impact on the participants' financial wellbeing.

The education sector was another physical arena where many of the participants experienced exclusion. An example of this is seen in Participant 30's narrative where she recalls how her lack of a wheelchair resulted in her being prevented from attending school. She recalls how her mother approached the school principal requesting that she be accepted into the school, but the principal responded, saying *"No, this is a school for normal children, not for disabilities. She can't come to this school because she doesn't have a wheelchair."* This excerpt highlights the notion of 'difference' which many members of society assign to persons with disabilities. Furthermore, it highlights how lack of access to assistive devices impacts on the individual's rights to education. In a similar example, Participant 25, a 28 year old female with a congenital absence of the arms and legs, reports *"I couldn't go to school because I didn't have a wheelchair…so my sisters were teaching me when they came home from school."* In these examples, exclusion results in a physical limitation for participants, so that they are unable to leave their homes or to engage in mainstream activities. Furthermore, the lack of access to assistive devices which results in exclusion from the education sector

further contributes to the high levels of unemployment among persons with disabilities. Therefore, limited employment opportunities do not only relate to difficulties in job creation or in the attitudes of employers towards hiring persons with disabilities, but also in terms of access to educational opportunities for persons with disabilities. This concurs with Sen's (2000) claim that unemployment can be a major causal factor predisposing people to social exclusion, since the exclusion does not only pertain to economic opportunities but also to the individual's opportunities to participate in the life of the community.

An additional arena of exclusion was seen in terms of access to healthcare. An example of this was given by Participant 12, a 36 year old man who had his leg amputated after a car accident. He describes returning home after being discharged from hospital and says *"The problem was that we did not have any money and my mother was not working. I had plaster bandages on my legs and at the hospital they told me to come back so that they could remove them. I decided to be my own doctor. I took a saw and cut them off. There was one young boy who was helping me. I also removed the wires that were coming from my leg after the operation."* In this extract the relationship between poverty and limited access to healthcare facilities is clear.

Many other similar examples were provided by women who had borne children. These narratives revealed barriers associated with physical access, as well as barriers created as a result of nurses' perceptions of women with disabilities. This is seen where Participant 3, a 50 year old woman with paraplegia as a result of a stab wound describes the barriers that she faced in accessing healthcare services while she was pregnant. She discusses the lack of emotional support received from her partner, and the expenses incurred when she asked community members who owned cars to transport her to the clinic. She says *"So my neighbour was helping me a lot, pushing me to the clinic for check-ups…but oh! It was embarrassing for me to be pregnant. I was afraid of myself, the way I was, and the nurses were asking 'who did this to you?' Like as a disabled person I was not supposed to sleep with a man, like I looked like an animal."* In this narrative, the relationship between physical barriers and stigma created by society is evident.

Exclusion was also reported in terms of participating in socially and culturally acceptable events. An example of this is seen, where Participant 30 describes her hesitance to attend weddings within her community. She says, *"People in the community, they look at you like you are an animal, laughing and pointing like it is the nonsense thing, like a show. So when you are going to a party, like a white wedding*[9]*, all of them are looking at you. So me, I am not comfortable going there."* These findings concur with those of Niehaus (1995), who reports that people with disabilities are often viewed as lacking in discipline and constraint and thus are likened to animals that cannot suppress or control their desires. In this way it becomes clear how, in addition to the physical dimensions of exclusion, emotional dimensions of exclusion emerged. These materialized in a number of different ways. The most common form of emotional exclusion was through the loss of friendships as a result of disability. While this did not appear to be a significant factor for all participants, a number of them did report that they had either lost friends or that the nature of friendships had changed post onset of the disability. This is evident where Participant 4 states *"It is no longer the same like the past because they (friends) ignore me, saying 'what can they do with a person that can't walk, not active anymore? Nothing.'"*; while Participant 6 said *"Since my friends heard that I am injured they never came to visit me."* Similarly, Participant 10 states *"My friends are still coming to visit me, but not all of them. Even though they visit me, it is not the same as before."* These experiences of altered friendships and social relations appeared to create a sense of isolation and marginalisation amongst participants. This is evident where Participant 1 says *"Most of the time I am alone"* and where Participant 6 says *"I am used to being alone now."*

The description above provides insight into the spatial and emotional dimensions of exclusion which serve as boundaries within which people with disabilities make sense of their experiences and create and tell stories about their lives. Thus, despite renewed calls locally and internationally for equitable access to services such as healthcare and education (White Paper on a National Integrated Disability Strategy, 1997; United Nations Convention on the Rights of Persons with Disabilities, 2006; Tumwine, 2007), people with disabilities continue

[9] In many African cultures couples getting married will have both a 'traditional wedding' in which traditional rituals are performed and traditional clothing is worn, as well as a 'white wedding' which is more representative of a western celebration. During a 'white wedding' the bride wears a white wedding dress (Smith, 2001).

to face physical barriers to equitable opportunities in a variety of ways. This is particularly worrying, given the fact that in South Africa, many people with disabilities continue to be confined to their homes, hidden from society, with limited access to social, political or economic freedom, thus contradicting their constitutional rights (South African Constitution, 1996).

The physical barriers to inclusion described above, are further impacted on by the limitations imposed by temporal boundaries, which are discussed in section 7.2 below. However, prior to reviewing the nature and effects of temporal dimensions on narrative construction, I will discuss the 'safe spaces' which persons with disabilities created in order to tell their stories.

7.1.2 'Safe Spaces' and the Physical and Emotional Dimensions of Inclusion

Despite the restrictions imposed by the spatial and emotional dimensions of exclusion, the very fact that all participants, regardless of the nature of their disability or the life experiences which they had endured were able to tell their stories implies that they were able to create a spatial and emotional context in which they felt safe. While this may have been partially impacted on by the fact that interviews took place in naturalistic environments which had been chosen by the participants themselves, it is also important to consider the value of creating a safe 'emotional space' where participants felt that their behaviours, thoughts, actions and physical attributes would not be judged. The notion that only certain stories may be told in specific contexts, while others are withheld (Frank, 1995; Riessman, 2004), is important to consider, given the trustworthiness and generalisability of the findings, as well as in the clinical implications of the study.

Churches and stimulation centres appeared to be the primary physical locations where participants felt safest to live out their stories. This is evident where Participant 7 says *"At church they treat me well, even giving me a chance to be master of ceremonies."* Participant 30 also highlights how the church was both an arena of inclusion and exclusion for her, where she states *"For me, I am feeling comfortable when I go to church. But even at church, some people are making me to feel depressed, saying 'shame, shame', but others are just saying "hello, how are you" treating me like a normal person."*

All participants who attended the stimulation centres displayed a sense of inclusion and group identity. This is seen where Participant 4 claims *"At home, most of the people don't want to stay with a disabled person, but here at the centre we sit together and share ideas. They put ideas in my mind and teach me new skills. So it is here that they encourage me to live the life that I want."* Similarly, Participant 3 says *"The centre built a lot of things in our minds…and now we are able to help other people like us. Although we have different challenges, we are all getting benefit. So even those that are struggling with ID books and disability grants, we encourage them to participate."* This quote demonstrates the ways in which institutions have the ability to contribute towards individual freedom (Sen, 2000) and highlights how the sense of group identity and belonging has facilitated a change in mind-set of many of the people attending the stimulation centres, instilling in them a sense of purpose. Participant 3 laments the physical dimensions of exclusion but returns to discussing the value that the stimulation centre has added to her life. She recalls *"There was a time when it was difficult for me to attend the centre because there was no one to push my wheelchair. Then one woman lent me her grandson to push me every day. Since then I am coping and enjoying life. So now, each of us who are getting the pension pays R20 per month to pay for food, and we are even able to pay the one who is cooking. It is just that those who are not getting the grant are asking when the government will think about them? So me, I am just encouraging them to be patient, and maybe one day they will get it."* This excerpt from the narrative highlights the value of group support, and reveals how, through the development of a common identity and purpose, the attendees at the stimulation centre have been able to create employment. However, in the midst of this positivity and sense of inclusion, constitutional discourses emerged, creating divisions between those who have been deemed 'disabled enough' to obtain disability grants and those who are not.

Finally, the settings where interviews were conducted and the 'emotional context' created in these interviews could have been viewed as either facilitating or hindering participants from telling their stories and providing insight into the reality of living with a disability in a rural area. While some participants revealed relatively little about themselves, the majority provided indications of the harsh reality of life in their communities and in this way, challenge the existing narratives and models of disability. These realities included, among

others, high mortality rates, the experience of interpersonal violence, the sense of being discarded and rendered 'useless' as a result of living with a disability, and the effects of poverty and social suffering. As an outsider, I was surprised by the pragmatic way in which participants described their experiences, and the honesty with which they recalled experiences of physical and emotional trauma. However, when I considered the fact that the research mediator was conducting the interviews, and she was known to all of the participants, I realised that this served as a form of narrative facilitation, since many of the participants were comfortable with her. Furthermore, as a woman with a disability, she has personally experienced many of the same experiences that the participants discussed. This was captured in the phrase used by five of the participants where they described their friendship with the research mediator to me by saying, *"wati bonke buntima bami"*, which in English can be translated to *'She knows me in my darkest places.'* This phrase implies a sense of shared knowledge which could not have been forged through an interview with an unfamiliar person. This relates to MacIntyre's (1981) notion of the socio-cultural context in which narratives are reconstructed in relation to "an implicit system of units and rules" (p.81). While the stories that emerged may have remained unspoken had the research been conducted in a less familiar setting or with a different conversational partner, the shared experiences between the participants and the research mediator served to create a 'safe space' in which participants were free to bear witness to their embodied experiences and talk about their lives.

In section 7.2 below, I will discuss the impact that temporal boundaries place on the development of narratives amongst persons with disabilities, and how, together with the spatial restrictions they impact on the development of a coherent narrative plot.

7.2 TEMPORALITY AND EMBODIED KNOWLEDGE: ATTEMPTS TO TRANSFORM LIVED EXPERIENCE INTO SPOKEN LANGUAGE

Carr (1986) states that in order to produce a 'coherent whole' a narrative requires a combination of past, present and future tense, each of which is mutually dependent on the others. This is expanded on by Mead (1934), who states that our ability to construct our pasts

in anticipation of our future is dependant on the development of a spatio-temporal-interpretive framework. Memories of the past and anticipations of the future have the potential to change as a consequence of the reframing effects of positioning during a passage of interaction (Mead, 1934). Mead (1934) claims that the past must be reconsituted in order for there to be continuity, and that unexpected events may cause problems in bridging contingent factors.

In this study, narratives were grouped in relation to tense according to the participants' use of present-tense and past-tense verbs (Riessman, 2008). It is acknowledged that since the data were collected in SiSwati and translated into English, the correct identification of verb tense was dependent on accurate translation as well as the participant's command of language. For this reason temporality was also viewed in relation to whether narrative events related to past or present experiences (Riessman, 2008), and whether the speaker displayed an ability to shift between temporal orientations within their narrative.

Within the sample of 30 participants, 20 of the narratives were told primarily in the past tense, while a further 10 were told primarily in the present tense. The fact that as many as a third of the narratives were told in the present tense is interesting since literature reflects that biographical narratives are usually told in the past tense (Riessman, 2008; Connelly & Clandinin, 1990). Although many of the narratives revealed some degree of overlap (for example where a narrative was told predominantly in the past tense, with some reference to the present and vice versa), on the whole, participants revealed a lack of fluidity in their ability to move between past, present and future. This is significant since Connelly and Clandinin (1990) state that even within a biographical narrative, there should be evidence of the ability of the narrator to shift between past, present and future, given that "the past conveys significance, the present conveys value, and the future conveys intention" (p.9). Koven (2012) adds that irrespective of the tense that a narrative is constructed in, it is important to identify how the storyteller relates that event to their current positioning in the present.

7.2.1 Stories told in the Past Tense

Most of the stories that were told in the past tense belonged to participants who had acquired disabilities. This is perhaps not surprising since the onset of a disability represents biographical disruption (Wilson, 2007; Damar & Du Plessis, 2010). However, all of participants whose stories were told in the past tense revealed an inability to create temporal shifts between past, present and future. This may be indicative of difficulties in moving beyond the traumatic experiences of their pasts (Frank, 1995). This implies the ability to only interpret the present in relation to the events of the past, with an inability to anticipate the future (Frank, 1995).

In instances where the participants' stories were told in the past tense, they typically were able to construct clear temporal and spatial boundaries pertaining to the onset of the disability. An example of this was produced by Participant 22, who sustained a bilateral deformity of his legs as a result of a mining accident. His narrative began with the following description of the onset of his disability:

> *"I became disabled in March 1995. There were many of us who were injured in Witbank[10]. I was taken to Kalafong[11]. They wanted to cut off my legs, but one German doctor refused. They did three operations, but I remained like this. I was admitted from 1995-1997. At work they gave me light duty until 1998."*

Notably, the participant begins his narrative by focussing directly into the onset of the disability. While this was undoubtedly a life-changing event for him, it is surprising that his description of events are clipped and to the point, devoid of all emotion. As can be seen in the excerpt above, the narrative is clearly demarcated in terms of year of onset of disability, the geographical location associated with the onset of the disability and the prominent characters during his life at this time. However, the participant is never really able to move his narrative beyond the past tense, and all other life events are interpreted in relation to the onset of the

[10] Mining town in the Mpumalanga Highveld
[11] Name of a hospital in the Gauteng Province

disability. The participant highlights this where he recalls how his wife left him shortly after his injury, and how his family accused her of bewitching him, causing him to become disabled. These descriptions of past events reflect not only the spatial boundaries in the narrative, but also the emotional boundaries which constrain the participant and prevent any form of active reflection on the present or anticipation of the future. Thus, the uncertainty evoked by the onset of his disability appears to have tainted his ability to 'live' in the present. This is evident where the participant discusses the fact that he remarried after the onset of his disability, but his thoughts have remained contaminated by the fear that his current wife will also leave him. This suspicion is heightened, due to his awareness of community members questioning his current wife, saying *"'...but he is disabled. What can he do for you?'"* The participant reveals a sense of vulnerability because of his disability, and due to the fact that he is unable to walk, he cannot follow her to find out if his fears are warranted. Thus his feelings of uncertainty are compounded by the limitations imposed by the spatial dimensions reflected in his narrative. As a result, his narrative repeatedly returns to the onset of his disability and the life-altering effects that this has produced, both on his body and on the socio-emotional aspects of his life.

In this narrative, it is apparent how the combination of an acquired disability with resultant changes in the participant's body, together with the uncertainty evoked by time and space, create narrow boundaries for the interpretation of experiences. In addition to contextualising the narrative relative to the geographical location where the disability was acquired, and the current confines that the participant finds himself in, the narrative is told both in the context of poverty, and in relation to cultural norms and values. The influence of psychosocial issues in the context of poverty appears to emerge where the participant reports that his main challenge is that his family is poor, making it difficult for them to afford to buy food. These psychosocial issues are further impacted on by the cultural models of causation which emerge, as seen where the participant discusses his family's belief that his wife bewitched him, causing him to be disabled. The discussion of bewitchment underlying the cause of disability, despite the impairment being treated in a hospital, once again highlights the interplay between traditional African and western models of causality and help-seeking behaviours.

A second example of a narrative told in the past tense is produced by Participant 7, a 35 year old female with a psychiatric disability. Although this participant begins her story in the present tense, describing the village where she lives, her family members are, and the fact that she has two children, she rapidly directs the story towards the past tense. She reports that her disability started *"In 1998, after getting a child"* and in this way creates a finite temporal boundary in relation to the onset of the disability as well as the associated emotional boundary of giving birth to a child. She then recounts the embodied changes that took place, including her inability to walk as she had previously, her inability to cook for her family, and more recently, her inability to feed herself as a result of severe tremors. This lack of independence appeared to have resulted in negative reactions from her family and community, which she recounts by saying *"from then, people were always laughing at me, calling me stupid."* Furthermore, her lack of financial independence appeared to limit her social engagements. She describes this by saying *"so then, my father started to take my R240 child grant, because when I get the money, I just use it. The truth is that I was forgetting about my children and mieliemeal*[12]*."* The participant reveals the ability to reflect briefly on the present, but this is done relative to her experiences in the past where she was more independent. This is seen towards the end of the interview, where she says *"so now I just keep quiet and think about my past, about the time when I was ok, thinking that maybe now, I could even have been working."*

Once again, in this narrative, the participant initially provides a clear temporal orientation towards the onset of the disability, but all other experiences are interpreted in relation to the past. Thus, the remainder of the temporal boundaries of the narrative are blurred as the participant has difficulty in moving between past, present and future experiences. The spatial boundaries that are created within the narrative include the participant's home, the clinic and hospital, and her church. Significantly, it is only in church where the participant reveals a sense of being accepted, resulting in a brief opportunity to reflect on the present. This is evident where she says *"it is only in church where they treat me well. Like now, we are divided into groups and we visit house to house, and they even give me a chance to be master of ceremonies."* Despite the fact that the participant introduces various spatial locations into

[12] 'Mieliemeal' is the local term for 'porridge' which is produced by grinding maize and is the staple diet within the community.

her story, these remain fragmented due to a lack of narrative coherence as a result of her inability to shift between the various temporal dimensions. This is further complicated by the effects of poverty, social inequality and limited access to information, as observed where she recalls the difficulties associated with accessing a disability grant, and her confusion regarding the mixed messages that she gets about how to take her medication from the clinic and the hospital.

It would appear that the unpredictable nature of time underlies the fragmented nature of the narrative. This unpredictability reaches its crux when the interviewer asks the participant if she plans to marry, and she responds by saying *"I cannot marry. I am disabled now. I just tell them, 'I will die on you.'"* This brief excerpt highlights the embodied unpredictability of living with a disability, as well as the unpredictability of living in the context of death. In this way, the participant alludes to the fact that death is something which is almost anticipated. Thus, the unexpected onset of her disability, the unpredictable bodily changes that have occurred, and the narrow spatial domains in which to actively engage in social activities, limit the boundaries within which her narrative is told, thus threatening narrative coherence.

Despite MacIntyre's (1981) suggestion that even in the presence of unpredictability, narrative reconstruction allows for continuity to be maintained, many of the participants in this sample were unable to move their narratives beyond the past tense as a consequence of embodied threats to the anticipated nature of time. Thus, the temporal and spatial limits imposed on the narrative appeared to impact on the personal and social interpretations of experience, revealing the participants' vulnerabilities. Subsequently, life events were interpreted and described not only relative to experiences of disability, but also through a lens of suspicion and mistrust.

7.2.2 Stories told in the Present Tense

Stories told in the present tense appeared to reveal the participants' inability to create a reflective space in which to integrate events of the past and to anticipate the future. As a result, these participants appeared to be caught in the unbearable present (Frank, 1995), revealing a sense of urgency in the present as well as a sense of vulnerability and futility.

Where stories were told in the present tense, participants typically began by launching directly into the challenges and difficulties with which they are faced. Most of these were created by the boundaries imposed by context and appeared to reflect psychosocial inequalities. For example, Participant 20, a 28 year old male with a bilateral congenital deformity of both feet, began his narrative in the present tense, stating, *"The biggest problem is that I am not working."* He goes on to say that because he is from Mozambique and does not have a South African identity document, it is difficult for him to find work, while at the same time, he does not qualify for a disability grant. He interprets this lack of ability to work in relation to his embodied experience of disability, saying *"You know, when you approach people they are saying 'this one is disabled. What is he going to be able to do?'"* These types of responses seem to have resulted in him resorting to dependency, stating *"So the only thing I can do is to ask my brother for R100 per month so that I can buy 12.5kg mieliemeal, so at least we can eat."* In this way, it is apparent how the lack of employment opportunities is integral to both his sense of self, as well as his ability to financially sustain himself and his family.

In this participant's story, the temporal orientation is limited to the immediate urgency of the present, embedded within financial uncertainty and food insecurity. It thus becomes apparent that the limitations imposed by poverty constrain his ability to plan ahead or anticipate the future, and the narrative reveals limited reference to his embodied knowledge as a person with a disability. While this may be due to the fact that he has a congenital disability and therefore, his embodied experiences have always been in relation to his disability, an "over-determination of troubles" (Frank, 1995, p.99) emerges, whereby all life experiences are interpreted in relation to food security. Through the telling of this story, limited to the "incessant present" (Frank, 1995, p.99), the participant reveals his anxieties, creating an emotional context of vulnerability and futility in relation to his dependency on his brother. Added to this, the unpredictable nature of time and concerns regarding where his next meal will come from appear to prevent any form of reflection on the past or anticipation of the future.

A second example of a story told in the present tense is produced by Participant 1, a 50 year old male, who is bedridden and has been confined to a small room for over 40 years. While his narrative begins with some reflection of the past, specifically in relation to the onset of his disability, it rapidly returns to the present and the emotional and psychosocial difficulties that he faces. Thus, while the temporal boundaries are predominantly limited to the present tense and the participant is physically restricted to the confines of his room, he is able to create distinctive emotional boundaries through which his experiences are interpreted. This is seen near the beginning of the interview where he reflects on his experience of embodied knowledge, by saying *"As disabled people, we are not sick in our minds. Mentally, we are thinking ok, we are just physically challenged."* However, the combination of his embodied experiences, limited access, and denial of basic rights are compounded by emotional barriers, evident where the participant says *"Sometimes I need to go to the toilet and there is no one in the house, so it is a problem for me. That thing makes me not want to continue with life. You know, these difficulties, they come and they make me to be unhappy, making me think that maybe it is better if I die."* In this way, the participant alludes to the futility of his situation as a result of the barriers imposed by his disability and the spatial confines within which he exists.

The emotional limitations described above are compounded by the psychosocial barriers that the participant is faced with, specifically the barriers to obtaining an identity book. This is revealed where he states that he applied for an identity document numerous times before it was issued and that he had waited in excess of 10 years since time of initial application to receive it. He reflects on this, stating *"The problem is if you are disabled, you are nothing. You are the last thing to think of. Even the ID people don't follow up because they think I will get a disability grant and they won't."* Despite the fact that this participant did eventually receive his identity document and subsequently was able to apply for a disability grant, his narrative remains in the present tense, and seems to reflect a sense of mistrust in the government.

This story highlights how emotional boundaries are compounded by the psychosocial inequalities which the participant faces. This raises the question as to what degree it is possible to create a coherent sense of self in the context of being denied an official identity

and attendant rights, and consequently what possibilities remain in order to create a coherent narrative that moves and entails possibilities, under such circumstances. In this way, the participant also reveals a sense of vulnerability and futility, which limit reflection on the past and provide a sense that the future is not worth anticipating.

The examples provided above of stories told in the present tense highlight how the creation of temporal and spatial boundaries contextualise the life experiences of persons with disabilities and reveal a sense of vulnerability and futility which limit their abilities to reflect on the past and imply a future not worth contemplating. These appear to have a direct effect on the individuals' abilities to create a coherent narrative.

5.2.3 The Absence of an Envisaged Future

None of the participants within the sample revealed any indication that they could envisage a future for themselves as individuals or as a collective in terms of a future for their community. While it is acknowledged that some participants did give an indication of goals that they would like to achieve in life (for example, Participant 1 said *"For me I would like to have an education"*, while Participant 3 stated *"I would like to travel alone")*, the participants also gave reasons why they believed they would not be able to achieve these goals. As a result, this seemed to influence their abilities to create futuristic intentions.

Markus and Nurius (1986) studied individuals' perceptions on future and possible selves and found that the notion of anticipating a future for oneself is both distinctly personal and social. Personal and social interpretations of experiences thus have the potential to affect the individuals' ideas of who they may become, what they may become, and what they are afraid of becoming (Markus & Nurius, 1986). Thus, the lack of envisaged futures which emerged in the current study could relate to the impact that stigma, isolation and disempowerment have on people with disabilities, resulting in a sense of being unworthy of anticipating the same type of future that other members of the community may envisage. This is alluded to where Participant 30 states *"I thought that it was only for normal people to love each other."* Furthermore, the participants' life experiences and the temporal and spatial boundaries imposed by these experiences have the potential to threaten the opportunity to envisage a

future. As highlighted in sections 7.2.1 and 7.2.2 above, where stories were told in both the past and present tense, the participants portrayed a limited ability to shift beyond the tense in which the story was told, implying a future not worth contemplating.

In addition to the boundaries imposed by disability and physical context, the participants' narratives were impacted on by the imminent presence of death, and thus its manifestation needs to be considered when attempting to understand embodied experiences of living in these circumstances. As far back as 1983, Riley suggested that death was taking on new meanings for both the individual and society (Riley, 1983). In a similar time period, Aries (1981) described how the dying no longer have control over their death. In the past, the dying were able to preside over their last days, saying their farewells, giving blessings and seeking pardon and thus approached the end of life in ways that had been observed since childhood and were not feared (Aries, 1974; 1981). In contrast, given the HIV pandemic and its associated stigma, the spread of communicable diseases and barriers to accessing appropriate treatment, death is now considered unpredictable, Furthermore, given the stigma associated with conditions such as HIV, many dying people remain hidden in medical institutions and managed by healthcare professionals who try to create their own concept of acceptable deaths (Ramphele, 1996).

Given the interplay between traditional African and western models of healthseeking behaviours discussed in Chapter 6, the conditions of dying in hospital may be considered to be inhumane and solitary, and are in contrast to traditional African rituals pertaining to death and dying (Ramphele, 1996; Meursing & Sibindi, 2000). As a consequence of a 'solitary death', the experience of grieving may thus also be expected to be solitary. For persons with disabilities, given their experiences of isolation and marginalisation especially in the context of death and dying, it is possible that they may anticipate a solitary death, fearing that they may not be mourned and may not be remembered after their death. This would imply a future not worth anticipating if it ultimately implies no future in the next life (Knox, 2008).

7.2.4 Summary of the Relationship between the Spatial and Temporal Dimensions of Embodied Knowledge

Sections 7.1 and 7.2 describe the spatial and temporal boundaries which serve as markers that delineate the context within which narratives are told and to whom they may be told, revealing the link between uncertainty, vulnerability and isolation and their effects on social support. The effects of the spatial and temporal boundaries on narratives of vulnerability, uncertainty and isolation relate to Shuman's (2012, p.129) notion of the 'tellability' of a narrative, implying that physical, social and emotional boundaries create the context within which stories are told.

While the literature reflects that narratives usually consist of a past, present and future (Markus & Nurius, 1986; Koven, 2012), the narratives in this study reflected participants' difficulties in creating temporal shifts, thus fixating the stories and limiting them to either the past or present tense. This resulted in a lack of fluidity between tenses, and obliterated the possibility of an envisaged future. The nature of narratives appeared to be divided into those that were told in the past tense and those that were told in the present tense. Koven (2012) reports that participants may describe neutrally, parts of events that occurred in the past, allowing the speaker to distance him/herself from an event by confining it within the boundaries of time and space, removed from the present. Alternatively, the speaker may produce a narrative in the present tense, and in this way minimise the boundaries of time and space in relation to when the event occurred, thus establishing an on-going reference to the 'here and now'.

While it is acknowledged that distinctions can be made between narratives told in the past and present, in this sample, all narratives were defined by the unpredictability of bodily changes incurred as a result of the disability. Thus, participants' own bodies appeared to be viewed as unpredictable and at times even volatile or fickle. This was further impacted on by the uncertainty created by living in the context of high mortality rates as well as the psychosocial effects of poverty. While these reveal a significant impact on embodied experiences and the ability to transform lived experience into a coherent narrative, they also provide opportunities for vulnerability, and in so doing, participants were able to reveal the reality of their lived experiences. Thus, despite the fact that participants were able to assert

their own positioning in narratives and were able to construct characters with whom they could create either proximal or distal relationships, the limitations imposed by confined and unyielding temporal and spatial boundaries resulted in a disjuncture between the relationships of characters to time and space. These disjunctures appeared to sabotage the creation of a coherent whole (Linde, 1993; Shuman, 2012), and in turn negatively impacted on the construction of a coherent narrative plot. This is significant, since Banks-Wallace (1998) states that temporality is central to the notion of emplotment, and that plots can only be created by means of negotiating events and characters in relation to time and place.

7.3 THE DIMENSIONS OF TIME AND SPACE AND THEIR EFFECT ON THE CONSTRUCTION OF A NARRATIVE PLOT

Ricoeur (1980) warns that a plot cannot be imposed but is produced by a complex moving back and forth between events and time structure until both are fitted together. It is therefore only through emplotment that the experience of time is endowed with meaning (Ricoeur, 1980). With this in mind, I was cautious in my attempts to purposefully identify and isolate plots within the narratives. I found that Clandinin and Connelly's (2000) three dimensional narrative inquiry space provided a valuable tool for identifying the disjunctures between personal and social interpretations of experience, and in the creation of spatial and temporal boundaries. This tool also allowed me to recognise the variety of narrative forms that participants produced, including stories told in the form of a chronology of events, stories in the form of numerous thematically-based episodes, and narratives that reflected no clear, discernible story.

A common feature, shared by all of the narratives was that they lacked coherence in terms of sequence and consequence. For this reason, I found that plots were difficult to identify, not only because the narratives lacked cohesion and order, but also because many of the narratives lacked reflection on the part of the narrator in making sense of the events that defined their stories. In this way, the narratives appeared to resemble Frank's (1995) chaos narrative. Frank (1995) refers to the chaos narrative as an 'anti-narrative' since it is produced without sequence, mediation, and without the narrator being able to self-reflect. This implies

that the narrative is told in the same way that the individual experiences life – without sequence or causality (Frank, 1995). Since sequence and consequence are the core components of a plot (Riessman, 2005), it follows that chaos narratives do not have a plot (Frank, 1995).

The limitations imposed by the physical and temporal dimensions of exclusion, social role devaluation, and the consequent lack of temporal coherence within the narratives appeared to reflect the participants' difficulties in constructing coherent plots. In this way, the stories told, and the excerpts reproduced in this dissertation are only able to provide limited insight into lived experience, since the pain, trauma and horror which is alluded to, is never concretised in words. Thus it remains unspoken, and the participants remain mute witnesses, not only with altered bodies, but with profoundly changed lives – physically, emotionally, socially and financially.

Although many of the narratives resonated with Frank's (1995) chaos narrative, a number of the participants made attempts to defy this type of existence. Examples of attempts to defy the chaos narrative included evidence of repeated efforts to apply for identity documents and disability grants, resourcefulness in terms of acquiring land, building homes, starting small businesses and starting stimulation centres. These attempts were, however, marred by stories of trauma, isolation, lack of support, disempowerment, limited access, violence, poverty, and food insecurity, negating any attempts to construct a coherent plot-line. These barriers, together with exposure to an overwhelming number of traumatic experiences and psychosocial inequalities resulted in weakened resilience among participants. An example of this is seen in the narrative of Participant 12, a 36 year old man who sustained a leg amputation as a result of a motor vehicle accident. He reports *"The thing that I wish for is to meet other people with disabilities so that we can share ideas or maybe start a project. The problem is that people are afraid to show up, and others don't come because people will talk. I saw that before, when I tried to start a soccer team. People started coming, but then other people in the community discouraged them because the team was started by a disabled person. My heart was so painful. I did not know what to do."* This extract reflects the impact that the community's assumptions and responses to disability have on the individual, once

again, highlighting the discrepancy between individual and societal conceptualisations of persons with disabilities.

Another example was provided by Participant 17, a 27 year old man who sustained paraplegia as a result of a gunshot injury during a hijacking. He discusses his attempts to start a stimulation centre in the village where he lives, and recalls *"I tried to start a centre here for people with disabilities. We tried to meet, but it didn't work for us. People stopped coming. They are saying they are hungry, no food to eat at home."* In this extract the effects of food insecurity become apparent, resulting in people with disabilities being forced to prioritise day-to-day survival, constrained by physical and socio-emotional limitations.

Thus, despite examples of attempts made by the participants to defy the chaos narrative, their storylines appeared to be dominated by the chaos imposed by unpredictable bodies, the effects of poverty, temporal uncertainty and the physical and spatial dimensions of exclusion. This is confirmed by Frank (1995) who states that destruction, humiliation and hunger negate the possibility of a coherent narrative, and that for individuals living in extreme poverty, life experiences cannot be anything other than chaos. Despite my agreement with this comment, the more time I spent dwelling with my data, the more uncomfortable I felt. I sensed that there was an element of originality within the narratives, yet I could not pinpoint it. This sense of uncertainty was confounded by the notion that the stories which the participants had shared with me challenged the existing narratives on disability. Underlying the experiences of trauma and disempowerment was a sense of defiance of alignment with the extant narratives and models of disability. The notion that I had missed something within the data resonates with Strauss and Corbin (2008, p.47) who state that inferences made from data should 'feel right' with the researcher. Given my predicament I returned to the principles of qualitative research, specifically that written by Morse (1994), Patton (2002), and Corbin and Strauss (2008). I resumed dwelling with my data and reading and re-reading transcripts, in an attempt to develop the sensitivity which "allows the researcher to grasp meaning and respond intellectually and emotionally to what is being said in the data and later to arrive at concepts that are grounded in the data" (Corbin & Strauss, 2008, p.41).

Eventually I realised that there was a sense of coherence within the narratives, but that this coherence did not conform to the spatial and temporal coherence stipulated in the literature (e.g. Mead, 1934; Carr, 1986; Clandinin & Connelly, 1990; 2000; Riessman, 2008), nor did it conform to the typical notions of sequence and consequence (Riessman, 2008). Instead, the coherence which seemed to be underlying the narratives was a sense of shared experience, largely pertaining to the violence which participants had embodied and internalised, and in this way a counter-narrative was developed. This is significant since Somers (1994) reports that counter-narratives "are a crucial strategy when one's identity is not expressed in relation to dominant public identities" (p.631). This will be discussed in detail in Chapter 8.

7.4 SUMMARY AND CONCLUSION OF CHAPTER 7

This chapter has highlighted how the restrictions imposed by spatial and temporal boundaries serve to limit the ways in which narratives are told, as well as the content which is shared. The dimensions of time and space appear to be significantly influenced by the context in which participants live – their access to education, healthcare, social services, information and social support – as well as the influence that poverty, food insecurity and social suffering have on individuals.

The spatial dimensions of exclusion were categorised according to physical and psychosocial barriers to participation in socially and culturally appropriate activities. The imminent presence of death within the community served to impose further restrictions on the boundaries within which people with disabilities were free to live and tell their stories. The experience of living in a 'time of death' coupled with the embodied limitations imposed by disability served to create a sense of uncertainty and vulnerability. These contributed to disjunctures between the spatial and temporal boundaries created within the stories, resulting in a lack of narrative coherence. Furthermore, the lack of fluidity demonstrated by the participants' difficulties in moving between past, present and future tenses prevented the establishment of sequence and consequence and as a result, the narratives were found to be lacking in plots. Consequently, the narratives remained as fragmented episodic events and the

ways in which participants made sense of their life experiences and revealed these in narrative terms denied adequate reflection of the past or anticipation of the future.

Based on the challenges faced in identifying plots, it is important to consider the limits of 'tellability' of narratives, and how this is affected by the individual's access to appropriate narrative resources, as well as by the limits imposed by stigma, trauma and other social and cultural implications and associations with disability. Thus it was significant to note that despite the experience of exclusion, shared knowledge between the research mediator and the participants served to facilitate exposing the reality of living with a disability in a rural area. This notion of shared knowledge seemed to allow for the dialogue of sensitive topics, such as the experience of abuse and violence to be openly discussed, whereas in a different context or with a different conversational partner, these may have been considered taboo subjects. Thus, despite the disjunctures between the temporal and spatial dimensions of narrative construction, and the lack of sequence and consequence, the narratives revealed a sense of coherence pertaining to the shared experiences of violence in response to disability. By acknowledging this reality, I propose that it is possible for new narratives of disability to emerge. These will be discussed in Chapter 8.

CHAPTER 8

Towards a Contextual Understanding of Disability: The Emergence of New Stories

"What makes a story good is the act of witness that says implicitly or explicitly, 'I will tell you not what you want to hear, but what I know to be true because I have lived it.' The truth will trouble you, but in the end you cannot be free without it."

Arthur Frank (1995, p.63)



Narrative interview outside a participant's home

In Chapter 7 I discussed the ways in which spatial and temporal boundaries defied the construction of coherent narratives among adults with disabilities, and as a result how narrative plots were difficult to identify. Part of the difficulty in identifying plots seemed to relate to my own expectations of what I assumed to be significant features within the participants' lives, as well as my own assumptions regarding how these would be narrated as 'life-changing events.' Holstein and Gubrium (2000) caution against this, stating that very often the events which an outsider may consider as life-changing differ from the way in which these are interpreted by the individual who has experienced them, and as a result, alternative narratives are produced. As I dwelt on the nature of the narratives in my sample, I returned to Frank (2012)'s caution that when conducting narrative analysis, researchers need to ask themselves what other narrative resources may lead to different stories or may change people's sense of possibility in such settings, and what may be preventing alternative resources from being mobilised.

By viewing the data set as a collective, I realised that all of the narratives did in fact reveal some form of plot, although these did not necessarily conform to traditional conceptions of emplotment as reflected in the literature (Ricoeur, 1980; Clandinin & Connelly, 2000; Riessman, 2008). The narratives reflected multiple forms of violence, and to this end, seemed to deny participants the ability to truly reflect on the past or anticipate the future. Thus, while the content of the narratives was similar to that contained within Frank's (1995) chaos narrative, a sense of sequence and consequence eventually seemed to emerge throughout the stories. The sequence was one of repeated violations of human rights on various levels, ranging from the inadequate implementation of government policies and practices, to others taking advantage of people who by nature of their disability or marginalisation would not or could not speak out. As a consequence, the participants' narratives defied the possibility of being organised within what may be considered a 'typical narrative structure'.

Despite examples of the participants defying mainstream disability identity stereotypes, repeated exposure to violence seemed to marginalise and disempower them. Frank (1995) reports that one of the features of the chaos narrative is where the "… life story ends before the narrative is over" (p.96), implying that the individual loses their need for language and consequently for themselves, once their bodies can no longer be healed or restored. The data

in this study reflected a need to speak and a need to be heard, but an inability to translate embodied experience into words. Frank (2012) also states that in the chaos narrative there are no resources for the individual to draw on, and thus their narratives remain as 'anti-narratives'. While it is acknowledged that access to resources for narrative construction were limited amongst participants in this study, it would appear that the available resources were not socially and culturally acceptable, (e.g. evidence of physical, sexual, structural violence) and as a result these experiences could not be reconstructed to reveal a sense of narrative continuity.

By providing individuals with the opportunity to tell their stories, this research put stories and voices into contact with each other and in this way allowed voices to be heard in unison, transforming the memory of traumatic experiences into dialogue. The notion of a dialogue between two or more people implies an acknowledgement of the reality to which people with disabilities are subjected. The new stories which are discussed in section 8.2 below, confront both the reality of living with a disability in a rural area, as well as societal morals and values, and the implementation of government policies and practices designed to support those who are most vulnerable in society. The content of these narratives was difficult to hear, and as a researcher I found it difficult to sit back and allow the participants to tell their stories of pain and torment, while at the same time seeing the physical and emotional effects sustained by multiple traumas, poverty and disability. Despite the effect that this had on me, my commitment was to bear witness to the reality of lived experience and to acknowledge this as the reality for the participants as well as other members of the community.

By providing adults with disabilities with the opportunity to tell their stories of isolation and alienation from society implies that they are given permission to shift from individualistic experiences of exclusion and social suffering, to a collectivist narrative, highlighting the effects that poverty, stigma and psychosocial inequalities have on the lived experience of disability. Although these narratives may be considered 'negative' because they are difficult to hear, by allowing people to align with them (or with parts of them) implies acknowledging that horrendous inequalities and systemic social ills exist, and it is only through acknowledgement that these issues can be addressed. This is of utmost importance, as Frank

(1995) states that unless the reality of lived experience is acknowledged, the individual who lives this reality is denied and "people whose reality is denied cannot be cared for" (p.109).

8.1.1 EMBODIED EXPERIENCES OF VIOLENCE

As described in Chapter 2, the experiences of various forms of violence are common in South African society (Norman et al, 2007; Matzopoulos et al, 2008), including the experience of structural, psychological, sexual, and physical violence, as well as deprivation (WHO, 2012). While Thornton (2002) points out that it is difficult to predict or anticipate violence, the literature reflects that contextual variables have the propensity to increase the likelihood of being exposed to violence. These contextual variables include poor levels of social support, financial instability, physical, cognitive or communicative impairment, and financial or emotional dependence on the perpetrator (Plummer & Findley, 2012; Ward et al, 2012). For this reason, persons with disabilities are at increased risk for being made victims of violence.

Despite the categories used to identify and classify violence, and the acknowledgement of variables that may predispose individuals to violence, it is important to bear in mind that violence, by its very nature occurs within spatial and temporal boundaries (Thornton, 2002). This implies that the effects of violence are only visible after the event has taken place. In this way, the emotional salience associated with violence has the potential to disrupt narrative plots by creating a sense of chaos, ultimately resulting in a void that cannot be filled (Thornton, 2002). This was observed in many of the narratives in the current study, and highlighted the ways in which violence violates the continuities of time, place, and social and cultural structures on which identity construction depends.

Despite indications provided that people with disabilities are more susceptible to violence than other members of the public (Nosek et al, 2001; Smith & Strauser, 2008; Powers et al, 2009; Fuller-Thomson & Brennenstuhl, 2012), society's failure to acknowledge this, has resulted in a lack of information into the causes, nature, prevalence, and experience of abuse amongst this group (Plummer & Findley, 2012; Hughes et al, 2012). Furthermore, in

developing countries, such as South Africa, violence prevention is still an emerging field within public health (Krug, Mercy, Dahlberg, & Zwi, 2002) and as such policies have failed to adequately address this need.

Krug et al (2002) report that causes of violence are complex and occur at many different levels within society. Plummer and Findley (2012) suggest that people with disabilities are at a particularly high risk of being exposed to violence through typical forms of abuse (physical, sexual and emotional) as well as violence that specifically targets their disabilities. This is because a disability makes an individual particularly vulnerable to violence as a result of exclusion from education and employment, dependence on others, reduced physical and emotional defences, communication barriers, stigma, and discrimination (Hughes et al, 2012). Furthermore, as a consequence of their compounded vulnerabilities, many people with disabilities are exposed to multiple forms of violence (Powers et al, 2009).

As described in Chapter 6, many of the participants positioned themselves in contrast to the mainstream disability identities. However, all of the participants framed their narratives relative to their experiences of various forms of violence and abuse of human rights. These are discussed in sections 8.1.1.1 – 8.1.1.5 below, in line with the WHO's (2012) guidelines for understanding the contexts in which violence may be afflicted. Figure 6 reflects how physical, sexual and psychological violence, as well as violence through deprivation, are underpinned by structural violence, and how these types of violence perpetuate the experience of structural violence through isolation and alienation. This is followed by section 8.1.2 where I discuss the impact that violence had on the participants and how this affected the way in which they made sense of their experiences, thus affecting narrative coherence. This is supported by Suarez-Orozco and Robben (2000), who state that people who have experienced violence face difficulties in narrating trauma, and consequently this challenges the 'tellability' of their narratives (Shuman, 2012).

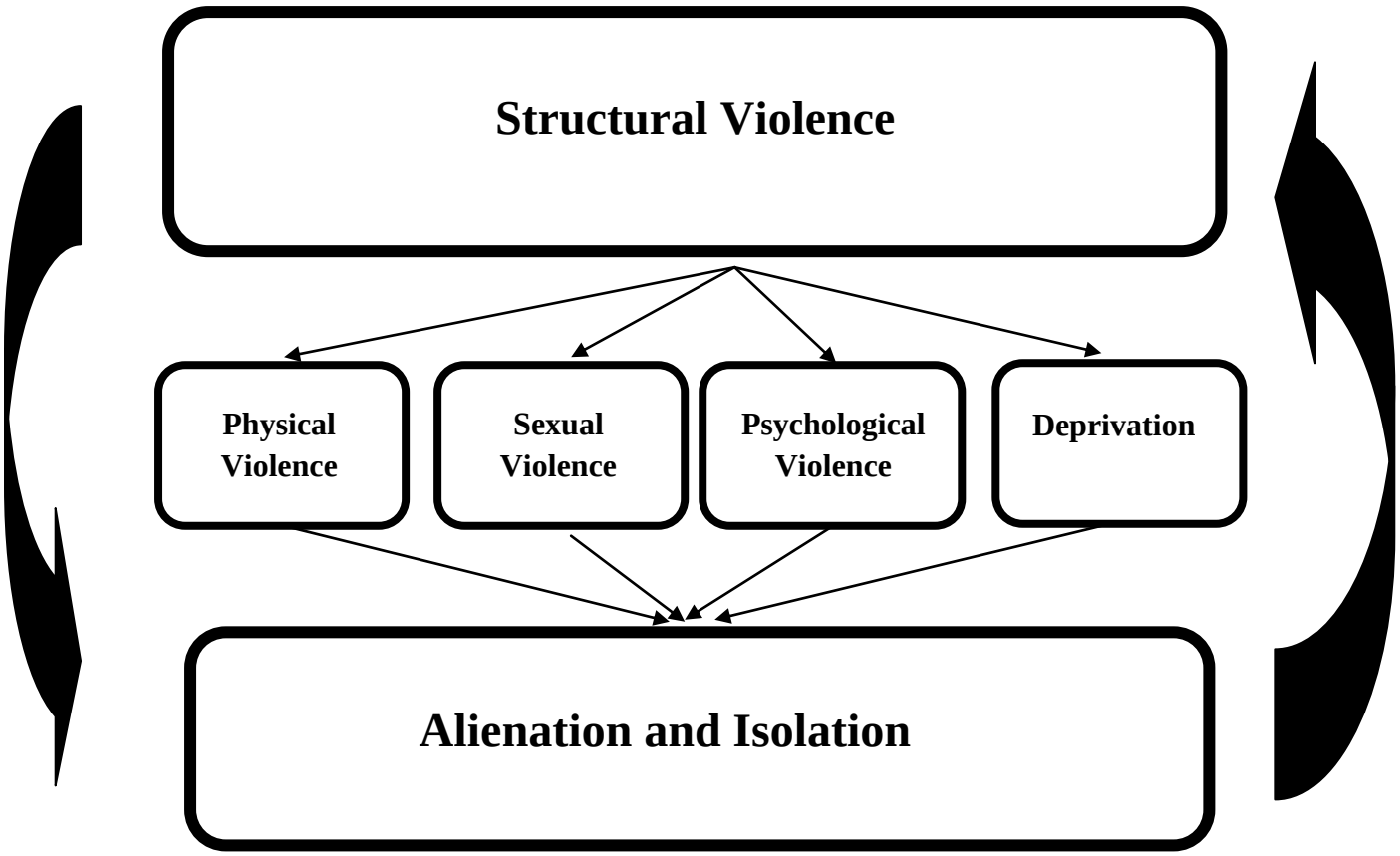


Figure 6: Visual Representation of the Types of Violence Experienced by Adults with Disabilities

8.1.1.1 *'If you are disabled, you are nothing'*: The Lived Experience of Structural Violence

Structural violence, as defined in Chapter 2, was the most common form of violence experienced by the participants. Farmer et al (2006) state that structural violence is often embedded within social structures and becomes ingrained in everyday experiences. In this way, structural violence becomes almost synonymous with social injustice and social oppression (Farmer et al, 2006). Although structural violence pertains largely to the implementation of policies and practices, it must be acknowledged that this takes place, directly or indirectly through human agency (Farmer, 1996). Farmer (1996) adds that while the poor are the primary victims of structural violence, a limited understanding exists with regard to the nature and distribution of this form of brutality.

Within the current study, structural violence was evident in barriers to access, including access to identity documents, disability grants, assistive devices, healthcare services, transport, education, and employment. Furthermore, evidence emerged of more subtle forms of structural violence, including barriers within communicative environments, specifically in healthcare settings, as well as in terms of access to information.

One of the most disabling forms of structural violence included barriers to accessing identity documents. This was evident in many of the participants' narratives. For example, Participant 1 reported on the barriers that he had encountered in accessing an identity document by saying, *'The problem is if you are disabled, you are nothing. You are the last thing to think of. Even the ID people are just thinking 'wooo, here is pension – he will get money and I won't.'"* Similarly, Participant 8 highlighted his despair as a result of numerous failed attempts to apply for an identity document, stating *"I think the government is throwing me away because they don't want me to have the ID. So up until today I am still using the pass book*[13]*."* This excerpt highlights the potential that structural violence has to defeat those who endure it (Farmer, 1996). Furthermore, Farmer (2004) suggests that these experiences of violence extend beyond our understanding of social inequalities, manifesting in the inequalities of embodied experiences.

Participants' reports also suggested that the education sector was fraught with structural violence, thus preventing persons with disabilities from accessing an education. Participant 30 recalled her experiences in the education sector, stating, *"At the school the principal was saying they could not admit me because that was the school for normal people. Another time she was saying, no, they could not admit me because I didn't have a wheelchair…you know, it was always a different story."* Narratives such as this one highlight the possibility which structural violence creates for 'bodies to whither slowly' (Farmer, 2004, p.315).

[13] Pass laws were designed to control the movement of Africans under apartheid. All black South African males over the age of 16 were required to carry a "pass book" containing personal information and employment history (Burger, 2012).

In relation to the employment sector, many participants reported on the difficulties encountered in accessing equal job opportunities. For example, Participant 11 reported *"I tried to get a job but they didn't want a disabled person. They only employ their favourite people. Nobody cares about us."* Similarly, Participant 14 reported *"Life is painful for me because I am not working. When I am looking for a job others are asking 'why?' because I am getting the disability grant. You see, it is just that I want to work. In the mornings my wife goes to work, leaving me behind with the child. It is difficult for me to accept that is how it should be."* In this excerpt, the value associated with positioning oneself as being employed is clear, particularly in relation to fulfilling the gender appropriate role of providing for one's family (Thornton, 2008). This highlights the fact that social inequalities lie at the centre of structural violence (Farmer, 2004). These inequalities are compounded by the participants' attempts to defy mainstream disability identity types, and highlight the disempowering effect that state subsidies can have on an individual.

The excerpts above highlight the way in which social inequities become embodied as lived experience amongst people with disabilities, and in this way life choices are structured through inequality, political violence and poverty. Furthermore, the experience of structural violence, combined with the challenges that it imposes, denies its victims a voice, thus rejecting the opportunity for rights or for history to be acknowledged (Farmer, 1996).

8.1.1.2 *'People in the community, they look at you like you are an animal'*: The Lived Experience of Psychological Violence

Psychological violence emerged as an extremely disabling barrier to human rights, affecting the way in which participants positioned themselves in relation to others. Many of the reports on psychological violence pertained to the reactions and responses of both family and community members in response to disability. For example, Participant 30 reported *"People in the community, they look at you like you are an animal. Some, when you are crawling, they are laughing and pointing, like it is the nonsense thing, like at the bioscope."* Similarly, Participant 10 reported *"If I need help, my family and neighbours are saying, 'aaahh…this one. It is not us who said she must be disabled. Now we are tired of her.'"* Plummer and Findley (2012) suggest that historical attitudes, together with limited mobility, lack of accessibility and social isolation have resulted in the marginalisation and oppression of

people with disabilities. These attitudes are dehumanizing and devaluing, and as a consequence serve to strengthen the negative cycle of psychological violence to which persons with disabilities are exposed.

Numerous reports emerged of psychological violence inflicted on pregnant women with disabilities by nurses at hospitals and clinics. Abuse of power in medical settings is also reported on by Legg & Penn (2013b) who found that reports of abuse by nurses were common among people with disabilities. For example, Participant 3, a 50 year old woman with paraplegia as a result of a stab wound reported, *"It was embarrassing for me to be pregnant. I was afraid of myself, the way I was, and the nurses were saying 'who did this to you?' Like as a disabled person you are not supposed to sleep with a man, like you are an animal. The other women at the clinic were pointing fingers at me, talking a lot, saying 'If I were you, I would not do that' or 'Stop this and don't do it again! Look at you!' like I have done something wrong, like I am not supposed to have feelings for a man."* This type of violence has the potential to significantly impact on the development of a coherent sense of self, as well as on the individuals' abilities to position themselves in culturally and gender-appropriate positions (Knox, 2008; Thornton, 2008). Kulick (2012) laments on the challenges associated with helping a person with a disability to find intimacy, claiming that 'the obstacles in the way feel frighteningly large.' In this way, psychological violence combined with barriers to intimacy appear to threaten the participant's identity as a human being, as evidenced by her reference to being spoken to as though she were an animal.

8.1.1.3 *'The men in my community were doing anything they liked to me':* The Lived Experience of Sexual Violence

Fourteen out of the fifteen female participants in the sample made reference to the fact that they had been sexually abused. While some of the participants stated this outright, others spoke about it in a metaphorical way. This may be due to the fact that the research assistant was also a female and therefore there may have been a degree of shared knowledge and experience that emerged within the discussions. Stokoe (2003) postulates that relationships within communities which link homes and household spaces are implicitly gendered, reflecting the structural dichotomies that locate women within the home as opposed to in the public sphere. Furthermore, it is documented that perpetrators of sexual violence towards

women with disabilities are usually known to the victim, and are frequently found to be husbands, caregivers or live-in partners (Milberger, Israel & LeRoy, 2003). In this way, women with disabilities are doubly exposed to sexual violence as a result of gender inequality as well as by nature of their disability (Jefferys, 2008). Thus, physical restrictions, together with a sense of isolation and reliance on others, place them at increased risk for sexual violence and abuse (Plummer & Findley, 2012).

Although it is documented that people with disabilities are at greater risk for being abused than able-bodied persons (Groce, 2004), I was still surprised how many participants either spoke outright or alluded to this form of violence. The reasons for divulging this information are unclear, yet it would appear that it could be linked to the notion of shared knowledge and shared experience between the participants and the research mediator. Furthermore, the nature of the question posed to the participants ("*can you tell us your story?"*) opened the floor for discussion of any topic or life experience which the participants deemed as relevant. In this way, the underlying principles of providing participants with a voice in narrative inquiry are highlighted.

An example of a participant who reported sexual violence was Participant 3. She recalled *"I was young and the men in my community were doing anything they liked to me. So I became a victim."* Similarly, Participant 6 reported *"This one neighbour was helping me, giving me food, but afterwards he was saying I was not thanking him properly – I must go inside the house to thank him."* This is explained by Thomas et al (2008) who state that the dependency experienced by people with disabilities makes them more vulnerable to sexual violence. Furthermore, Thornton (2009b) adds that sexual networks may be established in situations of dependency or where sex is exchanged for food or goods which would have otherwise remained inaccessible. Due to the fact that many people with disabilities are dependent on others for assistance with activities of daily living, an asymmetrical relationship is formed whereby reporting such abuse may result in losing a caregiver or support network (Thomas et al, 2008). In this way, marginalised groups, such as women with disabilities are more likely to be trapped within unstable sexual networks (Thornton, 2009b), increasing their risk for exploitation and for sexually transmitted diseases. This is particularly relevant in the context of poverty where people with disabilities are not only dependent on others for pushing their

wheelchairs, cooking, and fetching water but also where sex is used as a commodity in exchange for food (Stoebenau et al, 2011). Shakespeare (2012) reflects on the complexity of such relationships by stating that the experience of sexual violence and abuse reflects the locations that human rights discourses cannot reach or to which they offer no resolution.

These findings of sexual exploitation among people with disabilities concur with those of Kulick (2012), who shows how sex and disability highlight the limitations of the language of 'rights'. He implores the necessity of addressing the needs of people with disabilities without using the language of human rights, since rights are bound with duties and many people with disabilities are unable to fulfil gender and culturally accepted roles and duties. Thus, in order to address these needs, it is necessary to develop an approach that centres on "entitlements, the politics of passivity, and ethical engagement" (Kulick, 2012, p.17). This concurs with Nussbaum's (2007b) notion that 'entitlements are pre-political', implying that entitlements are bound within the language of human rights. In this way she highlights the need to address the underlying issues of power dynamics, poverty, and food insecurity if we are to address gender –based violence and sexual exploitation among women with disabilities.

8.1.1.4 *'My father beat me because I was disabled':* The Lived Experience of Physical Violence

A number of the participants reported incidences of physical violence. These pertained mostly to recollections of being beaten at school by teachers when unable to cope with the demands of the classroom, being physically punished for being disabled, or being attacked with knives and sharp instruments in order to release the demons which were believed to be causing the disability.

An example of a participant who recalled experiencing physical violence within the classroom was Participant 21. He recalls his experiences in the schooling system saying *"to learn together with normal people is stressful."* He goes on to say that when he was unable to provide the correct answer in the classroom, *"when I didn't know the answers the teacher would beat me and the other children would laugh."* This experience had a negative impact

on the individual, as evidenced where he states *"so then I was always isolating myself, feeling afraid, like I was not a human being."*

Another example of physical violence was portrayed by Participant 27, a 49 year old female with a visual impairment as a result of an illness. She reported violence inflicted by her father as he attempted to free her from the evil spirits which he believed had caused her disability. She reported *"My father beat me because I was disabled. He said I was bewitched and he beat me and tried to cut me with a knife."* Similarly, Participant 9 reported *"My brother beat me – not with his hands, but he slashed me with a bush knife. I even had to go to hospital so that they could stitch me."* While the health and emotional effects of this type of violence are potentially significant, these excerpts also highlight how the experience of physical violence results in individuals positioning themselves distally to other characters within the narratives. In so doing, the sense of 'disability as difference' (Woodward, 1997) is reinforced.

8.1.1.5 *'Without food there is no happiness'*: The Lived Experience of Deprivation

According to Plummer and Findley (2012) people with disabilities are targeted by perpetrators as a result of their perceived vulnerabilities which predispose them to exploitation, maltreatment and abuse. This is supported by Knox (2008) who claims that the obvious reason for targeting those who are most vulnerable in society stems from the fact that they are more easily bullied or bribed into silence, less likely to report experiences of violence, and are less likely to be believed if they do lodge complaints. This is compounded by the fact that people with disabilities do not always recognise violence, especially where exposure to violence has been lifelong or where it is insidious in nature (Plummer & Findley, 2012).

Violence by nature of deprivation was reported by a number of the participants, most commonly seen where food or money was withheld from people with disabilities. For example, Participant 7, a 35 year old female with a psychiatric disability reported, *"At home my parents won't share food with me. They say I must buy food for myself and cook and eat by myself."* A similar experience was reported by Participant 9, who reported conflict with

his brother in relation to food security, saying *"My brother is always saying 'Don't ask for food. There is no food for you here.'"*

Additionally, there was evidence of families who withheld money from people with disabilities. However, once the person with a disability started receiving their disability grant, the family members became cupboard lovers, trying to access the individual's disability grant funds. This is highlighted by Participant 20, who reported *"My family were always discriminating against me, treating me different. But then when I started getting the grant they were getting close to me, wanting money from me."* Similarly, Participant 12 claimed *"I thought that she loved me, but then no, I realised she only loved the money I was getting from the grant, not me."*

The discussion above highlights how deprivation is used as a form of punishment, and in so doing serves to strengthen the notion of difference among persons with disabilities, forcing them to be positioned distally from other members of society. Foucault (1977) explains deprivation as an inevitable consequence of imprisonment. It could thus be inferred that those who are imprisoned within their bodies, and isolated from society due to the limits imposed by structural violence, are inevitably faced with deprivation as a consequence of disability.

8.1.2 THE IMPACT OF VIOLENCE ON THE INDIVIDUAL

The descriptions above highlight the way in which the various manifestations of violence serve as a form of social oppression based on the limitations that they impose on individual expression and participation in mainstream community events. Incidents of violence are shown to create boundaries of time and space by setting them apart from ordinary time (Thornton, 2002). By creating a disruption, the moment of violence is given meaning, detracting from the existing narratives of cultural and community life. In relation to disability, violence serves to perpetuate the medical model, by reinforcing the notion of 'disability as impairment'. The combined impact of violence, poverty and extreme

marginalisation is shown to be profound amongst adults with disabilities within the current study.

Jefferys (2008) explains how society describes the experiences of people with disabilities in relation to biological flaws and in this way positions blame on the individual. In so doing, people with disabilities continue to be exposed to violence because society fails to acknowledge the vulnerabilities of this group. Thus, the embodied experience of violence is an intersection of history, biology and the political economy (Farmer, 2004). In this way, it is possible to understand that although many participants made attempts to position themselves in contrast to mainstream disability identities (as discussed in Chapter 6), the experience of repeated exposure to a variety of forms of violence had a significant impact on them and as a consequence, appeared to affect the way in which narratives were told. The most significant effect of multiple exposures to violence over extended periods of time appeared to be the internalised belief that violence and abuse was an expected part of one's life. These effects on the individual are seen, for example, where Participant 21 says, *"I was always feeling afraid, like I was not a human being"*, and where Participant 30 reports *"I was always thinking that love was not for me. It was only for normal people to love each other."* Similarly, Participant 3 recalls her response to the sexual abuse she endured, coupled with the nurses' responses to her when she was pregnant, saying, *"I was always afraid of myself, the way I was."*

Without the recognition of the experiences and effects of violence, it is impossible to engage in debates regarding the rights of persons with disabilities (Fuller-Thomson & Brennenstuhl, 2012), and thus, the absence of their voices have inhibited the development of appropriate policies and practices (Plummer & Findley, 2012). Furthermore, it is vital that the violence be considered in relation to context, since the experience of poverty contributes to the vulnerability of this population (Farmer, 1996). Thus, high levels of oppression and the devaluation of people with disabilities, together with the lack of attention to the various manifestations of violence, promotes barriers to agency, and enables the continuation of abuse.

The narratives of violence discussed above extend beyond the current literature of the lived experience of people with disabilities, particularly those documented locally. By incorporating these issues into research serves to acknowledge and validate the reality of living with a disability. Despite the negative physical and emotional effects that violence has on the individual, these narratives allow individuals to reveal their vulnerabilities, and in so doing, to bear witness by transforming memory into language. This serves to crystallise their experiences within history. Through their vulnerabilities, participants open up the possibility of constructing new realities of the lived experience of disability. These are discussed in section 8.2 below.

8.2 THE EXPERIENCE OF LIVING WITH A DISABILITY IN A RURAL AREA: THE EMERGENCE OF NEW STORIES

In this section I will describe four 'new types' of narratives that emerged within the data. While the nature of violence experienced by the participants is not a novel concept, and the content of narratives serves to re-inscribe the participants' alienation from society, I have considered the narratives to be 'new' as they reflect unacknowledged experiences of persons with disabilities in current paradigms of analysis. Each of these is discussed independently and in relation to a case study, highlighting the structure and functions of the storyline as an example. What appeared to be a core aspect of the emergence of these narratives was the participants' sense of vulnerability. This appeared to be vital, since the sense of exposure which vulnerability creates, allows for the opening up of new possibilities, and contrasts with the ways in which people with disabilities are currently positioned in the existing narratives and models of disability. The bio-medical model only allows for vulnerabilities that can be treated clinically, yet denies the possibilities of psychosocial vulnerability. The social model, by contrast places the blame for negative life experiences of people with disabilities on society, and in this way responsibilities are shifted away from the individual towards society. While the ICF may be viewed as a compromise between the medical and social models, it fails to adequately take context and culture into account and in so doing limits the ways in which disability and responses to disability can be understood. In so doing, the experience of disability is viewed as a static and universal convention, and people with disabilities are denied the opportunity to expose their vulnerabilities.

In sections 8.2.1 - 8.2.4 below, I present the 'new' narratives of disability which emerged from the data. Although these are neatly categorised according to a typology of four different narratives, the reality is that people and their experiences cannot be categorised so linearly. The various types of narrative are neither exhaustive, nor mutually exclusive. Instead they reveal a shifting sense of foreground and background experiences which make up the narratives of embodied experience. In this way, similar to Frank's (1995) typology of illness narratives, the stories provide extreme examples of experiences in order to provide parameters for "hearing the body within the story" (Frank, 1995, p.51). In this way, 'new narratives' distinguish themselves from the extant narratives and models as described within the current literature.

Cognisance must be taken of the fact that the stories are told not only through the individual's intimate understanding of embodied experiences, but also in relation to a multitude of other lived events, and culturally and contextually specific norms and values. Thus, I do not intend to limit the narratives or categorise individual experiences into predictable storylines, but I will try to highlight four alternative realities to those which are currently presented in the literature. In this way, I hope to be able to acknowledge new forms of the reality of lived experience for persons with disabilities.

8.2.1 *'They took the bullets out of my body but my spine was injured':* Stories Constrained by the Inescapable Past

The first type of narrative which emerged within the data were where participants appeared to be trapped within the trauma of embodied experience and as a result their narratives reflected an inability to escape the past. Eight participants in the sample (including Participants 8, 10, 11, 16, 17, 22, 24 and 26) provided narratives that reflected the trauma of being trapped within embodied experiences. Most of these narratives were dominated by events pertaining to the onset of the disability. Although all of the participants who produced these kinds of narratives had acquired disabilities, neither the way in which the disability was sustained, not aspects relating to age, gender or length of time since onset of disability appeared to be determining factors as to whether participants aligned with this type of narrative or not.

An example of a narrative constrained by the inescapable past was produced by Participant 11 (appendix 22), a 40 year old woman who sustained paraplegia as a result of a spinal cord injury during a protest march, 23 years prior to the interview. When asked to tell us her story, she began by saying

> *"In 1986 I was in Standard nine, now grade 11. There was a lot of apartheid in our area. We wanted the government to fix things, but they were not taking notice of us. It was the middle of the night and we met at (village name) stadium and started a protest march together with the other students from (name of school). During the protest, things started getting hectic. I was scared, and I wanted to leave to go home. On the way home we heard the sound of guns, but we didn't know where they were coming from. There were soldiers and they were trying to prevent us from fighting for our rights. We just wanted equal opportunities – we did not know the history. The next thing we knew their guns were pointed at us. Three men died and I had eleven bullets in my body. They took the bullets from my body but my spinal cord was injured. I couldn't walk anymore."*

There are a number of features which characterise narratives constrained by the inescapable past. Firstly, the speaker takes on a true 'narrator role', as described by Koven (2012, p.154) whereby she removes herself from the surrounding interaction (i.e. the interview) and holds the floor for an extended period of time, not waiting for responses or interjections from the listener. In this case, the speaker's ability to remove herself from the surrounding interaction seems to imply a reliving of the experience as it is narrated. Furthermore, the participant's extended role as a narrator, together with the lack of response anticipated from the listener indicates that this type of narrative may be rehearsed. The use of rehearsed narratives has been well documented in persons who have had strokes (e.g Ferguson & Harper, 2010; Ulatowska et al, 2011). Narratives are documented to take on the form of a rehearsed performance when the speaker has recounted the same story many times, either in his/her own mind as a way of making sense of the experience or through recounting the story to other people (Ferguson & Harper, 2010).

While there is some orientation to the spatial and temporal boundaries pertaining to when and where the event happened, the speaker provides limited information on her current life (in terms of where she lives, who her neighbours are, and whether or not she has children), but instead she launches immediately into the core issue – that being the onset of disability and how the disability was sustained. This is explained by Thornton (2002) who claims that violence impacts on the retelling of the past, and thus while violence may occur at the beginning of life stories it does not imply that the act of violence is fundamental to the individual's identity. Thornton (2002) adds that by situating violence at the beginning of a narrative makes it appear as though violence is located at the beginning of new social forms and new behaviours. In this way, the chaotic temporality of violence creates false perceptions about the impact that violence has on the individual.

Secondly, the narrative is produced in the past tense and is dominated by a single, significant event, which in this case is the onset of the disability. All subsequent events are also described in the past tense and interpreted in relation to the participant's disability. The boundaries of time and space are clearly defined in relation to the core event, but these are not maintained throughout the narrative. This is seen where the participant provides vague descriptions of attempts to find work by saying *"I tried to get a job but they didn't want a disabled person."* and where she describes the community's response to her pregnancy by saying *"people were not happy about my pregnancy. They were saying someone must be abusing me and that it is a sin to sleep with a disabled person."* In both of these examples the participant does not provide any indication as to who 'they' are, or where and when these events occurred, but immediately interprets them in relation to her disability, without providing any alternative perspective or reasons for these experiences. While her disability is likely to be a core reason for these subsequent life experiences, the participant does not reflect that there could be alternative reasons for these experiences.

A third feature of this type of narrative is that there are no real characters with any substance, but rather that it is the event itself, which holds the story together. In the example provided above, the participant mentions other students who were involved in the protest and the soldiers who intervened, but these characters are positioned somewhat anonymously in contrast to the life-changing effects that their actions had on her. The speaker's lack of

reflection on her own feelings or reactions, may serve two purposes. Firstly, it could be an indication of an inability to transform the horror of lived experience into words (Frank, 1995). Secondly, it could relate to the fact that her story is well rehearsed (Ferguson & Harper, 2010). However, regardless of the reason underlying the lack of reflection, the act in itself serves to limit the narrative to a specific time and emotional space within the individual's past, and as a consequence she seems to be held hostage, governed by traumatic memories within a severely altered body.

Following Ricoeur (1980) and his notion that it is the narrative plot which synthesizes experience within a narrative, one could say that the experience of being shot during a protest march constitutes the causal event of the plot of this narrative. The events which led to the participant's disability are presented at the very beginning of the story, and the dramatic way in which this narrative is told tends to dwindle after the description of the core event. Subsequently, the narrative becomes guided by the interviewer's questions. Thus, in the absence of continuity, the 'plot' remains a visceral description of an event, with no reflection of life experiences prior to the onset of the disability, nor any form of evaluation or ending. Furthermore, at times where the listener expects a plot to develop, it does not. This is seen, for example, where the participant says *"The next thing we knew their guns were pointed at us. Three men died and I had eleven bullets in my body."* At this point, I expected the participant to go into more detail about what happened next, how the people around her reacted, and what her own reaction was, but instead, this 'hole' in the narrative, which I as a listener needed to be filled was left unfilled and the participant moved the narrative eleven years later, to her experience of speaking at the TRC hearings.

In this type of narrative, the absence of a plot performs two roles. Firstly, it hints at the limits of making sense of lived experience through the use of spoken language. This type of narrative challenges the listener to acknowledge the speaker's experiences and interpretations without trying to enforce a sense of change. Frank (1995, p.110) states that the spontaneous response of most listeners, including health professionals and researchers is to try and 'drag the teller out of their story' and in so doing, provide some sort of 'therapy', but states that this may causes unintended harm to the patient or client. In order for healing to occur, the listener needs to bear witness to the story, and in this way, acknowledge the reality of lived and

embodied experiences on the individual. This implies that the chaos within the narrative can never be removed, and that it will always provide an orientation towards the individual's interpretations of experience. However, through the acknowledgement of the reality of this chaos and by allowing the chaos to be acknowledged as a form of biographical disruption, the listener holds the potential to allow the speaker the opportunity to position the chaos of the past in the background of new narratives. Thus, it is the vulnerability that the speaker exposes which creates an opening for understanding the boundaries which confine lived experience and the ability to transform horror into a coherent narrative.

8.2.1.1 Summary of Stories Constrained by the Inescapable Past

In summary, narratives aligned with an inability to escape the past, are dominated by a single event, told in the past tense, and with all other life events interpreted in relation to it. The narrator removes him/herself from the current situation and resorts to reliving the event. Although there is some evidence of time and space acting as constraining variables during the core event, the individual does not perceive temporal and spatial boundaries to be central to new life experiences since all experiences are interpreted in relation to the disability. This gives rise to a core event in the past becoming central to the individual's interpretations of lived experience, which defies the construction of a coherent plot. While this brings to the fore the limitations of spoken language as a means for understanding lived experience, the exposition of vulnerabilities calls for the acknowledgment of the turmoil in the individual's life as fundamental to the interpretation of new experiences. The risk, therefore in conversing with, or providing services to people who appear to be trapped in the inescapable past, is to force them to move beyond the trauma which defines them, and in so doing, not only deny the significance placed on the trauma in the individual's life, but to deny the individual telling the story.

8.2.2 *'I think the government is throwing me away because they don't want me to have an ID book':* Stories Defined by Constrained by Psychosocial and Political Inequality

The second type of narrative which emerged appeared to be where stories were dominated by the experience of psychosocial and political inequality. These included stories about the effects of poverty, food insecurity, difficulties in obtaining identity documents (even where participants were South African citizens), barriers to obtaining disability grants, and the

effects of lack of service provision, including water, electricity and sanitation; as well as fighting stigma and community responses to disability.

The sample revealed a total of 11 participants whose narratives seemed to be constrained by psychosocial and political inequality, including Participants 1, 6, 7, 9, 12, 14, 20, 21, 23, 28, and 30. Surprisingly, seven of these participants were grant recipients, which contradicted the belief that social grants have the ability to limit the direct effects of poverty (Woolard, Harttgen & Klasen, 2011). However, it is important to bear in mind that many of these participants had struggled for many years, fighting various forms of structural violence, and this compounded the additional psychosocial issues that they faced, most prominently food security and employment.

An example of a participant whose narrative aligns strongly with those constrained by psychosocial and political inequality is that of Participant 9 (appendix 23), a 52 year old male who sustained a physical disability as a result of a bilateral amputation of his legs. Participant 9 lives in a small village which is under-resourced in terms of the provision of basic services, such as water and electricity, as well as infrastructure, such as roads and sanitation. Participant 9's narrative portrays an over-determination of troubles in relation to not having an identity document rather than as a result of his disability, although this also plays a part. An over-determination of troubles is a classic feature of Frank's chaos narrative (Frank, 1995), making it impossible to determine the relationship between troubles. Although four of the participants who told these types of stories had congenital disabilities, the notion of 'loss' emerged as a defining feature within narratives pertaining to a loss of what may have been if they had not been disabled.

Participant 9 began his narrative by stating that his wife left him when he was no longer able to work. In this way, his unemployment was implicitly linked to his amputation and subsequent disability, although he did not overtly state this. Thus right from the beginning, the participant positioned himself as someone who had a relationship and who was employable, but who had lost these defining features of what used to be his identity. When probed as to why he perceives himself to be unemployable, he stated *"I don't have an ID*

book. That is my problem"' and in this way introduced the notion of both constitutional discourses and psychosocial inequality. The interviewer pointed out that there are people in the community who work, but who do not have identity books, to which he responded *"There are those people who are working, but a person like me, being disabled, where can I work?"* In this way, the participant draws an intersection between his disability and his psychosocial difficulties. His narrative goes on to describe the difficulties he faces, largely related to poverty and food insecurity, but he repeatedly returns to the challenges experienced in accessing an identity book. He reports

> *"I am living with my brother, but he is fighting with me a lot, shouting about the food that he is buying. Last time he was slashing me with a bush knife, saying 'Don't ask for food. There is no food here.' You see, without food there is no happiness. Even when I am asking neighbours, they are saying 'we are tired of you. It is not us who said that you must be disabled.'"*

The participant repeatedly drew a link between the lack of an ID book and poverty. When probed about his attempts to apply for an identity document, he said

> *"I cannot say life is easy for me, because I have been trying to apply for an ID at home affairs. From the 1970's when ID's came out, I was working on the mine without the ID. So I went to (name of place) to apply for the ID, and they told me 'you are too young.' Now, each time I go there, they are saying they don't help adults, only children. Until today, they are telling me those same words. So now, I am still sitting with the pass book, nothing else. Even sleeping at night is difficult because I am always thinking about the ID, because I can't do anything without the ID. I think the government is throwing me away because they don't want me to have an ID book. That is all that I am asking for."*

One of the key features of this type of narrative is the use of reported speech. While the interview is guided by the participant and is dominated by the difficulties that he has encountered and those that he deems as prominent features of his lived experience, a significant part of the narrative is produced using reported speech, and in this way the speaker not only replays the events that dominate the narrative, but also shifts control from himself to the person being quoted (Shuman, 2012). In this way, the narrative becomes dominated by constitutional discourses with the participant placing responsibility on the government for his difficulties. Furthermore, reported speech suggests that the words uttered were spoken in another context, and in this way the narrator is able to reclassify the message by creating an implicit commentary (Shuman, 2012). A further function of reported speech is its ability to convey depth and significance about a situation (Bakhtin, 1981). Koven (2012) describes how, through the use of quotation, the storyteller speaks as though he is reliving the narrated event, and in this way directs the listener's attention to the 'then and there' of the narrated event. Bauman (1986) states that moments of reported speech are often the focal point of the narrative, highlighting its point of maximal intensity. This is demonstrated in the extracts above, where the participant recounts the conflict between him and his brother over food, as well as where he recounts his neighbour's responses towards him, and in this way positions himself as a victim, attributing blame to others for his life experiences.

A second feature of this narrative is the predominant use of present tense. While the speaker does recount events from the past, he repeatedly re-orients the narrative into the present tense, with no evidence of an anticipated future. There is limited temporal and spatial orientation within the narrative, and the story is told with a sense of urgent immediacy of the here and now. This is highlighted in the extract above where the participant refers to *"hearing those same words until today"* and his difficulty sleeping *"at night"* which denotes a sense that he is unable to see beyond the here and now and his primary concern is day-to-day survival.

This type of narrative is devoid of individual characters, but dominated with constitutional discourses and the personification of government policies and practices. This reflects a perception that the individual is fighting power relations at national level, and serves to reinforce the individual's preoccupation with failed attempts to redress psychosocial inequalities. Foucault (1977) explains this type of psychosocial inequality as a 'hidden' form

of punishment exerted on a body that is deemed unworthy of rights. In this way, punishment is exerted by the authorities, not through the visible intensity of a horrifying public spectacle, but rather in terms of the sense of inevitability that it evokes in the individual (Foucault, 1977). In addition to the effects that this has on the individual, it perpetuates a sense of avoidance of the 'tortured body' (Foucault, 1977, p.14) and in this way, the individual's sense of embodied knowledge remains isolated within his own frame of reference. This serves to further distance the individual from society, with punishment centred less around physical torture, and more on the withholding of rights (Foucault, 1977).

Thus, in narratives constrained by psychosocial and political inequality, as a result of the lack of fluidity between past, present and future (Mead, 1934; Carr, 1986; Riessman, 2008), and the lack of sequence and consequence (Riessman, 2005), a true plot fails to emerge. Instead, the speaker provides an over-determination of troubles related to psychosocial inequalities, with no anticipated way out. This seems to underlie a sense of loss for what may have been, and a possible sense of guilt for the ways in which events have transpired in the individual's life. These are compounded by the cultural taboos associated with bewitchment (Mathangwane, 2011) and as a result may deepen the sense of guilt which the individual feels. This is explained by Frank (1995) who states that experience is shaped through imagination, rather than being encountered. Thus it is possible that imagination knows that the story could have been told differently, had the life been lived differently (Frank, 1995). This links to the use of reported speech throughout the narrative, where the speaker is absolved of responsibility.

8.2.2.1 Summary of Stories Constrained by Psychosocial and Political Inequalities

Narratives that are constrained by psychosocial and political inequality are defined by a sense of loss, and are compounded by thoughts of how life could have been lived differently, under different circumstances. The telling of the narrative is dominated by the use of reported speech which serves to shift control for the events and life experiences that dominate it. The narrative is told with a sense of urgency and the speaker has difficulty in reflecting on the past or anticipating the future, given the day-to-day struggle for survival. Consequently, it is not individual characters that initiate actions, but rather constitutional discourses which are personified as the source which denies basic rights. In this way too, responsibility is removed

from individual characters, and placed somewhat evasively on the government. In so doing, the individual remains marginalised and disempowered, revealing a sense of despair since 'the government' remains an abstract entity who cannot be turned to in times of need. This culminates in an over-determination of troubles related to psychosocial and political inequalities which deny the construction of a plot defined by sequence and consequence.

8.2.3 *'My heart was so painful':* Stories Defined by Searching for Coherence Amongst the Voices of Multiple Traumas

Although most of the narratives in this study produced evidence of competing voices, three of them were completely dominated by them. These included the narratives produced by Participants 2, 3 and 27. In these instances, participants provided evidence that their lives had been dominated by a multitude of traumas and as a result, their narratives were characterised by an inability to develop a coherent sense of self in the context of competing voices and counter-narratives.

An example of a narrative defined by the inability to construct a coherent sense of self was produced by Participant 3 (appendix 24). Participant 3 is a 53 year old woman who sustained paraplegia as a result of being stabbed during the war in Mozambique. While the violent way in which she sustained her disability and the subsequent effects of disability are central to her narrative, the multitude of other traumas that she has experienced but has never really had the opportunity to talk about, appear to fundamentally alter her story. The traumas that this participant experienced include living through the war in Mozambique, the violent way in which her disability was sustained as well as the injury incurred by her son, and the murder of her baby; the loss of her physical abilities, her relationships, and her belongings as a consequence of the war; the conflict experienced between the participant and her husband and the subsequent sexual abuse that she endured, the death of her mother – the only person who supported her, the negative responses of the community to her disability, specifically in response to her pregnancy, living in the context of HIV, and the overall effects of poverty and inaccessibility. As a result of these numerous traumas, the participant's narrative was dominated by each traumatic event fighting for dominance within her story.

When asked to tell her story, the participant began by documenting how her relationship failed as a result of her disability, by saying *"I was married, then I got injured, then my husband left me. We separated because I was now disabled."* She continues by describing how her disability was sustained, by saying *"I became disabled in February 1984. My husband was from Mozambique, so I went with him to Mozambique. It was Renamo[14], you know, the war, at that time. So they came to the house and they stabbed me."* It is significant to note the matter of fact way in which this violent attack is described, and the lack of emotive words used in this description. The participant rapidly shifts the orientation of the narrative away from her attack and documents her hospitalisation in Maputo, and the difficulties incurred when her parents wanted to bring her back to South Africa, two years after the incident, for better medical care. She describes her husband's opposition to her going back to South Africa and how her parents decided to take her home anyway. She also describes the difficulty of getting across the border after having lost everything, including her South African identity book and passport. She continues to describe the conflict between her and her husband, the numerous medical consultations that she attended and the difficulty involved in attending these appointments, given her disability. She emphasizes her mother's support during this time and discusses how, after the death of her mother, she was no longer able to attend her medical follow-up appointments because she had no one who would push her wheelchair.

She returns to discussing her unhappiness in her relationship, and the way in which the community responded to her disability, especially in relation to her intimate relationships, saying

> *"So my husband was working in Johannesburg at that time, and it caused problems in my life because I was not happy in my marriage. The problem was we were two wives with one husband. So on the days he was coming from Johannesburg, he was staying at my house and then tomorrow you hear news*

[14] The civil war in Mozambique (1977-1992) took place between the Mozambican ruling party, Front for Liberation of Mozambique (FRELIMO), and the Rhodesian and South African funded Mozambique Resistance Movement (RENAMO) (Schafer, 2007).

about me from the neighbours, like I am unable to work in the house but I can sleep with a man."

She continues to explain how she tried to get out of this relationship, but her husband refused, and began to abuse her sexually. She recounts this by saying

"I also became sick and no one was helping me. The other wife was telling people not to help me. I asked people from the church, and the pastors to help me, but they were all saying "no, there is nothing we can do." My mother was dead, also my mother-in-law, so it was just me, the husband, and the other wife. I was young and my husband was doing anything he liked to me. So I became a victim."

As the participant recounts her story of victimisation, she reflects on the poverty that she experienced after the war, and this brings her to what was arguably her most painful experience. She recalls:

"It was so painful, my heart was so painful. We had nothing. Everything was taken during the war. We didn't even have a chair. The neighbours were bringing me a chair so that I did not have to be on the floor all the time. All the furniture was burnt by the soldiers before we moved. My son was also injured during the war because they burnt the house and we tried to run away from the fire. I was carrying my small baby. The soldiers took the baby from my back and threw him into the fire. He burnt until he died. My elder son was lucky because the soldiers felt sorry for him. They grabbed him with their hands and walked a short distance. You know what? We were many in that house. They put us inside with other people and burnt the house. So the soldiers, we knew them, they were our neighbours, and

they were liking some people. The one with my son called me, and said 'run away with this child.'"

In the extract above, it is significant to note how the central event of sustaining a disability is alluded to but not discussed, highlighting the participant's inability to transform the combination of emotional and physical pain into words. This is also explained by Frank (1995) who states that association with one's own body may be considered dangerous since "the body is so degraded by an over-determination of disease and social mistreatment that survival depends on the self's dissociation from the body even while the body's suffering determines the life the person can lead" (p.103). The participant goes on to describe a multitude of traumas here, within a few sentences, and the staccato structure of her sentences and lack of chronological ordering highlights the embodiment of chaos (Frank, 1995). The information presented here is dense and complex, involving suspicion and mistrust (where people who had been neighbours became attackers during the war), the responsibility of being a mother and the fear of imminent death as the house was set on fire, the notion of being 'lucky' and being pulled out of the house with the opportunity to escape, only to have one son injured, her baby murdered and to sustain paraplegia as a result of being stabbed. Once again, it is startling to note the matter of fact way in which this aspect of the narrative is told, devoid of all emotion. The only part of this extract which denotes feelings and emotions is where the participant says, at the very beginning, *"It was so painful."* Frank (1995, p.103) describes this as the ability of the body to dissociate from 'it' and in so doing the individual attempts to deny the chaos which threatens to overthrow her life. However, the participant does not discuss her own injury in any way here, but focuses on her identity as a mother with two children facing murder by people who had previously been friends and neighbours.

The participant returns to discussing how she and her son were separated, how they were taken to different hospitals, and how she thought that she had lost her son too, as it took two years for them to be reunited. The narrative shifts to her discussion of the challenges of rebuilding her life from nothing, once she returned to South Africa. She moves to discussing how she fell pregnant and the way in which the community responded to her, saying,

> *"People were saying 'how can it be that I am pregnant?' They were asking me, how do I have sex with a man, being disabled? So the father of the baby was disappearing, because of all the talk from the neighbours. My days to deliver were coming, and I had no money to get to the hospital."*

She continues her account, recalling how she had to beg for money and assistance from neighbours to get to the clinic, and when she did get to the clinic she was transferred to the nearby hospital, where she gave birth to her baby. She then describes how the father of the baby returned to the scene, and how he sexually abused her when she said she did not want any relationship with him. She continues to discuss how, after some time, the father of the child became sick and some of his other girlfriends had passed away, and how the neighbours were saying that he had AIDS, but he denied it. The participant returns to her discussion of pregnancy and says,

> *"It was embarrassing for me to be pregnant. I was afraid of myself, the way I was, and the nurses were saying 'who did this to you?!' Like as a disabled person you are not supposed to sleep with a man, like you are an animal. The other women at the clinic were pointing fingers at me, talking a lot, saying 'If I were you, I would not do that' or 'Stop this and don't do it again! Look at you!' like I have done something wrong, like I am not supposed to have feelings for a man."*

The extracts above provide a complex description of the multiple traumas that this participant has endured. As a consequence, the narrative is defined by the challenges that she faces in establishing a coherent voice and a coherent sense of self within the narrative. In this way, the complex combination of horror and trauma threaten the individual's sense of self and ability to produce a coherent narrative.

In addition to the nature of the content, narratives that are defined by multiple traumas have a number of significant features. Firstly, although the participant takes on a narrator role, characterised by her consistent use of the personal pronoun 'I' as well as her extended accounts and the way in which the narrative is controlled (Koven, 2012), she portrays a variety of identities and continually shifts between a variety of positions, including being a mother, a disabled woman, a victim, a wife and a daughter. Consequently, as the participant changes her role in relation to the different events described, her position changes in relation to other characters. This implies that at times the participant aligns herself with the characters in the narrative, while at other times she positions herself in contrast to them, resulting in a distinction between personal and social interpretations of experience. This appears to have the effect of the listener questioning who this participant 'really' is.

The narrative is told in the past tense, and while the participant oscillates between different events in the past, there is an absence of reflection on the present, and no anticipation of the future. As a result, this sense of radical change from one moment to the next, results in unpredictability and chaos (Bamberg, 2012). In narratives characterised by multiple traumas, spatial boundaries are fairly clearly established, while temporal boundaries are poorly demarcated, resulting in a lack of cohesion within the narrative. In the example above, the participant clearly delineates the narrative spatially, by referring to the countries inhabited and her experiences in these countries, the effects of her husband working as a migrant labourer in Johannesburg, the clinics and hospitals where she was treated, and the physical location where the injury was sustained. On the contrary, only vague temporal boundaries are imposed on the narrative. The participant clearly positions the narrative in relation to the war in Mozambique, and her injury sustained in February 1984. All other events are described in the past tense but without reference to temporal boundaries, and with no sequential or chronological ordering, thus defying evidence that any of the events are sequentially related or of consequence to each other. In addition to the content of the narrative, the lack of temporal boundaries seem to make the narrative difficult to hear because the listener is unable to orientate themselves with regard to the temporal ordering of events or in relation to sequence and consequence.

The identification of a plot is difficult, as a result of the continually shifting and contradicting positions and roles which the narrator assumes and the lack of temporal cohesion within the

narrative. As a result the listener is forced to listen to the narrative in the way in which the individual experiences life – with no sequence or consequence, but continually facing up to one traumatic event on top of another. This negates the space for reflection, and compounds the experience of not only producing a chaos narrative, but also living a chaotic life (Frank, 1995). The challenge of this type of narrative seems to be the individual's inability to create a sense of self, as she is continually forced to shift positions in order to deal with the competing traumas in her life and the counter-narratives that threaten the construction of a stable and coherent narrative. The value of this type of narrative seems to be the individual's ability to identify, isolate and narrate episodic events which opens up an opportunity for slowing the narrative down and reconstructing the story in order to allow for reflection and interpretation of events, experiences and emotions.

8.2.3.1 Summary of Stories defined by Searching for Coherence

Narratives defined by fighting for coherence in the context of multiple traumas appear to be predominantly defined by the shifting roles and positions that the narrator adopts, preventing the development of a coherent sense of self. Consequently, a lack of association between the events of the past and present emerges, resulting in an inability to anticipate the future. This is compounded by the lack of temporal orientation within the narrative, making a plot difficult to identify. The value of this type of narrative appears to be the individual's ability to identify, isolate and describe episodic events, as these are precursors to developing a testimony (Frank, 1995). As the speaker tells their story, they take on the responsibility of becoming a witness for the atrocities that they experienced. This is shared with the listener, turning the narrative into moral responsibility for those who have heard it. In so doing, testimony to a reality which was previously denied is concretised. This appears to create a sense of moral responsibility to which society needs to respond.

8.2.4 *'I suffered and suffered a lot. So I will suffer until I die':* Stories Defined by the Horror of being a Mute Witness

The fourth type of narrative that emerged appeared to be where there was no story to tell. In these cases, the participants' life experiences appeared to be so dominated by physical and emotional pain, multiple traumas and psychosocial inequalities, that they defied the transformation of lived experience into words. In these narratives, the participants took very

short turns in the conversation, and despite the open-ended nature of the questions presented, answered in two-to-three word utterances. While cognisance is taken that some of these narratives were elicited from participants who had cognitive-communicative disabilities, their stories did not correspond with their use of language in more typical, naturalistic interactions. Thus it would seem that the emotional effect of their disabilities and their exposure to poverty, food insecurity and various types of violence have rendered them speechless.

Eight participants seemed to align their narratives with the experience of being a mute witness. These included Participants 4, 5, 13, 15, 18, 19, 25 and 29. The notion of being a mute witness implies a completely embodied experience which is so raw and painful, that it defies words. Sacks (1984) claims that in the chaos of traumatic experiences, muteness begins with body, where an individual does not associate with their body, and therefore cannot articulate feelings about their body and state of mind. In this study, embodied experience was related to disability, but was compounded by the effects of poverty, lack of access to running water and electricity, the burden of dependence in the absence of true support, and the imminent presence of death within the community. For these participants, spoken language imposed a significant limitation on their ability to make sense of and deal with their life experiences – to such an extent that some of the narratives defied producing a quotation that could be used to highlight the level of suffering experienced. In these narratives, true meaning and relevance of embodied experiences lay beyond what could be said, but without the ability to transform experiences into words, sense-making for the individual and for others, remained limited. Sacks (1984) describes this experience as the "claustrophobic terror of muteness" (p.144). Frank (1995) adds that being a mute witness caught within chaos, is a condition of horror.

In these narratives, alternative narratives produced by poverty and psychosocial inequality could be observed, but were not voiced. This is because "ultimately, chaos is told in the silences that speech cannot penetrate" (Frank, 1995, p.101). The counter-narratives observed included inaccessible rights, lack of policy implementation that further disadvantaged those who were most vulnerable, stigma, social isolation and exclusion, and the overriding effects of poverty and food insecurity. These counter-narratives were observed though the

participant's inability to produce a coherent narrative, their squalid living conditions, and their few social relations.

The core feature of being a mute witness appears to be the individual's inability to translate lived experience into words, and, as such, their inability to reflect on lived experiences. As Frank (1995) states, "those who are truly living the chaos cannot tell it in words. To turn the chaos into a verbal story is to have some reflective grasp on it" (p.98). Thus, by providing an example of such a narrative implies that the participant is in some small way able to distance herself from the narrative. In the example provided below, the form and structure, as well as the content of the narrative is pertinent to highlighting the emergent story. The narrative that most clearly highlights the notion of 'mute witness,' for the purpose of providing an example, was that of Participant 5 (Appendix 25). Participant 5 is a 54 year old female who has a physical, cognitive and communicative disability as a result of a stroke, and is the mother of a 13 year old girl with severe cerebral palsy. They live in a small village, not far from the local hospital but with poor roads, that make the village almost inaccessible from the main road. There is no provision of running water or electricity in this village. The home where this participant lives is a small two-room brick structure which, although it has a roof, does not have glass panes in the windows or a door, leaving it exposed to the elements, especially to rain and wind. The participant and her three daughters who live in this home do not have any form of sanitation, and are forced to use the pit latrine toilet on their neighbours' property, approximately 300 meters away.

Participant 5 was well known to the research mediator, although she had not seen her for some time. The interviewer was caught off guard by the participant's lack of story, and although the participant did not appear unwilling to participate in the study, she had very little to say. Below is an extract from her narrative:

Interviewer: Can you tell me your story?

Participant: I don't know how it happened. I know nothing.

Interviewer: Oh, you mean the stroke? When did the stroke happen?

Participant: The stroke happened a long time ago. I fell down. After that they took me to hospital. After that, I don't know.

Interviewer: What about your children? How is life with your children?

Participant: Aaahhh….I gave birth to them and I grew them. Little by little I grew them until they are old.

Interviewer: Are there challenges that you face?

Participant: Yes, we are suffering.

Interviewer: I knew you from before, and before, you always had stories to tell me. I don't understand why it is that today you can't talk?

Participant: I suffered and suffered a lot. So I will suffer until I die.

In this narrative, the speaker takes on the role most similar to an interlocutor role, given the neutral way in which she tells her story, and the short turns used, guided by the interviewer (Koven, 2012). In this way, the speaker answers the question without telling a story, supplying only minimal information, and creating short turn-taking exchanges between herself and the interviewer. The participant positions herself in a neutral position and denies herself agency and ownership of her experiences as seen where she states *"I don't know how it happened. I know nothing."* However, this lack of entitlement and agency is challenged by her use of the first person 'I' denoting ownership of her narrative. She provides very little insight into her own identity, as well as into the way in which she perceives that others respond to her experiences. In this way she defies the reflective interaction between the individual and social interpretations of experience, with these aspects of narrative identity being subsumed into a vacuum. This concurs with Frank's (1995, p.97-114) work where he

claims that for an individual who is living a chaos narrative, consciousness gives up the battle for ownership of experience, resulting in the lack of a self-story.

The non-narrative appears to evade the core issues that have compounded one another, rendering the individual devoid of words to describe experience. The narrative is told in the present tense, but contains no form of orientation, nor is it grounded within the boundaries of time and space. In this way, the geneses of the traumatic experiences that have rendered the individual speechless remain buried, and the listener has difficulty in orienting him/herself in relation to the story being told. In a similar way to narratives defined by fighting psychosocial inequality, the narratives of the mute witness defy the ability to reflect or anticipate. However, in narratives told by mute witnesses, the absence of temporal and spatial orientations leave the narrative ungrounded, and in this way, both the identity of the narrator and their life experiences remain intangible. Similarly, the narrative is also lacking in characters, and thus, the absence of a strong narrator, the absence of spatial and temporal orientation, and the absence of characters have the resultant effect that the narrative is lacking 'substance', with nothing for the listener to cling onto. This is explained by Frank (1995) who states that the attempted narration of chaos represents "the hole in the narrative cannot be filled in. The story traces the edges of a wound that can only be told around. Words suggest its rawness, but the wound is so much of the body, its insults, agonies, and losses, that words necessarily fail" (p.98).

The most significant feature of the extract presented above appears to be where the participant says *"I suffered and suffered a lot. So I will suffer until I die"* because this IS the entire narrative. Given that no real story emerges within this interview, and there is no evidence of sequence or consequence, there is no evidence of an articulated plot. However, the plot does emerge, not by listening to individual stories of mute witnesses, but rather in their collective narratives and by means of observing life experiences. The participant's comment on suffering is key to the collective plot, and reflects not only her own life experiences, but also a representation of lived experience for many people within the community. Thus the plot which emerges appears to be one of social suffering to the point where the intersection between disability, poverty and the trauma of everyday life lies beyond language or analysis or explanation. This implies that the need for understanding and intervention cannot be

confined to the limits imposed by spoken discourse, but rather calls for an alternative approach to dealing with social suffering.

8.2.4.1 Summary of stories defined by the experience of being a mute witness

The narrative of the mute witness is defined by what is lacking. The narrative is lacking in substance, temporal and spatial orientation, characters who initiate actions, and ownership of experience. Thus the plot emerges in relation to what is left unsaid, as well as in relation to the participants' living conditions. At best, I would be able to make a tentative assumption regarding plot if this type of narrative had been produced by only one or two participants. However, the fact that almost of a third of the participants produced similar narratives warranted further investigation, giving rise to a plot dominated by social suffering such that the listener cannot even begin to understand the complex relationship between multiple traumas mediated in the context of poverty.

8.3 SUMMARY AND CONCLUSION OF CHAPTER 8

This chapter has highlighted the underlying experience of a variety of manifestations of violence and reveals the impact that these have on the development of coherent and 'acceptable' narratives. This highlights how, despite comprehensive and well-designed policies, guidelines and legislation intended to protect the rights of its citizens, many people living with disabilities continue to be overtly and covertly discriminated against. These forms of exclusion have resulted in the perpetuation of physical, emotional and financial barriers to independence.

In addition, the 'unacceptability' of the content of the narratives makes them difficult to hear, and as a consequence narratives remain fragmented episodic descriptions. This is similar to Evans and Maines' (1995) findings on narratives of incest. The authors report that due to the unacceptable nature of the content of narratives, the teller has no culturally acceptable plotline to rely on and as a result the narrative remains fragmented, with the teller only able to hint towards the horror of lived experience. Furthermore, the content is uncomfortable to listen to and as a result, listeners run the risk of guiding the speaker towards a narrative form that

reflects a culturally acceptable plot. Hilfiker (1994) states that health is not so much a question of disease, and emphasises that medical factors are rarely the most crucial to healing. He adds that society is more comfortable in providing medical diagnoses than social diagnoses that shift the responsibility from the individual to the community and require massive change regarding what the body includes as parts of itself.

In line with the above, Frank (1995) acknowledges that listeners have an innate desire to hear narratives of resilience but cautions that it is essential to acknowledge that other realities exist. Part of the difficulty in acknowledging alternative realities is that we, as a broader society, are complicit in both the development of 'unconventional narratives' as well as in denying the reality of lived experience among certain marginalised populations within society. Frank (1995) describes these alternative yet denied realities as "the pit of narrative wreckage" (p.110) and warns that attempts to remove the individual from their 'narrative wreckage' serves only to deny the reality of experience and to compound the chaos, and in this way, inadvertently increasing social suffering (Fox, 2011). This raises significant clinical implications which are discussed in Chapter 9.

The reality of being complicit in denying the lived experience was alarming for me. At many points during the period of data analysis I was tempted to exclude the narratives which in retrospect reveal the experience of being a mute witness. During the initial stages of data collection, these narratives did not seem to 'say anything' and I was tempted to exclude them on the basis that they did not conform to the definitions in the literature as to what constitutes a narrative. Fortunately I found myself returning to these narratives repeatedly, until I reached the point where I was able to identify part of the reality of lived experience to which 'the lack of words' spoke. By excluding these narratives I would have further marginalised and discriminated against this very vulnerable population, and in this way, I too would have been complicit in denying the reality of lived experience and perpetuating biased research, negatively impacting on the development of evidence-based practice. These concerns are discussed in detail in Chapter 9.

Based on the above, a number of important policy, clinical and methodological implications arise from the findings of this study. However, over and above these implications, a number of broader philosophical questions pertaining to the relationship between vulnerability and responsibility emerge. This chapter has demonstrated how, through the process of telling stories about lived experience, individuals reveal their vulnerabilities, and through these vulnerabilities, responsibility is recognised and change may be evoked. Based on this, the notion of 'telling one's own story' emerges as a vital aspect of responsibility, since it is only when stories are told that words and embodied actions that they become reality. In so doing, they can demand to be heard and for society to respond. Chapter 9, therefore, will conclude by attending to the moral responsibilities that memory and responsibility place on both the individual and society.

CHAPTER 9

CONCLUSION

"Memory is a responsibility, because as it is told, it becomes witness, and reaches beyond the individual into the consciousness of the community."

Arthur Frank (1995, p.64)



Visually impaired participant pushing research mediator down the road, followed by home-based care worker

This thesis is about the experience of disability in a rural area. More specifically, it is about disability in the context of poverty, the ways in which disability is interpreted by those who are affected by it, as well as the ways in which individuals with disabilities construe other people's responses towards them. By obtaining first-hand narrative accounts, this study explored the lived experiences of adults with disabilities in rural South Africa. Interpretation relied on examining the relationship between personal and social perspectives, and the ways in which these are situated within the temporal and spatial confines of narrative construction. This necessitated scrutinizing the reflexive interplay between the content of narratives and the ways in which the stories were told.

This study has revealed disability to be an entangled web of social and cultural constructs. By foregrounding the social and cultural experiences of disability which emerged, I was able to explore aspects of lived experience that are normally cloaked in silence. This evoked a sense of unease and discomfort, and as a result, the findings do not give rise to a discrete cultural construct of disability nor a neat causal model indicating how social processes combine, resulting in predictable experiences. Instead a complex relationship between personal and social interpretations of experience is revealed, highlighting the impact of cultural norms, values, and roles on incorporating disability into one's identity.

The descriptions of the experiences of living with a disability in a rural area were woven into wider narratives about gender, family and community, and generational differences. These were further impacted on by the competing voices of western and traditional African models of explanation and intervention for disability, the impact of political processes on the individual and the resultant personification of constitutional discourses into life narratives. All of the stories were infiltrated by the experience of violence and the abuse of human rights, together with the uncertainty of life in a community ravaged by the effects of communicable diseases and high mortality rates. The combination of these effects resulted in a sense of vulnerability among participants, and consequently many of the narratives revealed a lack of coherence, limited sequence and consequence, and at times an inability to transform the horrors of lived experience into words. This gave rise to a sense of unpredictability, not only in relation to embodied experiences but also in relation to the participants' life trajectories. This resonates with the findings of Legg (2010) and Legg and Penn (2013a), who

report that illness and disability magnify the experiences of food insecurity, unstable support networks, financial insecurity, and uncertainty regarding attributions and causality.

The combination of disability, poverty, isolation, stigma and trauma which emerged rendered the participants vulnerable to exploitation. While some participants did report a sense of support from family and community members, the church and the stimulation centres, these voices were muted by the challenges imposed by context and disability in relation to poverty, access and loneliness. While a number of the participants provided evidence of resilience, their efforts to secure resources in the form of income, social support grants and food were hampered by financial instability, limited access to information and physical localities, and institutional disarray. This highlights the fact that resilience is multi-factoral, and is not only a personal characteristic, but also a feature of communities. The context of poverty, gender inequality, food insecurity, violence and disease influences the extent to which both individuals and communities can become resilient. This was evident in narratives where participants barely mentioned their disabilities, but instead focussed on the day to day challenges imposed by poverty, food insecurity and the stigma associated with disability and disease.

South Africa's history of struggle, political instability and violence undoubtedly influenced the findings of this study. In the words of Swartz (2012, p.36) "where the intersections of race and class are so clear, it would be a mistake not to see the links between the narratives in this study and the broader narratives of struggle." In this way, the African philosophy of *ubuntu*, which Fox (2011, p.100) describes as "the act of memory" is threatened by social decay and moral disorder. During the process of conducting this study, a number of contrasts emerged. Prominently, contrasts between desire and despair became evident, with persons with disabilities exhibiting desires to fulfil culturally and gender-specific roles while at the same time revealing a sense of despair in relation to their inability to do so. Inequities in terms of income were apparent, segregating those who were employed, those who considered themselves to be employable, and those who qualified for disability grants from to those who did not. In addition, disparities in terms of support, marked by the influence of family and community responses to disability were shown to significantly impact on the ways in which people with disabilities made sense of their life experiences. On the one hand, a sense of

kinship and community spirit was reflected but, on the other hand, this was contrasted by ruptures in society along the lines of ability, gender, age, disease, nationality, and income, revealing a breakdown in social functioning at all levels of society.

As Swartz (2011) states, these problems are too big, too pervasive and too complex to be explained by assuming narrow interpretations. Given the context of poverty, and the stark inequalities of social functioning, questions emerge regarding frameworks of interpretation of disability and their ability to provide insight into the social processes inherent in community life. Further questions emerge regarding how people with disabilities living within the confines of rural communities search for and assign meaning to their worlds. This opens a dialogue on the role of memory, vulnerability and responsibility in response to disability, and, in response to societal breakdown.

Broadly, this study has the potential to contribute to the socio-cultural understanding of disability, and thus to influence the development of culturally and contextually relevant and socially engaged practice. This requires a critical awareness of the influences of context and culture on the everyday life experiences of people with disabilities, and relies on the use of flexible and culturally appropriate tools which allow for the emergence of various interpretations of experience. In this way, this study demonstrates the value of applying a qualitative approach, specifically narrative inquiry, as a useful tool for exploring the socio-cultural and socio-political aspects of lived experience. This is important in terms of service delivery, since MacLachlan (2009) claims that in order to attain high standards of health it is important that researchers working within the field of disability interact with and understand contextual domains, including transport, education and employment.

9.1 RECOMMENDATIONS FOR SERVICE PROVISION

The results of this study reveal that current service provision in the fields of healthcare and social services provide only limited support to people with disabilities, and do not adequately take into account individuals' needs related to access, food security and poverty alleviation. In response to this, I argue that an understanding of both context and culture is fundamental

to the development of appropriate interventions that address the uncertainty, vulnerability and social isolation of people living with disabilities in rural communities.

An important question that emerged is whether the narratives of privileged, educated and/or urban people with disabilities would have been different to those obtained in this sample. While it is acknowledged that isolation and exploitation are areas of concern for all people with disabilities, it is clear that uncertainty, vulnerability, disempowerment and marginalisation are arguably key features of lived experience for people with disabilities living in rural areas. Although these features may be shared by all people living in rural areas, these themes appeared to be especially prominent within the lived experience disability, with many of the participants drawing on these issues and their political underpinnings in order to make sense of their life trajectories. Thus, in the context of poverty and disability, the divisions instilled by food insecurity, unemployment, and exclusion appear to be exacerbated.

While I do not suggest that the findings presented here are representative of all people living with disabilities in rural areas, I do believe that the acknowledgement of the reality of lived experience and the emergence of new stories may provide alternative opportunities with which others living in similar circumstances may align. In this way, collective memory is forged through the merging of individual experiences towards a publicly accepted statement of the ways in which history impacts on the present (Fox, 2011). While the content of the emergent narratives may be contextually specific, it is reasonable to anticipate that some of the experiences described by participants may transcend contextual differences and may thus be applicable in other settings. It is therefore important that the influences of context and culture are not only interpreted in terms of their effect on the ability to make sense of lived experiences, but also in terms of their effect on other people, including the family, community members, service providers and wider society, including policy developers. This seems to be particularly pertinent since responses to disability have the potential to perpetuate or bring to an end to the cycles of violence to which many people are exposed.

9.1.1 Clinical Recommendations

The findings of this study suggest that poverty, together with limited service provision, impaired access, myth and stigma, limits the ways in which the community is able to serve as a safety net for people with disabilities. This is supported by Farmer (1999) who suggests that human rights recourses that rely heavily on the government are unlikely to be successful. This calls for innovative ways in which the challenges imposed by poverty and access can be addressed using culturally and contextually driven techniques that foster a sense of agency and empowerment among those affected.

One type of culturally and contextually relevant initiative is through the development of support centres and networks. In contrast to the social model of disability which motivates for the integration of people with disabilities into society, disability groups and stimulation centres proved to be places where people with disabilities felt safe and free to inhabit and express their life narratives without inhibition. However, the notion of a support group needs to be carefully considered, specifically in relation to where the locus of control lies and who the driving force is behind the support group. This is important to consider since support groups in rural areas are often set up and run by hospital therapists, yet it is essential to take into consideration the motivation of the individuals for whom the support group is intended, as well as the roles of caregivers, family members and community members in healthcare and rehabilitation. This is elaborated on by Crawford (1994) who states that a basic prerequisite for development is the capacity of society to use its own resources to sustain itself.

The emergence of contextually and culturally rich data highlights the need for these aspects to be incorporated into clinical encounters and consultation rooms. This includes taking into account the variety of different models of causality and consequent health-seeking behaviours that individuals may pursue, in addition to the acknowledgement of conflict surrounding cultural and gender roles, and generational differences. While it is acknowledged that in the South African context, as in many other contexts, the healthcare provider and the patient may not share the same culture or background, an openness to concede this and discuss the impact of these issues may be fundamental to emotional and physical well-being. The act of embracing cultural and linguistic diversity thus has the potential to provide recognition to the daily challenges encountered by people with disabilities.

The findings of this study highlight the importance of understanding life experiences and priorities from the individual's point of view prior to imposing interventions that are neither culturally not contextually appropriate. The incorporation of the research mediator into this study demonstrated how this can be successfully done by employing a cultural broker who may be able to negotiate barriers to health imposed by historical, cultural, and linguistic factors. In this study, the notion of shared knowledge and shared life experience is highlighted where participants spoke of the research mediator, saying, *"wati bonke buntima bami"*, meaning *"She knows me in my darkest places."* This relationship is particularly noteworthy, when taking into account the extended periods of time that 'informal' care workers spend with patients, compared to the time spent with healthcare professionals (Swartz, 2012). Although a large body of literature exists, acknowledging that shared knowledge and an understanding of context and culture are important factors in the rehabilitation process, the implementation of such services is challenging particularly where healthcare providers do not share the same background as the client, and are trained according to biomedical models of treatment. A cultural broker has the potential to bridge this barrier, yet this relies on the healthcare provider being able to yield control and be guided from an insiders' perspective. Furthermore, it requires reflexive engagement in the recognition of the extent to which we are all complicit in perpetuating cycles of institutional violence.

The introduction of Community-Based Rehabilitation (CBR) guidelines (WHO, 2010) does point towards acknowledging the value of including a cultural broker into consultations. However, focussing purely on the training received by CBR workers (e.g. Tomlinson et al, 2009; Mannan & MacLachlan, 2010) only superficially addresses the core areas of concern. Tronto (2010) highlights that care workers are often almost as vulnerable as the people who they are assisting, reflecting societal distribution of power, and limiting the possibility of being treated as an equal partner in the consultation process (Tronto, 2005). Thus, failing to take into consideration the pervasive and important role of care-giving implies that those in positions of power have the opportunity to ignore and degrade those who offer these services (Tronto, 1993, p.111). By drawing attention to the inadequacy of care in society, particularly evident in cross-cultural and cross-linguistic encounters, implies a profound rethinking of society's moral and political decisions and priorities. For this reason, if CBR workers or any other form of cultural broker or mediator is to be included into healthcare consultations it is

imperative that they are truly valued and acknowledged and not treated as subsidiary team members.

While cognitive and communicative impairments are acknowledged to have the potential to influence the ways in which individuals make sense out of their lived experiences, and consequently their abilities to construct coherent stories that organize the past, present and future into a meaningful pattern, this thesis has highlighted the importance of understanding a variety of barriers to expression. In this study, barriers to expression appeared to extend beyond communicative impairments to include psychological, gender and cultural barriers. This finding contests current models of disability, including the social model and the ICF, as well as programmes developed to facilitate participation in activities of daily living (e.g. Law et al 2005; Parr, Pound & Hewitt, 2006 as cited in Legg, 2010) which imply that verbal impairment singularly precludes individuals from active participant in everyday life. These interventions focus on the individual without adequately taking the social nature of community roles into account, and the making a shift to a wider perspective difficult (Sen, 2000; Tomlinson, 2010). This implies that true inclusion and social cohesion is impossible without taking into account the social implications of gender, (dis)ability, and limited employment opportunities, which ultimately result in restricted social opportunities and 'life chances' (Tronto, 2010). The adoption of a wider perspective, however, has the potential to inform a transformed role for speech-language therapists, particularly those working in rural areas. For this reason, the need to identify and negotiate barriers to expression needs to be incorporated into the curriculum at an early stage so that speech-language therapists learn to facilitate appropriate interventions and referrals.

9.1.2 Policy Recommendations

This thesis draws attention to a number of instances where the implementation of policies fails the most vulnerable members of society. This concurs with the findings of both Pfeiffer (2003) and Farmer (2006) who claim that government structures and developmental aid systems frequently contribute to the process of structural violence by increasing income inequality or by reinforcing condescending attitudes towards marginalised communities. In many of the narratives, participants made reference to their rights and to the promises which the government had made, yet on which they had failed to deliver. In all of these instances,

the participants referred to the government in the third person 'they', but gave no indication that they were aware of whom to speak to or the processes to follow in terms of taking issues of concern forward. This highlights the need for improved channels of communication as well as improving the accessibility of rights for people with disabilities. Given South Africa's current state of economic, political and social disorder, an analysis of the implementation of policies designed to protect citizens with disabilities would be particularly useful. While the sense of disorder within government facilities has implications at national level, this state of turmoil has the potential to filter down into society and in this way, what occurs at national level may be mirrored in both social settings and consultation rooms.

Reflecting on the challenges imposed by physical access, limited education, and inadequate or unattainable information, the need for context-specific evaluations of the implementation of policies emerges. Sen (2012) however, highlights the need to acknowledge the two-way relationship between rethinking behaviour on the grounds of social justice, and the institutional need to advance the pursuit of social justice given the behavioural parameters of society. This implies the need to find a balance between the ways in which social justice is implemented in relation to the barriers instilled by deeply ingrained social behaviours. Thus, despite the fact that South African policies reflect the government's prioritisation of the needs of persons living in rural areas (Coovadia et al, 2009), the structural violence inherent in policy implementation needs to be addressed according to site-specific requirements. This is supported by Farmer (1999) who claims that the inappropriate implementation of government policies has the potential to violate the civil, economic and social rights of its citizens, and that societal inequality serves to perpetuate and cover these violations. Given the vast disparities in the South African context, it follows that not all vulnerable groups can be considered as equitable, and therefore a one-size-fits-all policy to address the needs of people with disabilities is unlikely to be adequate. However, site-specific information regarding poverty, epidemiology, and accessibility to services and information has the potential to address the discrepancies in policy implementation experienced by those in rural areas, and can be used to strengthen institutional ties and referral pathways.

Despite the policy shortfalls highlighted in this study, it is acknowledged that research itself will never be enough to initiate meaningful changes (Mji et al, 2009). The responsibility thus

falls on the relationship between government institutions, healthcare providers, and the individual members of society, as depicted in Figure 7 below. It is therefore necessary for the South African government, to review the ways in which models of care are applied, acknowledging that care is not only limited to personal and intimate relationships (Tronto, 2005), but extends to the ways in which governments show that they value their people. This is supported by Keller (2009) who highlights the importance of shifting the understanding of what it means to care from an ethic of interpersonal relationships towards a tool for analysing public policies and social practices. This would entail interrogating the intersectionality of disability, gender, race and class, and the ways in which these social categories serve to marginalise individuals within society. Consequently, this involves examining the political imperatives of what care actually means. Tronto (2010), however, points out that the ethics of care being embraced into a democratic society is unlikely, in the absence of a moral and political space which allows for caring to take place. This can only take place if institutions care about their own ways of working, and implies a re-evaluation of work ethic in all environments.

MacLachlan (2009) highlights the role of researchers in developing caring environments and claims that "researchers need to do more", highlighting not only the need for meaningful research, but also for social activism in terms of translating the needs of persons with disabilities into tangible goals. This involves service providers confronting the anxieties, silences, prejudices and injustices which exist in both policy documents and healthcare consultations, and to think differently about the roles of government, service providers, and individuals, and ultimately what it means to act responsibly.

As highlighted in Chapter 3, all extant models on disability were developed based on their ability to address the needs of a specific group on people during a specific time, historically and culturally (Smart, 2009). Previous studies into the field of disability have relied predominantly on the use of traditional models, such as the medical and social model, and more recently the World Health Organisation's International Classification of Functioning, Disability and Health Framework (2001) in order to develop an understanding of experiences related to disability. This has resulted in disability being increasingly described in terms of impairment, activity limitations and participation restrictions (Legg & Penn, 2013b). These

models do not take into account the individual, psychological and social dimensions of disability, since these variables are viewed as universal (Legg & Penn, 2013b), and thus, fail to adequately take into account the impact of context and culture on lived experience. In this way, the existing models serve to perpetuate cycles of inaccessibility (White & Tronto, 2004), which many people with disabilities face. This is of particular relevance in the South African context, where poverty, unemployment, violence and socio-political instability are dominating influences. It is therefore impossible to understand the lived experience of disability without taking these variables into consideration.

The results of this study demonstrate that the needs and rights of people with disabilities are not universal, and importantly, that those who are most in need of asserting their rights do not always have the language or ability to articulate their situations. Thus, as this study progressed, the frameworks of interpretation for understanding the psychosocial processes associated with disability with which I had been familiar, appeared to be increasingly inadequate. However, adopting a socio-cultural view of disability as depicted in Figure 7 below, allowed for the incorporation of both space and time into the understanding of lived experience, and in this way, lived experience was viewed as intimately related to the socio-political and cultural circumstances of people's lives. This resonates with Tronto's (1995) suggestion that the notion of 'care' be used as a framework for moral and political thoughts and actions, since the act of 'caring' has the potential to transcend the barriers imposed by language, culture, gender and (dis)ability. This approach requires not only a restructuring of policies and practices but also calls for social activism at various levels of society in order to gain a deeper understanding of the power relationships within society, and to establish a full account of the needs of persons with disabilities which is both culturally and contextually relevant. However, in order to do this, Tronto (1995) suggests that, as a society, we rethink the assumptions underpinning current social and political theories. This ties in with Nussbaum's (1993, 2007) theories on human capabilities and the ways in which society responds to those with impairments, thus raising the question of what deems a life worthy of human dignity. By adopting a model of care (Tronto, 1995) would allow for the creation of an empowering environment which caters towards people's material and social needs (Marmot, 2012). In this way, people with disabilities would be given the opportunity to live lives of dignity.

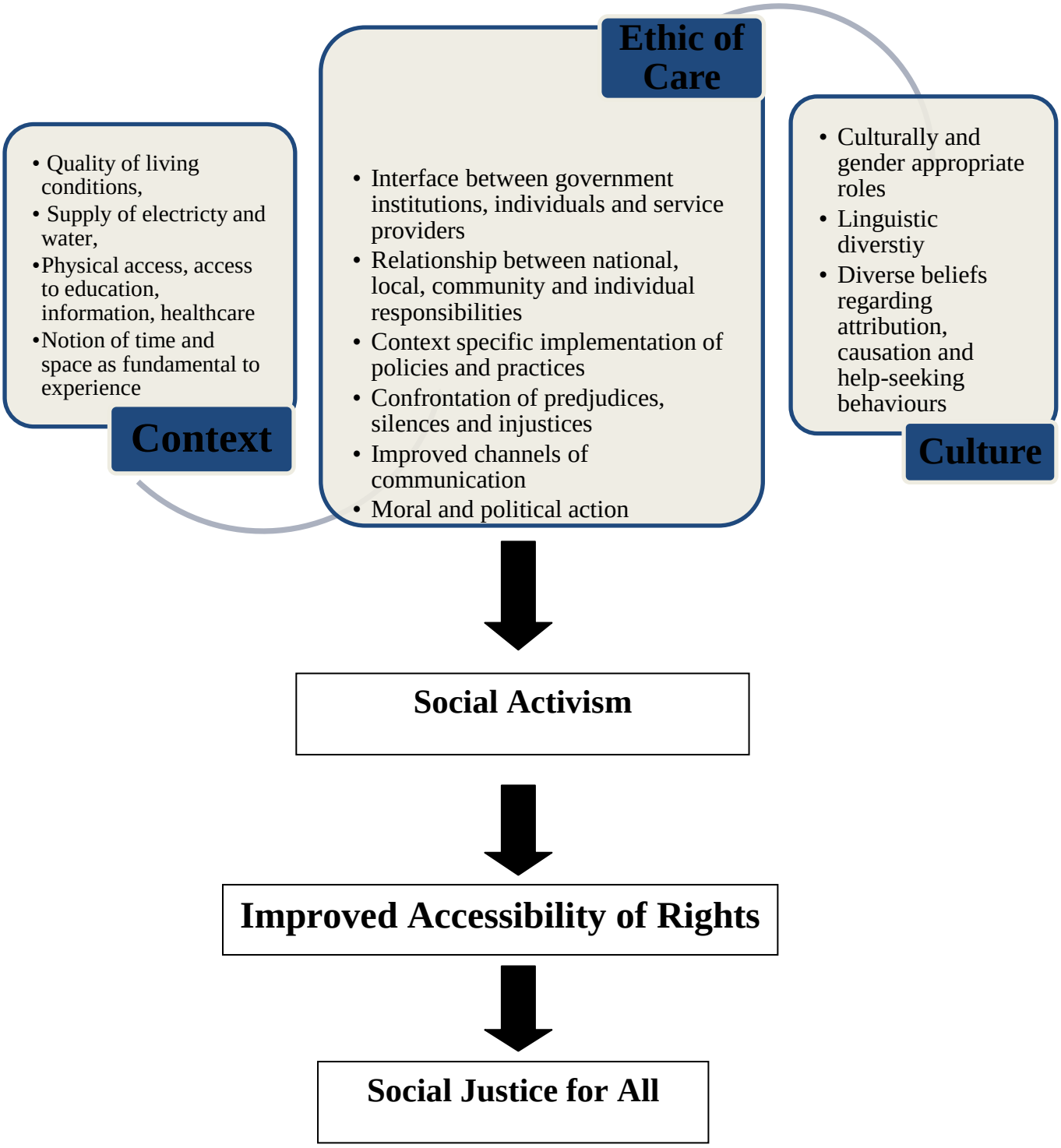


Figure 7: Model Depicting the Implementation of an Ethic of Care to Serve People with Disabilities

9.1.3 Theoretical Recommendations and Implications for Further Study

From a theoretical point of view, this thesis has demonstrated how empowering research has the ability to create an environment where muted voices can be heard. Conversely, however, as Fox (2011) states, the failure to take embodiment seriously can inadvertently lead to increased social suffering. As discussed in Chapter 5, a variety of different methods of analysis were applied in order to make sense of the data. A summary of the findings in relation to each form of analysis is provided in Table 7 below.

Table 7: Summary of methods of analysis and findings which they yielded

Method of Analysis	Summary of Findings
Frank's (1995) Illness Narratives	This framework provided insight into the various ways in which illness and suffering are embodied, and the associated experiential journeys involving suffering, uncertainty, and medical treatment. This highlighted the ways in which people with disabilities are marginalised from society. The initial analyses revealed that the social and contextual aspects which Frank (1995) refers to as core aspects of narratives seemed to be very different in the context of rural South Africa. However, these only provided limited insight into the role of time and space on narrative construction, together with the impact of context and culture in the formation of narratives and the act of storytelling.
Clandinin and Connelly's (2006) Three Dimensional Narrative Inquiry Space	This framework complemented Frank's (1995) illness narratives in that it focussed on the interplay between personal and social interpretations of experience. This allowed for culturally and contextually relevant information to emerge, and highlighted the nature of social role devaluation among persons with disabilities. This framework showed how marginalisation impacts on the integration of time and space into narrative construction, resulting in a lack of coherence. This framework, however, provided inadequate detail in terms of the ways in which participants positioned themselves and others in their stories and how this impacts on the ways in which they assign and take on roles and responsibilities.
Harré's Positioning Theory (1990, 1993)	This method was applied in order to develop an understanding as to how the participants positioned themselves and assumed roles and responsibilities as depicted through narrative construction. Specifically, this framework provided insight into the ways in which rights and duties are distributed during interpersonal interactions. This method of analysis allowed for a more detailed understanding of the relationship between personal and social interpretations of experience, and the cultural and contextual factors affecting social role devaluation amongst persons with disabilities in a rural area.
Braun and Clarke's (2006) Thematic Analysis	Thematic analysis was used in order to inductively generate theoretical categories, given that this framework is not bound to a specific theoretic paradigm. Themes were generated 'horizontally' across the data set and served to compliment the 'vertical' analysis applied using narrative analysis. The data were viewed as a whole, and unique and recurring themes were identified which served to both confirm and reject findings obtained using narrative analysis.

As can be seen from Table 7, narrative inquiry served as a method for understanding lived reality, and provided a number of unique insights into the lived experiences of people with disabilities that would have been impossible to achieve through the use of other methods, particularly those associated with the quantitative paradigm and those employing more rigid protocols such as structured interviews or surveys. This provided insight into the reality of lived experience, exposing a number of philosophical and political positions within society and highlighting the misfit between current models of disability, the implementation of policies and practices, and the needs of persons with disabilities. Thus the methods employed allowed for a nuanced view into the socio-cultural processes associated with living with a disability in a rural area.

The application of a qualitative methodology allowed for a number of unanticipated findings to emerge, including the fundamental role that exposure to violence plays in shaping the ways in which people with disabilities view themselves and the consequent influence that this has on narrative construction. Against this background, a new framework for analysing the ways in which individuals make sense of their lived experiences is suggested. Narrative inquiry seems to be a particularly valuable tool since the act of telling and listening to stories is both socially and culturally acceptable. This differs from traditional clinical approaches which rely on static conventions of identity and essentialising theories that assume the unity of an 'inner self' (Frank, 1995).

Significantly, the act of conducting research cross-linguistically seemed to strengthen the methodology applied in this study. Although I am a therapist, and have training and clinical experience in working with and counselling people with disabilities, the language dynamics that existed between myself and the participants prevented me from interrupting or re-framing their narratives. Although I found this extremely frustrating during the process of data collection, and I spent significant periods of time pondering over the trustworthiness of findings that had been translated, my inability to do any more than receive the stories appears to have served as a strength in the study, since it allowed for new narratives to emerge. It is thanks to these variables which I had formerly considered to be barriers to my proposed methodology that comprehensive personal accounts that were both contextually and culturally relevant were able to emerge. This highlights the importance of both Temple and

Young's (2004) and Squire's (2008) support for cross-cultural research in order to avoid narrowing the research field and thereby continuing to disadvantage previously neglected cultural-linguistic groups. Thus, in this study, the act of conducting cross-cultural research served to create an understanding of disability that is contextual rather than formal or abstract (Gilligan, 1993).

Despite the significance of results, the methodology did present a variety of challenges, and thus a number of recommendations for further study have emerged. The process of analysing SiSwati narratives was complicated, particularly given the limited published data available on the norms of narrative construction in SiSwati culture. This made it difficult to determine whether or not stories located within a single tense were to be considered within or beyond the culturally accepted norms of narrative construction. While the findings seem to indicate that narrative inquiry may be a useful clinical and research tool, further research that delves into the norms of narrative construction in SiSwati culture would be useful. Furthermore, research into the construction of culturally acceptable plots and the nature of characters and common themes in SiSwati narratives would serve as a guideline for the application of narrative inquiry as a tool for making sense out of lived experiences.

While the four new types of stories that emerged serve as an acknowledgement of the reality of disability in a rural area, these may need to be further investigated within a larger sample, as well as in a variety of different rural and urban contexts in order to determine their robustness in clinical application. In addition, a deeper understanding into the effects of violence and trauma on the life experiences of people with disabilities has the potential to inform not only the curriculum within the field of healthcare, but also the fields of social work and psychology, and may hold relevance in the development and implementation of policies and practices. In relation to this, insight into the use of metaphors used in narrative construction would be beneficial, since many of the participants made reference to being treated *"like animals"* with particular reference made to reptiles, such as snakes. While some published work on the symbolism of animals in witchcraft in African cultures exists (e.g. Wilson, 1951; Hammond-Tooke, 1974; Comaroff, 1985; Niehaus, 1995), a paucity of this type of literature exists in relation to the SiSwati culture, and therefore the relevance and significance of these metaphors was difficult to ascertain.

A number of unanswered questions remain, relating to roles within the SiSwati culture. These pertain to both gender and cultural roles and the ways in which these are or are not adapted for persons with disabilities. Research into this arena is particularly important, given the high burden of communicable disease in the South African context, high mortality rates, and the changes in family structure with a significant burden of care placed on the elderly and child-headed households, largely as a result of the spread of HIV and AIDS.

The experience of violence and the way in which it manifests in rural communities requires further investigation. This pertains particularly to the experience of structural violence encountered in accessing disability grants and identity documents, since this has a direct impact on the financial, nutritional and psychological wellbeing of people with disabilities. However, research into other domains in which violence is prevalent is also warranted. This includes research into the nature and prevalence of gender-based violence in rural areas, as well as violence between persons with disabilities and their caregivers. This is of particular relevance, given the Minister of Women, Children and Persons with Disabilities, Lulu Xingwanga's claim that gender-based violence represents a threat to South Africa's hard-earned freedom (Xingwana, 2013). This is supported by Jewkes (2013) who claims that the unacceptably high levels of gender-based violence in South Africa continues to contribute to the spread of HIV, as well as psychological distress. These effects have been shown to be heightened in rural areas (Nduna & Jewkes, 2012). The effects of gender-based violence are therefore magnified among women with disabilities in rural areas, given their increased vulnerability (Plummer & Findley, 2012). For this reason, communities need to be mobilised to fight the scourge of violence in society. This will entail setting up accessible routes for all members of communities to follow in order to report on violence, such as at stimulation centres. Furthermore, it will entail that those heading up such project are well trained to identify the various forms of abuse that people with disabilities may be exposed to and are equipped to work together with people with disabilities, including those with cognitive-communicative impairments, assisting them in reporting and addressing issues of violence in society. This requires both financial and emotional support to assist those affected.

Finally, research into the cultural constructions of self-representation among adults with disabilities has the potential to influence clinical interventions. While the notion of 'cultural

competence' is acknowledged in South African policies, an understanding of this abstract term cannot be assumed and for this reason detailed understandings of cultural constructions of the self are important in the development of policies and in the implementation of services. Detailed qualitative understandings of interpretations of disability have the potential to challenge existing models of explanation which in turn may influence the training of healthcare and social services providers. This could contribute to a broader theoretical understanding of the socio-cultural nature of disability in a field where political agendas have contributed towards disembodied constructions of the self. As the findings of this thesis demonstrate, narrative inquiry has the potential to serve as a powerful tool to facilitate personal and social healing. By nature of its flexibility and position at the intersection of ethics, curriculum development, service provision and policy development, narrative inquiry has the potential to acknowledge human rights violations of the past and in so doing restore dignity to those affected. In this way it is possible to begin a process of ensuring the culturally and contextually appropriate implementation of policies and practices as well as addressing the research needs of people with disabilities.

9.2 FINAL REFLECTIONS

This thesis has highlighted the socio-cultural complexities associated with living with a disability in a rural area, and has drawn attention to the need for a comprehensive and contextual understanding of the ways in which people with disabilities make sense of their life experiences. This includes the relationship between personal and social interpretations of experience, the importance of cultural and social phenomena in assigning meaning to experiences, and the ways in which the physical and emotional dimensions of inclusion and exclusion influence the experience of disability. While I have attempted to put forward a strong argument for the need to take cultural and contextual variables into account, Sen (2000), warns that a sense of contextual relevance should not make us overlook what can be learned from exploratory studies and applied within in other settings. It is thus, both possible and important to acknowledge and celebrate contextual knowledge, while at the same time to claim these values to be of universal importance (Sen, 2000).

As described in Chapters 7 and 8, the majority of the narratives contained an element of chaos, which made lived experience difficult to transform into words, and at the same time made the stories difficult to hear. Frank (1995) claims that chaos stories are difficult to hear because they threaten the listener's sense of predictability and coherence in the world. This is supported by Hilfiker (1994) who claims that society prefers medical diagnoses that require treatment above social diagnosis that necessitate massive changes in society. Similarly, clinicians have been found to display an inability to tolerate chaos since they see it as a critique of their clinical work (Hilfiker, 1994).

The narratives that emerged in this study are threatening because they do not only challenge our understanding of what it means to live with a disability in a rural area, but they expose ruptures in societal morals and values. The results of this thesis will hopefully provide some indication as to where societal breakdown may occur, including along social fault lines which develop in response to deeply ingrained forms of discrimination. Thus, it may be anticipated that societal breakdown may occur in relation to ability, gender, class and race, and among people who are considered to be different, poor or vulnerable. It is however, difficult to fathom from where this type of discrimination originates. While Farmer (2006) suggests that the simultaneous consideration of various social axes is imperative in discerning the origins of brutality, it is also important to take into account our own vulnerabilities and prejudices and how these may contribute to the perpetuation of cycles of violence. This can potentially be done through the process of narrative inquiry which allows for shifts in responsibility away from discourse pertaining to rights and regulations, towards responsive and responsible ways of thinking about our roles as individuals in our engagements with others.

Given my naiveté at the beginning of the research process, I found that I was unprepared for the harsh reality of the participants' situations as well as the moral and ethical dilemmas in terms of how to respond to such gross violations of human rights. I found myself questioning my role as a researcher and as a clinician in being complicit in the everyday violence which people with disabilities are exposed, and consequently how my own vulnerabilities would impact on the dissemination of results. I was guided by Atkinson (1997), who suggests that the standpoint of the researcher in the presentation of findings should be inspired more by ethics than methodological preoccupations or political affiliations. For the first time in my

career as a researcher, I fully encountered the enormous responsibility associated with research, particularly exploratory studies. I found that my accountability extended beyond the commitments made to the University Ethics Committee, and despite the fact that a number of authors (e.g. Frank, 2001; Patton, 2002) caution that the researcher is likely to encounter human suffering in qualitative research, I found that there were limited guidelines on how to negotiate my response to the human suffering that emerged within this research.

My experiences as a researcher, together with the findings which emerged in this study are not necessarily specific to the South African context, but emerge in stories about the experience of disability in all cultures and contexts. However, South Africa's history of apartheid and the subsequently ingrained culture of violence that persists in society today, together with social prejudice, poverty, corruption, unemployment and political instability have played a significant role in the erosion of social fabric, and in this way, bodily impairment has come to represent the symptoms of a more fundamental social problem. Based on the above, the essential coherence which bind communities together (Fottrell et al, 2012) is threatened by uncertainty, superstition, and societal breakdown.

In South Africa, the advent of democracy and 'a better life for all' has been juxtaposed by a heightened sense of fragility in the experience of everyday life. Given that the forces of globalisation bring a variety of economic, social and cultural influences into contact with each other, globalisation represents both a threat to traditional lifestyles, as well as an opportunity to provide new insights towards old problems (Sen, 2000). Thus, as globalisation is imminent, these factors need to be carefully considered, contextualized and addressed.

This is of particular importance, given that a major threat to globalisation is social exclusion (Sen, 2000). This study has highlighted numerous examples in which people with disabilities in rural areas are excluded both on a physical and an emotional level from everyday participation within the community. This type of knowledge has the potential to influence global understandings of disability and participation, and in so doing provides insight into both contextual circumstances and humanity.

Thus, while the results of this study point toward a number of clinical, theoretical and policy implications, these findings open up a dialogue pertaining to the concepts of vulnerability and responsibility and how these relate to the language of 'rights' in society. Sen (1979) reminds us that morality is not only concerned with equality, and for this reason, a re-framing and re-thinking of the notion of 'rights' is necessary. One way of doing this is through the adoption of a framework of care (Tronto, 1995), where the concept of 'care' is framed in relation to "responsibilities rather than rights, engagement rather than abstraction, and connection rather than separation" (Gilligan, 1993, p. 135). This is supported by White and Tronto (2004) who suggest that social relationships rather than individuality should be central to a framework of care. This implies addressing the misconception that only the vulnerable, poor or disabled have needs, since this distorts the reality of human interdependence and allows some members of society to shun their duties of responsibility (White & Tronto, 2004).

This notion of accountability is extensive and includes governments, healthcare and social service providers, researchers and community members, all of whom are either directly or indirectly affected by poverty, food insecurity and the increasing burden of disease. The findings of this study suggest that it is through the process of telling stories that we are able to connect with others and in this way create opportunities to tell and live our stories. However, as this thesis highlighted, not all experiences can be transformed into words. This calls for sensitivity in identifying the boundaries within which stories are told, and listening to, rather than ignoring the silences which frame narratives. In this way, it is possible to identify stories which resist being transformed into narratives. This requires flexibility and sensitivity in creating a space for stories to be told so as to allow for retelling, re-conceptualisation, and re-interpretation of lived experiences.

Our ability to listen to stories and to create spaces for stories to be told brings into question the ways in which we are able to respond to the themes of uncertainty, vulnerability and suffering. Following Levinas (1985), it is our responsibility to recognise and respond to others' suffering. However, the act of bearing witness to another person's suffering is a remarkable responsibility, and brings with it the inherent risk of misinterpretation or denying an individual's reality by attempting to force them out of the "pit of narrative wreckage" (Frank, 1995, p.110). Thus Levinas (1985) warns against the dangers of "pretending to know

another person's suffering" (p.84). A further risk in acknowledging and responding to suffering is to attempt to group or categorise it. Farmer (1999) warns that "to place the other under a category is a form of symbolic violence" (p.1489), and thus the claim to know another's suffering or to classify or categorise it is to take away a part of their integrity. This highlights the need to acknowledge the experience of violence, abuse of human rights, and our own vulnerabilities as human beings. However, caution must be exercised in the way in which this is done, since by reframing or re-categorising another person's experiences implies denying their experience. This has significant implications for those involved in the helping professions since the line between acknowledging and denying an individual's reality can be faint.

By providing people with disabilities with opportunities to tell their stories, we are able to offer them the prospect of re-imagining and re-framing their roles, and in so doing re-claiming and re-naming their lived experiences. This has the potential to create a counter-narrative of the reality of lived experience, which does not aim to deny or re-classify the experience of pain, suffering or the violation of human rights. As researchers and healthcare professionals, this involves acknowledging our own inabilities and vulnerabilities, and implies that quality of life does not depend on an existence which is free of pain and suffering, but rather an understanding of what it means to be human.

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Appendix 1 - Ethical Clearance Certificate

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (NON MEDICAL)
R14/49 Baratt

CLEARANCE CERTIFICATE	PROTOCOL NUMBER H0 90612
PROJECT	Context, culture and disability: A narrative inquiry into the life experiences of individuals directly and indirectly affected by disability in a rural area
INVESTIGATORS	Ms J Baratt
DEPARTMENT	Speech pathology
DATE CONSIDERED	12.06.2009
DECISION OF THE COMMITTEE*	Approved Unconditionally
NOTE:	

Unless otherwise specified this ethical clearance is valid for 2 years and may be renewed upon application

DATE 02.07.2009 CHAIRPERSON .....
(Professor R Thornton)

cc: Supervisor : Prof C Penn

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10005, 10th Floor, Senate House, University

I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure a approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

Signature

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix 2 – Guiding Questions for Interviews with Participants

Given the narrative approach that will be used, two open-ended questions will be posed to adults with disabilities during the interview, and depending on their responses, certain aspects will be probed. The questions that will be posed will be:

Can you tell us your story?

However, since the researcher will not be conducting the interviews, the following guiding questions which can used to probe some of the participants' responses will be included into the training of the research mediator:

- Can you tell me about your experience of living with a disability?
- What do you believe caused you to have this disability?
- Have you received any treatment for this disability?
- What is the most difficult or challenging thing for you about living with a disability?
- How do other people (your family and neighbours) feel about your disability?
- How do you think members of the community living in Tonga could make life easier for persons living with disabilities?
- What do you think are some of the difficulties facing persons who do not have disabilities in Tonga?

Appendix 3– Guiding Questions for Researcher and Research Mediator Reflections

- How did you feel about that visit?
- Was there anything that struck you during that visit?
  - Was it something that made you feel particularly happy or sad?
  - Why do you think that you reacted in that way?
- Do you think that you influenced the participant/s in any way?
- Do you think that based on the way in which you responded to this visit will influence you at any other visits in the future?
  - If so, in what way?

Appendix 4 – Information Letter for Research Mediator

Dear Lindiwe Thobela

As I have mentioned to you over the telephone I am doing a study looking at the experiences of adults living with disabilities in Tonga, the experiences of families and caregivers of adults with disabilities in Tonga, and the experiences, beliefs and perceptions about disability of community members who are not directly affected by disability. By carrying out this study I hope to be able to gain a better idea of the needs of persons living with disabilities and their families and in this way to influence the services provided by healthcare providers working in rural areas. I also hope to be able to identify barriers to the implementation of policies for persons with disabilities in rural areas. By doing this it will assist in the training of future healthcare providers to be sensitive to persons' with disabilities life experiences and needs including rehabilitation and medical services.

I would like to invite you to assist me in collecting this information for two reasons. Firstly you have an excellent understanding of disability, and the experience of living with a disability in a rural area; and secondly I have worked with you before on a similar study and I think that we have a good working relationship. If you agree to assist me I will provide you with in-depth training about the type of information that I will be looking for and how I would like to try and get this information from the participants. I will pay you for your time in the study according to the University of the Witwatersrand guidelines for paying research assistants which currently would work out to R145 per 8 hour day or R20 per hour.

Your role in the study would be the following:

- Identifying possible participants within the community
- Accompanying the me to the homes of the participants
- Conducting interviews with the participants
- Answering questions after each visit to each participant about how you felt about what the participant said.

I plan to collect this information between October 2009 and April 2010. I will be visiting Tonga 3-4 times over this period, and each time I will stay for 2-3 weeks. You will not necessarily have to work with me every day during this period, but rather we can meet to draw up a schedule for obtaining this information that will suit both of us.

- **Possible Risks**

Although I will be consulting with your supervisor, Mamsy Mashele for permission for you to participate in the study, it is time consuming and will require a fair amount of your time during the time that I will be spending in Tonga. While it may be possible for you to still do

some of your daily work, you may need to take some time out of your annual leave to participate in this study.

- **Possible Benefits**

You will be contributing to research that has been identified as important by DPSA, and a number of other government departments. This means you will be contributing to the training of future healthcare professionals and to the services offered to persons with disabilities in rural areas.

You will be acquiring new skills, including interviewing skills and research skills which may in turn help you in the type of work that you do on a daily basis.

If you agree to participate in this study I will discuss the terms of this contract with your employer in order to ensure that you do not lose any income while assisting me in this study.

Please consider the study and let me know if you would be prepared to assist me in carrying it out. You should not feel under any pressure to participate, however, if you do decide to participate I will ask you to sign a contract stating that you are committed to assisting me in carrying out the study over the period that I will be in Tonga. In addition all information gained will be considered highly confidential and no participants' names or personal information will be mentioned in the study.

If you have any questions or want to discuss the study you can contact me on my cell on 084 840 0046 or at work on (011) 717 4501. Alternatively you can send me a 'please call me' and I will call you back.

Yours faithfully

_____

Joanne Barratt

Speech-Language Therapist

Appendix 5 - Contract between Researcher and Research Mediator

Contract between researcher and research mediator

I L Thobela hereby agree to participate in the study concerned with looking at the experiences of adults living with disabilities in Tonga, the experiences of families and caregivers of adults with disabilities in Tonga, and the experiences, beliefs and perceptions about disability of community members who are not directly affected by disability.

I have read the information letter and the researcher has explained the nature of the study and I understand the aims of the study and what will be required of me.

I understand that all information gathered during the study is confidential and no mention will be made of the participants' personal details in any discussions other than those with the researcher.

I accept the remuneration offered to me in the information letter.

Signed:

L D . Thobela

Lindiwe Thobela
Research Assistant

Barratt

Joanne Barratt
Researcher

Date 24 April 2009

Appendix 6 – Information Letter for Coordinator of DPSA Services in Mpumalanga

Attention: Emily Ntuli

Disabled People of South Africa (DPSA)

Mpumalanga

Dear Madam

My name is Joanne Barratt. I am currently registered for my PhD degree and would like to carry out a study on the experiences of adults living with disabilities in Tonga, the experiences of families and caregivers of adults with disabilities in Tonga, and the experiences, beliefs and perceptions about disability of community members who are not directly affected by disability. By carrying out this study I hope to be able to gain a better idea of the needs of persons living with disabilities and their families and in this way to influence the services provided by healthcare providers working in rural areas. I also hope to be able to identify barriers to the implementation of policies for persons with disabilities in rural areas. By doing this it will assist in the training of future healthcare providers to be sensitive to persons' with disabilities life experiences and needs including rehabilitation and medical services.

This study is of particular importance to healthcare professionals working in rural areas since previous research has shown that a lack of understanding between healthcare providers and persons requiring their services has severe adverse effects on the efficacy of service provision.

I would like to request permission from you as the coordinator of DPSA services in Mpumalanga to conduct this study in Tonga. This study will make use of interviewing adults with disabilities, their families and members of the community, as well as observing participants in their natural contexts (such as in their homes) in order to gain a comprehensive idea of what it means to live with a disability in a rural area. All interviews will be conducted by the research mediator, Ms Lindiwe Thobela, who is the community-based rehabilitation worker in Tonga. Significant attention will be paid to the ethics of obtaining informed consent from all participants, especially those with cognitive or linguistic impairments in order to respect all participants rights to the choice to participate in research.

As the researcher, I am aware that there are inherent benefits and risks for participants participating in research. These include the following:

<u>Risks</u>

- Participants may experience anxiety or psychological distress when talking about their disability. Should a participant become distressed the interview will be terminated immediately. Counseling will be provided immediately by the research mediator who has received specialized training on counseling. Where necessary, a referral will be made to the Social Work department at Tonga

Hospital for counselling and possible further referral for psychological assistance at Rob Fereirra Hospital in Nelspruit. However, regardless of whether participants display distress at the time of the interview all participants will be provided with the research mediator's telephone number in case they feel they require counselling, and all participants will be followed up by both the researcher and the research mediator in the week following the interview.

- Participants may experience some discomfort or stigma from neighbours as a result of having the researcher and research mediator in their home. However, all participants will be made aware that should they wish to withdraw from the study at any point they may do so without any negative effects.
- It is not envisaged that participants will suffer any financial risks due to the study, but in the event that they are required to travel to meet with the researcher and research mediator, they will be reimbursed for their costs.

Benefits

There are no direct benefits for participants who decide to participate in the study. However, the following may be of benefit to the participants:

- Talking about a personal experience is proven in a number of situations to have a healing function. Vulnerable and marginalized groups, especially those with linguistic impairments are often not given the opportunity to tell their story. Therefore, participants may benefit from being given the opportunity to speak and be heard.
- Where relevant, if participants are identified as requiring specific services, such as rehabilitation services, or grants, they will be referred for these services and followed up by the research mediator as this is within her realm of work as CBRW for Tonga.

Please consider this request for permission to conduct this study which will contribute to improving service delivery to persons with disabilities in rural areas. Once the study is complete I will provide you with a written report on the findings and should you require it, a verbal presentation. In addition, where barriers or specific difficulties are identified, should you require it, I will assist you in addressing these issues with the relevant authorities.

Should you require any further information, please do not hesitate to contact me at work on (011) 717 4501 or on my cell phone on 084 840 0046, or via email at joanne.Barratt@wits.ac.za.

Kind regards,

_____

Joanne Barratt

Speech-Language Therapist

Appendix 7 – Permission to Conduct Study from DPSA

I EMILY NTULI give Joanne Barratt permission to conduct a study in Tonga study investigating the experiences of adults living with disabilities in Tonga, their families and caregivers of, and members of the community who are not directly affected by disability.

I have read and understood the information letter pertaining to the study, and understand the nature of, and aims of the study.

Signed:

Emily Ntuli
Coordinator of DPSA
Mpumalanga

Witness

Date: 27/05/2009

27. May. 2009 15:21 DPSA KANYAMAZANE No. 3280 P. 2

Appendix 8 – Information Letter for Coordinator of CBR Services in Mpumalanga

Attention: Ms Mamsy Mashele

Coordinator of Community-Based Rehabilitation (CBR) Services

Mpumalanga

Dear Madam

My name is Joanne Barratt. I am currently registered for my PhD degree and would like to carry out a study on the experiences of adults living with disabilities in Tonga, the experiences of families and caregivers of adults with disabilities in Tonga, and the experiences, beliefs and perceptions about disability of community members who are not directly affected by disability. By carrying out this study I hope to be able to gain a better idea of the needs of persons living with disabilities and their families and in this way to influence the services provided by healthcare providers working in rural areas. I also hope to be able to identify barriers to the implementation of policies for persons with disabilities in rural areas. By doing this it will assist in the training of future healthcare providers to be sensitive to persons' with disabilities life experiences and needs including rehabilitation and medical services.

This study is of particular importance to healthcare professionals working in rural areas since previous research has shown that a lack of understanding between healthcare providers and persons requiring their services has severe adverse effects on the efficacy of service provision.

I would like to ask your permission to contact Ms Lindiwe Thobela, the community based rehabilitation worker in Tonga to act as the research mediator in the study. The study will be done over six weeks between January and February 2010, during which time I will be staying in Tonga. Ms Thobela will not necessarily need to spend all of her time with me over this period. Should you agree to allow her to participate we will draw up a schedule for data collection which suits both of us. During the study, Ms Thobela's role will include the following:

- Identifying possible participants within the community
- Accompanying the me to the homes of the participants
- Conducting interviews with the participants
- Answering questions after each visit to each participant about how you felt about what the participant said.

While participating in this study in the capacity of research mediator will mean that Ms Thobela's usual workload will be compromised, it will mean that she will be contributing to

research that has been identified as important by DPSA, and a number of other government departments. This means you will be contributing to the training of future healthcare professionals and to the services offered to persons with disabilities in rural areas. In addition she will receive training on using a narrative framework interview which may improve her interviewing skills this interview technique strives to obtain an accurate and detailed explanation of the problem without the interviewer imposing their outlook on the interviewee. Due to the fact that Ms Thobela would be contributing significantly to the study, I would reimburse her for her time at a rate of R145 per 8-hour day or alternatively R20 per hour, which is in line with the University of the Witwatersrand guidelines for paying research assistants.

Please consider allowing Ms Thobela to participate in this study since not only will it strive improve the quality of services in rural areas, but will also allow Ms Thobela to contribute to research in South Africa and also to acquire new skills in terms of interviewing.

Once the study is complete I will provide you with a written report on the findings and should you require it, a verbal presentation. In addition, if the nature of interviewing skills that I will be providing Ms Thobela with proves to be successful in eliciting important case history information, I will happily provide training skills to other CBR consultants. Furthermore, where barriers or specific difficulties are identified, should you require it, I will assist you in addressing these issues with the relevant authorities.

Should you require any further information, please do not hesitate to contact me at work on (011) 717 4501 or on my cell phone on 084 840 0046, or via email on joanne.Barratt@wits.ac.za.

Kind regards,

_____

Joanne Barratt

Speech-Language Therapist

Appendix 9 – Permission from Mpumalanga Coordinator of CBR Services

Consent from coordinator of CBR services in Mpumalanga

I MAMSY give Joanne Barratt permission to contact Ms Lindiwe Thobela to act as a research mediator in her study investigating the experiences of adults living with disabilities in Tonga, their families and caregivers of, and members of the community who are not directly affected by disability.

I have read and understood the information letter pertaining to the study, and understand the nature of, and aims of the study.

Signed:

MAMSY MASHELE

Ms Mamsy Mashele
Coordinator of CBR services
Mpumalanga

Date: 23.04.2009

Appendix 10 – Information Letter for Department of Social Work, Tonga Hospital

Attention: Social Work Department

Tonga Hospital

Dear Sir/Madam

My name is Joanne Barratt. I am currently registered for my PhD degree and would like to carry out a study on the experiences of adults living with disabilities in Tonga, the experiences of families and caregivers of adults with disabilities in Tonga, and the experiences, beliefs and perceptions about disability of community members who are not directly affected by disability. By carrying out this study I hope to be able to gain a better idea of the needs of persons living with disabilities and their families and in this way to influence the services provided by healthcare providers working in rural areas. I also hope to be able to identify barriers to the implementation of policies for persons with disabilities in rural areas. By conducting this study it will assist in the training of future healthcare providers to be sensitive to persons' with disabilities life experiences and needs including rehabilitation and medical services.

This study is of particular importance to healthcare professionals working in rural areas since previous research has shown that a lack of understanding between healthcare providers and persons requiring their services has severe adverse effects on the efficacy of service provision.

Part of my study involves an in-depth interview with persons with disabilities and their families. The nature of the interview looks at personal experiences associated with disability and probes the way in which individuals and families have to make sense of disability. Due to the personal nature of the interview, it is possible that it may elicit emotional responses by the adults with disabilities and/or their families. Alternatively, questions may arise regarding accessing government grants.

I would like to ask permission to refer these participants to you should such a situation arise. Should you agree to consult with these participants, I will contact you to discuss your process for referral.

Should you have any further queries, please do not hesitate to contact me at work on (011) 717 4501 or on my cell phone 084 840 0046. Alternatively you can email me on joanne.Barratt@wits.ac.za

Kind regards,

_____

Joanne Barratt

Speech-Language Therapist

Appendix 11 – Information Letter for Department of Rehabilitation, Tonga Hospital

Attention: Department of Rehabilitation

Tonga Hospital

Dear Sir/Madam

My name is Joanne Barratt. I am currently registered for my PhD degree and would like to carry out a study on the experiences of adults living with disabilities in Tonga, the experiences of families and caregivers of adults with disabilities in Tonga, and the experiences, beliefs and perceptions about disability of community members who are not directly affected by disability. By carrying out this study I hope to be able to gain a better idea of the needs of persons living with disabilities and their families and in this way to influence the services provided by healthcare providers working in rural areas. I also hope to be able to identify barriers to the implementation of policies for persons with disabilities in rural areas. By conducting this study it will assist in the training of future healthcare providers to be sensitive to persons' with disabilities life experiences and needs including rehabilitation and medical services.

This study is of particular importance to healthcare professionals working in rural areas since previous research has shown that a lack of understanding between healthcare providers and persons requiring their services has severe adverse effects on the efficacy of service provision.

Since the participants in this study will include both persons who are currently accessing services at the hospital or surrounding clinics, as well as those persons who are not accessing these services, I may identify individuals who are in need of rehabilitative services, or assistive devices, such as wheelchairs or hearing aids. I would like to ask permission to refer these participants to you should such a situation arise. Should you agree to consult with these participants, I will contact you to discuss your process for referral.

Should you have any further queries, please do not hesitate to contact me at work on (011) 717 4501 or on my cell phone 084 840 0046. Alternatively you can email me on joanne.Barratt@wits.ac.za

Kind regards,

_____

Joanne Barratt

Speech-Language Therapist

Appendix 12 – Information Letter for Participants with Disabilities

Dear Sir/Madam

My name is Joanne Barratt. I am currently registered for my PhD degree and would like to carry out a study on the experiences of adults living with disabilities in Tonga, the experiences of families and caregivers of adults with disabilities in Tonga, and the experiences, beliefs and perceptions about disability of community members who are not directly affected by disability. By carrying out this study I hope to be able to gain a better idea of the needs of persons living with disabilities and their families and in this way to improve the services provided by healthcare providers working in rural areas. I also hope to be able to identify existing barriers which may be preventing you from accessing government policies. By conducting this study it will assist in the training of future healthcare providers to be sensitive to persons' with disabilities life experiences and needs including rehabilitation and medical services.

I would like to invite you to participate in this study. The study will involve the following:

- Allowing me, the researcher, and Lindiwe Thobela, the CBRW in the Tonga area who is assisting me with this study, to interview you about your life experiences, and specifically your experiences of living with a disability. This can be done in any place that is convenient for you, including in your home. We would like to be able to visit you a number of times in order to observe some of your daily activities and any difficulties that you may experience. We may also request to interview you again to follow up on some of the things that you said in the first interview that will help us to better understand what it is like to live with a disability.
- All of the interviews will be done by Lindiwe Thobela in SiSwati, while I will spend most time observing what daily life is like for your family and for your community. There is no set time for interviews. These may be as long or as short as you like. All of the interviews will be recorded so that the researcher can listen to it again at a later stage and have the interview written down from what was recorded. Once the information has been gained from the tapes, the tapes will be destroyed. None of your personal details or those of your family will be written down, although when I write up this study I may make use of things that you have said to highlight important points about living with a disability in a rural area.

Possible Risks

- It is possible that you may become upset during the interview since we will be asking you personal questions about your experience. Should you become upset, the interview will be stopped immediately, and should you require it, Lindiwe Thobela will provide you with counselling. If you are deeply upset by the interview, you may be referred to the Social Work Department at Tonga Hospital for further counselling. Remember also that you may refuse to answer any questions that you are not comfortable answering, and you may turn off the tape recorder at any time.
- It is possible that the other members of your community may think that you are receiving special treatment since we will not be visiting all members of the community and may treat you differently since you are receiving a visit from the researcher and from Lindiwe Thobela.

Possible Benefits

- You may feel better once you have had the opportunity to talk about your problems. In addition, should we become aware of any difficulties for which we can offer a solution, such as the need for a wheelchair, or difficulties with obtaining your disability grant, we will refer you to the relevant departments.
- You will be contributing to research in order to improve the services offered to persons living with disabilities in Tonga.

You should not feel under any pressure to participate and if you decide not to participate, this will not change any treatment or services that you may be receiving from Lindiwe Thobela, or at Tonga Hospital or at any of the surrounding clinics. In addition, if you decide that you would like to participate all information that you give us will remain confidential and none of your or any of your family members' names or personal details will be mentioned in the research. In addition, if at any time during the study you wish to withdraw from the study, you are free to do so with no negative consequences.

If you have any questions please do not hesitate to contact me on 084 840 0046 or to contact Lindiwe Thobela on 082 583 2897.

Kind regards

_____

Joanne Barratt

Appendix 13 – Informed Consent from Adults with Disabilities

I, _____ hereby agree to participate in the study investigating the experiences of adults living with disabilities in Tonga, their families and caregivers, and members of the community who are not directly affected by disability

I have read/had the information letter explained to me and understand what the study entails and what will be required of me.

I understand that participation is voluntary and should I wish to withdraw I may do so with no negative consequences.

I understand that all information gathered during the study is confidential and none or mine nor my family's personal or identifying details will be recorded in the study.

Signed _____ Witness _____

Date _____

Appendix 14 – Consent for Audio-Recording from Adults with Disabilities

I, _____ hereby give consent for my conversation with Lindiwe Thobela regarding my experience of living with a disability to be audio-recorded. I understand that once the information needed from the tapes has been gathered, the tapes will be destroyed. In addition, I understand that all information on the tape is confidential and that at no point will any reference be made to my or my family's personal details. I have also been informed that I may turn off the audio-recorder at any point during the interview should I wish that the information that I am giving not be recorded.

Signed _____ Witness _____

Date _____

Appendix 15 – Information Letter for Proxies of Adults with Disabilities

Dear Sir/Madam

My name is Joanne Barratt. I am currently registered for my PhD degree and am carrying out a study on the experiences of adults living with disabilities in Tonga, the experiences of families and caregivers of adults with disabilities in Tonga, and the experiences, beliefs and perceptions about disability of community members who are not directly affected by disability. By carrying out this study I hope to be able to gain a better idea of the needs of persons living with disabilities and their families and in this way to improve the services provided by healthcare providers working in rural areas. I also hope to be able to identify existing barriers which may be preventing you from accessing government policies. By conducting this study it will assist in the training of future healthcare providers to be sensitive to persons' with disabilities life experiences and needs including rehabilitation and medical services.

Due to the difficulties in obtaining true informed consent from adults with disabilities, especially those with cognitive or language impairments, I would like you to assist me by providing me with permission to interview (*name of person with a disability*) and to observe the daily activities of (*name of person with a disability*). Specifically, the study will involve the following:

- Allowing me, the researcher, and Lindiwe Thobela, the CBRW in the Tonga area who is assisting me with this study, to interview (*name of person with a disability*) about his/her life experiences, and specifically his/her experiences of living with a disability. This can be done in any place that is convenient for you, including in your home. We would like to be able to visit (*name of person with a disability*) a number of times in order to observe some of his/her daily activities and any difficulties that he/she may experience. We may also request to interview (*name of person with a disability*) again to follow up on some of the things that he/she said in the first interview that will help us to better understand what it is like to live with a disability.
- All of the interviews will be done by Lindiwe Thobela in SiSwati, while I will spend most time observing what daily life is like for (*name of person with a disability*) and his/her family community. There is no set time for interviews. All of the interviews will be recorded so that the researcher can listen to it again at a later stage and have the interview written down from what was recorded. Once the information has been gained from the tapes, the tapes will be destroyed. None of (*name of person with a disability*)'s personal details or those of your family will be written down, although when I write up this study I may make use of things that (*name of person with a disability*) have said to highlight important points about living with a disability in a rural area.

Possible Risks

- It is possible that (*name of person with a disability*) may become upset during the interview since we will be asking personal questions about (*name of person with a disability*)'s experience. Should (*name of person with a disability*) become upset, the interview will be stopped immediately, and should (*name of person with a disability*) require it, Lindiwe Thobela will provide with counseling. If (*name of person with a disability*) is deeply upset by the interview, he/she may be referred to the Social Work Department at Tonga Hospital for further counseling. (*Name of person with a disability*) will also be given the option to refuse to answer any questions that he/she are not comfortable answering, and may turn off the tape recorder at any time.
- It is possible that the other members of your community may think that (*name of person with a disability*) or your family are receiving special treatment since we will not be visiting all members of the community and they may treat you differently since you are receiving visits from the researcher and from Lindiwe Thobela.

Possible Benefits

- (*Name of person with a disability*) may feel better once he/she has had the opportunity to talk about his/her problems. In addition, should we become aware of any difficulties for which we can offer a solution, such as the need for a wheelchair, or difficulties with obtaining a disability grant, we will refer (*name of person with a disability*) to the relevant departments.
- (*Name of person with a disability*) will be contributing to research in order to improve the services offered to persons living with disabilities in Tonga.

You should not feel under any pressure to allow (*name of person with a disability*) participate and if you decide not to allow (*name of person with a disability*) participate, this will not change any treatment or services that he/she may be receiving from Lindiwe Thobela, or at Tonga Hospital or at any of the surrounding clinics. In addition, if you decide to allow (*name of person with a disability*) to participate all information that he/she give us will remain confidential and none of (*name of person with a disability*) or any of your family members' names or personal details will be mentioned in the research. In addition, if at any time during the study you wish to withdraw (*name of person with a disability*) from the study, you are free to do so with no negative consequences to him/her or to your family.

If you have any questions please do not hesitate to contact me on 084 840 0046 or to contact Lindiwe Thobela on 082 583 2897.

Kind regards

_____

Joanne Barratt

Appendix 16 – Informed Consent from Proxies of Adults with Disabilities

I, _____ as legal guardian and caregiver of _____ hereby agree to allow him/her to participate in the study investigating the experiences of adults living with disabilities in Tonga, their families and caregivers, and members of the community who are not directly affected by disability

I have read/had the information letter explained to me and understand what the study entails and what will be required of _____ (*name of person with a disability*).

I understand that participation is voluntary and should I wish to withdraw _____ (*name of person with a disability*) I may do so with no negative consequences.

I understand that all information gathered during the study is confidential and none of _____ (*name of person with a disability*) nor my family's personal or identifying details will be recorded in the study.

Signed _____ Witness _____

Date _____

Appendix 17 – Consent for Audio-Recording from Proxies of Adults with Disabilities

I, _____ as legal guardian/ caregiver of _____ (*name of person with a disability*) hereby give consent for _____ (*name of person with a disability*)'s conversation with Lindiwe Thobela regarding his/her experience of living with a disability to be audio-recorded. I understand that once the information needed from the tapes has been gathered, the tapes will be destroyed. In addition, I understand that all information on the tape is confidential and that at no point will any reference be made to _____ (*name of person with a disability*) or my family's personal details. I have also been informed that I may turn off the audio-recorder at any point during the interview should I wish that the information that I am giving not be recorded.

Signed _____ Witness _____

Date _____

Appendix 18 – Information Letter for Local Leaders in Tonga

Dear Sir/Madam

My name is Joanne Barratt. I am currently registered for my PhD degree and would like to carry out a study on the experiences of adults living with disabilities in Tonga, the experiences of families and caregivers of adults with disabilities in Tonga, and the experiences, beliefs and perceptions about disability of community members who are not directly affected by disability. By carrying out this study I hope to be able to gain a better idea of the needs of persons living with disabilities and their families and in this way to influence the services provided by healthcare providers working in rural areas. I also hope to be able to identify barriers to the implementation of policies for persons with disabilities in rural areas. By doing this it will assist in the training of future healthcare providers to be sensitive to persons' with disabilities life experiences and needs including rehabilitation and medical services.

This study is of particular importance to healthcare professionals working in rural areas since previous research has shown that a lack of understanding between healthcare providers and persons requiring their services has severe adverse effects on the efficacy of service provision.

I would like to request permission from you as a local leader to conduct this study in Tonga. This study will make use of interviewing adults with disabilities, their families and members of the community, as well as observing participants in their natural contexts (such as in their homes) in order to gain a comprehensive idea of what it means to live with a disability in a rural area. All interviews will be conducted by the research mediator, Ms Lindiwe Thobela, who is the community-based rehabilitation worker in Tonga.

As the researcher, I am aware that there are inherent benefits and risks for participants participating in research. These include the following:

<u>Risks</u>

- Participants may experience anxiety when talking about their disability. Should a participant become distressed the interview will be terminated immediately. Counselling will be provided immediately by the research mediator who has received specialized training on counselling. Where necessary, a referral will be made to the Social Work department at Tonga Hospital for counselling and possible further referral for psychological assistance at Rob Fereirra Hospital in Nelspruit. However, regardless of whether participants display distress at the time of the interview all participants will be provided with the research mediator's telephone number in case they feel they require counselling, and all participants will be followed up by both the researcher and the research mediator in the week following the interview.
- Participants may experience some discomfort or stigma from neighbours as a result of having the researcher and research mediator in their home. However, all participants will be made aware that should they wish to withdraw from the study at any point they may do so without any negative effects.

- It is not envisaged that participants will suffer any financial risks due to the study, but in the event that they are required to travel to meet with the researcher and research mediator, they will be reimbursed for their costs.

Benefits

There are no direct benefits for participants who decide to participate in the study. However, the following may be of benefit to the participants:

- Talking about a personal experience is proven in a number of situations to have a healing function. Vulnerable and marginalized groups, especially those with linguistic impairments are often not given the opportunity to tell their story. Therefore, participants may benefit from being given the opportunity to speak and be heard.
- Where relevant, if participants are identified as requiring specific services, such as rehabilitation services, or grants, they will be referred for these services and followed up by the research mediator as this is within her realm of work as CBRW for Tonga.
- The community may benefit from this study since it will allow for better understanding of the challenges facing persons in Tonga, especially persons with disabilities. It is hoped that the information obtained by interviewing participants will assist in developing policies and in training healthcare professionals to be sensitive to the needs of persons living in a rural area.

Please consider this request for permission to conduct this study which will contribute to improving service delivery to persons with disabilities in rural areas. Once the study is complete I will provide you with a written report on the findings, and a verbal presentation to you and to the community. In addition, where barriers or specific difficulties are identified, should you require it, I will assist you in addressing these issues with the relevant authorities.

Should you require any further information, please do not hesitate to contact me at work on (011) 717 4501 or on my cell phone on 084 840 0046, or via email on joanne.Barratt@wits.ac.za.

Kind regards,

_____

Joanne Barratt

Speech-Language Therapist

Appendix 19 – Consent from Local Leaders in Tonga

I _____ give Joanne Barratt permission to conduct a study in Tonga study investigating the experiences of adults living with disabilities in Tonga, their families and caregivers of, and members of the community who are not directly affected by disability.

I understand the information that has been given to me about the study.

Signed:

_____ _____

Local leader Witness

Date: _____

Appendix 20 – Example of Narrative Analysis using Clandinin and Connelly's Three Dimensional Narrative Inquiry Space (2000)

P. no.	Nature of Disability	M /F	Age	Interaction		Continuity			Situation/Place
				Personal	Social	Past	Present	Future	
1	Physical (bilateral lower limb paralysis since the age of 10 years)	M	50	Describes self as a good and handsome man – shows sense of humour. Believes his disability has prevented him from having a family of his own. Says neither his family nor the government can provide him with the assistance that he needs. Believes that inability to sit has prevented him from getting an education – says *'as long as you are living in the world you need to be educated.'* Asks about disability rights. Family never ask about what he would like from life. Believes that relationships are not long-lasting because	Says that only family he has is (was) his parents because he became disabled as a child so doesn't have own family. Believes disability has prevented him from having lasting relationships, having a family of his own, and being educated. Did not receive education prior to disability as parents did not believe that education was important. Was a shepherd looking after his father's live stock. In the community they believe that disability was caused by umuti – not respecting or upholding traditional customs. Shows an understanding that community will not understand or support	Remembers onset of disability – in 1970 was not well, then in 1973 started to lose sensation in legs, after which had difficulty walking. In 1975 parents took him to traditional healers but to no avail. Difficulty in accepting the situation. Clear description of onset of disability – was in the forest with friends, got a pain in his hip but managed to get home. Later that night, pain became worse and he was unable to stand up. Parents did not think it was important for him as a disabled person to get an ID book. Community as well as social services believe that	Although life is still difficult he is now getting used to the situation. View self as a dead person, confined to his bed. Family is supportive and helpful although he acknowledges that caring for him is not easy as he is completely dependent. Sister and her children are especially supportive. Although he receives social support he does not feel that he receives the assistance that he really needs. Friends are still visiting him, although some have died. Asks about rights. Family never ask about what he wants from life. Intimate relationships are not long-lasting. Believes that God has saved him.	Hopes that CBR will help him to be exposed to other people within the community. Desire for a relationship. Desire to be educated. Desire to have children. Desire to have things that belong to him. Wants constitution so that he can understand and tell other people about disability rights. Wanted to learn to use a computer and to be employed or to be able to start own business. **<u>Positive:</u> to be exposed to other people, to be educated, to**	Participant is bedridden and confined to a small room. This is the physical location where the story is told. He is also confined by his body which is paralysed although he seems to have some use of his arms. The participant's relationship with the research mediator, as well as his (limited) relationship with the researcher seems to facilitate a degree of shared knowledge which helps him to tell his story. Narrative is defined and contrasted by **desire** (to be educated, know his rights, have a lasting relationship, have children and possessions, learn new skills, be employed, and start a

P. no.	Nature of Disability	M /F	Age	Interaction		Continuity			Situation/Place
				Personal	**Social**	**Past**	**Present**	**Future**	
				girlfriends are afraid of having to nurse him forever, and think that they will not be able to have a sexual relationship because of his disability. **<u>Positive:</u> good, handsome, sense of humour, knowledge of disability rights, self insight.** **<u>Negative:</u> disability has prevented him from being educated, having long-lasting, relationships, having a family of his own, lack of emotional support, never been asked about what he wants from life.**	a relationship between a disabled person and an able-bodied person. Uses a song to illustrate feelings of despair related to disability. **<u>Main themes:</u> inability to have own family, parents did not believe in education and now disability has prevented him from receiving an education, community believes that disability is caused by umuti, awareness that community will not support a relationship between a disabled person and an able-bodied person, at one point cannot articulate despair associated with disability, so uses a song to articulate this.**	if you are disabled you are nothing, and don't want to issue ID books to prevent disabled people from accessing disability grants. Parents' belief that education was not important. Long delay in receiving ID book. **<u>Positive:</u> parents' help-seeking behaviours (taking him to traditional healer)** **<u>Negative:</u> onset of disability, traditional healers inability to help, difficulty accepting situation, parents' and community's belief that disabled people do not need identity documents, parents belief that education was not important.**	Says that sometimes life is so difficult that he thinks it would be better if he were dead – dependence a significant contributor. Spends a lot of time alone. **<u>Positive:</u> learning to accept situation, believes that God has saved him, desire to understand disability rights, receives social support from government and physical support from sister and her children** **<u>Negative:</u> dependence, confined to bed so views self as dead, thinks it may be better if he were dead, isolation, lack of lasting relationships, family do not ask what he wants from life, family and government assistance cannot provide him with emotional support that he needs, death of friends**	**understand disability rights, to have lasting relationships, to have children, to have things that belong to him, to learn computer skills, to start a business, to sing and make music.** **<u>Negative:</u> thoughts that maybe the situation would be better if he were dead.**	business) and **despair** (despair related to disability, dependence, inability to develop close and intimate relationships, lack of emotional support). Both of these are underpinned by thoughts of **death** (friends who have died, what will happen if sister dies and is not around to take care of him, and despair at level of **dependence** leading to thoughts that he might be better off dead) as well as an underlying sense of **hopelessness**. **<u>Positive:</u> desire** **<u>Negative:</u> despair, death, dependence, hopelessness**

Appendix 21 – Example of Analysis of Violence and Abuse of Power

P. No	Nature of Disability	Violence and Abuse of Power					
		Structural	**Physical**	**Sexual**	**Emotional**	**Financial**	**Deprivation**
3	50 year old female. Physical disability (paraplegia) secondary to being stabbed in the spinal cord.	**Poverty**. *'I had difficulties because I was depending on the grant. There was no other income, except the grant.'* *'I have to pay a lot of money because I am unable to do things for myself.'* **Access.** *'I had a problem going for my follow-ups, because my mother was dead and there was no-one assisting me to go to the hospital.'* *'I have goals that I want to reach in life, but I am limited due to my disability. Like I would like to travel alone but I cant push myself – I need a helper to be with me in order to travel. I cannot travel with a taxi – I need to ask for someone's car to take me from my house to Tonga hospital.'* *'There was a time when it was difficult for me to get to the disability centre because I didn't have*	Disability as result of a **physical attack**. *'I became disabled in February 1984. It was Renamo, you know, the war, at that time. So they came to my house and stabbed me with a knife on my back, on my spinal cord.'* *'My son was also injured during Renamo because they burnt the house and we tried to run away from the fire. I was carrying my small baby on my back. The Renamo people took my baby from my back and threw him into the fire. He burnt until he died.'* *'I would remain in the house the whole day. No one to help me and no food to eat.'*	*'The man would always come to my room and want to sleep with me.'* *'People are always wanting to know, how do I have sex with a man, being disabled.'* *'He was saying, "you are not thanking me properly, you are supposed to go in the house with me. It doesn't mean if you sleep with me I will leave a baby".'* *'As a disabled person, they think you are not supposed to sleep with a man. Like you are an animal.'*	**Abandoned** by husband. *'I was married, then I got injured, then my husband left me. We separated because I was disabled.'* Neighbours' perceptions of disability. *'On the days (my husband) came to my house, then tomorrow you will hear news from the neighbours about me, that I am unable to work in the house, but I can sleep with a man.'* **Conflict with husband** regarding **polygamy**. *'We were fighting a lot.'* **Lack of support.** *'The man's wife) was telling people not to help me.'* **Emotional effects of physical attack**. *My son was also injured during Renamo because they burnt the house and we tried to run away from the fire. I was carrying my small baby on my back. The Renamo people took my baby from my back and threw him into the fire. He burnt until he died.'* *'They took me and my son to different hospitals. It was more than a year that I did not see him. When they brought him to see me, I could not believe that he was still alive.'*	-	-

P. No	Nature of Disability	Violence and Abuse of Power					
		Structural	**Physical**	**Sexual**	**Emotional**	**Financial**	**Deprivation**
		someone to push me, so another gogo gave me her son to push me every day.' **Identity documents.** *'Many people do not have ID's but we still encourage them to participate.'*			**Community responses to pregnancy.** *'The nurses were always saying "who did this to you?"'* *'At antenatal classes others were saying "if I were you I would not do that" and others were coming to me and saying "don't do this again. Look at you!", like I had done something wrong.'* *'At (name of hospital) the nurses were preaching to me to close my womb. Everyone saying "stop", making it look like I am sick, not disabled.'*		

Appendix 22 – Abbreviated Interview with Participant 11

Interviewer: Hi (*name of participant)*. Can you tell us your story? What happened?

Participant: My name is *(name and surname)* and I am living in *(name of village).* In 1986 I was in standard nine, now grade eleven. There was a lot of apartheid in our area. We were not happy with the government. We wanted the government to fix things but they were not taking notice of us. It was the middle of the night when we met at Naas stadium and started a protest march together with the boarding students from (*name of high school)*. During the protest things started getting hectic. It was scary and I wanted to leave and go home. On the way home we heard the sounds of guns but didn't know where they were coming from. They were soldiers and were trying to prevent us from fighting for our rights. We just wanted equal opportunities; we did not know the history. The next thing we knew there were guns pointed at us. Three men died, and I had eleven bullets in my body. I was the only girl. I was taken to *(name of hospital)*, from *(name of hospital)* to *(name of hospital)*, and from *(name of hospital)* to *(name of hospital)* where I was helped. After three days three bullets were taken out of my body, but my spinal cord had been injured so I couldn't walk anymore. What I like about the doctors at *(name of hospital)* is that they care. They took the bullets out without a problem.

In 1997 I went to the TRC to testify about what happened. They promised us money. First we were given R50000 then we were promised to be paid R30 000 every month that is 3 billion over six years-which means is 1 million per year. But I had not received the money. I tried to contact them but did not get an answer. For now I'm depending to the grant nothing else.

Interviewer: You said that three people died during the protest. Who were those people?

Participant: The people who died were *(name)*, 8 years, *(name)* 14 years, *(name)* 21 years. *(name)* from *(name of village)* was also injured. He is still alive, but disabled.

Interviewer: This must be very challenging for you?

Participant: When I was discharged from the hospital I went to stay in *(name of village).* That is where I finished matric. I never lost hope. After matric I tried to get a job but they didn't want a disabled person – they only appoint their favourite people – nobody cares about us. Even today, I am not happy with our mayors because what do they do when Mbeki or Zuma come to this area? They take them to *(name of village)* and people like me who don't have legs can't get there. They don't even know that there are people like us in *(name of village)*. They must bring them to our area so they can see our place. Our roads are not accessible and our wheelchairs break easily. The president sees *(name of village)* and says that our area is rich. Why don't they bring them here?

Interviewer: Yes, those are problems that all of us with disabilities face. Can you tell me about some of your own challenges?

Participant: At *(name of village)* they don't like me, they think I am a trouble maker. It is only my family who likes me and *(name of person)*. He is always trying to look for a job for me. We have meetings and he tries to pave the way for me.

Interviewer: Have you tried to make a CV?

Participant: Aaaahhh…. people with disabilities are not taken seriously so that is why I didn't do it.

Interviewer: Do you have children?

Participant: I have four children - two girls and two boys.

Interviewer: Did you have them before or after your disability?

Participant: After the disability.

Interviewer: What did people say when they heard you were pregnant?

Participant: I was pregnant with my first born when I was 24 years old. People in my area they were not happy about my pregnancy. They were saying that someone was abusing me and it was a sin to be sleeping with a disabled person. They were saying many things and it was too much for me. Even my mother was not happy. She said to me *I think this is your first and last - no other children*. I had a positive attitude in my mind, because I was thinking like those children will be my future. So you see now my house is clean because of my children. If I listened to those people and had not given birth to children, where I would be today? For a long time my mother ignored me. She said she was fed up with me. One day I was sitting with my kids near the front door and my mother was outside. I sang a song that says death chooses his own people –when death arrives for me, my kids will suffer and become fulltime in street. So those words hurt my mother. She asked why I was singing that song. I said is nothing. She took two bowls and piled them with pap and seshebo. She gave it to my children and said don't worry about what your mother is saying - she is mad. But things are ok now, my mother passed away and I am with my kids now. I'm always remembering those words.

Interviewer: How were you treated at the hospital when you gave birth to your children?

Participant: In1992 *(name of child)* was born. *(Name of doctor)* who knows about my life was there for me. He treated me very nicely. I delivered normal. My second born (*name of child)* was born at a clinic assisted by *(name of nurse).* My third born (*name or child)* was also born at the clinic, assisted by *(name of nurse).* My fourth born *(name of child)* was born premature at *(name of hospital)* at seven months.

Interviewer: How was life after your mother's death?

Participant: It was so painful.

Interviewer: With whom are you staying now?

Participant: I'm staying with my kids. I'm looking after my mother's home. I cannot say there is no one giving me support. I've got one brother who likes me a lot. Even if I'm sick he is there for me. He will take leave and comes to bath and feed me. I don't know what to say about him. He is my brother, mother, father even my God the way he is treating me. My mother's last born is working at Robs. My other sister is playing another role. I don't buy clothes for me and my kids. She is buying them for us. I'm using my grant just for food and for furniture for my house. My brothers and sisters don't want me to suffer.

Interviewer: Thank you for sharing your story with me.

Participant: Ok. Thanks

Appendix 23 – Abbreviated Interview with Participant 9

Interviewer: Can you tell us your story?

Participant: My story is like this. It is a problem because I'm no longer working. I wasn't able to maintain my wife anymore so she met another man and he took her.

Interviewer: Why are you not working?

Participant: I don't have ID book, that's my problem.

Interviewer: So that's the problem that is not allowing you not to work.

Participant: Yes.

Interviewer: But there are people working around here who don't have ID's.

Participant: They work, but a person like me being disabled, where can I work?

Interviewer: When did you become disabled?

Participant: In 1990

Interviewer: Why?

Participant: I was sick because of witchcraft here at *(name of village)*, so I went to *(name of hospital)* where they decided to cut off my feet.

Interviewer: What happened after amputation?

Participant: I came back home.

Interviewer: Then when you came back home?

Participant: Since I came back nothing is happening, I'm still sitting at home.

Interviewer: With whom are you staying?

Participant: With my brother.

Interviewer: How is life at home?

Participant: Life is difficult as I'm not working. He is maintaining me but fighting with me, shouting a lot about the food he is buying. We ended up at the chief s court, but they told him that he must support me.

Interviewer: Did he ever beat you?

Participant: Yes, he beat me. He slashed me with a bush knife. I even went to hospital.

Interviewer: He slashed you with a bush knife while you are disabled, not walking, and not able to run away? Why?

Participant: I don't know.

Interviewer: What was the problem?

Participant: We were fighting for food. He used to say '*don't ask for food, there is no food for you here'*.

Interviewer: Tell me exactly what happened, until you were taken to hospital.

Participant: He didn't beat me but he slashed me with a bush knife.

Interviewer: Did you go to Tonga?

Participant: No, I didn't open a case.

Interviewer: Where do you sleep at home?

Participant: There is one child who applied for an RDP house. So when he went to the authorities they said this house belongs to me. So I went in and slept there because they said it is for disabled people.

Interviewer: So after sleeping in the house what happened?

Participant: After that my family was talking a lot about this house, like saying this house is not for me. So I told them one day that I will go back to the chief and report them about what they are doing. So they stopped talking.

Interviewer: Where are your children?

Participant: I've got one staying at *(name of village)*.

Interviewer: Staying with whom?

Participant: The child is staying with his uncle.

Interviewer: Where is his mother?

Participant: I heard that she is homeless. It is long time now since I saw her. I don't know if she still alive or not.

Interviewer: Is your son visiting you?

Participant: Yes, he is coming, but he is married now.

Interviewer: Does he have an ID?

Participant: Yes, his uncle assisted him.

Interviewer: What your son doing to assist you as a disabled father?

Participant: He was only working temporally, not getting enough money. He was working at *(name of company)*. So for now he is at home, not working.

Interviewer: So the time he was working, did he help you with something?

Participant: The time he was working he was coming, buying food for me.

Interviewer: So now he is not working.

Participant: He is at home, not working.

Interviewer: So how is life now?

Participant: I cannot say life is not easy for me because I have been trying to apply for ID at home affairs. They said they don't help adults, only children. Until today they are telling me same words. I'm still sitting with the letter from tribal office.

Interviewer: Besides the pension what else is a problem for you?

Participant: You see, without food there is no happiness. You keep on asking people and they get tired of you, saying *'ah this one. It is not us who said he must be disabled. Now we are tired of him.'* So there is a place where I can go and cry because at *(name of hospital)* they don't fix this problem for me.

Interviewer: As you see your life now, how do you get help here in the centre?

Participant: For me, it is better here because they give me food. Even if I go back home without getting food, I don't mind, they help me a lot here.

Interviewer: For now that's the only thing you need now. Don't you think in the community you can get assistance because there are counsellors, and the chief, and other people that can help?

Participant: I didn't think about going to them.

Interviewer: Because your story is big, there is this girl, *(name of girl)*, staying here at *(name of village)*. She is a community counsellor, try to speak with her, they know her here at the centre. Try to ask her how she can help you.

As time goes on, do women come to you, or you are thinking about what are you going to be able to give them?

Participant: You are right. I propose to women, but they always ask me what I'm going to give them because I'm not working and have no money. And if she visits you, you have to buy drinks even again the next day. So only to find that nothing happens.

Interviewer: Does time come to you to think that you are a man?

Participant: Yes, because it is just my legs that are amputated. Up here I'm fine. I can still feel.

Interviewer: I'm asking because as people with disabilities, our feelings are not disabled but we are just physically challenged. There are women with disabilities, how do men with disabilities who are not working get those women?

Participant: I cannot know the wisdom of people, because people use their own tactics to get those women. So we are not the same.

Interviewer: So from the shebeens you don't see them?

Participant: Ah, even if they are there, I'm not going there always.

Interviewer: Ok, there are diseases these days. Do you know about them?

Participant: Yes, I know about them because they are always preaching about them.

Interviewer: You don't think about abstaining to protect yourself?

Participant: Yes, I think about that. Like if I propose to someone and they refuse, I quickly say *'Ah, I'm safe'*. If I get sick it will be a problem for me. Who will give me money to go to hospital.

Interviewer: Who will nurse you?

Participant: There is no one because my mother is dead.

Interviewer: Your hope is in your brother. Is your sister-in-law around?

Participant: Yes.

Interviewer: What does she say?

Participant: She cannot do anything. She is listening to her husband only. If he says *'don't give him food'* it will be like that.

Interviewer: Are you sometimes sleeping without food?

Participant: Since the chief spoke to him, even here at the centre they called him and discussed the problem with him, it is better now. I'm getting food.

Interviewer: It was solved here at the centre plus the chief talked with him so he is afraid?

Participant: The chief promised to chase him if he does it again.

Interviewer: So he is afraid now.

Participant: Yes, it is much better.

Interviewer: Ok, what do you wish that God can help with?

Participant: It is the ID. Even sleeping during the night is difficult because I'm always thinking a lot about the id because I can't do anything without an ID.

Interviewer: Before you were staying here, where were you living? How did you come here, from where?

Participant: We came from *(name of village)*, both of us and we came to stay here. That was 1960. Actually we were from *(name of area)* in a place called *(name)* farm.

Interviewer: So there was a problem of getting an ID?

Participant: In 1970 ID's came out because I was working in mine without an ID. So when I went to *(name of place)* for an ID they said *'you are too young, your time hasn't come'*. In 1970 they said I can apply. That was for the pass book, is what I heard. So since then I didn't change it.

Interviewer: Why not?

Participant: I can't tell you.

Interviewer: Why you don't take it and apply for an ID?

Participant: Last time I was doing that, but they were telling me I'm too old to get an ID.

Interviewer: Eish…it is difficult. Then what about the chief?

Participant: They gave me a letter to go with it to home affairs. Even in 2008 I applied for it but still nothing.

Interviewer: Where?

Participant: At the Tonga offices.

Interviewer: Did they give you a copy of the form?

Participant: No, they didn't.

Interviewer: What can you say about disability in the community?

Participant: I don't know because people with disabilities are challenged in different ways.

Interviewer: What would you like to tell the community that they must do with people with disabilities?

Participant: We have leaders here in the centre. They talk to people in the community. Like last time they were telling people about our rights. So *(name of leader at centre)* was trying to talk to people. The even called us to *(name of village)* so that we can tell us about our rights.

Interviewer: Do you hear what I am asking? I want you to tell me what can you say to the community about people with disabilities. What can you teach them, like caring for people who are disabled?

Participant: I can tell them not to oppress us or not to look down on us.

Interviewer: If is weekend, how do you feel at home?

Participant: I don't feel ok, even though they give me food, but it is not the same as when I'm in the centre. I feel good in the centre. My life is here. I think the government is throwing me away as they don't want me to have an ID book. That is all that I am asking for.

Interviewer: The problem is just that you cannot ask the government while you are sitting here. You need to stand up and go to the offices. Ask to speak to the managers until you get what you want. Is your son helping you to get ID?

Participant: I can say he is trying but without money because he is not working. He just supports me when I go to clinics and home affairs offices.

Appendix 24 – Abbreviated Interview with Participant 3

Interviewer: Can you tell us your story?

Participant: I was born without a disability. I became disabled when I was older. I was married, then I got injured. Then my husband left me, we separated because I was now disabled. So after all this I realized that I have to own my own stand and make things happen. I went to the chief's tribal office and I asked for a stand. So they gave me one, and I built a house. I'm staying here with my children. There are two, the other one is a grandchild. I'm maintaining them with the grant I'm getting from government.

Interviewer: Were there difficulties that you met as a mother being disabled when raising your children?

Participant: I had difficulties because I was depending on grant. There was no other income except the grant.

Interviewer: So you don't have someone in your life now?

Participant: I do have someone but he doesn't help me with anything. I'm thinking of quitting this relationship and staying alone. I think it is better.

Interviewer: How did the disability start? What happened? When did it happen?

Participant: I became disabled in February 1984. My husband is from Mozambique. I went with him to Mozambique. It was Renamo, you know, the war, at that time. So they came to the house and they stabbed me.

Interviewer: With what?

Participant: They stabbed me with a knife – on my back, on my spinal cord.

Interviewer: Who brought you home from Mozambique?

Participant: My mother decided to go to Maputo and fetch me because I was already disabled. That was November 1986. She went to all offices to fill out the documents needed in order for her to bring me back to South Africa. I came back with my mother together with my elder son. It was easy because I was having a South African ID.

Interviewer: When your mother came to fetch you, what did your husband say?

Participant: My father asked permission from my husband to fetch me from Mozambique to take me back to South Africa, as my husband was working in Johannesburg. The reason was that my father wanted to take me to hospital was because they thought that maybe I will get better. So my husband refused. My father decided to just send my mother to fetch me. So when my mother got there she asked me if I'm happy to go. I said yes because I knew that they wanted to help me to go to doctors and the hospital. From the pains I was feeling I thought I would get better.

Interviewer: At that time were you unable to sit up?

Participant: I was able to sit up, and even walk with a walking frame. I was trying to pull my legs to toilet. I got helped in a hospital in Mozambique. So they realized that no, it was too difficult for me then they issue wheelchair for me from South African Hospitals.

Interviewer: So since you came back home, did your husband ever come to visit you, or check how your condition is now?

Participant: After I was back home, I wrote a letter to him to Johannesburg, telling him that I'm back home and the condition is no better. He never came until my mother died and we buried her. He heard that and then he just came after sometime – saying he is here because of my mother's death.

Interviewer: You were having one child?

Participant: Yes because the other one died when I got injured. So I gave birth to a girl in 1996 here in South Africa.

Interviewer: Then you got a wheelchair from the government hospital here. How is it going with the pension?

Participant: When I was back from Mozambique I was attending at *(name of hospital)*, from *(name of hospital)* they referred me to *(name of hospital)*, to orthotist. I went there they measured me, asking me a lot of questions like they wanted to know how did I get injured. So they said I'm supposed to go to Pretoria for a check-up. I had a problem because my mother was dead and she was the one assisting me to go to doctors or hospital. So I continued using a wheelchair up until now as I'm able to move from one point to another point, able to do daily living activities.

Interviewer: So since then are you able to stand up?

Participant: To stand up is difficult. I was shocked one day because I knew that the leg without a problem is the left one. Then in 2006 I fell from the bed and broke it. So they sent me to *(name of hospital)* to be fixed. So from there I'm afraid to stand with this leg.

Interviewer: So now you are using wheelchair. You had friends before the injury – what is happening are they still your friends, are they still visiting you or what?

Participant: My friends they never ran away from me. They were still friends, still visiting me even now. They never change because I'm disabled, no.

Interviewer: So they are still coming?

Participant: Yes, even my relatives.

Interviewer: What difficulties did you met along the way?

Participant: I had a difficult time, like I have goals that I want to reach in my life but I'm limited due to my disability. Like I would like to travel alone but I can't push myself – I need a helper to be with me in order to travel. I cannot travel with a taxi I need to ask someone's car to take me from my house to *(name of hospital)*. I have to pay a lot of money now because I'm unable to do things for myself.

Interviewer: Now you are disabled – and you were walking before. What about your relatives – do they care about you – do they assist you? How do they?

Participant: In the first stage of my disability it was difficult for me. Especially when I was unable to go out – not seeing people. It was painful for me. But since I was with my mother and I had a wheelchair, my mother used to say put these shoes on and go outside for fresh air. Meaning the orthotic shoes. Then I would say to my mother *'no I can't go outside with these shoes'*. It was bad for me.

Interviewer: How long did it take? Tell me the story. What was happening?

Participant: Another thing it was caused by was that I was not happy in my marriage. We were two with one. Two wives with one man. So my husband, when he was coming from Johannesburg, he was not coming to my house. He was staying at the other wife. On the days he came to my house and sleeps, then tomorrow you will hear news from neighbours about me, that I'm unable to work in the house but I can sleep with a man. When I heard that my heart was so painful, that next time when he came to my house, I chased him because of what his wife was saying about me. I told him I don't like it.

Interviewer: When you chased him, what did they say?

Participant: We were fighting a lot. He would say *'I'm your husband you don't have to do this'*. He ended up not coming to my house. So then we moved to *(name of village)* so they would try to organize visitors, they gave my room to visitors and I had to sleep in the sitting room, then he would come to was to sleep with me, but I also chased him. So I became a victim. I got sick and no one was helping me. His wife was telling people not to help me. Even with a car to take me to hospital. So I tried to ask people going to the church of ZCC, I tried to ask the pastors to help me with the tea that they cooked in church. But the other wife, she just said *'no, there is nothing'*.

Interviewer: What about your mother-in-law?

Participant: She was also dead. It was just me, my husband and the other wife. I was too young and the wife was doing anything she liked to me. So one day I asked my sister to go and call the Pastor from the church. The Pastor arrived, then the wife asked the pastor what he wanted here, who called him? The Pastor explained his coming. That wife said to the Pastor because she sent her younger sister behind my back I'm not going to do anything anymore. She said my sister must come and marry the husband so that so that she can be able to do things for me. The pastor turned back – didn't do anything for me. Another thing that she was doing when the husband was in Johannesburg, she would bath and dress to kill and go out for the whole day. I would remain with the house with the children. No food to eat. No one to cook. I started there trying to move, sitting up on chair, cooking – trying to stamp mieliemeal because we were stamping it there in Maputo. So the neighbours knew the story – they were seeing everything that was happening there.

Interviewer: It's still painful?

Participant: Yes, it's still painful. I was having to borrow a chair from neighbours in order for me to sit up better, because we didn't have anything. All the furniture was burnt by Renamo before we moved. My son was also injured during Renamo because they burnt the house and we tried to run away from the fire. I was carrying my small baby, the Renamo people took my baby from my back and threw him into the fire – he burnt until he died. My elder son was lucky because one of Renamo people felt sorry for him - he just grabbed him with hands, and walked with him for a distance. You know what, we were many in the house. They put us inside the house with other people and burnt the house. So the Renamo people, they were liking some people, the one with my son called me and said *'run away with this child'*.

Interviewer: All your relatives were in South Africa, you just alone there?

Participant: Yes because of marriage. So my son was burnt on the head. We were taken to different hospitals. I took me a year for me to see him again. I also stayed a year in the hospital in Maputo. When I ask them to bring my son to see him, to believe that he was still alive, they refused – especially my husband and his wife. So he was first discharged from the hospital. So my husband and his wife when they came to visit me I was giving them things to give my son. He was so surprised to find that I was alive because he was told that I was dead. Ok it passed. So I moved to stay with my mother in the Town (Maputo) with other people where we asked just a room in order for my mother to nurse me because I didn't get care there was no one to help. So my husband came with my son because I asked him to bring him. In the morning he took him. I screamed and cried because I didn't want him to go. The Renamo was still on, they were still killing people. It was like they didn't want me anymore, but they wanted my son. So my husband brought my son back to me, but he said that if his mother comes she will take the child back. So every time she came to visit my son was running away. He ended up staying with me until today. So they gave up so then my father arranged for me and my son to come back to South Africa.

Interviewer: So you came back home. How was it to be home?

Participant: So we came back, but then my mother became not well. She died because my father was married to two wives. My father didn't like the place where my mother died. He went to *(name of village)* to buy a site there. He stayed there with the other wife. Things changed now. I realized that my mother is gone now. I have to stand for myself. No one will help me. I went to tribal office. I asked for a site because I was already receiving a pension - and there was my

young sister who was working, but temporary job – She was boosting us, buying food and other things for us. So I built a house for myself and things changed.

Interviewer: How was life different then?

Participant: I saw a difference. Things changed because I was able to do things for myself.

Interviewer: So you got partner and then you were pregnant?

Participant: After I got a partner, I experienced a lot of problems because I got pregnant. That man was married to many wives. People were talking a lot. Especially the wives of the man because they said I left my husband to take their husband. They said the baby I'm carrying is not their husband's. They wanted to know how do I have sex with the man, being disabled. I was going up and down with the baby because the man was already disappearing due to the talks of the wives. When I meet him I asked, *'Why you are not coming anymore?'* I said to him *'Please give me money because I'm also sick as you can see.'* He said *'ok I will'.* Then I never saw him again. My body and feet were swollen. He didn't care about that. My young sister asked him *'Why are you doing this to my sister, don't you see that is disabled, please do what you are suppose to do.'* He then promised. One day we saw him coming with his car and he stopped there. My child went to him, he just threw R50. He was upset because of the way sister spoke to him. Remember, I was still pregnant. My days were coming to deliver so I was going to clinic now and then.

Interviewer: How did you get to clinic?

Participant: My neighbour was helping me a lot, the one married to (name of person).

Interviewer: How was she helping you?

Participant: She was pushing me with wheelchair to the clinic for check-ups. She was a good person to me.

Interviewer: Was it because you were staying alone?

Participant: Yes. So, one day I went for antenatal class at the clinic, and they said *'We are referring you to (name of hospital) because you have high blood pressure.'* It was Wednesday, so I waited for two days at home because I was trying to find the man, the father of the baby, so that he could take me to *(name of hospital)*. I asked my neighbour to tell me if she see him. So on Thursday my neighbour call me and say he is there at (surname of neighbour)'s family. I asked her to call him. He came to my house, so I told him what they said at the clinic and asked him to transport me to *(name of hospital)*. He said, *'No I can't do that.'* When I asked him why, he said because he needed to go and order tomatoes. I said '*fine, do it this morning then you can help me this afternoon'*. He said ok. Then he showed up with Mr (surname) and I asked my neighbour, (name), to come with me. When we arrived with Mr (surname), I asked (name of neighbour) to go and tell him that I needed money as they were admitting me – because he was in the car, he didn't get out. He gave (name of neighbour) R5. I won't forget that, so I could buy food. This man is so stingy, he never gave me a cent since I met him. He never came back to hospital to see me. Days were numbered for me to deliver the baby. The doctor said sign here because you will deliver your baby with caesarean. I delivered my baby with operation. My sister came to fetch me from the hospital and took me home with taxis. I stayed with my baby. After that my high blood became too much high and I was swollen, even though I had stopped eating salt as they told me in the hospital. I was home now and I was swollen and having difficulty breathing. One of my neighbours, (name of person)'s wife came to see me – and found that I couldn't even move. She ran and called her husband, saying *'Can we please take her to the clinic?'* He used his car. Together with his wife they rushed me to clinic. It is Tuesday, at the clinic they said rush to Naas clinic, there is a doctor. We found Dr *(name of doctor)* still busy. I gave him a letter wrote by the Sister in clinic. He gave me pills that drained the swelling, and the review date. I became a very nice and slender after Dr *(name of doctor)*'s treatment. I decided to separate with the man. I just told myself that I have a man, and that man is the government and he is looking after me so why should I worry? I continued caring for children, maintaining them – without any problem. One day he saw the child in the

street and he was surprised that she is big now. Remember he did not see her from 1996 up until now 2009. As I'm talking to you today, the day before yesterday he was here.

Interviewer: What did he want?

Participant: He was trying to apologise. I said to him '*thank you for giving me a baby girl because now she is looking after me. Doing everything for me'*. He said '*but you are not thanking me. You were supposed to go with me in the house'*. I said '*for what – I don't need another baby or a man in my life anymore'*. He said '*it doesn't mean if I sleep with you I will leave a baby. I can sleep with you without receiving a baby'*. I said '*it is too late – can you please just go. I don't want to see you anymore in my life'*. So he stood up and left.

Interviewer: Because the child is old?

Participant: Yes and is because I didn't have grudges against him, so he was taking advantage of me because I knew him from Mozambique.

Interviewer: Does he maintain the child?

Participant: No.

Interviewer: So he is coming back to leave another child?

Participant: Eish – he doesn't do anything for this child. The only money from this man is that R50 that was asked by my young sister and the R5 that he gave me at Shongwe. As the child was born in 1996 and 1997 he use to come here. He gave me R100 and say I must buy clothes for the child. That was the last money. Then he met her on the street he gave her R5. So I cannot say he support her because he is just showing off to people that it is his child. He thought I denying the child to visit him – I say no. Because the child never visit there.

Interviewer: Do the other wives care about the child?

Participant: Before no one was calling but now a days his wives they greet us, showing care to my child. I think it is because the husband is very much sick. I heard that they were fighting with the husband, and it is like they didn't want to sleep with him due to the sickness. So now the wives realized that I don't have any problems with them. They started to tell me news of their husband. Before the man was very sick. I asked him if he is using condom when he is sleeping with his wives. He says '*No –he can't do that – what is a condom?'* So I said to him, *'that's why you want to sleep with me because you don't use condom.'* They said we must condomise to protect ourselves but he is not capable to do that. He said his wives are refusing to sleep with him because they think that he has AIDS. I told him to go to hospital. He got sick and became very, very thin. Finally he went to the hospital and he started to take treatment, from there he became better. Now his tummy is big. You know God loves me because there was a time where he was transporting people from here to Maputo. So he was busy there with girlfriends. One of the girlfriends died. So his wives came and tell me the news. After the dying of the girlfriend because of AIDS, he stopped transporting people to Maputo. He married another woman in (name of village). His wives delivered news to me and after some time they said he is sick now. So it is like they were happy the way things turned around on him. So I used to chase him because he was taking advantage of me as I was giving advice to him to look after his life. Last time he said to me '*ja – you didn't love me you were pretending'*. I said *'no I loved you but you rejected me and your child. You think I was supposed to go to a farm to work there being disable. No way'*. I didn't touch a man until today.

Interviewer: Are there other stories you want to tell me?

Participant: My son passed matric but I didn't have money for him to continue tertiary level. My young sister is married now. So she tried to call him, looking job for him, but it was temporary job. So it stopped and he came back home and sit, until his friends called him to KFC – so he is working there but my heart is still painful that I'm unable to help the situation. So there was time where he was involved with a girlfriend and she became pregnant. Her parents chased

her. She stayed with us until delivery - that was 2006. So this woman saw another man outside and left the child with me. The child is here.

Interviewer: Is the mother of the child schooling?

Participant: She is schooling. I thanked her because she realized that she is not longer staying with the child then she transferred the grant for child to my account.

Interviewer: So she was not careless?

Participant: No, she was not.

Interviewer: Your second born doesn't have child?

Participant: No, she is still young, she was born in 1996.

Interviewer: In what grade?

Participant: She is doing grade eight.

Interviewer: I want to ask you something, when you are pregnant, going to clinic for antenatal how was it?

Participant: It was like embarrassing for me to be pregnant. I was also afraid of myself the way it was, because the nurses wanted to know *'who did this to you?'* As disabled person I was not supposed to sleep with man. Like I look like animal.

Interviewer: When you went for antenatal classes you were meeting with small children being pregnant and you are the only older person. Did they say anything?

Participant: They were pointing fingers at me, talking a lot, saying '*if I were you I was not going to do that*'. Some they came straight to me and say stop '*this don't do it again look at you'*, like I've done something wrong. I am not supposed to sleep with a man. I just said to myself these people they don't think I have blood and feelings like them. My blood also moves like theirs. So let me not entertain what they are saying.

Interviewer: I know how difficult it is when you are a disabled mother being pregnant, others telling you to stop.

Participant: At *(name of hospital)*, the nurses were preaching to me, to close my womb with operation. Every one saying stop it making it look like I'm sick not disabled.

Interviewer: Did you close the womb?

Participant: No I didn't until today.

Interviewer: What about when I came here to talk to you about the rights of disabled people?

Participant: After I came to stay here I discovered that many people don't know you. So I used to tell them about you. In the project I remember people from child line they came and asked our details. We gave them. They wanted to know who is encouraging us. I said it is Lindiwe Thobela. So your encouragement worked for us. Like you said disabled people must be helped by the government but government cannot visit house to house. We need to be together in a group form so they know we are here. Then the government will come and assist us. And it worked because then social workers came and were taking our details, even helping us to get grant. It was so easy because we were at the disabled centre running our project. That centre built in our minds lot of things. We are able to help other people like us. Although we have different challenge we are all getting benefit. Some they don't have ID book – but we encourage them to participate.

Interviewer: What's your project?

Participant: Sewing mats, making shoes, wood work and other stuff.

Interviewer: Are you feeling bored?

Participant: No, we are very much busy there. Maybe at home I can be bored but there no. We share ideas and are cooking and eating together.

Interviewer: Where is the money coming from to support the projects?

Participants: It is difficult for us, so we are donating R20 each of us, those who get pension. So we cook from the R20. And we all put R10 to open the bank account. There was time that was difficult for me to go to the centre because I didn't have someone to push me so another grandmother gave me her son (name of son) to push me every day. So I didn't have problem anymore. Since you left us here we are still coping and enjoying life. We don't have problem now because government gave us a grant. We don't struggle with anything. We even manage to pay the one who is cooking, but those who are helping us for free they used to ask if government will think about them, because they give the service for free. I keep on encouraging her it will become one day just be patient.

Interviewer: So your stories are finished now?

Participant: I didn't finish school and my heart is painful because I can only write on the register not other things. I don't know how to write a business plan. After (name of person) left the people at the centre chose me as secretary bit I can't write because I stopped schooling when I became pregnant in school.

Interviewer: So you don't think you can go back to night school?

Participant: I think I will try because I heard that the adult school is open.

Interviewer: I think it will help you.

Appendix 25 – Abbreviated Interview with Participant 5

Interviewer: Can you tell us your story?

Participant: I don't know. I know nothing.

Interviewer: Do you have children?

Participant: Yes

Interviewer: How many of them?

Participant: There are seven.

Interviewer: Do you stay with them?

Participant: Yes, here.

Interviewer: Who is maintaining them?

Participant: I am maintaining them.

Interviewer: Out of the seven children, one is disabled. Why?

Participant: Yes, I don't know what the cause is. I think it is bad luck.

Interviewer: What did you do in the end?

Participant: My elder sister took them, so she was looking after them but problem she was not working. She did not have money to maintain them. It was difficult for me. I was working on the farm because we were separated from their father due to the fact that he was having five wives. So I asked them to come back.

Interviewer: Do you have children that are younger than *(name of child with disability)?*

Participant: Yes there are small children but they are old now.

Interviewer: So they are old now?

Participant: Yes

Interviewer: Since you gave birth to *(name of child with disability)* with a disability, where did you get the wheelchair from?

Participant: The first help I got was at *(name of hospital)*. I stayed for a long time with that wheelchair, then I went to *(name of hospital)* to change it. So I went with *(name of another daughter)* to get that wheelchair

Interviewer: Ok.

Participant: Now I need the new one because also the second one is broken.

Interviewer: So *(name of child with disability)* is disabled, using wheelchair, and then you started. How did your disability start?

Participant: I don't know how it happened, I don't know anything.

Interviewer: How did the stroke affect you? Are you epileptic?

Participant: No, I don't know, they never told me that.

Interviewer: Do you have high blood pressure?

Participant: Yes, they say so.

Interviewer: When did the stroke attack you?

Participant: Tell them *(name of daughter).*

Interviewer: No, I want to know from you, not from other people.

Participant: This stroke happened long time ago. I fell down. After that they took me to hospital but I don't know what happened after that.

Interviewer: Do you take pills?

Participant: Yes I do. I have them now.

Interviewer: Where is the father of this home?

Participant: He is staying at his home.

Interviewer: Why are you not staying with him?

Participant: Aaaahhh….we separated.

Interviewer: Why did you separate?

Participant: Aaaaahhhh….life is too difficult.

Interviewer: Did you separate before or after the birth of *(name of child with disability).*

Participant: We separated after all the children were born.

Interviewer: Does he ever come to see his children?

Participant: No, he never does that.

Interviewer: *(To researcher) Eish, this is difficult.*

Researcher: *It's ok. Ask her if there is anything about disability or about life in Block A that she wants to tell us. If that is all she can tell us, that is fine.*

Interviewer: So you said there is no man in this house?

Participant: Yes, there is no man here

Interviewer: What are the difficulties that you met with growing up the children?

Participant: Aaahhh…I gave birth to them and I grew them.

Interviewer: I mean difficulties in growing them.

Participant: Little by little I grew them until they are old.

Interviewer: Did you meet problems? I remember you from long ago and you always had stories to tell me, so today, I don't understand why it is difficult for you?

Participant: Yes, we were suffering.

Interviewer: From what? Like what?

Participant: I suffered and suffered a lot. So I will suffer until I die.

Interviewer: Because the story I know about you, I don't get from you today.

Participant: Yes, we knew each other long time ago.

Interviewer: Ok, it is difficult, I think we can stop now.