

HOW USING ASSISTIVE TECHNOLOGIES (ATs) AFFECT THE
INTERPRETATIONS OF THE ABILITY-DISABILITY CONSTRUCT OF
PEOPLE WITH ADULT-ONSET LOCOMOTOR DISABILITIES.

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DECLARATION

I, Muzite Precious declare that this research project entitled “How using Assistive Technologies (ATs) affect the interpretations of the ability-disability construct of people with adult-onset locomotor disabilities” is my own piece of work. It is submitted for the degree of Master of Arts in Diversity Studies at the University of the Witwatersrand, Johannesburg. To the best of my knowledge, it has not been submitted before for any other degree or examination in any other university and that all the sources I have used or quoted have been indicated and acknowledged as complete references.

..... [Signature of candidate]

.....day of 20.....

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DEDICATIONS

This work is dedicated to my mother Mrs Norah Muzite.

LIST OF ABBREVIATIONS

ATs - Assistive Technologies

UN- United Nations

IE - Inclusive Education

DART- Disability Action Research Team

UNESCO - United Nations Educational, Scientific and Cultural Organization.

CRPD- Convention on the Rights of Persons with Disabilities

ICI - International Classification of Impairments, Disabilities and Handicaps

WHO-World Health Organisation

CWD- Children With Disabilities

CBD-Central Business District

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ABSTRACT

This study focused on how assistive technologies (ATs) affect the ability-disability construct of adult-onset locomotor disabled individuals in the South African city of Johannesburg. Its main aim was to understand the socialized use of assistive technologies in adult-onset locomotor disabilities and to unravel how the socialized use of assistive technologies affect the users' interpretations of the ability-disability construct; through the perceptions of the participants within a developing world context. Relatively, there have been few ATs studies in South Africa and they have excluded the 'voice' of the disabled people. Ten conveniently sampled adult-onset locomotor disabled individuals participated. An interpretive technique in the form of semi structured one hour interviews was used for data collection. The descriptors of events for the thematic analysis were the patterns or themes in which participants were constructing the narratives of their lives. These patterns were formulated using Braun and Clarke (2006) six stages of identifying, analyzing and reporting patterns within the data.

Transcribed texts from the ten semi-structured interviews were subjected to thematic analysis based on how the participants perceived their assistive technologies. Four central themes emerged which centred on how people perceived their ability-disability; the social acceptability of ATs, accessibility factors and new trends in assistive technologies. The research findings indicate that most adult onset disabled individuals in a South African context tended to embrace the promises of technology centred on positive attributes such as: improved communication with others, increased mobility, physical safety, personal autonomy, control over one's body and life, independence, competence, confidence, the ability to engage in the workforce and participation in the wider community. Although such positive attributes seemed to reinforce perceived ability as the boundary between disabled bodies, technology was blurred. However, this perceived ability was found to be rather misleading since it was premised in the same medical and social discourse that 'disabled' individuals. The participants' narratives were constantly constructing and reconstructing the way they perceived themselves as able or disabled. The studies therefore recommend that, disability narratives on the perception of ATs should be viewed as fluid, complex and multi-layered.

CHAPTER ONE

INTRODUCTION

This chapter provides a brief overview of contemporary worldwide trends in societal perception of assistive technologies (ATs) and disability studies in general. Furthermore, it seeks to position the study on “how assistive technologies affect the interpretations of the ability-disability construct of people with adult-onset locomotor disabilities” as in accordance with international as well as national statutory instruments such as United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD 2007) and the Constitution of the Republic of South Africa (2006) governing and policing the rights of people living with disabilities. It gives a brief description of the knowledge gap, the statement of problem, objectives of the study, the research questions and a justification for the study.

1.0. Background

I remember my reaction when the wheelchair first came-I cried my soul out. God, why have you forsaken me? Questions and endless tears! The nursing staff helps me up and placed me on this ‘object’. I hated it with all my heart; to me it represented my helplessness (Zulu 2004, p.24).

Zulu's depiction of wheelchairs highlights the socialized attitudes towards disability, in which societies often view assistive technologies as symbolising helplessness, as expressed by Zulu. To him, being on a wheelchair was like a death sentence. Zulu, now a tireless campaigner for the cause of people with disabilities, expresses his disappointment, fear and contempt of a wheelchair when he was paralysed in an automobile crash at the age of 23.

Divya Babbar (2014), another individual using a wheelchair, also reveals the offensive, ridiculous and absurd things people say to wheelchair users. She writes, “I was having dinner

and, when it was my turn to order, the waiter pointed at me and asked my friend, ‘what will she have?’” (p.1)

These are just a few of the numerous embarrassing moments encountered by people using some form of assistive technology. This is in stark contrast to the position taken by the National Standardisation of Provision of Assistive Devices in South Africa which highlights that:

Assistive devices should include those that promote the independence of a disabled person, contribute to disabled people functioning in society, facilitate communication for disabled people, and improve the quality of life of disabled people (National Standardisation of Provision of Assistive Devices in South Africa 2003, p.4).

Such embarrassing moments similar to those faced by Babbar, occur even as contemporary societies claim tremendous improvements in the way people living with disabilities are treated.

It is against such a background that this research sets out to examine how using assistive technologies for people with adult-onset locomotor disabilities affect their interpretation of the ability-disability construct in a South African context in the twenty first century.

1.1. Problem statement

Disability and Assistive Technology studies are largely dominated by a dichotomous representation of the ability-disability construct which is the idea that society consists of two distinct groups, those who are able bodied, and those who are disabled. To fall within the second category has major consequences for how you are viewed and ATs, especially those that are visible such as wheelchairs, crutches and prosthetic limbs ‘mark’ the user as belonging to the category of disabled. This means one has little chance of evading the stigmatisation.

Yuval-Davis (2006) attempts to theorise the ability-disability construct by paralleling it to a 'politics of belonging' "which influences "boundaries that separate the world population into 'us' and 'them" (p.204). The ability-disability construct is thus problematic in that people tend to be seen in terms of their disability, and their various forms of ability are often overlooked as Perkins (2004) illustrates:

This might not be a problem if the behaviours thus referred to were the same across all of these conditions. Unfortunately they are not and therefore the terms lack discrimination and are hardly adequate as diagnostic descriptors (p.367).

A lot of literature has been written on the intersections of disability and assistive technologies (AT), for example Gronlund, Lim and Larsson (2010) focused on the inclusion of assistive technologies and Inclusive Education (IE) in a developing world context in Tanzania and Bangladesh. In the developed world, there is a notable trend towards using high tech-computerised ATs due to the early recognition of inclusivity principles in such societies as well as their advanced industrialised economies. This is highlighted in the large volumes of research which seek to assess the feasibility of high tech ATs. Examples are Comb (2000) and McCreadie and Tinker (2005) who assessed the acceptability of ATs to older people and examining the feasibility, acceptability and costs of introducing ATs to their homes in England.

Relatively, there have been few ATs studies in the developing world. South Africa is no exception as there have not been many ATs studies over the last decade. South African studies on ATs include a study carried out by the Disability Action Research Team (DART) of McLaren, Philpott and Hlophe (1997) focusing on assessing the accessibility, affordability, and appropriateness of ATs in KwaZulu-Natal.

Whilst a majority of these studies are pioneers in the contemporary study of ATs and disability in South Africa, they nevertheless focus “on a body that assumedly should be free of any physical disabilities” (Lupton and Seymour (2000, p.1852).

Furthermore, social researchers have been criticised for not taking enough note of lived accounts and narratives of people living with disabilities in their disability research yet it is through these narratives that the ability-disability constructs are forged. Yuval-Davis concurs with this and highlights that:

Identities are narratives, stories people tell themselves and others about who they are (and who they are not). Constructions of belonging, however, cannot and should not be seen as merely cognitive stories. They reflect emotional investments and desire for attachments: ‘Individuals and groups are caught within wanting to belong, wanting to become, a process that is fuelled by yearning rather than positioning of identity as a stable state (2006, p.201).

Thus, this research seeks to give people living with onset disabilities a voice in their own affairs focusing on how their personal narratives and lived accounts shape and reconstruct their perception of their ability-disability through use of their ATs.

1.2. Research Question

How do using assistive technologies (ATs) affect the interpretations of the ability-disability construct of people with adult-onset locomotor disabilities?

1.3. General Objective:

This research study aims to:

1. Understand, through the perceptions of the participants within a developing world context, the socialized use of assistive technologies in adult-onset locomotor disabilities, and to unravel how the socialized use of assistive technologies in adult-onset locomotor disabilities affects the users' interpretations of the ability-disability construct.

1.4. Specific Objectives:

1. To understand how the use of Assistive Technology brings about issues of differences and 'othering' from the perspective of people with adult-onset locomotor disabilities
2. To explore how issues of the 'technological divide' are portrayed and possibly intersect along gender, ethnicity and class from the point of view of people living with adult-onset locomotor disabilities in South Africa.
3. To identify and outline the triumphs and challenges faced by adult-onset locomotor disabled people in South Africa when they interact with their environments using assistive technologies.
4. To highlight new trends in the use of assistive technologies from adult-onset locomotor disabled peoples' perspective.

1.5 Justification

The rights of people living with disabilities are enshrined in the United Nations (UN) Convention on the Rights of Persons with Disabilities (2007). In their fact sheet, the UN estimates that "about fifteen per cent of the world's population, or 650 million people live with a disability" (UN Fact Sheet 2014, p.1). This officially makes people living with disabilities the world's largest minority, yet they continue to live in abject poverty and discrimination. The UN fact sheet reiterates "20 per cent of the world's poorest people are disabled, and tend to be regarded in their own communities as the most disadvantaged" (UN

Fact Sheet 2014, p.1). In addition, there is an intersection of disability and gender, in that as the UN fact sheet concurs “Women with disabilities are recognized to be multiply disadvantaged, experiencing exclusion on account of their gender and their disability”(2014, p.1) .

As a signatory to the Convention on the Rights of Persons with Disabilities, South Africa is mandated to incorporate the Convention into its own Constitution. The rights of people living with disability are enshrined in Chapter Two of the Constitution of South Africa (1996) which contains the Bill of Rights that prohibits all discrimination on one or more grounds, including “origin, colour, sexual orientation, age, disability, religion, conscience, belief and culture” (S.A.Const. art.9, §2). This clearly is in line with the UN Convention which clearly states that “countries are to recognize that all persons are equal before the law, to prohibit discrimination on the basis of disability and guarantee equal legal protection (Convention on the Rights of Persons with Disabilities 2007; Article 5, p.7)”. Yet persons living with disability constantly face discrimination and prejudice as highlighted in the anecdotes depicted earlier.

Society as a whole generally stigmatises disability as well as the use of assistive technologies such as wheelchairs, prostheses, walking sticks and crutches as a misfortune, even a catastrophe. This has been highlighted in studies by McCreadie and Tinker (2005) in North America, although these two scholars focused on the acceptability of older people to assistive technologies without any specific reference to any disability. However, most of the disabled people get impaired later in adulthood. As Burtchardt (2003) points out:

The majority of disabled people experience the onset of their health problem or impairment in adulthood. According to a survey carried out in the mid-1990s, 11 per cent of disabled adults of working age were born with a health problem or

impairment, 12 per cent became disabled during childhood, and the remaining three-quarters became disabled during working life (p.5).

Thus, through accidents and chronic diseases, including strokes, people are at great risk of becoming disabled later on in their life and having to use some form of assistive device for the remainder of their life. Yet, as already highlighted, such devices carry negative connotations of helplessness, begging and homelessness in contemporary society, which could result in the othering of the disabled people.

Therefore, it is paramount that this research seeks to give people living with disability a 'voice' on how they perceive their own assistive device. This research seeks to address this topic by presenting findings from a qualitative research project based on semi-structured interviews with ten adult-onset locomotor disabled people in the South African city of Johannesburg. The main focus of the study will be to explore the ways in which technologies affect their interpretation of the ability-disability construct.

Disability Studies research has attracted criticism for its failure to capture and reflect the experience of disability from the perspective of the disabled people themselves. Charlton (2000) in his book, *Nothing About Us Without Us*, echoes the same sentiments in writing that:

Until very recently most analyses of why people with disabilities have been and continue to be powerless and degraded have been mired in an anachronistic academic tradition that 'understands' the status of people with disabilities in terms of deviance and stigma. This has been compounded by the lack of participation by people with disabilities in these analyses (p.1).

There is an evident need to engage in emancipatory disability research which has been defined as a “radical new approach to researching disability issues, characterized by accountability to disabled people and their organizations in an empowering manner” Oliver (1992) in Barnes (2003, p.3). Such emancipatory research should also be synonymous with the global movement of social justice which has been used by UNESCO in bringing inclusiveness in education, and has been defined by Ainscow and Sandill (2008) as “aiming to eliminate social exclusion that is a consequence of attitudes and responses to diversity in race, sex, social class, ethnicity, religion, gender and ability” (p. 408).

Thus, this research advances emancipatory disability research as it strives to ultimately empower vulnerable disability groups who seemingly have been pushed to the edges of society and ‘othered’ because of their use of assistive technologies.

1.6 Outline of the Study

This thesis is organised as follows: Chapter one presents the background to the study, problem statement, research objectives and justification. The literature review and theoretical framework are presented in chapter two. Chapter three presents the methodology employed in the study as well the data analysis and data interpretation process. Chapter four presents the result analysis and discussion whilst chapter five has the conclusions of the study.

The research was limited to adult-onset locomotor impairments, that is, impairments which limit movements of the body as a whole that are acquired later on in life. For example, loss of limbs through an accident, amputation, or chronic illnesses such as strokes, multiple sclerosis, rheumatoid arthritis, amyotrophic lateral sclerosis and osteoarthritis. This excludes congenital disabilities, such as spina bifida.

In addition, the research does not include institutionalized participants in protective institutions such as hospitals, schools and palliative care institutions as the study wishes to understand disabled people's perspectives of how broader society perceives people who use assistive technologies in daily life within "normal" society.

CHAPTER TWO

LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK

Introduction

This chapter presents a review of the literature and provides the conceptual framework for the study of disability and assistive technology discourses. The literature review begins with a definition of terms, and then moves on to the theoretical framework that is embedded in Disability and Assistive Technology studies. Finally, the chapter concludes with a critique of insights in existing literature on the intersections of disability, gender, class, and race and disability narratives.

2.1 Definition of terms

Any meaningful engagement in a disability discourse should begin with definitions of terms. Oliver and Barnes (2012) reiterate this and note "such definitions and arguments become authoritative and are assumed to provide generalised explanations for the multiple deprivations associated with disablement and a justification for intervening by health and social welfare professionals in disabled people's lives" (p. 11).

2.2 Disability

The World Health Organisation (WHO1980) and the International Classification of Impairments, Disabilities and Handicaps (ICI) currently offer a biopsychosocial definition of disability which uses a threefold typology of impairment, disability and handicap. Thus,

impairment according to Oliver and Barnes (2012) refers to "any loss or abnormality of psychological physiological or anatomical structure or function" (p.13).

Disability denotes "any restriction or lack resulting from an impairment of ability to perform an activity or in a manner or within the range considered normal for a human being" (WHO (1980) in Oliver and Barnes 2012, p.13). Handicap is defined as" a disadvantage for a given individual, resulting from impairment or a disability that limits or prevents the fulfillment of a role that is normal for those individuals" (WHO 1980 cited in Oliver and Barnes 2012, p.13).

Locomotor disability is defined by Ethirajan, Felix and Govindarajan (2012) as "a person's inability to execute distinctive activities associated with moving, both he/she and objects, from place to place and such inability resulting from affliction of musculoskeletal and/or nervous system" (p.37). Locomotor disabilities have been found to be the leading form of disability in developing countries such as India and South Africa. This has been illustrated in an Indian study conducted by Ethirajan et al (2012) which depicted the prevalence of locomotor disability as "1.97% or 19 per 1000, followed by hearing disabilities which were 8 (0.81%) per 1000, Visual 7 (0.75%) per 1000 and behaviour disabilities were 4 (0.44%)" (p.38).

The term 'onset' emphasises that the individual is not born with that particular disability but 'picks it up' later in life as a result of accidents, age and other chronic illnesses such as sugar diabetes, strokes etc.

From the WHO (1980) definition of disability, it is clear that some attempt to place disability within a social context has been made by incorporating the range considered normal for a human being. This socialisation of disabilities and impairments is imperative because according to Oliver and Barnes (2012) "the social world differs from the natural world in one fundamental respect, human beings give meanings to objects in the social world and references and check that they are correct. Subsequently orientate their behaviour towards these objects in terms of the meanings give to them". (p.14). Thomson (1997) concurs with this notion of socialising disability and firmly declares that "I want to move disability from the realm of medicine into that of political minorities, to recast it from a form of pathology to a form of ethnicity" (p.6).

2.3 Assistive technology

Assistive technology (AT) is defined by Cowan and Turner-Smith (1999), as "any device or system that allows an individual to perform a task that they would otherwise be unable to do, or increases the ease and safety with which the task can be performed". (Cowan and Turner-Smith 2005 cited in McCreddie and Tinker "p.91). Bugaj and Norton-Darr (2010) give a broader definition and highlight that in the United States of America "the term assistive technology device means any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain or improve functional capabilities of a child with a disability"(p.13). The authors are quick to point out exceptions as they express that AT does not encompass a medical device that is surgically implanted, or the replacement of such a device. Thus, technically in the United States this definition excludes cochlear implants, pacemakers and prosthetic legs such as those used by Oscar Pistorius, the Olympic champion.

However, in South Africa, a definition of ATs which excludes surgically implanted devices seems not to apply as highlighted in the National Standardisation of Provision of Assistive Devices in South Africa. The standardisation gives a broader definition of ATs which also encompasses surgically implanted devices such as prosthesis as it defines “assistive devices (ATs) as “key mechanisms by which disabled people can participate as equal citizens within society” (National standardisation of provision of assistive devices in South Africa 2003, p.4).

A study conducted by Cowan, Fregly, Boninger, Chan, Rodgers and Reinkensmeyer (2012) in America revealed new trends emerging in the use of ATs worldwide particularly in the issue of locomotor disabilities. The study highlighted that ATs which were now widely used in cases of locomotor disabilities were high powered wheelchairs, prosthetic limbs, functional electrical stimulation, and wearable exoskeletons. Cowan et al (2012) highlights improvements in the use of these ATs as they note “the unifying theme or trend of the research we observed is a more seamless integration of the capabilities of the user and the assistive technologies” (p.2).

However, despite these new global trends in the use of ATs, the concept of ATs, similar to disability, operates in various intersections of legal, medical, political, cultural and literal narrative discourses. Thus this research seeks to uncover these associations through critically analysing ‘disabled’ peoples lived experiences with these assistive technologies.

Key concepts: Assistive Technologies (ATs), Disability, Adult-onset locomotor disabilities and ability-disability construct.

2.4 Trends in assistive technologies studies

A lot of research has been done on assistive technologies and disability. For example Gronlund, Lim and Larsson (2010) focused on the inclusion of assistive technologies and Inclusive Education (IE) in a developing world context in Tanzania and Bangladesh.

In the research, although it was generally acknowledged that effective use of assistive technologies (AT) can help governments in developing countries achieve inclusive education by helping children with disabilities in schools, the researchers discovered that despite the importance and positive impact of ATs, prior research on the use of AT in inclusive education especially in developing countries is limited.

In addition, Gronlund et al (2010) also cited two remarkable findings in their study. The first is that ATs were not being utilised at all in schools in the developing world and in instances where they were of some use, it was usually in the form of low tech and low cost solutions such as slate, stylus and paper for manual writing, white canes, wheelchairs and such like. The researchers attribute this to the general trend of exclusion and discrimination faced by children with disabilities (CWD) as they highlighted “education of children with disabilities (CWD) is contested in developing countries. Hence, the focus is mainly on identifying these children and making them go to school” (Gronlund et al 2010, p.12).

In the developed world, there is a notable trend of use of high tech-computerised ATs due to the early recognition of inclusivity principles in such societies as well as their advanced industrialised economies. This is highlighted in the large amount of research which seeks to assess the feasibility of high tech ATs. Comb (2000) assessed the value addition of assistive technologies such as computer based programs through using the learner centered

perspective. McCreadie and Tinker (2005) assessed the acceptability of AT's to older people and examining the feasibility, acceptability and costs of introducing AT's to their homes in England.

This research seeks to empower the disabled individuals themselves by giving them agency over their narratives and experiences of ATs and to highlight how these narratives shape the ability-disability construct.

2.5 Theoretical perspectives in assistive technologies

2.5.1 Medical lens

In scrutinising disability narratives, Harbour (2010) insists on focusing on certain narrative discourses which she terms "lenses" in which disability narratives are positioned. In her research on young adults living with Down syndrome, she picks up two essential lenses in which disability narratives are positioned: the medical and the social-cultural lenses.

Most of the literature rooted in disability studies focus on a body that assumedly should be free of any physical disabilities. Oliver and Barnes (2012) concur with this and highlight that "such a medical discourse of disability is routinely reaffirmed by the activities of policy makers, professionals and mainstream scholars and researchers who in one way or another explain disability in terms of medical diagnosis of individual pathology "(p.11). The portrayal of the disabled body as grotesque, crippled, weak and deranged, resides in a medical narrative discourse which was identified by Harbour (2010) in her research on disability narratives of young adults with Down syndrome. The Medical Model of disability is rooted in science and views the disability as the overarching distinguishing characteristic of an individual. In

addition, the medical model looks at disability from a deficits-based, pathological perspective through the deterministic labels that are used in describing the disability. This is highlighted in the following narrative by Farrell (1994):

In *Count Us In*, Emily, Jason's mom, reported that the doctor stated after Jason was born that: "Your child will be mentally retarded. He'll never sit or stand, walk or talk. He'll never be able to distinguish you from any other adults. He'll never read or write or have a single meaningful thought or idea. The common practice for these children is to place them in an institution immediately, Go home and tell your friends and family that he died in childbirth (p. 3).

The portrayal of disability in a medical discourse is rife amongst narrative representations of disabled people as well as mainstream media. Philips (1990) highlights, "since the advent of the disability rights movement, euphemistic references to disabled persons in narratives have replaced more repugnant terminology" (p.850). For example, Phillips identifies one common euphemism used to refer to disabled people 'damaged goods' which operates in a medical discourse and more often refers to products than to people. Those failing to meet such standards such as the disabled are classified according to Philips (1990) as "irregulars, seconds, damaged goods" (p.850).

It is then easy to deduce that the medical lens is rife and very dominant in disability discourse. This raises further questions particularly on how exactly then does this have relevance on the main objectives of this research: which is a study of the perceptions of the ability-disability constructs of people using ATs. Mankoff, Hayes and Kasnitz (2010) marry disability studies and the assistive technology field. As they highlight "Disability studies and assistive technology are two related fields that have long shared common goals— understanding the experience of disability and identifying and addressing relevant issues"

(p.3). The authors cite the medical discourse as highly popular in literature on disability and assistive technology discourses and it allows medical practitioners to diagnose reliably and recommend particular ATs for specific disabilities.

However, the same authors are quick to criticise the medical model for labelling of people into fictitious ‘disability’ groups as Mankoff, Hayes and Kasnitz (2010) reiterates “However, if the medical model prevails, a person with an impairment might, justifiably, be asked to forgo his/her autonomy forever” (p.4).

The medical discourse in disability narrative has been soundly criticised for undermining ‘Societies being’ highlighted by Archer (2000) in that it undermines the role of social factors on individuals with disabilities and that “it is not the individual who originates meanings, in each generation we are born into an ongoing cultural tradition, from which they are individually appropriated through the process of socialisation” (p.86).

2.5.2 Social lens

Thus, the medical narrative lens in assistive technology and disability studies fails to capture the seminal societal discourse that disables an individual. This is rooted in social and cultural values regarding understanding disability. In short, the Socio-Cultural Model looks to understand the relationship between the person with disabilities and the environment that surrounds them. This includes cultural judgments about identity and being viewed in prejudicial ways by many nondisabled people in society. It is highlighted aptly in the following mini-narrative by Burke (1995):

Many people recognize me from my role as Corky Thatcher on “Life Goes On,” an ABC-TV series for many years. Corky has Down’s syndrome as do I. Only I call it Up syndrome, because having Down syndrome has never made me feel down” (p. 9).

The social lens has been applied to disability studies by Mankoff, Hayes and Kasnitz (2010) who similar to Thompson (1999), propagate the idea of plucking Disability Studies from an impairment discourse to a social one as they explain “Medical models can be characterized by a focus on fixing an impairment; social models may lead to a shift from cure to care” (p.4).

In AT studies, social theory has the same influences of uprooting perceptions from a medical lens to a more dynamic social perspective. A wheelchair on its own can be an inanimate object incapable of eliciting any emotion. Clearly it is society’s interpretations of such technologies that have a domino effect on the users’ perceptions of such technologies. Oliver and Barnes (2012) coin a term, ‘the social oppression theory of disablement’ which can be used to describe how a society's negative perceptions of, for example wheelchairs as denoting elements of helplessness might then be passed on to users of such wheelchairs who might develop negative attitudes towards themselves because of ‘sticky’ associations of helplessness with the wheelchair.

This might help explain why, for instance, a grade two student in an inclusive class in South Africa might resist wearing her hearing aids in class. It might alienate her from the rest of the class and lead her to be stigmatised as Zulu’s harrowing depiction of wheelchairs earlier depicted in the introduction.

However, the social lens does not come without its shortfalls and top on the list is the idea that social theory heavily undermines biological discourse at the unfortunate expense of the person living with disabilities. Mankoff, Hayes and Kasnitz (2010) share the same sentiments and points out the demerits of the social lens “if disability is truly defined only by society, the

experience of impairment is to some extent invalidated, and the possibility of the need for medical treatment side-lined” (p.4).

2.5.3 Discourse of trauma in assistive technologies and adult-onset disabilities

How exactly narratives on onset disabilities operate in a traumatic discourse is depicted in Frankish and Bradbury (2012). They explain how traumatic narratives dictate what can and cannot be put into words and the ways in which the body and our experiences and sensations escape being represented in words. Although Frankish and Bradbury’s (2012) research focused on exploring the stories grandmothers tell their grandchildren about their experiences under apartheid in a South African context drawing on trauma theory, the same discourse may apply to onset disability narratives and assistive technologies.

This is particularly true in the case of disability research which has earlier been characterised by a ‘conspiracy of silence’ as disabled individuals were denied a voice to express their narratives similar to the intergenerational trauma emphasised by Frankish and Bradbury (2012). Disability narratives have existed in a ‘cocoon’ of silence that suggests that there exists a prohibition on open disclosure, on touching through speech painful or shaming matters.

The silence of the disabled people has served a similar function with that of intergenerational trauma in that it leads to the further suppression of the disabled voice as “silences also function as a way of communicating rules, myths and meta-messages to which the family may unquestioningly adhere” Ancharoff, Munroe, & Fisher (1998) cited in Frankish and Bradbury (2012, p. 296). Silence seems to be an active ingredient in creating and maintaining

a disability identity which is meant to protect the disabled people themselves and their families from post trauma reactions of disability particularly in the case of onset disabilities.

Since this research is centered on onset disabilities, which can be traumatizing, the seminal theme of traumatic narratives is evident as disability in these cases is achieved through accidents and illnesses.

The coherence of our identities is constructed in narratives as McAdams' (2000) theory of Life Story identity highlights how 'being and becoming' disabled breaks or interrupts this coherence and requires that people tell a new narrative of who they are in the world, thus breaking the silence of the disabled figure.

The discourse of trauma in disability narratives and ATs as leading to the reconstruction of narratives is aptly illustrated in Zulu's anecdote in the introduction of this research report in which he uses extremely painful choice of words such as 'thing' referring to the wheelchair to postulate the deep rooted melancholy that resonated in his impairment.

The traumatic narrative by Zulu also highlights how individuals have to re-navigate their stories as they grapple with their new disability identity. Such reconstructions have enormous impacts on the way individuals perceive their assistive technologies as well as gender.

2.5.4 Disability narratives and assistive technology in a post-modernist sense

From the above discussion, it is clear that the medical, social and the discourse of trauma that onset disabilities and assistive technologies are positioned in are problematic in the sense that they tend to view the disabled body as an anomaly which has to be rectified through some

external intervention. As Mankoff, Hayes and Kasnitz (2010) highlight “Some social and medical models rest uncomfortably on an assumption that the goal is normality, which is the elimination of disability” (p.4).

Since Disability Studies have evolved over the decades with more growth in individual autonomy and technological innovations, an ‘ideal’ theoretical network would be more flexible and cater for individual differences. This is exactly what a post-modernist perspective to disability entails as it privileges each individual’s unique lived experience, complete with the complexity and nuance of everyday life. The post-modernist perspective has also been hailed for noting that disability and assistive technology are premised in cultural spaces and therefore attempts to understand each individual within that cultural space. This is very essential in a South African context which has a total of eleven national languages each representing a different culture.

This project proposes that disability research should then be positioned between two forms of narrative enquiry, which are narrative realism and narrative constructivism best depicted in Fay’s (1996) question “do we live stories or just tell them?” Thus in Fay’s words “it attacks the false dichotomy that presumes that narratives are either lived or told. Instead, borrowing from Fay, disability narratives should be “in life and not just about it” and they “tell ongoing stories which the narrators constantly tell themselves as a condition for being able to perform any intentional actions whatsoever” (p.191).

2.5.5 Adult-Onset disabilities, poverty, class and race in South Africa

The personal narratives of disabled people have been ignored and sidelined in most disability studies and social research. McAdams (2000) highlights how discourse and power interact in

narrative representations by dictating which stories are told and which are kept silent as they point out, “even in a given society, different stories compete for dominance and acceptance, women, disabled people and minorities have been deprived of the narratives or the texts by which they might assume power and take over their lives” (p.11).

Yet, as McAdams reiterates in his life story model of identity, narratives are an integral configuration of self in the adult world and people use narratives to “reconstruct the personal past, perceive the present, and anticipate the future in terms of an internalized and evolving self-story”. Thus, this concurs with Stuart Hall’s (1997) notion of difference as having a linguistic background, the use of language and narratives as a model of how culture works as he reiterates “difference matters because it is essential to meaning, without it meaning could not exist” (p.234) . It is interesting to realize how the dynamics of the othering process in race, class, gender and ethnic discrimination, homophobia and xenophobia can be used to subsequently theorise othering processes between abled and disabled bodies.

Meaningful disability research needs to focus on the narratives of people with disabilities and also look at how these intersect with various positionalities of gender, race, class, and ethnicity.

Although the interface between technology and 'disabled' bodies is not an uncommon field of study in South Africa, the relationship between adult-onset locomotor disabilities and Assistive Technologies still remains an issue in South Africa that needs addressing, particularly to determine issues of differences and 'otherness' that come with using the ATs.

The relationship between poverty and disability has been strongly established in most industrialised countries and in developing countries such as South Africa but as Emmett

(1993) challenges “less attention has been devoted to the ways in which disability and illness are intermediated by other inequalities, including gender and race.”(p.207) Gender and race play a pivotal role with both disability and mortality reflecting racial inequalities in both developed and developing countries such as South Africa as Emmett (1993) points out:

“Within developing countries such as South Africa, data on disability rates are more fragmented and less reliable. However, data that do exist indicate that similar trends exist. In particular, in South Africa with its history of colonial subjugation and racial oppression, racial inequalities, poverty and disability are intertwined in complex configurations that are difficult to unravel” (p.207).

In most developing countries, including South Africa individuals likely to be disabled later in life are the less privileged individuals working in the factories, farms and mines that mark the Johannesburg landscape and other South African cities. The high prevalence of chronic illnesses such as strokes, arthritis and osteoporosis in South Africa has left most individuals at higher risk of developing some form of locomotion impairment establishing the being and becoming dichotomy highlighted by Burtchardt (2003).

Thus, taking note of different dimensions on which disabilities and assistive technologies are premised such as class, race and economy and it automatically parallels disability studies and assistive technologies with other social struggles such as those against racism and sexism. It immediately casts away the notion of the ‘other’ as the oppressor and as Charlton (1998) points out “it situates oppression in the realm of systems or structures that marginalize people for political-economic and socio-cultural reasons and not in the ideas of others” (p.22). Charlton refers to this as the political economy of disabilities.

2.5.6 Gender and Adult-Onset disabilities

The intersection between disability and class is far reaching to encompass gender. In a South African context, it is vivid that disability is gendered in the sense that being disabled and being a woman is perceived and constructed as a double tragedy. Thomson (1997) concurs with this and highlights that:

A firm boundary between 'disabled' and 'non-disabled' women cannot be meaningfully drawn just as any absolute distinction between sex and gender is problematic. Femininity and disability are inextricably entangled in a patriarchal culture as Aristotle's equation of a woman equals man with disability highlights (p.27).

Thomson emphasizes the careful examination of intersections of gender and disability in that not only has the female body been labelled deviant, but historically in some parts of Africa, Asia and Europe, some traditional practices have configured female bodies similarly to disability. Practices such as foot binding, clitoridectomy, corseting and female infanticides in some parts of Asia, Europe and Africa were and are socially accepted, encouraged and are even compulsory. Worse still, women who use some form of assistive technology such as crutches and wheel chairs face what Thomson has called "asexual objectification" the assumption that sexuality is inappropriate in disabled women.

Despite a huge volume of research on disability narratives and masculinity being largely androcentric, there is also a shift in how some researchers are finally getting to explore the link between femininity and disability masculinity. According to Ratele (2008) "Any person can theoretically occupy masculinity, any female can occupy the space of masculinity from which she can rule" (p.5). Disability studies have neglected the experience of disabled

women: that when writers talk about "disabled people", they are in fact talking about disabled men; Saying "people" when they mean "men" (Thomson 1997, p.28).

In general, women with disabilities and using some form of assistive technology such as a wheelchair are deemed as less attractive and Thomson (1997) reiterates " disabled women must sometimes defend against the assessment of their bodies as unfit for motherhood or of themselves as infantilised objects who occasion other people's virtue" (p.28). Narratives of female bodies are characterised by what Thomson has coined asexual objectification which is the assumption that sexuality is inappropriate in disabled women. Thus, narratives of women with disabilities depict a struggle of defending themselves against asexual objectification as highlighted by Wade's poem of self-definition:

I'm the Gimp,

I'm the Cripple,

I'm the Crazy Lady,

I'm a French kiss with cleft tongue. ("Wade 1987", cited in Ferris 2005)

In this poem Wade articulates an identity for herself, an element constant with McAdams (2000) life story model of identity in which people continually try to construct and reconstruct their disability. Her narrative allows the shift from grotesque to Haraway's (2013) cyborg which is a hybrid of machine and organism which assumes a greater deal of agency. Thomson (1997) concurs with such an emancipated figure of a woman with disability and notes that it is "similar to the grotesque as liminal but freed from its negative connotations" (p.114).

However, despite gaining heavy ground, feminist perspectives on disabilities have been criticised for assuming double standards, particularly in cases of feminist abortion which according to Thomson (1997) “seldom questions the prejudicial assumption that ‘defective’ fetuses destined to become disabled should be eliminated”(p.26). There are also disparities in feminist disability movements in cases of chronically ill or disabled women who want to carry out euthanasia as highlighted in the narrative of Brittany Maynard who decided to end her own life in November 2014 because she had advanced brain cancer.

Furthermore, the concerns of older women who are often disabled tend to be also ignored by younger disability feminists and there are also large disparities in race and class and ethnic dynamics regarding how women with disability are generally perceived by contemporary society. In this sense, black women who are disabled carry a double ‘burden’ of being disabled whilst being black at the same time may result in more discrimination, less access to medical care and most importantly education. This is sadly the case in a South African context in which intersections of blackness and disability may carry negative associations of hopelessness, asexuality, begging, weakness and impurity which is often not the case with their white disabled counterparts.

Therefore, the narratives of black women with disabilities carry an extra burden of trying to, in McAdams (2000) term, ‘construct’ a black female subject that displaces the negative cultural images generated by South Africa’s and America’s aggregate history of racism and sexism. Thomson (1997) through her research on African-American disabled women challenge contemporary researchers of disability studies to reconstruct these negative connotations associated with black disabled bodies. She notes:

Such a collective project of cultural revision challenges the African-American woman writer to produce a narrative of self that authenticates black women's oppressive history yet offers a model for transcending that history's limitations. (p. 103).

Intersections between disability and masculinity have been a much covered field of research and the general depiction is that of a hegemonic androcentric portrait of an emasculated man through disabilities. Gerschick and Miller (1995) concur with the image of the emasculated disabled body and states "for a male, the weakening and atrophy of the body threatens all cultural values of masculinity, strength, activeness, speed, virility, stamina and fortitude" (p.183).

Gerschick and Miller (1995) introduce the concept 'hegemonic masculinities' against which men who are disabled experience 'embattled identities' because of the conflicting expectations placed upon them as men and as people with disabilities. Gerschick and Miller highlight how some sort of disability identity crisis erupts due to this comparative analysis with hegemonic masculinity when they state "On the one side, contemporary masculinity privileges men who are strong, courageous, aggressive, independent and self-reliant. On the other, people with disabilities are perceived to be and are treated as weak, pitiful, passive and dependent" (p.183). Thus for men with disabilities, being recognized is difficult if not impossible to accomplish.

The narratives of men living with disabilities highlight clearly this conflicting dilemma between disability identity and hegemonic masculinity as Gerschick and Miller offers this mini-narrative:

You know, if you go to a restaurant with somebody, it's always the man's place to pay the bill and stuff like that, whereas I find if you're disabled it's not necessarily your place to pay the bill, because you're the poor little disabled person that presumably hasn't got much money [...] I find it highly frustrating when I go in with another able-bodied person, and they automatically present the bill to the able-bodied person instead of me, and I have on occasions said. "Actually, I'm paying the bill", they have said "OOPS, sorry!" and got rather embarrassed (p.183).

Contrary to the beliefs that masculinity is all about testicles, there have been major shifts in the perceptions of disability masculinity as static. Contemporary research has attempted successfully to portray disability masculinity in a post-modernist discourse, which highlights it as fluid and forever under reconstruction. Gerschick and Miller (1995) share the same sentiments and highlight "Recently the literature has shifted towards understanding gender as an interactive process" (p.185). This interactive process concurs with the concept of imaginary positioning and the production of a self. Ratele (2008) highlights the fluidity of disability masculinity by stating that "there is unscrewing of masculinity from its place, masculinity is thus at once a position which individuals inhabit but also constantly try to rearrange and work to contour to their lives so as to understand the world" (p.5). The spiralling process of negotiating masculinity in disabled males is highlighted in the following anecdote:

I felt asexual for a long time because a man's sex was supposed to be in his penis, and I couldn't feel my penis. So that contributed to my feelings of being asexual; it didn't occur to me that it felt good to have the back of my neck licked, or that it felt good to have my arms stroked lightly. Stroking the wrists, then to the arms, then up the arms,

is a sequence that I've since learned can be very exciting. (Shakespeare, Gillespie-Sells & Davies (1996, chapter 4)

The extract highlights how disabled men slowly shift opinions of what they perceive as being masculine against a hegemonic masculinity background and then at the end finally reconciling and regaining their masculinity.

The intersections that lie between the social disability narrative discourse and masculinity is highlighted by Ratele (2008). He identifies that the concept of 'masculinity' is actually a construct. Therefore, masculinity thrives on social discourses as Ratele (2008) epitomizes "rather than being original productions, men's expressions of a masculine self are "always readily made, always social first and personal second" (p.5).

Thus as conclusion, it is clear that any meaningful disability and ATs research should incorporate the lived and told stories of individuals with disabilities themselves and careful study of such stories will reveal that they operate under discourses such as trauma, medical and social which subsequently have consequences for the way they perceive, reconstruct and in Ratele's (2008) terminology "unscrew masculinity from its place' (p.5).

CHAPTER THREE

METHODOLOGY

Introduction

This chapter describes the methodology used in establishing how an assistive device affects the interpretation of the ability-disability construct of people with adult-onset locomotor disabilities. It provides detailed information on how the objectives of the study are achieved. It explains the research setting, the study design, the sample size, the research instrument, ethical considerations and the procedure followed in obtaining the information. It then concludes by outlining the preferred method for data analysis used to interpret the information and the limitations of the study.

3.1 Study Population and Sample Size

In this section, the researcher adopts the method used by Mama (1995) in her study on race, gender and subjectivity in London, through providing a brief description of the research participants as they were at the time of the research. This has the effect of drawing the audience closer to the research participants early in the research which is a good disposition of any interpretive research design.

The ten participants are introduced under the pseudonyms that are used to identify them wherever they are subsequently being quoted.

Jenna is a thirty six year old white woman who has quadriplegia following an unsuccessful operation at the age of fifteen. At the time of the interview she was staying in Sandton, an extremely affluent suburb situated in the metro of Johannesburg. Sandton is often cited as a materialistic centre and refuge of the white flight from the Johannesburg CBD and as Bell and McKay (2011) maintain that “access to Sandton’s services including education and

medical services were notoriously segregated along strict racial lines” (p.27). In post-apartheid South African society however, it is becoming increasingly stratified along ‘class’ lines, that is, income and socio-economic status, more than race”.

Jenna uses an assortment of ATs ranging from a highly automated wheelchair, a manual wheelchair to a highly sophisticated customised kitchen and bedroom.

UmaThirteen is a Mozambican immigrant who came into South Africa some fifteen years ago. He was involved in a train accident which left him with one leg and a total of thirteen fingers and toes, therefore the pseudonym ‘UmaThirteen’ which he insisted should be adopted in the research. UmaThirteen resided in Diepkloof at the time of the interview which is a township of Johannesburg and is sometimes referred to as Diepmeadow, and considered as a single township with the nearby Meadowlands. Diepkloof was established in 1959 to accommodate people being removed from Alexandra and is predominantly black populated. The majority, like UmaThirteen, dwell in shanty makeshift zinc housings called ‘Mukhukhu’. UmaThirteen has also used a variety of assistive technologies ranging from arm crutches at the time of his accident to which he later changed to a prosthetic leg citing many reasons.

Maslovo is a twenty-three year old coloured man from Orlando East in Soweto, Johannesburg, which borders Diepkloof. Orlando East shares similar socio-economic characters with Diepkloof. It is described as the first township to be established in greater Johannesburg area, established in 1932 as a segregated African township on the outskirts of ‘white’ Johannesburg. Maslovo is monoplegic following a severe automobile accident in which he also suffered severe memory loss as he cannot recall any events leading to the accident. He has used different ATs at different stages of his life after the accident which range from arm crutches, a wheelchair, a walker, computers and social media.

Charles is an 85 year old retired white man who lost his left leg due to chronic diabetes. Charles is using a prosthetic leg and some crutches as his assistive devices. The interview was carried out at his home in Strijdom Park, a middle density suburb where the participant is residing with his wife of 50 years.

Mr Nasira is a fifty three year old South African Indian who is using a prosthetic limb and a wheel chair. His impairment followed an amputation to his right leg after a botched robbery in his homestead in Lenasia which is in Soweto and historically was predominantly populated by a large Indian population. However, today Lenasia has seen a considerable boom in black population and is a vibrant and thriving community.

Mrs Khumalo is a fifty nine year old black woman who is retired after a serious car accident which left her monoplegic on the right leg. She resides with her husband in Voslorus, which was formed in 1963 when Black Africans were removed from Stirtonville because it was considered by the government too close to a white town. It is regarded as a township and exhibits many similarities in service delivery and population to Soweto.

Sheila a white, forty- eight year old woman from Kensington who has monoplegia after suffering from chronic sclerosis and osteoporosis. Sheila was forced to go on forced early pension as her condition deteriorated. She used different assistive devices in her lifetime such as a cane, wheelchair, surgical waist braces and a home-made stroller from a shopping trolley. She remarkably also uses the social media to reconstruct her ability such as Facebook and WhatsApp and she is very passionate about her social media. At the time of the interview she was volunteering at a local disability workshop in Kensington.

Johan is a 34 year old white man who is quadriplegic after a rugby accident playing in a major league. At the time of the interview Johan was a full time student at one of the local universities in Johannesburg and he described himself as passionate about disability issues.

Johan comes from a middle class Afrikaner family and he uses a variety of state-of the-art ATs such as a fully automated wheelchair and a laptop with customised software. What is remarkable about Johan is his reliance on social media such as Skype and twitter and he uses these frequently, reconstructing his ability. It is worthy to note that the interview was held via Skype.

David is a coloured 57 year old man who has monoplegia following a hit and run case when he was just 3 years old. What is striking about David is that he refused to use any assistive devices such as a crutch or wheelchair all his life until two years ago when a colleague convinced him to use a crutch as he was constantly prone to falling over his ‘bad’ leg. The researcher met him on a public bus and that is when the conversation started and he had very insightful ideas based on his experiences in public spaces such as public buses.

Thulani a twenty four year old black man living in Diepkloof, Soweto. Thulani has multiple sclerosis which was diagnosed late. It has rendered him paraplegic, having to use a wheelchair and crutches. He resides in a five roomed house with his single mother, aunt and six nephews. He is a professional DJ/producer/IT specialist and he expresses how his disability has been a major drawback to his budding career. Due to the progression of his sclerosis, Thulani has found use of his manual wheelchair excruciating and an almost impossibility. Therefore he has applied for an automated wheelchair and 4 months had elapsed since he had made the application.

3.2 Study Approach and Data Sources

An interpretive technique in the form of semi structured one hour interviews was used in the project to study ten conveniently sampled adult onset locomotors disabled individuals.

The interpretive approach was ideal in this case because it is defined by Terre Blanche, Durrheim and Painter (2006) as a technique which “attempts to understand phenomena from within their context using the context of *verstehen*” (p.348). Terre Blanche et al go on to define *verstehen* as synonymous to empathy. It is the same empathy that Oliver and Barnes (1990) thought was lacking in contemporary disability research which lacked principles of emancipation and social action. Deborah and Seymour (2000) in their study titled “Technology, selfhood and physical disability” in Australia also used the interpretive participatory technique with major success and it was as they put it “extremely useful in providing some recent accounts of the lived experience of using technologies for people with disabilities” (p.1854).

Initially, the researcher approached notable disability centres in Johannesburg such as the AIM Disability workshop in Kensington and the National Disability Council near East gate. These centres which are mainly Non-Governmental Organisations then asked for volunteers from their data base of participants who matched the following research criteria:

1. Participants had acquired the adult-onset locomotor disability later on in their life that is ranging from 19 years to 87 years. This age group was chosen because it conveniently fell in the age group of human participants which can be interviewed without the consent of a care giver.
2. Participants were using some form of assistive technologies such as a cane, wheel chair, prosthetic limb, computers, strollers, and so on.
3. For circumstantial reasons, all the ten participants lived in Johannesburg at the time of the research and had lived there throughout their adult lives, that is to say, for at least 10 years prior to the research period.

The participants were not institutionalized at the time of the interview. Institutionalization would not have offered the researcher a genuine glimpse into how participants are confronted with society's attitudes in their daily lives as they use their ATs to make their way in ablest environments.

4. All the ten participants had diverse backgrounds in terms of race, class, gender, class and ATs they used. This allowed the researcher to get a broader range of experience.

Once the researcher managed to get three participants, the remaining seven participants were brought into the study through the snowballing technique as participants referred the researcher to people who they knew who would have loved to partake in the study. The snowballing technique proved to be easier because, participants who were genuinely interested in partaking in the research were immediately identified.

3.3 Instrumentation

This study made use of an unstructured interview which was ideal for discourse analysis in that it provided rich detailed data which was to be analysed using reference to the way information fell into familiar patterns.

The opening question for the interview was:

Do you mind telling me a bit about yourself? (What is your name? Where you were born? What is your age? Where do you work, where do you live? And so forth.

This question was designed to establish good rapport between the researcher and the participant to allow genuine conversations. It also made up part of the background research which focused on the interviewees' age, socio-economic background and "race" as these are independent variables that may affect the findings.

The next questions then focused on the disability itself and into more details of the research as highlighted in Appendix A.

The interviewer throughout the interview made use of open questions and minimal prompts to encourage participants to engage in rich and in-depth narratives.

3.4 Ethical considerations

Ethical considerations were monitored and evaluated throughout the data gathering and analysis of information. Written and signed consent of each individual was sought before interviewing (Appendix 2).

For Johan who had to do a skype interview, a written consent form was forwarded through an e-mail and it was only when the researcher had a signed written consent that the interview was conducted. The researcher also followed principles of informed consent in the interviewing stages through briefing all participants of the nature and possible outcomes of the study. Such ethical practices are in line with Human Sciences Research Council in South Africa (HSRC) which recommends stringent ethical procedures to be followed when dealing with human subjects, especially vulnerable groups such as the disabled people.

The one hour long interviews also resulted in fatigue and discomfort among some participants. To counter this, the one hour interview was divided by two or more 10 minute breaks (depending on individuals) to enable participants to take a breather and refresh. This was highlighted in the cases of Mrs Khumalo who suffered from chronic hypertension and the interview had to be broken into short breaks in order to give the participant time to recover.

The researcher also encouraged participants to be open and honest on whether they felt any physical strain or fatigue. In such cases, the interview was stopped immediately and could

only be resumed on the participant's indications. The researcher also had good referral points to primary health care facilities such as nearby clinics, hospitals and a Psychologist if there ever was need for such services which fortunately was never the case.

The researcher also made it a point to make follow-up phone calls to ensure that there were no emotional repercussions from the interviews.

Furthermore, the researcher abided with non-coercive procedures throughout the interviewing period and all participants were informed of their rights to withdraw at any time for any reason at any stage in the interviewing process. In addition, the researcher in an attempt to maintain the comfort of the participants during interviewing allowed them to pick an appropriate setting for the interview. Interestingly, the participants' choices ranged from quiet lounge rooms to elegant office rooms during lunch hours and breaks. This had the effect of putting the participants at ease and allowed them to share meaningfully their experience with the interviewer.

The researcher also vowed to maintain confidentiality of participants by not revealing sensitive information and maintaining anonymity through use of pseudonyms, which the participants were allowed to pick for themselves. The same pseudonyms were used in the transcribing and final data analysis stage.

To ensure that ethical procedures were adequately met, the whole project had to undergo strict ethical scrutiny by the University of Witwatersrand ethics board members before the research was commenced.

3.5 Results analysis and interpretation

Transcribed texts from the ten semi-structured interviews were subjected to thematic analysis and the descriptors of events for the thematic analysis were the patterns or themes in which participants were constructing the narratives of their lives. These patterns were formulated using Braun and Clarke (2006) six stages of identifying, analyzing and reporting patterns within the data as highlighted below:

1. Immersion of the researcher in the data set and transcribing of data verbatim.
2. The researcher first began by engaging in a thorough reading of all the seminal literature, journal articles and publications on the interface of disability and technology, identifying major discourses and themes in disability narratives.
3. Generating of initial codes in a systematic fashion.

When it came to the interviews and transcription, the researcher then started to select what seemed interesting by setting the transcripts and the digital audio against the growing background knowledge, to identify major codes in the data corpus. Initially, about 17 codes were identified from the transcripts and each code was assigned a different colour code to make it presentable as highlighted in the table below:

Figure 1: Table highlighting initial codes in stage three of Braun and Clarke (2006) six stages of data analysis

Code number	Code description	Code
1.	Disability inability	Dark red

2.	Disability ability	Red
3.	Environmental factors	Bright green
4.	Quality of ATs	Grey
5.	Improvisations on ATs(sculpting)	Yellow
6.	New trends in ATs	Orange
7.	class and racial issues in ATs	Brown
8.	Social media as AT	Black
9.	The othering of the other (conflicts between persons with disability)	Blue
10.	Medical discourse in AT's	Pink
11.	Social discourse in AT's	Orange
12.	Fluidity in use of ATs	Purple
13.	Societal representations of ATs	Dark yellow
14.	Gender and ATs	Violet
16.	Accessibility issues in ATs	Teal
17.	AT's at the work place	Dark green

4. Collection of codes into potential themes

The next stage of the data analysis concentrated more on merging some of the codes and discarding some through focusing more on the key objective of the study: which was representations of the ability-disability construct posed by constructs of assistive technologies. This saw the emergence of possible six themes as highlighted below in figure 2.

Figure 2: Table highlighting pattern representations of the data in stage four of Braun and Clarke (2006) six stages of data analysis

ThemeName	Colour code
1. Percieved constructs <ul style="list-style-type: none">• Ability constructs• Inability representations• Social construct• Medical construct• Gender and ATs	Red
2. Factors determining ability-disability constructs <ul style="list-style-type: none">• Environmental	Green

<ul style="list-style-type: none"> • Quality of ATs • Class and race issues • Accessibility issues • Othering of the other 	
<p>5. Societal representations of AT's</p>	Light pink
<p>6. New trends in At's</p> <ul style="list-style-type: none"> • Fluidity of AT use • Improvisations • Sculpting 	Yellow
<p>7. Use of social media as ATs.</p>	Blue

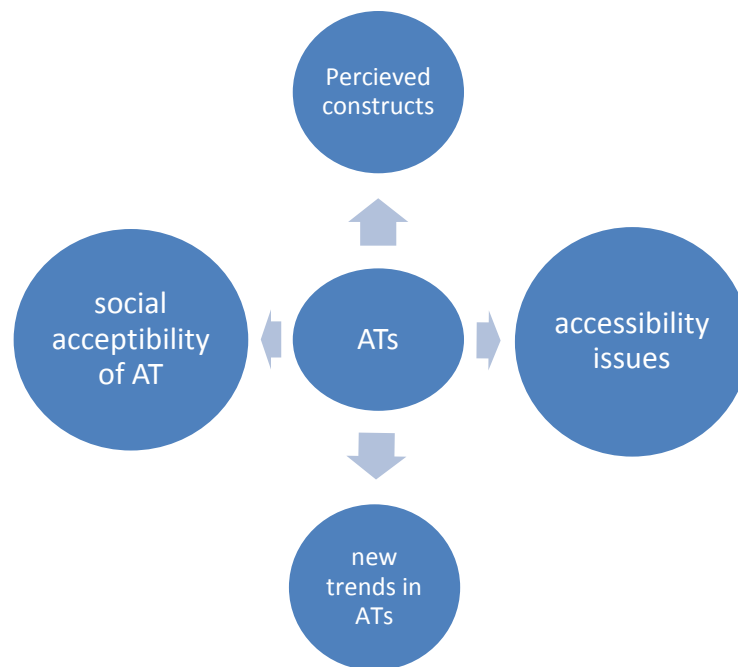
8. Review of themes

The six possible themes were further refined into four as some of the remaining themes, such as theme five and six were merged together into one.

9. Defining and naming themes.

The final four themes were named and presented as follows in figure 3.

Figure 3: Final thematic presentation of themes in the data



The four themes generated were then used as descriptors of events from which narrative accounts of participants were made into meaningful patterns.

Thus, thematic analysis allowed the researcher to have clear meanings extracted from the data and not just generalising. It also allowed the capture and analyses of lived experiences of people living with impairments and in the process conceptualising humanity as being constantly under construction and reconstruction through narratives. Such an attribute is consistent with the concept of narrative constructivism by Fay (1996) which argues that stories are actually lived and being told at the same time.

The method of thematic analysis through analysis with the pattern descriptors allowed the researcher to understand the experience of the participants with their ATs. However, thematic analysis had shortcomings such as the development of ambiguity in the stories of the ten participants. Complexity in the lived stories of the participants made it more difficult to use thematic analysis. For example, most participants had numerous perceptions over different

ATs they were using in their lives and this multi-layered nature of stories made it a huge task for analysis. Such complexity in narratives concurs with Fay's (1996) post-modernist depiction of narrative identity as constantly under construction and very dynamic.

Shortfalls of thematic analysis in this research also stemmed from compromises made to ethical considerations. This was highlighted in that sharing of stories reinforced the discourse of friendship between the researcher and participants and it became really difficult to disengage professionally at the end of the project. However, the researcher countered this by making up at least one follow up phone call to each participant in the study.

3.6 Translation issues

Since most participants used English in their interview, the language of transcribing was English for the six of the ten participants. The remaining four participants, who were UmaThirteen, Maslovo, Mrs Khumalo and Thulani chose to communicate in their vernacular isiZulu language and so transcribing was done in isiZulu. The interviews were then translated to English by the researcher who could speak and write both languages. Advantages of personal translations in this case were that the interviewer was given opportunity to familiarise more with the data and to pay close attention to cross cultural meanings based on the way different participants perceived their ATs.

CHAPTER FOUR

RESULTS INTERPRETATION AND DISCUSSION

4.0 Introduction

This chapter discusses the findings of the study. It positions the study in the realm of similar studies on the interplay of assistive technologies and disability whilst simultaneously identifying significant patterns and trends.

4.1. Ability reconstructed. “The promise of technology”

The most trending thematic representation which cut across all ten interviewees was that of acceptability of ATs. A remarkable pattern unfolded in which participants embraced their AT based on specific attributes of the ATs they were using. This is strikingly consistent with the findings by Deborah and Seymour’s (2000) research in which they noted certain acceptability attributes of ATs such as “communication with others, mobility, physical safety, personal autonomy, control over one's body and life, independence, competence, confidence, the ability to engage in the workforce and participation in the wider community” (p.1855).

This acceptability of ATs due to concerns over mobility and control over one’s body is postulated by Jenna immediately in her interview when she remarks:

Well with the wheelchair? It was pretty much immediately. I knew I was quadriplegic and I knew I had to get around.

Jenna fully grasped the implications of being immobile and losing autonomy as a person with quadriplegia. To her the wheelchair was ‘God sent’ as it immediately reconstructed her frustrations and desperations of not being able to be mobile and self-sufficient. The

wheelchair to Jenna seemed to represent a new lease of ability. It offered her the hope that Moser (2006) refers to: “The promise of technology for disabled people in which technologies, and especially new information and communication technologies, are thought by many to hold the power to bridge and even undo disability”(p.374). She illustrates this “promise of technology” vividly when she remarks:

And when I got my first wheel chair after lying in hospital for seven and a half months...I was really EXCITED because it meant now I was mobile, could get around.

UmaThirteen, a Mozambican immigrant who lost his leg in a railway accident and is now using a prosthetic leg also expresses the “promise of technology” when he made the decision to change from using crutches to buying a prosthetic leg. To him this move offered the ‘promised land’ of autonomy as it meant he could assume some rejuvenated ability to work for his family. This is highlighted in the following statement:

Well, I've got a son, I have to eat. So if I go with crutches I can't work and I want to eat, [switches to Zulu] bengizwa nje lapho nalapho songithe kuxono ngithenge icatulo, sizonginceda nesinye sikathi, ngikhone kuthi ngibambe ngapha nangapha uyabona? (I was hearing here and there (about employment) so I said it is better that I buy a prosthetic leg which will help me some other time so that I will be able to work for myself)

The ability construct is also portrayed by the ‘promise of physical safety’ which ATs offer through countering the serious physical threats that adult-onset locomotor disabilities offers. This was particularly true amongst the oldest participants who faced greater physical health threats such as falling and bone breakages due to their onset disabilities. This is strikingly similar with McCreadie and Tinker’s (2005) model for understanding the acceptability of ATs to older people in which safety between the disabled individual and the environment is

paramount to their accessibility. McCreadie and Tinker (2005) highlight that “The ATs helped them to bridge the gaps between the limitations imposed by their disability and environments and the everyday activities and tasks that they wanted to perform” (p.101).

In this research, the acceptability of ATs based on their attribute to reconstruct the health and safety ability is epitomized through the narratives of David, a 57 year old man who felt his physical safety reinforced by the use of a crutch as he mentions:

Two years ago, you see I didn't have any difficulty in getting around, but I had a problem in falling, and the boss said why don't you use a crutch, and I didn't fall again, but the problem started with my legs, and they say I am putting too much pressure on this leg.

The intersections of old age and onset disabilities around the central theme of reconstruction of the health safety attribute is also highlighted by Charles who is 87 and the oldest of the interviewees. Charles, who is using a prosthetic leg and a crutch, cites clearly how using his ATs has led him to claim his safety as he risked falling and hurting himself without them:

Yeah, I walk without it (the crutch) but prefer not to; because if I fall I might break a leg and then I would have bigger problems.

Whilst older participants in the study embraced eagerly the ability to preserve their safety and health that comes with ATs use, the younger generation seemed to emphasise more heavily the reconstruction of their communication abilities, ability to engage in the workforce and involvement in broader community activities.

For example, Johan, a 34 year old who is quadriplegic, relies completely on social media

platforms such as skype and Facebook to communicate with his family and friends and this somehow creates a more abled extension of the self as he is no longer disabled on the social media platform.

Okay yeah, I use social media ,ummm I use skype a lot because when I am at university I skype with my parents from time to time ,that's very useful to keep in touch ,mmm and then Facebook , I don't use it as such ,but I just sometimes browse through it ,once a week ,just to see what people are up to, then twitter I'm not on twitter ,that's basically it

Sheila, a 48 year old paraplegic woman also postulates the same sentiments of enhanced ability in communication in the form of a computer and a smart phone. These technologies seem to transcend ordinary human biology and merge with disabled bodies into Haraway's (1991) "cyborg" which she aptly defines as "an organism, a hybrid of a machine and organism, a creature of social reality as well as a creature of fiction" (p.2). Although Haraway's cyborg was situated in a largely post-modernist feminist context, it can also be applied to disabilities studies in that boundary between man and machine becomes obscure due to the usage of assistive technologies, enhancing the ability construct. The blurred lines between ATs and disabled bodies are highlighted intrinsically when Sheila could not make use of her WhatsApp application and she literally 'cracked'

Yes, in the beginning of the year, I've been to visit that friend I'm staying with now, between December and January, I used to be in my room all the time. I stayed by myself and kept to myself; I don't mix with people because it was just a matter of communication. You know things like that, keep yourself to yourself and keep your nose clean. After i came back after that holiday, I found that I can't do that anymore. I'm now used to having more and my phone packed up, I had another Nokia phone and it packed up, ummm. I only had WhatsApp and my phone packed up and I

couldn't communicate with him and you know i actually came to a point when yaah yaah, I cracked. I literally cracked because there was no communication with the only person I had become family with because I didn't have any, yaah so definitely technology is a big thing.

Although the attribute of ATs to enhanced communication ability is central in this research, it is not a new phenomenon. Deborah and Seymour (2000) also found similar results in their research on AT and disability identity in Australia and they established that with some research subjects "computer technologies allowed many people to engage in communication with others, including those who had similar disabilities to themselves" (p.1856).

However, what is dissimilar in this current study is the fact Deborah and Seymour's research was done a decade ago and since then social media has evolved to spectacular heights which were unimaginable back then with the 'convergence' of technology.

4.2 The social acceptability of assistive technology: Enabling or disabling?

Moser (2006) defines convergence as "when one type of information stored in one form, mode channel or device are incorporated into another" (p.374). The convergence of media means that disabled people now feel more able to claim their agency and be more social in a whole new realm which Moser (2006) has termed "digital disability in a techno science world" (p.5).

Therefore, in this almost utopic digital world, the central theme of enhanced disability with the 'promise' that comes with technology resonated resoundingly. It really seems that technology delivers on its promise!

However, Moser (2006) proves this statement might as well been spoken too soon as he makes a pledge of his own to interrogate such promises through "a set of tools and resources for such an inquiry, and offer analyses and discussion of the generative and transformative

power of technologies in the lives of disabled people”(p.374). Moser, similar to Thomson, attempts successfully to position disability in a social dimension and critiques the ‘promise’ of technology as problematic since it is still premised in a highly patronising medical discourse that views disabled bodies in a deficit lens. Moser (2006) reiterates “The point of departure is that ‘disabled’ is not something one is but something one becomes, and, further, that disability is ordered and enacted in situated and quite specific ways. A set of questions follows from this: What roles do technologies and other material arrangements play in enabling and or disabling interactions?” (p. 374).

Charlton (1998) attempts to clarify this by quoting the great Mexican novelist Julio Cortazar when he cites; “nothing can be denounced if the denouncing is done within the system that belonged to the thing being denounced” (p.22). Charlton goes on further to parallel the disability cause with other oppressed groups such as racial, gender and sexual oppression. A meaningful critic therefore of ATs should avoid the common trap that Malcolm X and Marta Russell fell in of perceiving that the basis of oppression lies in the other whilst in actual fact it is according to Charlton “the systems or structures that marginalize people for political-economic and socio-cultural reasons”(p. 22).

The frustrating way in which systems and structures continually oppress disabled people is highlighted through the interviewees accounts on how society continues to shun them and label them as ‘freaks’ despite the promise of technology.

This is highlighted through accounts by Jenna who still felt alienated and frustrated by society despite having achieved tremendous levels of mobility and independence through use of her automated wheelchair.

It was a huge bash to my self-esteem and when you look at them they will quickly look away so in my mind at the time I thought “they don’t want to be caught looking

at me because they are not thinking nice things. So that's what started depleting my self-esteem the way people were looking. It's probably comes to what was going on through my imagination and probably it was also because when I was young I used to go past the Openscow which was a school for disabled children I used to say" oh my word I don't wanna go to those freaks!

Since Jenna in this extract testifies to having harbored and entertained discriminatory opinions towards persons using ATs at some stage in her life and to some extent even in the present tense, it can then be justified to argue that it is indeed societies that construct inability of people using ATs and not the technology itself.

The way societies are organised to construct perceptions of inability was more profound in the work place in which most research participants were constantly reminded of their inability and even going to extreme extends of being fired or given an early retirement when they started using different forms of ATs.

This is highlighted by Jenna who despite being an experienced worker at her company, was still looked down upon and constantly reminded of her supposed inability. This is shown in the following interview extract when she was excluded from a team building holiday by her supervisors just because the venue was not wheelchair friendly:

I was called into the office and was told that I couldn't go because I hadn't been in the department long enough but I have been in the company the whole time. If it was for the time in the business I was there so them telling me that I couldn't go because I had not been in the department long enough was just an excuse because they had already chosen the place they wanted to go to which wasn't wheel chair friendly.

Sheila, another participant in the study, also exposes the construction of inability and ‘disability’ itself by societal structures at the work place when she was unceremoniously put on pension as an elementary teacher because her boss thought her use of a walking cane at school was inappropriate. She expresses her dissatisfaction in the following lines:

As far as the cane is concerned, that’s why my boss put me on pension, because he looked at me walking with that cane on the playground and he said the parents said they think I’m hitting the children with that cane, they don’t see my cane as a walking device because I’m struggling to walk but as a disciplinary tool.

The theme of the disabling constructions of societal structures is epitomised in Mr Nasira and UmaThirteen who were all ‘released’ from work after getting disabled and using assistive devices. In Seymour’s (2000) terminology these are ‘signifiers of disability’ and “overtly bespoke of disability” (p.1858). In UmaThirteen’s case such visible ATs was in the form of crutches and in Mr Nasira’s case it was a wheelchair. In these instances ATs are portrayed as the nemesis for its user since it immediately establishes a disabled person as the other who has to always try to adjust and try to fit in. Thus to fit into this pressure for social integration, Umathirteen and Mr Nasira tried to use more socially invisible “acceptable” ATs such as the prosthetic limb in both cases and a converted car in Mr Nasira’s case. It was when such devices were used that participants began to regain their agency and ability based on societal acceptance as UmaThirteen emphasises:

If into isindayo, the time mangisebensisa ama critches hangeke ngiyi pate, uyabona?

So manje ngiyakhona kuti ngizienzela yonke into. (If things were heavy, the time I was using crutches, I couldn’t carry them, but now I can do anything.

The abled body is seen as the privileged positionality true to Johnson’s (2001) concept of privilege as unaware since the majority of the able bodied co-workers of the interviewees

seem to profess ignorance on the daily hassles their disabled workmates go through. This is aptly described by Jenna:

“Well: Ok, my first job was a switch board operator and because they needed a disabled person for the staff complements I suppose and, so I was the token disabled person coming for the switch board operator and I proved to them, proven myself to them within the first month, so they earmark me for an admin position. I think I surprised them, so they moved me into the admin position a month later. Again I proved myself to them; I learned quickly and started taking responsibilities of other staff members”.

4.3 Societal representation: a construction of disability or ability?

Besides harbouring stigma towards people using ATs, society represented by community members, family, friends and co-workers portrayed astonishing levels of ignorance which only served to further construct helplessness and inability among onset disabled individuals in the study.

Societal ignorance towards ATs in a South African perspective proved to be alarming. Even family members and close friends were guilty of this as highlighted by Jenna’s account about her friends:

Yeah, as I said I didn’t have problems making friends, but I found out that they are not always one hundred sure of what wheel chair friendly means [Laughing]. I’ve got a friend who invited me to see her new friend and she says it’s a one hundred percent wheel chair friendly and that’s only inside the house, because I found out that there is a whole flight of stairs to get up to her place and she didn’t see that as being an obstacle and it happens often when someone will say let’s go here let’s go there don’t

worry its wheel chair friendly but then you will get to the steep ramp or they will be just one step and they don't think that's a problem but that won't get me up the step either [laughing]

This creates perceptions of hopelessness and inability in the disabled individual as the perceptions of family and friends are usually profound in shaping constructs of ability and disability. In Charles's case it is highlighted through his wife who seems like she is always 'out to get him' as she is always leaving obstacles in his way which his prosthetic leg could never be able to get around.

Society's ignorance was seen as a factor for constructing disability particularly in public transportation systems and malls in which society generally portrayed lack of knowledge on how to interact meaningfully with people using assistive technologies. This is shown through David's experience whilst using the public bus system. People showed lack of knowledge of negotiating spaces with disabled people such as reserving a seat for the disabled and giving way to them so they could pass as he emphasises:

And sometimes you get, you want to get out of the bus and people are behind you they get angry because you are taking too long to get out.

Charles also expresses frustration aimed at people who are ignorant at his local mall when he points out:

I sometimes go to Pick and Pay and sometimes people they don't look where they are going and I have to use my walker [holding it up as some weapon] and I use it [laughing] if they get in my way.

Thus the findings of this research are consistent with the social theories of disablement which maintain that society is the one that constructs disability.

When society tended to be supportive in the study to people using ATs, a construct of ability was constructed in the narratives of the participants. This is exemplified through David, who acknowledges that some bus drivers were actually very friendly and occasionally assisted him when he notes:

They stop for you like in the morning, the stop is far but they drop me right at my work, so they drop me closer to my work.

UmaThirteen also praises the support he received from his society despite early derogatory remarks of being a migrant person living with disabilities. This makes him feel he can be able to work and provide for his family, reinforcing his ability as a caregiver.

Maslovo brings in intersections of race and societal representations of ATs as he is caught between two worlds: the coloured community from his mother's home and the black community in Soweto from his father's. He notes a difference in the way these two communities perceive people using ATs. In his opinion because of the black culture's orientation towards the family concept, they tended to be more supportive and perceive ATs more positively than the coloured community. He highlights in the study:

That's what I was telling you kuthi mangi bheka amacoloured nabo udarky [black people], mina ngi prefer abodarky. .Uyabona amacoloured izinto zabo abazikohlwa kuthi ubenzani.(That is what I was telling you that when you look at coloureds and black people, I would prefer black people. Coloureds don't let go of grudges and they will never forget what you did to them).

Maslovo's statement can be placed in McAdams (2000) post-modernist life story model of identity in which people continually try to construct and reconstruct their disability through lived accounts narratives. Therefore, whatever he is experiencing may not be true and representative of all people with onset disabilities using some forms of ATs.

4.4: Ability-inability construction: Intersections of gender with assistive technologies.

4.4.1 Masculinity reconstructed

A common theme in the research was that of an emasculated disabled body whose inability is amplified through the participant's use of some form of assistive device. This was epitomised through UmaThirteen who highlighted Gerschick and Miller's (1995) 'embattled masculinity identities' as he struggled to come to terms with his onset disability and all the challenges that come with the use of crutches. The central themes on masculinity which most of the research participants alluded to resonates strongly with Gerschick and Miller's (1995) perception of disability and ATs as threatening hegemonic masculinity's values such as strength, activeness, speed, virility, stamina and fortitude. This in turn had a strong influence on how participants constructed themselves as abled and unable.

UmaThirteen portrays an emasculated disabled figure with less strength, stamina and activeness following his onset disability and having to use crutches when he notes:

Because, eish (.) *Maune abatwana mele ubanakele kuti badhlile, baye skolweni. Kufuneki imali into injalo () so mangihaba namacrutches, vele haikho into ngizoenza (.) there nothing i could do because i was using crutches. It's like that. Beingeko idhlela yokuti ngisebenze.* (Because, when you have kids you have to work for them to eat, so they go to school. Money is needed that is the way it is and so when I was

using crutches, there was nothing I could do. There was nothing I could do because I was using crutches .It's like that. There was no way I was going to work.

Thus, UmaThirteen unconsciously paints a portrait of a flawed man cruelly positioned against an androcentric and hegemonic presentation of masculinity. He perceives himself as not fit to be called a 'man' as he could no longer work and provide for his family as he was immediately fired from work. His use of crutches harboured connotations of helplessness and this serves to construct central themes of inability and 'disability' to assistive devices.

Issues of emasculation as a result of using crutches comes to a standstill for UmaThirteen when his wife leaves him because he was left unemployed as a result of his inability to be agile at the steel factory where he was working when he states :

YAAA!Yaaah!:::umfazi wam, umama wabatwana bam, hangiti ungiyekile the time bengilemele (),wangiyekela,wavele wati abatwana bakho mathole mina ngizo cubeka pambili ngoba ngilemele,kushoo kuthi hangeke ngisa khona kuenza nix. Uyabona,bekangi biza nemanye amagama,kushoo kuthi besithandana ngoba bengisebenza.(My wife, the mother of my kids, left me the time I got injured. She just said take your children and I will continue my life because I was now disabled. She meant I could not do anything calling me names. It meant she only loved me because I was working).

Mr Nasira also expressed this threatened emasculated disability figure when he points out his inability to protect his homestead and wife in case of a burglary:

Now I will be honest with you, I'm not a violent person; I'm not a violent person, okay. I am a very cool and calm person, but if somebody has to get into my house now, okay right now I don't have a weapon, but let's just say if I had a gun, those big shot guns, the pump action shot gun, I would sit here with it me next to me because if I see a guy in my yard, wanting to get into my house, I will tell you straight, I will

shoot him from where I'm sitting, which is about three metres away, I won't be able to walk but I will kill him, I don't care what the law says. What is he doing in my yard? This is my property. What the f... is he doing in my yard? I will kill him, I don't care, because he is not going to think twice to kill me, he will walk in here, shoot me dead, and do what he wants. So I don't care what the law says, because in this country there is no law.

Despite his protestations, it is clear that to Mr Nasira the major concerns stem from a deep rooted fear of failure to protect his family from burglars and neighbourhood crime.

For Charles, an 85 year old white male, emasculation was not centred on the loss of strengths and stamina to provide basics for the wife and family such as a steady income and safety as highlighted by Umathirteen and Mr Nasira. Most of his fears where directed at the inability to do activities such as exercising, going to church and asserting dominance over his wife of fifty years shown through this narrative:

And anyway they seem to leave stuff everywhere and you can't get pass it, my wife seems to like that, she put boxes and stuff in my path sometimes [laughing] I would smack her.

He comments briefly about feeling emasculated through confrontations with his neighbours when he is exercising:

They are not in the same position (as me). They don't get me up, and they tease me-they say run move, I can't go quickly, so my running speed and my walking speed is the same [laughing]

It seems that what Russell (1998) calls 'intersections of race and masculinity' which evidently apply in an disability context in that even the disabled black body does not escape

the stereotypes of black masculinity which have been “fixed on the body, on physicality, physical strength, and as a site for European fantasies about black male sexuality”(p. 611).

This is highlighted by exposing how the narratives of black disabled participants using ATs signified the loss of masculinity which is heavily biased on physical strength and providing basics for the family. For their white counterparts however, emasculation generally meant loss of ability to engage in some past time such as sports and exercise.

Another way of looking at this is that ability and inability are constructed through intersectional lenses of age and masculinity. The older participants using ATs perceived their emasculation on a different platform with younger ones. This view is reinforced by the fact that participants who cited emasculation with reference to physicality and sustainability are all middle aged whilst those who cited less physical masculinities such as Charles were well of in their late life. This view is supported by the following narrative from Charles:

No need to, you see when you are this old as I am, nothing works for you anymore [laughing]. I suppose they come in all types, you see the ones of prosthesis used by Oscar, well he is young, and I haven't run in while [laughing]. You get to an age whether you neither can't nor wont. I can run a little bit but I can't exercise too much.

4.4.2: Hegemonic masculinities in AT

The concept of hegemonic masculinity has been defined by Morrell (1998) as “a way of explaining that though a number of masculinities coexist, a particular version of masculinity holds sway, bestowing power and privilege on men who espouse it and claim it as their own”(p.608). In the research, ability and disability constructs were interpreted differently along this hierarchy. For instance, Morell (1998) realised that in the United States of America, hegemonic masculinity is overwhelmingly the masculinity of white, ruling class

men, which has also been true in a South African context in the wake of the Apartheid regime.

However, in the research, there seems to be a 'turning of tables' event as the narrative of Mr Nasira who is South African Indian highlighted:

Okay, look, being Indian, I am still classified as black, but I'm not black enough! I'm not black enough! And that's the truth, that's why I battle to get a job, like I told you earlier on, you will get a black disabled man, you get an Indian disabled man, let's take myself as an example and you get a coloured disabled man and out of the three the black man will get the job first because he is black and that's the truth, and that's the truth.

This interpretation of blackness as representing hegemonic masculinity has a direct influence on how Mr Nasira constructs his ability as someone using ATs. He views himself as hopeless as he feels his race, which is Indian, is being discriminated against by the disabled majority in South Africa who are black.

4.43: Femininity and Assistive technologies: A case of ability or disability?

4.44: Feminine disability constructed

Of the three women participants in the research, two of them highlighted the central theme of having lost their agency to a greater extent since they acquired different forms of onset disabilities and started using diverse forms of assistive technologies. The striking feature of this perceived loss of agency is that it is positioned in androcentric ideologies in which the male figure is perceived as the hero.

This is best highlighted by Sheila whose sclerosis and osteoporosis gradually worsen throughout her childhood leaving her dependent on different assistive technologies in her adulthood such as a walking cane, surgical waist braces, walking trolley, specially designed shoes and computers. In her late childhood, her father is the over protective, authoritative 'hero' who constantly reminds her of her inability as she slowly succumbs to her sclerosis as she illustrates:

According to my father, he always told people when people ask ME [pointing towards herself] He always answered on my behalf [laughing] he says she's got a problem. What idea does that put in people's mind? If somebody else tells them that this person has got a problem. You see? It's better for me to answer for myself, so when I failed standard eight in the first place, he promised me if I passed he will give me a camera you see like a bribery, pass and you get this reward, and when I didn't pass he said "we expected it didn't we?"

Later on in her early adulthood, as her disability has worsened she continues to exhibit this dependence on the male figures in her life. This time it is transferred to her boyfriend who drives her to work every day on his way to drop his daughter at her university. Sheila expresses her frustrations and concern of this dependent coexistence with her boyfriend when she exclaims:

So, I moved and I'm now staying in Heidelberg, travelling from Heidelberg to Kensington every day, ummm, which is a problem because I can't afford to pay transport to the person that's bringing me here and his daughter is studying at Wits, there is always a thing that if he –when she finishes and it might be for another two years, when she finishes there he may feel the need to find something closer to home, I've got no transport. So there is that real need for me to find employment.

Jenna, another woman who is quadriplegic and using different forms of assistive technologies also expresses her frustrations of being overly dependent on her husband financially and emotionally despite being quite capable of taking care of herself as she is a qualified counsellor .She expresses this concern when she highlights:

MONEY! MONEY!, these things cost money, and if I had not met my husband who has paid for these things I would not been able to pay for them on my own and I would have plodded on with anger and frustration and resentment.

Inability is also constructed among women participants in the study using ATs in the sense that some of them highlighted the perception held by themselves and by their society as not capable of having children. This is epitomised through Sheila who even before she gets married, begins to question her physical ability to have her own children. She did not have the physical capacity to pick up other people’s babies when she worked as a pre-school teacher as she had surgical braces around her waist preventing her from fully gaining her balance:

Also at this stage at the back of my mind I cannot even pick up a new born baby, and that becomes problematic. So what does it mean for me as a woman? Am I going to have children?

At this point in her life, Sheila began to use a walking cane to balance herself so she could interact better with the children at the pre-school she was working at. However, her feminine ego took a big blow when the principal decided to put her on early pension because he felt that the cane was actually inappropriate and thought she might be using the cane to beat the children! As she notes:

Six months later, my boss said NO:: you can’t manage like this, I was walking with a cane at that stage, that somebody gave me as a present, and the (the boss) said “this is not good enough, ummm, the parents are thinking strange thoughts because you

walking with a cane, What are doing with a cane? Walking around the children and it's not also good for the children because they knew that I couldn't control them anymore.

This could be paralleled with the asexual objectification Thomson referred to in which women who are disabled are seen as not attractive and not able to bear children. The incident reinforced the inability perceptions in Sheila because to her this simply meant that she was not good as a mother as a woman and mother. She went on to have a female sterilisation and she clearly cites and justifies her decision:

So he puts me on pension, he said, that was somewhere in December, he said this is your final day, you go on holiday and that's your pension. That also clinched the deal as far as children were concerned, I realised that was it, and I had a sterilisation in 1996 so that was that.

4.45. Feminine ability reclaimed: ATs and disabilities

Despite the central theme of feminine inability through the construction of use of ATs hovering strongly throughout the study, there was also a rare glimpse of ability being constructed among some female participants.

For example, Jenna actually attributed her approachable disposition to the use of her wheelchair as she now perceives herself more friendly and welcoming to people. This she feels is the reason why she managed to get herself more friends and a husband as she feels such qualities are what partners search for:

Exactly, but I found out that I will probably be equal to a lady whose probably has got some weight on her than the perfect model, in terms of men's preferences and wanting to approach. I found out they have no issues approaching me and I've had

lots of guys who would be interested without me having to approach or show who I am. So it has not been an issue.

This reconstruction of the ability to be presentable, social and attractive by Jenna whilst using a wheelchair contradicts to a greater extent asexual objectification ideology in which women who are disabled and using assistive technologies are always deemed unattractive and not fit for motherhood. On the contrary, Jenna's narrative implies the opposite as she perceives that men who are disabled and using some form of assistive technology face the brunt of asexualisation as she comments about her friend:

He lives in Port Elizabeth and he is a clinical psychologist and yeah he has got a huge house and everything except a mate. He doesn't have a girlfriend; he just can't get it right because he is almost a quadriplegic. So he needs somebody to do things for him, he can't really do things for other people. He can drive, he has a combi which he puts everything inside but the women he gets involved with doesn't stick around. They stay for a little while and he will spoil them, buy them presents and flowers and take them out, treat them well, but never enough for them. They still want a man who can protect her and whisk her off her feet literally and he can't do any of that. So for them it's undesirable.

Such unattractiveness of males with disabilities who are using assistive technologies concurs with the concept of 'unscrewed' masculinities. The male disabled body is stripped of hegemonic masculinity qualities such as physical strength, fortitude, activeness, speed, virility and stamina by societal perception of such assistive technologies such as a wheelchair or prosthetic limbs.

4.5 Attributes of the Assistive technology

4.5.1. Accessibility issues

The different ways participants perceived inability and ability through use of their assistive technologies was also attributed to issues of technology accessibility. Accessibility of ATs refers to “equitable access to transport, information (and information technology), public buildings and services” (Albert, Cook, Janice and Polgar 2014, p.3). Accessibility issues are at the core of the main principles of the Convention on the Rights of Persons with Disabilities (2007) and since South Africa is a signatory state, one would expect accessibility issues to be taken very seriously.

However, in this research, all the ten participants expressed facing some difficulties in accessing assistive technology and this resonated across race, class and cultural divides. For example, Jenna who stays in an upper class suburb and is married to a well off entrepreneur feels left behind in the technological race of access especially in a South African context, as she points out:

First off all, I think it's highly important to have things made in our own country. We need to have people with experience making these things and having them patented here and then selling them at a cheaper price than having to bring them overseas. That will make things cheaper and bring the price of these things down in terms of shipment but the footprints, the environment environmental footprint, having to bring stuff over with, I'm very conscious about that as well, I don't like having to rely on other countries for the thing we need because it makes it expensive and the majority of people in this country can't afford it, and they have to struggle though life. It's only when you become fortunate like me that when you can afford it and although I'm grateful I also feel guilty for the people who can't afford it and have to struggle in life.

Although Jenna clearly can afford most assistive technologies, she expresses her discontent at the lack of innovativeness in creating local patents and poor governmental organisation of South Africa as a developing economy to have competent ATs available to ordinary people.

This realisation leads her to put less trust in the assistive technologies she is already using as she believes they lack in quality and this further constructs her perception of inability as she is unsure of her ATs. This finding parallels the findings of Eleweke and Rodda (2000) who carried out a study on enhancing inclusive education in developing countries. They cited inadequate facilities and personal training programs, lack of funding structure and absence of enabling legislation as the chief hurdles in implementing inclusive education in developing countries.

A study on assistive technologies in Kwazulu Natal, South Africa by McLaren, Philpott and Hlophe (1997) also produced similar findings by attributing poor use of assistive technologies to “high cost of assistive devices to the lack of knowledge regarding available services, the attitudes and perspectives of service providers and the idea that the assistive devices service is centralised”. (1997, p.3)

Such an inhibiting environment in developing countries such as South Africa would then lead to users of such ATs to lack in confidence as they feel left behind. This is the case with Jenna and this serves to perpetuate perceptions of inability and insecurity.

The problem of access through lack of facilities, funding and legislation aggravates to situations whereby assistive technologies are inaccessible to the ordinary. This is highlighted in the study through UmaThiteen who had to wait for a long time to raise money as a street vendor so he could buy his prosthetic leg. To participants without medical aid coverage such

as Jenna, gaining access to the appropriate technology is a challenge as expressed by narrative of Thulani who is unemployed and desperately needs an automated wheelchair as progression of his sclerosis meant he could not operate a manual one. He explains the conditions at his local hospital at Baragwaneth Hospital in Soweto:

There is lack of wheelchairs, with mine it took me two months to get it and the other thing I have to wait for the electrical one because this one is a part- time, and I have a problem with the hand, so if I'm moving it, I hurt my hand.

Even Jenna and Mr Nasira who have middle class backgrounds seem to struggle in acquiring assistive devices such as an automated wheelchair. Jenna's wheelchair costs thirty-five thousand rands and Mr Nasira's prosthetic limb ranges between seventy-five thousand rands and one hundred thousand rands. Mr Nasira also had a car converted to be driven by an individual with paraplegia and it costs him thirty-five thousand rands and he expresses empathy to those unable to access such technology:

Okay I'm gonna give you the honest and blank truth, to be disabled in this country is a disgrace because you don't get a lot of help, okay my case I was fortunate enough like I said because of GPAD I got this leg, but can anyone afford 75 000 rands, right now this leg is a 100 000 rands, can you afford a one hundred thousand rands? You can't, so to me disability is a curse! Okay.

This citation from Mr Nasira illustrates clearly how the frustrations and emotions associated with failure to get access to some crucial assistive technologies perpetuates perception of inability and hopelessness among poorer classes of onset disabled individuals .This point is echoed by Deborah and Seymour (2000) who points out in their own research.

The development and marketing of new technologies are bound to an economy privileging profit rather than an economy of need. These technologies, therefore, are far more accessible to the socioeconomically privileged in society. (p.1858)

This once again positions ability and inability constructs brought by assistive technologies along class and racial lines as the wealthy stand a better chance to construct ability through access to better quality assistive technologies. The reverse can be said about poor people who are likely to construct inability perceptions of ATs as they at most times cannot afford the right ATs for their disabilities and have to make do with what they can afford.

This is epitomised by UmaThirteen who felt he was not able to fend for his family when he was using crutches and had to gruel through hard work to buy himself a prosthetic leg which made him feel more able to work and look after his family. Intersections of poverty and assistive technology are described as a paradox by Mitchell and LaPlante (1992) who in their research made a startling discovery that it was poor people in societies who later on were likely to use some form of assistive device in their life as they point out “

People whose family incomes are below the poverty line are somewhat more likely to use assistive technology devices than those whose incomes are above the poverty line, 5.6 percent band 5.0 percent, respectively (p.5).

4.52. Environmental constraints

The majority of participants cited environmental constraints in their ecological spaces as contributing to their interpretations of the ability-disability construct when using ATs. A case in point is Jenna who cites inaccessible living spaces such as flats, malls and offices as not ‘assistive technology friendly’ leading to feelings of helplessness and inability, She points out about the flat she was living in with her mother before she got married:

But going home was another story because I lived in flat where there was stairs so my mom had to take me up and down the stairs all the time. Otherwise friends will do it and eventually when she got married, the husband at the time would do it. Mmm, but we

could not move out because we didn't have money at the time or a place with better equipment, ramps or anything like that. So there was a very big challenge and going out a car park was another story because we parked our cars on the verge across the road so we had to go off a curb across the road and then to the parking area.

The significance of 'assistive technology friendly environments' in shaping perceptions of ability among people with adult-onset locomotor disabilities is illustrated when Jenna gets married and her partner built her a house compatible with her disability as it has wheel chair ramps , a customised kitchen and bedroom. This allows her to claim back her ability as she can now do all things she could not do in her mother's flat such as baking and cooking for herself.

However, this contribution to her self-esteem and ability seem to be like a drop in the ocean as she soon realises that the world outside her home is still not adapted to cater for people with wheelchairs. She still gets a rude awakening every time she goes to the local mall or work where she once had to be excluded from a company party because the venue was not wheel chair friendly! She expresses her dismay at the realisation that she is safe as long as she is in her four walls:

Jenna : Well, obviously my home is now built for me, so that's okay ,but when I get to other places to buildings, things like that, they are not always properly equipped for a person in a wheelchair, there might be a disabled parking, but you get out of the car and you wanna get on a ramp to get into a building and the ramp is very steep, its small and steep or its long and steep, it's not on a proper incline ,with the proper length, that can gradually bring you up on to the surface where you wanna get to.

David, another participant who the researcher met on a public bus, uses a crutch and he expresses the numerous challenges he faces using the public transport system every day to work. Although David emphasis societal perceptions such as ignorance of commuters who refuse to give up a seat designated for the disabled for him as a major hurdle, he also emphasises the environmental hurdles such as buses with stairs which make it hard for him to get on the bus easily. He cites these physical hurdles:

No you see the double decker is nice but the single decker buses have got steps, and I don't sit upstairs because that's a lot of steps.

UmaSlovo who was using crutches at the time of being discharged from hospital also expresses his concern over the set-up of his home which was not wheelchair friendly as some areas were totally inaccessible to him as he points out:

Like the wheel chair when I wanted something on top of the room divider, yaa mangifuna izinto ziphezulu kumele ngicele usisi wami nomama wami bangisize, bangiphe lento leyo iphezulu. (When I want things on top (of the room divider) I have to ask my sister or mother so they help me and they give me that thing which is on top)

Such physical environmental constrains constructed perceptions of inability to most participants in the study as they are constantly reminding them of their disability as there is a limit of what they can and cannot do.

The role of environmental constraints in the curving out of ability and inability constructs of those using ATs highlighted in this study strongly correlates with findings by McCreadie and Tinker (1995) in which they designed a model for understanding the accessibility of ATs among older people in which housing type was seen as also a major factor in how older

people accept ATs.

4.53. Questions on ATs validity, reliability and safety

Another major finding from this research which closely parallel McCreadie and Tinker's (1995) model for understanding the accessibility of ATs among older people in The United Kingdom is the issue of quality of the ATs themselves which is closely tied with issues of accessibility and environmental issues. Validity of ATs refers to whether the right AT is designated to the right individual. All of the ten participants highlighted a boost in perceived ability and self-efficiency when they were recommended the right AT for their disability. This theme resonates strongly with that of lack of personal training and competent professionals who have the daunting task of making recommendations for outpatients with an onset disability.

A seminal pattern was woven in the research in which participants attributed their perceived ability or inability to whether they thought they were using the right AT or not for their specific onset disability following a doctor's recommendations. For example, Jenna appreciated her automated wheelchair as the health professional who recommended to it had gone a long way to ensure that it was not just any wheelchair, but one customised especially to cater for her disability, which is quadriplegia, her body and limb size and so on as Jenna states:

The doctors were discussing with us that there are certain types of wheelchairs, I must find something that is going to be comfortable with me ,they had to measure my body to see how long the seat needed to be from the foot plates because they don't want the knees to be elevated up past the hip area because it can cause pressure sores the hips degenerate so that when you wanna start to do physiotherapy with back slats the hips

will lock on the seated position, if you sit like that for long and the tendons will shorten and once they start to shorten it will be very impossible to straighten them again.

Because Jenna got ‘The’ wheelchair which was specific to her needs and not just any wheelchair, she developed a deep attachment to her ATs and this reinforced perceptions of ability as she felt there is nothing she could not do. This is highlighted by the emotional connection she attached to her wheelchair over the years that in Haraway’s sense “there ceases to be a boundary between man and machine” reinforcing ability as Jenna points out:

YES, it is helpful; I’m very dependent on it to the point that when I have to change from one wheel chair to the other it’s quite traumatic because I start to rely on every single little part of the wheel chair.

Unfortunately, Jenna is only one of a few of onset disabled individuals in this study and South Africa as a whole few could afford such professional and qualified informed recommendations on ATs. Most research subjects in this study recall having an AT such as a wheelchair imposed on them as part of the ‘medical procedure’ of being released as an outpatient as highlighted in the following interview accounts:

UmaThirteen: “It was in 2007, 19th of July and immediately after in Hospital they gave me two crutches (.) I didn’t like crutches so I changed to buy this leg”.

Maslovo:

They were telling me they can’t discharge me without the wheelchair” I was also using the walker when they discharged me. I wouldn’t say I was mad. I was using the walker because I had no choice.

Sheila:

But with the surgical corset only comes up to the middle of the back area, and controls

that discomfiture, but it doesn't control the lower back area. So it is limited as far as far as that is concerned and since i do not have severe upper back injuries I'm no longer using that, it's not serving any purpose.

Mrs Khumalo:

Without a wheelchair they wouldn't discharge me, but they said they would discharge me if only they see a wheelchair, so family they organised a wheelchair for me, then it was brought to the hospital and I was discharged, because they said they didn't want me to get more injured at home on my own, so when they saw the wheelchair they discharged me but still I was told not to get off from the wheelchair.

As highlighted clearly in the last account by Mrs Khumalo, Health practitioners, particularly in a South African context, are concerned with the delivery of services such as assistive technologies but very little attention is paid to ensure the quality and suitability of the ATs.

This affects the interpretation of ability-disability amongst adult-onset locomotor disabled individuals as they are not always comfortable with their ATs and therefore perceive it as alien and a violation to their freedom and not an extension of their being.

4.6 New trends in the perceptions of ATs

4.6.1. Personal motivations and preferences

New trends in how people using ATs perceive the ability-disability construct have emerged in this research which are more in alignment with the post-modernist disability paradigm which privileges each individual's unique lived experience, complete with the complexity and nuance of everyday life. Baltes and Carstensen (1996) in McCreadie and Tinker (1995)

juxtapose disability studies with aging and state “as recognised by the proponents of ‘successful ageing’ people have different ways of adjusting, and this affects their perceptions of the advantages and utility of ATs” (p.102).

Central to this theme of difference in lived experience was the issue of attitude and personal resilience in a discourse of traumatic disabling experiences. Since this study was on onset disabilities which were acquired through various traumatic experiences represented through automobile accidents for Maslovo, Mrs Khumalo and David, botched house robbery for Mr Nasira; the discourse of trauma insinuated to the way these individuals perceived their ATs later on in life. Traumatic discourse was highlighted through Jenna’s comments about the day she first saw the wheelchair after a botched operation:

At that time I thought I was going to recover and I wouldn’t need a wheelchair but they said NO you’ll have to think as if you going to be in a wheelchair even if you are not going to be. You are going to need one to get from place to place, if its temporary, it’s a necessity and I was like “alright fine.

Mrs Khumalo also expresses the effects of deep trauma which also shaped the way she interpreted her ability –disability construct through use of her wheelchair when she noted:

I started to think if now: Am I never going to walk? Am I going to be on wheelchair? And that time I was thinking that was forever! I never thought that it was a process to a complete healing; I didn’t know that I was going to heal, I was going to come out of this THING, and I thought it was permanent thing.

However within this discourse of trauma, some individuals still managed to reconstruct their ability in a positive way through personal resilience and maintaining a positive attitude towards their ATs and life in general. This ensured that they did not succumb to the traumatic

experiences of their disability. Such an individual was Charles who maintained a positive energy despite having a leg amputated:

Obviously you got to be thankful with what you got, fortunately at church they pray for you, which also helps. It could have been worse. They could have cut my leg all the way up to here [pointing to the upper part of the leg]. At least I've still got my knees and I can bend. [Chuckles] and it's also a very good weapon for kicking with.

Thus, individual differences of lived experiences which in turn shaped their perception of the ability-disability constructs resonated strongly in this research in support of a post-modernist perspective on disability and assistive technology study.

4.62. Fluidity in the use of ATs.

Research findings in this study also revealed a new trend of fluidity in the way individuals use their ATs. This differs from findings of the (DART) of McLaren, Philpott and Hlophe (1997) and Jakovljevic & Buckley (2011) in that these studies took dichotomous positionalities of 'either using or not using ATs' without actually considering that a single individual can use different ATs at different stages and times in their life time. Such fluidity reinforces Haraway's idea of the 'cyborg' which creates blurredness between technology and human bodies. In the study such fluidity is demonstrated through Jenna who uses a multitude of ATs just to get by a single day such as an automated wheel chair, a manual wheelchair she bathes with, monkey straps to help her in holstering up, and a customised kitchen and bedroom.

Mr Nasira also blurs the lines between technology and disabled bodies through demonstrating high fluidity in his use of ATs as he uses a high –tech prosthetic leg, an automated wheelchair and a fully converted car suitable for a person with paraplegia. This has the effect of

constructing ability as these individuals can actually do anything that is associated with able bodies.

However, this fluidity of ATs use can be criticised for being positioned in the dominant social and medical discourse in which disabled bodies are still construed as the anomaly and in which able bodied status can only be achieved through technological alterations.

Furthermore, the fluidity of ATs use is also not immune to class, race and gender divides demonstrated earlier to be problematic in the way certain individuals have access to ATs at the expense of others. This is highlighted in the research in the cases of people like Umathirteen, who by virtue of being an unemployed person living with disabilities has only access to a low-tech prosthetic limb and Thulani, also unemployed is only using a manual wheelchair as he cannot afford an automated one which he desperately needs due to his worsening sclerosis.

4.63. Improvisations and adaptability of ATs

A common theme which emerged from the narratives in the study was the issue of improvisations of assistive technologies as most of the participants negotiated and juggled with the shortcomings of lack of accessibility of ATs in a developing world context. It is the same adaptability that McDonald (2003) referred to as ‘humanising technology’ as he points out:

we are an inventive and adaptable biological species with deep socio-cultural and spiritual needs and desires that lives largely, in the developed world, in a ‘technosphere’, a synthesised artificial world of our own making”(p.183).

This adaptability and fluidity in intersections of disability and technology resonates strongly with a post-modernist sense of disability which views disability as ever shifting and contextual.

For example, Jenna uses some home-made straps for helping her with holstering up and lying in bed and she refers to these as monkey chains originally designed for hospitalised patients. She also had to have personally customised kitchen with specially designed cupboards for someone with quadriplegia as she proudly highlights:

For example, in a cupboard, when you have a corner cupboard even an able-bodied person doesn't like to put things in the same corner because it's a shift to have to have to pull out things all the way out, so I've got something which takes away the effort that after you have opened the door to the cupboard there is a tray that's fits all the way down to the cupboard and the stuff will be sitting on the trays, and you can push it out and close the door. And I've got another one which the doors which pulls out all the way from the cupboard, they are like a vegetable rack, so it makes life easier as well.

This meant that Jenna could now be able to reclaim her ability through making drastic changes in her life in terms of the ATs she was using. Most of the improvisations were not professional recommendations but were based purely on her own perceived need and realising that the ATs she had been referred to were very limited in helping her in restoring this ability construct.

The theme of improvisations of ATs is also deeply rooted in a socio-cultural discourse in which participants shuns clearly visible and 'disabling' ATs to less visible and socially acceptable ones. For example, UmaThirteen had to ditch the crutches he was using because society members targeted him and labelled him as unable shown through the way he was immediately dismissed from work. Only through prescribing a prosthetic limb for himself is UmaThirteen able to regain his ability as his disability becomes 'invisible'.

Sheila also improvise her ATs when she wears her braces for sclerosis on top of clothes

rather than the usual underneath as the braces were uncomfortable on her raw skin. This situates disability in a social discourse in the sense that immediately when she starts to wear the braces on top of her clothes rendering her impairment visible to community, she starts to feel helpless and unable as community ignorance and stereotypes starts to frustrate her, reminding her of her disability as she point out:

So I wore it on top of my clothing so if you walking down the road and people see you with it, it looks like and you know that old fashioned corsets that women used to wear? and they think I'm wearing it to lose weight [laughing].I have to explain to them, see these little things at the back those things actually hold my spine up so that it doesn't bend, and it did help me in my posture in that it supported so that I don't slump all the time in the upper body and yaah I've had to wear this THING, so that certainly made an impact on people on the way they perceived.

Thus, participants in the research were trying to reconstruct their lived stories through the improvisation of ATs. The success of this improvisation determined whether participants were able to claim ability or disability constructs. However the problem with improvisation was that it aimed at achieving ability which was still heavily dependent on a medical and social discourse which still perpetuates discrimination of people using ATs.

CHAPTER FIVE

CONCLUSION AND RECOMMENDATIONS

5.0. Introduction

This section provides a conclusion for the research titled; how do assistive technologies affect the interpretations of the ability-disability construct of people with adult-onset locomotor disabilities?

5.1 Conclusion

Through in-depth interviews on ten adult-onset locomotor disabled individuals in the city of Johannesburg in South Africa on how they perceived their assistive technologies, four central themes emerged. These themes were centred on how people perceived their ability-disability; the social acceptability of ATs, accessibility factors and new trends in assistive technologies.

Through thematic analysis, the researcher managed to unravel findings which concur with Fay (1996) narrative constructivism in that the participants' narratives were constantly constructing and reconstructing the way they perceived themselves as able or disabled. Thus contrary to most research studies which had concentrated a lot on dichotomous representations of ability-disability, this research highlighted that disability narratives on the perception of ATs are in fact fluid, complex and multi-layered. Thus it challenges policy makers in the field of Disabilities and ATs to avoid generalisations and instead take note of individual lived experiences.

The research findings also highlighted that most adult-onset disabled individuals in a developing world context, tended to embrace the promises of technology centred around positive attributes such as improved communication with others, increased mobility, physical safety, personal autonomy, control over one's body and life, independence, competence,

confidence, the ability to engage in the workforce and participation in the wider community. Such positive attributes seemed to reinforce perceived ability as the boundaries between disabled bodies and technology was blurred.

However, this perceived ability was found to be rather misleading since it was premised in the same medical and social discourse that 'disabled' individuals. This discriminatory discourse thrived on social stigma which is illuminated in the study through societal perceptions of ATs which tended to be disabling, particularly in the work context and public places such as malls and buses. This societal rejection was mirrored in the resentment of people with onset disabilities of their ATs, particularly those which render their disability highly discernable to society such as wheel chairs. However, in cases where society was supportive and embraced individuals with open arms, ability constructs emerged as participants were able to accept their ATs.

The study also revealed how interactions of technology and disability are positioned in a gendered discourse. Participants in this study perceived inability the most when they juxtapose their femininity or masculinity against hegemonic representations. However, in some instances, these hegemonic representations are challenged by the participants and it is then that ability constructions are reconstructed. Thus, it was clear that it is indeed societal representations that influence disabled perceptions on their ATs and disability in general.

The research also depicted that participants tended to construct their ability-inability as disabled individuals around a central theme of accessibility of ATs which still remain an issue in a developing country's context. Most participants had accessibility problems with ATs particularly in the form of environmental constraints such as ATs-unfriendly

accommodations, public spaces such as malls, buses and inaccessible working spaces. Inaccessibility was also represented by the technological gap between race, class and social cultural groups in which the low class and common participants only had access to poor quality-low tech assistive devices whilst on the other hand the rich and upper class individuals had access to high tech ATs.

The research also managed to reveal new trends in the usage of ATs amongst adult onset disabled individuals such as the fluidity in which younger participants used ATs as they tended to use multiple ATs to reshape their ability. Central to this was the issue of the use of diverging technologies such as computers, laptops, smart phones and social media in redefining the ability of individuals with locomotor impairments as it allowed them to communicate more easily with family and friends in ways that previously was impossible for disabled individuals.

Since this qualitative research was bound by time constraints, it is important that more emancipatory research on ATs and disabilities should be done in developing countries where issues such as accessibility and technological divides based on class, race and other social cultural factors are common. Such research should place the disabled individuals in the helm of their own lives by emphasising the importance of their lived experiences and narratives. It should also encompass different disabilities and not locomotor disabilities only.

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Appendix A: Interview Schedule



DST-NRF South African National Research Chair in Critical Diversity Studies

Wits Centre for Diversity Studies



RESEARCH INSTRUMENT: SEMI-STRUCTURED INTERVIEW SCHEDULE

Institution: University of Witwatersrand

Department: Humanities

Academic qualification: MA Diversity studies

Opening

A. (**Establish Rapport**) [shake hands].) My name is Precious Muzite and I am currently completing my Masters in Diversity Studies at the University of the Witwatersrand, Johannesburg.

.(**Purpose** My current research is entitled: “How using assistive technologies affects the interpretations of the ability-disability construct of people with locomotor onset disabilities”

C. (**Motivation**) I hope to use this information to help

1. Understand through your point of view, how the use of your device (wheel chair, cane, prosthesis), is accepted and interpreted by family, friends and others.
2. Understand how the way family, friends and others view your device (wheel chair, cane, prosthesis etc. affect the way you feel about your disability.

The interview should take about an hour and there is strict adherence of rights according to the University of Witwatersrand ethics research protocol (anonymity, right of withdrawal, sharing of interview data etc.). Your participation in this research is voluntary and it is entirely dependent on your consent for the audio recording session which will form a greater part of the data analysis of the project.

The interviewer will also make references to a competent counselling service in cases of emotional disturbances resulting from the interview.

Have you understood everything? Do you have any questions you might want to ask?

Question list

1. Do you mind telling me a bit about your yourself (your name ,where you were born, raised, your age, where you work, live and so forth. [part of background research should focus on interviewees' age, socio-economic background and "race" as these are independent variables that may affect the findings]
2. Do you mind telling me a bit about your disability? (What it is? how it happened?)
[How do you feel your disability has affected your relationships with the people around you (family, friends and colleagues)?
3. When did you start using your wheelchair/crutches/prosthesis? [whatever it is that the respondent is using]
4. What made you decide to use a wheelchair/crutches/prosthesis? (Advice from doctor, family, own desire)? Did you feel you had any choice?
5. How has your wheelchair/crutches/prosthesis been helpful?

6. Are there ways in which your wheelchair/crutches/prosthesis has/ have been difficult to use or not helpful?
7. How do people react to your wheelchair/crutches/prosthesis both at home and in public (taking public transport, at restaurants, at social events)?
8. How do these people's reactions make you feel?
9. Do you feel your understanding of how society thinks about disability has changed as a result of your
 - becoming disabled
 - Using AT?
10. Overall, how do you feel about your wheelchair/crutches/prosthesis?

Note: The interview ends by asking (a) if there is any important point the interviewee would like to highlight and which the researcher didn't ask during the interview and (b) if they have any questions with regards to the talk I have just had or the research project more broadly.

Appendix B: Informed Consent form



DST-NRF South African National Research Chair in Critical Diversity Studies

Wits Centre for Diversity Studies

University of the Witwatersrand, Johannesburg



Interview Agreement

I, _____ (name), agree that I am participating willingly and voluntarily in an audio-recorded interview on this day _____ (date) at _____ (place).

I understand that these interviews form part of a research project on “: How using assistive technologies affect the interpretations of the ability-disability construct of people with locomotor onset disabilities. The project is carried out on behalf of the DST-NRF South African Research Chair in Critical Diversity Studies at the University of the Witwatersrand, Johannesburg.

I understand the rationale and nature of the research and I understand the costs and benefits of my participation for myself.

I understand that the interviewer will make references to a competent counseling service in cases of emotional disturbances resulting from the interview and I understand that I will participate in an approximately 1 hour interview.

I understand that the Research Chair may use the information from these interviews.

I understand that I will be given a pseudonym and that my identity will remain anonymous.

I understand that the interview will be recorded so that the researcher may more accurately reflect my views in the report and participation in this research is solely based on consent to have the interview audio recorded as this will contribute immensely to the data analysis part.

I understand that my interview transcripts will be not be shared with other participants.

Should I wish, the researcher will share the findings with me. I understand that I need to give my phone numbers which are as follows----- so that he can contact me when the findings are available. I also understand that the findings will not be available immediately.

I understand that I may discontinue my participation at any stage of the research.

I understand and agree to the above terms and conditions.

Signature (Participant)

Date:

Signature (Researcher)

Date:
