“Half a man?” Still a human: Narratives on the impact of a spinal cord injury on coloured men living with paraplegia

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When my uncle turned me around, I stared in his face and I said, “Uncle Pedro, please don’t tell me that I am paralysed. Please don’t!” At the hospital, I looked at my mother and I said to her, “Mummy, I already know what is wrong with me. Mummy, I just need one thing, if you can tell me that you are okay, then I will be okay.”
- Allen Josephs (2017, 4 July).

I was thinking that I am not a person again. I am not normal. I am paralyzed.
- Norman Isaacs (2017, 23 June).

Hulle sê dat dit deur my maniere is dat ek ’n halwe man is. Hulle sal sê, “Kyk, daar kom daai halwe man!” (Afrikaans original)

They say it is through my manner that I am half a man. They will say, “Look, here comes the half-man!”
- Oppies van Wyk (2017, 2 August).

What needs to be noted is that the wheelchair does not change who we are in terms of our character, but it highlights our flaws.
- Ridah Classen (2017, 12 July).

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ABSTRACT

There is an overwhelming body of research in the Global North that focuses on the narratives of the impact of a spinal cord injury on men living with paraplegia, while existing research in South Africa and the Global South lacks knowledge on these narratives. This study explored the narratives on the impact of a spinal cord injury on fifteen coloured men living with paraplegia on the Cape Flats. This study adopted a life story approach, as a primary research methodology, and examined how these men constructed and told their life stories, how meanings and experiences of living with paraplegia were conveyed, and how they negotiated the intersection of disability, masculinity, race, class and sexuality in their lives. A participatory action research (PAR) methodology, photo-voice, was used as a complimentary methodology which depicted how these men visually represented the way they think main-stream society sees them and the way they see themselves. Drawing on Frank's (1995) work on narratives and illness, this study used two life stories and theoretically shows how life stories with a central focus on paraplegia as a spinal cord injury are constructed and narrated. Through a narrative thematic analysis, themes and sub-themes highlighted the complexities and tensions in the construction and performance of masculinities after the injury. The following themes emerged from the narratives: feelings of shame and infantilization, a loss of independency, dehumanizing social perceptions of being a man living with a disability, vulnerability to violence, and challenges in sexual intercourse and intimacy. The narratives also show that a man in this context can develop a positive sense of self through learning to live independently, strategies to prevent violence, redefining sex, and redefining what it means to be a man and 'disabled'.

ACKNOWLEDGEMENTS

Producing this body of work has been an enormous and humbling privilege that came with many challenges. The challenge of constantly questioning, *“What does it mean for me, a young, able-bodied, coloured male researcher to be doing this work?”* And, *“Can I take on the responsibility of showing empathy and care through attentively listening to sensitive narratives that must be truthfully retold?*” The challenge of waking up at 05:00am during winter, travelling for about two hours to and from the homes of the men I spoke to, in the dark, cold, and sometimes rainy weather of Cape Town. Many times, I anxiously sat in the train, saying silent prayers as I was concerned about my safety on the train and in the community that I, an outsider, entered. I had sleepless nights of reflecting on the painful and resilient stories told. I had to face the unpredictable times of dealing with my emotional response to these stories. I had to learn to be patient with myself in learning what I did not know and unlearning what I thought I knew. It is through overcoming these challenges that this work has been an enriching journey. I could never have produced something as meaningful, important, thought-provoking, and valuable without the following individuals:

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I want to thank Bridging Abilities for their support in recruiting members whom I could speak to. I also want to thank the various friends who introduced me to people who were willing to share their stories. The number of men who availed themselves for interviews exceeded the limit for this study.

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Lastly, I want to thank God for *always* asserting that I can do all things through Him who strengthens me.

DEDICATION

I dedicate this body of work to those who never imagined that their bodies matter. To those who have been marginalized, oppressed, misunderstood, perceived as 'not human enough' and 'half a man'. To those who have been subjected to silence by the loud, painful, and flawed perceptions of disability from the ablest society.

This is for you – because, this is you.

PREFACE

Over the past two years (2016 – 2018), I worked as a research intern at a company called Paragon - situated on a mining site in the Gauteng Province. The company manufactures underground mining support products and personal protective equipment such as knee guards, arm guards, belts, and safety nets. On the first day of work, the manager took me on an orientation tour of the various workshops where the mining safety equipment is manufactured. I was introduced to several employees and to each department's working responsibilities.

I was intrigued by the distinct racial, class, and socio-economic status divide within the company. The employees working in the offices were mostly white, Afrikaans speaking, and had a degree or diploma from a University or College. The employees working in the workshops were all black, underprivileged, with no formal education, and mostly IsiZulu and Sesotho speaking males and females. Many of them stared at me as I politely greeted. I could feel a strong and uncomfortable disconnect between the employees and myself.

My privilege, which had always been invisible to me, became visible the moment I entered their space. It was evident in the way I portrayed myself – wearing a black suit (which I assumed was the appropriate attire to give a good first impression), the way I eloquently conversed in English (which is not even my mother tongue), and the enthusiastic way the manager introduced me as a Masters' student from the University of Cape Town. The above privileges allowed me to walk and talk confidently with the manager about the 'work' that I could choose to do in the company. The awareness that I was privileged made me feel uncomfortable; I was forced to confront feelings of superiority towards the workers. This awareness of my relative privilege contributed to the divide that was so apparent in my encounter with the workers who did the hard labour in the workshops but looked like me. I could see the generative trajectory of hard labour that my mother, grandmother, and great grandmother had to endure for me to be in the position of privilege that I currently find myself in.

I tried to supress the feeling of discomfort that I was experiencing and not to interrogate it at the time. As we entered the last workshop, I was surprised at what I saw. The workshop was filled with about 30 black men sitting in wheelchairs, stitching knee guards and arm guards. The manager explained that these men were mine workers who migrated from different parts of South Africa and the African continent, to work underground on the gold mines in the

Gauteng Province. The men in this workshop all had a spinal cord injury because of different rock falling accidents underground, and as a result they have been living with a condition known as paraplegia since the onset of their accidents. Paraplegia is a spinal cord injury that results in the paralysis of the body from the hips downwards (Cole, 2004). The owners of the Paragon Company created a different kind of work[1] for these men.

I was perplexed to see so many men sitting in wheelchairs, half paralysed, under one roof. I had never seen anything like this before. I was in awe knowing that these were all mine workers, who travelled from afar to dig for gold and who put their lives in danger to provide for their families. Yet, despite their condition, they were still committed to their responsibility as providers. They sat in their wheelchairs and did what is often viewed as ‘feminine’ work in the gender division of labour (Connell, 2014). They sat around a rectangular table, talking, sometimes singing and laughing out loud. They gossiped amongst themselves - while folding and unfolding material. They cut, stitched, sewed, and patched fabric on the knee and arm guards. This is the work in the company that is reserved for bodies classified as ‘differently abled’[2].

I went home with many unsettling thoughts. I realised how I often take for granted the fact that my body allows me to do the things that I want to do: walk, jog, sit, stretch and move around. After a spinal cord injury like paraplegia, the body does not function in those ways. There is often no sensation and movement from the waist, downwards. This part of the body is usually considered to be partly absent and lifeless (Cole, 2004). Yet, that part of the body must be looked after.

I wanted to know these men and I desperately wanted to listen to their life stories. The next day the manager asked me what department interests me most. Without hesitation, I responded by telling him that I am mostly interested in working on the site and in the workshop with the men sitting in wheelchairs doing stitch work. He looked surprised and asked me, *“Why do you want to work with them? They are such miserable and unhappy people.”* I responded, *“Because they are miserable and unhappy.”*

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[1] For a detailed overview of labour for previous mine workers who acquired a spinal cord injury through underground rock falling accidents and are currently deployed by Paragon factory, see the companies heritage page: https://www.stitchwise.co.za/index.php/about-us/heritage [2018, August 04]

[2] Paragon factory owners describe “disabled mine workers” as “differently abled employees” see: https://www.stitchwise.co.za/index.php/about-us/heritage [2018, August 04]

The company tasked me with observing employee behaviour in the workshop and writing a report on the intersections of gender, disability, and labour. I wanted to speak to the men in wheelchairs to get a nuanced understanding of what it means for them to do the work that they are doing. Upon approaching them, I found that all of them speak *'fanakalo'*[3]. For safety and communication barriers, mine workers are obligated to learn *fanakalo* before they go underground. Because I do not speak *fanakalo* and neither do I speak an African language, I could not have the kind of conversations that I desired to have with them. I realised how powerful, important, and limiting verbal communication can be. Because of my lack of knowledge about *fanakalo* and my inability to speak an African language, I could only observe and begin to imagine what it must be like sitting in a wheelchair, paralysed, away from home and doing the same kind of work every day.

I wrote and submitted an observational report to Paragon at the end of the internship. My inability to write their stories motivated me to do a master's degree in Gender Studies at the University of Cape Town, on the impact of a spinal cord injury on coloured[4] men with paraplegia. I contacted a non-profit organization called, Bridging Abilities[5], which has different centres around the Western Cape that offer support groups and physical activities to people living with a disability. Bridging Abilities introduced me to coloured predominantly Afrikaans speaking men with paraplegia who attend the centre in Macassar on the Cape Flats[6]. Bridging Abilities generously provided me with a space to converse with these men.

The fact that I am also Afrikaans speaking meant that we could have conversations in a language that they were comfortable with. This made it easy for them to share lived experiences. In addition, our shared race, ethnicity, gender and culture, as well as my familiarity with constructions of masculinities on the Cape Flats meant that I could listen in a

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[3] According to Hurst (2018), fanakalo is a pidgin of South African languages that is predominantly constructed from IsiZulu, mixed with some English and Afrikaans. Fanakalo is taught and spoken in mines to encourage a cohesive communication flow among all mine workers, particularly those who do not necessarily have a language in common.

[4] The term coloured is a racial identity in South Africa that was imposed by the apartheid racial classification system. This system discriminated, categorized and dispriviledged people according to their race. The coloured racial identity refers to people of mixed racial origins. Adhikari (2005), posits that coloured people were not White enough to be classified as White South African's and neither were they Black enough to be classified as Blacks. Even during post-apartheid South Africa, this 'in-between' racial identity continues to have a deep historical, social, economic, and political meaning that impacts those who self-identity as coloured. Within the context of democracy though, the term 'black' includes blacks, African coloured, and Indian. For the purpose of this research, I will use the terms black and coloured to distinguish between black Africans and coloureds.

[5] For more information about Bridging Abilities see: http://bridgingabilities.co.za/ [2018, August 04]

[6] During apartheid, coloured people were forcibly removed from areas in Cape Town by the Group Areas Act. This act restricted coloured people to townships on the Cape Flats. The population in these townships predominantly consists of coloured people and the dominant language is Afrikaans.

way that enabled me to understand how these stories are constructed and to latch onto the meanings and experiences that they conveyed. Furthermore, I could express and candidly articulate every detail of their life trajectories, and in doing so, our communalities became a tool of empowerment for these men.

I remember the day I first encountered these men. I was fascinated by their resilience that was strongly portrayed in the way that they merely carried on with their lives and endured their condition. This resonated with my observations of the mine workers. I spent time watching them do physical activities. Afterwards, I would speak to some of them about random things, like the weather, life at university, their backgrounds and life in general. Through these informal discussions, I realised the magnitude of their stories and how silent their narratives of living with paraplegia had been for so many years. I was grateful for the positive responses from the men who were willing to generously share their stories.

During the long and often tedious search for relevant literature around masculinity and disability, I came across a book called, *'Still Lives: Narratives of Spinal Cord Injury'*, by Jonathan Cole (2004) – a consultant in clinical neurophysiology, professor, and author. The book explores the narratives of twelve, white, and upper-middle class individuals' experiences of living with a spinal cord injury. Cole (2004) explores what it is like to live in a wheelchair, without sensation and movement in the body. I was particularly intrigued by the candid, powerful, and comprehensive narratives that Cole (2004) presented in *'Still Lives'*. This exposed me to different ways of thinking, of phrasing questions, and it introduced me to new ideas that I could explore further.

As much as different ways of thinking will always be the first commendations that come to mind when I think of *'Still Lives'*, Cole (2004) only focused on the narratives of white, privileged, upper-middle class individuals who could all afford an automatic wheelchair and access private health care. Based on my interactions with the men from Bridging Abilities, I observed that Cole's (2004) book spoke about experiences and ways of living with a spinal cord injury that were significantly different to those of the working and lower - middle class, marginalized, coloured men living with paraplegia in Macassar. For example, the white men from *'Still Lives'* (2004) all had knowledge about spinal cord injuries prior to their accidents. They had sufficient resources to educate and care for themselves and their condition, and they lived in suburban areas where safety and mobility is not necessarily a concern. The influence that race, class, culture, and social location had on the content of the narratives became more evident each time I read the book. I often felt like I was not reading a narrative in a language that adequately represented or related to the experiences of the group of coloured men that formed part of my research.

The stories told in *'Still Lives'* (2004) are not invalid, neither are they untrue and insignificant. They are important and do relay experiences of lives impacted by spinal cord injuries. They convey the popular, public face of spinal cord injuries representing the master narrative (Nelson & Lindemann, 2001), one based on Western, middle to upper middle class, English perspectives. However, the stories that I present are largely, untold narratives. Albeit some content in understanding a spinal cord injury may always have existed, the language used to convey lived experiences that informs the public's understanding on what it means to live with a spinal cord injury is unique, especially in a South African context.

I wanted to speak to men with a spinal cord injury - specifically those living with paraplegia - not as an employee wearing a black suit, and not as a master's researcher from the University of Cape Town, but as a caring human being who is truly interested in listening attentively and trying to understand what it means to live with paraplegia. I wanted to enter their space - wherever it may be - to listen to their life stories; stories expressed in their own time and in their own words, to me, a stranger to their world. I felt that by exploring the life stories of these men in some depth, I would begin to contribute towards creating a more nuanced understanding of what it means to live with paraplegia in a marginalized, predominantly working and lower middle class, coloured community.

I began by writing of "men living with paraplegia" and never about "paraplegics", "disabled" or "the disabled". This was a conscious effort on my part to take seriously Brisenden's (1986, pg.175) comment that, "the effect of this is a depersonalization, a sweeping dismissal of our identity, and a denial of our right to be seen as people with our own uniqueness." Therefore, I recognize that the men I spoke to, was a person first and foremost.

CHAPTER 1

INTRODUCTION

1.1 Introduction to Masculinity and Disability

There are multiple masculinities that exist within a geographical location or social context. These masculinities comprise as dominant or hegemonic masculinities, alternative and subordinate masculinities (Ratele, 2008). Hegemonic masculinity is defined as the most dominant form of masculinity that is prevalent in a social context or location (Morrell, 1998). It presents itself through notions on what 'real men' look like, what 'real men' do, and ultimately, what is expected of them as men (Morrell, 1998; Shefer, Bowman, & Duncan, 2008).

According to Ratele (2008), heterosexual patriarchal capitalist masculinity is the hegemonic form of masculinity in South Africa. This means that hegemonic masculinities among homosexual men, for example, are often perceived as subordinate to constructions of masculinities among heterosexual men (Morrell, 1998; Gqola, 2007; Ratele, 2008). Another example of the way in which hegemonic masculinities presents itself is in the context of coloured men living on the Cape flats. Apartheid had an impact on the racial, political and economic marginalization of coloured heterosexual men on the Cape Flats which has contributed to the construction of violent masculinity (Salo, 2003; Moolman, 2004).

I became aware of the normalisation of violence on the Cape Flats through my previous research study (Louw, 2015) conducted with coloured fathers on their experiences of fatherhood. While one participant and I were seated in his living room, and before the interview commenced, we heard three-gun shots from outside the house. It sounded like it was inside the house. I was stunned as I realised that I was the only person who was afraid and in absolute shock. The residents of the house all ran to the window to see who was shot. Thereafter, life just carried on while someone had died through gang violence outside their yard.

Suburbs on the Cape Flats are characterized by poverty, unemployment, high alcohol and drug rates, high crime rates, exclusion from dominant society, and gang violence. This is evident in the work of Boonzaier (2005, 2008) who shows the prevalence of domestic and intimate violence against women in heterosexual relationships on the Cape Flats, as well as the work of Moolman (2004) who posits that the reproduction of what it means to be a man on the Cape

Flats is performed through gang rape. Other theorists who focus on research in marginalized communities have shown that gangsterism represents what it means to be a “real man” on the Cape Flats (Salo, 2005; MacMaster, 2007; Cooper, 2009; Anderson; 2010).

Subsequently, all these forms of violence portray hegemonic masculinity in ways that symbolises and values brutality, physical strength, power, control, bravery, and dominance (Moolman, 2004; Boonzaier, 2008; Ratele, 2008). Through this representation and depiction of hegemonic masculinity, other kinds of masculinities, particularly disabled masculinities, are often silenced and become subordinate.

For example, men living with a spinal cord injury, such as paraplegia, represent a threat to prevailing notions of coloured hegemonic masculinity on the Cape Flats in a variety of ways (Ostrander, 2008). One example is that coloured hegemonic masculinity engages in violence in the form of knives, guns, fists and rage, which is an affirmation of manhood, and important in challenging offensive and oppressive disputes, as well as taking revenge (Morrell, 1998; Shefer, Bowman, & Duncan, 2008; Ostrander, 2008). Subsequently, men with paraplegia are confronted with the incapacity and inability to physically stand up from their wheelchairs and challenge this kind of violence through physically fighting to protect themselves (Ostrander, 2008; Shuttleworth, Wedgwood, & Wilson, 2012). Theorists have argued that the loss of sensation and movement in the legs of men with paraplegia, often makes them feel powerless, helpless, and a burden, since they have to depend on others to protect them from the predominantly violent hegemonic masculinity in their community (Shakespeare, 1999; Ostrander, 2008; Shuttleworth, Wedgwood, & Wilson, 2012).

Moreover, the above example shows a distinction in the performance and embodiment of masculinity among able-bodied men and men with paraplegia. This contributes to a social and cultural representation of men with paraplegia as “less than”, because showing physical strength through violence, as in the case of coloured men, is such a prominent normative expectation of hegemonic masculinity (Morrell, 1998; Ouzgane & Morrell, 2005; Shefer, Bowman, & Duncan, 2008; Ratele, 2008). Through this mechanism, men with paraplegia are often undermined by hegemonic masculinity. This dominant form of masculinity silences other masculinities through power and privilege (Morrell, 1998; Ratele, 2008) as the existence of men with paraplegia as whole human beings is rarely acknowledged.

The prevailing discourse on disability and masculinity signifies a one-dimensional understanding of the lived experiences of men with physical disabilities. The discourse on disability is mainly informed through social and cultural representations of disability as a tragedy (Arneil, 2009) and vulnerable (Gill, 2006; Ellis, 2008). The language used to generally represent disability is demeaning (Shakespeare, 1994), limiting, and deprecating (Arneil, 2009). Examples of such pejorative language are found in terms such as: ‘pitiable’, ‘cripple’, ‘broken’, ‘burden’, or ‘sinister’ (Briant, Watson, & Philo, 2011). These views on disability create potentially anecdotal social stereotypes (Ellis, 2008; Schwartz et al., 2010). This can be discriminating, devaluing, patronising and dehumanising (Shakespeare, 1994). The ways in which people with disabilities are depicted in the media, film, television, and socially and culturally, creates a single story (Adichie, 2009) – as their representation and exploration of human experience is ‘incomplete’. Their experiences are often silenced by the notion that they cannot speak for themselves (Shakespeare, 1999; Hanass-Hancock, 2009).

It is undeniable that the media, film, television, and various socio-cultural contexts, have constructed idealised forms of hegemonic masculinities. These forms have an integral role to play in the way we think and see the world, ourselves and others. Theorists have stated that these sources form the foundation of our understandings, attitudes and assumptions about people with disabilities (Shakespeare, 1999; Briant, Watson, & Philo, 2011 & 2013; Happer & Philo, 2013). The research presented here resists this singular understanding of disability and masculinity by contributing to work aimed at dismantling these problematic understandings and representations of disability and masculinity. To achieve this goal, a concerted effort is made in this thesis to explore and investigate in some depth, the individual life stories of coloured men living with paraplegia, and the impact which this injury has had on them and their sense of manhood.

This research therefore exposes prevailing social representations of disability and self-representativity. This is achieved through creating photo-stories on the ways in which men with paraplegia think people see them, and the ways in which men with paraplegia ultimately see themselves. The combination of the methodological approaches of life stories and photo-voice employed here, therefore contributes to the development of meaningful and rich knowledge on the social and self-construction of disability, race, and masculinity (Rice, Chandler, Harrison, Liddiard, & Ferrari, 2015; Shamrock, Smith, Gray, Cameron, & Oprescu, 2016).

Scholars who have conducted similar research on the lived experiences of people with physical disabilities have argued that existing research is primarily focused on exploring the experiences of white, western, middle-class and physically disabled people from Northern/Western countries (Meekosha, 2011; Rice et al., 2015; Shamrock et al., 2016), while very little research is focused on the life narratives on the experiences of people living with a physical disability in countries in the Global South. These scholars argue that this North/West focus creates a one-dimensional story as it only reveals the experiences of a dominant racial group, in most cases only a gender category, from a specific geographical location. Meekosha (2011, pg. 667) puts forward an important and relevant question to this work, namely: "Do disabled people in the 'Southern' countries share the same experiences, issues and ideas?"

In summary, existing research on disability and masculinity lacks knowledge on the impact of paraplegia on coloured men living with paraplegia in South Africa, with a working and lower middle-class socio-economic status, who have previously been marginalized by mainstream society. This research centres on the life stories of coloured men with paraplegia and it exposes the complexities embedded in studying the intersections of identities. It also broadens our understanding of what happens when aspects of identity such as race, disability, masculinity, sexuality, culture and class interweave and collide.

1.2 Research Purpose, Aim, and Objectives

The purpose of this research is to explore the life stories of coloured men living with paraplegia. These men all attend Bridging Abilities Organization in Macassar on the Cape Flats in the Western Cape. The aim is to investigate what it means to be a coloured man on the Cape Flats living with a spinal cord injury such as paraplegia. The objectives of this research are: (1) to examine how these men construct their life stories in relation to paraplegia, and (2) to investigate how meanings and experiences of living with paraplegia are conveyed in their life stories, and lastly, (3) to use photo-stories as a tool to explore the ways in which they think that they are socially represented by others and to compare this with the ways in which they represent themselves.

1.3 Research Questions

1.3.1 Main Research Question:

- How do coloured men living with a spinal cord injury narrate the impact that paraplegia has on their lives?

1.3.2 Sub-Questions:

- How do coloured men with paraplegia negotiate the intersection of disability, masculinity, race and sexuality in their lives?
- How do these men visually represent the way they think main-stream society sees them and the way they see themselves?

1.4 Research Rationale

Through conducting extensive research on disability and masculinity, I found that there is a significant gap in existing literature and research on the narratives of people with spinal cord injuries within the African continent and in South Africa specifically. Research in disability studies within South Africa and the African continent mainly focuses on areas like poverty and disability, HIV/AIDS and disability (see Wazakili, Mpofu, & Devlieger, 2006; Rohleder, Swartz, Schneider, Groce, & Eide, 2010), intellectual disability (see Kromberg, Zwane, Manga, Venter, Rosen, & Christianson, 2008; Njenga, 2009; Adnams, 2010; Mckenzie, McConkey, & Adnams, 2013), disability and poverty (see Loeb, Eide, Jelsma, Ka Toni, Maart, 2008), as well as sexuality and disability (see Wazakili, Mpofu, & Devlieger, 2006; Peta, Mckenzie, Kathard & Africa, 2017). There is minimal research within the African context that focuses on the narratives of people living with a spinal cord injury such as paraplegia. Motives to produce this work is to contribute to the body of knowledge on the intersections of masculinity, disability, race and sexuality in South Africa and the Global South.

In contrast, there is an overwhelming amount of research in the Northern and Western countries that focuses on the ways in which physical disability impacts the lives of those living with physical disabilities. Some of this research also focuses on the ways in which disability is constructed and perceived by mainstream society. It then became apparent that there are flawed, and skewed perceptions of disability as seen from social and cultural representations of disability often portrayed through television, film, the media, and culture.

Subsequently, my interest in social change through research is always to challenge flawed perceptions and social representations. This mean, challenging, dismantling, and eradicating dominant social perceptions of masculinity and disability to change the ways in which masculinity and disability is socially represented and defined in the community and broader society. This is the transformative work that I have committed to ‘doing’.

Finally, as mentioned in the preface, this work was inspired by the book, *'Still Lives'*, by Jonathan Cole (2004). I was interested in taking further Cole's (2004) ideas about white, upper middle-class people with spinal cord injuries and applying these ideas to explore the experiences of paraplegia amongst a racially and socio-economically marginalized group of men in South Africa. Therefore, this body of work hopes to contribute to the production of decolonial knowledge.

1.5 Outline of Chapters

I present the outline of the chapters within this thesis in the tables below, followed by a detailed description of the content within each chapter.

Chapter One	Introduction
Chapter Two	Literature Review
Chapter Three	Methodology

Table 1.5.1 Outline of chapters one to three

An overview and in-depth review of literature relevant to this study is presented and discussed in chapter two. This chapter presents a nuanced understanding of a spinal cord injury. Subsequently, I focus on a specific level of spinal cord injury, paraplegia, where an in-depth discussion on paraplegia follows. The chapter then reviews previous literature on disability and masculinity. The chapter draws on a significant amount of research from the Northern/Western countries on the experiences of men living with spinal cord injury because of the lack of South African and African research on the topic. However, the chapter also draws on prior research conducted in the Global South on the experiences of those living with physical disabilities that is relevant to this study.

Chapter three introduces the relevant demographical information of the men who participated in this study. This chapter focuses on the methodological framework, approaches, and procedures that were used to execute the study. Subsequently, the analytic methods used in this study is presented and discussed. The analysis of the material is presented across three chapters.

Chapter Four	Case Studies: Life story of Kenneth du Plessie and Carlo Klink
Chapter Five	Challenges to becoming a ‘disabled’ man and redefining masculinity
Chapter Six	Photo-stories on social-representation and self-representation of disability

Table 1.5.2 Outline of chapters four, five and six

Chapters four is the first chapter of analysis and contains two case studies. The first case study is an analysis of the life story of Kenneth du Plessie. The second case study is an analysis of the life story of Carlo Klink.

Chapter five presents a variety of sub-themes that emerged from the narratives across all the men in the study. The first section of the chapter focuses on the intersection of race, disability, masculinity and sexuality. It explores the ways in which disability challenges masculinity by showing the tensions in embodying, constructing, and performing masculinity. The second section of the chapter also focuses on what it means to be a ‘disabled’ man and hopes to introduce new ways of thinking about disability and masculinity.

Chapter six contains an analysis of the photo-stories created by the men in the study. The first section of this chapter focuses on the photo-stories that explored social representations of disability. The second section of this chapter focuses on the photo-stories that the men in this study created on self-representations.

Chapter Seven	Conclusion and future recommendations

Table 1.5.3 Outline of chapter seven

The final chapter, chapter seven, includes my conclusions, limitations, and future research recommendations that emerged from the study.

CHAPTER 2

LITERATURE REVIEW

2.1 Defining Disability

Research shows that social scientists find it challenging to define disability in a way that is comprehensive, uncomplicated, and consistent world wide (Kaplan, 1999; Filmer, 2008; Grönvik, 2009). Various theorists have asserted the actual challenge in defining is that disability is often defined in a controversial way and the definition often varies depending on context (Filmer, 2008; Rice et al., 2015). Various kinds of approaches are identified in relation to the definition of disability.

2.1.1 Medical Model of Disability

One of the most dominant approaches to defining disability is described by the “medical model” of disability. This model focuses on the physical limitations of the individual caused by impairment (Hughes & Paterson, 1997; Kaplan, 1999; Oldman, 2002; Dabhi, 2015). Similarly, Marks (1999 as cited in McDougall, 2006) states that the medical model of disability views disability as a condition, illness, or sickness that needs diagnoses, cures, and treatments. The medical model of disability also categorizes those with impairments as ‘disabled’.

2.1.2 Disability as Human Diversity

Papadimitriou (2008) challenges the idea that disability can be viewed as a condition, illness or sickness, by arguing that disability is either something that people become as they can do something or cannot do something, rather than it being something that people are. From this, Papadimitriou (2008) defines disability as a form of human diversity.

2.1.3 Functional, Administrative, and Subjective

Grönvik (2009) identified three ways of defining disability: disability as functional limitation, administrative definition of disability, and a subjective definition of disability. Grönvik (2009) puts forward the idea that disability as a functional limitation is derived from the medical model’s understaning of disability because it categorizes people with disabilities as ‘disabled’. Subsequently, disability is understood as blindness, deafness, or other kinds of changes in bodily structures which lead to impairment that needs treatment or cure (Grönvik, 2009). However, it is labelled as a functional limitation because the effects of the impairment has an impact on the individual’s capacity to perform ‘normal’ activities (Grönvik, 2009). Similarly, Dabhi (2015), also defines disability in this way, by viewing disability as any loss of ability to perform an activity within the range of what is considered ‘normal’ due to their impairment.

This understanding of disability as a functional limitation is similar to how the World Health Organization’s International Classification of Functioning, Disability and Health, define disability. According to Filmer (2008), they explain disability as an umbrella term that covers all impairments, activity limitations, and participation restrictions as part of a broader classification scheme that simultaneously considers three main domains: body functioning and structure, activities and participation, and environmental factors.

An administrative definition of disability entails a specific criterion that is needed to receive support grant from the state (Grönvik, 2009). Furthermore, subjective disability is a definition created or defined by people with disabilities (Grönvik, 2009). This definition looks into ways in which people with disabilities define their disability. It also means that inclusion in the identity category of ‘disabled people’ is completely voluntarily.

It is clear that there are generally broad understandings and interpretations of disability that makes it quite complex to define. What all these studies have in common is the notion that disability has something to do with the body. However, another approach to defining disability is one which places more emphasis on society and the social environment and not so much on the individual or the ‘disabled’ body; this is the social model of disability.

2.1.4 Social Model of Disability

This study takes the position of understanding disability through using the social model of disability as a theoretical framework. The social model of disability is presented in order to provide a more theoretical and nuanced understanding of disability as a social construct and not a medical deviance. Examining perspectives from a theoretical point helps uncover some of the dominant value positions leading to misrepresentations, stereotypes, and assumptions of disability held by society. I recognize that the social model is not necessarily a flawless lens through which disability is understood and I acknowledge the various critiques that scholars have levelled against this model. However, what is maintained and emphasised here is that the model is a highly valuable tool in the paradigm shift towards anti-oppressive notions of disability.

The social model of the British disability movement was developed in the 1970s by activists in the Union of the Physically Impaired Against Segregation (Shakespeare & Watson, 2001). It is also known as 'the minority group model' (Donoghue, 2003) and 'the big idea' of the British disability movement (Hasler, 1993 as cited in Shakespeare & Watson, 2001). The social model of disability arose as a critique of the medical approaches to disability which completely erased the individual experiences of disabled people from the medical standpoint (Humphrey, 2000). The medical standpoint was challenged by the movement which claimed that people with impairments were disabled by a social system that created barriers to their participation in society (Hughes & Paterson, 1997).

This model puts an emphasis on human ignorance and misunderstandings of disability or 'difference' that are developed though personal and societal prejudices of sex, gender, race, and ability, in any social context. Society imposes disability on people with physical impairments through the use of social codes and norms (Siebers, 2001). This is oppressive as it isolates and excludes disabled people from full participation in society (Shakespeare & Watson, 2001).

The social model of disability makes a clear distinction between the impairments that people have and disability (Hughes & Paterson, 1997). It defines impairment as a loss or lack of physiological, psychological, anatomical structure or function (Hughes & Paterson, 1997; Kaplan, 1999; Shakespeare & Watson, 2001; Dabhi, 2015). For example, lacking all of or part of a limb in the body may lead to disability. It defines disability as a social oppression and not the form of impairment (Shakespeare & Watson, 2001). Although the distinction between an impairment and disability is made quite clear by the model, it is important to stress that the model does not disregard concerns relating to impairment - like the importance of medical treatment or rehabilitation (Siebers, 2001).

The model has been successful in breaking the link between impairment (the body) and disability (the social creation) (Shakespeare and Watson, 2001). It has replaced a traditional or 'medical model' understanding of disability - in which the problems arose from deficits in the body - with a social understanding, in which the problems arose from social oppression (Shakespeare & Watson, 2001). Consequently, debates on disability have been shifted from a bio-medical view to discourses on the social construct of disability and what it means to navigate or participate in society as a disabled individual.

The social model of disability has been critically analysed by various scholars (Hughes & Paterson, 1997; Humphrey, 2000; Siebers, 2001; Shakespeare & Watson, 2001) and has shown many positive outcomes. It has proved to be successful in the sense that it was used as a political strategy to identify, challenge, and remove barriers that disabled people faced (Shakespeare & Watson, 2001). These barriers include the devaluing and negative representations of disabled people in films, media, and culture. This also pertains to inaccessible and exclusive education systems, working environments, discriminatory health and social support services, inaccessible transport, houses and public buildings and amenities (Oliver, 2004).

Furthermore, the barriers are designed and created by non-disabled people. It is clear that the model puts a strong emphasis on the notion that people with impairments are disabled by society (Siebers, 2001; Shakespeare & Watson, 2001). The model confronts these barriers by dismantling it and promoting a more inclusive society through advocating for social change and transformation in society rather than medical cure or rehabilitation for disabled people (Shakespeare & Watson, 2001).

The model has also challenged people with disabilities perception by providing a broader perspective and exposing them to different ways of understanding their experience (Hughes & Paterson, 1997). The model underlined that it is not ‘their own fault’ that they experience discrimination, oppression, prejudice, and social exclusion, but that it is society’s fault, and that society needs to change and take responsibility for this projection (Hughes & Paterson, 1997; Shakespeare & Watson, 2001). The achievement has been to expose the actual cause of disability; discrimination and prejudice. Furthermore, it puts an emphasis on the fact that advances in social justice is required rather than medicine (Siebers, 2001). It is unfortunate though, that even though the model exposes issues of discrimination and oppression, society still continues to discriminate, exclude and oppress people with impairments (Oliver, 2004). This shows that a model is not enough to break practices of discrimination, exclusion, and oppression.

Some scholars have critiqued the social model of disability (Humphrey, 2000; Siebers, 2001; Oliver, 2004). The first critique is that the social model of disability is unable to deal adequately with the realities of impairment (Oliver 1996b, as cited in Oliver, 2004). However, as Oliver (2004) states, the social model is not about the personal experience of impairment but about the collective experience of disability. This critique proves to be a misunderstanding of what the social model actually means.

The model has also been critiqued for not taking into consideration the subjective experiences of ‘pain’ relating to both impairments and disabilities (Oliver, 2004). There has also been a criticism that the social model is unable to incorporate other social divisions like race, gender, sexuality and so on. However, this does not mean that it is impossible to do so (Oliver, 2004). Despite these reservations, the social model of disability is fitting for this study as it views disability as a label that is used to imposed upon those who are differently abled.

Since this study is primarily focused on the lived experiences of disability, the social model of disability is of relevance because it argues that disability is socially constructed. The model explains how disability is viewed, understood, and defined through the lens of society. It highlights the violent perceptions by society that are limiting, diminishing, dehumanizing, discriminative, and oppressive. Therefore, this study this study seeks to understand how coloured men define and understand themselves as men with a disability. Because it is difficult to set clear boundaries between what counts as disabled and non-disabled (Rice et al., 2015), this research study solely focuses on complete paraplegia as a physical disability.

2.2 Defining Paraplegia

Paraplegia is defined as an acute, traumatic lesion of the neural elements of the spinal cord that results in temporary or permanent loss of sensation and motor deficit or bowel/bladder dysfunction (Dabhi, 2015; White & Black, 2016). This causes a paralysis from the middle of the body (hips, legs and lower body), downwards (Parkinson, 2009).

Paraplegia is usually the result of traumatic spinal cord injury (TSCI), which is basically the result of the loss of movement and function that is highly dependent on the extent of damage to the spinal cord or even areas around the spinal cord (White & Black, 2016). The damaged areas of the spinal cord that result in paraplegia are the upper thoracic (T1 to T8), which is the area approximately in-line to the chest, as well as damage to the lower thoracic (T9 to T12). Damage of the lumbar and sacral area results in poor function of flexors and hips, also resulting in paraplegia (Parkinson, 2009; White & Black, 2016).

The severity of the damage depends on the degree of anatomical injury to the cord (Holdsworth, 1954). For example, if the spinal cord is intact, complete recovery will occur after a significant period of time (Holdsworth, 1954). If the spinal cord is partly divided, then partial recovery of sensation and motor power will occur (Holdsworth, 1954). If the spinal cord is completely divided the isolated segments will recover local reflex activity and the paralysis will become of the upper motor neurone type, the anaesthesia remaining unchanged (Holdsworth, 1954).

Thus, during the period of suppression it is impossible to immediately establish to what degree the cord has been damaged and whether the spinal cord is intact or not.

There are two categories of paraplegia, namely complete paraplegia and incomplete paraplegia (Dobkin et al., 2007; Parkinson, 2009). A patient will be categorized as having complete paraplegia when there is absolute damage in the region of the spinal cord (Parkinson, 2009; White & Black, 2016). Incomplete paraplegia is only the result of partial damage to the spinal cord region (Dobkin et al., 2007; Parkinson. 2009; White & Black, 2016). This means that an individual with incomplete paraplegia is only paralysed for a specific period of time, and after rehabilitation, they are more likely to walk and use the muscles (Dobkin et al., 2007).

Paraplegia was discovered or analysed during and after the First World War as a disability that resulted from gunshot wounds (Holdsworth, 1954; Dabhi, 2015). Paraplegia was also known as the most common injury in civilian life (Holdsworth, 1954) and was regarded as a permanently disabling condition. The first serious attempt to analyse and work on a rational treatment for paraplegia was made immediately after the First World War (Holdsworth, 1954). Research shows that 90% of paraplegics died within one year as they were treated under unimaginable difficulties, while only 1% survived for more than 20 years (Dabhi, 2015). After the Second World War, more attention from the medical world was drawn to paraplegia (Dabhi, 2015) as thousands of men returned to the United States as paraplegic.

Despite the First and Second World War being associated with paraplegia, much of what is traditionally linked to masculinity seems to be generative of paraplegia such as violence, fast cars, sport, recklessness and risk, and work. For example, recent research shows that motor vehicle accidents are the largest cause of spinal cord injury, causing approximately 42.1% of all injuries (Mirovsky, Shalmon, Blankstein, & Halperin, 2005; Dabhi, 2015). Rock falls on mines are the second (Siziya, Muula, Ryan, & Rudatsikira, 2010; Van der Merwe, Steyn, & L'Abbé, 2010) causing about 26.7% of the injuries (Dabhi, 2015). Other incidents that may cause damage to the spinal cord include: sport (Tasiemski, Bergström, Savic, & Gardner, 2000; Schmitt & Gerner, 2001; Sparks & Smith, 2002; Sparkes & Smith, 2005; Toth, McNeil, & Feasby, 2005), recreation (Tasiemski et al., 2000; Schmitt & Gerner, 2001; Toth, McNeil, & Feasby, 2005), and violence such as gunshots and knife stabbing (Putzke, Richards, & DeVivo, 2001; Mirovsky et al., 2005; Raul, Deck, Meyer, Geraut, Willinger, & Ludes, 2007; Ostrander, 2008).

Research also shows that men are more prone to spinal cord injury than women: 82% of spinal cord injuries are male and 18% female (Tasiemski et al., 2000; Putzke, Richards, & DeVivo, 2001; Mirovsky et al., 2005; Raul et al., 2007; Dabhi, 2015). Moreover, Dabhi (2015) suggests that the mean range of spinal cord injury is between the ages of 15 and 44. It can be emotionally devastating for relatively young individuals to know that they are paralyzed. There is not so much research on disability that specifically focuses on paraplegia conducted in South Africa, but an ample amount of research conducted internationally that focused on different experiences of living with paraplegia, exists.

2.3 Disability Studies in South Africa

Recent research on disability in South Africa has focused on three focal areas within disability studies such as HIV/AIDS and disability (Wazakili, Mpofu, & Devlieger; 2006; Rohleder, Swartz, Schneider, Groce, & Eide, 2010), intellectual disability among children (Christianson, Zwane, Manga, Rosen, Venter, Downs, & Kromberg, 2002; Kromberg, Zwane, Manga, Venter, Rosen, & Christianson, 2008; Njenga, 2009; Adnams, 2010; Mckenzie, McConkey, & Adnams, 2013), and disability and poverty in South Africa (Loeb, Eide, Jelsma, Ka Toni, Maart, 2008).

HIV/AIDS is a serious epidemic globally and has received the most attention within disability studies in South Africa (Wazakili et al., 2006; Rohleder et al., 2010). For example, a study by Wazakili, Mpofu, and Devlieger (2006) explored the experiences and perceptions of sexuality and HIV/AIDS among young people with physical disabilities in Nyanga, a township in Cape Town, South Africa.

The results showed that the participants had limited knowledge about sexuality and HIV/AIDS, and the risk of contracting HIV infection seemed to be relatively new and fraught with misconceptions and stereotyping that disabled people have no sexual life (Wazakili, Mpofu, & Devlieger, 2006). The participants' decisions and choices regarding sexual behaviour stemmed from the need to be loved, accepted, and secured, which were more important than practicing safe sex (Wazakili, Mpofu, & Devlieger, 2006). Moreover, the experiences and perceptions about sexuality and HIV/AIDS among young people with physical disabilities were organized and discussed in themes such as the inter-relatedness of socio-cultural issues, factors increasing risk to HIV/AIDS, and their response to risk.

The theme of socio-cultural issues highlighted the majority of the participants' experiences of negative attitudes from their community which resulted in feelings of discrimination and marginalization (Wazakili, Mpofu, & Devlieger, 2006). The participants often felt that they were devoid of human feelings because their communities' understanding of disability was loaded with negative connotations such as witchcraft or curses (Wazakili, Mpofu, & Devlieger, 2006). As a result, some of the participants felt socially isolated as a response to discrimination and stigmatization. Only a few participants experienced positive attitudes through support, love, and acceptance from friends and family.

The study also explored the participants' vulnerability to HIV/AIDS. It was found that disabled female participants believed that sexual relationships, including marriage, were not good for them because they felt insecure in sexual relationships. More on their reasoning is unknown, except that Wazakili, Mpofu and Devlieger (2006) suggest that these female participants may have believed that they were asexual beings, and not affected by HIV/AIDS.

Subsequently, the findings show that there were a few disabled female participants who engaged in sexual relationships but usually had multiple secret sexual affairs (Wazakili, Mpofu, & Devlieger, 2006). This increased their vulnerability to HIV infection. The disabled male participants were more open to engaging in sexual relationships and did not find it a challenge approaching women (Wazakili, Mpofu, & Devlieger, 2006).

Economic factors like the social grant provided to disabled people by the South African government, seemed to be a significant contributor to the vulnerability of HIV infection among disabled people (Wazakili, Mpofu, & Devlieger, 2006). This monthly grant gives disabled people the privilege of being more financially secured than non-disabled unemployed people, and opportunistic lovers took advantage of disabled people by engaging in sexual relationships for the benefit of living from the grant (Wazakili, Mpofu, & Devlieger, 2006). This also places disabled people at risk of contracting HIV infection.

Awareness of HIV/AIDS risk and response was the last theme explored in the study. It was generally found that the participants did not protect themselves through safe sex (Wazakili, Mpofu, & Devlieger, 2006). Even though some of the participants were well aware of their vulnerability to HIV, none of them had been for an HIV test because they were afraid of knowing their HIV status (Wazakili, Mpofu, & Devlieger, 2006).

More recent research on disability and HIV/AIDS focused on the role that organizations for representing disabled people play in addressing the HIV/AIDS epidemic among disabled people (Rohleder et al., 2010). The findings were from a nationwide survey of disabled organizations in South Africa. It was generally found that organizations that represent disabled people are well aware of the significance of teaching and addressing HIV/AIDS awareness (Rohleder et al., 2010). However, disabled people were largely excluded from these messages because they had difficulties in accessing general health care or even attending these organizations (Rohleder et al., 2010). The research highlights the need for increased cooperation and collaboration between relevant parties in order to facilitate the changes necessary for disabled people to access needed health information and care (Rohleder et al., 2010).

Similarly, Eide and colleagues (2011) explored ways in which access to information about HIV/AIDS are distributed among disabled people and focused on disabled peoples' knowledge of preventing HIV and access to health care services in South Africa. It was generally found that gender, level of education, and geographical differences, are key predictors for access to information and knowledge about HIV/AIDS among disabled people (Eide et al., 2011). It was found that there were significant gender differences with regards to information; knowledge and access to services highlight the need for gender specific prevention strategies among disabled people (Eide et al., 2011). This study also found that many disabled people lack correct information and knowledge about programmes aimed at preventing HIV/AIDS (Rohleder et al., 2010; Eide et al., 2011). Although this study is not focused on knowledge and preventation of HIV/AIDS among people with disabilities, it is important to acknowledge the relationship between the prevalence of the HIV/AIDS epidemic and disability in South Africa. This also shows why much attention has been given to conducting research on HIV/AIDS and disability in South Africa, whereas very little research focuses on the life stories of people with disabilities.

Intellectual disability has received more attention than physical disability in South Africa. This is probably because intellectual disability is the largest impairment in South Africa and Africa (Christianson, Zwane, Manga, Rosen, Venter, Downs, & Kromberg, 2002; Kromberg, Zwane, Manga, Venter, Rosen, & Christianson, 2008; Njenga, 2009; Adnams, 2010; Mckenzie, McConkey, & Adnams, 2013). Most of the research conducted on intellectual disability in South Africa focused on children with intellectual disabilities (Christianson et al., 2002; Kromberg et al., 2008; Adnams, 2010). Although this study is not focused on intellectual disability, it is important to give a brief overview of the nature of disability research conducted in South Africa. This also shows that there is a need in understanding the lived experiences of physically disabled people in South Africa.

Adnams (2010) focused on the epidemiology, policy, and services for children and adults with intellectual disability. It was found that even though there are policies and services available for the population with intellectual disabilities in South Africa, there has not been much recognition of and provision for their needs (Adnams, 2010). There is no clear understanding of the needs of people with intellectual disabilities in South Africa. These findings are from a literature analysis of surveys and questionnaires on intellectual disability in South Africa. This stresses the idea that perhaps disability should be explored and understood through narratives of life-stories of disabled people where the recognition and provision for their needs can be told through their life stories. There are other South African and African researchers who also researched intellectual disability and reiterate the fact that negative attitudes towards disabled people are pervasive (Njenga, 2009), and that they experience social exclusion on a greater level than their able-bodied people (Njenga, 2009; Mckenzie, McConkey, & Adnams, 2013).

Loeb and colleagues (2008) conducted research addressing issues around poverty and disability in the Eastern and Western Cape Provinces, South Africa. Through detailed questionnaires they investigated the level of living conditions and details of the disability experience in resource-poor areas of those provinces. They compared the responses of disabled people to non-disabled people. From their study, a major finding was that even though disabled people get a monthly grant from the government, many disabled people living in the Eastern and Western Cape provinces are living in extremely poor conditions (Loeb et al., 2008). Their results put an emphasis on the exclusion of disabled people from society, which is evident in the lower numbers of employed disabled people (Loeb et al., 2008).

In acknowledgement of the exclusion of disabled people from mainstream society, Maart and colleagues (2007) investigated the experiences of disabled people with regard to environmental barriers in an urban as opposed to a rural setting in the Western Cape. It was found that disabled people from the urban areas experienced more barriers with regard to mobility and accessibility which had an impact on their social interactions. Services related to housing, legal services, and education, were experienced as bigger barriers in the urban Western Cape than in rural Eastern Cape.

There was a significant lack of positive role models in the rural areas in Eastern Cape which could also contribute to discrimination and negative attitudes. This lack of positive role models may be a result of the beliefs regarding the causes and nature of disability which is attributed to witchcraft in the rural areas. In general, this study found that housing, transport, education and labour present major challenges to people with disabilities (Maart et al., 2007).

As previously stated, much of the research on disability in South Africa has been conducted through questionnaires and surveys which may be limiting in expressing the lived experience of disability. There is also not a clear link in the South African literature between masculinity and disability. There is overall, a lack of focus on the lived experiences of men with paraplegia in South Africa. Moreover, Swartz (2014) puts forward various challenges to developing disability research in the Global South. Swartz (2014) proposes is that experiences of disability cannot be generalized due to the relatively small sample sizes that researchers use. Narratives from these samples are often filter through the lenses in which researchers read and interpret the narratives. Secondly, Swartz (2014) proposes is the issue of expertise. This pertains to the lack of understanding that researchers may be trained and skilled within a particular area of research and disabled people may be experts in other areas. Thirdly, Swartz (2014) argues that remuneration pertains to the challenge of not conflating one construct with another. Fourthly, Swartz (2014) argues that more rigorous epidemiological methods is needed to determine evidence. Lastly, Swartz (2014) states that the challenge is in having high expectations and low expectations from research and researchers.

2.4 International Studies on 'Disabled' Masculinities

It is necessary to investigate how people with physical disabilities talk about their lived experiences of disability in a South African context, so as to add to the international research that has been conducted on the experiences of men living with physical disabilities and paraplegia.

DeSanto-Madeya (2006) conducted research on the experiences of people living with paraplegia five to ten years after the injury. The study presented seven themes used to explicate their experiences. The first theme, *'looking for understanding to a life that is unknown,'* explores the continuous quest to find purpose and understanding from within themselves, society and health care providers to living a life that remains relatively unknown even years after the injury (DeSanto-Madeya, 2006). The theme, *'stumbling along an unlit path,'* explores challenges in the drastic change in life goals and dreams, and essentially what it means to adjust and adapt to a lifestyle filled with uncertainty (DeSanto-Madeya, 2006). This theme also highlighted both the physical and psychological impacts on the individuals that appears to be more devastating than the inability to walk (DeSanto-Madeya, 2006).

The theme, *'viewing self through a stained-glass window'* explicated their perception of self which dominates much of their worldview (DeSanto-Madeya, 2006). However, the the respondeds could not clearly describe the ways in which they perceive themselves, thus nuance meaning about the self was not developed. Through the theme of *'challenging the bonds of love'* which explored ideas around sexuality and intimacy, showed that sexually intimate connections with others can either be strengthened or strained (DeSanto-Madeya, 2006). This theme also highlighted that paraplegia not only impacts those living with the injury but also family members, frieneds, and and significant others (DeSanto-Madeya, 2006).

'Being chained to the injury', expressed the participants' loss of independence because of their continual need for help (DeSanto-Madeya, 2006). *'moving forward in a new way of life'*, showed was a theme that showed how the participants' learned to live with paraplegia and learning to accept the injury by not allowing negative attitudes to impact the ways in which they experience life (DeSanto-Madeya, 2006). Lastly, *'reaching a new normalcy'*, focused more on the participants' abilities and their successes in life despite their inability to walk (DeSanto-Madeya, 2006). From this study, a significant finding was that society does not understand spinal cord injury and that there is a lack of education and exposure to paraplegia which leads to misconceptions, avoidance, and rejection (DeSanto-Madeya, 2006). These societal perceptions of paraplegia correlate strongly with findings in the present study, and, speaks to the need of raising awareness in more direct and impactful ways. The photo-stories and the exhibition which grew out of those stories, is an attempt to address this lack of visibility and understanding about paraplegia.

Ostrander (2008) conducted a study on eleven men living with a spinal cord injury. These men acquired the injury through violence, mostly gunshots. The study explored the impact that this violently acquired injury may have on the identity of the participants who are a part of a racial and ethnic minority in America. It was interesting that all the men spoke about the drastic change from being able-bodied to disabled (Ostrander, 2008), particularly the change pertaining to their masculinity. For example, many of the men spoke about their masculine identity which diminished in several aspects of their lives (Ostrander, 2008). Narratives among the men were explicated through notions of their choice of intimate partners, sexual encounters, body image and self-defence as safety (Ostrander, 2008). This text sheds light on the often violent and physical forms of macho masculinity that exists in context of social, economic and political exclusion and marginalisation, and provides some contex for framing the location of the Cape Flats in South Africa where the current research was conducted.

In the theme *'intimate partners'* Ostrander (2008) explains that the participants' expressed that they are afraid of being perceived as a burden to their intimate partners. For that reason, they chose not to have intimate relationships with their partners. This is an interesting finding that is in contrast to the previously stated South African finding where the male participants living with a physical disability were more open to engaging in sexual relationships and did not find it challenging approaching women (Wazakili, Mpofu, & Devlieger, 2006).

With regard to the *'sexual encounters'*, the men were more focused on how the injury had impacted the frequency of sexual encounters (Ostrander, 2008). Because they could not engage in what is perceived as 'traditional' sexual encounters or rather heteronormative sexual relations, many felt that their masculinity was threatened. An interesting finding is that some of the men mentioned that when they discovered that they could still sexually please their partners, they felt more like a man (Ostrander, 2008). This link between sexuality, intimacy and masculinity is an important one, and will receive attention in this thesis.

'Body image' was another theme explored in the study. Ostrander (2008) found that the participants became aware of how their bodies had changed and how it had an impact on their sense of masculinity. Through the theme of *'self-defence'* the men expressed concerns about safety and mentioned that ever since the injury, they did not feel safe in their neighbourhoods because they could not defend themselves from gangs (Ostrander, 2008). This theme of safety and self-defense, particularly in the violent township setting of the Cape Flats, will also be explored here. In the last theme, *'disability and race'*, Ostrander (2008) found that the injury did not affect their racial identity. In the study, the most explicit way that the injury manifested itself was in how the participants found it challenging to redefine their understanding of masculinity.

From the previous literature cited on the representation of disability on film, media, and culture, it is evident that researchers have focused more on the negative ways in which the disability is portrayed and experienced as opposed to the positive ways in which disability has an impact on the lives of people with disabilities. Duvdevany, Buchbinder and Yaacov (2008) conducted a quantitative research study that describes and analyses the positive experiences encountered by fathers living with paraplegia in the context of social attitudes towards parents with paraplegia. The study focused on how these fathers cope with negative attitudes toward their parenting and their actions to facilitate their children's acceptance of and adjustment to their disability.

In the study, the fathers spoke of the negative and even latent social attitudes towards their disability that would often diminish their self-esteem (Duvdevany, Buchbinder & Yaacov, 2008). It was found that fear was expressed that their children would adopt society's negative attitudes toward them and towards people with disabilites, and that a sense of shame would create an emotional distance between them and their children. However, the fathers did not internalize social oppression but confronted society's negative and imposing attitudes toward their fatherhood (Duvdevany, Buchbinder & Yaacov, 2008).

Moreover, the participants' expressed confidence in their abilities to overcome the obstacles placed by society (Duvdevany, Buchbinder & Yaacov, 2008). They showed awareness of the negative attitudes toward them, and they choose to challenge these attitudes. They showed initiative in discussing their disability openly every time their children asked questions or when they identified their lack of knowledge of the situation (Duvdevany, Buchbinder & Yaacov, 2008). They also provided information about their functioning in real life. The findings also indicated that bringing the father's disability out into the open in the father–child relationship provides an opportunity for the father to break down the obstacles of ignorance and negative attitudes in his children's social circles (Duvdevany, Buchbinder & Yaacov, 2008). Although the research conducted in this thesis did not involve parent-child relationships with respect to paraplegia, it does focus on the relational component between men with paraplegia and their partners, and sheds light on the structure of these relationships and the attitudes and perceptions that inform and sustain it.

Similarly, Weitzner and colleagues (2011) conducted a study on the positive individual experiences of living with paraplegia. The findings from this study revealed levels at which disability was viewed positively by paraplegics: '*self*', '*peers*', and '*disability community*' (Weitzner et al., 2011). Several aspects of the individual contributed to this positive view of disability such as personality, spirituality, support systems, and acceptance of one's disability (Weitzner et al., 2011). In this study, it was found that the participants' used their disability to advocate for themselves, for personal growth as their disability was perceived as a catalyst for self-discovery and self-improvement, even by changing their attitudes in a positive way (Weitzner et al., 2011). The participants explained that their disability was also used to educate nondisabled people on their disability (Weitzner et al., 2011).

In this study, disability was also perceived positively as their lives slowed down and they were able to learn new hobbies and discover new talents (Weitzner et al., 2011). Work was an aspect that positively contributed to their experience of paraplegia (Weitzner et al., 2011). The participants mentioned that work was important to them and often contributed to feeling of self-worth. Finally, disability was also perceived positively as it improved family relationships, to learn new hobbies and talents, and to find a new career (Weitzner et al., 2011).

The participation of peoplewith disabilities in sport has also been used as a way of empowering people with disabilities. It has been used to challenge negative assumptions and perceptions of physically disabled people and has highlight the positive experiences of participating in sport. It brings to light the abilities of people with disabilities. One of the most well-known sport activities for people with disabilities is wheelchair rugby (Sparkes & Smith, 2002; Smith & Sparkes, 2005; Lindemann, 2008; Lindemann & Cherney, 2008).

Smith and Sparkes (2005) conducted research on the narratives of a small group of men who suffered spinal cord injury through playing sport. The narratives were framed around both the negative and positive ways in which the injury has shaped the men. Through the life narratives, a central theme of hope was explored. The men expressed multiple meanings of hope from their experiences of living with a spinal cord injury through sport.

Lindemann & Cherney (2008) conducted research on the communicative practices in using sport as rehabilitation for quadriplegic athletes in wheelchair rugby. Players may come to new understandings of their disability (Lindemann & Cherney, 2008). This focus on developing new understandings about themselves as people with a disability is a central theme in this present thesis.

Furthermore, the research findings highlight tactical performances of disability that challenge ableist assumptions of people with disabilities (Lindemann & Cherney, 2008). The findings also alter definitions or understandings of disability and strategically enacted and reify ableist notions of competitiveness, athleticism, and the body (Lindemann & Cherney, 2008). Participation in wheelchair rugby also creates shared meanings about disability, gender, and masculinity which may reinforce conventional understandings of gender and ability (Lindemann & Cherney, 2008). For example, many of the athletes with disabilities aspire to characteristics that are commonly associated with traditional masculinity in sport, such as the well-muscled or bulky-build and attractive looking body. These athletes may aspire to these characteristics as they feel that they are challenging stereotypes of the disabled as sick or weak (Lindemann, 2008; Lindemann & Cherney, 2008).

The fact that people with physical disabilities participate in a sport such as wheelchair rugby definitely communicates a strong message to society. It shows ableist society that those with physical disabilities are not as weak, passive or frail as society perceives them to be (Lindemann, 2008; Lindemann & Cherney, 2008). Their participation in sport communicates a new way of looking at disability that challenges society's perceptions of disability. Not only does the participation in sport communicate a strong message to the ableist society, but it also challenges the physically disabled people's self-perceptions. It proves to them that the stigma and stereotypes associated with them are untrue and helps them to view their disability as less limiting (Lindemann & Cherney, 2008).

Other ways in which the participants felt empowered was through the build and gain of muscle and developing more control over the movement of their bodies which also challenges negative perceptions of disabled people. However, their aspiration for strength and mobility may be guided by an ableist ideal of the athletic body (Lindemann, 2008; Lindemann & Cherney, 2008).

A recent study by Shamrock and colleagues (2017) investigated the lived experiences of people with physical disabilities in Timor Leste. The participants in the study produced rich photographs of their own lives (Shamrock et al., 2017). This study is one of few photo-voice studies of people with disabilities. The study revealed four themes with sub-themes relating to the lived experiences of physical disability. The first theme was *'barriers and enablers in Timor Leste'* (Shamrock et al., 2017). This theme had several sub-themes one of which explored the traditional view of disability; which is the basic conception that disabled people cannot be independent, they cannot work, and take care of themselves. There is also fear expressed in being disabled or having a disabled family member (Shamrock et al., 2017).

Subsequently the following sub-theme was the *'experiences in early life'* (Shamrock et al., 2017); these experiences were based on feelings and experiences of exclusion and being teased because of their disability. The other sub-theme was *'education'*; most of the participants had the common goal of attending university, however, they often experienced access problems like no elevators, or the stair as a barrier, and difficulties getting to university (Shamrock et al., 2017). *'Gaining employment'* was another sub-theme explored; physically disabled people in Timor Leste found it difficult to get jobs due to the attitudes of employers and some institutions having active policies of exclusion (Shamrock et al., 2017).

Another finding from the study was that the participants demonstrated *'personal resilience'* (Shamrock et al., 2017) which contradicted dominant traditional notions of disability. This finding also had sub-themes such as *'an ability to attract mentors'* (Shamrock et al., 2017); the participants spoke of having a mentor from an early age to help and support them through challenges and helping them resist the stigmatizing attitudes towards them. Another sub-theme was the *'ability to creatively solve problems'* (Shamrock et al., 2017); this theme explores create ways in which the participants learned to live positively with their disability (Shamrock et al., 2017). The sub-theme of *'Re-inventing the story of disability'* (Shamrock et al., 2017); explored successes of the participants and their achievements acquired through their disabilities. It challenges prevailing notions of disability and it shows that anything is achievable (Shamrock et al., 2017).

'Working in the disability sector' was another theme in the study (Shamrock et al., 2017). In this study all the participants worked in the disability sector. Thus, the theme highlights some of the challenges and experiences of working in a sector that they can physically relate to (Shamrock et al., 2017). For example, the difficulty in practicalities due to the remote areas in which some physically disabled people stay in, and how the roads are not conducive (Shamrock et al., 2017). Another example is '*finding hidden people'*, this basically means that it was difficult finding physically disabled people to engage in talks on disability in the area (Shamrock et al., 2017). *'Disability rights and advocacy'* was another sub-theme (Shamrock et al., 2017), in this theme the participants spoke of the importance of the work they do and that they see it as advocacy.

In the theme *'context of Timor Leste'* two sub-themes were explored. The first sub-theme is *'change is evident but slow'* (Shamrock et al., 2017); this theme explores more of how there are significant potential for policy changes in Timor Leste, however, this change seems to be slow (Shamrock et al., 2017). *'The benefits of being a new small country'* was the last sub-theme explored in which participants mentioned that the legislature is still evolving, and inclusive policies are still being designed (Shamrock et al., 2017). This basically spoke of the inclusive processes that are put in place. The study also puts an emphasis on moving away from Western ideas and understandings of disability. It also urges researchers to investigate the perspectives and lived experiences of disability from a non-western perspective. However, the study only draws on physical disability which may include a range of disabilities and not necessarily paraplegia. The gender of the participants is also unknown, and thus there is no clear link in how disability affects the constructions of masculinity.

Keeping the above reviews of the literature in mind, I made a conscious choice in this thesis to use photo-stories as a way of visually depicting attitudes and perceptions of paraplegia, so as to raise awareness about the injury and to advocate for disability rights. Showing the positive outcomes that can emerge amongst those living with paraplegia informs much of my research presented here.

Other studies have put an emphasis on the fact that disability greatly affects masculinity because men with disabilities have to engage in an intense battle between their disability and masculinity (Lindemann & Cherney, 2008; Ostrander, 2008; Coston & Kimmel, 2012). Coston and Kimmel (2012) assert that the challenge that men with disabilities often have to face is against the ideologies of hegemonic masculinity and their position in the social order. Moreover, Coston and Kimmel (2012) state that in the process of attempting to affirm their masculinity, men with disabilities attempt to make up for their shortcomings by over-exaggerating the masculine qualities that they possess.

Other research related to spinal cord injury and paraplegia focused more on the experiences of rehabilitation after spinal cord injury (Sand, Karlberg, & Kreuter, 2006; Hammell, 2007; Lugo, Salinas, & García, 2007; Lindberg, Kreuter, Taft, & Person, 2013), sexual functions of paraplegic men after spinal cord injury (Sipski, Alexander, & Gomez-Marin, 2006; Anderson, Borisoff, Johnson, Stiens, & Elliott, 2007; Dahlberg, Alaranta, Kautiainen, & Kotila, 2007; Giuliano, Sanchez-Ramos, Löchner-Ernst, Del Popolo, Cruz, Leriche, & Casariego, 2007), and the quality of life after the spinal cord injury (Westgren & Levi, 1998; Hammell, 2004; Hammell, 2007). A significant finding that has been consistent across these research studies suggests that the quality of life after spinal cord injury can be rich and fulfilling if society is prepared to enable and support this. This finding is significant as it shows that there is a primary need for social change in the way society perceives and treats disability. Perhaps this need can be met through a comprehensive narrative and depiction of disability through self-representations of disability.

An extensive amount of research has focused on the psychological impact that spinal cord injury has had on paraplegics as well as the coping strategies employed to assist paraplegics with the necessary support in moderating the psychological impact (Kennedy, Marsh, Lowe, Grey, Short, & Rogers, 2000; Kennedy, Duff, Evans, & Beedie, 2003; Thompson, Coker, Krause, & Henry, 2003; Sherman, DeVinney, & Sperling, 2004; Pollard & Kennedy, 2007; Migliorini, Tonge, & Taleporos, 2008). Recent research has also focused on the experience of posttraumatic growth for people with spinal cord injuries (Chun, & Lee, 2008; Duvdevany, Buchbinder, & Yaacov, 2008; Weitzner, Surca, Wiese, Dion, Roussos, Renwick, & Yoshida, 2011; Griffiths & Kennedy, 2012; Kalpakjian, McCullumsmith, Fann, Richards, Stoelb, Heinemann, & Bombardier, 2014).

2.5 Conclusion

In this literature review, it is clear that globally there is an overwhelming amount of research on disability. Albeit researchers in South Africa have conducted incredible work on disability in a South African setting (e.g Watermeyer et al., 2006; MacLachlan & Swartz, 2009), with a growing body of literature focused on women’s experiences of disability (see Mohamed & Shefer, 2015; Majiet & Africa, 2015; Peta, Mckenzie, Kathard & Africa; 2017), the intersection of race, disability and masculinity is still understudied in Southern Africa and the rest of the Global South. These gaps in the literature indicate the need for contemporary research that explores the intersections of disability, masculinity, and race, in a more concentrated and contextually defined way.

CHAPTER 3

METHODOLOGY

3.1 Introduction

In this chapter, I introduce the research context as well as the relevant demographical information of the men who participated in the study. I discuss the theoretical and methodological framework, approaches, and procedures that were used to execute the study. Subsequently, the analytic methods used in this study is presented and thoroughly discussed. I examine the various strategies that were used to maintain trustworthiness throughout the study, followed by a brief discussion on the limitations of the study. I conclude with a reflective analysis of my positionality throughout the research process.

3.2 Theoretical and Methodological Framework

3.2.1 Intersectionality as Theoretical Framework

This study adopted an intersectional approach to interrogate the framing of coloured masculinities in South Africa. The theory of intersectionality addresses the multi-dimensional and complex circumstances of identity and oppression for an individual (Collins, 1990). This theoretical framework acknowledges how the construction of social identities such as race, gender, disability, social class, religion and sexual orientation are multi-dimensional and how these multi-dimensional identities are defined or interplay within the social location of the individual (Collins, 1990; Nash, 2008; Moolman, 2013).

Intersectionality also identifies the ways in which structures or forces of oppression operate in society (Collins, 1990). It recognizes how these structures create inequalities and social exclusion (Collins, 1990; Nash, 2008). The systems of oppression are those that are constructed and reinforced by dominant groups in society (Collins, 1990; Nash, 2008). These are usually maintained and reinforced with language (e.g. “half a man” or “crippled man”), social interactions (e.g. avoiding a conversation with someone in a wheelchair because the social perception is that people with disabilities cannot speak), as well as institutions, laws and policies. Systems of oppression are not only limited to the ways in which language is used, but also includes racism, class stratification, heterosexism, gender inequality, and ableism.

The theory of intersectionality acknowledges that social identities and systems of oppression intersect (Collins, 1990; Nash, 2008; Moolman, 2013). This means that peoples lived experiences are shaped by the ways in which their social identities intersect with each other and the ways in which these identities interact with systems of oppression. The meaning of intersectionality can be shown more clearly using the metaphor of a painting in a gallery. The different colours, shades, and contours intersect and weave together to create a portrait that is exhibited within a specific space. The intersecting colours, shades, and contours represent the different social identities that are embodied and represented within an individual. The gallery represents the social location in which the portrait or identity is situated. This social location may be accessible to only a select group of people – the privileged. Subsequently, the marginalized are excluded from all the resources and social networks that the gallery has to offer.

Intersectionality thus recognizes the countless and different relations of social power that exist between various social locations (Collins, 1990; Moolman, 2013), and acknowledges the complexities within social identities. As such, a social identity such as race (e.g. coloured) and gender (e.g. male) is not studied in isolation. Instead, intersectionality recognizes that social identities such as race (e.g. coloured) and gender (e.g. male) constitute each other (Stuart, 1992). One identity (e.g. race) cannot explain the degree of inequality experienced without the intersection of the other identities (e.g. race, gender and disability). This means that an individual can experience a combination of racism, sexism, and ableism simultaneously as part of his or her everyday life (Stuart, 1992). For example, in the South Africa context with its legacy of apartheid, where race was used as a primary mechanism to enforce separation and inequality through the intersection of race with gender, sexuality, class, culture and the like, we find particular perceptions of coloured identity on the Cape Flats that emerged out of the apartheid setting.

Intersectionality is thus a useful theoretical framework for this study. It challenges the status quo and universal assumptions that there is a collective experience about what it means - for men - to live with a physical disability. Because intersectionality acknowledges differences among individuals, it is used in this thesis to challenge the assumption that white, western, middle-class and physically disabled men from Northern/Western countries (as seen in Cole’s 2004 work) share the same lived experiences as physically disabled men in South Africa and the African continent.

This thesis therefore acts against reducing men to the nature of their disability, but rather focuses on how social context impacts the meaning that is constructed around that disability. Therefore, the theoretical framework of intersectionality employed here, challenges hierarchy, hegemony, and exclusivity in its approach to analysing lived experience (Nash, 2008).

Moreover, intersectionality becomes a critical lens that provides a way of articulating the complexity informing the coexistence of multiple social identities and ways in which these impact the lived realities of the men in this study (Moolman, 2013). Also, this theoretical framework has the potential to produce additional in-depth knowledge that may further disrupt traditional perceptions about masculinity and disability.

In summary, one cannot discuss the construction of identity through an intersectional framework, without also discussing the construction and sites of oppression relating to these intersecting identities. The men in this study are intersectional subjects because paraplegia intersects with their other social categories such as race, gender, class, sexuality and religion, all of which may disadvantage them. Thus, an intersectional framework validates these men's experiences by centring their voices which thus far, have been ignored by mainstream society (Nash, 2008). Their voices have been silenced through their experiences of discrimination and stigmatisation based on the intersection between their disability, masculinity, and racial identity, amongst others. Rawing on their life narratives invite us as listeners, readers, and viewers, to enter their realities and increase our understanding of how one social category is shaped by another (Riessman, 2008). Through using an intersectional framework, this study contributes to the body of knowledge on what it means to be a coloured man living with a physical disability on the Cape Flats. This significantly contributes to an understanding of an intersectional framing of masculinities as central in the production and reproduction of social identities (Moolman, 2013).

3.2.2 A Narrative Approach as Methodological Framework: Individual life stories

Life-stories are the constructions of an individual's identity through the process of telling stories from one's life from the individual's point of view (Riessman, 2008; Syed & Azmitia, 2008; Bathmaker & Harnett, 2010). I particularly chose to use a life story approach for this study as I agree with Josselson's (2006) idea that all human beings are natural story tellers. Bearing this in mind, our lives are storied from the day we are born (beginning) to the day we die (end). In between the beginning and the end, there may be tragic or exciting moments. This may be perceived as the climax of our life story.

Smith and Sparkes (2008) put forward the idea that through our narratives, there is an urge to actively construe meaning in our experiences of hardship, victory, illness, love, loss, confusion, joy, and sadness. We find meaning and understanding of our experiences in the ways we construct, organize, and express our narratives around the experience (Smith & Sparkes, 2008). Thus, narratives are a way of telling about ourselves and our lives, but also a means of understanding and knowing.

Reismann (1993, as cited in Smith & Sparkes, 2008) states that society and culture 'speak themselves' through an individual's story. Moreover, the men in this study could share life-narratives and photo-stories (which gave an artfulness and texture to their narratives) on the problematic ways in which they are socially and culturally perceived. As such, their narratives challenge and resist social oppression and discrimination, simultaneously putting forward narratives of social change and transformation. Thus, this kind of narrative approach bears a promise of fashioning a kind of scholarship that seeks to practice a deep fidelity to the possibilities of societal and individual transformation, resistance and living life differently (Smith & Sparkes, 2008).

Using a narrative approach for this study has made me realize that telling stories can be therapeutic - to the story teller and the listener. I agree with Frank (1995) that there is healing in telling life stories - especially those constructed around pain, suffering, loss, and tragic events. Through listening to the men's life stories that were mostly constructed through pain, loss, and suffering, and to even embrace them in their moments of vulnerability expressed through tears, has made me aware of my own experiences of pain, loss, and suffering, and has given me a new understanding of my experiences. I have found that sometimes through telling, we find closure in our wounds.

3.3 Context of the Study

In this section, I contextualize the area in which the men in this study reside. Providing a geographical, social, economic and political context is important as their narratives are deeply rooted within this context as was evident among all the men who participated in this study.

Figure 3.1 below is a topographic map of Macassar - a predominantly coloured area on the Cape Flats with a population of approximately 32 356 people (Census, 2011). Approximately 89% of the Macassar population self-identify as coloured (Census 2011). Macassar is home to many people who were evicted from its white neighbouring areas, like Strand and Somerset West, during the apartheid era, and even after Apartheid, the community still lacks development in relatin to social and economic issues (Hammett, 2009). Some of the men in this study attested to the inequality and unjust ruling of the apartheid reign. They did so through recalling some of their painful memories of being forcefully moved to Macassar. They had to learn to build a culture and a community among people from different areas.

Figure 3.1. Topographical map of Macassar, Western Cape

3.4 Motivations for Studying this Population

I chose to study the construction of masculinity, disability, and coloured identity, as it is a rarely elucidated intersectional phenomena in South Africa. I am deeply situated within the coloured population due to our shared historical, cultural, and social affiliations. I was not only interested in exploring the intersections of these social identities, but also analysing the experiences of those whose racial, gender, social and cultural identities I share. Furthermore, as a scholar and student in the social sciences who proactively engages in what Pumla Gqola (2007, p. 117) calls “transformative gender work” though advocating for social change and transformation in society, I want to contribute to knowledge about the social representations of coloured masculinity and disability on the Cape Flats, and in the Global South. I want to contribute to existing knowledge about what it means to live with paraplegia by amplifying the voices of those who are marginalized, socially excluded, discriminated against, and silenced by dominant voices among able bodies who lack insight and understanding about physical disability and the experiences of the disabled.

3.5 Execution of the Study

The following section of this chapter provides more detail on the men in this study. It focuses on the approaches and procedures that were used to execute the study.

3.5.1 Research Sample

To address the research questions, this study was conducted with fifteen, working-class, unemployed, coloured men with paraplegia. As previously stated, paraplegia is defined as an acute, traumatic lesion of the neural elements of the spinal cord that results in temporary or permanent loss of sensation and motor deficit or bowel/bladder dysfunction that causes paralysis from the middle of the body downwards (White & Black, 2016). These men fulfilled the following inclusion criteria: (1) clinically diagnosed with complete paraplegia; (2) male; (3) racially self-identify as coloured; (4) English or Afrikaans speaking; (5) 18-60 years old at the time of the interviews; and (6) residing in the Western Cape. Most men identified as heterosexual, while one identified as homosexual.

Speaking to 15 men with paraplegia allowed for a good number of rich narrative accounts. All the men had the spinal cord injury at least two to twenty years prior to the study. All the men were Afrikaans speaking, while a few preferred to construct and tell their life story in English. The ages of these men ranged from 25 – 58 years with a mean age of 43 years. Due to their unemployment status and the limited resources available in their community, it can be assumed that these men are part of the poor and working-class majority that is reflected in research on disability in South Africa. This shows that people with disabilities are found to be amongst the poorest, most vulnerable and marginalized (Adnams, 2010), and remain defined by the legacies of inequality of the apartheid era even after 24 years of political democracy.

3.5.2 Sampling Strategy

This study primarily relied on purposeful sampling due to the common demographic characteristics shared among the men and their status as members of the Bridging Abilities Organization. Purposeful sampling is defined as the deliberate choice that the researcher makes in choosing potential respondents due to the characteristics of interest that they possess (Tongco, 2007). The primary characteristics of interest that these men possess is their race, gender and level of spinal cord injury. The goal of this sampling strategy is to understand each man's experience as socially constructed from his own perspective and understanding of his reality (Cuadraz & Uttal, 1999).

3.5.3 Introducing the Men

Allen is an intelligent twenty-nine-year old man. At the time of our conversation, he was busy completing an Honours degree in Politics and Public Administration. His youthful spirit and sarcastic humour have attracted a vast number of friends from religious youth groups and university. At the age of eightteen, he went on a youth camp and volunteered to be the first to dive in the ocean from a cliff. His body hit a submerged rock in the ocean. Upon being rescued by his uncle, he uttered the words, *"Uncle Pedro, please do not tell me that I am paralyzed."*

Norman is thirty-seven-years-old, married, and a father. He was twenty-five years old when he witnessed a gang robbing a pensioner and bravely attempted to protect the pensioner. In the chaos of screaming and fighting, he was shot in the spine. His wife, Anne, is the sole breadwinner in the house.

Michael is a forty-year-old man who worked underground as a mine worker since the age of twenty. Four years later, he was the only one out of five mine workers who survived an underground rock-fall accident. After rehabilitation, the mine deployed him to work for a factory which supplies safety and supporting gear to mine workers.

Carlo is a charismatic twenty-nine-year-old homosexual man. At the age of eightteen he went clubbing with his aunt and her boyfriend. Driving back home in the early hours of the next day, they collided with another motor vehicle. At the time of our conversation, he was studying for his grade-12 June exams. He aspires to study psychology and to use his life story as a testimony to his community.

Kenneth is a quiet and wise fifty-five-year old man. He has been unemployed for twenty years since meningitis severely damaged his spinal cord. The injury has contested and strengthened his faith in God. His experience of living with the injury has given him a nuanced understanding of what it means to be a human.

Franklin is a charming forty-year old man. At the age of fourteen he was a part of the "Evil Bastards" gang in his community. He robbed and stole from people for his own survival. At the age of thirty-two he was incarcerated in Pollsmoor prison for six years. He then joined a gang in prison and was known among the wardens as the *"good looking man with bad intentions."* In his last year of incarceration, he volunteered to play rugby in a sections match. The intensity and brutality of bodies colliding during the match was so severe and violent that Franklin injured his spinal cord.

Oppies is an amusing forty-seven-year-old father and husband. The hit-and-run accident occurred at the age of twenty-eight. He stood along the side of the road waiting for a taxi to take him home after work. A truck driver lost control over his vehicle, hit Oppies, and drove away. Seconds thereafter, the motor vehicle behind the truck drove over Oppies body laying in the road and drove away. Oppies laid paralysed until a few other cars stopped to assist him. Since the accident, Oppies has been unemployed.

Albert is a bulky built fifty-four-year-old man who became paralysed at the age of forty-nine. After five years of living with paraplegia, he still finds it a mystery that he woke up paralysed on a Monday morning before work. Medical experts had diagnosed him with complete paraplegia, however, Albert does not know the cause of the injury. He immediately lost his job. His wife divorced him after the first year of living with paraplegia.

Ridah was a talented cricket player. He is thirty-three years old. He holds a university degree in marketing. Although he is unemployed, acquiring financial independence is important to *"break the generational curse of poverty"* in his family. At the age of twenty-six, he was driving home on the M5 highway from a cricket match at the Newlands Cricket stadium, when he lost control over the vehicle. He had no memory of how the accident happened as *"everything happened in a spilt second."* He only recalls waking up, paralysed, after five weeks in ICU.

Wendell is a fifty-five-year old unemployed father and husband. He is involved in his local church's ministry. For over a decade, he worked as a long-distance delivery truck driver. Three years ago, another delivery truck driver lost control over his vehicle and collided with Wendell's truck. Although Wendell survived the accident - paralysed, the other truck driver died.

Devon is a talkative, stylish and tattooed twenty-seven-year-old father and husband. He is known as the *"cool guy"* in his community. He is unemployed but worked as a clerk at an accounting firm before the accident. Devon and his five best friends were in a motor vehicle accident. Devon was the only one severely injured.

Enrico is a self-confident and unemployed thirty-six-year-old man. He was shot at the age of twenty-eight through gang violence. During our conversation, Enrico mentioned that he always knew that the gang fights in his community would be the reason for his death. The bullet he was shot with hit and severed his spinal cord. The chaotic scene was described as a *"close to death moment."*

Johan was thirty-five years old when he felt an intense pain in his back. He accumulated a back injury after years of lifting heavy material at work. After three years, he went for a back operation which resulted in severe spinal damage. His doctor promised that paralyses will only be temporary. However, he has been living with paraplegia for fifteen years. His wife is the sole breadwinner.

Kurt is a fifty-three-year-old father and husband. There was nothing more electrifying than the adrenaline and pleasures that he felt while racing on his motor bike. At the age of forty-three, Kurt was in a motor bike accident. Albeit he cannot recall the event of the accident, he recalls the feeling of being alive while speeding on the bike on the day of the accident. His wife is also the sole breadwinner.

Gavin was twenty-eight years old when he was shot and paralysed due to gang involvement. His injury occurred while his gang robbed a local store and were confronted by the owner of the store who fired several shots at Gavin's gang. The day of our conversation was the eight-year anniversary of his injury.

Figure 3.3 Photograph of the men (consent was given to expose their identities) in this study

Table 3.4 Overall sample demographics (*n* = 15)

Gender: Male	15
Race: Coloured	15
Sexuality:	
Heterosexual	14
Homosexual	1
Injury level:	
Complete Paraplegia	15
Injury acquired:	
Sickness	3
Motor Accident	6
Gunshots	3
Sport	1
Recreational activity	1
Rock falls	1
Average age (Current)	28 years (range: 27 - 55 years)
Average age (When injured)	34 years (range: 18 - 52 years)
Time since injury:	
Less than 5 years	4
More than 5 years	11
Marital status:	
Married	6
Single	9
Highest grade completed:	
Less than high school	7
High school diploma	8
Employment status:	
Employed	1
Unemployed	14

3.6 Recruitment

All men were recruited from a Non-Governmental Organization, named Bridging Abilities, in Stellenbosch, Western Cape. Bridging Abilities caters to many individuals of different ages, races, gender identities, and various physical impairments. Many members of the organization are outpatients from the Western Cape Rehabilitation Centre. The organization serves in teaching individuals with disabilities various skills to develop their abilities. The organization also assists them in their transition from rehabilitation to living in the community as independently as possible. The organization has various sites around the Western Cape. The site in Macassar mostly consists of individuals with spinal cord injuries, and particularly focuses on physical exercises and sports to strengthen their muscles.

The co-founder of Bridging Abilities was the gatekeeper in this study. She willingly assisted in the recruitment procedure. Having the co-founder of the organization as the gatekeeper as opposed to recruiting the men through advertisement or emails, was effective since men rarely respond to advertisements or email invitation (Oliffe & Mroz, 2005), and she encouraged them to meet with me.

The recruitment procedure included introducing the aim and focus of the study to all men who fitted the inclusion criteria. These men were told that the aim of the study was to explore the ways in which paraplegia has impacted their lives, and to explore the ways in which race, masculinity, and disability intersect within their lived experiences. The research procedure and ethical considerations such as confidentiality and informed consent - which is discussed later in this chapter - were explained to them. After these detailed explanations and addressing their questions, many were interested in being a part of this study. In fact, the number of volunteers exceeded what the study could cater for. Those who volunteered were selected according to their availability. I kept a record of those who were not selected, so as not to exclude the possibility of a future study.

3.7 ‘Data’ Collection and Procedure

This study utilized a qualitative approach. Within the parameters of qualitative research, the research of hand adopted a narrative approach to life stories as a primary methodology, and photo-voice as a secondary methodology for ‘data’ collection. Integrating life-stories and photo-voice as a double layer of insight and understanding enriched this study. It offered a more complex and sophisticated understanding of paraplegia, masculinity, and coloured men’s lived experiences of living with paraplegia on the Cape Flats.

3.7.1 Procedure of Life Story Conversations

I approached each man individually after the co-founder of Bridging Abilities introduced me to the men as a group. I began by introducing myself and telling them small truths about me. I told them about the small conservative town I am from. I shared some stories about my transition from the small town to the Mother City. They enjoyed listening to these stories and were quite interested in knowing about me. So, I shared more stories about my life. I told them about my interests and passions. I told them about my previous research interest and how it has changed over the years. Through these conversations, I found that they became comfortable in asking questions and speaking to me. It was only then that I told them about my interest in listening to their life stories, in knowing who they are, what they do, how they got injured, the ways in which the injury had impacted their lives, and ultimately, what it means to live with paraplegia.

I explained that my role as a researcher was to listen carefully to their stories. This would include asking some questions for clarification. Subsequently, I informed them about the focus of the study and I explained that there would be two meetings. The first meeting would focus on the life story, and the second meeting will focus on the photo-stories. I told them that their involvement was completely voluntary, but also emphasized that if they agreed to share their life story then it would be important for them to stay committed throughout the various stages of the study. I assured them that it was my responsibility to commute to their homes on days that they could not meet at the organization. I then gave them the opportunity to express concerns and then to confirm whether they were willing and open to sharing their life story with me. Once they confirmed their willingness to speak, I asked them to complete a consent form (see Appendix A), and scheduled dates and times to meet.

Bridging Abilities gave me an office to use on the scheduled days of meeting the men. Most of them agreed to have the conversations at the organization in the assigned office space. A few men invited me to their homes because they felt that their home was more intimate and comfortable for sharing sensitive stories. Although this meant that I was going into an unfamiliar community and home, I agreed to these requests because I knew that this was more convenient for them and that being in their space of comfort or sanctuary would give them more control and agency over the conversations.

Travelling to their homes made me more cognizant of safety issues that I was not aware of when agreeing to these meetings. There were times when I got lost and had to ask strangers for directions or sat in a taxi not knowing the route to the destined home. Seeking to protect the men's confidentiality, I never informed any of my friends or supervisors about who I would be meeting on the day and where the meeting would take place. This contributed to my anxiety of feeling unsafe when I entered unfamiliar places.

On the day of the interview, I found that most of them were nervous because they did not really understand how to construct a life story. Asking them to speak about their life was too broad, especially when it came to divulge in some specific details about their personal stories. Thus, I started the conversation by telling them to imagine that I was the author of their biography and that my role was to write their life story. I told them that they could start narrating from whatever point they felt was the easiest, and in whatever language they feel most comfortable speaking. I was hoping that this strategy would contribute to the agency and courage that they sometimes needed to speak. And it did.

Most of the men were comfortable speaking to me. I mostly just listened to them and rarely referred to the designed interview schedule (see Appendix B) because I did not want to interrupt the flow of their stories (Oliffe & Mroz, 2005). Furthermore, they covered the content documented in the interview schedule without me asking. For instance, they spoke about their memories of childhood and adolescent years, prominent experiences of adulthood, memories of the accident and what it means to them now. They reflected on their journey of living with paraplegia in quite deep and profound ways. The conversations were two to three-and-a-half hours long. The length of the conversation challenges Oliffe and Mroz's (2005) finding, that men who speak to male researchers do not readily express themselves and that responses to questions may be short and superficial.

However, the nature of the conversations with the men in this study were informal rather than the more formal ‘question-answer interviews’, and this contributed to the men’s openness in sharing stories. The conversations were voice-recorded and transcribed. More on the transcriptions and translation process is explained later in this chapter.

Towards the end of the conversation, I asked them to reflect on what it was like speaking to me. All of them said that the experience of reflecting on their life story was difficult because it took them back to a painful, traumatic, and challenging time in their lives. This was evident in the fact that most of them cried at some point during the narration of their lived experiences. Sharing emotions challenges research that suggests that men are self-contained and unlikely to share emotions (Oliffe & Mroz, 2005).

On the contrary, they also mentioned that speaking made them feel good because they felt that sharing their stories was an opportunity for them to be heard and understood. Men like Allen, Michael, Norman, Johan, Kenneth and Albert, expressed that they learned a lot about themselves through the process of reflecting and sharing. Moreover, Kiser, Baumgardner, and Dorado (2010) and Frank (1995) put forward the idea that telling stories facilitates healing. This was evident in that the men felt that sharing their stories was therapeutic, and that speaking somehow made their burdens easier to carry, especially because I framed the questions with so much care and respect.

Many of the men felt empowered, respected and validated by being asked questions about their lived experiences, especially since they were the experts of their own stories. For many of them it was the first time that they ever shared their experiences about their journey of living with a spinal cord injury. They held the view that able-bodied people were not really interested in hearing about such experiences. As such, they were curious to know how their stories would unfold in this research and how it would contribute to the production of knowledge and social change. They were humbled to know that their stories matter, and that they - and their stories - are important. Before closing the life story conversation, I informed them about the second meeting which focuses on the photo-stories aspect of the research. More is explained in the photo-voice training section below.

3.7.2 Photo-voice

Photo-voice is a Participatory Action Research method in qualitative research that was developed by Caroline Wang with Mary Ann Burris (Wang & Burris, 1997). This methodology is used to document experiences and realities through photographs with the aim of creating awareness about lived experiences for social change (Wang & Burris, 1997). The photographs are accompanied by a narrative that describes the significance of the photograph. This methodology is founded on the principles of feminist theory, constructivism and documentary photography (Hergenrather, Rhodes, Cowan, Bardhoshi, & Pula, 2009). It is also based on the notion that the participants are the experts regarding their own realities (Baker & Wang, 2006).

This method empowered the men as it allowed an interchange of roles among myself as a researcher and the men as respondents (Oliffe & Bottorff, 2007; Allen, 2012). For example, the men with paraplegia took on the role of a researcher (Allen, 2012), by taking responsibility in controlling and creating photo-stories through photographing people, objects, or places that are significant to their experiences. They then analysed the photographs through engaging in photo discussions which allowed them to construct and tell a narrative around the significance of the photographs. My role as the researcher was not to research, but to facilitate the process of creating photo-stories and to interrogate their construction of photo-stories. One aspect of photo-voice that I appreciated was the shift in power from my role as the researcher to the men (Harley, 2012).

Similar to other findings (see Wang, Cash & Powers, 2000; Oliffe & Bottorff, 2007; Hergenrather et al., 2009), this method was useful in working with marginalised people as it confronted the ‘unspoken’ through photographs. The photographs provided a voice and a language that promotes social change through an exposure of issues or attitudes that need to be confronted, changed, and challenged (Wang, Cash & Powers, 2000; Oliffe & Bottorff, 2007; Tijm, Cornielje & Edusei, 2011; Mizock, Russinova, & Shani, 2014).

Essentially, the aim of the photo-stories was to provide the reader with a visual and descriptive insight into the ways in which these men think that they are socially perceived and the ways in which they perceive themselves. I was particularly pleased in using photo-voice for this study because another powerful aspect of the methodology is that it takes the reader (and myself) to a place and a time and gives insight into an experience in such a way that words alone cannot do (Harley, 2012).

3.7.3 Materials and Resources

There were several materials and resources involved in carrying out the photo-voice aspect of this research study. The cost items for equipment included: eight Canon IXUS 175 digital cameras (see Appendix C). This type of camera was chosen because of its practical use and quality of pictures. I used fifteen memory cards as each of the male participants was given a memory card to avoid confusion about the authorship of photographs. Lastly, I printed out the photographs that they captured to use as part of the photo-voice discussion (see chapter 8). The already available resources included: a notepad for analytical observations, a laptop to download and store the photographs, an office space in which photo assignments and discussions were facilitated, and a tape/voice recorder to record the conversations.

3.7.4 Photo-voice Introduction and Training

As stated earlier, at the end of the life story conversation, the men were introduced to the photo-story aspect of this research. I did so by explaining that photo-voice entails taking on the role of a researcher by using a digital camera as a tool to create visual and textual content through photographs. I explained that the expectation is to (1) photograph the ways in which they think people see them, and (2) photograph the ways in which they see themselves, and then (3) to construct a narrative around the significance of the photographs.

I initiated a discussion on social representation and self-representation by showing them a photograph that I took as part of a photo-story project - on the construction of identity and sexuality - that I participated in a few years ago (see Appendix D). I explained the significance of the photograph - in relation to the ways in which I see myself. The fact that they engaged in a dialogue about the social and political context of the photograph from my photo-story, revealed that they understood the expectations of the project. This engagement also highlighted different views of seeing and interpreting a photograph.

I explained to them that carrying a camera implies holding authority in terms of making decisions on the ways in which the camera is used, or how the shoot is directed (Tijm, Cornielje & Edusei, 2011). I pointed out, however, that there are ethical issues to consider. Subsequently, I discussed the ethical issues involved in creating photo-stories. This included highlighting issues like their safety and also the safety of those they photographed. I then discussed the ethics involved in taking pictures of others (Wang & Burris, 1997; Tijm, Cornielje & Edusei, 2011).

I did so by posing the following questions: How do you politely approach someone about taking a picture of them? Is it acceptable to take pictures of other people without their knowledge? These questions allowed them to engage in a dialogue around the ethical implications of photographing others.

I then explained that each person they choose to photograph must sign an informed consent document (see Appendix E) which gives permission for them to be photographed, and for photographs to feature in the study and exhibitions. When they understood the roles and expectations around creating photo-stories and the ethical issues involved, they were asked to complete another informed consent form to show that they give permission to participate in this aspect of the study (see Appendix F). Thereafter, digital cameras were distributed. Each man was given a digital camera. Safety aspects of using the digital camera were addressed. This included a thorough talk on how to protect the camera. For example, ways to hold it and ways to prevent the camera from falling.

This was followed by an in-depth explanation on how to operate the camera. This included a talk on how to switch the camera on and off, charge the batteries, and how to use the flash. I demonstrated that the camera should be held with both hands when capturing the photo (Wang & Burris, 1997; Harley, 2012). I then demonstrated the different ways to photograph a family or group of people using longitudinal or horizontal shots, posed or natural shots, and how symbols of community or culture might be photographed (Wang & Burris, 1997).

I then asked them to show and explain the mechanical and operational aspects of the camera to ensure that they understood how to use it. This also included taking a practice shot - of any object or person - in my presence, and to explain the significance of the photograph that they took. With some practice, I found that it was reasonably easy for them to handle the digital camera and photovoice proved to be an accessible method. Giving them the small task of taking a practice shot helped in developing their understanding on the different ways in which messages can be conveyed through giving meaning to objects, people, and places. Lastly, details on the photo assignments were explained to them.

3.7.5 Identification of Photo Assignments

The men were given two photo assignments. The first photo assignment asked them to (1) photograph the ways in which they think people see them. I asked them to think about their spoken and unspoken interactions with people, and then I asked, *"when people see you, how do you think they see you?"* This allowed them to portray their interpretation of what society understands about disability and how they themselves understand disability as a social construct. This assignment allowed them to think deeper about social issues and representations around their race, disability, and masculinity. Essentially, the aim was to get them to show a deeper understanding about the realities of prevailing issues surrounding disability and representation in and around their community (Fleming et al., 2009; Newman et al., 2009).

The second photo assignment asked them to photograph the ways in which they see themselves. I asked them to think of it as such, *"what do you see when you look in the mirror? So, imagine that the camera lens is the mirror through which you see yourself and how you would like others to see you."* This encouraged them to show how they would like to be seen, understood, and 'accepted'. Moreover, this assignment allowed them to represent themselves in ways that may resist stigmatizing representations (Kessi, 2011) and to challenge prevailing deficit discourses on people with disabilities.

They were given two weeks to complete this assignment. Within the two weeks, I availed myself to facilitate the production of their photo-stories. I always encouraged them to be open in engaging with members of their community and family for assistance or perspectives, especially regarding the first photo assignment, which is geared twards gaining an understanding of the ways in which they think society sees them. After the predetermined period of two weeks, we had our second meeting to discuss their photo-stories.

3.7.6 Discussion of Photo Assignments

When we met for our second meeting, I was surprised at the vast number of photographs that they captured. Among the fifteen men, there was a total of 120 photographs. The photographs were stored on a memory card and then transferred to the laptop where each participant' photographs were stored in a folder under his name. The laptop allowed them to see the photographs in a larger view which made it easier for them to select the most prominent ones.

They were asked to select three photographs from each photo assignment that best depicted the message that they wished to convey (Tijm, Cornielje & Edusei, 2011; Shamrock et al., 2016). The men were encouraged to take some time to reflect on the significance of the photographs selected before any critical discussion took place (Hergenrather et al., 2009; Tijm, Cornielje & Edusei, 2011). They were expected to explain the image in the photograph, what it represented, the significance of the image, and how it could contribute to social change. Through this process, they essentially produced photo-stories (Kessi, 2011). Ultimately, their photographs were accompanied by narratives about their lives, their communities, beliefs and aspirations, the way in which they perceive themselves, others, and finally, the social changes that they feel are needed in their communities.

I provided a few prompts to assist them in the creation of their phto-stories. I asked questions such as: *"Who took the photo?", "Where was it taken?", "Why did you take this photo?"*, *"What does it represent?"*, and *"What does it mean to you?"* Subsequently, this developed into narratives that showed their impressions of how people see them and how they see themselves. The aim was to empower these men through the thought process of narrating their photo-stories. The narratives that emerged from the photographs informed notions of social representation and self-representation which confronted issues on race, disability, and masculinity.

The discussion meeting was between 60-90 minutes long in a language that they felt most comfortable with, which was either Afrikaans or English. With their permission, the entire discussion was recorded, using a portable voice recorder. I transcribed the discussions myself. The conversion of the voice recordings into a written form was primarily part of the initial stage of the analysis of the data.

3.7.7 Dissemination of the Photo-Stories

Together with an assistant curator, Daniel Rautenbach, we curated an exhibition[7] of the photo-stories and narrative poems from the 30th of July to the 15th of August 2018 at the University of Cape Town's Centre for African Studies Gallery (see Appendix G).

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[7] Follow the link and enter the password to view a short video of the exhibition: https://vimeo.com/288057032
Password: still-human (if required)

The exhibition was a public event, but formal invitations were sent to community members and leaders, scholars and activists, policy makers, and advocates for people with disabilities, with the intention of building partnerships for community change (see Appendix H).

The men in the study collectively chose twelve photo-stories to exhibit on A2-sized prints on the walls of the gallery. Six of the photo-stories were based on the ways in which the men think society sees them, and the other six were on the ways in which the men see themselves. The physical positioning of the photo-stories was exhibited in a way that was parrallel to the height of people on wheelchairs. This was intentional to create awareness of how spaces can be accessible to people with disabilities.

A layout of Kenneth's narrative poem (see chapter 4) was exhibited on a wall in the gallery. The narrative poem was written on a long sheet of paper and was positioned in the middle of the wall and rolled down to the floor. This also created access to all and allowed able bodied people to engage with the poem by rolling it out on the floor or bending over to read it. Carlo's narrative poem (see chapter 4) was exhibited through a voice recording of him reading the poem. This was played in the background of the gallery and allowed people to hear his life story as they manuevered through the space.

Catalogues were handed out to people at the door of the gallery. This included information about the research study, the exhibition, and biographies of myself and the curator. The catalogues also included the two narrative poems for people to read and reflect on these stories in their own time.

There was a photo-book in the gallery which included all the photo-stories that were not exhibited on the walls of the gallery. Because of the large number of photo-stories, we could not exhibit all the stories through printing it out on the A2 boards. Instead we decided to exhibit it in a different way which was to put it all in a photo-book.

Some extracts from the life story conversations with the men were exhibited through vinyl writings on the walls of the gallery. These extracts gave some insight into the social and self-representation of a spinal cord injury, more specially in relation to coloured men with paraplegia.

The exhibition will later also move to the community hall of Macassar as well as other art galleries like the North-West University Gallery and Goodman Gallery in Cape Town. These exhibitions will be open to the public and these spaces will be curated in a way that allow the men in my study to ‘speak’ or advocate for themselves through their photo-stories.

3.7.8 Gesture of Appreciation

It was important to remunerate the men by showing respect and appreciation for their significant contributions to this study (Oliffe & Mroz, 2005). Therefore, at the completion of the study, all the participants were provided with a photo album of the photographs they took throughout the duration of the study. The photo album serves as a nonmonetary incentive. The six selected photographs of each man were enlarged and printed on a photo board with the significance of the photograph printed next to the photograph (as will be exhibited in the galleries) and given to them as a gift for participation.

3.8 Analysis of ‘Data’

3.8.1 Narrative Thematic Analysis

Narrative thematic analysis was used to analyse the life stories and photo-stories of the men in this study. Narrative thematic analysis includes two components of the life stories and photo-stories. The first component puts an emphasis on the ‘told’. This refers to ‘what’ is said (the content) in the life story and photo-story (Reissman, 2008), which was then converted into themes (Ross & Green, 2011). The second component interrogates ‘how’ and ‘why’ the content of their narratives was narrated in the way that it was (Reissman, 2008).

To achieve the first component of narrative thematic analysis, a thematic analysis was used. As previously mentioned, this component of the analysis was particularly interested in the content of the dialogue of the men. It focused on ‘what’ was said in the life stories of these men and the significance that they attributed to their photo-stories. According to Braun and Clarke (2006), thematic analysis is used to identify, analyse, and report on patterns or themes that are most prominent in the narratives. I particularly used this approach of analysis as it is known to organize and describe data in rich detail (Braun & Clarke, 2006).

In this study, there were seven stages within the process of analysis, namely: (1) the selection of photographs, (2) transcription of the discussion of these photographs and narratives of life-stories, (3) reading and familiarizing myself with the ‘data’, (4) writing overviews, (5) constructing narrative poems, (6) generating codes from the transcriptions, and (7) defining and naming the dominant themes.

In the first stage of the analysis, the men were asked to select three significant photographs from each photo-assignment that adequately and wholly depicted their experiences. They were then asked to critically discuss the significance of each of the selected six photographs. In this stage, the men played an active role in the analysis of their photographs (Wang & Burris, 1997).

In the second stage of the analysis I transcribed both their life story conversations and photo-story discussions. The third stage of analysis involved spending a considerable amount of time reading through the photo-stories and life stories to familiarize myself with them.

I then realized that there was a significant difference in the ways in which the life stories were constructed and told among the men. As previously mentioned, some men started narrating their story from the day that they were born to the present time (a ‘full’ life story), others started from the day of the accident to the present time (from the ‘middle’ of their life story), some only shared experiences of the present time (the end of life story), and others narrated from the present time back to the day that they were born (narrating back in time).

I then decided to include a fourth stage of analysis which encompassed writing a brief overview of each life story. This allowed me to see how differently the stories were told, what was said, and what was silenced. It was interesting for me to see how the men’s age in relation to the age of the injury played a vital role in how the stories were constructed and narrated. It was during this stage that my supervisor encouraged me to think about new and creative wats in which to present traditional qualitative ‘data’. This quest led to the constructing of two narrative poems from the qualitative ‘data’; these two poems conveyed the differences in how the stories about what it means to live with paraplegia were constructed and narrated. My supervisor and I were of the opinion that this way of fostering ‘data’ could well expand interpretive skills, raise consciousness about the social world, and bring about a unique perspective to the research study.

Similarly, theorists like Richardson (2000) and Furman, Lietz, and Langer (2006) argue that the goal of presenting ‘data’ though a narrative poem is to inspire an empathic, emotional reaction, and allows the reader to develop a deep personal understanding of the affective lived experiences. Representing ‘data’ through poetry has become an emerging and important tool of qualitative research (Richardson, 2000; Furman, 2004; Furman, Lietz, & Langer, 2006; Janesick, 2016).

Using narrative poems were valuable for various reasons. Firstly, the men spoke poetically throughout their narratives as they used an array of evocative and expressive metaphors to describe experiences. Furman (2004) regards such use of metaphors as an essential element of poetry. Janesick (2016) refers to this as ‘found data poems’, which is poetry found in the narrative and spoken transcripts. Secondly, a narrative poem communicates a range of lived experiences in an evocative and holistic manner (Richardson, 2000; Furman, Lietz, & Langer, 2006; Janesick, 2016). For example, it draws the reader into the life experiences of the men (Janesick, 2016), and provides the reader with insight into how masculinity was constructed before the injury. Furthermore, it encapsulates significant detail around the accident, and provides a nuanced understanding in the construction of masculinity after the accident as well. In the process, complexities about living with paraplegia become evident.

Therefore, the fifth stage of the analysis included choosing two narratives that were vastly unique in that they were differently constructed and told. For example, Carlo’s narrative was constructed from birth to the present, while Kenneth’s narrative was constructed from the present to the accident. In terms of group dynamics, Carlo happened to be the youngest while Kenneth was the eldest. Kenneth was also the one who had been living with paraplegia for the longest time, and his experiences were powerfully and metaphorically narrated. Carlo also happen to be the only man in the study who identified as homosexual. Given the richness of the range of narratives at my disposal, the decision to select two narratives was a strategic choice. Firstly, the selection of these two narratives offered the most interesting opportunities for engaging with the ‘data’. Secondly, I had to consider the word limit for my thesis, which meant that difficult choices had to be made; choices that had to be adequately justified and defended within the scope of the word limit.

I repeatedly listened to the recordings of Carlo and Kenneth's conversations while reading the transcribed conversation 'data'. I particularly focused on how they spoke about the impact that the injury had on their lives; such as the words that were emphasised, repeated, and expressed. Listening to the sound and expression of their words encouraged me to construct two powerful narrative poems that are presented as 'data'.

The process of constructing narrative poems from the transcribed qualitative conversations were as follows: I copied phrases and sentences that highlighted their experiences of the impact of the injury on their lives and transferred these to another word document on the computer. I arranged the phrases into stanzas and ensured that these stanzas represented the narrative flow so that the poem unfolded sequentially in the order in which it was spoken. As such, the poems are 'free verse' and does not necessarily fit poetic forms.

In the process of arranging the poem in stanzas, I found it challenging to think about the essence of the men's words and having to make decisions about what was essential to include and what to exclude (Furman, 2006; Furman, Lietz, & Langer, 2006). I honoured their pauses, repetitions, and wrote their exact words in the language that they spoke. Therefore, some parts of the narrative poems may contain grammatical difficulties. Presenting the 'data' in the way that it was told to me, evoked the expression of powerful emotions that might not have been easily presented in the traditional qualitative 'data' representation form.

Utlizing a narrative poem structure made it possible for me to reduce very dense conversations from about forty pages into a ten-page narrative poem, that were easily digestible (Furman, Lietz, & Langer, 2006) and maintained the fullness, depth and richness of the conversations. The narrative poems were treated as text. I analysed extracts from the poem thematically and apart from these poems, I also included a broader analysis and discussion of all the men's narratives more generally.

To include a general and broader analysis and discussion of the narratives, I incorporated the sixth stage of thematic narrative analysis. This involves the process of generating codes from the transcribed data of life-stories, narrative poems, and photo-stories (Braun & Clarke, 2006). Inductive coding was used to code the ideas that emerged from the discussions. This means that interesting features within the transcriptions were systematically coded across each transcription. For example, while reading through the transcripts, I used one-word labels or short phrases that stood out and contributed to answering the research questions.

Even though I was looking for themes of similarities and differences, I also considered how the stories cohered along a story line. I was interested in *how* these men constructed stories and *how* they made meaning out of their experiences. Thus, the use of language was crucial in this regard. I agree with Reissman (2008) in that language is a resource as it communicates meaning and puts an emphasis on certain points. For example, I found that most of the men used certain words, idioms, metaphors, and other figures of speech to describe their lived experiences. By looking for ambiguity, irony, paradoxes, and tone contained within the content of their life stories, I could pay careful attention to the functions of language and the meanings they convey. This is a particularly important component of thematic narrative analysis (Reissman, 2008). Subsequently, I could see that the narrative became layered which offered a richer account and generated more significant findings (Reismann, 2008; Ross & Green, 2011). During the seventh and final stage of the thematic analysis process the dominant themes were clearly defined and named.

Overall, the thematic part of the analysis helped me to understand what the focal points of the stories were. The narrative part of the analysis helped me to understand and attach meaning to the similarities and differences that I found across the men's stories. Together these analyses provided a more nuanced understanding of their lived experiences.

3.9 Translation and Interpretation

Temple and Young (2004, pp. 174) state that language is essential in constructing narratives on lived experiences and for understanding our sense of self. I encouraged the men in this study to share their life stories and photo-stories in a language that they felt most comfortable in and which they felt would capture the full scrutiny and richness of their experiences (Polkinghorne, 2005). I wanted them to understand that their language was relevant and that it would enable them to practice agency and power in constructing and describing their social worlds. Thus, even though all the men in this study are Afrikaans speaking, four men chose to construct and tell their narrative in English, while eleven men chose to do so in Afrikaans.

The men were relieved to know that they could share their stories in their home language. They assumed that the expectation would be to speak English as they know that the University of Cape Town is an English institution. This initially made them feel hesitant about their participation in the research project.

However, the shared understanding of the Afrikaans language and racial matching between the men and myself made them feel at ease in sharing their stories. This was evident in a response made by one of the men, *"ja, so nou kan ons openlik gesels in Afrikaans" ["yes, so now we can openly converse in Afrikaans"].*

During the analysis stage of the research, I translated extracts from the Afrikaans transcripts of their narratives into English. Temple and Young (2004) argue that researchers who can translate the 'data' themselves are best suited to do cross language data analysis. Both professionally and personally, I have extensive experience in speaking, working and living across languages. I am constantly entrapped in the dilemmas of translated worlds. I grew up speaking Afrikaans and English interchangeably. I attended an Afrikaans high school. Even though I see English as a valued second language, it is sometimes difficult to articulate and fully express myself in this language that I do not consider my own. However, the practice of writing, teaching and studying in English made it easier for me to find ways of expressing and articulating myself in this language.

Furthermore, I had also previously worked as a research assistant with Afrikaans 'data' collected from among Cape coloured women. My responsibility was to transcribe the 'data' and translate some of the Afrikaans dialect. Also, on the domestic front, I am quite familiar with rendering everyday translated communication between family, friends and colleagues. Moreover, to ensure the accuracy of my translations in this thesis, I confirmed my understanding of words and phrases with my co-supervisor who is born and bred on the Cape Flats and knows the slang. Before discussing the issues within the translation process, it is important to identify my epistemological position within the process of translation.

One of the epistemological positions that I hold is that I cannot relate to the experiences of living with a disability, thus I attempted to remain neutral throughout the translation process, letting the narratives guide my analyses, before forming my own opinions. My translations and interpretations of the narratives corresponded with my supervisors understanding of the translated narratives as my supervisors tried to remain objective about a lived experience that they do not necessarily relate to in the same way as the men with paraplegia.

I cannot dispute the power relations involved in translating and interpreting a narrative or experience from Afrikaans into English. For instance, it was quite possible for me to manipulate the meaning of the Afrikaans narrative in the process of translating into English.

However, I was familiar with the geographical and social location in which these men reside, thus, how I understood and interpreted their stories was parallel to the meaning that they wished to convey in their narratives. In this way, I tried to stay true to the translation and interpretation of their lived experiences, guarding against acts of manipulation.

Albeit there was no confusion in interpreting or translating narratives of those who spoke fluent Afrikaans - the same way in which I speak and understand the language – there was some confusion with regards to the differences in how the language was used, spoken and understood among some men from the Cape coloured communities. It is important to address the implications of the relative positions that the men in this study hold within the language hierarchies (Temple & Young, 2004). I found that there was a language hierarchy within the Afrikaans language because of how differently it is spoken and understood in different social and geographical locations. For example, I speak Afrikaans fluently because of the predominantly white Afrikaans schools that I attended in the North-West province. Some of the men from the Cape Coloured communities spoke *Afrikaaps* or more formally known as *Kaaps*. This language is a unique variety of Afrikaans predominantly spoken by Cape coloureds on the Cape Flats and Cape Metropole area. According to Blignaut (2014:45) *Kaaps* is defined as a colloquial language that is historically bound to specific geographical locations in Cape Town such as the Bo-Kaap and District Six areas where people of mixed racial descent have lived for over a century.

Kaaps speakers use English words interchangeably in their talk. Afrikaans speakers, like myself, may understand *Kaaps*. However, there are some phrases and words that are unique to *Kaaps*. There are differences in dialect and meanings of metaphors and idioms. These differences became apparent through the conversations with the men, more so through the process of translating *Kaaps* to English. Because *Kaaps* is not considered an official South African language, it is often frowned upon, while Afrikaans is considered more esteemed or the ‘correct’ way of speaking Afrikaans. This difference in power may also influence the translation of meaning (Temple & Young, 2004).

When ambiguity or confusion in the use of words or phrases occurred, I always asked them to repeat it for clarity. I reminded them that they were the experts of their stories and lived experiences, and that I had little knowledge about their experiences, thus it was important for me to fully understand what was being said (Oliffe & Mroz, 2005). After they clarified a word or phrase, I would give my understanding and interpretation of the word or phrase.

They would agree or correct my interpretation. Therefore, it was particularly important for me to employ the member checking approach of rigor and trustworthiness. This required me to present to the men a draft of the findings chapters for them to confirm that the translation and interpretation of their stories were accurate. This approach is further discussed in the following section of the thesis.

There were also language specific conditions in the translation from Afrikaans to English that may have influenced the final research product (Temple & Young, 2004). For example, directly translating a phrase from Afrikaans to English, sometimes resulted in a change of sentence structure, segmentation and rearrangement of the phrase to bring across the true meaning in English. Sometimes the semantics of the Afrikaans phrase was lost in this rearrangement and reconstruction of the phrase to English. There were times when I had to stop the translation process and think carefully about the meaning of the phrase before continuing to translate it into English. The structural differences of Afrikaans and English contributed to difficulties in bringing across the cultural meanings that were deeply embedded in linguistic expression (Temple & Young, 2004).

I chose to include the Afrikaans text as well as the translated text in the analysis chapters as I wanted their stories to be representative of their position (Temple & Young, 2004). Even though issues of translation and interpretation were appropriately managed, it must be said that any person reading this body of work will probably produce their own understanding of the text because our understandings and interpretations of text is influenced by our different lived experiences (Temple & Young, 2004).

3.10 Ethical Considerations

After I introduced myself and explained the purpose of the study, and before the conversation on their life story commenced, I briefed the men on the ethical issues around their involvement in the study.

3.10.1 Autonomy

The men in this study were informed that the conversations would be confidential as the protection of individual confidentiality is vital for the retaining of their dignity (Wassenaar, 2006). I told them that I was the only person with access to the tape recordings and that these recordings would be stored in a safe.

I also relayed that their identities would be protected using pseudonyms in the transcripts and research dissertation. Like the findings of Arendell (1997), some men objected to the idea of pseudonyms and did not mind waiving their confidentiality. These men insisted that their names be used in the research dissertation. They asserted that the focus of the study was on their life stories and as such it was important for them to see their names telling their stories. However, I still maintained confidentiality for those who agreed to the use of pseudonyms to protect their identity. Before submitting the research, they would have the opportunity to ensure that their stories were accurately depicted and narrated.

3.10.2 Non-maleficence

Considering the sensitive nature of this research, and that speaking about their injury may be an emotionally distressing experience for them (Corbin & Morse, 2003), the men were assured that they would not be obligated to respond to questions that made them feel uncomfortable. They were also assured that they would be treated with fairness and equity during all stages of the research, and that the research process would not cause them any harm.

3.10.3 Informed Consent

The men were introduced to three types of consent documents that they had to complete. The first informed consent document (see Appendix A) was based on the general ethical procedures such as the principles of respect for persons, beneficence and justice (Blanche, Kelly & Durrheim, 2006). It provided an outline of their rights and responsibilities and entailed a clear, detailed, and factual provision of appropriate information regarding the nature of the research study (Meltzoff, 1998). This consent document included the following information: (1) the focus and aim of the study; (2) the use of pseudonyms to protect their identity; (3) the assurance of confidentiality; (4) and that their involvement was voluntary, and that they had the right to withdraw at any time. They were asked to formalise their consent through signing the document. This would serve as written proof of their agreement to participate in the study.

The second consent document (see Appendix F) was based on the photo-story element of the study. This document included the same information as the first document. However, it required a formalised agreement regarding their participation in this aspect of the study. The third consent document (see Appendix E) also included the same details as the first and second consent document. In addition, this document also required a signature from the persons who featured in the photographs, as having granted permission to be photographed.

Should a photograph be taken of a minor, then the parent or legal guardian would be required to sign the document. It was also made clear that this document also serves as permission from the persons featured in the photograph to use the photographs for exhibition and publication purposes to promote the goals of the study.

3.10.4 Debriefing

After each individual conversation, the men were debriefed on the aim and focus of the study. They were then informed about the fruitfulness of their stories and the vast potential it has in producing insightful and important knowledge. They were given the opportunity to ask questions or express any concerns regarding their stories and involvement.

3.11 Rigor and Trustworthiness

For the sensitive and difficult nature of this study, certain mechanisms were used throughout the process of conducting and writing the research which ensured that reliability and validity - or the rigor of the study - was achieved. These strategies included prolonged engagement, rich description, triangulation, member checking, and peer examination.

3.11.1 Prolonged Engagement

Prolonged engagement was one of the strategies that was used to assess the rigor and trustworthiness of this study (Creswell & Miller, 2000; Krefting, 1991; Onwuegbuzie & Leech, 2007). This involved spending about four hours, two days per week, at Bridging Abilities, two months before the research commenced. The men became accustomed to my presence in their space (Onwuegbuzie & Leech, 2007). Moreover, spending sufficient time with the men at Bridging Abilities helped in building trust with them, getting to know their culture and language, and it allowed me to identify and document recurrent patterns and themes that emerged through observation (Krefting, 1991). For example, Kenneth was always tired and did not engage much in the physical exercises but enjoyed conversing with the other men, while Carlo’s jokes and bubbly personality always made everyone laugh.

3.11.2 Thick, rich description

Prolonged engagement greatly contributed to writing thick, deep and rich detailed accounts of the men. This strategy establishes rigor and trustworthiness through detailed descriptions of the setting, the attitudes of the men, explicit events and behaviours (Creswell & Miller, 2000; Onwuegbuzie & Leech, 2007). These descriptions create authenticity and were especially helpful in the development of the case studies. It was important for me to write these descriptions in a truthful and comprehensive manner that allowed insight into the context of these men, and ultimately, allowed the readers to develop a closer connection with the descriptive events or unfolding of conversations (Creswell & Miller, 2000).

3.11.3 Triangulation

I also used triangulation to enhance the rigor and trustworthiness of the research study. This involved the convergence of multiple perspectives and understandings for mutual confirmation of the development of the case studies and thematic themes (Krefting, 1991; Creswell & Miller, 2000). The multiple perspectives were assessed through comparing perspectives and interpretations with one another so as to cross-check the transcriptions of the narratives, and to then finally reach a stage of confirmation regarding the interpretation of the narratives (Krefting, 1991). This study specifically used the triangulation of data methods. This means that the themes of the narratives as well as the notes from the prolonged engagement, transcriptions of the life story conversations, and transcriptions of the photo-stories, were all compared (Krefting, 1991) by myself, my research supervisor, co-supervisor, and academic mentor/critical friend. Through triangulation, the analysis of the narratives minimized distortion from my single perspective, allowing the stories to make sense to more than one person. Therefore, the analysis sought to convey a faithful representation of the themes that emerged from their narratives.

3.11.4 Member Checking

Krefting (1991) posits that the ability of the men to recognize their experiences in the research findings may be central to assessing rigor and trustworthiness. For this reason, the continual testing of interpretations and conclusions with the men was employed. This approach was executed through ‘reporting back’ by providing each man with a draft of the findings section. They were asked: (1) to confirm that the interpretation of their experiences was accurate and that the themes made sense; (2) whether their responses were developed with sufficient evidence; (3) and whether their experiences were not misinterpreted.

This strategy aimed to establish if their narratives had been accurately translated and interpreted. Contrary to the findings of Oliffe and Mroz (2005), the men in this study showed interest in revisiting the conversation through carefully and thoroughly reading through their transcripts – some of over 30 pages. After reading through it, they were involved in the analysis process that was important in shaping the research study.

3.11.5 Peer Examination

This process involved a close and intense review and discussion of transcriptions and the final analysis with my supervisor and co-supervisor (Creswell & Miller, 2000). This procedure was used throughout the process of the study. There were countless sessions of debriefing on the evolving design of the study, insights, and concerns that emerged. My assumptions were greatly challenged by my supervisor and co-supervisor, and they constantly introduced ways in which I could further enhance the methodological and analytical process. In these sessions, they were a soundboard for my ideas, and were good at playing devil's advocate through interrogating the methodology and analytical process and my interpretations of the narratives.

As a researcher, I believe that it is important to take responsibility for attaining trustworthiness throughout the research process because it contributes significantly to the quality of the research. Therefore, I agree with theorists, such as Morse and colleagues (2002), that without rigor, research is worthless and loses its utility.

3.12 Reflexivity

In this section, I provide a detailed reflection on the awareness of my own positionality and the ways in which this may have influenced the research process and outcome of the study. I explore this process of developing awareness through a critical self-reflection on the intersections between my own positionality as 'the outsider'and 'the insider'. Occupying these positions requires an understanding that the researcher's socio-political context, in relation to issues of race, gender, class and language, forms part of narrative interpretation (Dwyer & Buckle, 2009). My own process of self-reflexivity is an act of respect towards the men whose stories are told in this study.

According to Guillemin and Gillam (2004), reflexivity in qualitative research is the continual process of critical reflection on the kind of knowledge produced and the ways in which such production occurs. For Darawsheh (2014), being reflexive means being transparent as a researcher, about recognizing one's own situatedness in conducting research and analysing 'data'. Berger (2015) contributes to this notion of transparency by suggesting that the researcher may have an influence on the setting, the respondents, the questions asked, 'data' collection methods and interpretation.

Various theorists within qualitative research studies have suggested that reflexivity involves an internal dialogue and critical self-evaluation of the researcher's positionality and power relationship with respondents (Guillemin & Gillam, 2004). In addition, focus is also directed to the researcher's presence, actions, feelings, and preconceived perceptions that may influence the construction of knowledge (Guillemin & Gillam, 2004; Watt, 2007; Darawsheh, 2014; Berger, 2015). The value of reflexivity in this present study was used to improve the rigor of the research by recognizing the limitations of the knowledge produced (Guillemin & Gillam, 2004), and to facilitate an understanding of how paraplegia impacts the lives of coloured men living with the injury, as well as how the research impacts me as the researcher, and how I impact the research.

3.12.1 The Outsider: 'Out of place' on the Cape Flats

The outsider is defined as a position occupied by researchers who do not have much commonality with the group being studied (Breen, 2007; Dwyer & Buckle, 2009). Occupying this position has contributed to me feeling 'out of place.' I began to explore the notion of feeling 'out of place' through dialoguing with myself in my journal. I wrote the following entry the night before I embarked on the first journey to Macassar to talk to prospective participants for my study. I chose this piece as it adequately reflects my fears and anxiety of being an 'outsider' to the world of those living with paraplegia.

> I am afraid that they will ask: "why me?" How would I respond? Is it disrespectful of me to confidently stand against or in front of their wheelchair, gaze down at them as I approach them to be a part of this study? I am feeling anxious. (Journal entry, 7th June,2017).

I took a train from the Southern Suburbs[8] of Cape Town to Macassar, feeling anxious, afraid, and self-conscious that I would look like a lost stranger on the train and in the community. These feelings spoke to my sense of alienation from the community I was entering in to. I ensured that my belongings were hidden because muggers who wander around often target those who look ‘out of place’. I did not only look out of place, I also felt out of place, and I did not want to be noticed. I intentionally tried not to overdress. I wore dirty sneakers and an oversized hoody – like many working-class men on the Cape Flats. Previous experiences of conducting research with coloured men had taught me that they can feel intimidated when ‘interviewed’ by a formally dressed researcher (Louw, 2015). This finding is echoed by male researchers such as Oliffe and Mroz (2005) who have conducted research with men from working class backgrounds.

I secretly used my phone to locate myself on Google Maps to ensure that the train was heading in the right direction. I whispered to the stranger next to me, *“where do I get a taxi from the train station to Macassar?* The people in the taxi all seemed to know each other. I was the only silent person until I had to shout: *“dankie driver” – “thank you driver.”* Everyone turned their heads to look at me. I knew that I had introduced myself as the stranger, the outsider, entering the community.

Upon my arrival at the Bridging Abilities centre, a few men in wheelchairs welcomed me. I greeted them politely and tried to engage them in conversation. In these conversations, I became more aware of my shifting identities, and the layers of differences that had privileged me when compared to them. I became aware of my race, gender, class, physical ability, age, sexual orientation, theoretical and political stances. Developing this awareness allowed me to get a sense of my own location within the research, and how such locations may impact the conversations with the men, and ultimately, affect the outcome of the study. For example, when I introduced myself, I mentioned that I was currently studying at the University of Cape Town. Gavin made me aware of how the affiliation with the University positioned me as an outsider to their immediate reality and to the broader social realities of being coloured on the Cape Flats.

GAVIN: “Jy is van ‘daai’ coloureds wat dit gemaak het in die lewe, jy’t nie jou lewe gewaste nie.”

“You are of ‘those’ coloureds that made it in life, you did not waste your life.”

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[8] Suburbs in the south of Cape Town and along the slopes of Table Mountain. The Southern Suburbs is close to the University of Cape Town and known as the more affluent areas of Cape Town.

He placed me in the category of coloured people that *"made it in life".* I was amongst those elite group of coloureds who *"made it"* out of their communities, out of the intergenerational curse of poverty, violence, crime, gangsterism and addictive substance abuse. Gavin placed himself in a category of coloured people who 'did not make it' in life. I looked at the faces of the men around him, some nodded in agreement, and others smirked as our eyes met. This was their space; one they were familiar with and which they share with others 'like them'. I was quickly made to realise that I did not belong – not only because I was able bodied, but also because of the type of coloured I represented in that space. My outsider status was therefore being exposed to multiple levels. I then allowed the conversation to unfold.

JOHAN: "Waar is die universiteit?"

"Where is the university?"

GAVIN: "Dit is mos die een daar by die berg"

"It is the one by the mountain"

The men stared at me with wonder. I anticipated this reaction as I have learnt that the perception that many people on the Cape Flats have of coloured people who study at the university is not as simple as Gavin puts it. The general perception is that coloured people who study at the University of Cape Town are "better coloureds" than those who remain on the Cape Flats. The association of the University of Cape Town with being able to access white privilege stands out here, especially since the majority of those on the Cape Flats are still excluded from sharing in such privileges. I became aware of how the boundaries of my relations of belonging shifted between who I was in the middle-class Southern Suburbs of Cape Town and how I was being represented on the Cape Flats. In fact, I was now overly conscious of how I was representing myself in these two contexts.

For example, on the Cape Flats, I consciously dressed and spoke like the men who lived there. In the Southern Suburbs, I was more attentive to the clothing I wore; I only spoke eloquent English and I often rejected speaking and engaging in Afrikaans. These interchangeable identities signify my reality which highlights a degree of privilege, especially in the sense that I could access the world of those on the Cape Flats, while they in return, could not really access my world in the Southern Suburbs. This speaks strongly to the power dynamic inherent in our relationship. It was a dynamic I would have to negotiate with great care, if I was to make any headway in my study. My ability to shift identities based on social location and interaction is exemplified in Wendell's comment.

WENDELL: "Waar in die kaap bly jy?"

"Where in the Cape do you stay?"

I always struggled with how much information I could share about myself (even during the life story conversations). I was aware that sharing truths about myself was important because I expected the same exchange from them. I gradually became more sensitive and responsive to their personal questions about me. I answered Wendell by telling the group that I resided in an apartment not too far from the University. Many of the men said that they had never been to the Southern Suburbs of Cape Town; their realities were far removed from the culture and elite lifestyle in the Southern Suburbs. Wendell mentioned that I am *"lucky"* to live in comfort. Indeed, it is the assumption that those who live in the Southern Suburbs, on the slopes of the mountain, live in comfort.

Kurt told me how difficult it is for him to live in the house where he currently resides. Many of the men nodded as they agreed that their homes are not spacious enough for them to manoeuvre in. I remained silent, because I could not share in their experiences of living in a home that is uncomfortably small. After acknowledging that I am an outsider to their realities by showing empathy in attentively listening to some of the truths that they shared on their lived realities, I felt that they were more comfortable in sharing more about their lives. Despite the limited space, some men invited me to their home to share their life story. I entered their sacred place - where they felt safe and comfortable.

Many had never put their experiences into words because no one had been interested in listening to what it means for them to live with a spinal cord injury. These men had not explored ways to explicate their experiences or convey their emotions in words. They never thought that their stories were important. Subsequently, they did not know how to construct a life story. I told them to imagine that I was the author of their biography and that I was interested in their life story. I told them, as Berger (2015) writes, that *they* were experts of their lived experiences and as an outsider to this lived experience, I wanted to understand how the injury had impacted their lives. I acknowledged that I was an able-bodied person who was unfamiliar with the injury, but that I was hoping to learn from them. In this way, others would also gain insight into what it means to live with paraplegia.

Similar to Berger (2015), I also took an open-ended approached to the conversations which allowed the men to narrate their life stories innovatively. For example, I told them that they could start to narrate their life stories from which ever temporal point felt comfortable. As a result, each story was differently constructed and told. Each story evoked poignant emotions within the men and me. I was always moved by their bravery and resilience while sharing sensitive stories. I was moved by how they spoke about who they were and who they are. Many never imagined that they would be paralysed. They made me aware that a spinal cord injury can happen to anyone - at any time. They reminded me to be more appreciative of the present moment. As the outsider who may never understand what it means to live with paraplegia, I was constantly reminded of what it means to be human.

I transcribed the conversations immediately after each meeting, and after about two days, I had the next meeting scheduled. During some conversations, I realized that I was still overwhelmed by the previous life story. This required on-going reflection as my thoughts and emotions were constantly in conflict. My thoughts always convinced me that because I am an outsider, I could easily detach from one life story to listen to the next one the following day. I underestimated how emotionally attached I became to the teller and the story. Perhaps it was because I occupied an outsider position that I could not easily make sense of the heaviness that I felt after each life story conversation.

It was ironic that I always felt emotionally drained and tired, as though my emotions were at war because of the deepness of their stories. Therefore, even though I felt this way internally, I found strength in their stories to present myself in a way that did not reflect the fatigue. I had to put on a façade that always ‘appeared to be’ ready to listen. These conflicting reactions may have had an impact on the ways in which I heard, understood, and potentially even disregarded certain aspects of their narratives. As a result, this may have influenced my ability to present the narratives as candidly and sincerely as the voices of the men in this study. All I could do was to represent their voices as authentically as possible to capture the whole person. So, I was constantly aware of my need to be true to them.

Conducting life story research on the experiences of men living with paraplegia is challenging. Watt (2007:87) states that, “conducting research, which looks so intensely at the personal lives of others, is not for the faint hearted.” Not only are the individual lived experiences vastly different, but they are told from different stages of self-healing to make sense of their experiences (Frank, 1995), as well as helping me, potentially, to understand the nature of living with paraplegia. Speaking to the men required me to reflect on how to carefully phrase and rephrase questions depending on whom I spoke to. The challenge in negotiating the phrasing of questions over the course of the study is expressed in an extract from my journal entry:

> Sometimes I want to ask them direct questions to receive direct responses. I am concerned that this may be insensitive and may hurt them. I hope that they will be honest in telling me that they do not feel comfortable in answering my questions. (Journal entry, 12th June 2017).

Some questions were difficult for them to answer because it required them to revisit some painful moments and to reflect on 'when' and 'how' their life changed. It required them to articulate their lived experiences in a way that was comprehensive to an outsider. After the fifth life story, I found solace when some men explained that disability is a lived experience that cannot easily be explicated, and that it must be lived to truly understand what it means. Men like Albert, Kenneth and Carlo made me aware of this truth.

ALBERT: "jy sal nie weet hoe dit is nie tot dat jy dit oorkom"

"you will not know how it is until you experience it"

KENNETH: "mense wattie meeste het om te sê, sal nooit, vi 20 jaar in hierdie skoene kan loepie."

"people who have the most to say, will never, be able to walk in these shoes for 20 years."

CARLO: "once hulle in my skoene gaan wees sal hulle 'n ander persepsie het van my."

"once they are in my shoes they will have a different perception of me."

As an outsider, I did not always understand their interpretation of the medical explanation of the injury. I was desensitized to certain information. For example, Albert cried while talking about his experiences of the inefficiency of medical assistance from the local hospital. I felt detached from his emotions because I am privileged in that I have a medical aid scheme. Thus, I never have to wait for long periods for medical assistance while in pain.

Breen (2007) puts forward the idea that sometimes researchers who occupy the position of the outsider can be desensitized to the use of ‘language’. This was evident in my experience of speaking to, or about, people with disabilities. For example, I initially referred to the men as “disabled” and “paraplegic”. Johan corrected me by saying that he did not identify as “disabled” and that it was rather offensive to speak of “disabled”, “the disabled” or “paraplegic” men. Through learning about the importance of language, I consciously wrote about “the men in the study” and “the men”, “they” or “them”, both to respectfully acknowledge my position as an outsider in relation to their experiences as insiders, and to avoid leaving the impression of fully understanding or speaking from the experience of living with paraplegia.

Being an outsider therefore helped me to identify my limited understanding in relation to their experiences. However, the ability to be reflexive and to articulate the limitations involved is enhanced by drawing on the insights of the men in this study who are experts in explicating their lived realities. I believe that my position as an outsider in relation to their lived experiences made them feel comfortable in sharing their life stories (Berger, 2015). The depth of their stories attests that they felt comfortable speaking about emotionally and psychologically difficult experiences. This was also evident in the hours that I spent in their homes. Perhaps it was because of this position that they did not necessarily withhold information, but rather over-explained experiences. Perhaps it was comfortable for them to speak to me because of the very reason that I was a stranger to their world, someone who possessed no knowledge about what it means to live with paraplegia.

This was evident in the talk about sex and sexuality because the ‘incapacity’ of sexual intercourse was difficult for some married men to talk about. They only spoke about their experiences of sexual intercourse later in the conversation, while many unmarried men spoke about these experiences quite early in the conversation. Some married men often avoided eye contact while talking about sex. Their responses were short and sometimes vague. I had to prompt them with questions for clarification. In Lesch and Adams (2016) study on the experiences of sexual intimacy among heterosexual coloured couples in South Africa, their participants also showed discomfort when responding to questions relating to sexual intercourse. Lesch and Adams (2016) argue that this discomfort may be due to the social perception in the coloured community that sex is private and should not be talked about. Therefore, the men were resistant in sharing their experiences.

In addition, one can argue that it was more difficult for them because I am not married and much younger than them. The position of the space between being unmarried and young, made me sensitive enough not to persue uncomfortable questions about sex.

As I reflect on the outsider position, I realise how fluid positions like the ‘outside’ and ‘insider’ are. There is also a ‘space between’ because I did not always remain the outside or the insider. I become more aware of this when I realised how immediate and real their stories are to me. I carry their stories with me as I reflect on their narratives before I sleep - and sometimes in my sleep. I carry their stories with me as I teach about them. I cannot separate myself from this research. As my positionality affects the analysis, so does the analysis affect who I am and who I am becoming. I agree with Dwyer and Buckle (2009, pp. 61) that, “the intimacy of qualitative research no longer allows us to remain true outsiders to their experiences, because of our role as researchers, we do not qualify as complete insiders. We now occupy the space between.”

3.12.2 The Insider: “Just like us”

The insider refers to a position occupied by researchers who belong, or share characteristics, or experiences among the group of population under study (Breen, 2007; Dwyer & Buckle, 2009; Greene, 2014). Our communal identities such as race, gender and language were important in the production of this work as it positioned me as an insider in some respects. This position contributes to elements such as rapport (Williams & heikes, 1993), openness and vulnerability (Dwyer & Buckle, 2009) which were facilitated through prolonged engagement with the men before meeting to talk about their life stories.

Our shared identities as male allowed the men to speak about their experiences of humiliation in the lack of control over their bowel and bladder, and the shame and embarrassment that they often experienced in their sexual ‘incapacity’. Various theorists have found that men who speak to male researchers are more direct, as opposed to speaking to a female researcher where experiences are often filtered (Oliffe & Mroz, 2005).

Dwyer and Buckle (2009) argue that shared membership automatically provides a level of trust and openness that would likely not have been present otherwise. Carlo, who identifies as homosexual, assumed that I was homosexual. Therefore, he may have felt comfortable in talking about his experiences of sexual intercourses with men prior to the injury. However, he spoke about these experiences with the assumption that I knew how the power dynamics or control and pleasure unfolds in homosexual intercourse.

This relates to Williams and Heikes (1993) suggestion that men who have conversations with men usually assume that they share certain background experiences. Furthermore, some of the men assumed that I was heterosexual.

KURT: “Jy weet mos hoe vrouemense aangaan wanneer ons hulle chise”

“You know how women can react when we approach them”

ENRICO: “jy weet hoe operate ons op die flats”

“you know how we operate on the flats”

Theorists like Kanuha (2000), Brannick and Coghlan (2007), and Greene (2014) who had occupied the insider position in their research, advise insider researchers not to make assumptions about the meaning of phrases, but to probe respondents as much as if they were outsiders. To avoid these deferring responses, I often asked them to explain what they meant by these statements. Subsequently, conversations on sexual intercourse with their intimate partners became easier because of our shared gender identity and shared language.

Because I had some knowledge on the population group - as I previously conducted research with coloured men on the Cape Flats - I had a preunderstanding of nuances about the construction of masculinities on the Cape Flats, the culture, the language and everyday jargon which facilitated an easier entry into this study. Therefore, the way in which these conversations were orchestrated in a communal language around the table, felt as though we were just men having conversations that ‘men usually have’ in a language that is comprehensive and easy to articulate. Perhaps this would not have been possible if my gender and racial identity was different.

WENDELL: “Ek voel goed om hier oor te praat, want jy is ’n man net soos ek”

“I feel good to talk about this, because you are a man just like me”

Most of the men cried at some point in our conversation. Expressing this kind of vulnerability without feeling ashamed, implied that they were comfortable with me. Sometimes their deeply personal and painful life stories made me cry too.

During these times, I could not focus on their narratives because of the distraction of my self-reflections on their experiences, my perceptions, and the privileges that I embody. I always allowed myself to be human by showing emotion in what I heard and felt, albeit I was aware of how much emotion to show, as I did not want them to withhold important information. Acknowledging my emotional response was important as this response can shaped my interpretations of their narratives (Mauthner & Doucet, 2003). However, I am indebted to the men who showed vulnerability through emotion, because they did not suppress the way they felt, neither did they withhold the experiences that made them cry.

I have discussed the different roles and positions that I occupied throughout the collection and analysis of the ‘data’, and ultimately, the impact this may have had on the outcomes of the research. This was discussed through an analysis of the position and role of the outsider and the insider. Through a reflection on my experiences of occupying spaces like the outsider and the insider, I conclude that occupying these spaces makes the researcher’s own positionings transparent, but also sharpens a critical awareness that facilitates the ability to be authentic and honest in accurately and adequately presenting the narratives as they were shared with me.

CHAPTER 4

CASE STUDY'S: THE LIFE STORY OF KENNETH DU PLESSIE AND CARLO KLINK

4.1 SECTION A: THE LIFE STORY OF KENNETH DU PLESSIE

4.1.1 Introduction

It was interesting for me to listen to the ways in which the men in this study began to construct their life stories. Some men like Carlo, Oppies, Johan, Wendell, and Devon started narrating their stories from their day of birth to the present, whereas men like Ridah, Enrico, Kurt, Allen, Franklin, Michael and Norman began their stories from the day of the accident to the present, and only briefly spoke about childhood memories. Kenneth, Albert and Gavin started narrating their story from the present time moving backwards to the injury and life before the injury. All the stories were told differently. There was no similar sequence of structure of life events. Some spoke more about their life before the injury. Others spoke more about the day of the accident and the injury. While others spoke less about life before the injury but more about life after the injury. Because their stories were so uniquely told, their narratives provide a vast perspective and contextualization of lived experiences around the intersection of race, disability, masculinity, sexuality, class and social location. This multi-dimensional perspective greatly contributed to the richness of their narratives.

In this chapter, I present the life story of Kenneth du Plessie who identifies as heterosexual, the oldest in this study, and had lived with paraplegia for twenty years. I also present the life story of Carlo Klink. He identifies as homosexual and the youngest man in this study. He lived with paraplegia for nine years. These life stories are unique in the sense that they show how life stories pertaining to a spinal cord injury are differently constructed and told. These narratives also suggest that the age of the narrator may influence the ways in which the stories are told.

In this section of the chapter, I focus on Kenneth's life story. His story is composed and told through a narrative poem that was constructed from the transcription of his life story conversation. Considering the plot of his story, and the tensions underlining his experiences of how paraplegia impacts his life, I primarily draw on Arthur Frank's (1995) work on storytelling and will argue that the storyline of Kenneth's life story is a restitution narrative.

This chapter does not focus on what is said about the impact that paraplegia has on his life, as this is discussed in the other chapters of analysis (chapter five and six). Instead, this chapter focuses on how narratives are told about paraplegia.

4.1.2 Introducing Kenneth du Plessie

Kenneth is a 55-year-old coloured man living in Macassar. He is unmarried with no children and worked as a time-keeper on a building site for a courier company in Somerset-West. At the age of 35, a spinal cord injury left him with a complete T4 diagnosis (no sensation and no movement) and he has been unemployed since the injury. Kenneth appears introverted and calm - quite inhibited and soft-spoken. He only speaks when addressed and most of the time he seems lost in his own thoughts. However, when he does open to share his thoughts, he shares generously.

4.1.3 Orientation around the Conversation

It was raining on the day we arranged to meet. I was unsure if Kenneth would be at the Bridging Abilities organization, as many of the men with paraplegia prefer not to be on the road and in their wheelchairs in the rain. Taking this possibility in consideration, I arrived a few minutes earlier than arranged – so that I would mingle with the men who were there, with the hope that one of them would be ready and willing to speak to me.

To my surprise, Kenneth was freely stirring around on his wheelchair whilst waiting for me. I smiled when I saw him, and he smiled in acknowledgement when our eyes met. After shaking his hand in greeting, I graciously asked him whether he was ready to talk to me. He gently stroked his hand through his grey hair and softly responded, *"ek het baie seer vandag" – "I have a lot of pain today"*. I looked at him and showed empathy by suggesting that we postpone. Kenneth however, was adamant to continue our meeting, especially since I had travelled by taxi and train for two hours just to meet with him.

He asked me to push him to the office that was allocated for hosting these private conservations. I was quite surprised at how light he felt in the wheelchair. After entering the office, I offered to make him a cup of coffee, and while doing so, I explained that I was interested in listening to his life story, which he could relay in whatever language or structure he felt most comfortable with. I reassured him of the absolute confidentiality of the conversation. We were seated in the middle of the office. The office felt bigger than usual with Kenneth's petite body in the chair. He avoided eye contact and seemed deep in thought.

From where I was sitting, his body looked weak and exhausted and he seemed to be in quite a bit of pain. He nodded his head in agreement that he understood the expectation and purpose of having the conversation. Before I asked him whether he was ready to begin, he just began talking.

4.1.4 The Conversation

Kenneth started speaking a few seconds before I pressed the record button. He spoke gently; as if every word was challenging to utter. The spontaneous spasms between him thinking, or between words and phrases, allowed him to take his time in speaking. It seemed as if he was carefully thinking of what, and how, he could tell a comprehensive story. To me, the almost uncomfortable silences between him thinking and speaking created the impression that he might not have been ready to share his life story. Perhaps he felt limited in the language he used to adequately describe his experiences, or perhaps his hesitance was in relation to whether I would be able to understand what he is saying, or whether he could trust me. Maybe Kenneth was still trying to make sense of his experiences, and he just needed time to unpack, dismantle, and reflect on who he was, and what his life was like, 20 years ago. The intimate space between us in the middle of the spacious office felt heavy. And for the first time, I questioned whether I was ready to hear his story.

4.2 *The Narrative poem of Kenneth du Plessie*

i *(Introduction)*

Ek het altyd gestremdes gesien
nooit myself
in 'aai skoene geplaasie.
Ieman inne rolstoel
was manet,
ieman met crutches
was manet.

I have always seen disabled people
never placed myself
in those shoes.
Someone in a wheelchair
was just that,
someone with crutches
was just that.

Ek het altyd gedink
aan miswaardigheid,
en altyd gedink:
‘*ek salit nie maakie’,*
‘ek sal my liewe weg niem’,
‘ek salie met 'it kan liewe nie’.

I always thought
of disgrace,
and always thought:
‘I will not make it’,
‘I will take my life away’,
‘I will not be able to live with it’.

Soes as ieman praat
oorre siekte
wat djy nogie gehad hettie,
djy het net jou eie persepsie.
Ma as djy 'it experience,
soesie effek wattie siekte het,
dan het djy ’n different begrip.

Like if someone talks
about an illness
that you have not had,
you only have your own perception.
But if you experience it,
like the effect of the illness,
then you have a different
understanding.

ii *(Foreword to becoming paraplegic)*

Toe gebeur'it.
Die pil van hell;
die battles
die trials en tribulations,
alles,
wat ekkie viwag hettie.

Then it happened.
The pill of hell;
the battles
the trials and tribulations,
everything,
that I did not expect.

'it het alles van my ve'eis
om rerag diep te krap
vi selfmoed.
Om rerag yt te sien na môre,
wan alles het verkeerd gegaan,
en elke dag,
’n struggle vi survival.

It took everything from me
to really dig deeply
for self-motivation.
To really look forward to tomorrow,
because everything went wrong,
and every day,
was a struggle for survival.

iii *(The story of becoming paraplegic)*

Ek het siek gewôd
oppie boupersiel.
Net ’n kopsee gekry;
’n verblindende kopsee.
Die intensiteit het vinnag progress
na ’n daaglikse hoofpyn.

Maandagoggen
toe ek opstaan om toilet-toe te gan,
was 'it soe moelik
om te trap.
'it was see
en swaa
om saggies te trap.

Ek het ’n paa drippels op ’n slag gepee,
unsteady gestaan,
duislig gewies,
met ’n swaa gewig op my kop.
'it het my lat woner,
of 'it nou my niere kan wies.

Ek konnie byrie dokte yt kommie.
Die ambulance het gekom.
Ma omdat daa nie bloed wassie,
sê hulle dat 'it nie ernstig issie.
Alhoewel ek vi hulle vedydelik het
dat ekkie kan reg op bly nie,
sê hulle dat ek plaaslike hospital toe moet gan.

Ek hettie krag gehad'ie.
My eetpatroon was uit gewies.
My kop was see en my lyf was swak.
Ek was net innie bed
wan 'it was soeveel moeite
om te loep en te beweeg.

Die volgende Maandagoggen
toe ek opstaan om toilet-toe te gan,
struikel ek.
En ek val.
Toe wiet ek
dat ek hospital toe moet gan.
wan 'it was iets critical.

I got sick
on the building site.
Just got a headache;
A blunt headache.
The intensity rapidly progressed
to a daily headache.

Monday morning
when I got up to go to the toilet,
it was so difficult
to walk.
It was sore
and difficult
to walk softly.

I urinated a few droplets at a time,
stood unsteady,
was dizzy,
with a heavy weight on my head.
It made me wonder,
whether it could be my kidneys.

I could not get to the doctor.
The ambulance came.
But because there was no blood,
they said that it is not serious.
Although I explained to them
that I cannot stay upright,
they said that I must go to the local hospital.

I did not have energy.
My eating pattern was out.
My head was sore and my body was weak.
I was just in bed
because it was so much effort
to walk and to move.

The following Monday morning
when I got up to go to the toilet,
I stumbled.
And I fell.
Then I knew
that I must go to the hospital
because it was something critical.

Daai Maandag, 14 April 1997,
wassie laaste tree wat ek gegie het
innie hospital.
My koors was hoeg.
Ek het deurmekaa gepraat
en niks van myself gewiettie.

That Monday, April 14, 1997,
was the last step that I took
in the hospital.
My fever was high.
I spoke confusingly
and knew nothing about myself.

Die dokte het my op ’n bed lat sit.
Ek konnie staanie.
Ek konnie balance hou nie.
Ek hettie mee control oo' my blaas gehad'ie.
'it was te veel vi my.
Ma hy het my oo'tuig
dat ek oraait sal wies.

The doctor got me to sit on a bed.
I could not stand.
I could not keep balance.
I no longer had control over my bladder.
It was too much for me.
But he convinced me
that I will be alright.

Die dokter het vedydelik;
“*Meningitis het afgegaan tot in jou spinal cord*
en het baie skade gedoen.”
Hy het probee,
deu beweging,
vas stel hoe ve' die damage is,
en gevra waa ek kon voel het op my liggam.

The doctor explained;
“Meningitis has gone down into your spinal cord
and did a lot of damage.”
He tried,
through movement,
to determine how far the damage had progressed,
and asked where I could feel on my body.

iv *(Realization)*

Die volgene oggen,
toe maak ek my vuil oppie bed.
'it was ’n venedering.
Toe die nurste my was,
besef ek dat ietssie reg issie.
Ek besef dat ekkie kan voel waa hulle wassie.
Ek besef dat ek vilam is.

The following morning,
I dirtied myself on the bed.
It was a humiliation.
When the nurses washed me,
I realized that something was not right.
I realized that I could not feel where they’re washing
I realized that I am paralyzed.

Hulle sit ’n kateter in,
vedydelik dat ek ’n T4 paraplegic is.
Hulle sê ek het geen control
oo' my blaas en bowel nie,
en salie voel as ek number one of two wil doen nie.
In my gedagte was die realisation:
‘is dít nou my liewe?’

They put in a catheter,
explained that I am a T4 paraplegic.
Said I have no control
over bladder and bowel,
and would not feel if I wanted to do a number one
or two.
In my mind the realization was:
‘is this my life now?’

v *(Hope)*

Die dokte belowe my;
dat ek binne ses maande wee sal loep,
ek weer aktief sal wies,
dat my gevoel wee terug sal kom,
en al die dinge.
Ek hou toe aan sy belofte.
Dit het my hoop gegie.

The doctor promised me;
That within six months I would walk again,
I would be active again,
that my sensation would come back again,
and all these things.
I held onto his promise.
It gave me hope.

vi *(Failure from the health system)*

Binne die ses wieke in Tygerberg hospital
kon ek sien dattie mense baie min kennis het
oo' mense met sulke gevalle.
Ek was onkundig oorie behandeling,
ma die personeel was net soe onkundig.
Nee rerag!

Ek het bedsere gehad
omdat nieman my omgedraai hettie.
Ek het ’n massiewe druksee gehad.
Druksere is baie algemeen vi mense
met spinal cord injury.
'it is iets wattie gou gesond sal raakie,
my bloed sirkulasie issie mee dieselle nie,
en my gesondheidstelsel was op sy treurigste.

Within six weeks in Tygerberg hospital
I could see that people have very little knowledge
about people with such cases.
I was unknowledgeable about the treatment,
but the staff was just as unknowledgeable.
No, really!

I had bedsores
because nobody turned me around.
I had a massive pressure sore.
Pressure sores are very common among people
with spinal cord injury.
It is something that does not heal very quickly,
my blood circulation is no longer the same,
and my health system was at its most sorry state.

vii *(Coming home)*

Toe kom ek hys toe.
Vilam.
Sonne ’n rystoel.
Sonne ienage rehabilitasie.
Hulle onslaan my net soe.
My mense wietie wat om met my te maakie.

'it was ’n traumatiese tydperk.
Ek was afgetakel deurie siekte
en deurie realisation dat ek nou op my eie is.
En al die vrae soes:
‘hoe gan djy nou maak?’
Alles was vi my ’n bêg.
Ek was niks soner rehabilitasie.

Then I came home.
Paralyzed.
Without a wheelchair.
Without any rehabilitation.
They discharged me just like that.
My people do not know what to do with me.

It was a traumatic period.
I was broken down by the disease
and by the realization that I was now on my own.
And all the questions like;
“what are you going to do now?”
Everything was a mountain for me.
I was nothing without rehabilitation.

viii (Continued failure of the health system)

Baie tye sit ek innie hospital,
en wag…
Soms sien ek net een suste.
Ek sit daa die heledag in pyn,
dan het hulle nie ees pille nie,
ma 'an sê hulle vi my:
“Koop vir jou ’n panado!”

Many times, I sit in the hospital,
and wait...
Sometimes I only see one nurse.
I sit there the whole day in pain,
then they do not even have pills,
but then they say to me:
“Buy yourself a panado!”

ix *(Coming home again)*

My ma het my gehelp,
my gewas en gevoer.
Tot ’n district suste
wat hie byrie hospital gewêk het,
na die hys toe gekom het
om na my druksere te kyk en my dressings te doen.
Dit moet elke dag gedoen wôd.
Soms twee kee ’n dag.

Sy het oek my mense gewys wat om te doen
om voo te kom dat'ie druksere nie vererg nie.
Sy het my gehelp om ’n rolstoel te kry.
'it wassie soe maklik vi mense gegie nie.
Ôs moes 'it huur vir R100 elke maand,
ennie disability grant was manet R300.

Toe kry ek 'it.
Ek hettie ees gewiet hoe om 'it te gebrykie.
Ek kon net sit in 'it,
en wag,
vi ieman om my te stoot.
Die suste het oek ’n plan gemaak
om my Conradie toe te stuu vi rehabilitasie.

My mother helped me,
Washed and fed me.
Till a district nurse
who worked here at the hospital,
came to the house
to look at my pressure sores and do my dressings.
It must be done every day.
Sometimes twice a day.

She also showed my people what to do to
prevent the pressure sores from worsening.
She helped me to get a wheelchair.
It was not easily given to people.
We had to rent it for R100 every month,
and the disability grant was just R300.

Then I got it.
I did not even know how to use it.
I could just sit in it,
and wait,
for someone to push me.
The sister also arranged
to send me to Conradie for rehabilitation.

x *(Recovery and empowerment in rehabilitation)*

Ek was daa vi 18maande,
omrede vi my druksere.
Hulle het my op bed rus gesit virre jaa.
Daa het hulle my gelee
hoe om op my eie te liewe
en na myself te kyk.

I was there for 18 months,
because of my pressure sores.
They put me on bed rest for a year.
There they taught me
how to live on my own
and to look after myself.

Hulle het my gelee
hoe om my eie kos voo te berei,
spôt te doen,
hoe om vannie bed tot innie rystoel te gaan;
sonne lat mense my help.
En as ek uitval,
en dan moet ek self vannie vloer af opstaan.

As ’n paraplegic
is daa nog baie wat djy kan doen
vi jouself.
Soe 'it was ’n veilige environment
wan daa is altyd personeel,
daa is altyd mense
wat raad kan gie.

They taught me
how to prepare my own food,
to do sports,
how to move from the bed into the wheelchair
without people helping me.
And if I fall out,
then I must get up from the floor myself.

As a paraplegic
there is still a lot that you can do
for yourself.
So it was a safe environment
because there is always staff,
there are always people
that can give advice.

xi *(Not so bad)*

Daa was ’n jong seun in my saal
wat inne motorongeluk was.
hy het sy kop en nek see gemaak
en kan niks vi homself doenie.
Hy kannie ees praatie,
Hy sit net daa.

Ek het gesien
hoe gelukkig ek is
om nog my arms en hande te kan gebruik.
Soe daa het ek kans gesien
om yt te kô
en klomp moontlikhede
om wee soe na as normal an te pas.

Toe kô ek yt rehabilitasie yt.
Mense het altyd angebied om my te help.
Ek wou nie hê hulle moet my helpie
wan ek wiet die tyd sal kô
wanne ek 'it nie mee kan doen vi myself'ie
dan salit oraait wies dat hulle my help.

There was a young boy in my ward
that was in a car crash.
He hurt his head and neck
and cannot do anything for himself.
He cannot even speak,
He just sits there.

I saw
how lucky I am
to be able to still use my arms and hands.
So there I saw a chance to come out
and a lot of possibilities
to adjust to as close as normal

Then I came out from rehabilitation.
People have always offered to help me.
I did not want them to help me
because I know the time will come
when I cannot do it for myself anymore
then it will be alright if they help me.

xii *(Pressure sores and pain)*

Ma my vrien,
'it wassie lankie.
Na soe paa jaa
toe hettie druksere wee soe êg geraak,
soe êg geraak
dattie dokte gesê het:
“Ons het nie ’n opsie hierso nie,
ons sal jou binnekort begrawe.”

Die sere is sieltergend.
Iets wat jou siel briek.
Daagliks is ek in pyn,
’n langdierige pyn,
wat my volg soes ’n skaduwee.
Dit is my realiteit.

Die massiewe druksee
het ’n groot gat gelos
op my heep.
En na tien jaa issit die eeste kee
wat ek velos is
van druksere af.
Nou kan ek angan soes ’n normale parapleeg.

But my friend,
it was not long.
After a few years
then the pressure sores became so bad again,
so badly infected
that the doctor said:
“We do not have an option here,
we will bury you soon.”

The sores are soul-vexing.
Something that breaks your soul.
Every day I am in pain,
a long-lasting pain,
which follows me like a shadow.
That is my reality.

The massive pressure sore
left a big hole
on my hip.
And after ten years it's the first time
that I've been relieved
from pressure sores.
Now I can go on like a normal paraplegic.

xiii *(The daily reality)*

Om elke dag op ’n rolstoel te sit,
vat aan jou lewenslus.
Elke dag is dieselle ding.
Elke dag is 'it ’n battle.
Elke dag antwood ek dieselle vrae.
Daa issie ’n aner way nie.

To sit on a wheelchair every day,
Takes from one’s lust for life.
Every day is the same thing.
Every day it's a battle.
Every day I answer the same questions.
There is no other way.

xiv *(Community's perceptions)*

'it isse geweldige emosionele anpasing.
Soes onkundige mense
wat my sien oppie rolstoel.
Hulle praat somme starag met my
asof my brein oek gestrem is,
asof ek oek stadig is van begrip;
asof ekkie mooi ka verstanie.

Ek kan hulle nie kwalik neemie.
'it is ma hulle perception.
Wat ek het om te sê
gaan min impak maak op hulle.
Soe ek stee my nie aan hulle nie,
Ek lat 'it gaan.

It is a tremendously emotional adjustment.
Like unknowledgeable people
who see me on the wheelchair.
They talk slowly to me
as if my brain is also disabled,
as if I am slow in comprehension;
as if I cannot understand well.

I cannot be angry with them.
It is just their perception.
What I have to say
will make little impact on them.
So I do not bother myself with them,
I let it go.

xv *(Unsafe streets in the location)*

Om mense te trust is moelik in Macassar,
elke tweede person wil ’n mens rob.
Selfs'ie mense wat my wil stoot,
rob my,
vat wat ek het,
en los my net daa.
In **dié** gemeenskap is **alles** moontlik.

As ek twee outjies sien aan kô,
moet ek kyk hoe opsigtelik my foon is,
wan aners vat hulle 'it.
As hulle my sak agte my rug sien,
sal hulle my goed steel.

Ek wiet as ’n ou my skoene wil uittrek,
sal hy 'it doen.
Ek sal niks kan doen nie;
behalwe miskien skree.
Die êgste ding is,
hulle haloep nie ees wegie.
Ek voel soe breekbaar.

Ek issie altyd veilag'ie.
Selfs 'ie mense wat my stoot,
se liewens is oek in gevaar.
Soe as ekkie skollies sien,
moet ek ma altyd dink:
‘Wie van hulle gaanie eeste move maak?’

Trusting people is difficult in Macassar,
every second person wants to rob you.
Even the people who push me,
rob me,
take what I have
and just leave me there.
In **this** community, **everything** is possible.

When I see two guys approaching,
I must be wary of how visible my phone is,
otherwise they will take it.
If they see my bag behind my back,
They will steal my things.

I know if a guy wants to pull my shoes off,
he will do it.
I cannot do anything;
except maybe shout.
The worst thing is,
they do not even run away.
I feel so fragile.

I'm not always safe.
Even the people who push me,
their lives are also in danger.
So if I see thugs,
I always must think:
‘Who of them is going to make the first move?’

Ek moet altyd byrie venster wies.
Ek moet altyd bewus wies
oo wat om my angan.
Wan ek issie altyd veilag'ie.
Ek kô yt ’n gemeenskap yt
wa mense nie nog worry oo jou
op ’n rolstoel nie.

Daai issie realiteit waarin ôs liewe.
Ôs bly nie tussen blankes 'ie.
Soe ek kan nie kwaad wiesie.
Wan ek beloewe jou,
hulle doen 'it vi geld;
omdat hulle iets norag het.

Hulle wassie goeie values geleer'ie.
Hulle was gelee om te steel,
vir alles,
wat hulle nie hettie.
Om te **vat**
sonne om skuldig te voel.

I must always be on the look out.
I must always be aware
of what goes on around me.
Because I am not always safe.
I am from a community
where people do not worry about you
on a wheelchair.

That is the reality we live in.
We do not live among whites.
So I cannot be angry.
Because I promise you,
they do it for money;
because they need something.

They were not taught good values.
They were taught to steal,
for everything,
that they do not have.
To **take**
without feeling guilty.

xvi *(Manliness and sex)*

Dan is daa oek dinge
wat ekkie mee kan doenie.
Kyk, soes seks.
Ek issie mee seksueel aktief'ie,
wan ek kan geen seksuele sensasies voelie.
Ek voel niks.

Then there are also things
that I cannot do anymore.
Look, like sex.
I'm no longer sexually active,
because I cannot feel any sexual
sensations.
I feel nothing.

As ek ’n meisie sien
het 'it geen fisiese impak op my nie;
ek kry nie ’n ereksie nie.
Ek kan miskien
'it in my kop imagine,
of an iets dink,
ma my liggaam reageer oekie daaop'ie.

Soe 'it is ’n geweldige aanpassing
vi'al as djy seksueel aktief was
en onne die geselskap van vrouens.
'it issie iets wat jy maklik kan oo' praatie.
Ek bedoel, ek salie somme sê:
“I can’t rise to the occasion”.

Ek het al oral seks gehad.
'it maak my net hartseer;
hoe mee ons speel,
en elke segment van die moves.
'it gaan mos oo my volle manlikheid;
ommie alpha male te wies,
die ‘ou in die stuk’ te wies.

Soe as ekkie die vrou kan bevriedigie;
as ekkie ha tone
kan laat omkrulie,
as ekkie ha lat hyg
na asem nie,
gaan 'it ’n ytdaging wies.

My vrien,
Djy kan ma watse smooth operator wies,
al die mooi woore sê
wattie meisie se pantie sopnat maak,
of wat ha lat flou val,
as djy nie op **‘daai’** seksuele vlak kan funksioneer nie,
Kan 'it ’n personal en geestelike challenge wies.

Deu my eie selfsugtigheid
en omdat 'it ’n ytdaging sal wies
omme gesonde vrou met needs te bevriedig,
wil ekkie betrokke wiesie.
'it kos ’n spesiale person
om daai pad samet my te stap.

If I see a girl
it has no physical impact on me;
I do not get an erection.
Maybe I can
imagine it in my mind,
or think of something,
but my body does not react to it.

So this is a tremendous adjustment
especially if you were sexually active
and in the company of women.
It is not something you can easily talk about.
I mean, I will not just say:
“I cannot rise to the occasion”.

I have had oral sex.
It only makes me sad;
the more we play,
and each segment of the moves.
It is about my full manliness;
to be the alpha male,
the ‘main guy in the piece’.

So if I cannot satisfy the woman;
if I cannot make her toes curl around,
if I do not take her breath away, it will be
a challenge

My friend,
You can be a smooth operator,
say **all the beautiful words**
that will make the girl’s panty soaking wet,
or will make her faint,
if you cannot function on **‘that’** sexual level,
it can be a personal and spiritual challenge.

Through my own selfishness
and because it will be a challenge
to satisfy a healthy woman with needs,
I do not want to be involved.
It takes a special person
to walk that path with me.

xvii *(Reflection)*

Daa is altyd iets
wat ôs amal nie tevriede met issie.
Ôs het ma amal ôse gebrek.
Myne is manet mee opsigtelik as joune.
Ek kannie my gebrek wegstiekie.
Soe 'it maakie van my 'n ytsondering nie,
ôs is amal gekraakte kleipotte.

There is always something
that we are all not satisfied with.
We all have our own disability.
Mine is just more visible than yours.
I cannot hide my disability.
So it does not make me an exception,
we are all cracked clay pots.

xviii *(Grateful to God)*

Elke dag wanne ek wakke skrik
is ek dankbaar
vi God;
dat ek liewendag is,
dat ek asem kan haal,
en dankbaar as ek 'ie oggen
sonne 'n pyn wakke skrik.

Na my siekte
het ek baie gelowig geraak.
Ek besef dat miskien issit God
wat met my gepraat het deu my siekte.
Dinge maak nou mee sin in my liewe.
Die liewe wat ek geleef het
wassie die liewe wat ek moes geliewe hettie.

Every day when I wake up
I am grateful
to God;
that I am alive,
that I can breathe,
and grateful if I wake up in the morning
without a pain.

After my illness
I became very religious.
I realize that maybe it was God
who spoke to me through my illness.
Things now make more sense in my life.
The life I lived
was not the life I should have lived.

xiv *(synopsis of living with paraplegia)*

Die realiteit van my ervaring
was 'n thriller.
'it was êg.
'it is nou oore klomp jare
wa dinge nie rerag mee saak maakie.
As djy nie sterk issie,
sal djy 'it nooit maakie.

Soe mense wattie meeste het om te sê,
Sal nooit,
vi 20 jaar,
in hierdie skoene kan loepie.
'it issie elke dag
wat ek 'n smile op my gesig hettie,
Ma vandag is ek oraait.

The reality of my experience
was a thriller.
It was bad.
It has been over several years now
where things do not really matter anymore.
If you are not strong,
you will never make it.

So people who have the most to say,
will never,
for 20 years,
be able to walk in these shoes.
It is not every day
that I have a smile on my face,
but today I am alright.

4.3 Analysis

4.3.1 The Restitution Narrative

Frank (1995) puts forward the idea that there are various types of narratives that can be told through constructing stories on experiences of living with illness or pain. He proposes three central narrative genres: restitution narratives, quest narratives, and chaos narratives (Frank, 1995). I argue that Kenneth's story on his experiences of living with paraplegia is told in the same way that a restitution narrative is told. A restitution narrative is one that is based on the notion of restoration (Frank, 1995). It centres the idea that there is hope for the body to be "fixed" after experiencing illness or a severe injury such as paraplegia (Frank, 1995). The restitution narrative states that the healthy body may suddenly experience pain and deterioration, however, no matter how severe it may be, the restitution narrative outdistances suffering and promises that the body will recover after following the necessary remedies. Frank (1995, pg. 77) states that the plot of the storyline in a restitution narrative is: "Yesterday I was healthy, today I am sick, but tomorrow I will be healthy again". We find such a restitution narrative plot strongly portrayed in some parts of the storyline in Kenneth's narrative. Consider the following example:

KENNETH: Ek het nooit myself in 'aai skoene geplaasie… ek siek gewôd… ma vandag is ek oraait

I never placed myself in those shoes… me getting sick … but today I am alright.

Subsequently, this storyline is also portrayed in the middle of his narrative:

KENNETH: 'it wassie lankie… Toe hettie druksere wee soe êg geraak… En na tien jaa issit die eeste kee wat ek velos is van druksere af. Nou kan ek angan soes 'n normale parapleeg

it was not long… then the pressure sores got worse… and after ten years it is the first time that I am saved from pressure sores. Now I can live like a normal paraplegic.

This phrase assures the listener that no matter how challenging Kenneth's journey was, the possibility of moving beyond suffering and pain remained probable, which is parallel to a restitution narrative (Frank, 1995).

4.3.2 'The Wounded Storyteller'

The storyline of a restitution narrative seems simple; an individual becomes ill or acquires an injury, they follow the prescribed procedures to cure the illness or injury, and even though they may experience challenges, they overcome the illness or injury and their body is as healthy as it was prior to the illness or injury. The plot of a restitution narrative is filled with talks of tests and different treatments to experience a healthy outcome (Frank, 1995). For Kenneth, these testS and treatments are referred to as, *"battles, trials and tribulations."* It is through his *"battles, trials and tribulations"* that Kenneth's story is not a singular narrative. His story does not fit one narrative type. Frank (1995) posits that through telling stories, other narrative types may be combined and simultaneously or continually interrupt each other. Although Kenneth's narrative is predominantly a restitution narrative, he articulates his experiences of living with pain and confronting challenges of living with paraplegia, which intensifies as the story progress. It is through this progression that aspects of his story are also told through a chaos narrative.

According to Frank (1995), the plot of a chaos narrative imagines that life never gets better after an illness or injury. The stories in a chaos narrative have no coherent sequence of telling (Frank, 1995). This results in the narrative being hard to hear and is often perceived as not telling an actual story (Frank, 1995). I remember the moment Kenneth started narrating his life story. His voice was soft and hoarse. I had to sit closer and listen attentively because I felt lost in his narrative. He was exhausted and had intense pain. The pain was the most embodied form of the story. Frank (1995) states that it is this embodied form of the story that makes it difficult for the listener to hear in a chaos narrative.

Because his narrative was difficult to hear, I was not motivated to transcribe his life story. When I eventually started transcribing it, I ensured that I was seated in a quiet room and I had to increase the volume of the voice recorder to listen more clearly. I then realised what a proper story he was telling and how difficult it was for me to hear it in his presence. Perhaps I felt overwhelmed by the depth of his story in the moment he narrated it. Perhaps his story was, as Frank (1995) puts forward, anxiety provoking which inhibits hearing. His story reminds me of what it means to be human, and the reality that I, or any of my friends and family, may experience living with paraplegia in the same ways as Kenneth. This is also an element of a chaos narrative; it tells a story of how easily any one of us can be undone (Frank, 1995). This is anxiety-provoking.

There were also silences in-between phrases and words that I could not interpret. Frank (1995, pg. 101) reminds us that the “chaos is told in silences that speech cannot penetrate.” Kenneth used metaphors to penetrate this silence. The silence in between words and phrases, and the use of metaphors to describe pain and his experiences of living with paraplegia, also supports the argument that a chaos narrative emerged as his story progressed. The metaphor: *“Die pil van hell” – “The pill from hell”*, is used in the beginning of his life story to give the listener an indication of the challenge of living with paraplegia. Swallowing a pill from hell can be interpreted as a suffering that is unbearable to live with.

He reiterates the impact that paraplegia had on his life by saying: *“Alles was vi my ’n bêrg” – “Everything was a struggle for me”*. This implied the extent of the difficulties that he was confronted with on a daily basis. He informs the listener that, *“Die realiteit van my ervaring was ’n thriller” – “The reality of my experience was a thriller”*, which can be interpreted as an intense experience with a high degree of intrigue, suspense, and intensity, where living with paraplegia is as Kenneth states: *“’n struggle vi survival” – “a struggle for survival.”*

Kenneth becomes more descriptive in his experience of living with pain as our conversation progressed. He describes the pain as *“’n langdierige pyn, wat my volg soes ’n skaduwee”* - *“a long-lasting pain that follows me like a shadow.”* This implies that there are days when the pain never leaves even though he uses medication. However, at some point the pain leaves him - like shadows do. This is clear when he says, *“ek is dankbaar as ek 'ie oggen sonne ’n pyn wakke skrik” – “I am grateful for the mornings I wake up without pain.”* Frank (1995) argues that it is metaphors such as these which enacts the storyline as they are reflexive reminders of what the story is about. In Kenneth’s narrative, the story is about pain, suffering, and endurance. His words suggest the rawness of his experiences. It is almost as though he speaks about the wound of paraplegia because it is as Frank (1995, pg. 98) suggests, “much about the body, its insults, agonies, and losses, that words necessarily fail.” Perhaps Kenneth is, as Frank (1995, pg. 98) states, “the wounded storyteller.”

4.3.3 The Plot of a Restitution Narrative

What is clear in Kenneth's narrative is the coherent sequence of events that leads to a restitution narrative. In the sequence of events, there are also three movements of the restitution narrative that unfolds. It is important to note that although chaos is evident in the occurrence of these events, the coherent sequence in which Kenneth narrates these events puts forward the idea that the plot resembles a restitution narrative. The first movement of the restitution narrative unfolds as Kenneth speaks of the physical misery and physical symptoms that he experiences (Frank, 1995) which led to the diagnosis of meningitis. For example, he starts narrating the beginning of these events from the Monday morning when he woke up for work and experienced much difficulty with walking to the toilet. He relays feeling unsteady and dizzy with a heavy weight on his head.

According to Frank (1995), the second movement of the restitution narrative introduces the remedy, which occurs in more than one instance in Kenneth's narrative. The first instance is when Kenneth called the ambulance, hoping that they would provide him with the necessarily treatment. He hoped that if he received medical advice or help, he would be healed. The paramedics could not provide the services that Kenneth expected. Instead they advised him to go to the local hospital. Due to Kenneth's delay in going to the hospital, Kenneth felt his body deteriorating. After a few days, he could not walk. He felt weak and had no appetite. The headache intensified. A week later when he stumbled to the toilet and fell, he realized that his condition was crucial and that he needed to go to the hospital.

Other instances of remedical action occur through various encounters with medical doctors at the local hospital. Kenneth took his last steps in the hospital. He spoke confusingly. He experienced a loss in balance and lost control over his bladder. His body had rapidly and severely deteriorated. The doctor who examined him explained that meningitis had severely affected his spinal cord. This resulted in paraplegia. However, the doctor promised Kenneth that he will be 'good as new' – normal. The doctor promised that within six months he would be able to walk again, and that sensation would return to his body. Kenneth felt hopeful and placed his trust in the competence of the medical doctor. This relates to Frank's (1995) argument that the competence of the medical doctor and treatments prescribed, coupled with an explanation of the possible outcome, is one of the prominent aspects of a restitution narrative on illness or injury. This relates more towards the normalization of the body.

After being hospitalized for almost two months, Kenneth developed bed sores and a massive pressure sore on his hip that affected his blood circulation and immune system. After being discharged from the hospital, he returned home without a wheelchair and without rehabilitation. His family did not know how to take care of him. He describes this period as: *"'n traumatiese tydperk. Ek was afgetakel deurie siekte" – "a traumatic period. I was broken down by the illness."* The health system failed him as they did not assist and treat his condition in the ways that was required. For example, Kenneth recalls occasions when he had to wait for long hours to be assisted by medical staff at the local hospital. He would sit in pain, and after many hours, would leave without having received any assistance and without any pain medication. These are the kinds of tests that Kenneth had to endure while hoping that the health system would support him. Instead, they failed him.

The third and last instance of introducing remedies in Kenneth's case was through the district nurse that generously offered to treat his pressure sores. She taught his family how to take care of him and ensured that he went for rehabilitation. In rehabilitation, he was put to bed rest for a year - for the pressure sores to heal. After a year, he started with the rehabilitation program supported by physiotherapists, psychologists, and doctors. He returned home after his time in rehabilitation, but after a few years the pressure sores reappeared and got worse. Kenneth describes the pressure sores as, *"Sieltergend. Iets wat jou siel briek" – "Soul-vexing. Something that breaks your soul"*.

The third movement of the restitution narrative is the physical comfort that Kenneth shows (Frank, 1995) after ten years, having been freed from pressure sores. Kenneth makes it clear that he can now continue living his life like a normal man with paraplegia. Kenneth shows how his life got better after every treatment and encounter he had with the medical doctor, district nurse, and rehabilitation staff. These institutional influences gave Kenneth hope that if his body gets the necessary treatment and care, he will be well and live a healthy life (Frank, 1995). They reassured him that there are, as he says, *"klomp moontlikhede om wee soe na as normal aan te pas"* - *"a lot of possibilities to adjust to as close as normal."*

The restitution narrative puts an emphasis on reinstalling normality through taking and maintaining the necessary precautions to cure the body. In Kenneth's narrative, participating in the rehabilitation programs and thereafter being an active member of Bridging Abilities organisation shows his desire to be cured; to walk again.

The restitution narrative states that what will cure the body is physical interventions – in any form – thus Kenneth shows how actively participating in rehabilitation programs and physical exercises facilitated by Bridging Abilities is part of reinstalling normality. It is almost as if Kenneth's narrative implies: *"as long as I am committed to the physical activities at Bridging Abilities to strengthen my muscles, I can sustain an illusion of physical performance, and as long as I can buy painkillers, my bodily pain will disappear."* This perception shows the agency that the restitution narrative affords Kenneth (Frank, 1995). For example, the responsibility of taking medicine, going for regular check-ups, being active in physical exercises, and finally, getting to a place of saying, *"vandag is ek oraait"* - *"today I am alright."*

4.3.4 Conclusion

This section of the chapter focused on Kenneth's life story. His story is composed and told through a narrative poem that was constructed from the transcription of his life story conversation. I argue that Kenneth is, as Frank (1995, pg.98) states, "the wounded story teller" because he was in physical pain when he narrated his life story, and he tells a story of living in pain. There were moments in our conversation where the physical pain caused him to stop narrating for few minutes. The way he gasped after every spasm hinted into the reality of living with a spinal cord injury. Kenneth's life story was told in *Kaaps*, the language in which he felt comfortable in narrating and candidly describing his experiences through the use of metaphors.

His life story was constructed from the present to the cause of the injury, and then carefully describing the ways in which paraplegia had impacted his life. The plot of his story resembles a particular genre of story-telling, namely, a restitution narrative (Frank, 1995). This narrative is based on the idea of restoration - that the body will be 'fixed' after following the necessary remedies (Frank, 1995). The restitution narrative puts an emphasis on reinstalling normality through taking and maintaining the necessary precautions to cure the body. Thus, the plot of the narrative is filled with talks of tests and treatments to 'restore' the body (Frank, 1995). In the sequence of Kenneth's restitution narrative, three movements unfold: (1) the physical misery and physical symptoms that he experiences, (2) exploring remedies with the help and assistance of medical experts, and (3) the physical comfort from being 'cured'.

However, Kenneth narrative shows that stories are not constructed and told in a unified way (Frank, 1995). They do not fit one narrative type. Narrative types may overlap, combine, and interrupt each other. Kenneth's restitution narrative is interrupted by the chaos narrative genre (Frank, 1995).

The chaos narrative is one that is filled with challenges which was explicated through experiences of “trials and tribulations”. This narrative type imagines life never getting better (Frank, 1995).

The flow of themes that Kenneth explored in his narrative is: His perceptions of disability prior to the injury, the traumatic experiences leading to the diagnosis of meningitis and paraplegia, the rapid deterioration of the body and realization of paralysis, the hope to be ‘normal’, and the disappointment in failure from the health system. He also explored: The reality of living with paraplegia in a marginalized community, the challenges in sexual intercourse and intimacy, devastating experiences of pressure sores, the recovery and empowering experiences of rehabilitation, and lastly, gratification for a second chance to live. Overall, Kenneth’s story shows that pain, suffering, and endurance is part of what it means to be human.

4.4 SECTION B: THE LIFE STORY OF CARLO KLINK

4.4.1 Introduction

In this section, I focus on how Carlo's life story is composed and told through a narrative poem that was constructed from the transcription of his life story conversation. Here I also draw on Arthur Frank's (1995) work and argue that Carlo's storyline is a quest narrative. I use two facets of the quest narrative proposed by Frank (1995), a memoir and manifesto, to substantiate this argument. This chapter only focuses on the kind of narrative and how the story is told. More descriptive detail on what Carlo says in his narrative is analysed in the following analysis chapters (chapter five and six).

4.4.2 Introducing Carlo Klink

Carlo Klink is a 29-year-old, lower to middle-class, coloured man who openly identifies as gay. He is currently unemployed, but in the process of obtaining his National Senior Certificate (grade 12 school-leaving certificate). He has an interest in pursuing a degree in psychology and a desire to work with children, especially with the youth in his community. He is an active member at the Bridging Abilities organization where he sometimes takes the role of a team leader in the physical exercises. Carlo is enthusiastic, quite dramatic, extremely talkative, and is overall an entertaining person. He is honest, direct, and regards his life as an open-book, which is signified in one of his most commonly used phrases, *"vra my enige iets!" – "ask me anything!"*

4.4.3. Orientation around the Conversation

I met Carlo the first day when the founder of Bridging Abilities formally introduced me to the members of the organization. When it was time for me to approach the men with paraplegia, I walked up to Carlo, only because he was nearest to me. Carlo smiled when he saw me walking towards him. I reintroduced myself in a less formal manner. I told him about the research study and its interest in the life stories of coloured men with paraplegia. I asked him whether he would be willing to speak to me about his life and what it means for him to be living with paraplegia. He was enthusiastic and elatedly responded, "*Ja, ek kan baie praat, ek hou van praat!" - "Yes, I can talk a lot, I like talking!"*

I was relieved by his response - especially because I was unsure about how these men felt about an ‘outsider’ listening to their life stories. After his positive response, I realised that there are those who are comfortable and willing to embark on a journey of reflection on their life, but I was also cognisant of the fact that it would mean delving into semsitive and traumatic moments that may or may not have been fully resolved. So as much as I was relieved by Carlo’s positive response and his openness and willingness to talk to me, I was also concerned about whether he understood the gravity of what was expected of him, and whether he was ready to revisit defining moments, moments that had changed his life forever, and to share these with me. I suppose I was concerned about whether he was ready to engage in a conversation that he may never have had before.

He invited me to his house and I appreciated the invite because it felt like he gave me - the outsider - permission to enter his space. It felt like he gave me permission to listen, to question, and to meet the people who are important to him - his immediate family. My lack of familiarity with the area, made me anxious about finding my way to his house.

I arrived at his house and rang the doorbell. I could hear his mother calling his name. I was at ease knowing that I had arrived at the right house. He opened the door, welcomed me in, and introduced me to his mother. Carlo led the way to the kitchen and offered me something to drink. We engaged in a meaningless conversation in the kitchen, and although I thought we would move into a living room, we remained in the kitchen. I suppose the kitchen was a space he felt most comfortable in, since it was quite spacious and accommodated his wheelchair.

The kitchen felt warm and homey. I could feel that the intimate space we created in the spacious kitchen was safe. I was relaxed, quite settled, my chair was warm, and I felt that the time was right. I reminded Carlo that this is not an interview, but a conversation about his life. I told him that he could start narrating it from wherever he wanted to and that he could tell it in whatever way he wanted to, and in whatever language he felt most comfortable in. He took a few seconds to think, and then he asked, *“van die begin tot die einde?”* - *“from the beginning to the end?”* And I said, *“Yes”*.

4.5 *The Narrative Poem of Carlo Klink*

i *(My rebel life)*

Ek was 14 jaar oud
toe begin my lewe;
my rebel lewe.
Toe begin ek experimenteer
met alle soorte dinge
soos clubs, drugs, wyn, en unprotected sex.

I was 14 years old
when my life began
My rebel life.
Then I started experimenting
with all kinds of things
like clubs, drugs, wine, and unprotected sex.

ii *(Coming out)*

Toe begin ek uitvind dat ek eintlik gay is.
Ek het nooit ’n gevoel gekry van ’n vrou af
soos die gevoel wat ek kry as ek aan ’n outjie dink.
Maar van die age van ses jaar het ek al geweet
want my hart het vinnig geklop aan my ander chommie.
Joh! Ek wou altyd he hy moet pa wees!

Op 17 toe raak dit vir my boring.
Vir my was ’n uitdaging ’n outjie in ’n relationship
met ’n meisie.
N man wat dink hy kan nie val nie.
Ek was baie oor outjies met muscles
want ek het vroulik gevoel.
Ek was nooit aan die giving kant nie,
altyd aan die receiving kant;
en ek begin experimenter met hulle
in unprotected sex.

Then I found out that I was gay
I never felt anything for women
like the feeling I get when I think of a man.
But from six years I already knew
because my heart raced for my friend.
Joh! I always wanted him to be the dad!

At the age of 17 I became bored.
To me a challenge was a guy in a relationship
with a girl.
A man who thinks that he can never fall.
I was very fond of muscular guys
because I felt feminine.
I was never on the giving side,
always on the receiving side;
I started experimenting with them in
unprotected sex.

iv *(Drug addiction)*

Ek het *Tik*[9] begin gebruik.
Ek het net buite die wereld gevoel;
’n feeling wat ek nie kan beskryf nie.
Ek het dit elke dag gedoen.
Toe vat dit my oor,
heeltemal oor.

I started using *Tik*.
I just felt outside the world;
a feeling that I cannot describe.
I did it every day.
Then it took over my life,
completely took over.

---

[9] Tik is a slang for a drug formally known as crystal methamphetamine. It is a cheap, powerful and addictive drug that is most commonly used in poor communities.

Op 17 jaar los ek die skool in standard nege
om drugs voltyds te doen.
Ek het begin steel in die huis;
nie groot goed nie,
net my ma se jewellery en geld gevat,
om te gaan verkoop vir drugs.

At the age of 17 I left school in standard nine
to do drugs on a full-time basis.
I started stealing in the house;
Not big things,
Just my mother’s jewellery and money,
to sell for drugs.

Toe vind my pa uit
dat ek gay is.
Toe word ek uit die huis gesit.
Hy het baie dinge van my af verwag;
soos dat ek sal uitspraal en skool klaar maak,
en dat ek ’n meisie huis toe sal bring.
Hy kon nie verstan
dat sy seun vroumens klere aangetrek het nie.

Then my father found out
that I am gay.
Then I was kicked out of the house.
He expected many things from me;
Like being bright and finishing school,
and that I would bring a girl home.
He could not understand
that his son dressed in women's clothes.

(The story of becoming paraplegic)

Op 20 was ons in die ongeluk.
Dit was so past 5 se kant die Saterdag oggend,
15de November 2008.
Ons het uit die club uit gekom:
ek, my aunty, die driver, en so ander outjie.
Die driver was onder die invloed van drugs en
alcohol.

At 20 we were in the crash.
It was around 5 on Saturday morning,
15th of November 2008.
We came from a club:
me, my aunty, the driver, and another guy.
The driver was under the influence of drugs and
alcohol.

Ek het agter in die kar getiep
langs die ander outjie.
My aunty het voor gesit met die driver.
Ons driver het 160km/h om die draai gery.
Toe maak ons ’n kop-aan-kop botsing
binne in die security bakkie,
hier op die stop by die circle.

I fell asleep in the back of the car
next to the other guy.
My aunty was in front with the driver.
Our driver drove 160km/h around the corner.
Then we made a head-to-head collision
with the security bakkie,
here at the stop at the circle.

Die outjie wat langs my agter gesit het
is morsdood.
Die twee in die security bakkie
is ook dood.
Ek, my aunty, en die driver
is al wat lewe.

The guy who sat next to me
died on the scene.
The two guys in the security bakkie
also died.
I, my aunty, and the driver
were the only ones who survived.

(Realization)

Ek was in a coma vir ’n week en ’n half,
ICU vir 3 weke.
Toe ek wakker word
het ek vir myself gedink en self agter gekom
dat ek niks kan beweeg en voel
in my bene nie.
Toe weet ek self,
ek is verlam.

I was in a coma for a week and a half,
ICU for 3 weeks.
When I woke up
I thought to myself and realised
that I could not move and feel
anything in my legs.
Then I knew,
I'm paralyzed.

(Acceptance)

Toe maak ek vrede met dit
sommer net daar,
want ek gaan nie beter word nie,
ek is nou verlam.
Die ongeluk het mos nou gebeur,
daar is niks anders wat ek kan doen nie.

In Groote Schuur hospital
was daar was ’n wit outjie wat langs my gele het.
Hy was ook verlam.
Hy was in ’n motor fiets ongeluk
omdat hy hom self dood wou gemaak het,
so dit was sy eie skuld.
Ek het lekker met hom gepraat en gesê:

“jy is die een wat jouself moet vergewe,
ek is die een wat in depression moet gaan
want ek was net ’n passenger.
Dit was nie my skuld nie.
Hoe gouer jy jouself gaan aanvaar en vergewe,
hoe gouer gaan jy beter word.”

Then I made peace with it
there and then,
because I won’t get better,
I am now paralyzed.
The accident, in fact, happened,
there's nothing else I could do.

In Groote Schuur hospital
there was a white boy next to me.
He was also paralyzed.
He was in a motorcycle accident
because he wanted to kill himself,
so it was his own fault.
I talked to him and said:

“You must forgive yourself,
I should be depressed
because I was just a passenger.
It was not my fault.
The sooner you accept and forgive yourself,
the sooner you will get better.”

(Rehabilitation)

Ek was vir drie maande rehab toe.
Daar leer hulle jou hoe om met jouself aan te leef.
Hulle gee vir jou oefening en so.
Ek het baie jokes gemaak met die male nurste,
hulle het baie van my gehou,
want ek het net ge ‘go with the flow’ met hulle.

I was in rehab for three months.
There they teach you how to live with yourself.
They give you exercises and so on.
I had a lot of fun with the male nurses,
they loved me very much,
because I just ‘went with the flow’ with them.

Om ander mense daar te sien
wat ook verlam is het my gelukkig gemaak.
Net om te sien
hoe hulle saam leef met hulle toestand,
en dat ek nie alleen is nie
het my hoop gegee.

To see other people there
who are also paralysed made me happy.
Just to see
how they live with their condition,
and that I am not alone
gave me hope.

(Mourning and blaming)

Baie van my vriende kon nie gekom het nie
want dan huil hulle net.
Hulle wou my nie so sien nie.
Maar toe ek uit kom
toe sien hulle dat ek dieselfde person is.
Ek is net verlam.

Many of my friends could not come
because they would just cry.
They did not want to see me like that.
But when I came home
they saw that I’m the same person.
I'm just paralyzed.

Maar my pa het dit baie hard gevat.
Hy het baie gehuil.
Hy kon dit nie aanvaar het nie.
Hy het my ma blameer.
Hy het vir my ma gesê,
“dit is deur jou
wat jou kind vandag verlam is.
Jy het hom na die pad toe gestood.”

But my dad took it very hard.
He cried a lot.
He could not accept it.
He blamed my mother.
He said to my mother,
“It is because of you
that your child is paralysed today.
You sent him to the streets.”

(Second chances)

Ek het toe stil gesit en samet hom gepraat,
en vir hom gesê
dat dit niemand se skuld is nie,
en dat ons bly moet wees
dat ek nog lewe.
Die Here het my ’n tweede kans gegee
want ek kon dood gewees het.

I sat him down and talked to him,
and said to him
that it's nobody's fault,
and that we should be happy
that I am still alive.
The Lord gave me a second chance
because I could have died.

Ek het die driver lankal vergewe.
Ek het hom lankal vry gespreek.
Ek dra nie vir hom in die hart nie
want hy het dit nie aspris gedoen nie,
alhoewel hy my nog nie verskooning gevra het nie,
vergewe ek hom.

I forgave the driver a long time ago.
I’ve set him free a while back already.
I do not carry him in my heart
because he did not do it on purpose,
although he did not ask for forgiveness yet,
I forgive him.

(Coming home with paraplegia)

Om weer terug by die huis te wees was swaar
want ons huis was klein,
en ek was nie ’n huis person nie;
ek hou mos van in die straat wees.
Ek moes baie vinnig aangeleer het
dat ek nie net kan opstaan en gaan nie.

To be back home was difficult
because our house was small,
and I was not a house person;
I love being in the street.
I had to learn very quickly
that I cannot just get up and go.

(Community’s perceptions)

Ek het nie om gegee
wat mense van my sê nie.
Soos hulle my op skool moffie genoem het
was dit dieselfde adaption met die rolstoel.
Once hulle in my skoene gaan wees
sal hulle ’n ander persepsie het van my.
Hulle was nog nie hier waar ek is nie.

I did not care about
what people said.
Just like they called me girl names at school
was the same adaptation with the wheelchair.
Once they are in my shoes
they will have a different perception of me.
They have not yet been here where I am now.

Voorheen het ek gelike om manne te challenge
wat ek van hou.
Nou sien hulle my in ’n ander lug;
as iemand wat nou gehelp moet word.
Hulle kyk neer op my,
omdat ek nie meer daai
spankelinge en jolly ou is
met hakke en lang hare nie.

Previously I liked to challenge men
I liked.
Now they see me in a different light;
as someone who needs to be helped.
They look down on me,
because I'm no longer that
sparkling and jolly guy
with heels and long hair.

(word from the Prophet)

Op die ouderdom van 25
bring die nurse wat vir my werk
’n vrou Prophet.
Ek het toe ’n besluit geneem
om nie aanmekaar ’n dronkie te wees
in ’n rolstoel nie,
dit is nie kwaai nie.
Ek het besluit om my hart vir die Here te gee
en geestelik te lewe
want ek het dit nooit geken nie.

At the age of 25
the nurse who works for me introduced me
to a female prophet.
I then made a decision
not to remain a drunkard
in a wheelchair,
It is not cool.
I decided to give my heart to the Lord
and to live spiritually
because I never knew that kind of life.

(A changed person)

My lewe het baie verander.
Ek is nie meer op drugs nie.
Ek drink nie meer nie.
Ek loop nie meer clubs nie.
Ek is nie meer daai person wat ek gewees het nie.
Ek is nou by die Here.
Ek is nou ’n ander person.

Nou gaan my lewe net voorentoe.
Ek is besig om my matriek te doen.
Ek wil graag sielkunde swot
en met kinders werk wat ek kan help
en guide,
en vir hulle se dat dit nie die way is om te gaan nie.
Ek is nou 4 jaar by die Here
en 9 jaar in die rolstoel;
my storie is net ’n lewens testimony.

My life has changed a lot.
I'm no longer on drugs.
I do not drink anymore.
I do not go to clubs anymore.
I'm no longer the person I've been.
I am with the Lord now.
I am now a changed person.

Now my life is just going forward.
I am doing my matric.
I would like to study psychology
and work with children whom I can help
and guide,
and tell them that it's not the way to go.
I have been with God for 4 years now
and 9 years in the wheelchair;
My story is just a life testimony.

4.6 Analysis

4.6.1 The Quest Narrative

Stories are defined as a quest narrative when the teller accepts the injury, and then constructs and tells a narrative in which the injury is defined as a quest - a belief that something is to be gained through the experience of acquiring and living with the injury (Frank, 1995). This becomes clear in Carlo's narrative. For example, through the journey of living with paraplegia, Carlo learned to forgive his parents, the driver who caused the accident, and himself. He stopped clubbing and stopped abusing drugs and alcohol. He fully converted to Christianity and now lives a spiritual life. He is completing his high school career so that he can study psychology and use his knowledge and experiences to teach children not to live the life that he lived - a rebellious life. Ultimately, he wants to use his life story as a testimony to inspire others, especially young people in his community who are from a similar background to him, to accomplish and achieve their goals despite the physical barriers or social challenges that they may face. Carlo's career and life choices following the injury are significant, and shows that he is now a changed person.

4.6.2 A Memoir

Frank (1995) discusses facets of a quest narrative in much detail. Within Carlo's narrative, two facets of a quest narrative are pertinent: a memoir and manifesto. According to Frank (1995), a memoir is a moderate style of telling a quest story. This involves the combination of the story of the injury and other stories of the teller's past. Telling a memoir is like an autobiography (Frank, 1995), because of the chronological order in which it is told. Carlo's narrative shows this element of a memoir as he chronologically shares stories of his past - narrating from the beginning of his life (birth) to the present moment. However, this style of telling could also be influenced by the fact that I had said *"yes"* to his question of telling his story: *"van die begin tot die einde" ("from the beginning to the end").*

Carlo starts narrating his past from the age of fourteen when he started experimenting with alcohol, drugs, and clubs. He also came out about being gay to his aunt and friends at this stage. He talks about the age of fourteen as the beginning of his "rebellious life." Carlo continues narrating his life story chronologically and reflects on his life at the age of seventeen, when he became addicted to drugs, dropped out of school, and admitted to his father that he was gay. At the age of seventeen he also experimented with heterosexual men and unprotected sex. He continued with this lifestyle until the age of twenty when the motor car accident happened.

Frank (1995) states that the injury may be perceived as an interruption to the lifestyle lived. This is reflected in the way in which Carlo told his narrative, since the accident happened as they were driving home from the club, in a drunken and tired state. The accident therefore interrupted the rebellious life that he was living to the fullest at that time.

Frank (1995) argues that telling memoirs are usually inspired by a close to death experience. One can argue that the accident was a close to death experience for Carlo because both men in the other vehicle involved in the accident as well as the man who sat next to Carlo, died. Carlo only gained consciousness in the ICU and it was there that he realized that he was paralysed. It is also clear in Carlo's narrative that memories of his past life interrupted the story of the accident and the injury. Even though he has lived with paraplegia for nine years, he spends more time narrating life before the injury, as opposed to talking about the injury itself and life thereafter. The combination of the story of the injury and other stories of the past, the chronological order of events, and the inspiration of a 'close to death experience' are the significant attributes of Carlo's narrative that are pertinent elements of a memoir in a quest narrative. However, Carlo's narrative also shows how the manifesto facet of the quest narrative is pertinent in his story.

4.6.3 A Manifesto

Frank (1995) purports that narratives on experiences of disability often combine facets of memoir and manifesto. A manifesto posits that what has been learned is prophetic and demands social action (Frank, 1995). This is evident in Carlo's narrative, as he explains how his home nurse introduced him to a prophet who prayed for him. It was at this point that Carlo repented and exchanged his rebellious lifestyle for a godly life. Carlo perceives paraplegia as part of God's plan for his life. He understands the injury as something that needed to happen in order for him to stop living an ungodly life. His accident and subsequent conversion were also the signal he needed to encourage young people in his community to stop substance abuse, and to learn from his mistakes. Through his condition, he was able to show them that despite living with paraplegia he was still capable of achieving his goals and living a healthy and spiritual life. Carlo thus uses his narrative to reach out to others with the hope of bringing about social change in his community.

Moreover, this echoes Frank’s (1995) argument that tellers of quest stories often realize a sense of purpose in their injury and develop the idea that the injury itself forms part of a bigger journey in their lives. For example, in Carlo’s narrative, one could argue that his injury is a spiritual journey that has given him a renewed purpose for living. This purpose is to serve God and use his life story as a testimony. He also makes it clear that although there is nothing he can do about the paralysis, he wants to change the way people think about disability. This is parallel to Frank’s (1995) argument that quest stories imply that the teller has been given insight and the ability to share his/her enlightenment with others.

4.6.4 Conclusion

This section of the chapter focused on Carlo’s life story. His life story is also presented in a narrative poem that was constructed from the transcription of his life story conversation. The storyline of Carlo’s life story is a quest narrative (Frank, 1995). For example, the general storyline and progression in Carlo’s narrative starts from the circumstances that led to the accident, then the accident scene, his realisation and acceptance of paraplegia, his parent’s reaction to paraplegia which was expressed through anger and blame, and lastly, Carlo expressing gratitude for second chances. More specifically, Carlo narrative starts with stories about his rebellious past which includes: drug addiction, alcohol abuse, clubbing, dropping out of school, coming out as gay, and engaging in unprotected sex with heterosexual men. Carlo speaks about the ways in which his life has changed in positive ways after the injury. These positive ways include: accepting the injury, forgiving his parents and the driver who caused the accident, stopped clubbing and stopped abusing drugs and alcohol, converted to Christianity, living a spiritual life, completing his high school career, aiming to study psychology, and through his life story he wants to inspire young people in his community. Thus, the injury is defined as a quest.

Carlo narrates these experiences through implementing two particular facets of a quest narrative, namely a memoir and manifesto (Frank, 1995). A memoir facet involves stories about the injury and other stories about his past life. However, stories of his past life interrupt the story of the accident. This is evident in that he speaks more about his life before the injury, as opposed to the injury itself and life thereafter. The combination of the story of the injury and other stories of the past, the chronological order in which he narrates these events, and the inspiration of a ‘close to death experience’ are pertinent elements of a memoir in a quest narrative (Frank, 1995).

Carlo’s narrative also shows how the manifesto facet is pertinent in his story. He shows that what he learned from acquiring paraplegia, was prophetic and the experience learned from acquiring paraplegia demands social action (Frank, 1995). He argues that the purpose of the purpose of the injury is to change his rebellious ways of living, to serve God, and to use his life story as a testimony to inspire others.

4.7 Conclusions on Case Studies

The life story of Kenneth and Carlo reflects three narrative structures proposed by Frank (1995). The three narrative structures include the restitution narrative, chaos narrative, and quest narrative (Frank, 1995). Presenting these life stories in relation to one another shows how stories of paraplegia are unique as they are differently constructed and told.

Kenneth’s life story reflects a restitution narrative structure since he tells the story of getting sick, and how meningitis affected his spinal cord. This resulted in his body deteriorating, and through various challenges of being treated, his body finally restores. What becomes clear in Kenneth’s life story is his own subjectivity because the doctors, district nurse, and therapists are the hero’s in the story (Frank, 1995) as they are responsible for restoring his body and saving his life. During the challenging periods of suffering from pain and a huge pressure sore that no medical treatment could heal, the restitution narrative failed, and Kenneth had no narrative that he could use to tell the story of his body deteriorating. Therefore, he used elements of the chaos narrative to ‘complete’ his story.

In the chaos narrative, Kenneth tells stories of living with pain on a daily basis. The health system fails him as medical experts were unable to treat his pain and take care of his pressure sores successfully. In this narrative, the challenge of living with pain and paraplegia proliferate into the deterioration of his body which lead to the loss of his job, income, and inadequate medical care. However, the chaos story is no longer chaos when the district nurse assisted in cleaning his pressure sores and assisted in applying to rehabilitation. Kenneth’s narrative then moves towards a restitution narrative as therapists at rehabilitation and Bridging Abilities helps to restore his body to ‘normality’. Through Kenneth’s life story, it becomes clear that narrative structures can continually interrupt each other in order to form a ‘complete story’. This means that not all stories of paraplegia are restitution, chaos, or quest narratives, but that stories of paraplegia can simultaneously be restitution and chaos narratives.

Carlo’s life story shows how paraplegia is lived as a quest because acquiring and living with paraplegia had changed him and his life for the better. He claims a new sense of self and believes that paraplegia has been responsible for this change of being. He learned meaningful lessons that gave him new insight into life. He wants to pass these lessons on to others. Subsequently, Carlo’s quest is that his story must be a testimony. Frank (1995) confers that the quest narrative is a testimony. In this study, the quest narrative was a dominant narrative told among all the men. This asserts that stories about disability are usually told as a quest (Frank, 1995).

The three narrative structures helped me to hear differences and similarities in the ways in which stories about paraplegia are being told. Carlo’s narrative style of telling stories about himself and others, includes action, drama, and comedy. His narrative was told in an enthusiastic and charismatic tone, one that reflects his openness to sharing his experiences, but also one that constructs the experience of paraplegia as positive. However, the fact that Carlo is such an “open-book” could be a defence mechanism. Being an open book can also be a way of hiding failure and weakness.

Kenneth’s narrative style is as he defines it, “a thriller”. This includes action, drama, and suspense. He spoke about his life as a dreadful, chaotic, and soul-vexing experience, and he did so in a gentle and husky voice. The sound of helplessness in his voice, but a reflection of contentment in his voice. The way the narrative sounds, constructs the experience of paraplegia as negative, as life never getting better after the injury.

Although both narratives show a linear storyline, the progression of the story and the order of events is different among the two life stories. Carlo’s life story was told in a chronological order. For example, he starts narrating his life story from the age of fourteen to the present. He organized experiences in that order to tell what he perceives as a cohesive story. Kenneth’s story, on the other hand, is not told in a chronological order. He narrates his life story from the present moment, moving back in time to the accident. The order of events allowed me to hear what was not being told.

For example, Kenneth did not speak about his life as an able-bodied man. He did not share stories on his experiences of growing up, previous romantic relationships, being happy, or the ways in which he experiences life as an unmarried man. Carlo, on the other hand, spoke more about his life as an able-bodied man, as opposed to the details of the ways in which the injury had impacted his life.

The way he narrated his life story was more of a synopsis of the ‘detailed’ story. However, Carlo had no memory of the accident scene, while Kenneth, who actually experienced his failing body over a period of time. In other words, if diagnosed early, his meningitis might have been treated, and his paralysis prevented.

The three narrative structures also allowed me to see similarities in the ways in which stories on paraplegia are told. For example, both remembered the exact time and day of the accident. This speaks to the prominence of the event that changed their lives. What is also similar in their stories is how they narrate that part of transitioning to living with paraplegia in a marginalized community, which involved growing a “thick skin”, which spoke to the toughness and strength needed to survive. For example, Carlo says, *“once hulle in my skoene gaan wees sal hulle ’n ander persepsie het van my” (once they are in my shoes they will have a different perception of me).* This resonates with what Kenneth says, *“mense wattie meeste het om te sê, sal nooit, vi 20 jaar, in hierdie skoene kan loepie” (people who have the most to say, will never, for 20 years, be able to walk in these shoes).* This also reflects the difficulty in constructing and telling a story about paraplegia because it can only be fully understood as a lived experience.

Gratitude for life and second chances is similar across the ways in which they narrate their life stories. Second chances allowed them to rectify mistakes of the past and gives them the opportunity to live life right; to do right actions; to enter into healthy relationships that make them ‘whole’ (physically, emotionally, spiritually). So, another dimension to life is added after the accident – a dimension ignored in their previous life, particular religion and spirituality.

What is also clear in these life stories is that religion plays an important role in their rehabilitation. In the absence of sensation and movement from their waist down to their legs, their spiritual connection deepens and becomes more profound as they draw their strength and sense of purpose in life from religion. It is as if religion fills a void for the both of them and offers a view beyond disability. Perhaps it is because of the close to death experience that they became more aware of the perils of worldly pleasures. This spiritual dimension also creates a new type of masculinity because through spiritual renewal they go about reconstructing their life, discovering another way of existing, differently than before, so that ultimately, they can attain a sense of who they are. Religion thus becomes a gateway to realising other ways and possibilities of being a coloured and paralysed male in Macassar.

CHAPTER 5

CHALLENGES TO BECOMING A ‘DISABLED’ MAN AND REDEFINING MASCULINITY

5.1 Introduction

As a single, young, able-bodied man from a middle-class background, who only needs to take care of himself, I forget how much it means for certain men to be the breadwinner in their family. Throughout this study, the men candidly expressed how drastically their lives have changed since the injury. Through reflecting on their narratives, I became aware of how dangerously diminished some men can feel when they are not able to embody the traditional role of the independent man, who provides and protects himself and his family. Therefore, I argue that each theme explored in this section of the chapter, relates to the challenges and tensions in the intersection of disability, masculinity and sexuality.

5.2 SECTION A: CHALLENGES TO BECOMING A ‘DISABLED’ MAN

This section of the chapter examines the ways in which disability, masculinity and sexuality intersect through three broad themes that emerged from the analysis of the narratives. Each of these themes are supported by extracts from the transcribed narratives as well as from the literature.

The first theme, ‘infantilization and shame’, focuses on the immediate period after the onset of paraplegia to the period before rehabilitation. It examines the experiences of the loss of physical and financial independence after the injury. Furtherore, it explores notions of self, masculinity, and dependency.

The second theme, ‘vulnerability to violence’, draws on notions of power, control and physical strength. It highlights the reality of living with a disability on the Cape Flats. This theme is supported by two sub-theme categories. The first sub-theme category, ‘powerlessness’, explores the physical limitations of paraplegia, as well as the resilience and submissiveness to violent hegemonic masculinities on the Cape Flats. The second sub-theme category, ‘strategies to prevent violence’, addresses alternative ways of contesting violent hegemonic masculinities on the Cape Flats.

The third theme, ‘challenges to sexuality’, shows how the physical limitations of the body may impact intimate social engagements. A sub-theme category is also present here, namely, ‘I can’t rise to the occasion’, which explores ideas on sexual intercourse, performance of masculinity, and self-esteem.

5.3 Infantilization and Shame

All the men in this study shared narratives on how they believed that they would never be able to do the things that they did prior to the injury, like walking, dressing themselves, driving, plumbing, and even going to the toilet. This realization made them aware of the link they made between the loss of their physical independence and paraplegia. The loss of physical independence amongst people with disabilities - determined by the loss in individual capacity to do things for oneself, was consistent in the findings of other studies (See Galvin, 2005; DeSanto-Madeya, 2006; Dabhi, 2015).

Men like Devon, Albert, Ridah and Wendell expressed sadness in their experiences of dependency on others to assist them in the things that they could not do for themselves. This increasing dependency made them feel as though they were being treated like an infant. Consider Devon, for example, who had been living with paraplegia for the last two years. He poignantly expressed feelings of shame due the loss of physical independence.

DEVON: Ek was ’n bietjie skaam, want ek sit in ’n stoel en word gestoot. Ek pee myself nat, en maak my broek vuil want ek het nie beheer oor al daai dinge nie. Ek moes ’n katetel gebruik met ’n sakkie. Ek voel skaam, want nou moet iemand my skoon maak, my hande was so swak dat ek dit nie self kon doen nie.

> I was a bit shy because I sit in a chair and get pushed [around]. I peed on myself and dirtied my pants because I do not have control over all those things. I had to use a catheter with a bag. I feel ashamed, because now someone must clean me, my hands were so weak that I could not do it myself.

Here Devon expresses feelings of shame in that his identity as a man is diminished to that of an infant due to the increased dependency on others. He had to depend on others to change and assist him with his bowel movements and to clean his body. His sense of masculinity, which is signified through being physically active is diminished to a state of “uselessness” and “neediness”. This “neediness” contributes to a great deal of shame.

Feelings of shame in relation to the loss of physical capacity to do things for oneself seems to be a pertinent experience across other studies on individuals with disabilities (see Cole, 2004; Galvin, 2005; Saxton, Curry, McNeff, Limont, Powers, & Benson, 2006). Devon continued to express feeling belittled and states that watching his wife do the things that he could not do for himself was a, *"groot knaak" – "a big crack"*, in his life.

Albert had been living with paraplegia for more than five years and often feels as though he is a burden to his family in asking for assistance in the things that he could not do. Feelings of being a burden to others is consistent in other studies (see Cole, 2004; Galvin, 2005, Saxton et al., 2006; Ostrander, 2008). Because Albert perceives paraplegia as a burden based on his reliance on others, also introduces an element of feeling morally inferiority. Galvin (2005, pg. 403) research shows that being a burden and feeling inferior contributes to feelings of shame because the "fulfilment of these needs is seen in terms of 'burden' and 'self-sacrifice.'" Consider Albert, for example, who expressed his frustration in being a burden to his family.

ALBERT: Elke keer moet ek roep, *"bring gou vir my daai, bring gou vir my die, help my gou."* Die mense het nie altyd die gedult nie, en hulle het nie lus vir dit nie.

Every time I must call, *"bring that quickly, fetch this quickly, help me quickly."* People do not always have the patience, and they don't always feel like it.

During Albert's diagnosis procedure, the doctors explained to him that his sickness had severely affected his spinal cord. Albert was perplexed since he had no knowledge about spinal cord injuries or what it meant to live with such an injury. The only thing he understood about the injury was when the doctor explained that he would be like a baby. Even then, Albert did not gasp the full intensity of this statement. He only became aware of what it actually meant when he realised the extent to which his loss of physical independence impacted him.

ALBERT: Die dokters sê vir my: *"Mnr, jy is nou weer soos 'n babatjie. Jy sal nou moet weer leer om te loop."* Dit is 'n verskrikelike gevoel. Dit kraak jou af. Dit voel of jy klaar is met die lewe.

The doctors said to me: *"Sir, you are now like a baby again. You will have to learn to walk again."* It's a terrible feeling. It breaks you down. You feel as if you're done with life.

Ridah acquired paraplegia through a motor accident. He does not remember much about the accident. He only remembers feeling dead after waking up five days later in the Intensive Care Unit. Through his experiences of living with paraplegia for the last seven years, he firmly contributed to the narrative of shame and the idea of infantilization. He emphasized the need for assistance from others in relation to an infant needing care and assistance from others to survive.

RIDAH: I can't exist without people in my space. It is probably the most difficult thing that I had to face. Life changes, our lifestyle changes, everything changes, now you are dealing with a big person who is a baby.

Like Devon who mentioned that being treated like an infant is a crack in his life, Albert also says, *"dit kraak jou af",* which could also be translated and interpreted as the literal meaning of *"it brings you down"* from being a grown, physically strong and independent man, to being weak and dependent like a baby. It could also be interpreted as the figurative meaning of *'bringing you down'* emotionally, spiritually, and psychologically.

The reality of losing physical independence, and the experience of feeling ashamed and infantilized, is emasculating. This was also echoed among male respondents in Cole's study (2004). In this study, Norman and Franklin are the only men who shared narratives on their thoughts of committing suicide after they learned that the injury had impacted their masculinity through the loss of their physical independence. Since the onset of paraplegia, Norman felt trapped in his body and viewed his current body as something that did not belong to him. Due to the loss of independence and the shame he felt about being in this body, he contemplated suicide on numerous occasions but could never get himself to do it.

NORMAN: I was thinking of killing myself because this is not a life. I can't live like this, because I looked like I was a child.

Here Norman's feelings of shame is viewed in relation to his inability to do what he did prior to the injury (Galvin, 2005), and his dependence on others (Galvin, 2005, Saxton et al., 2006; Ostrander, 2008). Feelings of shame here is related to the physical changes and limitations of the body (Cole, 2004; Galvin, 2005). These factors contributed to Norman's perception of being treated like a baby and his subsequent thoughts of committing suicide.

Franklin acquired paraplegia in a rugby match he played during his stay period in Pollsmoor prison. He described the moment of contact when he broke his neck as, *"'n skok in my liggam"* – *"a shock in my body"*. Franklin also had no knowledge about spinal cord injuries. After his doctor explained to him that he would have to learn independence like an infant, he pleaded with his doctor to give him an injection that would kill him, because being treated as though he was a baby at the age of thirty-six meant that his life was not worth living. Franklin closed his eyes as he reflected on the day that he had this conversation with his doctor.

FRANKLIN: Sy [the doctor] het gesê ek sal moet leer om dinge te doen soos wat 'n baba leer om dinge te doen. Dit was seer. Ek het vir haar gesê, *"gee vir my'n dood inspuiting"*, toe sê sy vir my, *"you must say, 'God, thank you that I survived.'"*

She [the doctor] told me that I would have to learn to do things like a baby learns to do things. It was painful. I told her, *"euthanise me"*, then she said, *"you must say, 'God, thank you that I survived.'"*

The fact that Franklin was adamant and willing to sacrifice his life because he could not imagine living a life of dependency whilst simultaneously relearning independence, is very telling. However, the doctor made him aware that he had been given a second chance. All men expressed gratefulness about being given a second chance. This was also found among respondents in Cole's (2004) study.

The above representations of feelings of shame and infantilization shows the extent to which the injury had impacted these men's sense of masculinity, and more importantly, how the injury had impacted their lives. Furthermore, the narratives show how strongly the need of constant care and assistance is strongly associated with feelings of shame and embarrassment. The drastic emasculation process in which grown men are reduced to an infant-like status is significant here. Because of this, men like Norman and Franklin were consumed with thoughts of committing suicide. However, the fact that they are still alive, albeit with paraplegia, allows one to argue that perhaps they may have developed a different understanding of what it means to be a man. This is what I aimed to explore later in this chapter.

5.4 Vulnerability to Violence

According to Seedat, Van Niekerk, Jewkes, Suffla, and Ratele (2009), dominant patriarchal notions of masculinity sustains violence in South Africa. This is evident in that theorists argue that hegemonic patriarchal notions of masculinity are often embodied and performed through toughness, street fights, rage, bravery and risk-taking (Seedat et al., 2009; Jewkes & Morrell, 2010). Several of the men in this study mentioned that living in Macassar is not safe due to the high prevalence of gangsterism within the community (Moolman, 2004; Salo, 2005; MacMaster, 2007; Boonzaier, 2008; Cooper, 2009; Anderson; 2010).

Even though some of the men in this study were part of gangs prior to their injury, they still felt unsafe. These men understand that being in a wheelchair on the streets means that they are vulnerable and targets for muggings, harassment and physical assault at any time of the day (Waxman, 1991). In keeping with the findings of Ostrander (2008), these men fearfully expressed concerns for their safety and inability to physically protect or defend themselves from gangsters and muggers.

5.4.1 Powerlessness

Wendell, for example, was confronted with the reality of his inability to physically defend himself on the day of the car accident. He recalls being stuck and paralysed in a delivery truck waiting on an ambulance, while begging muggers not to take his phone as he had important numbers stored on it.

WENDELL: [accident scene] die eerste ding wat gebeur het was, die ouens rob my net daar, steel my foon en my goed. Ek skree, *“moet nie my goed steel nie, al my nommers en goed is daarop”*, terwyl ek net daar lê.

The first thing that happened was that the guys just robbed me on the spot, stole my phone and my stuff. I shouted to one of them, *“Don’t steal my stuff, all my numbers and things are on my phone”*, while I just laid there.

Two years later, he was approached by two muggers in Macassar. Wendell explains the occurrence to me.

WENDELL: As ek in die straat ry, en ek het my sak agter op my rolstoel, en in my sak is dit net my water bottle en my pee bottle, maar dan sal die ouens my sak steel want hulle dink daar is geld in, die man sal my sak vat en weg hardloop.

> If I ride in the street, and I have my bag on the back of my wheelchair, and the only things in my bag are my water bottle and a bottle to urinate in, but then the guys will still steal my bag because they think there's money in it, the man will simply take my bag away from me and run away.

Kurt was recently robbed. His newly bought shoes were ripped off from his feet. He explains how the robbery unfolded.

KURT: Ek sien die ou kom aangestap. Ek sien hoe hy my skoene kyk. Sy eyes is net aan my takkies. Hy trek my takkies af, en dan loop hy nog weg, hy hardloop nie eers weg nie, want daar is niks wat ek aan dit kan doen nie.

> I see the guy walking. I see how he looks at my shoes. His eyes are fixed on my takkies. He pulls off my takkies, and then he walks away, he does not even run away, because there's nothing I can do about it.

Wendell and Kurt felt powerless as they could not physically defend themselves from the men who perpetuated violence against them. Both these men attest that it is usually young men in their communities who often perpetuate violence. This finding is also demonstrated in a South African based research study which asserts that men who perpetuate violence in marginalized communities are often aged between 15 and 29 years (Seedat et al., 2009). I could see that Kurt was emotionally scarred and perhaps still traumatized when he explained the occurrence to me. The tone in his voice dropped. The corners of his eyes were filled with tears. I then asked him how he felt in the moment of seeing how the mugger walked away with his pair of shoes.

KURT: Moodeloos. Hy staan voor my en dan lag hy my uit in my gesig en sê, *“jy kan my niks maak nie man. Jy is niks werd nie!”* Dit werk op ’n mens. Dit maak jou seer. Maar wat kan mens doen?

> Hopeless. He stood in front of me and then he laughed in my face and said, *“you cannot do anything to me. You're worth nothing!”* It works on a person. It hurts. But what can one do?”

Here, the feeling of powerlessness is strongly conveyed. Although Kurt rhetorically asked me, *“wat kan mens doen?” – “what can we do?”* He knows that there is nothing that he can do. This shows how power intersects with masculinity, violence and ableism. Robbing Kurt was not just about taking his possessions from him, it was also about robbing him of his dignity.

It is more than just the physical act of robbing; it is the emotional, mental and psychological impact that such robbing represents. So, robbing here becomes a symbol for so much more that coloured men with paraplegia experience. These factors impact their understanding of what it now means to be a man.

Like a respondent in Ostrander's (2008) study, Norman expressed his frustration about his lack of mobility in that it prohibits him from physically defending himself. He did so by recalling his self-defence strategies prior to the accident, and how this has now changed.

NORMAN: What puts me off is that I cannot just grab the person because he insulted me. In the past I could just run after him or go to his house with a gun. Now that makes me very angry.

In Kenneth's experience, it is not only gangsters or muggers who rob, but even those he thought he could trust - like the people who willingly push him in the wheelchair.

KENNETH: Hier in die gemeenskap is daar elke tweede person wat 'n mens probeer verneek. Selfs die mense wat my stood… hulle vat wat ek het, en dan los hulle my net daar.

Here in the community every second person tries to rob you. Even the people who push me… they take what I have and just leave me there.

He continued: Ek voel breekbaar. Partykeer kan ek nie kwaad wees vir hulle nie, want ek weet dat hulle dit doen vir geld, omdat hulle iets nodig het. Ek kan nie kwaad wees nie want ek weet dat hulle geleer was om te steel vir alles wat hulle het, en om te vat wat hulle kry, sonder om skuldig te voel daar oor.

I feel fragile. Sometimes I cannot be angry with them because I know that they are doing it for money, because they need something. I cannot be angry because I know they've been taught to steal everything they have, and to take what they get, without feeling guilty.

Kenneth's maturity reflects in this response. Although he feels vulnerable and fragile when he is targeted, he shows some understanding and empathy in the reality of the lived experiences of the muggers in his community. Kenneth understands that robbers live in poverty and they need to survive, but it does not mean that it is acceptable. Kenneth still feels fragile when he is targeted. Here the issue of fragility is accompanied by an understanding of why people in his community rob.

This understanding suggests that accepting paraplegia allows him to be accepting of other external factors happening around and to him. Therefore, he endures the violence.

5.4.2 Strategies to Preventing Violence

Men like Wendell, did not always know what to do when confronted by muggers, simply surrendered. Oppies on the other hand, explained that paraplegia did not prohibit him from physically and verbally defending himself. He proposes that men with paraplegia should not always surrender. Oppies recalled an incident where he physically defended himself whilst sitting in the wheelchair.

OPPIES: Daar is baie ouens wat grappe maak en sê, *"Oppies, wanneer kom haal jy jou Carvella's?"* Ek verstan daai is 'n grap, ek aanvaar dit. Maar toe hoor ek die een ou sê, *"kyk daar is die halwe man, ek wonder hoe maak hy kinders?"* Toe ek daar terug gedraai het, toe gee ek hom 'n klap! Sulke goed is persoonlik. Jy kan nie sê ek is half nie, ek bedoel, hoe gaan jy voel as iemand vir jou sê jy is half?

There are many guys who make jokes and say, *"Oppies, when are you coming to collect your Carvellas?"* I understand that is a joke, I accept it. But then I heard one guy say, *"look, there's the half man, I wonder how he makes kids?"* When I turned around, I slapped him. Such things are personal. You cannot say I'm half, I mean, how will you feel if someone says you are half?

This experience of Oppies shows that men with paraplegia are not always powerless and helpless. There is physical strength in their arms and hands. Albeit they may feel afraid to reclaim their physical power by challenging the dominant and violent able-bodied male in a physical fight, Oppies showed that without resistance and fear, physical self-defence is possible. He asserted his power, and manliness, without the use of a weapon. Perhaps the concern is not so much on the physical strength, but rather the difference in speed and mobility among the mugger and the man in the wheelchair. For example, the mugger can easily run away – as Oppies said – while the man in the wheelchair may find it challenging to move away from the fight or to even follow the mugger. Subsequently, Oppies highlights a social and cultural perception that some men in his community have of him in the wheelchair, namely, that he is 'half a man' because half of his body is paralysed, and he can only engage in half the things that men do, like have sex and reproduce children, as stated in his extract above.

Kenneth shared strategies that he implemented in preventing violent attacks. He also speaks to men in wheelchairs by asking them to be more cautious and observant.

KENNETH: Jy moet altyd op die venster wees. As ek sien daar kom twee outjies aan, moet ek kyk hoe opsugtelik is my foon, want as hulle my foon sien, weet ek dat hulle dit sal vat… Daai is die lewe waarin ons lewe in ons gemeenskap. Ons bly nie tussen blankes nie.

You must always be on the lookout. If I see that there are two guys approaching, I must see how visible my phone is, because if they see my phone, I know that they will take it... That is the life we live in our community. We do not stay amongst whites.

Many of the men I spoke to never found themselves in a life-threatening situation where they had to physically defend themselves. They never thought about what they would do if they were robbed, harassed, or physically assaulted. It was only in our conversation that they became aware of the possibility of being physically assaulted or robbed on the streets or in their home. After much thought, Allen and Johan both said that they would hand over their possessions as their lives are more valuable.

ALLEN: I have never experienced it before, and I have not thought about it, but I would rather just hand over my things and ask him to let me go.

Allen shows that he does not need to prove that he is a man because the degree of his injury does not allow him to fight back. Ridah puts forward the idea of self-defence as not necessarily a physical act of violence but rather a verbal one. For example, speaking up for oneself or shouting while being robbed. This way of defending himself is part of his reconstruction of manhood.

RIDAH: We need to use what we have. I have a loud voice and I will be able to scream my lungs out if I get robbed, and I know someone will hear me. I think that shouting or screaming can also be a way of protection.

Even though some men have thought about strategies to defend themselves from violence in their community, none of these strategies are proactive steps in the fight against violence. What becomes evident in their experiences of violence is as Waxman (1991, pg. 188) states, “hidden acts of brutality.” Most people on the streets do not see these acts of violence and neither do they hear about it.

As much as everyone in Macassar experiences violence in some way or another, violence against people with disabilities are silenced. These men attested to this, in that I was the first person with whom they shared their experiences of being robbed and harassed. The reason for their silence stems from feelings of shame and embarrassment due to their inability to defend themselves in their current state. This puts an emphasis on the silence around the experiences of brutality and violence against oppressed victims (Waxman, 1991). Therefore, these men show that they often have no choice but to endure the violence, especially knowing that actively engaging in hegemonic masculinity means to participate in violence. Thus, the inability to physically defend and protect themselves challenges dominant understandings of what it means to be a man in their communities (Ostrander, 2008). This 'incapacity' to physically defend themselves contributes to feelings of helplessness, powerlessness, uselessness, and worthlessness. Ultimately, this emasculates them.

5.5 Challenges to Sexuality

According to Sakellariou (2006), sexual intercourse is one of the most pertinent traits of masculinity. In the social context of the men in this study, questions related to: '*how many women a man sleeps with'*, *'how often he has sex'*, and *'different ways to sexually satisfy a woman'* contribute to notions of what it means to be a man. Jewkes and Morrell (2010) argue that a man is expected to lead and control sexual relations within a heterosexual relationship. This is central to the discourse of the 'male sexual drive' which purports that sex is a male-centred activity - an uncontrollable urge that is central to the biological make up of a man (Shefer & Foster, 2001; Braun, Gavey, McPhillips, 2003). However, due to the extent of the injury, many of the men in this study cannot have penetrative sex. Thus, they choose not to have sexual relations because they cannot engage in sexual intercourse in the same way as they did prior to the injury. It is difficult for them to meet the heteronormative expectations of how to sexually satisfy a woman.

5.5.1 "I can't rise to the occasion"

Devon candidly expressed the challenges that he experiences in sexual intercourse. He mainly focuses on the ways in which the injury has affected the extent to which he can sexually engage with his partner.

DEVON: My sex lewe het verander soos in drasties baie. Kyk ek kry nie meer ’n ereksie nie, ek kan nie meer ejaculate nie, so dit is net heeltemal anders. Die feit dat ek nie meer kan ejaculate nie is so frustreerend, dat ek belangsteling verloor het.

My sex life has changed like drastically. Look I don’t get an erection anymore, I cannot ejaculate anymore, so it is just completely different. The fact that I cannot ejaculate is so frustrating that I lost interest.

Many of the men echoed Devon’s response regarding the drastic change in their sex life. The inability to get an erection and ejaculate due to the loss of sensation and paralysis, frustrates them. This finding mirrors previous work (see Sakellariou, 2006; Ostrander, 2008). This finding also contributes to that of a South African study by Hunt, Braathen, Swartz, Carew, and Rohleder (2018) who explored the practical and subjective experiences of people with disabilities regarding their sex lives and experiences of sexuality. The frustration that respondents expressed in ‘having satisfying sex’ from the findings of Hunt et al (2018) is closely related to the challenges that the men in this study encountered. Kenneth also has no sensation; therefore, he cannot get an erection and ejaculate. He also feels frustrated by the lack of sexual satisfaction.

KENNETH: Dit is ’n geweldige aanpassing. Veral as jy sexueel aktief was en onder die geselskap van vrouens, en nou moet jy dit altyd in aagneem wanneer jy in ’n gesprek is met ’n vroumens. Ek moet atyd vir myself sê, *“ek is paraplegic en ek sal nie sexueel die vroumens kan bevredig nie.”* Ander meisies het nie altyd die begrip oor dit nie. En dit is nie iets wat jy maklik oor kan praat nie, ek bedoel ek sal nie sommer sê, *“I can’t rise to the occasion”.* As jy nie so effektief is op daai vlak nie, dan gaan dit ’n anderste saak wees om ’n gesonde vrou met needs te bevredig.

It is a constant adjustment. Especially if you were sexually active and always in the company of women, and now you always have to consider your condition when you are in the company of women. I must always tell myself, *“I am a paraplegic and I cannot sexually satisfy a woman.”* Other women do not always comprehend it. And it is not something that you can easily talk about, I mean, I won’t easily say, *“I can’t rise to the occasion.”* If you are not as effective on that level, then it will be another situation to meet the needs of a healthy woman.

The adjustment from being sexually active prior to the injury to being sexually inactive is still an adjustment for Kenneth - and for most men in this study. The adjustment concerns not only sexual inability or incapacity, but also the limitation of pursing social or emotional intimacy with women - especially those whom they are sexually attracted to. Kenneth distances himself from these women because he feels too ashamed to constantly explain the extent of the injury and the inability to hold an erection and ejaculate. Kenneth makes it clear that being a man means to sexually arouse and satisfy a woman (Shefer & Foster, 2001; Braun, Gavey, McPhillips, 2003). The fact that he does not meet this expectation diminishes his masculinity and forces him to question the meaning of his masculinity.

Kenneth highlights the lack of knowledge that people have around spinal cord injuries, especially the lack in understanding about the sexual complexities that men with spinal cord injuries are confronted with. This lack of knowledge and having to constantly explain the cause and extent of their injury was also echoed through the other men's narratives. Furthermore, Kenneth mentioned that it is not easy to explain these complexities, for example, he says, *"I won't easily say, 'I can't rise to the occasion'",* which shows the difficulty in explaining that he cannot get an erection in the moment of intimacy, or that he cannot meet the expectation of performing sexually and satisfying a woman's sexual needs.

Kenneth also confirms that part of a man's responsibility is to sexually satisfy a woman, but in his case, the challenge is in communicating *this inability* to her. He did mention that sexual intimacy makes him feel fragile because of his inability to perform sexually and that communicating this to a healthy woman made him feel emasculated. The constant comparison between his performance of masculinity before and after the injury, is thus a constant source of frustration, forcing him to consider what he has lost. The limitation that Kenneth expresses in sustaining a sexual relationship confirms the findings of Hunt et al (2018).

Kenneth thus made the decision not to engage in sexual intercourse with a "healthy woman" because of his sexual limitations. It is interesting how he differentiates between himself and the woman, by implying that he is the unhealthy one, and the woman is healthy. It is almost as if Kenneth sees paraplegia as a sickness, something that has impacted his health and manliness.

Johan speaks about his strong desires to still have sex with his wife. He reiterates that he is a man, and sex is what men desire most. This view confirms Shefer and Foster's (2001) argument that heterosexual male sex-drive is a biological urge for men. Johan spoke about the pain of not being able to satisfy this urge.

JOHAN: Dit was nogal seer gewees. Ek bedoel ek is 'n man, ek begeer nog dit. Ek meen ek is getroud, my vrou soek daai… En toe dit stop toe het dit my baie seer laat voel.

It was painful. I mean I am a man, I still have that desire. I mean I am married, my wife wants that… and when it stopped, it was a painful feeling.

In contrast to the men who have no sensation, the extent of Allen's injury allows him some sensation. Sometimes he can get sexually aroused, erect and ejaculate. However, he never knows when he has the sexual capacity to do so. As a result, he chose not to have sex because he cannot always meet the expectation to sexually perform. In the extract below, Allen recalls a recent sexual experience.

> ALLEN: It is bad and not as satisfying, because of that comparison that I can make of being able bodied. When you are an able-bodied person it is more spontaneous, it can happen easier, but when you are disabled it is more of a planned kind of thing.

Allen focused specifically on how the injury had an impact on the spontaneity of his sexual encounters. For example, now he must plan to have sex, whereas before the injury, sex was spontaneous; in any place at any time. This mirrors the findings from respondents in Ostrander's (2008) study who expressed that the injury had an impact on the frequency of sex and spontaneity of their sexual encounters.

Allen mentions that sex as an able-bodied person is more satisfying. He also puts forward the idea that perhaps sex is not bad and dissatisfying if one is born with a disability or loses sensation prior to being sexually active. Because he had sexual intercourse prior and after the injury, he can make a clear distinction between those experiences. I asked Allen how he felt about being sexually active after the injury, especially since many of the other men could not engage sexually. He spoke about a time (after the injury) when he told his father that he had sex with a woman.

> ALLEN: My father does not want us to have sex before marriage, but I don't know whether it is a male thing, but now that I am sexually active and disabled, it is almost like I am scoring one for the team. It is almost like he is proud that I am moving on with my life, and it is almost like he sees me more like a man who is disabled because I am doing that. But for me it is like there are greater attributes that make me more of a man than just this 'one item'. I don't think I feel more of a man by doing it.

Allen shows the centrality of heterosexual sex to meanings of 'being a man'. His father's response confers that sex is a male-driven activity (Shefer & Foster, 2001). However, he asserts that for him sex is not as important trait of masculinity as it is for his father. His father's ideas of manhood are based on traditional notions of masculinity, while Allen challenges those notions and abides to a more contemporary understanding of what it means to be a man. For example, Allen's father considers sex as an achievement considering Allen's paralysis. However, Allen makes it clear that sex does not define his masculinity. Furthermore, his experience of unsatisfying or ‘bad sex’ as a man living with paraplegia echoes the findings of Hunt et al (2018), who found that physically disabled respondents in their study found it difficult having satisfying sex.

Most men in this study choose not to engage in sexual intercourse because it is difficult for them to perform sexually and meet expectations of sexually satisfying a woman. Thus, the inability to perform sexually results in an unsatisfying sexual life (Sakellariou, 2006). Generally, sex was defined as something sensual which is meaningless if it cannot be felt. Good sex was defined as ‘satisfying sex’ where one can perform sexually and meet sexual expectations (Braun, Gavey, McPhillips, 2003). ‘Bad sex’ was defined as unsatisfying sex where one is incapable of performing sexually.

Most of the men feel fragile in moments of intimacy. This makes it difficult for them to explain their sexual incapacity to their partners. The fragility in explaining their sexual incapacity may be, as Hunt et al (2018) posits, due to the fear of negative appraisals from their partners. However, the men only noted that explaining the complexities around the level of their injury is challenging because not everyone understands what it means to live with paraplegia. There is still a strong desire for these men to have sex, not only because they consider it as an important trait of their manhood, but because they were sexually active prior to the injury, thus they know what sex feels like. However, the decision not to engage in sexual intercourse made them reflect on their previous perceptions of what it means to be a man. Ultimately, their sexual incapacity made them question their understating of manhood.

5.6 Conclusion

In this section of the chapter, the men in the study expressed how their identity as a man, was diminished to that of an infant, due to the increased dependency on others. They had to depend on others to feed, clean, empty their bowel, dress and push them in the wheelchair. Feelings of shame, embarrassment, infantilization, and being a burden to others, came with this dependency. Subsequently, the loss of physical independence contributed to the loss in their masculinity, because their sense of masculinity was constructed and defined according to the degree of physical independence. This is consistent in the literature on masculinity and disability (see Cole, 2004; Galvin, 2005; DeSanto-Madeya, 2006). Furthermore, the loss of physical independence was humiliating and emasculating. As a result, a few men considered committing suicide.

Some men expressed experiences of feeling powerlessness due to their inability to fight and protect themselves, and their families, from the prevailing violence that occur in their community. This is consistent with the findings of Ostrander (2008). The men in this study show vulnerability in their masculinity through the inability to fight back against men who perpetuate violence through mugging, harassment and physical assault. Violence had a lasting effect on the emotional, psychological, and mental health of the men who were robbed from their possessions and dignity.

Subsequently, some men in this study understand that they are more vulnerable to violence, thus they learned strategies to defend and protect themselves from violence in their community. These strategies include learning to surrender, using their arms and hands to fight back, using their voice to scream and shout for help, and to be cautious and observant on the streets.

The men in this study also show how paraplegia challenges their masculinity through sexual performance. The fact that they cannot have ‘satisfying sex’ because they cannot get an erection and ejaculate, shows the challenges in sexually satisfy a woman. This is consistent with other findings (see Cole, 2004; Sakellariou, 2006; Ostrander, 2008; Hunt et al., 2018). Furthermore, the inability to engage in sexual intercourse diminishes their masculinity and sense of self-esteem.

5.7 Introduction

In this section of the chapter, I explore strategies and redefinitions that contribute to understandings on how the men in this study negotiate the intersection of disability, masculinity and sexuality. These strategies and redefinitions are supported by extracts from their transcribed narratives as well as previous research findings. Some themes include photographs from the photo-stories to substantiate the textual meaning. However, the analysis does not focus on the photograph itself, but rather on textual meaning.

5.8 SECTION B: STRATEGIES AND REDEFINITIONS

The four themes that emerged in this section are as follows: The first theme, ‘learning to live independently’, explores the ways in which the men in this study find ways to regain their independence, practise their agency, and reclaim their identity by redefining what it means to be a coloured man and a man living with paraplegia.

The second theme, ‘I don’t need help’, shows that the men in this study can live independently. They argue that it is offensive when able bodied people offer to help them as it implies that they are not capable of doing things for themselves. This theme shows how they have found different ways of doing things that they did prior to the injury.

The third theme, ‘differently abled sex’, shows how the men in this study engage in intimate and innovative ways of giving and receiving pleasure that does not presecribe to normative penetrative sex. This theme consists of two sub-theme categories. The first sub-theme category, ‘unsatisfying sex’, shows how some men experience alternative sex acts as unsatisfying. The second sub-theme category, ‘satisfying sex’, shows how some men experience alternative sex acts as satisfying, and ultimately, how these acts leads to new meanings of sex and masculinity.

5.9 Learning to Live Independently

This section unpacks the narratives of Kenneth, Allen, Carlo, and Franklin who shared stories of hope and determination in their quest to embrace living with paraplegia and relearning how to be physically independent. One could argue that perhaps these men showed determination in gaining physical independence to prove to society (and themselves) that they are men who do not need to depend on others. These men were committed to the plan set by rehabilitators and occupational therapists in teaching them to live with paraplegia as independently as possible. For example, Kenneth shared his experience of relearning independence and how important rehabilitation was in assisting him throughout this process.

KENNETH: Sonder rehabilitasie is jy niks nie. Alles is'n berg. Hulle het my geleer hoe om op my eie te leef en na myself om te sien. Hulle het my geleer hoe om my eie kos voor te berei, sport te doen, en al die dinge. Hulle leer jou hoe om van jou bed tot in jou rolstoel te kom. As jy uit val, dan moet jy van die vloer af kan opstaan om vir jouself te kan help. Daar het hulle my geleer hoe om myself te help sonder om rond te kyk vir mense.

Without rehabilitation you are nothing. Everything is a hurdle; another mountain to climb. They taught me how to live on my own and to care for myself. They taught me how to prepare my own food, do sports, and all those things. They teach you how to get from your bed to your wheelchair. If you fall, then you must be able to get up from the floor and help yourself. There they taught me how to help myself without looking around for people.

In Kenneth's narrative above, he showed determination and willingness in relearning independence. Although he tried, and sometimes fell (literally and figurately), he knew that he was in a safe environment where he could trust and rely on the medical staff for assistance. There was a sense of pride in overcoming challenges (physical, psychological, and emotional) throughout the process of relearning independence. Men like Norman, Allen, Franklin and Carlo echoed this experience. According to them, rehabilitation had a positive impact on the way that they felt about themselves and their sense of masculinity. Rehabilitation helped to shift the perception of 'being a baby' to 'being a man'.

NORMAN: At the training they try to make you sit. After they see that you are trying to sit then they give you the weights. Every day they increased the weights. When they see that you are better, they throw the ball to you, and then you must catch it. Sometimes when they throw the ball, I must move to catch it, but then I fall. But the more I did these things, the more I did not feel like a baby anymore.

FRANKLIN: Ek ontmoet vriende wat in rolstoele sit, en dit het my gemotiveer. Dit het vir my gesê ‘as die ander manne kan aanpas en dan kan jy ook aanpas.’

> I meet friends who sit in wheelchairs, and that motivated me. That told me that ‘if the other men can adjust then you can also adjust.’

Some men like Norman and Franklin felt good about themselves after achieving goals. Men like Kenneth, Devon and Allen found it challenging achieving goals that required physical movement. But they remained determined and driven to try. It is through pure determination, drive and perseverance that they were reminded of who they are. These men were enacting certain traits of masculinity that they had been exposed to all their lives, such as drive, determination and perseverance to live as independently as possible because that is what it meant to be a man. Kenneth and Devon reiterate this below.

KENNETH: Ek het nie opgegee nie, want dit is nie in my om te verloor nie.

> I did not give up, because it is not in me to lose.

DEVON: Alhoewel hulle my gewys het hoe om dit te doen, was ek nog altyd bang ek val. Ek was so bang vir val, dit is nie eers snaaks nie. Maar ek moes altyd myself herinner het dat ek ’n man is en nie ’n kind nie.

> Although they showed me how to do it, I was always afraid to fall. I was so scared of falling, it is not even funny. But I always had to remind myself that I am a man and not a child.

From their narratives, it is evident that being a man means not giving up and losing a battle or challenge. Instead, it meant overcoming challenges, no matter how hard or difficult the road was. These men also made a clear distinction between the kinds of mistakes that children are permitted to make, but which are not tolerated amongst men. For example, according to Allen, to helplessly lay in bed is associated with babies, and according to Devon, being afraid of falling is a child-like fear. Thus, through the challenges of learning to live independently, they were constantly reminded of who they were as men and that persevering to live as independently as possible is what men do.

Rehabilitation provided the men in this study with a community of people who all had spinal cord injuries and had acquired the injury though similar instances. This sense of belonging is also something that many of the men never had while able-bodied.

Seeing the resilience of people who were in more traumatic accidents with more extreme levels of injury, made their resilience stronger, and gave them a sense of hope and encouragement to live with paraplegia. Furthermore, the community of people in rehabilitation always (silently) reminded them that they were not alone.

FRANKLIN: ’n man wat altyd vir my encourage het se hele system werk nie. Dit het vir my moed geskep want die man het klom geld, maar hy kan nie praat nie, hy praat met sy oe. Dit het vir my gesê, ‘die wereld is nie verby vir jou nie, jy het nog ’n voorreg om te kan sien, praat, en gaan tot by plekke.’

> A man who always encouraged me, his whole system is not working. It gave me hope because the man has a lot of money, but he cannot speak, he speaks with his eyes. This told me, ‘the world is not over for you, you still have the privilege to see, talk, and go to places.’

Similarly, Kurt reflected on his experience of being in rehabilitation and explained this experience through a photo-story in Figure 5.1 below.

Figure 5.1 Kurt photo-story on community.

KURT: Dit laat ek nie so minderwaardig voel nie. Ek dink nie so min van myself nie. Dit laat ek dink dat ek nie alleen is nie. Dit wys vir jou, as jy nou almal daai mense sien met verskillende beseerings, dan besef ek dat ek nie so erg as die volgende person wat erger is nie. Nou dit gee vir my altyd moed want ek is nie alleen nie.

It does not let me feel so unworthy. I do not think so little of myself. It makes me think that I am not alone. It shows you, if you see all those people with different injuries, then I realise that my condition is not as severe as the next person with a more severe condition. Now this always gives me hope because I am not alone.

Ridah reflected on his experiences of rehabilitation. He did not mention much about how the people in the space created a community and a sense of belonging. However, he spoke more about rehabilitation being a space of reflection; for him to think deeply about life after rehabilitation.

RIDAH: that period was very much needed for me, I could never just come home. It was a period where my family could prepare themselves for what was coming ahead, but also to prepare myself for what lays ahead. I think then only the realisation of the things I needed to do for my future, came upon me, it really struck me hard.

Most of the men stayed in rehabilitation for about three months. The primary goal of rehabilitation was to learn how to live with paraplegia as independently as possible. Rehabilitation was the place where they accepted living with paraplegia. It was only after they accepted their condition that they committed to the process of relearning independence. Seeing people with more severe and traumatic spinal cord injuries gave these men hope and inspired a sense of gratitude for being alive. Rehabilitation helped these men to gain strength; physically, emotionally, and psychologically. Ultimately, rehabilitation was a space of community, healing, acceptance, forgiveness, learning and reflecting.

5.10 "I don't need help"

After rehabilitation, some of the men joined the Bridging Abilities organization where they do physical exercises every week to strengthen their body. Learning to live independently is an ongoing process since their bodies can not operate the way it did prior to the injury. These men are therefore still seeking alternative ways of doing things – independently. This remains a daily challenge, but despite this, these men refuse assistance or help from others. They find it offensive if anyone offers to help.

Respondents in research conducted by McDougall (2006, pg. 389) claim that “assistance or help from others reduces their identity to this single distortion of dependency”. Oppies echoes this finding.

OPPIES: Mense bejammer my te veel, en ek like dit nie. Soos miskien as jy my wil stood, ek hou nie van dit nie. Dit vernieder my baie.

People pity me too much, and I do not like it. Like maybe if you want to push me, I do not like it. It humiliates me a lot.

Oppies finds it humiliating when people offer to help him because he does not understand why people feel the need to do so. He questions the motives of those wishing to assist him. Accepting assistance would indicate that he is perceived as being incapable. It could also signal the way in which others wish to express empathy. McDougall (2006) argues that society’s perceptions of ‘disabled’ people suggests that their disability is only entitled to pity, and perhaps this explains society’s gesture towards helping those who are perceived as ‘disabled’. Furthermore, Kenneth explains that living an independent lifestyle means to not accept help from others, because he knows that they will not always be there, and he also understands that a time will come when he will need them to help him.

KENNETH: Ek wou nie hê dat mense my moet help nie. Ek weet die tyd sal kom wanneer ek dit nie meer vir myself sal kan doen nie, en dan sal dit oraait wees dat hulle my help.

I did not want people to help me. I know the time will come when I will not be able to do it for myself anymore, and then it will be okay for them to help me.

Norman also contributed to this experience by explaining what it means to live independently and that he does not need any help from others.

NORMAN: If I wash my clothes, I take my clothes and put it in the bath, then I pour the water and the powder and wash my clothes. Everything I do for myself.

Allen also strives to live as independently as possible. He says that living a physically independent life means to live a ‘normal’ life. Therefore, he aspires to be physically independent.

ALLEN: I think what drives me the most is that I feel like my life must be as ‘normal’ as everyone else. My greatest dream is to be independent, not to prove it to people, but just for me.

From these responses, the men were adamant in expressing the need to be physically independent. Sakellariou (2006) puts forward the idea that one of the primary traits of being male is to be independent. The men in this study showed the value of independency. It was strongly emphasised that help would only be welcomed if they asked for it. In this sense they felt humiliated when people randomly offered to help them since this implied that they were being pitied or perceived as incapable. From these responses, these men challenge the social perception that disability is synonymous with dependency (McDougall, 2006).

5.11 Differently Abled Sex

Some men mentioned that even though they could not have penetrative sex, there were other ways of sexually satisfying their partners - and to some extent, themselves. They acknowledged that this constituted a different form of sexual intimacy.

The sub-theme, ‘unsatisfying sex’, draws on the stories of Kenneth and Devon, as their stories convey a yearning and an adhering to the heteronormative male sex drive. In spite of engaging in alternative sex acts, like oral sex and the injection used to maintain an erection, they still feel emasculated because they cannot ejaculate. Engaging in differently abled sex is unsatisfying for them and does not lead to new ways of reconceptualizing and thinking about sex and masculinity.

The sub-theme, ‘satisfying sex’, presents the sexual experiences of Wendell and Gavin. These two men engage in differently abled sex, like affection, whispering, kissing and caressing sensitive areas on the body, which they define as satisfying sex. This satisfying sexual experiences and intimacy leads to new understandings and acceptance of the sex act and masculinity.

5.11.1 Unsatisfying Sex

Kenneth spoke about his experience of having oral sex. He highlights that it does not meet the ‘standards’ of normative penetrative sex, thus even though it is a different way of engaging in sexual intimacy, it is just as unsatisfying as what ‘normative’ penetrative sex would be for him. This shows that differently abled sex does not lead to new ways of thinking about sexual acts for Kenneth. His experience of oral sex shows the tensions between his idea of masculinity and what it means to be sexually involved with a woman.

KENNETH: Ek het al soos oral sex gehad maar dit maak my net hartseer. Hoe meer ons speel, elke segment van die moves… my volle manlikheid, dit is mos waaroor dit gaan, om die alpha male, die 'ou in die stuk' te wees, as jy die vrou kan bevredig, as jy haar tone kan laat omkrul en haar laat juig na asem. Jy kan maar watse smooth operator wees, jy kan maar al die mooi woorde sê wat die meisie se pantie nat maak, maar as jy nie op 'daai' sexuele vlak kan funksioneer nie, dan kan dit nogal 'n uitdaging wees vir jou.

> I have had oral sex, but it only makes me sad. The more we play, every segment of the moves... my full manliness, that is what it's about, to be the alpha male, to be the 'guy in the piece', if you can satisfy the woman, if you can let her toes curl and let her gasp for air. You can be a smooth operator, you can say all the beautiful words that will arouse a woman, but if you cannot function on 'that' sexual level, it can be a challenge for you.

Kenneth used interesting and ambiguous metaphors that informs his understanding of masculinity. The metaphor, *"die ou in die stuk" – "the guy in the piece"*, can be interpreted as the main character in a film scene, one who epitomises sexual attraction, the one who gets all the attention, and whom everyone wants to be with. It could also be interpreted as the man penetrating the woman, where *"die stuk" (the piece)* is referred to as the vagina. This description of what it means to be a man and having sex, gives some insight into the kind of thinking that informed his understanding of masculinity and sexuality prior to the injury.

He also shares his understanding of good sex which is related to the discourse of the 'male sexual drive', centring sex as a male-centred activity (Shefer & Foster, 2001; Braun, Gavey, McPhillips, 2003). Kenneth defines it as an intercourse that involves an explosion of orgasms; the woman becoming really aroused and curling her toes. Through achieving this, he is regarded as the "alpha male". He mentions that it is heart-breaking for him only to be able to engage in oral sex because he knows that he cannot meet the sexual expectations of being the "alpha male" that he was, prior to the injury. He uses that as a constant reminder to himself that he is living with paraplegia and that he cannot perform sexually in the same ways as he did before. Kenneth still sees sexual intimacy and sexual intercourse as the domain of a whole man, and as a result, he is painfully aware that he no longer resembles this wholeness.

In rehabilitation, Devon enquired on ways to have sexual intercourse. Medical experts advised and trained him to use the injection that would help him get an erection. The injection does not give him sensation; thus, he cannot ejaculate. Devon's core focus was therefore on obtaining an erection so that ultimately, he was able to sexually satisfy his partner.

Devon photographed the injection equipment as part of his photo-story as depicted in Figure 5.2. below. He also explained the significance of the photograph.

Figure 5.2. Photograph captured by Devon as part of photo-story

DEVON: Jy spuit dit mos nou in, dit werk soos in 120%, dit hou jou solid! Vir 'n uur! Dit was so bad! Ek het verwagtinge gehad… ek het geweet dit sal anderste wees, maar ek het nie verwag dit sal so bad wees nie.

> You inject it, it works like 120%, it keeps you solid! For an hour! It was so bad! I had expectations… I knew it would be different, but I did not expect it to be so bad.

The injection worked in that he could rely on it to maintain an erection. The use of the injection shows how the medicalization of disability is centred around 'fixing' the body and the injection also signifies the pressures on men to live up to traditional notions of active male sexuality (Shefer & Foster, 2001). Furthermore, Hunt et al (2018) posit that people with physical disabilities who may not meet the normative standards of ability or embodiment, especially with regards to sexual intercourse and the expectations thereof, may find it frustrating and may consider the use of medical assistance in achieving a 'normal' sexual experience. However, Devon disliked it. This is contrary to the findings in Hunt et al (2018) who found that respondents who relied on medication felt a great relief in that they could sexually satisfy their partners, and this made them feel 'normal'. However, Devon argues that the erection creates an expectation for him also to experience a pleasant sexual sensation.

He mentioned that after an hour he had to fake an orgasm just to ‘meet’ his partner’s expectation of ejaculation, even though he could not ejaculate.

DEVON: Ek gaan nie vir jou jok nie, ek het honestly sleg gevoel. Dit was amper soos jou manlikheid word weg gevat. Want as jy ’n man is, en jy kan nie iemand satisfy nie, dan wat the hell?

> I am not going to lie to you, I honestly felt bad. It was almost as if your manliness gets taken away from you. Because if you are a man, and you cannot satisfy someone, then what the hell?

Like many of the men, Devon mentioned with agony that his inability to sexually satisfy a woman without the use of an injection, made him feel as if his manliness was stripped away. For Devon, being a man meant being able to perform sexually and to satisfy a woman’s sexual desires, thus he purports that not being able to perform in this way makes him question what it means to be a man. This perspective is contrary to that of Allen who previously argued that sex is not a determinant of manliness.

Findings from this subtheme contributes to the theme, ‘*finding sexual mutuality’* in the findings of Hunt et al (2018), whose respondents expressed different ways of loving their intimate partners and adjusting to their sexuality. However, it is interesting that some of the men in my study did not express that differently abled sex is an achievement or a way to prove their worth as a lover, as found in Hunt et al (2018).

Kenneth and Devon have shown that an engagement in ‘differently abled sex’, which includes oral sex and the use of medication for erectile dysfunction, allows them to conform to norms surrounding the gender performance in sexual intercourse, which constructs them as the active subjects of heterosex (Shefer & Foster, 2001). However, they still feel sexually inadequate because of not being able to live up to sexual norms of masculinity.

5.11.2 Satisfying Sex

Wendell spoke of challenging the norms which define conventional sex and sexuality through differently abled sex. This form of intimacy and receiving pleasure entails showing affection through kissing, caressing, whispering, and feeling. This is similar to some of Galvin’s (2005, pg. 408) respondents who voiced the opinion that becoming disabled had resulted in “better love making” because they were not restricted to prescriptions of normative penetrative sex. Wendell assimilates kissing, caressing, whispering, and feeling, into the sensual feeling of sex by imagining that he is having sex with a woman, despite not being able to do so. He develops a new attitude to sexuality through acts of imagining and showing affection.

WENDELL: Selfs as sy my nek soen, of my hou, en in my ore vluister, voel dit soos seks.

> Even if she kisses my neck, or holds me, and whispers in my ear, it feels like sex.

Wendell's draws on romantic discourse to narrate his sexual experiences. This kind of sensual engagements show that there are different ways of expressing sexual intimacy and sexual intercourse, just as much as there are different understandings of what constitutes sex. This shows the extent to which the understanding and reconceptualising of the sex act has changed. So, sex takes on new meanings, and for these men to embrace these new meaning attached to the sex act, represents a reimagining, a reconstruction of their fragile masculinity. This signals a "coming into being" of their new masculinity.

Gavin also shares this experience of sexual intimacy and sexual intercourse through a photo-story that he created. This is depicted in Figure 5.3 below. He explains the significance of the photograph and how it relates to his experience of intimacy.

Figure 5.3. Photograph of Gavin's photo-story.

GAVIN: Sometimes just being close to her makes it feel like I am sexually connected. She will sit on my lap and kiss me all over, she will talk to me in that voice man, you know, that sexy voice man, ya, and then and I will also respond, that's how I know that we are making love in that moment.

The upper parts of Gavin's body that have sensation become more sensitive, and he assimilates this sensitivity to that of sex. This is similar to Nick, one of Sakellariou's (2006, pg. 106) informants who said: *"some parts of me have become more sensitive, my bosom for example. My nipples are very, very sensitive to touch… I feel a bit like a woman when this happens."* Gavin's photograph and the significance thereof shows that sexual intercourse is more about the closeness that is shared with his partner rather than the pleasure of penetrative sex. Present here is a symbolism of intimacy that even the physical act of sex does not necessarily achieve. So much more meaning and intensity is attached to the simple gestures of kissing and touching between Gavin and his partner, and this takes their intimacy, and their constructions of femininity and masculinity, to a deeper and more profound level. Gavin has thus successfully transitioned to a new understanding and acceptance of the sex act.

Furthermore, Gavin's response shows that he has a voice for articulating how he is feeling, unlike many able bodied heterosexual coloured couples in South Africa. For example, Gavin says *"she will talk to me in that voice man, you know."* This is in contrast to the findings of Lesch and Adams (2016) study on the experiences of sexual intimacy among heterosexual coloured couples in South Africa, which showed that coloured men struggle with naming and explaining their sexual experiences with respect to sexual desire and pleasure. Gavin's photo-story shows how in touch and vocally explicit he is about his newly formed understanding about sex and sexuality.

Wendell and Gavin have shown that an engagement in differently abled sex, which includes: showing more affection, kissing, caressing, stroking the body, imagination, and would not exclude medication for erectile dysfunction, and oral sex, does not let them conform to norms surrounding the gender performance in sexual intercourse. This constructs them as the active subjects of heterosex (Shefer & Foster, 2001). These two men redefine sex and reclaim their sexuality through differently abled sex. This is consistent with the findings in Hunt et al (2018) who found that people with acquired disabilities reclaimed and redefined their sexuality in relation to their disability. Wendell and Gavin took the initiative in finding different ways of engaging in sexual intercourse and pleasure and can therefore be considered active sexual agents since their partners respond to their sexual overtures (Shefer & Foster, 2001).

It is undeniable that differently abled ways of sexually satisfying their intimate partners creates a sexual expectation to engage beyond oral sex. The imagination of how they could have engaged in sexual intercourse if they were able-bodied makes some of them feel emasculated, because they are constantly reminded of their sexual incapacity and inability to perform sexually through penetrative sex - without relying on medication.

Subsequently, it has been found that living with paraplegia does not only have an impact on the men themselves, but it also affects the sexual relationships with their intimate partners. Some men with paraplegia have a desire to have an intimate partner, but the problem seems to be ‘finding someone to do it with’ (Sakellariou, 2006). This challenges the assumption that people with physical disabilities are asexual (Peta, Mckenzie, Kathard & Africa, 2017). This perception of masculinity among men with paraplegia does not only rest with them; it is also intimately connected with the ways in which their partners view them.

Therefore, the men in this study who are in relationships, may not necessarily experience a loss of masculinity or a diminished self-esteem if their partners too, share their perspective that sex is not the only significant determinant of masculinity. Subsequently, having an intimate partner positively influences their self-esteem. This also reshapes traditional understandings of masculinity.

5.12 Conclusion

In this section of the chapter, the men shared stories of how empowering rehabilitation was as the space facilitated an acceptance to the injury and themselves. The sense of community in rehabilitation made them aware that there are many people with more extreme levels of injury. Rehabilitation also facilitated the process of learning to live with paraplegia. They were confronted with challenges as their physical strength and ability were tested. The men showed how traditional notions of masculinity - such as showing determination and perseverance in gaining physical strength to live as independently as possible – were implemented in reclaiming their identity as a man and defining what it means to be a man living with paraplegia. Thus, their perception of ‘being a baby’ shifted to ‘being a man’.

Furthermore, the men show how difficult it is to live with paraplegia in a marginalized community. People in their community often think that people on wheelchairs need help or assistance to get to places, or to do things that they could do before the injury. These men expressed how humiliating and offensive it is when people offer to help them because it reinforces the idea that they are incapable of doing it themselves and that they are dependent on others. This is consistent in the findings of McDougall (2006).

Some men in this study show a yearning and an adhering to the heteronormative male sex drive, despite their inability to erect and ejaculate. They engage in ‘unsatisfying sex’ through exploring alternative sex acts, like oral sex and the injection used to maintain an erection. However, they still feel emasculated because they cannot ejaculate. On the contrary, other men experience ‘satisfying sex’ through exploring different ways of showing sexual intimacy like affection, whispering, kissing and caressing sensitive areas on the body. This satisfying sexual experiences and intimacy leads to new understandings and acceptance of the sex act and masculinity. This was also consistent in other findings (see Cole, 2004; Galvin, 2005; Sakellariou, 2006; Ostrander, 2008; Hunt et al., 2018).

CHAPTER 6

PHOTO-STORIES OF SOCIAL REPRESENTATION AND SELF-REPRESENTATION OF DISABILITY

6.1 Introduction

In this chapter, I present the findings from the photo-stories created by the men in this study. Although there were many overlapping similarities among the photo-stories, only a selected few – which differ significantly from one another – are presented. Overall, the photo-stories tell a narrative of the men's social experiences of disability: of the dehumanization, discrimination, systematic and social exclusion, oppression, and social prejudice labelled against them. The self-representations of disability represented within these photo-stories also reveal ways in which these men want to be seen, understood, and accepted in society.

6.2 *Social Representations of Disability*

In this section I explore ideas around the social representations of disability evident in the photographs taken by these men. Social representations can be defined as common-sense knowledge that are produced particularly through engaging in social and political interactions (Howarth, Andreouli, & Kessi, 2012). This kind of knowledge is produced by communities to create meaning from social and political realities, or ultimately, to make sense of the world in which they live.

In the analysis, the idea of disability as 'the other', becomes evident through the eyes of the men in this study. Siebers (2001) argues that the category of 'the other' is a dominant discourse on the representation of people with disabilities in society. Mohamed and Shefer (2015) argue that the notion of 'othering' stems from a particular culture's construction of normalacy, and the 'othering' of bodies are those that do not fit into this cultures idea on what constitutes as 'normal'. Therefore, the 'othering' is strongly related to systems of power and privilege (Mohamed & Shefer, 2015). This section of the chapter draws broadly on social representation theory (Howarth, Andreouli, & Kessi, 2012). This section relates understandings of social representation theory and ideas of 'disabled' bodies as 'other' (Siebers, 2001). These are used as analytical lenses to reveal these men's perceptions of the ways in which they think society sees them.

6.2.1 Objectification and Dehumanization

Shakespeare (1994) argues that people with disabilities are objectified by cultural representations that often perceive them as objects rather than subjects. Devon's lived experiences support this argument as his photo-story offers some insight into the way in which he - and perhaps others with disabilities – is often seen, namely, not as human, but as an object. In his photo-story, he mentioned that he avoids going to shopping centres because people stare at him strangely. The way they stare makes him uncomfortable and self-conscious about being in the wheelchair. In other words, his status as 'other' is exemplified in the ways that others view him. He describes the look on people's faces as an expression that normally surfaces when one is surrounded by dirt or in a foul-smelling place. Through this, his identity and status as a human being is reduced to garbage. Through the stares of the public, he perceives himself as an object of waste and not as a human.

Through Devon's explanation of the photograph below (Figure 6.1), he uses descriptive verbs such as "unworthy", "nothing", "disgusting", and "stinking", to describe the ways in which he thinks that he is perceived. These descriptive words relate to Shakespeare's (1994) notion of objectification - as these words emphasize the experience of feeling dehumanized. Therefore, Devon finds it difficult to navigate in and around social spaces.

When Devon reflected on the photograph, he became aware of the shopping bags that the man in the photograph was carrying. It struck him as quite a big coincidence that the man carrying shopping bags was also gazing down on the garbage in front of him at the same time. For Devon, this accurately depicts the ways in which people in the shopping centres carry their shopping bags while gazing down on him. This makes him feel like dirt. Figure 6.1 below is Devon's photo-story on the ways in which he thinks people see him.

Figure 6.1. Devon’s photo-story of a man looking down on garbage.

DEVON: Mense kyk vir my so vuil aan, as of ek minderwaardig is of dat ek soos niks is nie. Was jy al by ’n sewage drain? Dit is hoe mense hulle neus op trek wanneer hulle my sien. Die foto is van ’n morsige plek en stink plek, want dit is hoe ek dink hulle my sien. Ek voel nogal sleg.

People give me dirty looks, as if I am unworthy or not worth anything. Have you been to a sewage drain? That is how people pull their noses when they see me. This picture is of a filthy and foul-smelling place, because that's how I think they see me. I feel quite bad.

Johan shares a similar perception to that of Devon. He also contributes to Shakespeare's (1994) notion that people with disabilities are often perceived as objects rather than subjects. Johan explained that sometimes when people look at him, they sniff, and their facial expressions imply that he reeks of excretion. He took a photograph of a broken toilet pot to signify this impression. Johan's human identity is diminished to the object of a broken toilet pot as depicted in Figure 6.2 below.

Figure 6.2. Photo-story of Johan perceived as a broken toilet pot.

JOHAN: Wanneer mense my sien is dit amper of ek 'n niks is nie. Hulle kyk my aan as of ek stink soos die toilet pot in die foto. Dit is rerig as of ek 'n stukkende vuil toilet pot is. Kyk, meeste mense is leesbaar. Dit is in die manier hoe hulle neer kyk op my. Dit laat my terug getrokke voel.

When people see me it's almost as if I'm nothing. They look at me as if I stink like the toilet pot in the picture. It's as if I'm a broken and dirty toilet pot. See, most people are readable. It's in the way that they look down on me. It makes me feel withdrawn.

Johan expressed feeling inferior to others. This inferiority makes him feel socially excluded in his community, and broadly speaking, in society. Both Devon and Johan's photo-stories emphasise depictions of objectification. They are perceived as 'the other'; something not quite human.

These photo-stories highlight some of the invasive practices - dominated by stares, arrogance, and hostility that able-bodied people inflict on people with disabilities in public spaces (Morris, 1991 as cited in Shakespeare, 1994). These invasive practices are used as a distancing mechanism to create a barrier, a divide between what is perceived as normal and abnormal. It is an exclusionary practice, that takes away any semblance of humanity that those living with disabilities, possess.

Coward (1984, as cited in Shakespeare, 1994, pg. 289) puts forward the idea that the stares confer power, by arguing that the inability of people with disabilities to stare back or to even take on an aggressive look, portrays subordination. The fact of the matter is that people with disabilities often feel embarrassed and irritated by the harassment of persistent stares, and because they do not want to risk attention, they try to ignore the stares by averting their eyes from able-bodied people.

DEVON: Ek voel dat ek hulle net wil vra, *‘hoekom kyk jy vir my so? Is daar ’n probleem? Het jy nog nie iemand gesien wat in ’n wheelchair is nie?’* Ek wil nie lelik wees nie, so dan beweeg ek ma’net aan.

I feel like I just want to ask them, *‘why are you looking at me like that? Is there a problem? Have you never seen anyone in a wheelchair?’* I don’t want to be mean, so then I just move on.

In Devon’s response to the stares, it is interesting that he is concerned about hurting the feelings of those who stare at him, especially since his onlookers do not share this concern. Subsequently, Shakespeare (1994, pg. 288) puts forward an argument that defends the stares by able-bodied people. He argues that the “stares and unwanted attention” from able-bodied people are not to objectify people with disabilities and is not done from a position of ‘othering’ them. Instead these “stares, comments and unwanted attention are legitimate tactics in respect to disabled people.” However, through the photo-stories constructed by Devon and Johan, it is evident that they do not consider the “stares and unwanted attention” as a “legitimate tactic in respect”, in fact, they perceive it as rude, arrogant, and disrespectful.

Kurt is of the opinion that people first see his wheelchair before they see him. He states that his disability is visible because of the wheelchair. As such people do not recognize the body in the wheelchair. He argues in this sense, that his wheelchair, rather than his injury, is disabling because it makes his condition visible and his human identity invisible. Figure 6.3 below is a photograph of the wheelchair that is the first and only object that people see.

Figure 6.3. Photo-story of Kurt’s disabling wheelchair.

KURT: I took this photo because I just feel like the first thing that people see is the wheelchair, which is my disability, they cannot see beyond that. It is like they do not see me.

Kurt relates disability to visibility. Dear et al (1997) purport that the visibility of an individual’s disability plays a crucial role in what is regarded as a socially acceptable physical appearance. The degree of visibility of an individual’s disability may thus conflict with socially accepted standards of appearance (Dear et al, 1997). Therefore, Kurt feels that people completely disregard the fact that he is more than just a man sitting in a wheelchair, but they do not even see him as a man since they do not see him at all. His wheelchair thus becomes fully representative of his identity; it is imposed upon him, leaving no space for him to articulate his own sense of self. His ‘disabled’ physical body and the wheelchair are viewed as one: a faceless entity.

The above photo-stories reflects a disjuncture, a clash in the ways in which able-bodied and people with disabilities view each other. Part of this research is to shed light on this clash in perceptions and to develop and establish new ways of viewing between the public and those with disabilities.

6.2.2 Rejects: Voiceless and Incapable Men

Michael is the only employed man in this study. He works at a factory on a mining site. His job entails applying glue to material on the sockets of knee and arm guards that are used as safety equipment for underground mine workers. Michael experienced much discrimination and oppression in his workplace since the patching of knee and arm guards was the only job assigned to him and other black men with paraplegia. This makes him question whether living with paraplegia means that he is perceived as incapable of doing any other kind of work in the factory. Michael's question regarding being limited by his employer to performing only one type of work echoes Shakespeare's (1994) assertion, that people with disabilities are often viewed as incapable people. In this sense, decision-making roles are taken away from persons like him. Instead, decisions which impact him personally, are made for him by others, signalling a loss of personal agency in the workplace.

Michael took the digital camera with him to work because this is where he spends most of his time. He photographed the "rejects" container (Figure 6.4) that he sits next to everyday while 'fixing' the knee and arm guards that are considered as rejects. The "rejects" container and the work that Michael does, signifies the ways in which he thinks people - especially more senior employees - see him. Figure 6.4 below are photographs captured by Michael followed by their significance.

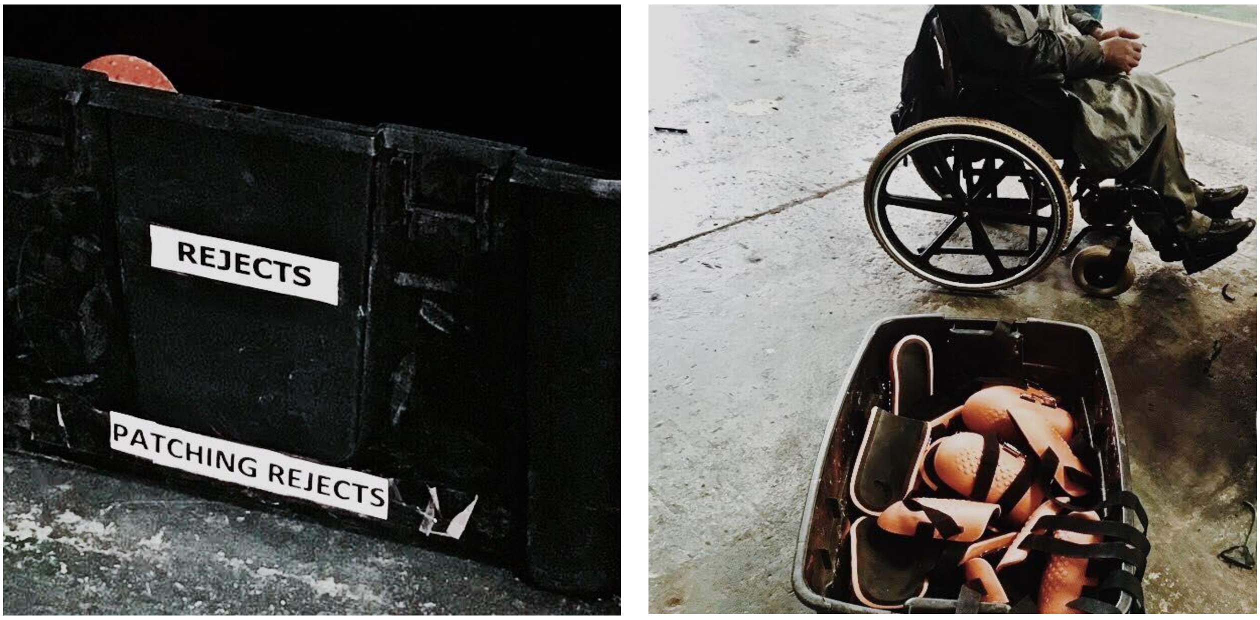

Figure 6.4. Michael's photo-story on working at the factory

MICHAEL: When people see me do work there, they see me as a reject, not good enough for nothing. I work in a factory where I stitch and glue knee caps and arm guards. I feel like I am a reject patching rejects because they say that is what I must do.

The labels on the container, namely "rejects" and "patching rejects" is significant to his identity - as a human and employee in the workplace. This constantly reminds him of the degrading of his identity and dignity to that of a "reject" only capable of "patching rejects". This contributes to his experience of exclusion, discrimination, prejudice, and oppression. Michael is supervised by two able-bodied women in the workshop while the men with paraplegia do the stitch and glue work. In Michael's view there is a clear distinction between the different types of work that able-bodies do, while the work performed by people with disabilities constitutes one common task that seems to strengthen the perceptions of inability, incapability, and irrelevance among those living with paraplegia at his workplace. Michael's photo-story shows how, historically, people with disabilities have been excluded from opportunities to learn and develop in other areas of work (Swartz, 2014). His photo-story puts an emphasis on the need to address this form of exculsion and discrimination. In similar ways as Devon, Johan, and Kurt, the objectification of Michael's identity as a human being is reduced to a reject; something incapable, inadequate, and less valuable.

Michael's photo-story echoes the findings of the research conducted by Dear et al (1997) who focused on the social and spatial production of disability. Throughout their research, it was found that space not only reflects the social construction of disability, but also produces and perpetuates disability. This means that physical space does not only play a role in exposing the social distance between abled and disabled bodies, it also acts to reinforce and enforce the boundaries between them. Similarly, Gerschick (2000) argues that space creates and sustains social notions of disability.

If we consider the space where Michael works, the workshop is conducive for him and other men in wheelchairs to move around. Because the workshop mostly consists of men with paraplegia and is designed to 'accommodate' them, their 'otherness' is noticeable. They feel that they are disabled because the space limits and constraints Michael and his fellow colleagues in wheelchairs as they are expected to do the same kind of work. This is related to Goofman's (1961) notion of the 'total institution'[10] in prisons because the workplace does not offer the men in wheelchairs other working positions in the factory. Thus, the physical construction of space in the workshop excludes them from the social context of the rest of the mine and makes them more aware of their physical difference.

Ridah found that people often think that paraplegia is not his only disability. He explained that sitting in the wheelchair represents multiple disabilities. Because paraplegia is not a condition that people can see, for example, his legs are not covered in a bandage; there is nothing that tells that he is paralysed. Thus, when he is in public spaces, people speak slowly and loudly to him, while others will speak about him to the people he is with – presuming that he cannot hear or speak for himself. By challenging this social representation of paraplegia, Ridah took a photograph of his friend (with consent) wearing a scarf wrapped around his mouth. Figure 6.5 below illustrates how paraplegia is socially misunderstood, and how he is often perceived as someone that cannot speak for himself.

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[10] Goffman (1961) puts forward the idea that the prison is a 'total institution' since inmates are governed by routine structures and regulations that control their every movement.

Figure 6.5. Ridah’s photo-story representing ‘no voice’

RIDAH: I would go out with family and friends, and they would speak about me, but not to me. They would speak about me in front of me. They would speak to my mother, they would speak to my father, they would speak to my sister, all about me, but they would not speak to me. ‘How is he doing?’ But I am right here – ‘I am very well, thank you.’

It is undoubtable that perceptions of the men with paraplegia as the “other” and the reactions they prompt have enormous consequences in their lives. For example, visible characteristics like the wheelchair or even race, may cause these men to be dismissed from job opportunities without further reflection, or demoted to performing menial tasks that undermine their agency – like the ‘patching of rejects’- which can make them feel under-valued and consequently contribute to a low self-esteem. The reactions from society may also have a greater impact on the men’s psychological and emotional well-being. These men may avoid social or public spaces due to the ways in which they think society sees them. This is disabling.

6.2.3“Half a man”

Albert expressed that living with paraplegia means that he sometimes must depend on others to assist him with the things that he cannot do. Because of the dependency on people to feed, wash, dress and empty his colostomy bag, sometimes assist in cleaning up after his bowel movements, and some days push him in the wheelchair, makes him feel as though he is perceived as a baby. Sometimes Albert feels ashamed and embarrassed to ask for assistance because he thinks that his identity as a grown man is reduced to that of a baby.

He is more aware of being perceived as such when he sees mothers pushing their babies in a stroller. Albert can relate to this kind of dependency and care, because for him, being in a wheelchair is like being in a stroller; dependent on someone to push him around and take care of him. Figure 6.6 below is a photograph - captured by Albert - of a mother pushing her baby in a stroller. This photograph depicts the way in which Albert thinks people view him, because this is how he often feels.

Figure 6.6. Photo-story of Albert representing the notion of being treated like a baby

ALBERT: Die foto het ek geneem want dit het my terug gevat na die tyd toe hulle vir my sê: *'Mnr, jy is nou weer soos 'n babatjie. Jy sal nou moet weer leer om te loop.'* Dit is 'n verskrikelike gevoel want ek het gedink wat moet ek nou weer doen om weer soos 'n babatjie te wees? Ja, ek het soos 'n baba gevoel omdat ek niks kon gedoen het nie. Mense om my het my ook soos 'n baba hanteer. Hulle wil my altyd rond stoot, daar is altyd iemand wat my wil voer, was, en help om aan te trek. Dit is nogal verskriklik, dat ek so groot is en so klein voel.

I took this picture because it took me back to the time when they said to me, *'Mr, you are now like a baby. You'll have to learn to walk again.'* It's a terrible feeling because I thought about what I had to do to be like a baby again? Yes, I did feel like a baby because I could not do anything. People around me also treated me like a baby. They always want to push me around, there's always someone who wants to feed me, wash, and help to dress me. It's rather terrible that I'm so big and feel so small.

Oppies expressed how people, but especially men, in his community would tease him because of his inability to walk and engage in the 'manly' things that he could do prior to the injury. Some of the activities that he did includes: sex, soccer, carpentry work, and being part of a gang. Now he is perceived as 'half a man'. He would explain to them that the lower part of his body is paralysed. Some men laugh and tease him by calling him, *"die halwe man" – "the half man"*. He is known as *"die halwe man" – "the half man"* in his community because he cannot "do the things that men do", and because half of his body is paralysed.

Shakespeare (1999) provides some insight into why men like Oppies, and possibly Albert, are perceived as a baby or half a man. Shakespeare (1999) argues that men with disabilities often represent fragility, weakness, vulnerability, and their physical appearance together with the severity of their condition, does not allow them to identify or belong in structures and systems of the hegemonic masculinity that is prevalent in their social context.

Furthermore, the vulnerability in masculinity exposed by Shakespeare (1999) above, gives insight into the significance of performance as a construction of masculinity, especially in the social location that these men reside in. If men cannot perform in the ways that they are expected to perform (as men) in these communities, then they are socially and culturally perceived as not being 'man enough' and are constantly threatened by able-bodied heterosexual men who wish to assert their dominance over other men. What becomes evident here is that notions of hegemonic masculinity undermine the capabilities of men with disabilities thereby contributing towards the prejudices labelled against people with disabilities.

Oppies the *'half man'* cannot engage in the dominant practices of hegemonic masculinity in his community. He felt vulnerable, because he does not fully embody what it means to be a 'man'. One can argue that the "other" identity is projected onto Oppies because he is socially regarded as only 'half a man'. Figure 6.7 below is a photograph that Oppies asked his wife to take. The photograph shows half of Oppies body in the wheelchair. He specifically wanted to show the part of his body that is paralysed as it prohibits him from being part of the hegemonic systems of masculinity in his community.

Figure 6.7. Photo-story of Oppies depicting his social identity as *"die halwe man" – "the half man"*.

OPPIES: Hulle sê, dat dit deur my maniere is wat ek 'n halwe man is. Hulle sal sê, "kyk, daar kom daai halwe man", daai is persoonlik. Jy kan nie sê, ek is half nie, ek bedoel, hoe gaan jy voel as iemand vir jou sê jy is half? So ek wil wys dat my liggam nie half is nie. Maar ek het bene. Ek is 'n volle man.

They say that it is through my manners that I'm half a man. They will say, "look, here comes that half-man", that's personal. You cannot say I'm half, I mean how will you feel if someone tells you that you are half? So, I want to portray how they see me, that I don't have half a body. But I have legs. I am a full man.

Oppies highlights that in his community, paraplegia is understood as a punishment for the ill-mannerisms and attitudes that he had towards people prior to his injury. Perceptions of him as being 'half a man' brought about by his state of paralysis, is seen as 'punishment for being a bad person'. This has led to him avoiding the streets because he finds the name-calling hurtful. In many instances, he felt the need to prove his masculinity by attempting to physically fight with the men who teased and provoked him, but always felt disappointed by his lack of physical strength to do so.

Furthermore, he felt the pressure to engage even more in the 'manly' things that he could do, to prove hos worth as a 'complete' man. The pressure to constantly prove his worth as a man was humiliating. However, that was in the past. Oppies has now reached a stage where he feels less pressured to prove his manliness to people in his community because he acknowledged that he cannot change society's perceptions of him, nor their perceptions of disability.

From these photo-stories it becomes evident that masculinity is socially defined through performance and that the inability to sustain such performances, makes masculinity vulnerable. For example, Ostrander (2008) purports that the inability of men with disabilities to perform certain functions, violates social conceptions of what it means to be a man. This appears to be true in the photo-story of Oppies who is perceived as half a man because he cannot live up to society's expectations of manliness. This is also reflected in Albert's photo-story of being perceived as a baby, dependent on others, and in Ridah's story where the perception is relayed that men living with paraplegia cannot speak for themselves, also in Michael's story where his feelings of rejection is encapsulated in the type of work assigned to men with disabilities in his workplace.

6.3 Self-representations and Disability

Through my analysis, it became evident that social-representations of disability were almost inseparable from self-representations of disability. Therefore, I explored the concepts of self-representation and social representation in relation to each other, by asking the men to photograph the ways in which they see themselves. Through their photo-stories, they challenged prevailing negative social discourses and representations of disability. In the process they reclaimed their identity and redefined the meanings attached to disability. Findings from this section contributes to the development of the affirmative model (Swain & French, 2000) and active model of disability (Levitt, 2017).

The affirmative model of disability sees disability as non-tragic and is rooted in the lifestyles and life experiences of people with disabilities, with a particular focus on their positive social identities (Swain & French, 2000). This model is significant because it directly confronts and challenges people with disabilities to validate themselves, to share their experiences, and to address the meaning of 'disability' (Swain & French, 2000). The affirmative model is essentially developed by those who themselves have disabilities.

The 'active' model of disability was developed by Levitt (2017) and focuses on how the individual and collective actions of people with disabilities may reduce the restrictions and effects of their disability. This model asserts that people with disabilities can act against misrepresentation, social exclusion or participation, prejudice, oppression and discrimination through actively engaging in individual (e.g. self-help) and collective activities (e.g. support groups or activism) to empower themselves.

An important realisation on my part was the recognition that throughout our conversations on the significance of each photograph, there was also a discussion on what the ‘disabled’ identity category meant to these men. In some conversations, the men took some time thinking about the ‘disabled’ identity category and considered quite carefully whether it relates to how they see themselves. I allowed this process of thinking and reflection to unfold, since it is only through critical reflection that they could begin to theorize who they are.

6.3.1“The same as any other person”

Most of the men rejected the identity category of ‘disabled’. This finding is echoed in a study conducted by Watson (2002), whose respondents were socially perceived as ‘disabled’, but refused to self-identify as ‘disabled’. Johan explained this thoroughly by differentiating between himself and an able-bodied man. He argued that although he now did things differently to what he did prior to the injury, there were many things he could do as well as - and sometimes even better than - able-bodied men. Those things which he could no longer do, was not significant to his sense of masculinity and self-identity. Therefore, he rejects the label of ‘disability’ in the construction of his self-identity. Figure 6.8 below elucidates on his perspective of self.

Figure 6.8. Johan’s photograph (captured by his team mate) on his rejection of disability through self-representation.

JOHAN: Die foto wys dat ek is dieselfde as enige ander person. Ek is net so gesond soos jy, ek dink soos jy, daar is baie dinge wat ek kan doen soos jy en miskien beter as die person wat sy bene kan gebruik. Ek sit ma'net in 'n rolstoel. Ek ry die rolstoel en dit is as of ek loop. So dit is nogal baie seer wanneer mense se dat ek gebreklik is.

This photo shows that I am the same as any other person. I am just as healthy as you, I think like you, and like you, there are many things that I can do, maybe even better than the person who can use his legs. I just happen to sit in a wheelchair. I ride in the wheelchair and it is as if I am walking. So, it is very hurtful when people say that I am disabled.

Johan's photo-story runs parallel to the purpose of the action model of disability. He directly draws attention to his actions in relation to his disability. Johan depicts the effects of engaging in support groups, such as Bridging Abilities, where he and other men come together to engage in physical activities to strengthen their muscles and to encourage each other to develop a positive sense of self. Levitt (2017) argues that engaging in support group activities reduces the effects of disability. This is evident in Johan's photo-story where he emphasises that paraplegia is insignificant to his self-identity. He does not see himself as different to able bodied people. He states that he is, "*dieselfde as enige ander" – "the same as any other."* Paraplegia does not affect the way he thinks about himself and his location in the world.

Johan acknowledges the wheelchair as a distinguishing factor in his relationship with able-bodied people but uses it simply as an alternative means of mobility, as he states that being in the wheelchair is like walking. His photo-story is also central to the affirmative model of disability (Swain & French, 2000). He shows that he has developed a positive identity as he does not see himself as the "other" or different to able-bodied people. He is healthy and shows that he leads a fulfilling and satisfying life, thereby affirming his identity.

Albeit his narrative is centred around the ability to think, speak, and perform as able-bodied people do, he does show how physical strength and ability is related to his sense of masculinity. The photograph depicts Johan lifting weights, which is generally considered as a 'manly' physical exercise. Johan did not explicitly relate the photograph to the heteronormative and hegemonic construction of masculinity which emphasises physical exercises for muscle, strength and maintaining a 'good-looking' body image. However, the photograph strongly shows what he did not explicitly say - that he is a man, who engages in physical and 'manly' activities, as most able-bodied men do.

Similarly, Michael argued that able-bodies are responsible for creating barriers and differences that are socially exclusive. His argument echoes the social model of disability (Shakespeare, 2006) which states that it is society that disables people with impairments. For example, Michael's work in the factory is a barrier created by able-bodied people in management positions and represents the limitations that others place on his abilities, leaving him no choice in the matter. Living with paraplegia does not mean that he cannot do some of the work performed by able-bodied people. Furthermore, Michael and his colleagues reject the 'disabled' identity category because their working environment is designed for men in wheelchairs. His photo-story contributes to the development of the affirmative model as he, together with his colleagues, were able to construct a collective positive identity amongst themselves.

According to Swain and French (2000), developing a collective identity and being a part of such a social grouping is a benefit as it brings about change in social perspective and impacts the understanding of the 'disabled' as an identity category. Michael's photo-story in Figure 6.9 below was captured by his colleague and signifies no difference in his ability to perform tasks compared to his able-bodied colleagues.

Figure 6.9. Michael's photograph representing no difference between himself and able-bodied colleagues.

MICHAEL: It is not in my mind to think that I am disabled, because everything that I want to do, I do. My mind is working. So, if your mind is working and your hands is working, you can do many things. Legs are just for going.

Albert also does not define himself as 'disabled'. His understanding of disability is more of a mental inability - a condition that affects coherency in the way one would think and speak. However, he argues that paraplegia is a condition that needs to be taken care of by doing exercises that will help with blood circulation and the strengthening of muscles. He explained that his photo-story (below) challenges the notion that those in wheelchairs are 'useless', or that they are 'incapable of performing or participating'. Figure 6.10 below is a photograph that Albert took of his team mates playing sport.

Figure 6.10. Albert capturing his team mates playing sport which represents strength and ability to perform

ALBERT: Ek voel nie dat ek gebreklik is nie. As jy nou nie jou hande kan gebruik nie, en jy kan nie jou verstand kan gebruik nie, is dit 'n gebrek wat jy het. Ek kan my hande en verstand gebruik. Ek is nog altyd dieselfde mens.

> I do not feel that I am disabled. If you cannot use your hands and you cannot use your mind, that is a disability that you have. But I can use my hands and mind. I am still the same person.

Albert’s photo-story contributes to the development of the action model (Levitt, 2017), by showing that the collective action of people with disabilities can challenge negative social representations and stereotypes of disability. Consequently, for people with disabilities to collectively participate in action (activities or activism) shows how inclusion in social life can reduce the effects of disability (Levitt, 2017), whether it may be physical or psychological. Furthermore, his photo-story shows how people with disabilities can benefit from a support group (Levitt, 2017), like Bridging Abilities, where they learn from each other, and operate as a community. The support group also provides them with ways to learn how to enhance their lifestyle whilst living with paraplegia. Thus, the support group exposes him to ways of reducing the impact of paraplegia in his life. Being open and accepting of such lessons, enhances and enriches his outlook.

Albert’s photo-story also relates to the affirmative model of disability (Swain & French, 2000). Firstly, he develops a positive social identity through his muscle strength and improvement. He gains a sense of importance as he is part of a team who cannot perform adequately without him. Secondly, the support group is a space for him, and other men, to collectively express their anger and frustration about society’s perceptions of disability, as opposed to it being a personal problem (Swain & French, 2000). Subsequently, Bridging Abilities is not only a space for physical exercises, but a space for them to build a sense of unity that enables them to challenge the prevailing negative discourses on disability.

Oppies also does not see himself as different to able-bodied people. He argues that paraplegia did not change his humanity, therefore, wants to be recognized as a human being. He rejects 'disability' in the construction of his self-identity. Figure 6.11 below is a photograph of Albert that Oppies captured as part of his own photo-story. Through this photo-story, Oppies argues that his sense of self has not changed.

Figure 6.11. Photograph of Albert captured by Oppies in constructing his self-identity.

OPPIES: I am a human being, I am still a human being. As jy asem haal, en dan is jy nog 'n mens. Ek lewe nog, my brain en my gedagte is nog daar, ek is volledig, ek kan net nie loop nie, dit is maar al. Ek doen baie goetes beter as die persoon wat kan loop want ek het die gedagte en verstand.

I am a human being, I am still a human being. If you breathe, and then you're still a human. I'm still alive, my brain and my mind are still there, I am complete, I just cannot walk, that is about it. I do a lot of things better than the person who can walk because I have the thought and intellectual ability"

Allen sees himself as differently abled. He learned to do things that he could do prior to the injury in different ways. His family and people in his community are often surprised at how proactive he is in achieving his goals because he challenges their perceptions that people with physical disabilities cannot do anything for themselves. His photo-story shows that through dedication and perseverance to perform, he can resist and overcome social barriers that stand in the way of him achieving his aspirations.

Allen's photo-story is parallel to the action model of disability (Levitt, 2017). Allen implemented the necessary actions to pursue a university degree regardless of how disabling the institution may be - especially considering the difficulty he has in gaining access to lecture spaces. He also had to learn how to make use of the resources provided by the institutions Disability Unit. Being this active within the academy decreases the extent to which paraplegia impinges on his aspirations. Figure 6.12 below is a photograph of Allen on his graduation day, showing that he can achieve his goals in differently abled ways.

Figure 6.12. Representation of differently abled body

ALLEN: I just say that I am differently abled. It means that you must do it in a different way to achieve it. Now that I am studying at university, my family and friends are proud, but I just feel 'why are you proud? This is what normal people do. They finish high school, go to university, move out, and things like that.' I think what drives me the most, is that I can carry my own weight. My life must be as 'normal' as everyone else."

Kenneth problematised the notion of normality through the way he sees himself. He suggests that being normal means that we are all ‘disabled’. He does so by using the metaphor of a cracked clay pot which signifies that our bodies are “cracked clay pots”; imperfect. The photo-story in Figure 6.13 below represents equality in representation among the men in the photograph.

Figure 6.13. Photo-story of Kenneth representing “cracked clay pots”

KENNETH: Ons het almal onse gebrek. Myne is manet meer opsigtelik as joune. Ek kan nie my gebrek wegsteek nie, dit is opsugtelik as wat kom. Maar elke een het maar sy te kort koming. Niemand is perfek nie. So dit maak nie van my ’n uitsondering nie. Daar is altyd iets wat ons nie tevrede met is nie. Ons is almal gekraakte klei potte.

> We all have our disability. Mine is just more visible than yours. I cannot hide my disability, it is as visible as can be. But everyone has a shortcoming. Nobody is perfect. So, it does not make me an exception. There is always something that we are not satisfied with. We are all cracked clay pots.

Contrary to the other men in this study, Kenneth does not reject the ‘disabled’ identity category. Instead he challenges the social understanding of what it means to be normal. He argues that we are all disabled. He recognizes that his disability is external and visible, whereas someone else’s disability might be more hidden. Thus, he embraces paraplegia and understands it as a ‘normal’ aspect to being human. He states that we are all flawed in some way or another, and that is what makes us human. So, paraplegia for him represents part of the humanity’s struggle and search for meaning and inner peace.

Most of the men in this study rejected the ‘disabled’ identity category because they do not define disability as a physical inability or physical impairment, but rather a mental inability. However, they acknowledged that they live with paraplegia, and that they cannot use their bodies in the same way as they could prior to the injury. Even though they show a great understanding of their self-identities, their construction of self-identity becomes a struggle, because they must constantly challenge the dominant and persistent social representations of who they are.

6.4 Conclusion

The men chose to participate in the *‘Half a man? Still a huMan’* photo-story aspect of the study to depict their experiences of the ways in which they think people see them, hoping to raise awareness and bring about social change in the (mis)understanding and (mis)conceptions of disability within their communities. The action to rectify and challenge the social construction of disability through self-representation is a product of self-determination, agency, and choice (Watson, 2002). Through agency and being intentional about the action that they take, they reaffirm their sense of self and challenge those identities ascribed to them (Watson, 2002; Swain & French, 2000; Levitt, 2017).

Photo-voice as a methodological tool was useful in that the men claimed the power to construct and convey social and self-representations of disability. This allowed them to expose flawed and oppressive notions in their self-identities, especially those that often marginalise and silence their experiences of living with paraplegia. This type of participation shows an awareness that highlights the need for change in the general public’s perceptions of disability. Therefore, findings from this section shows how closely related the affirmative model and action model of disability are with respect to the overlapping focus on positivity and active engagement in the lives of those living with paraplegia.

The findings from the photo-stories on self-representation contribute to the development of the active models in several ways. Firstly, the findings show how these men actively engage in ways to reduce the impact of disability in their lives. These actions contribute positively towards their social identities. The fact that these men are confident enough to leave their homes and engage in society, participate in sport and exercise, and create photo-stories in public spaces, shows how they have reduced the constraints of their own disability (Levitt, 2017).

Secondly, the support group not only facilitates strengthening the body, but also the development of positive mental attitudes (Levitt, 2017). Developing strong mental and psychological attitudes is both empowering and cathartic. Their active engagement in support groups thus represent an important component of activism.

Activism is also an aspect of the active model of disability (Levitt, 2017) because it encompasses actions put into play and enforced by people with disabilities in order to combat exclusion and to change society's attitudes towards them. Photo-voice has been a powerful tool in facilitating this kind of activism as it not only addressed the concerns of people with disabilities, but also showed how they are able to reclaim their identity through a reflective process of redefining who they are. My role as the facilitator in the photo-stories, has exposed me to important and creative ways of producing knowledge. This process has also made me realise that it is not only the responsibility of those living with disabilities that are required to engage in this kind of activism, but that a commitment from society at large is also required to bring about large scale, effective and meaningful change in the lives of those affected by disabilities.

CHAPTER 7

CONCLUSION

Acquiring a spinal cord injury such as paraplegia results in a drastic change in lifestyle, identity, and self-perception. This study has shown the extent to which paraplegia can devastate and challenge the lives of coloured men affected by this injury. In these conclusions, I will draw together the insights gathered through the research process and the analysis of findings, highlighting the central themes and discussing the theoretical and material implications thereof. We have seen the fragility of these men, but also the remarkable resistance and tenacity in overcoming the unimaginable and realising the empowering possibilities for achieving new ways of being. The road to recovery is a long and difficult one, and is circulated by feelings of shame, infantilization, loss of independence, dehumanization, inadequacy, vulnerability and sexual incompetence. The findings presented here reflect and expand current scholarship on disability and masculinity.

The challenges that the men in this study experience, signify what it means to be a coloured man on the Cape Flats. Their narratives show that a man living with paraplegia in this context can eventually also develop understandings of themselves as masculine that is valuable and a way to reclaim a sense of self through learning how to live independently, representing themselves in the ways in which they want to be accepted, understood and perceived, and approaching, doing and thinking about life and what it offers, differently. Through a process of acceptance and internalising the need to exist and to persevere in the pursuit of meaning, they come to recognise the need to redefine who they are in their multiple roles as men and also as men who live with paraplegia. This study is unique in that the themes pertaining to the intersection of disability, masculinity, race, sexuality, class and social location, presents interesting narratives on what it means to be a man, what it means to be a man living with a disability, and ultimately, what it means to be human.

In keeping with the literature on disability and social representation, findings from this study show that feelings of shame experienced by these men stems from the community’s perception that disability is often perceived as a curse or punishment for doing wrong unto others. Furthermore, these feelings of shame are also linked to their previous status in the home and in the community, a status that is drastically diminished since the onset of paraplegia.

The power they held by virtue of simply being able-bodied men, who were in control and performed particular roles which signified the ‘cool man’ or the ‘alpha male’, had been reduced to accompany their diminished status of ‘crippled’ and ‘disabled’ men.

In addition, the shame experienced by these men is also related to their diminished ability to be independent. In this study, the loss of independence is signalled as a challenge to their core belief on what it means to be a man, because in their context, being a man means being able to provide financially for one’s family and oneself. Being a man also means being physically independent. The loss of such independence leads to the perception that they need to be “pitied” and are in a state of “helplessness”, in constant need of assistance and care from others. This adds to their feelings of disempowerment and emasculation. This marks some of the initial phases of living with paraplegia, where hopelessness prevails.

Another important phase is marked by the rehabilitation period, for those who are able to access it, where these men are taught how to live with paraplegia as independently as possible. Rehabilitation is important for gaining physical strength and for learning different ways of doing the things that they could do, prior to the injury. This finding shows that men with paraplegia can be taught how to live independently. Rehabilitation challenges the notion that a man living with a disability needs to be completely dependent on others. This study has shown that rehabilitation facilitates the process of understanding more about the injury and allows for a redefining of what it means to be a man living with paraplegia. The process of rehabilitation also helps these men reclaim their self-identity by providing them with a sense of worth that they are still men. In addition, rehabilitation facilitates a process of acceptance of the injury as well as forgiveness, of themselves and others, in their journey to recovery. Rehabilitation also creates a sense of shared community with others who have spinal cord injuries, providing a much-needed sense of belonging.

What has further emerged from this study is that there exists much tension between the rehabilitation experience and having to return home, to their communities, to confront the realities of what it really means to live with a disability in a marginalized setting. Here it becomes apparent that the extent to which men living with paraplegia and who have undergone rehabilitation, have to deal with the prejudices, stereotyping, insensitivities and objectification imposed on them by able-bodied community members. What stands out here is society’s inability to humanise disability, as theorized in social models of disability (Shakespeare & Watson, 2001), opting rather to engage with a ‘disabled man’ as opposed to a man with a disability. Subsequently, the wheelchair comes to render a visible representation of the disability itself, thereby silencing the voice of the man who lives with the disability, preventing his ability to articulate his own sense of self.

Moreover, feeling exposed and vulnerable, especially to violence is something pervasive experienced across the majority of coloured men living with paraplegia on the Cape Flats - an area which is notorious for its high rates of violence and crime. In these communities, being a man means to exercise physical strength and power through violence, as a form of protection over oneself and one's family. Within this context, coloured men living with paraplegia find it extremely difficult (if not near impossible) to live up to the hegemonic ideals of masculinity.

Subsequently, their inability to engage in hegemonic practices of masculinity leads to feelings of emasculation and shame, exposing not only their physical vulnerability, but also the psychological and emotional vulnerability as well. The notion of 'exposure' is an important one here, since it casts a public light on the deficiencies and inabilities that these men in wheelchairs possess, in terms of measuring up to masculine ideals, not only in the eyes of able-bodied men, but also able-bodied women. The latter speaks to these men's vulnerability of not being able to perform in heteronormative penetrative sex and sexual roles with their partners, which again signals their male status as being "less than". The inability to perform sexually, to 'rise to the occasion', and to sexually satisfy their partners, presents an emotional and psychological challenge within their relationships.

What has also emerged from this study, are the ways in which these men have created possibilities for redefining the meanings associated with certain actions and roles, as a way of reaffirming their status as men. With respect to the sex act, for example, we find that they have taken the initiative in learning other ways of sensually and sexually satisfying their intimate partners. Although oral sex and using the injection to enable an erection has been noted as viable options for satisfying sexual partners, such feelings of satisfaction are not always mutually experienced, specially by the men living with paraplegia who still yearn for and hold on to conventional ideas of sexual satisfaction, something that they are not able to experience. In this sense, the use of the injection shows how the medicalization of disability is centred around 'fixing the body' which signifies the pressure on coloured men with paraplegia to maintain tradition notions of what constitutes sex.

The move to redefine and reconceptualise what constitutes as sex is thus a powerful one, and one that ushers in new ways of being a man, albeit with paraplegia. The reconfiguring of the ways in which intimacy and pleasure can be expressed through kissing, caressing, affection, touching, and imagining, thus creates a new terrain, filled with promising possibilities for creating alternative forms of mutual sexual enjoyment and fulfilment, which are not restricted to prescriptions of normative penetrative sex. More importantly, these acts of reimagining and redefining the practices of manhood, creates a space for the reconstruction of fragile masculinities. This signifies a 'coming into being' of a new type of masculinity that refuses to be paralysed by the hegemonic ideal. The creation of this alternative way of being a man is a powerful realisation of what it means to be human.

This study also shows how stories about disability are differently constructed and told. Such stories comprise of the restitution, chaos, and quest narrative structure (Frank, 1995). Although the majority of the men tell quest narratives – narratives that reflects something positive is to come out of the disability, some men also show how narrative structures can interweave in order to tell a 'complete' story about a lived experience. This signifies that being human is to share complexities of lived experiences, and to organize these experiences in a cohesive story, which allows us to make sense of who we are.

This study has also shown that coloured men living with paraplegia can become active agents in challenging the dominant negative social perceptions about disability in their communities. Through creating photo-stories, they were able to construct more positive and self-affirming representations of themselves as capable men. Their photo-stories were also used as a tool to educate and raise awareness amongst the community, about their need for acceptance. Through this, the men were able to reclaim their identity and redefine what it means to be 'disabled'. Their newly acquired independence as men living with paraplegia ushered in alternative ways of doing things, allowing them to claim the right to define themselves as differently-abled, thereby asserting to themselves and others, that they are still men.

The photo-story aspect of the study has proven to be an effective tool for creating social awareness about the (mis)understanding and (mis)conceptions of disability within their communities. The photo-story narratives show the extent to which the social construction of disability needs to be challenged and taken up as a social justice issue. The self-representation of paraplegia in these photo-stories, speak to the great determination and agency that those who live with disabilities, need in order to survive and claim a legitimate space in the world.

Through being intentional about the action that they take, people with disabilities reaffirm their sense of self and challenge those marginalised and oppressive identities ascribed to them. In this sense, the employment of the affirmative model (Swain & French, 2000) and the action model of disability (Levitt, 2017) has shed much needed insight into the degree of positivity and active engagement that does exist in the lives of those living with paraplegia.

The findings from the photo-stories on self-representation contribute to the development of the action model (Levitt, 2017) in several ways. Firstly, the findings show how these men who live with paraplegia actively engage in ways to reduce the impact of disability in their lives. These actions contribute positively towards their social identities. The fact that these men are confident enough to leave their homes and engage in society, participate in sport and exercise, and create photo-stories in public spaces, shows the extent to which people who live with disabilities can become actively engaged in reducing the constraints that they, and others, impose.

Secondly, the role played by support groups in terms of facilitating the strengthening of the body and developing positive mental attitudes, is an invaluable one. Developing strong mental and psychological attitudes is both empowering and cathartic. Furthermore, the sense of shared community and solidarity that the men develop with each other in these spaces, gives them a strong sense of self-worth, affirmation and legitimacy as men who are differently-abled. Their active engagement in support groups thus represent an important component of activism around the intersections of disability, race, gender, and class.

Photo-voice has shown to be a powerful tool in facilitating this kind of activism as it not only addresses the concerns of people with disability, but also shows how they are able to reclaim their identity through a reflective process of redefining who they are. My role as the facilitator in the production of the photo-stories, has exposed me to important and creative ways of producing knowledge. This process has also made me realise that it is not only the responsibility of those living with a disability that are required to engage in this kind of activism, but that a commitment from society at large is also required to bring about large scale, effective and meaningful change.

One of the critical conceptual limitations of this study is that it only focuses on how paraplegia has impacted the lives of working-class, coloured men, from Macassar in Cape Town. Subsequently, the narratives of those with different disabilities and from a different socio-economic, racial and gender backgrounds are silenced. However, the current project can be validated since insufficient research has been conducted in South Africa on the narratives of coloured working-class men, living with paraplegia. In this way, this study contributes towards a more enhanced and sophisticated understanding, about this particular defined grouping, a marginalized minority in the South African setting.

It is also important to acknowledge that the relatively small sample of 15 coloured men with paraplegia are not representative of the lived experiences of all coloured men living with paraplegia. Therefore, the results cannot be generalized, although it does offer enriched insight into the themes associated with disability, thus enriching the scope of enquiry. Furthermore, it may be said that these men, who are members of the Bridging Abilities organization, have taken proactive steps towards accepting and learning to live with paraplegia through self-development and creating awareness of disability in their community. Even though these men could have different values to those who are not members of Bridging Ability, the aim of this study is not to generalize the findings to a broader population, but rather to explore unique experiences of individuals to debunk, challenge and rewrite the stereotypical and seemingly homogenous narratives on paraplegia that currently exists. The individual narratives explored in the current study allows us (especially those who are able bodied) the opportunity to view paraplegia beyond their physical limitations, but as complex and dynamic beings in search of meaning and a sense of belonging.

For future research recommendations, it would be interesting to use photo-voice methodology to explore notions on self-representation of the ‘disabled’ body image and sexuality, as this approach may effectively challenge stereotypes on sexuality. I recommend an exploration of the meaning(s) of feminist ethics of care as a reflexive theoretical framework in doing research on the life stories of people with disabilities. I am interested in exploring narratives, and photo-stories, on the (re)construction of masculinity and the idea of ‘fixing the body’ through the recently implemented walking suits for people with spinal cord injuries.

As a researcher, the richest lessons that I learned about the spinal cord, the different levels of the injury, and the impact it has on the physical, emotional, psychological and even spiritual dimensions of self, are through the stories told by the men in this study. I know now, that as an able-bodied man, I can never truly understand what it means to live with no sensation and no movement from the waist, downwards. I do not know what it is like to wake up in physical pain and to live with pain.

The experience of the trauma and the psychological and emotional turmoil associated with becoming paralysed is something that I cannot speak to, other than to say that, disability is a lived experience. In this sense, it is important that these stories are told and that they continue to be told in creative, authentic and enriching ways that can enable real, transformative change, not only in the lives of those living with disabilities, but also in South African society at large.

As responsible researchers, who take our roles as agents of social change seriously, we must allow the stories of our research participants to breathe life within the body of works we produce. This is what it means to take decolonial knowledge production seriously. It is not only through practicing a radical sense of empathy and care, but also through embodying it, which has taught me what it means to be human. To conclude, I cannot reiterate this better than one of the men in this study, who made me aware that we all have our disabilities, some are just more visible than others.

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Appendix A: Participant consent form

UNIVERSITY OF CAPE TOWN
IYUNIVESITHI YASEKAPA • UNIVERSITEIT VAN KAAPSTAD

Participant Consent Form

Thank you for participating in this study.

This study is interested in exploring your life story and your experiences of living with paraplegia. The following conditions will be met:

1. Your real name will not be used in any source (thesis or articles). Instead, you will be given a pseudonym.
2. All attempts will be made to keep your identity anonymous.
3. Your participation is entirely voluntary.
4. The interview material will be used, presented and analysed within my Master’s thesis and might also be published as academic articles or reports.

I agree to and understand the terms set out above.

Participant Name: ……………………………..………..

Participant Signature: ……………….……………………

Date: ………………………………………………………

Declaration by Researcher

I have given a verbal explanation of the research project; its procedures and risks and I believe that the person responsible for the participant has understood that explanation.

Researcher: …….…………………………………..

Signature: ………….……………………………

Date: ……………………………………………..

Appendix B: Interview schedule

UNIVERSITY OF CAPE TOWN
IYUNIVESITHI YASEKAPA • UNIVERSITEIT VAN KAAPSTAD

Interview Schedule

Introduction of the researcher

The purpose of this research is to explore the life stories of coloured men living with paraplegia. These men all attend Bridging Abilities Organization in Macassar on the Cape Flats in the Western Cape. The aim is to investigate what it means to be a coloured man on the Cape Flats living with a spinal cord injury such as paraplegia. The objectives of this research are: (1) to examine how these men construct their life stories in relation to paraplegia, and (2) to investigate how meanings and experiences of living with paraplegia are conveyed in their life stories, and lastly, (3) to use photo-stories as a tool to explore the ways in which they think that they are socially represented by others and to compare this with the ways in which they represent themselves.

a. Motivation:

I hope to use this information to provide a window into how a spinal cord injury impacts the lives of men living with paraplegia.

b. Time Line:

The interview should take about 60 - 90 minutes. Are you available to respond to some questions at this time?

c. Ethical considerations:

Your involvement and participation is valuable in this study.

I respect your decisions, experiences and responses to the proposed questions. Therefore your participation is completely voluntary and you have the right to withdraw from the study at any time without a penalty.

You have a right to privacy through not sharing information that you do not feel comfortable in sharing.

Do take note that although the interview is voice recorded, your name will not be mentioned on the tape, and pseudonym and interview numbers will be used.

You are now required to sign this consent form as proof of permission to partake in the study. If you do have any questions or concerns, you are more than welcome to voice them now before we commence the interview process.

(**Transition:** general demographic information)

Body

a. Tell me about your experiences of growing up as an abled bodied person?

(**Transition**)

b. What was the cause of you being wheelchair bound?

c. How has it impacted your life?

d. In what ways has your life changed from being able bodied to disabled?

e. Can you tell me more about your experiences of being in a wheelchair? Maybe you can draw on some examples. (Perhaps think about your good experiences, think about your bad experiences, or your challenges).

f. What do you think are people’s perceptions of you in wheelchair/disabled?

g. What is it that you would like to change about people’s perception of disability? And how do you think you can change this?

h. What is your perception of yourself in a wheelchair?

Closing

a. I appreciate the time you took for this interview. Is there perhaps anything you think would be helpful for me to know?

Appendix C: Image of digital cameras

Appendix D: Example of photo-story exploring sexuality

I don’t like the idea of “coming out”. Who do I come out to? I am drawn to the idea of “becoming.” This notion recognizes that I am constantly in a space of transformation. It is human-like to change and to evolve into the best you that you can be in a particular time and space. I have learned to be comfortable in the discomfort of transitioning, and becoming, and to truly embody my sexuality. I am wearing a dress to break the boundaries, even the internal boundaries that I have carried with me for years.

Appendix E: Consent form for persons photographed

UNIVERSITY OF CAPE TOWN
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Consent form for persons photographed

This study is interested in exploring the life story’s and experiences of those living with paraplegia. This aspect of the study explores the social representation and self-representation of disability.

Hereby I give consent to the photographer to take a photograph of myself. I also give consent for the photograph to be shown in public spaces and to feature in a thesis, academic articles, and exhibitions.

Your real name will not be used in any source (thesis or articles). Instead, you will be given a pseudonym.

I agree to and understand the terms set out above.

Name: ……..…………………………..

Signature: ……………….……………

Date: …………………………………..

Photographer

Signature: ……………….……………

Date: …………………………………..

Appendix F: Consent form to participate in photo-voice project

UNIVERSITY OF CAPE TOWN
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Participant Consent Form

Thank you for considering participation in this research. This aspect of the study is interested in your photo-story on the ways in which you think people see you, and the ways in which you see yourself.

Hereby I give permission for the photographs I took to be exhibited, published, and used to promote the goals of the study.

Participant Name: ……………………………………..

Participant Signature: ………………….………………

Date: …………………………………………………..

Declaration by Researcher

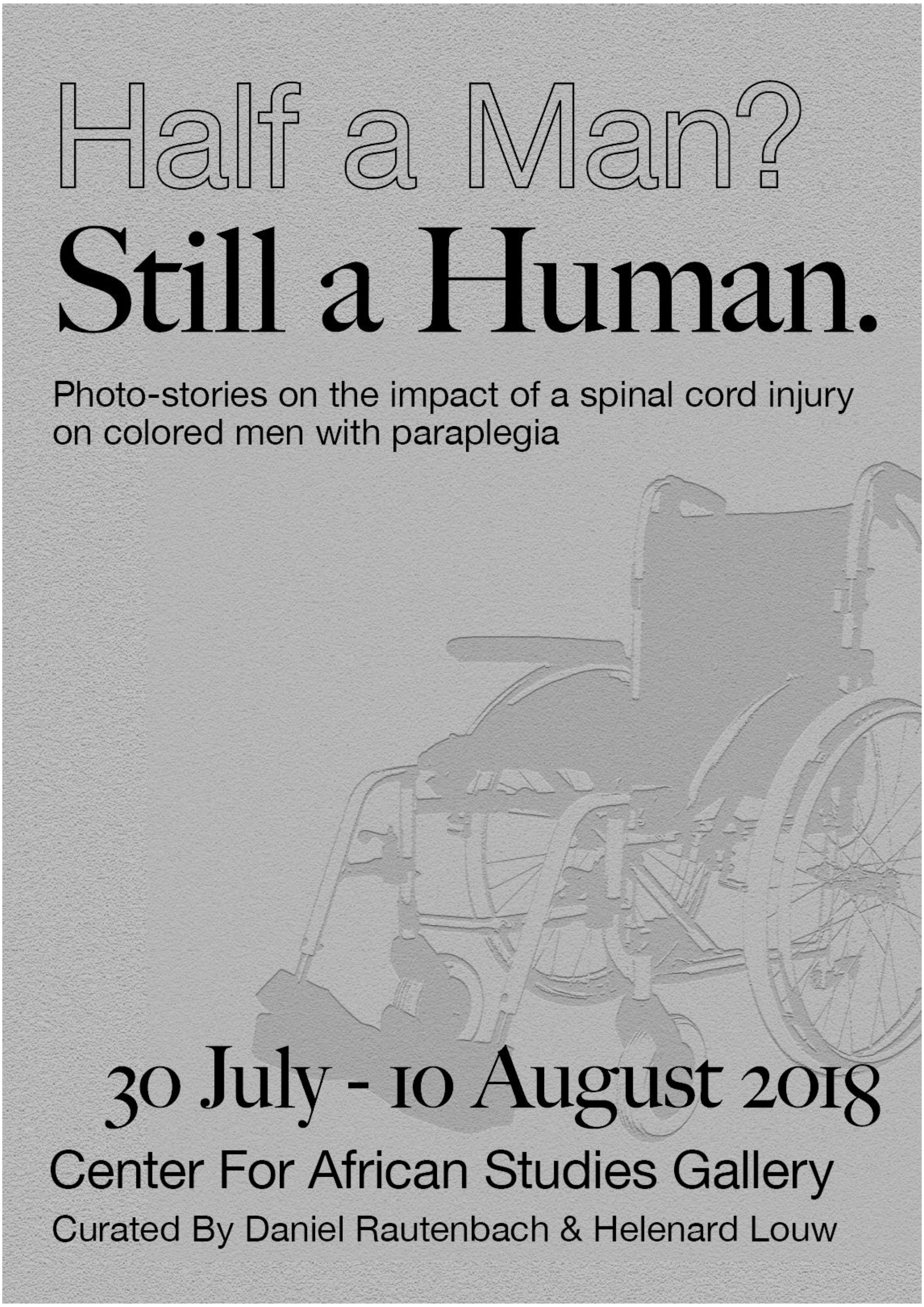
I have given a verbal explanation of the research project; its procedures and risks and I believe that the person responsible for the participant has understood that explanation.

Researcher: ………………………………………….

Signature: ………………..……………………………

Date: ………………………………………………….

Appendix G: Exhibition poster



Half a Man?

Still a Human.

Photo-stories on the impact of a spinal cord injury
on colored men with paraplegia

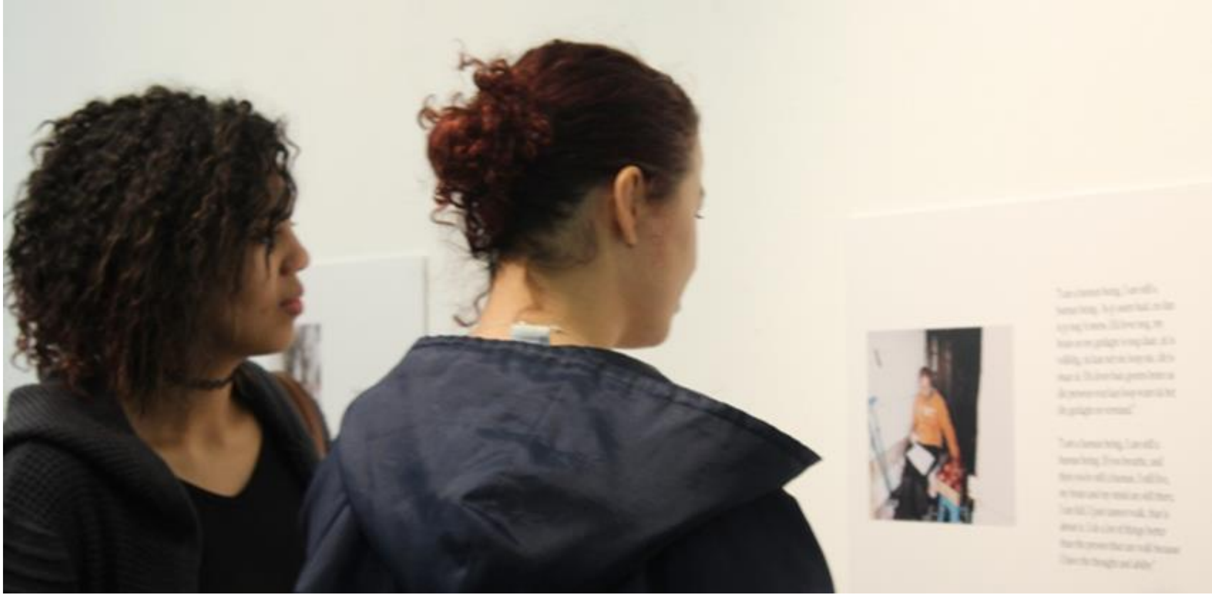
30 July - 10 August 2018

Center For African Studies Gallery

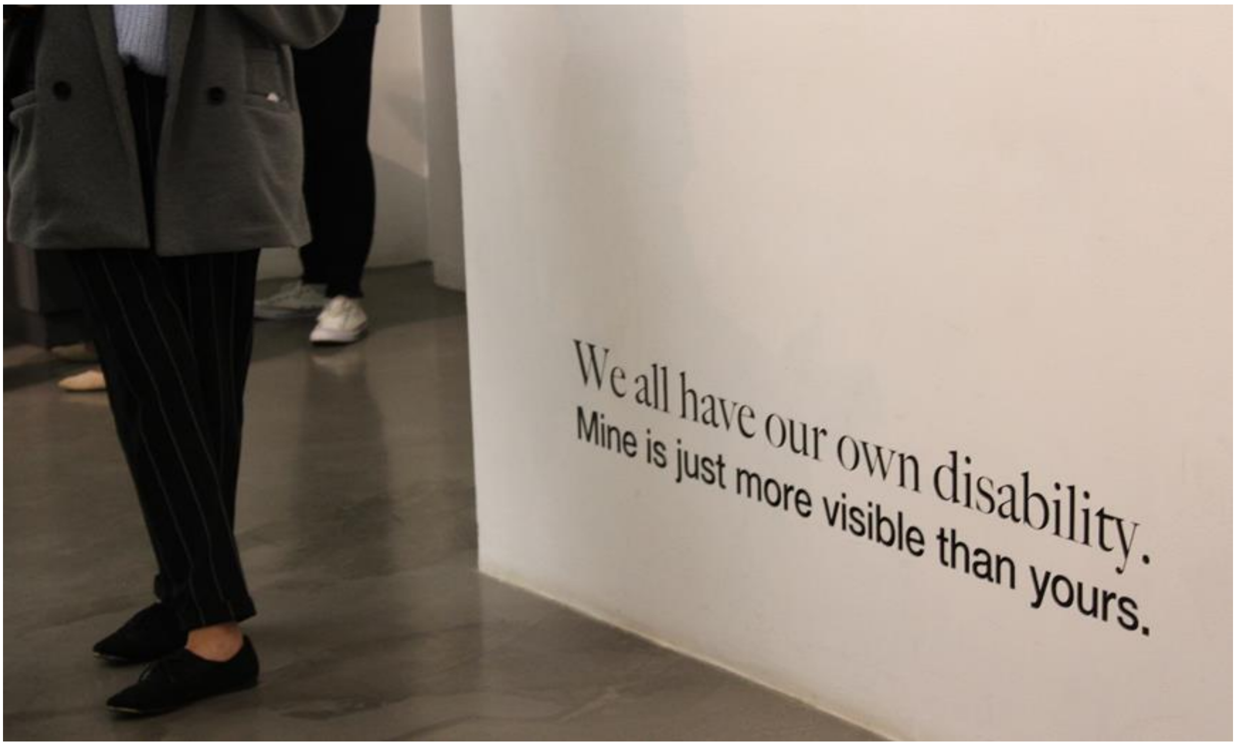
Curated By Daniel Rautenbach & Helenard Louw

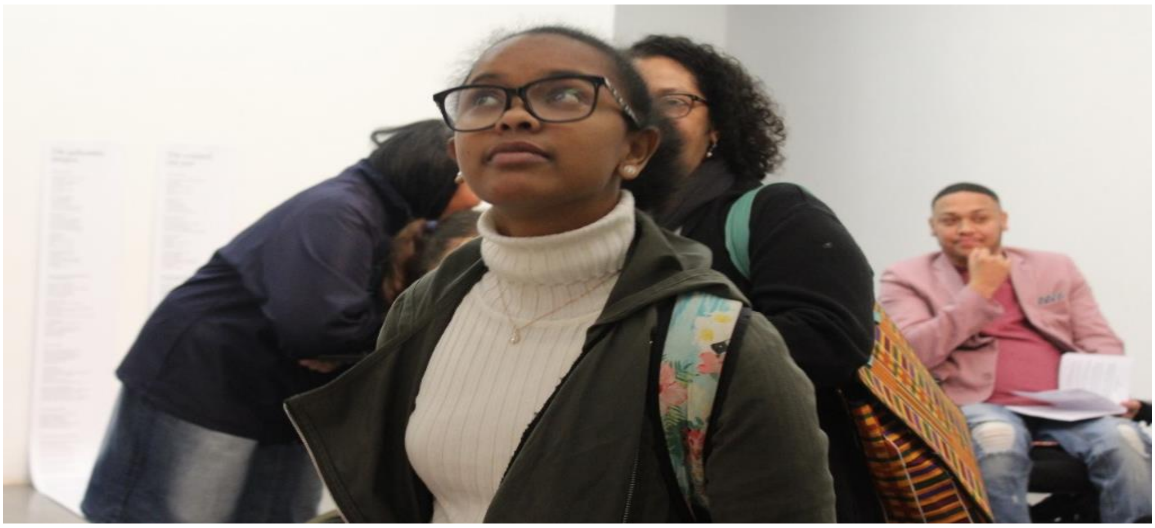
Appendix H: Exhibition photographs


Half a Man?
Still a Human.

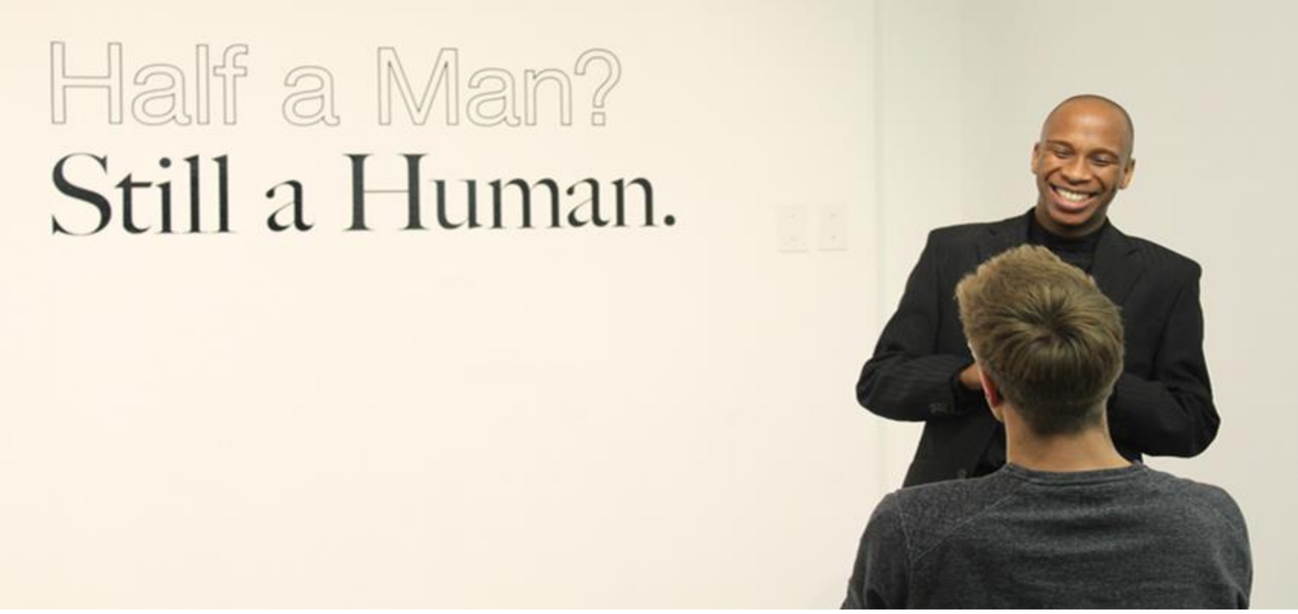


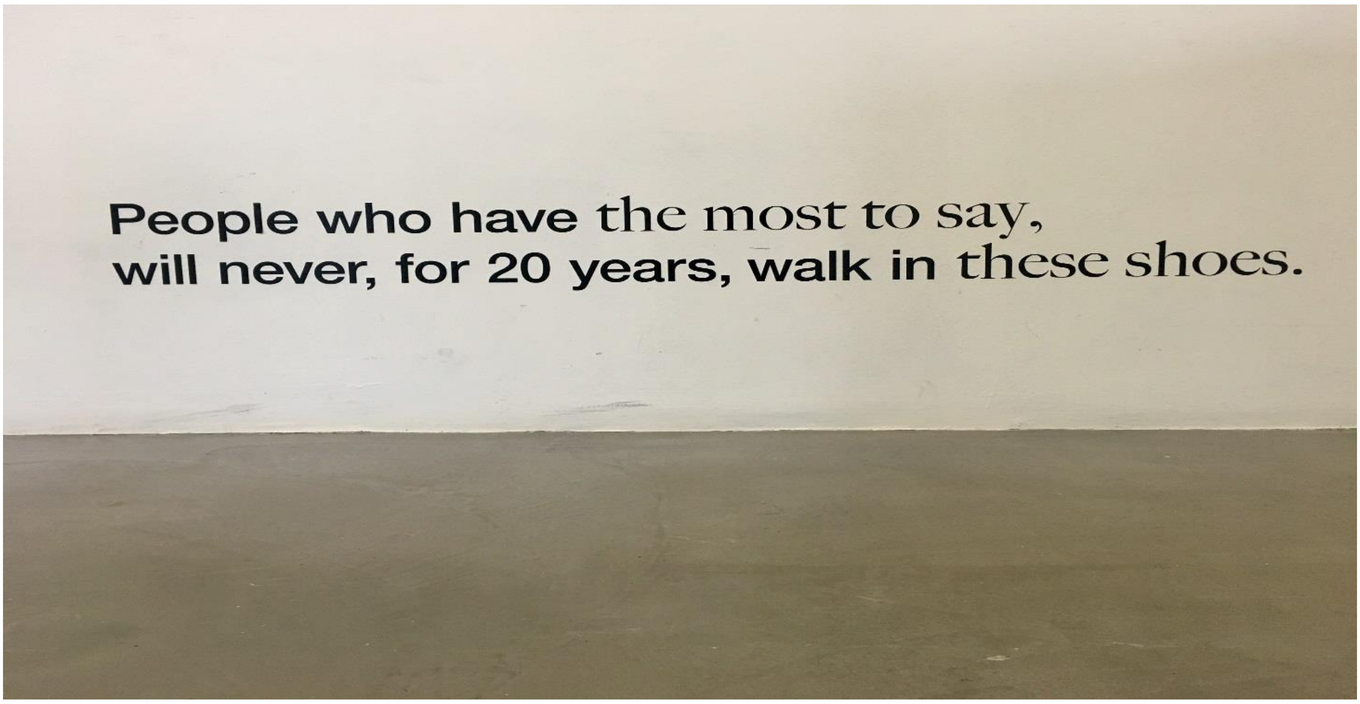

y story to be
estimon


We all have our own disability.
Mine is just more visible than yours.

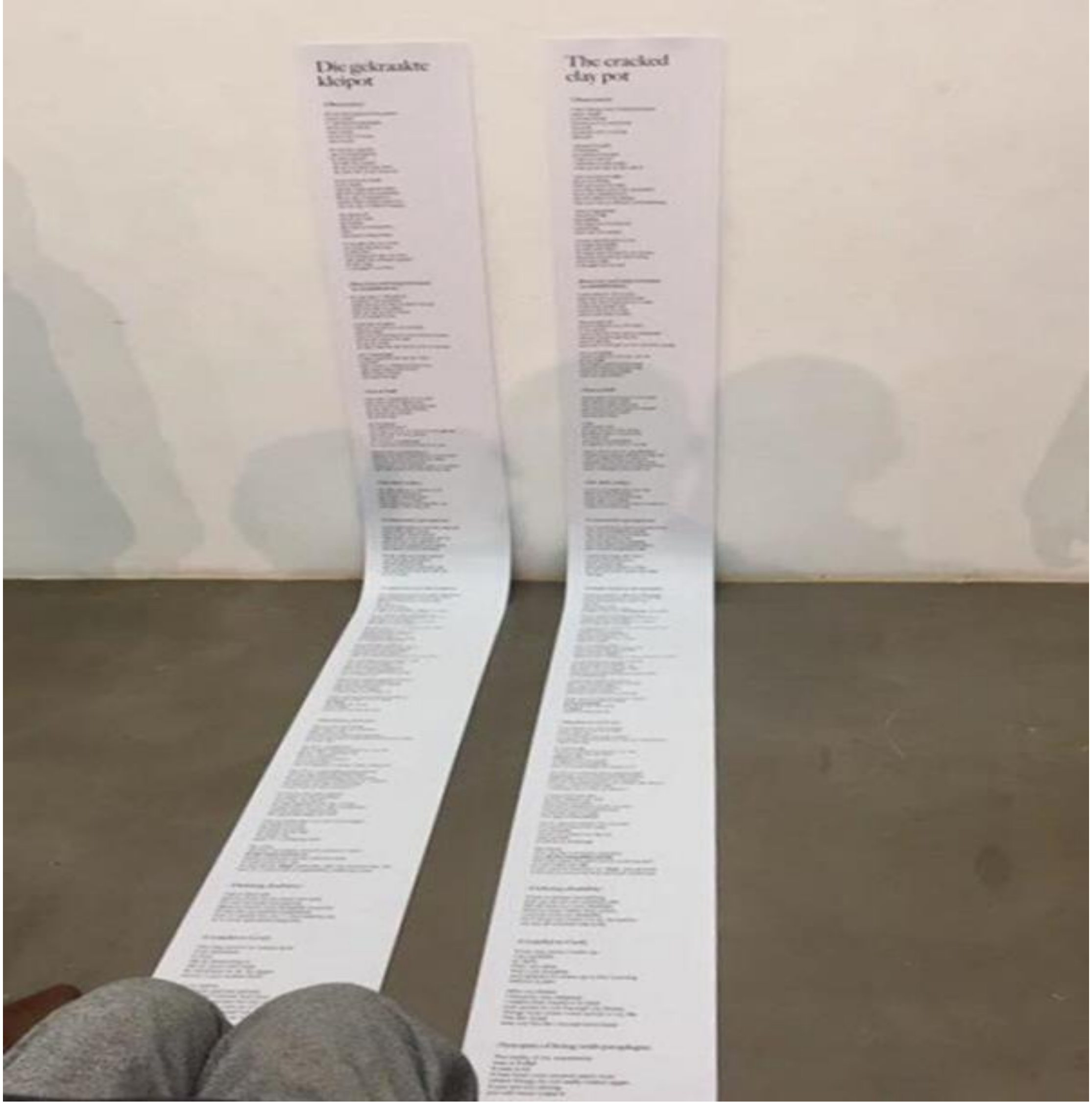



ho have the most
for 20 years, walk


Half a Man?
Still a Human.


People who have the most to say,
will never, for 20 years, walk in these shoes.

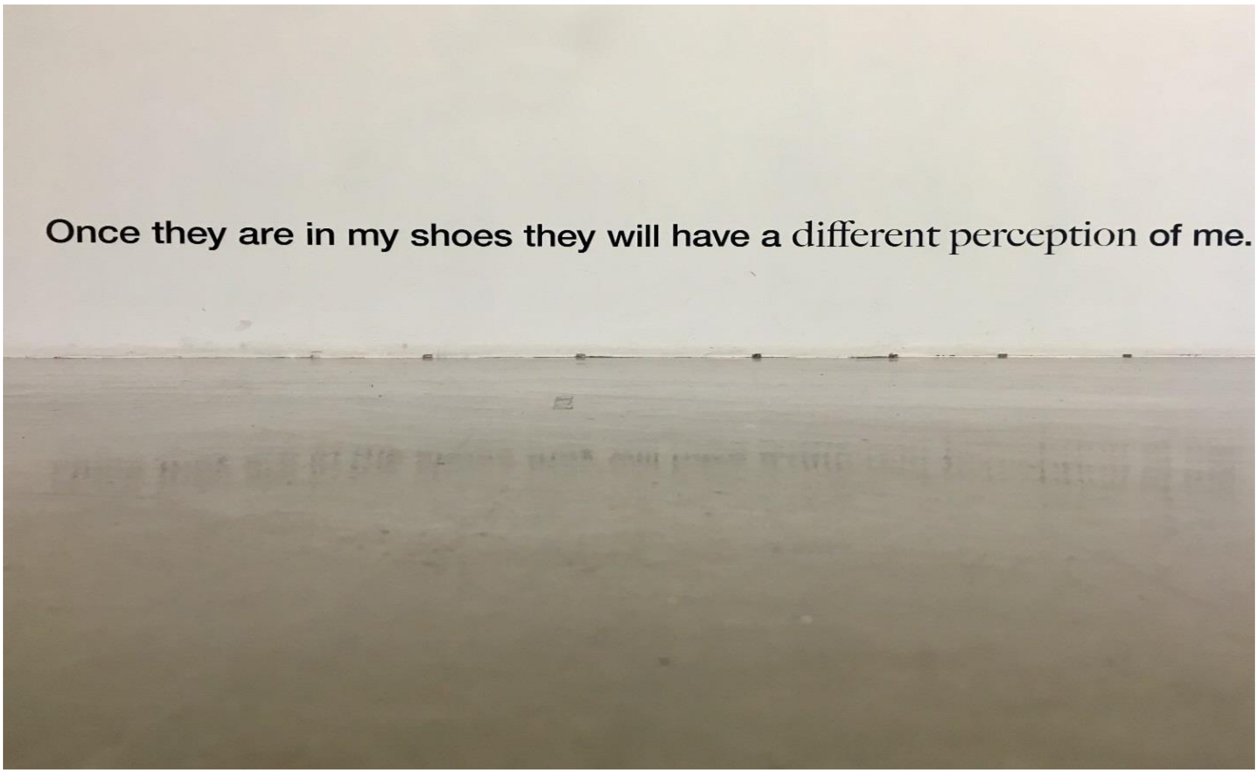
"I would go out with family and friends, and they would speak about me, but not to me. They would speak about me in front of me. They would speak to my mother, they would speak to my father, they would speak to my sister, all about me, but they would not speak to me. "How is he doing?" But I am right here - "I am very well, thank you."



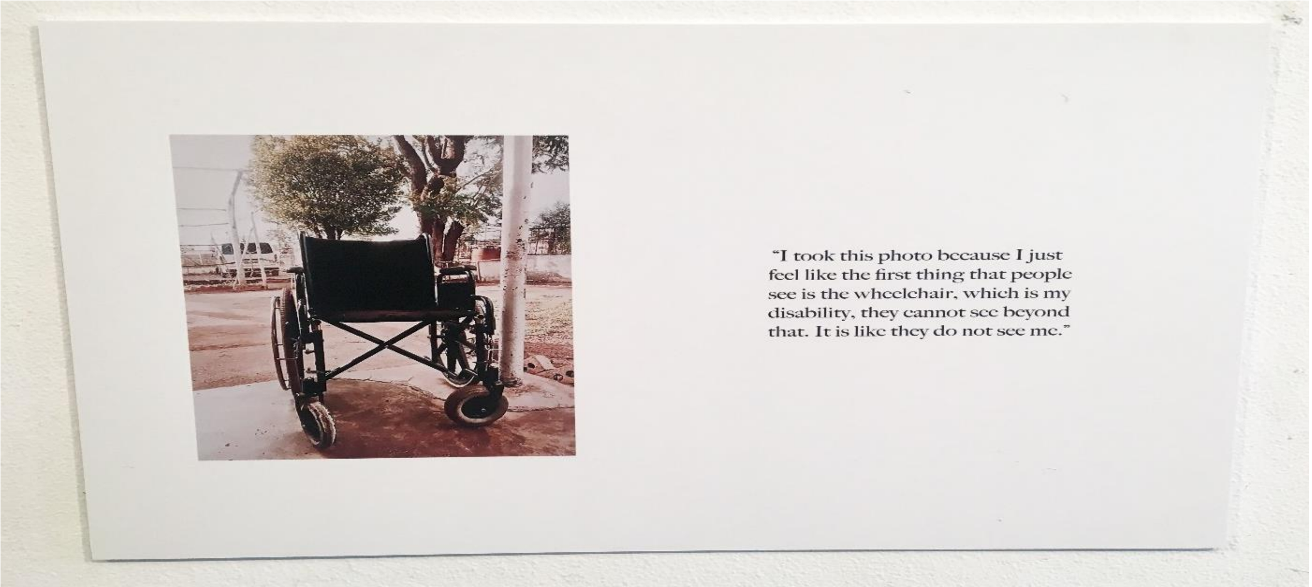
"Die foto het ek geneem want dit het my terug gevat na die tyd toe hulle vir my sê: "Mnr, jy is nou weer soos 'n babatjie. Jy sal nou moet weer leer om te loop." Dit is 'n verskriklike gevoel want ek het gedink wat moet ek nou weer doen om weer soos 'n babatjie te wees? Ja, eke het soos 'n baba gevoel omdat ek niks kon gedoen het nie. Mense om my het my ook soos 'n baba hanteer. Hulle wil my altyd rond stoot, daar is altyd iemand wat my wil voer, was, en help om aan te trek. Dit is nogal verskriklik, dat ek so groot is en so klein voel."

"The picture I took because it took me back to the time when they said to me, "Mr, you are now like a baby. You'll have to learn to walk again." It's a terrible feeling because I thought what should I do again to be like a baby again? Yes, I did feel like a baby because I could not do anything. People around me also treated me like a baby. They always want to push me around, there's always someone who wants to feed me, wash, and help to dress me. It's rather terrible that I'm so big and feeling so small."

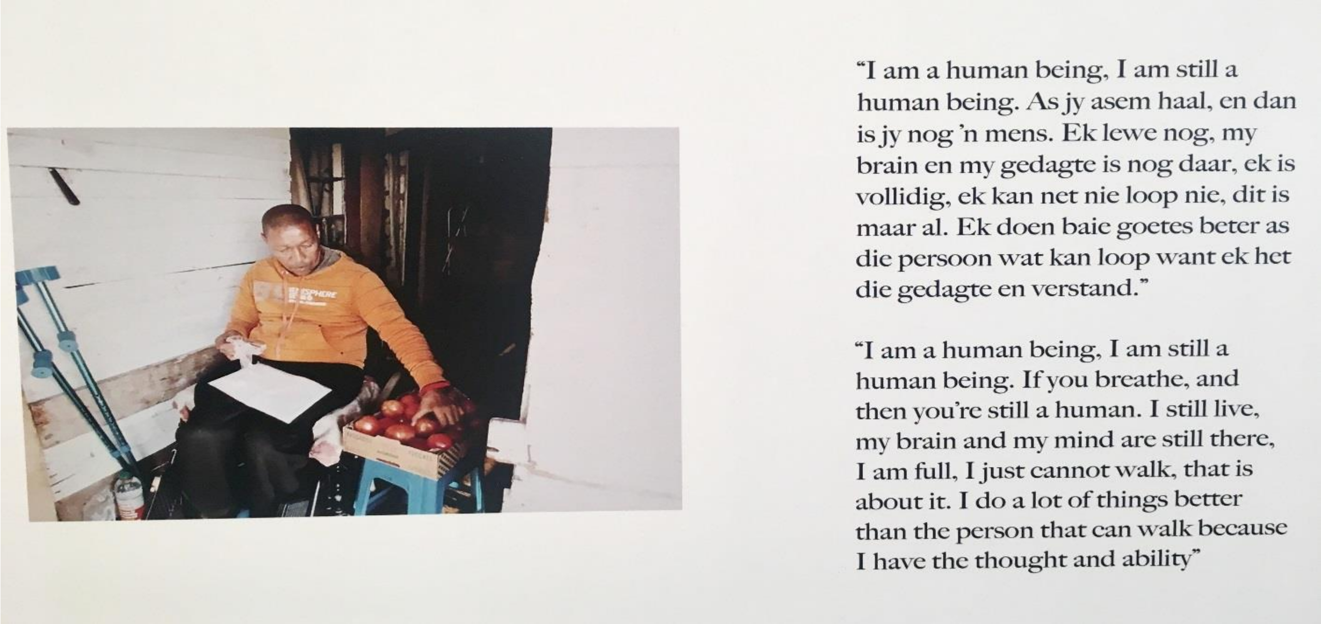
We are all cracked clay pots.



Once they are in my shoes they will have a different perception of me.



"I took this photo because I just feel like the first thing that people see is the wheelchair, which is my disability, they cannot see beyond that. It is like they do not see me."



"I am a human being, I am still a human being. As jy asem haal, en dan is jy nog 'n mens. Ek lewe nog, my brain en my gedagte is nog daar, ek is vollidig, ek kan net nie loop nie, dit is maar al. Ek doen baie goetes beter as die persoon wat kan loop want ek het die gedagte en verstand."

"I am a human being, I am still a human being. If you breathe, and then you're still a human. I still live, my brain and my mind are still there, I am full, I just cannot walk, that is about it. I do a lot of things better than the person that can walk because I have the thought and ability"


life testimony


We are all cracked clay pots.


Half a Man?
Still a Human.
Auto Atlantic


Half a Man?
Still a Human.


FORGET IT

Appendix I: Spoken Word Poem (read at exhibition)

It is almost a commandment,
A thing we learn from a young age,
Don’t look at the man, or woman who reminds you of your mortal self.
Mind you, it is never put this way.

But we learn,
Our senses absorb all the lessons,
Your eyes never look directly at anyone who does not walk on two feet like you,
Your body swerves in all the other directions avoiding them like the plague.
We do not want to have kids like them,
This thing sticks, it is a punishment.
For what? No one gets to that.

“You are scared”,
I wish I could’ve responded.
I wish I had also not been scared.
We are scared at how malleable our own body are,
Afraid that that man, or woman or child reminds us of the same body we are in.

Now you are faced with what boundaries look like,
You are looking into mirrors that spell out your hypocrisy,
Build structures and all sorts of things that make it hard for those whose bodies do not fit into your default expectations,
You are looking into mirrors and I imagine your reflection sticking its tongue out at you,
Look what you’ve done, look how you too could be different tomorrow,
Look at what you’ve done,
Look at what you’ve taught the children.

Tell them it is fear,
Look them in the eyes and say you are afraid of how easily these vehicles we are in could be injured,
How easily malleable they are.
Tell them when you see that woman, man, or child, your eyes dodge them because you are afraid of seeing the kinds of lines you have drawn that may implicate you tomorrow.

Tell them there were no boundaries and disabled-ness until things were constructed and left people out.
Tell them you are afraid when you think of how mortal your own body is,
How you are afraid to be what you have made people out to be.
Tell them you want to start from scratch, in a new world maybe.
Where there aren’t any rules as to how bodies should be to enter buildings,
Maybe then, we’ll learn to soar on any amounts of limbs one has.
But for now tell them, that you are afraid.

By Sisipho Makambi

Appendix K: Song dedicated to society (written and performed for exhibition)

Die struggle – Jayson George

Die's ‘n nuwe song
En hier het ek ‘n nuwe note
Luister, dink mooi, vat ‘n bietjie note
Hier's ek, met ‘n nuwe lyric oppie boat
Ek is oppie water, kalm en ek raak net koud
Van alles wat ek sien, kykie, raak nooit oud
Die dinge wil nie change nie ek raak benoud
En niemand kan my nou face nie ek raak net stout
Want almal wat nie wil hoor nie dra net goud

Chorus
En ek sien hoe die wereld verby gaan x2
En ek kyk na die ma's en die pa's hulle worry nie vannie kinders nie but ek staan
Ek kyk na die son en die maan, but ek het vergiet,
Hulle kan my nie sien nie van ek is hier in ‘n gebied
Waar die son ‘n lied
Plaas in jou ore en jy kan my nie hoor nie van jy is net siek

Hoekom moet mense altyd kyk en jou afdruk
Hoekom sal mense nooit help n jou reg ruk
Ek dink is tyd dat os mense moet ‘n change maak
Ek dink is tyd dat os mense nou moet wys raak
Dag by dag raak os swak want ‘n ma is te bang om aan ‘n kind te raak
En os sien alles raak
Os is bang om te praat
Want die staat is corrupt
Hulle's almal in ‘n gat van… geld en rykdom

Ek dink is tyd dat ons stemme nou moet uitkom
Uitkom
Met die dinge wat ons pla
En die dinge wat ons seer maak
Maar net jy kan dit reg maak
Maak staat op jouself
Moenie verswak
As die dinge, as die dinge bietjie swaar raak
Want net jy kan dit reg maak
Kykie broer, net jy kan dit reg maak

Nou checkit uit, die is die struggle va ons daaglikse liewe (lewe)
Almal wil nou gangsters raak, kinders se ouers moet biewe (bewe)
Almal dink os is die lost generation
Ja, maar luister gou nou mooi na die nuwe revelation
Die lewe is insane
Mense lewe nou in vain/wyn (pun)
Drugs en alcohol gesmokkel
En dit cause ‘n klompie pain/pyn

Ek voel die wind waai
En my maag begin te draai
Gaan os nou ‘n change maak of is ons almal net guys

Die is die tyd om vir jouself te prove
Vergeet maar van die government die battle was gelose
Gesnooze
My broe
Hulle’s almal net fools
Ons is almal nou verlore en dis ons wat moet choose

Die struggle is so real mense het tyd om nog te speel,
die is die nuwe reality
Dis die coloured mentality
Streng kinders en gehoorsame ouers
Ek hoop jy luister mooi
want die problem kan by jou is
ouers is so bang om aan ‘n kind te raak
maar hulle het vir ons mos so groot gemaak
ja die lewe het gechange
en apartheid is verby
gaan ons nou is change maak
van dis ‘n brand new day

die beat is so hard
soos die nuwe generation
maar die’s maar my opinion
my naam is Jayson
luister mooi, na die boodskap vir jou
want dit le nou by ons om die nation te bou
hulle het mos gedink os is die lost generation
maar luister na my lyrics
hulle was almal mistaken
ons lewe maar net om ‘n change te maak
maar die mense bly net negative
en almal wil ons haat
praat
ja
so wat maak dit nou saak
maak staat op jouself
want ‘n boom begin mos met ‘n saad
ek hoop jy kry die message en jy begin om te luister
positive, in jou brein
ons is die coolest generation!

Chorus
En ek sien hoe die wereld verby gaan x2
En ek kyk na die ma’s en die pa’s hulle worry nie vannie kinders nie but ek staan
Ek kyk na die son en die maan, but ek het vergiet,
Hulle kan my nie sien nie van ek is hier in ‘n gebied
Waar die son ‘n lied
Plaas in jou ore en jy kan my nie hoor nie van jy is net siek