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*Together in Excellence*

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**MEN LIVING WITH HIV AND AIDS: A NARRATIVE STUDY OF MALES'  
EXPERIENCES OF LIVING WITH HIV AND AIDS IN BUFFALO CITY  
METROPOLITAN MUNICIPALITY IN THE EASTERN CAPE PROVINCE OF SOUTH  
AFRICA**

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**A THESIS SUBMITTED IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR  
THE MASTERS DEGREE IN RURAL DEVELOPMENT**

**JUNE 2014**

## Declaration

I Tendai Emmanuel Gumbie do hereby declare that this thesis is entirely my own work, except where it is attributed to other authors or sources. This work has not been submitted for a degree in any other university.

Dated at.....this.....day of.....2014

Signed.....

## **Dedication**

This thesis is dedicated to my mother, Ruth Gumbie, for her unflinching and steadfast financial, emotional and psychological support over the years. I greatly appreciate all this. Without your love and support I could not have managed to complete this project. I love you Mummy !!

## **Abstract**

According to UNAIDS (2012b) men continue to have a higher HIV and/or AIDS mortality rate compared with women. The aim of this thesis was to elicit, analyse and understand the “insider” accounts of the life experiences of men living with HIV and/or AIDS. Particular emphasis was placed on investigating whether there were similar themes, emotions and meanings expressed in the narratives of the participants, with regard to their sexual practices and experiences and how these practices and this chronic illness impacted on their masculinity construct.

A qualitative approach of semi-structured interviews was utilised to obtain data from eight men living with HIV and/or AIDS in the Buffalo City Municipality, in the Eastern Cape Province of South Africa. A narrative analysis approach was used to analyse and interpret the data.

The study found that most of the participants adhered to a hegemonic masculinity construct, characterised by risky sexual practices. The study’s main finding was that before their diagnosis with HIV, the participants reported having multiple sexual partners, inconsistently using condoms and not initiating voluntary testing for HIV.

Furthermore, the study found that the participants understood and described their masculinity constructs through three distinct factors: firstly, through social factors such as being a bread-winner, being married or being a father; secondly, through material possessions such as owning a house, a car and having a job and, thirdly, through sexual factors namely, being able to have unprotected sex and being involved with multiple sexual partners. This suggests that masculinity is socially constructed through social schemas. The study also found that most of the men

reported experiencing stigmatisation and/or discrimination from either family or community members as their most negative experience and their attached emotions suggested a weakening of their masculinity construct. In conclusion, the study's findings highlight the need for a continued understanding of masculinity constructs.

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## Acronyms

AIDS	Acquired Immunodeficiency Syndrome
ARV	Anti-Retroviral
FBI	Federal Bureau of Investigation
GDP	Gross Domestic Product
HIV	Human Immunodeficiency Virus
HSRC	Human Sciences Research Council
IPV	Intimate Partner Violence
MDG	Millennium Development Goals
NSDA	Negotiated Service Delivery Agreement
SABC	South African Broadcasting Corporation
TB	Tuberculosis
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
VCT	Voluntary Counselling and Testing
WHO	World Health Organisation

# **Chapter 1**

## **Overview of the Study**

### **1.1 Introduction**

This chapter seeks to give a general orientation and overview of the whole study. It includes the background of the study, the problem statement, research questions, aims and objectives, theoretical framework, limitations and significance of the study, as well as a chapter outline.

### **1.2 Background of the Study**

With the development and rapid increase in the spread of HIV and/or AIDS, young people's risky sexual behaviour has brought about a massive shift by social researchers worldwide to the study of gender, gender roles and human sexual practices (Shefer and Foster, 2008, cited in Steyn and Van Zyl, 2009). South Africa has not been left out in this worldwide shift to study sexual practices and as a result, numerous studies have been done on men and masculinity, and their sexual beliefs, knowledge and practices as it is widely believed that gender roles shape sexual practices (Hearn, 2004). This study attempts to contribute to this growing body of knowledge by studying and interpreting narratives of sexual practices and experiences of males living with HIV and/or AIDS in Buffalo City Metropolitan Municipality, in the Eastern Cape province of South Africa. These narratives are seen to be overridingly important in understanding the spread of HIV and AIDS.

UNAIDS (2012b:6) states that "the global community has embarked on an historic quest to lay the foundation for the eventual end of the AIDS epidemic". Therefore studies of

gender and masculinity are of significance for the better understanding of the factors and practices that influence the continued spread of HIV.

### **1.3 Problem Statement**

Despite considerable and rigorous research around HIV and/or AIDS worldwide and in South Africa, the epidemic continues to spread in certain parts of the world. Issues around risky sexual behaviours, mind-set and behaviour change as well as gender roles in sexual relations still need to be understood in greater detail. Thus, it may be useful to begin formulating useful and relevant policy directed at men based on all the studies that have been conducted on this epidemic. This study aims to elicit, explore and better understand the sexual behaviours of men through their illness narratives and why these behaviours make them highly susceptible to contracting the HI virus in the hope that policy directed at curbing the spread of HIV amongst men, and by implication women can be formulated.

### **1.4 Research Questions**

In trying to answer the main research question, which is an attempt to gain further understanding and knowledge into the experiences of men living with HIV and/or AIDS, attention will be paid to the following specifics:

- What significant events occurred in the lives of men living with HIV and/or AIDS before and after being diagnosed with the virus?
- What emotions do participants attach to their experiences of living with HIV and/or AIDS?
- What challenges, struggles, obstacles and positive experiences have they encountered as men living with HIV and/or AIDS?

## **1.5 Research Aims and Objectives**

The principal aim of the study is to explore the narratives of men living with HIV and/or AIDS. In order to achieve this aim the following specific objectives will be pursued:

- To elicit narratives of significant events that occurred in the lives of men living with HIV and AIDS.
- To investigate the emotions of men living with HIV and/or AIDS.
- To explore and understand the challenges as well as the positive experiences of males living with HIV and/or AIDS through their narratives.

## **1.6 Theoretical Framework**

According to Peterson and Bredow (2009, cited in Mateo and Kirchhoff, 2009:107) a theory is “a set of interrelated constructs (concepts, definitions and prepositions) that presents a systematic view of a phenomenon by specifying relations among variables in order to explain and predict the phenomenon”. In other words, a theoretical framework is used to describe, explain or predict the occurrence of a phenomenon, and is the basis for the method used to answer the research questions (Leedy and Ormrod, 2005). This study follows Raewyn Connell’s radical feminist approach to masculinity constructs as its theoretical foundation. This theoretical foundation adheres to the beliefs that masculinity constructs, primarily hegemonic masculinity, which is driven by the need to oppress, subjugate, and conquer women (sexually) as well as ‘weaker’ men (subordinate masculinity) is one of the fundamental reasons why socially constructed understandings of masculinity continue to be a hindrance in the fight to combat the spread of HIV.

## **1.7 Masculinity and Hegemonic Masculinity**

### **1.7.1 Masculinity**

Masculinity constructs will be used as the theoretical framework for this study in understanding health-related behaviour including the risky sexual behaviours of hegemonic masculinities. Reeser (2009: 1) defines masculinity as a “set of qualities, characteristics or roles thought to be or ascribed to males, with the constructs of masculinity (too masculine, mostly masculine) varying in their degree according to historical and cultural contexts”. Kelly (2007:136) also defines masculinity as the behaviours found in average men. This is similar to Connell’s beliefs about masculinity. According to Connell (1995:67) “masculinity assumes that one’s behaviour results from the type of person one is. That is to say, an un-masculine person would behave differently being peaceable rather than violent, conciliatory rather than dominating, hardly able to kick a football, uninterested in sexual conquest, and so forth”. In other words, “normal” men adhere to the constructs of masculinity and are viewed as masculine, while any man who deviates from the “norm” is viewed as un-masculine.

### **1.7.2 Hegemonic Masculinity**

Just as there are different kinds of men the world over, so are there also different types of masculinities. Connell (1995) makes mention of two distinct types of masculinity. The first is hegemonic masculinity which she (1995:77) defines as “the configuration of gender practice which embodies the currently accepted answer to the problem of the legitimacy of patriarchy, which guarantees (or is taken to guarantee) the dominant position of men and the subordination of women”. This understanding of masculinity is the most common in studies of Southern African men and is economically, politically, socially, physically and culturally exalted at any given time (Groes-Green, 2009:288). In

other words, hegemonic masculinity is the socially accepted standard of behaviour that all men should portray and adhere to and although not all men practise it, all men benefit from it.

According to Duck (2009:287) “hegemonic masculinity emphasizes patriarchy, heterosexuality, subordination of others (both men and women), economic security, physical dominance, marriage, children and jobs”. Courtenay (2000:1388) also believes hegemonic masculinity includes “leadership, strength, power and authority”. However, economic access is believed to be the most important and major component of masculinity (Connell and Messerschmidt, 2005 cited in Duck, 2009:288). Any deviation from the above such as sickness – lack of control over one’s body - is associated with weakness and is viewed as not being manly and masculine (Duck, 2009:300).

Courtenay (2000:1389) believes hegemonic masculinity uses some health-based beliefs and behaviours to reinforce itself such as the “denial of weakness or vulnerability, emotional or physical control, the appearance of being strong and robust, dismissal of any need for help, a ceaseless interest in sex, the display of aggressive behaviour and physical dominance”. This suggests that men who adhere to the constructs of hegemonic masculinity perceive themselves as being immune to illness, injury or emotional weakness.

In a study of young men in Maputo by Groes-Green (2009) it was revealed that most of the participants believed that having a stable job, being financially stable and able to provide for girlfriends (being the bread-winner), and also having many sexual conquests were all characteristics of a hegemonic masculinity. In the absence of the above,

violence and sexual power against women are used to assert their hegemonic masculinity (Groes-Green, 2009:288). The findings of the research, illustrate the concept of 'hegemonic masculinity' in that they show how the men understood sexual conquests and material possessions as factors that symbolised an adherence to this masculinity type.

The second type of masculinity mentioned by Connell (1995) is subordinate masculinity or protestant masculinity, which according to Groes-Green (2009:289) "represents those that undermine the goals of a dominative hegemonic masculinity". Gay and academically inclined men are presented as examples of this type due to their association with femininity (Lusher and Robins, 2010). Thus, subordinate masculinity does not seek dominance or control over others but can be said to be compassionate while striving for equality in all spheres of life. Many studies have used the concepts of hegemonic and subordinate masculinity to shed light on the prevalent gender inequalities and injustices, especially in South Africa (Groes-Green, 2009).

In addition, Campbell (1997) concludes, based on her investigation, that the ways in which men understand their masculinities and how they identify with them plays a key role in shaping how they seek sexual satisfaction and intimacy. Campbell (1995, cited in Morrell, 2001) states that the process of social identity construction is context-dependent and situation-specific. This means that the way men living with HIV and/or AIDS view, understand and respond to their illness is dependent on their environment, community, culture and the roles they play within these communities and society.

For the purpose of this research, masculinity, primarily hegemonic masculinity, will be used as a concept in trying to understand the experiences of HIV positive males. Many elements of hegemonic masculinity are closely related to the “typical” high-risk behaviours associated with HIV transmission (Lindegger and Quayle, 2009:43). According to Lindegger and Quayle (2009:43) these behaviours include “multiple sexual partners, unprotected sex, use of alcohol before sex and, in some cases sexual violence”. According to Brown et al., (2005 cited in Lindegger and Quayle, 2009:51) “this association is so strong that, in some places, being HIV-positive itself has become a badge of manliness”. Males recognize the importance of these behaviours as markers of successful masculinity, and therefore feel considerable pressure to perform them, and to be seen performing them.

Furthermore, Lindegger and Quayle (2009:50) believe that “although there are variations in specific forms of hegemonic masculinity, there is remarkable empirical consistency in constructions of hegemonic masculinity related to high-risk behaviour for HIV transmission across geographical, cultural and linguistic divides in Africa and elsewhere”.

Because the study seeks to elicit the narratives of males living with HIV and/or AIDS and to explore and understand how they frame their narratives with regard to their experiences, this theoretical framework can be a useful departure point in understanding the complex and diverse experiences of men living with HIV and/or AIDS.

## **1.8 Significance of the Study**

The findings of this study may be significant in influencing policy formulation that is directed at changing men's attitudes, behaviours and perceptions of socially acceptable masculinity constructs which are largely characterized by risky sexual behaviour. The findings may also influence policy that is directed at encouraging men to be more health conscious and seek medical help. This may result in a decrease in the HIV mortality rates amongst men.

## **1.9 Chapter Outline of the Research Dissertation**

The chapter outline of this research study is as follows;

### **1.9.1 Chapter 1: Overview of the Study**

In this chapter the studies research topic on men living with HIV and/or AIDS and how this disease affects their lives is explained in brief as the background of the study. This chapter also explains the research problem surrounding the inadequate knowledge on men living with HIV and/or AIDS and their experiences. It also contains the aims and objectives of the study. Finally, the research questions that the study seeks to answer, as well as the significance of the same study, are discussed.

### **1.9.2 Chapter 2: Literature Review**

This chapter discusses the literature on HIV and/or AIDS worldwide and in South Africa, as well as studies of gender and masculinity and their effects on the spread of HIV. The chapter also discusses the socio-economic and psycho-physical impact of HIV and/or AIDS on the sufferers, family structure and the community. Factors that exacerbate the continued spread of HIV as well as the conceptual framework of masculinity, and policy governing work on HIV and/or AIDS and their links to the study are also discussed in this chapter.

### **1.9.3 Chapter 3: Research Methodology**

This chapter discusses the research participants' demographics. It also elaborates on the research design and the methods by which data were collected, analysed, interpreted and finally reported.

### **1.9.4 Chapter 4: Data Presentation, Analysis, Interpretation, and Discussion of Findings**

This chapter presents and discusses the analysis and interpretation of the findings of the narratives of men living with HIV and/or AIDS in the Buffalo City Municipality.

### **1.9.5 Chapter 5: Summary and Conclusion**

This chapter summarises the findings, and concludes the study.

## **1.10 Conclusion**

The continued spread of the HIV and/or AIDS pandemic, which is largely characterised by higher male mortality rates, continues to be a problem. Thus, in an effort to understand why the virus causes higher male mortality rates, the study's principal aim is to explore the narratives of men living with HIV and/or AIDS in an attempt to better understand their sexual practices and behaviours, as well as the challenges, struggles and obstacles they face while living with HIV and/or AIDS and how these experiences have influenced their masculinity constructs.

This chapter also draws attention to the use of qualitative research methods of semi-structured interviews to elicit illness narratives from the participants. Crossley's (2000) narrative analysis method is utilised to analyse the gathered data. Masculinity, particularly hegemonic masculinity theory is used as a statement of assumption or departure point. Masculinity is understood to be socially and culturally constructed and is viewed as the behaviours found in average men (Kelly, 2007).

The following chapter reviews the available literature and related work that have been conducted in contemporary studies. The literature was drawn upon in order to form a base from which this study centred its work.

## **Chapter 2**

### **Literature Review**

#### **2.1 Introduction**

A report by UNAIDS (2012b:6) states that “the global community has embarked on an historic quest to lay the foundation for the eventual end of the AIDS epidemic”. As a result, in the last two decades, numerous strategies and programmes have been put together to combat this deadly pandemic, such as scaled-up anti-retroviral (ARV) therapy and transformed national AIDS responses which have generated broad-based health care achievements (UNAIDS, 2012b:12). Slowly, efforts to curb the HIV and/or AIDS pandemic appear to be paying off. Findings from UNAIDS (2012b:12) research indicate that the number of people dying from HIV-related causes in sub-Saharan Africa declined by 32% between the years 2005 and 2011. However, this region still accounted for 70% of all the people dying from AIDS in 2011 (UNAIDS, 2012b:12).

Although enormous efforts have been made to curb the spread of, and indeed, understand patterns of HIV prevalence, particularly in sub-Saharan Africa, the virus continues to spread relentlessly. Prevalence rates have been linked to behavioural, social and cultural norms, which highlights the need to understand the particular social and cultural contexts in which the virus spreads. This study aims to address this need by focusing on the experiences and behaviours of men infected by HIV. In so doing it hopes to provide insight into individual and social factors that contribute to the continued spread of HIV and/or AIDS.

This chapter discusses the history and origins of the HI virus, global and regional HIV statistics, illness and HIV, stigma and HIV, masculinity and HIV, and the socio-economic impact of HIV on the individual, the family and the country as a whole.

## **2.2 Why a study of men's susceptibility to HIV and AIDS?**

According to the World Health Organization (WHO) (2008) cited in UNAIDS (2012b), women constitute 50% of all HIV global infections, and 60% of all HIV infections in sub-Saharan Africa. So why study men and not women? The reason for a study of men living with HIV is that, although the rate of HIV infection in men is lower than it is in women, men tend to have higher mortality rates from AIDS than women (UNAIDS, 2012b:71). This is because gender norms of masculinity discourage men from seeking medical attention early and also from admitting to ill-health (UNAIDS, 2012b:71). Men show consistently lower rates of HIV testing than women, lower CD4 counts when accessing treatment, as well as poorer adherence to treatment regimes. This has been documented across Southern Africa and South Africa is no exception (UNAIDS, 2012b:71). Hence, a study of men is crucial to try and find out the underlying factors, events as well as experiences that lead to this phenomenon of a higher HIV mortality rate amongst men. While this research does not attempt to explain these links, it certainly endeavours to explore the experiences of HIV positive males in an effort to better understand the underlying factors, events and experiences that lead to higher HIV mortality amongst men.

## **2.3 The Origins of HIV and/or AIDS**

HIV is an acronym for the human immunodeficiency virus which is a virus that targets and weakens the human immune system (Sepkowitz, 2001). According to van Dyk

(2012:38) HIV is spread through unprotected vaginal or anal intercourse, with heterosexual intercourse being the primary mode of transmission in sub-Saharan Africa. HIV infection is a progressive condition that leads to the development of acquired immunodeficiency syndrome (AIDS) which if untreated will lead to death. The progression to AIDS is measured by a specific human immune system cell count, referred to as a CD4 cell count. An uninfected person usually has a CD4 cell count of 500 or more (Sepkowitz, 2001). A CD4 cell count below 250 signals the occurrence of specific diseases in association with an HIV infection (Sepkowitz, 2001). In the absence of treatment, around half of the people infected with HIV develop AIDS within ten years (Sepkowitz, 2001).

The most common initial conditions symptomatic of AIDS are firstly pneumocystis pneumonia (40%), a form of pneumonia caused by a yeast-like fungus. Secondly, cachexia (20%) which is a “wasting syndrome” characterised by a loss of body mass which cannot be re-gained nutritionally and, thirdly, oesophageal candidiasis which is an “opportunistic” infection of the oesophagus caused by a fungus (Aliouat-Denis et al., 2008). As the immune system weakens with the progression of AIDS, a host of additional conditions may develop, such as tuberculosis (TB) and some forms of cancer (Aliouat-Denis et al., 2008).

HIV was first discovered in 1981 by the Centre for Disease Control (Sharp and Hahn, 2011:1). Genetic research identifies the disease as originating from West-Central Africa (Sharp and Hahn, 2011). Numerous theories attempt to explain the origins of the virus in humans. One such theory suggests that the virus originated from contact with chimpanzees that had HIV - type infections (Sharp and Hahn, 2011: 2). These primates

were usually hunted for bush meat which is a common practice in West Africa (Williamson and Martin, 2010 cited in van Dyk, 2012:6). It is believed that the transference from chimpanzee to humans came about when the hunter was bitten or cut while hunting or butchering the animal (van Dyk, 2012:6). Humans are believed to have come into contact with the blood and/or mucus of these animals and this led to the origins of the disease in humans. The earliest documented origins of this disease stem from the Congo in 1950's, with some evidence of it also being present in Haiti. It is believed that an unknown individual from Haiti introduced the virus into the United States around 1969 (Gilbert et al., 2007). The epidemic at the time then spread rapidly among high-risk groups (initially, promiscuous homosexuals) (Gilbert et al., 2007). According to Gilbert et al., (2007) by 1978, the prevalence of HIV among gay male residents of New York and San Francisco was estimated at 5%, suggesting that several thousand individuals in the country had been infected.

Thus, the origins of HIV and/or AIDS are presumed to have been two-fold, from the Congo as well as from Haiti. The African strand is thought to have come from bush meat, and spread due to many social events and occurrences (Gilbert et al., 2007:18566). While the spread of the Haitian strand of the virus was exacerbated after Haiti became a popular sex tourism destination in the mid-1970's (Gilbert et al., 2007:18566). The two strands then evolved and spread from location to location culminating in the current global pandemic (Gilbert et al., 2007).

There are, however, a number of competing theories about the origins of HIV, none of which has been fully substantiated. These include the assertion that the polio vaccine, which was produced from the cell cultures of kidneys of infected African green monkeys

in the 1950s, caused AIDS when administered to humans (van Dyk, 2012:5). There are also conspiracy theorists who believe that HIV was developed by the Federal Bureau of Investigation (FBI) to destroy the third world population, with others believing it was created by the apartheid government in South Africa (van Dyk, 2012:7).

But a most compelling critique of the origins of HIV is given by Alan Cantwell (1993) in his book *Queer Blood: The secret AIDS genocide plot*. Cantwell (1993) puts forth the notion that the HIV virus originated in America. He refutes the idea that the virus originated from chimpanzees in Africa. Cantwell (1993) argues that the first proven case of HIV was discovered in New York City in 1979, while the African AIDS epidemic was only discovered in 1982. Cantwell (1993) believes the virus was invented by the US government in a bid to rid America of the many healthy gay men and their liberation movement, who at the time were fighting for their rights. Thus, the theory laying the origins of AIDS at the doorstep of Africa has been advanced by many scientists in an attempt to blame Africa as a doomed, diseased and dark continent where AIDS was discovered and originated. However, it is important to note that none of these theories has ever been scientifically proven and the exact origins of the AIDS epidemic remain open to debate.

#### **2.4 Global and Regional Statistics, Demographics and Trends of HIV and AIDS**

According to UNAIDS (2012b:8) sub-Saharan Africa is still the worst affected region in the world, accounting for 69% of all the people infected by HIV worldwide. The UNAIDS (2012b:8) reports that since the start of the pandemic almost 70 million people have been infected by HIV and/or AIDS and about 35 million have died from it. At the end of 2011, it was estimated that about 34 million people were living with HIV (UNAIDS,

2012b:8). In sub-Saharan Africa it is estimated that nearly 1 in every 20 adults (4.9%) is living with HIV and this accounts for almost 69% of people living with HIV worldwide (UNAIDS, 2012b:8).

According to the World AIDS Day report by UNAIDS (2012a:7), South Africa has the highest number of people living with HIV in sub-Saharan Africa, estimated to be approximately 5.6 million people. It is also estimated that Nigeria has 3 million, Kenya and Tanzania has 1.6 million, Uganda and Mozambique has 1.4 million, Zimbabwe has 1.2 million and Zambia and Ethiopia have just under a million people living with HIV and/or AIDS, respectively (UNAIDS, 2012a:7).

In South, South-East and East Asia almost 5 million people are living with HIV and this is 25 times less than the HIV prevalence rate in sub-Saharan Africa (UNAIDS, 2012a:8). The regions most heavily affected after sub-Saharan Africa are the Caribbean, Eastern-Europe and Central Asia where 1% of all adults were infected by HIV in 2011 (UNAIDS, 2012a:8).

UNAIDS (2012b:8) in its annual report states that the numbers of newly infected people fell sharply between 2001 and 2011 to 2.5 million people which saw a 20% decrease from 2001. A sharp decrease in new infections was noted in the Caribbean (42%) and sub-Saharan Africa (25%) particularly South Africa (41%), the country with the highest HIV infection rate. The reasons for this decline are varied and open to some debate. For example, claims have been made that campaigns and strategies employed to change mind-sets and behaviours of “high-risk” groups have become effective, while other claims identify the introduction of the ARVs as the catalyst to reduced HIV prevalence.

However, an inverse trend was noted in Bangladesh, Indonesia, Philippines, Sri Lanka, Middle East and North Africa. In other words, the HIV infection rate increased over the same ten year period (UNAIDS, 2012b:10).

## **2.5 The Gendered Aspect of HIV and AIDS in Africa**

One of the biggest characteristics of HIV and/or AIDS is the distinct difference in infection rates between men and women. Women and young girls are twice as likely to contract the disease as males of the same age as they do not control safe sex practices (Isaksen et al., 2002:13). The higher rates of HIV contraction amongst females is not only explained by the biological differences in the risk of contracting the disease but also by cultural and social factors (Isaksen et al., 2002:13). The way most traditional African societies define what masculinity, femininity and sexuality are makes women more susceptible to contracting the virus (Isaksen et al., 2002:13).

According to UNAIDS (2000) as cited in Isaksen et al., (2002:13), in most parts of Africa girls tend to have their first sexual encounters with older, more sexually active men who are more likely to have been exposed to HIV, while young men at the same stage of their sexual life generally do not have sexual relationships with more heavily infected age groups. Thus, such socio-sexual patterns may partially explain significant differences in the rates of infection between young boys and girls. Young women engage in sexual relations with older men for social and economic reasons while older men get involved with young women, which may inadvertently reduce their chances of HIV infection (Isaksen et al., 2002:14). In a study conducted in Dar es Salaam of 51 adolescent girls, it was found that the vast majority of the girls were involved with men

twice their age with half the girls admitting that their partners were already married (Silberschmidt and Rasch, 2001:1816).

This study shows that the phenomenon of 'sugar-daddies', that is, older men who seek sexual relationships in return for financial gains with young girls (Machel, 2001:86), has increasingly become popular, with younger 'safer' girls. These girls are thought to be too young to contract the virus and they become sexually involved with older men who are perceived as being more knowledgeable about sex and HIV, with promises of financial security in return (Silberschmidt and Rasch, 2001:1816).

Women are undoubtedly the worst affected by the HIV and/or AIDS epidemic in Africa, and this is a result of the unequal responsibility and access to resources within the household (Isaksen et al., 2002:14). The Tanzanian Poverty Reduction Strategy Paper (2001b) cited in Isaksen et al., (2002:14) acknowledges that there is a gender bias in the control of household resources and this suggests that women are placed at a significant disadvantage within their own homes, let alone in society, making the situation for women very difficult (Isaksen et al., 2002:14). Isaksen et al., (2002:14) suggest that high levels of female illiteracy, little or no economic independence from the household, as well as weak attachments to labour markets - other than informal markets – are factors that contribute to the burden experienced by women. As a result, women may become involved in high risk sexual commercial activity (sex work) because their social and economic conditions offer few alternatives (Isaksen et al., 2002:14).

Women who are not sexually active for commercial purposes are also exposed to the virus. This is because social and cultural norms are more lenient on men, allowing them

to have multiple sexual partners and, in some cultures, multiple wives (polygamy) (Herdt, 1997:10). Labour migration also increases the risk of men – who are frequently the household breadwinners – returning to their homes infected by HIV and spreading the disease to their spouses. (Isaksen et al., 2002:14). Thus, women in Africa are more vulnerable to contracting the disease due to numerous socio-economic imbalances that exist in African societies which are perpetuated by capitalism.

Furthermore, although it is well documented that women are more likely to be infected with HIV, so are men who have sex with other men. This group in urban areas is 13% more likely to contract HIV than the general population of that country (UNAIDS, 2012b:25). However, this is difficult to determine conclusively due to the lack of in-depth studies of this group. There is, however, empirical evidence that suggests a rise in the rates of HIV infection in south-east Asia, and to a large degree the rest of the world amongst men who have sex with other men (UNAIDS, 2012b:25). The biggest challenge amongst this group is the inconsistent use of condoms, with gay men in only 13 of the 96 countries surveyed, acknowledging that they used condoms 75% of the time (UNAIDS, 2012b:28).

Another challenge with this group of men is that in most countries, including South Africa, no studies have been conducted with regard to their rates of HIV infection. As a result, very little is known about their sexual practices (UNAIDS, 2012b:28). It is made more difficult for men having sex with men when their sexual orientation is criminalised by governments, for example in Zimbabwe and Uganda. This may leave them with no choice but to conduct their sexual activities in hiding for fear of victimisation, which in turn may lead to low rates of HIV testing and counselling. Another issue related to

gender is that only 10% of countries engage men and boys in their national AIDS response programmes. Most of the resources and programmes are directed at women and girls (UNAIDS, 2012b:71). The section below will explore in some detail some of the programmes that have been implemented at global and national levels in an attempt to curb the spread of HIV and/or AIDS.

## **2.6 Global and National Legislation and Policies on HIV and AIDS**

### **2.6.1 Millennium Development Goals (MDG's - Global)**

Political willingness as well as policy has been crucial in the fight against HIV. HIV and/or AIDS policy is shaped by governments whose policies then translate to national, regional and global programmes that are put in place to curb the spread of HIV as well as treat and care for people living with HIV.

Since the 1990's the United Nations has focused on international development goals and targets which were to be universalised so as to achieve harmony, equality and better lives for all the citizens of the world (Annan, 2006:1). These goals were known as International Development Targets (Annan, 2006:1) and at the turn of the century, in September 2000 at the United Nations, 189 member states unanimously agreed to adopt the Millennium Declaration (Fay et al., 2003:1).

According to Binagwaho and Sachs (2005:1), the Millennium Declaration, also referred to and commonly known as the Millennium Development Goals (MDG's), is "the world's time-bound and quantified targets for addressing extreme poverty in its many dimensions – income poverty, hunger, disease, lack of adequate shelter, and exclusion – while promoting gender equality, education and environmental sustainability". There

are 8 broad goals, with 15 targets which are to be monitored through a set of 48 indicators, and the aim is to achieve these goals by the year 2015 (Fay et al., 2003:1).

The Millennium Development Goals according to Binagwaho and Sachs (2005:xviii) are to:

1. Eradicate extreme poverty
2. Achieve universal primary education
3. Promote gender equality and empower women
4. Reduce child mortality
5. Improve maternal health
6. Combat HIV and AIDS, Malaria and other diseases
7. Ensure environmental sustainability
8. Develop a global partnership for development.

The goal that relates to and is relevant to this study is goal number 6 – Combat HIV and AIDS, Malaria and other diseases. This goal has 2 targets which are, firstly, to have halted and begun to reverse the spread of HIV and/or AIDS by 2015. Secondly, to have halted and begun reversing the incidence of malaria and other major diseases by 2015 (Binagwaho and Sachs, 2005:xviii). To achieve these MDGs national governments in partnership with their neighbours at a regional level needed to come up with policies and plans of implementation by 2006 in order to achieve the targets set for 2015 (Binagwaho and Sachs, 2005:3). However, the United Nations places greater emphasis on national governments planning and implementing policies so that these governments

may be held accountable in the event of failure as it will be hard to hold regional partnerships accountable (Binagwaho and Sachs, 2005:3).

Therefore, South Africa as a member of the United Nations, committed itself to fighting HIV and AIDS. The South African government acknowledged the challenge of HIV and as a result put together a national policy and plan to combat the spread of HIV. This plan is implemented and run primarily by the Department of Health in collaboration with other departments and civil society organisations. The plan is known as the Negotiated Service Delivery Agreement (NSDA) and includes VCT and the roll-out of free ARV treatment to all the people living with HIV and/or AIDS. With these policy documents targets in mind, this study's primary aim is to better understand men and their sexual behaviours and experiences which put them at high risk of contracting HIV and to better understand men's health practices after contraction of the virus - such as treatment and condom use which is significantly linked to HIV mortality. Such understanding, however, necessitates the conceptualisation of "masculinity" and in the next section a discussion of masculinity theory attempts to shed light on this important concept.

## **2.7 Masculinity and Hegemonic Masculinity Theory**

Definitions of the masculinity concept are given in Chapter 1 of this dissertation and will be used as points of departure in relation to the findings of the study. Masculinity concepts are intimately tied to the way an ill person experiences and understands their illness and this is because gender is culturally constructed. In the book *Masculinities*, Connell (2005) explores masculinity and demonstrates the way it is carried out in everyday life through sets of actions, behaviours, and in the relationships between men and between men and women.

Connell (2005) incorporates essentialist/biological explanations of masculinity with theories of social constructivism that view masculinity as fundamentally a cultural product. Two opposing notions of the body have dominated discussion of this issue in recent decades. The first notion simply interprets the dominant ideology into language of biological science, where the body is viewed as a natural machine, which produces gender difference through genetic programming, hormonal difference, or the different role of the sexes in reproduction. In the second notion, which has greatly influenced the humanities and social sciences, the body is more or less a neutral surface or backdrop on which social symbolism is imprinted (Connell, 2005:45).

While Connell presents both perspectives of masculinity, she adopts a framework more aligned to the latter, one that views masculinity and the body as socially defined. To understand how masculinity is enacted in everyday life, Connell (2005:76) argues that “to understand gender, then, we must constantly go beyond gender. The same applies in reverse. We cannot understand class, race, or global inequality without constantly moving towards gender”. Therefore, according to Connell, an intersectional analysis is crucial in order to fully uncover the entangled relationship between social factors and relations at both micro- and macro-levels.

Connell (2005:77) uses the term “hegemonic masculinity”, derived from Antonio Gramsci’s analysis of class relations where the word “hegemony” refers to the “cultural dynamic by which a group claims and sustains a leading position in social life”.

Connell (2005) then uses the concept of “hegemonic masculinity” in her studies of gender to demonstrate how this concept is taken to legitimise patriarchy and guarantee the dominant position of men and the subordination of women. Connell (2005:82) expresses how the behaviours men adopt in their relationships with other men and with women play into the hands of “patriarchal dividend” which enables them to gain “honour, prestige and the right to command”.

While both of Connell’s books on masculinity have largely contributed to the fields of gender and masculinity studies, sociologist Anthony Synnott in his book, *Re-thinking men: Heroes, villains and victims* (2009), argues that Connell’s pro-feminist position views all men as similar and homogenous in nature and presents them as power-hungry villains. Although patriarchy is deeply entrenched in the social structures and institutions of societies in the West, Connell’s analysis as Synnott (2009) demonstrates, presents men as beings void of emotions and feelings, whose sole purpose is to subordinate and subjugate women for their own personal gain.

However, Connell and Messerschmidt in their work titled, *Hegemonic Masculinity: Rethinking the concept* (2005), outline how hegemonic masculinity might only apply to a minority of men but represents the most honoured and exalted way of being a man. In particular, they explore how masculinity is not a fixed entity embedded in the body but rather, configurations of practices that are accomplished in social action and that can differ depending on the social context (Connell and Messerschmidt, 2005). In other words, they argue that masculinity is culture-dependant. The authors also explore the

ways that the concept of hegemonic masculinity has been criticized. They believe it is framed within a hetero-normative understanding of gender that ignores difference and exclusion within gender categories. Similar to Connell's book *Masculinities* (2005), the authors illustrate the way that masculinities and identities are contextually dependent and therefore, there exist many different conceptions of masculinity.

The importance of masculine embodiment for identity and behaviour emerges in many contexts. Bodies participate in social action by outlined courses of social conduct - the body is a participant in generating social practice. It is important to note and understand masculinities as not only being embodied, but also by addressing the interlinking of embodiment and social context (Connell and Messerschmidt, 2005:851). In other words, in order to understand the way that masculinity is embodied by men, it is important to see it as a notion that is not fixed, but rather, constantly redefined by cultural and social context through the relationships men have with other men and women. Thus, masculinity constructs evolve over time.

While Connell and Messerschmidt's (2005) article on hegemonic masculinity is useful because it highlights the flaws of the concept of hegemonic masculinity and how it is often framed within mixed norms of gender relations, the authors still appear to make generalisations that do not apply to all men. In particular, it seems that Connell and Messerschmidt (2005) both fail to address men's lived experiences and the struggles they endure in order to uphold what is deemed socially acceptable "masculine behaviour". Therefore, they argue that masculinity is culturally constructed. However,

they do not provide any examples of how it is played out in everyday life nor do they acknowledge or identify how masculinity can change over time.

Furthermore, Connell and Messerschmidt (2005) seem to present men as being on a pre-determined quest to subordinate women. In doing so, they rely too heavily on a macro-scale approach that does not consider the lived experience of masculinity. My research will focus on men living with HIV and/or AIDS in Buffalo City Municipality but the data I collect about the intersection of masculinity, illness, and manhood is not representative of all men. It is rather a set of narratives based on individual experience that will demonstrate pluralised masculinities and the heterogeneous character of men's lives. Petersen (2009:205) believes men's masculinities are pluralised and heterogeneous, and are "differentiated according to class, ethnicity, age, sexuality, and place of residence". Therefore, masculinity cannot be understood as a one-size-fits-all model. It is neither singular nor homogenous, but is rather heterogeneous and diverse. Hence, it is crucial to understand that men's experiences of living with HIV and/or AIDS will be different from individual to individual.

## **2.8 Is masculinity in crisis?**

It is often stated that masculinity is going through a crisis. Edwards (2006:2) argues that over the past four decades or so the critical studies of masculinity have changed highlighting this crisis. Edwards (2006:2) puts forth a three-phase or 'wave' model of critical studies of masculinity. The first wave, the sex role paradigm developed in the 1970's applied primarily to direct questions of masculinity and covered issues around

sexual roles, the socialisation of masculinity as well as the dangers men faced regarding their psychological and physical well-being (Edwards, 2006:2).

Immense criticism of the first wave by pro-feminist authors, who felt that it politically implied that there was some level of equality between the sexes, instigated the birth of the second wave in the 1980's (Edwards, 2006:2). The sex role theory brought to light the hegemonic masculinity (Connell, 1987) which was viewed as dominant and oppressive towards more "subordinate" men who at the time were largely black, working class and gay. (Edwards, 2006:2). Consequently, the second wave of the critical studies of masculinity is centred on power, and its complex and multifaceted connotations and implications about society (Edwards, 2006:2).

The third wave of critical studies of masculinity is relatively more complex than the first two waves. It is not easily defined and is found across disciplines from media, cultural and fictional studies to even the social sciences (Edwards, 2006:3). It is influenced by post-structural theory – the study of objects, for example a text, and the systems of knowledge that influenced its production – with its common theme being representation (Edwards, 2006:3). Change and continuity are factors which influence historical and contemporary masculinities and identities discourse (Edwards, 2006:3).

Therefore, as highlighted above, masculinity discourse and conceptions have evolved over time. Masculinity studies were first shaped around men's sexual prowess, and later turned to men and the power/influence they yielded in society. However, in contemporary masculinity studies, masculinity cannot be aligned to one aspect or factor of society. It is rather inter-twined in all aspects of social life as will be shown by the

narratives of the participants. Thus, as our understanding of masculinity discourse has changed with time, so too should the social constructs and ideals of masculinity, especially regarding men and their sexuality. Because of the need to uphold the social constructs of masculinity, men are placed at great risk of contracting and dying of HIV and/or AIDS.

## **2.9 Social factors that influence masculinity constructs**

### **2.9.1 Masculinity and Sexuality**

Because HIV is largely spread through sexual contact, it is important to analyse what part masculinity and male sexuality plays in the spread of HIV. Masculinity is socially and culturally constructed and as a result extra pressure is put on boys and men to be knowledgeable and experienced when it comes to sex (Mane and Aggleton, 2001:25). Because of the need to appear more knowledgeable, boys and men do not seek information about sex or condoms and this puts them at greater risk of contracting the virus (Rao Gupta, 2000:3).

Gender socialisation leads men to believe that multiple sexual partners from the age of adolescence will bring about experience and knowledge (Rao Gupta, 2000:3). This behaviour is reinforced by socially constructed terms which are used to describe promiscuous men such as 'player', 'Casanova', 'stud', and 'Don Juan' (Smiler, 2012). These terms act as positive reinforcement and seem to applaud men for risky sexual behaviour.

### **2.9.2 Masculinity, Homosexuality and HIV/AIDS**

Gay men are viewed as adhering to the constructs of subordinate masculinities which in a power hierarchy rank below the dominant hegemonic masculinity (O'Neil and Hird,

2001:211). O'Neil and Hird (2001:211) imply that heterosexual men, in terms of structural power, view gay men at "best as having conditional power and at worst, non-existent". This means that hegemonic masculinity does not recognise subordinate masculinities as possessing any socially structured power.

Connell (2000,123) suggests that HIV and/or AIDS is one of the best things that happened to the gay community as the gay movement was taking shape in the late 1970s into the 1980s. Connell, through studies of gay men, found that these men became 'defensive' and viewed HIV as a positive reason for single-partner relationships, settling down, and cohabitation in order to reduce sexually risky behaviours (2000:123). This was encouraging and a positive step within the gay community in the fight against HIV and/or AIDS in the 1980s as gay men then became activists for safer sex, prevention, and carers for those who were infected (Connell, 2000:124).

Connell (2000:125) believes this began what she termed "informal bare-foot HIV/AIDS educators" who took pride in their sexuality as well as in their education and then sharing of knowledge around HIV and/or AIDS with others. Connell (2000:126) believed that through these bare-foot educators HIV and/or AIDS prevention and education could reach working-class gay men as it has done with affluent gay men and thus start a process of collective empowerment. However, over time, studies regarding the gay community and HIV and/or AIDS have fallen short with only 22 sub-Saharan African countries reporting on this cohort in 2012 (UNAIDS, 2012b:28). Another challenge is that very few countries acknowledge including this cohort in their national AIDS

strategies. As a result, it has become increasingly difficult to analyse and study the effects of HIV on the gay community, particularly in South Africa (UNAIDS, 2012b:28).

Furthermore, a study of mineworkers from Pondoland in the former Transkei (presently in the Eastern Cape Province of South Africa) by Moodie in the 1980s brought to light the inequality in structural power amongst men viewed as adhering to the ideals of hegemonic or subordinate masculinities (Moodie, 2001:297). These men lived and worked on the mines and were away from their wives and families for long periods of time and, as a result, resorted to having sex with other men in order to satisfy their sexual desires (Moodie, 2001:303). Young men in the mining compounds would become 'wives' of more senior, experienced miners (boss boys), providing them with both domestic and sexual services in exchange for money or protection. Some young men reportedly had multiple lovers and condom use was left to the discretion of the senior men (Moodie, 2001:303).

The young men did this for money which would enable them to become "full men more rapidly back home" by being able to pay *lobola* (bride price) or to build a homestead in their villages (Moodie, 2001:306). When the young men grew older and more experienced on the mine they would then call for a 'divorce' and in turn become a 'boss boy' and find their own 'wives' (Moodie, 2001:305). Thus, the system made young men take on subordinate masculinities on the mine, in order to take up hegemonic masculinities back home (Moodie, 2001:306).

In the study above, heterosexual men are willing to engage in sex with other males because of the unavailability of women, for money as well as for security. Thus, men

who have sex with other men are similar to women, in that they are at the “mercy” of men who adhere to the constructs of hegemonic masculinity when it comes to their sexuality and contracting of HIV. Because the men who adhere to the constructs of hegemonic masculinity possess more power in the sexual relationship, they are able to determine unsafe or safe sex practices as found by Moodie (2001). In the event that the men cannot assert their dominance through sex, violence is used as an alternative.

### **2.9.3 Masculinity, gender-based Violence and HIV and AIDS**

Gender-based violence is sexual, physical or emotional abuse perpetrated against an individual (mostly women) based on their gender which causes physical or psychological harm and humiliation and which perpetuates the subordination of women (Heise et al., 2002:6). Gender-based violence involves a number of different violations directed at women or girls such as wife abuse, sexual assault, forced prostitution, dowry-related murder, marital rape, female genital mutilation, corrective rape, as well as sexual abuse of female children (Heise et al., 2002:6). In a study conducted in Swaziland and Tanzania, one in three girls between 13 and 24 years of age reported experiencing at least one incident of sexual abuse before the age of 18 (UNAIDS, 2012b:74). According to UNAIDS (2012b:74) gender-based violence, in addition to violating women’s human rights, is both a cause and effect of HIV transmission.

In South Africa in 2003 a young woman aged 21, Lorna Mlosana, was gang raped by 5 men in Khayelitsha, a township in Cape Town (The Guardian, 2003). It was reported that after these men had finished taking turns raping her, Lorna then told them she was HIV positive and the men then killed her (The Guardian, 2003). Another such incident is a story of “corrective rape”. Lungile Dladla, a lesbian from Johannesburg, was raped by

a man in 2010 and later contracted HIV from the rape incident (SABC, 2013). She was raped for simply being a lesbian and being attracted to people of the same sex. “Corrective rape” or “curative rape” is rape perpetrated against lesbians in the belief that they can be “cured” or “corrected” of their same sex attraction (SABC, 2013). According to the SABC (2013) in a study conducted by the Human Sciences Research Council (HSRC) of South Africa and Columbia University, of the 500 lesbians sampled across four southern African countries around 10% of them were found to be HIV positive. Heise et al., (2002:6) in a 15 country qualitative study of women’s HIV-risk, found that women related profoundly troubling experiences of forced sex within marriage. Respondents frequently reported being physically assaulted to have sex and/or to engage in a sexual activity that they found degrading or humiliating.

The high risk of HIV transmission for women can be understood better when relating it to a study by Decker et al., (2009) of 20 425 husband and wife-dyads which provided both intimate partner violence (IPV) data and HIV test results. The study found that one third (37.4%) of the women experienced IPV, 0.4% of the husbands and 0.2% of the wives were HIV infected. Compared with non-abusive husbands, abusive husbands demonstrated increased odds of HIV infection outside the marital relationship (Decker et al., 2009). The study also found that those men who committed IPV were more likely to engage in risky sexual behaviours such as multiple partners, no condom use, and sex with commercial workers (Decker et al., 2009).

These studies, and numerous others (Dunkle et al., 2004; Silverman et al., 2007), show the extent to which violence against women is being perpetrated. They also show how susceptible women and men – rapists and promiscuous men - are to the virus.

Although, issues related to gender-based violence are not reported in the findings of this paper, it is important to note that they are related to constructs of hegemonic masculinity and, therefore, there is a need to further understand these violent behaviours of men. In some cases men's violent and abusive behaviour is aggravated by alcohol abuse.

#### **2.9.4 Masculinity, alcohol abuse and HIV and AIDS**

According to Kalichman et al., (2007:141) alcohol is the most commonly used psychoactive substance and alcohol use is amongst the most prevalent behaviours related to high risk HIV and STI infection. According to Weinhardt and Carey (2001) cited in Kalichman et al., (2007:141), research since the 1980's has repeatedly shown that there is a significant relationship between alcohol use and risky sexual behaviour among some populations, especially amongst those with the highest rates of HIV infection.

Two out of three people infected with HIV live in sub-Saharan Africa (UNAIDS, 2006, cited in Kalichman et al., 2007:141) and this coincides with the world's greatest HIV and AIDS burden, because southern Africa also consumes one of the greatest quantities of alcohol per region in the world (Kalichman et al., 2007:141). For example, in South Africa, individuals who drink consume an average of 20 litres of alcohol per year, which represents one of the highest volumes per capita of alcohol consumption in the world (Parry, 2005, cited in Kalichman et al., 2007:141). According to Shisana et al., (2005) cited in Kalichman et al., (2007:141), 40% of southern African men and 15% of southern African women drink alcohol, with significant numbers drinking heavily and according to Kalichman et al., (2007:142), like elsewhere in the world alcohol use is

frequently associated with high-risk sexual behaviour in southern Africa, but unlike elsewhere in the world, the implications of alcohol use for risks of HIV infection are greatest in southern Africa because HIV prevalence rates are highest here.

Furthermore, Kalichman et al., (2007:145) draw attention to the fact that men are more likely to drink frequently than women, but women drink in greater quantities. Kalichman et al., (2007:145) go on to highlight that gender differences in alcohol use illustrate one of several ways in which women's risks for HIV are attributable to men's behaviour because while under the influence of alcohol, men are less likely to use condoms during their sexual encounters.

Also, men are more likely to drink with women who are not their sexual partners, but women are more likely to drink with men who are their sexual partners (Kalichman et al., 2007:145). This highlights the potential risk of promiscuity amongst men who drink as they lose their inhibitions and tend to seek sexual interaction (Hoyle et al., 2000). All this places men who consume alcohol at a higher risk of HIV infection than men who do not consume alcohol. Furthermore, men who consume alcohol are more likely to use violence on their partners which then places women at risk of contracting HIV from their partners (Kalichman et al., 2007:146).

Therefore, alcohol use before sex is a characteristic of the constructs of hegemonic masculinity and is closely linked to the spread of HIV. This link may also be helpful in understanding men's behaviours when influenced by alcohol. Alcohol use may determine men's sexual behaviours and practices; if they feel the desire to have sex, if they use condoms or not after consuming alcohol.

### **2.9.5 Masculinity and Health**

It is well-documented that most men generally do not look after their health hence men's AIDS mortality rates are generally higher than women's across the world (Edwards, 2006:14). According to Lee and Owen (2002:4), men are reluctant to seek help for medical or psychological issues, avoid expressing or showing emotion; take part in aggressive and unsafe sexual behaviours and attitudes and are highly involved in risky behaviours such as crime and aggressive conflicts. Men with regard to HIV do not test as they perceive a positive diagnosis and treatment a challenge to their masculinity (Duck, 2009:285). Duck (2009:285) believes men "act on the premise that their ambivalence about going to a doctor protects them from any potential bad health news that could place restrictions on their sexuality".

Men often view their bodies as machines that are indispensable instead of viewing their bodies as mortal entities that need care and attention (Edwards, 2006:14). Charmaz (1995, cited in Courtenay, 2000:1389) found that in an effort to preserve their masculinities men with chronic illness often work diligently to hide their weakness/disability. They cited an example of a man with diabetes, unable to manoeuvre both his wheelchair and cafeteria tray, who would skip lunch and risk a coma rather than request assistance (Charmaz, 1995, cited in Courtenay, 2000:1389).

The lack of awareness about their health, coupled with societal and cultural pressures to fulfil gender stereotypes of promiscuity, and risky sexual practices place men at a higher risk of contracting HIV (Lee and Owen, 2002:43; Duck, 2009). African traditional masculinity, in its mildest form, encourages men to engage in predatory sexual

behaviours, binge drink, spend money recklessly and boast about sexual conquests (Lee and Owens, 2002:45).

Rao Gupta (2000:3) argues that because men feel they have to appear more knowledgeable about sex and sexual performance they tend not to seek information about the dangers of risky sexual behaviour. As a result, this places them at risk of being infected by HIV. After contracting the virus, many men do not test nor adhere to treatment regimes and neglect their health (UNAIDS, 2012b:71).

Therefore, social and cultural constructs of masculinity deter men from consistently caring for and looking after their health. In the event of illness, these constructs discourage men from seeking medical attention until it is absolutely necessary (Skovdal et al., 2011:11). HIV and AIDS are bodily states intimately connected to notions of health and illness. For this reason, the discussion below progresses to the topic of the body, illness and the dominant response to illness, bio-medicine.

## **2.10 The body, bio-medicine and illness**

### **2.10.1 The body and illness**

According to the Oxford Dictionary of Synonyms and Antonyms (2007:309) pain is defined as a feeling of “suffering, agony, torture, torment and discomfort”, while illness is defined as “poor health, disease, ailment, disorder, complaint, malady, affliction and infection” (2007:219). Therefore, pain and illness can be understood as any negative or distressful feeling the body experiences which results in the need to alleviate and end this experience, with pain closely associated with illness.

It is important to note and understand that HIV, AIDS and its treatment may at times cause great pain, discomfort and even illness to the body (van Dyk, 2012:118). Some of the illnesses and side-effects associated with HIV and its treatment include, but are not limited to, gastrointestinal and flu-like symptoms, headaches, dizziness, vivid dreams, rashes, hepatitis, kidney toxicity, pancreatitis and many more (van Dyk, 2012:118).

According to Williams and Bendelow (1998:159) “the body is rarely ever ‘present’ in everyday passive life, but comes ‘alive’ when we fall sick, feel pain or when our bodily images begin to deform, for example, through disability or chronic illness”. Suddenly the body becomes a “central aspect of experience” (Williams and Bendelow, 1998:159). Severe illness can make one want to “leave” one’s body and leave the illness behind as it becomes unbearable (Williams and Bendelow, 1998:159). The rationalizing of this illness thus divides the individual into the ‘I’, separated from the body, and this experience is known as psycho-physical dualism (Williams and Bendelow, 1998:159). The diseased body can be said to then take on a mind of its own against the self, which has goals to alleviate the suffering through two components – hermeneutical and pragmatic components (Williams and Bendelow, 1998:160).

The hermeneutical component is filled with pain, discomfort and suffering, which directs the body to seek “meaning, legitimacy and understanding” of this negative experience (Williams and Bendelow, 1998:160). While at the pragmatic level, the body aims to rid itself of the illness and if this is not possible, the body then tries to master the pain and suffering (Williams and Bendelow, 1998:160). This sees the body and the self, working together in order to find relief and rid the individual of the illness and suffering (Williams and Bendelow, 1998:160). However, in some cases the self fails to resolve the “issues”

with the body and this results in the individual being taken over by the illness, with the illness feeling like something inside them such as a demon or evil spirit (Williams and Bendelow, 1998:160). This increases the 'subjectification' of the individual by their illness (Williams and Bendelow, 1998:160).

People suffering from an illness such as HIV and/or AIDS, not only endure the physical effects of this illness but, they also suffer from the psycho-social effects which include isolation, loneliness, stigmatisation and dependency syndrome (Williams and Bendelow, 1998:161). According to Charmaz (1983) as cited in Williams and Bendelow (1998:161), one of the fundamental forms of suffering for those enduring chronic illness is the loss of self. This is because illness is an emotional experience but triggers severe cognitive and social responses (Williams and Bendelow, 1998:161). Simply stated, one may go 'mad' or 'lose one's head' because of severe illness.

Therefore, men suffering from a chronic illness such as HIV and/or AIDS will most likely experience similar feelings and emotions to those mentioned above. They most likely feel severe pain due to their illness and probably also feel that the illness has taken over their lives. These negative feelings could be severe and manifest in the form of depression, isolation and/or neglect caused by a loss of employment, stigma and/or discrimination by family or community members or from their perceptions of a positive HIV diagnosis which they most likely believe signals an imminent death. However, with HIV medicine becoming more readily available, sufferers now feel they have a chance of living a longer and more fulfilled life.

### **2.10.2 Bio-medicine and illness**

We are taught to perceive medicine as the source of healing for our illness, but Williams and Bendelow (1998:161) argue that medicine may in actual fact reinforce the split between the emotional and the physical dualism instead of healing it. This results from two factors. Firstly, when individuals seek the help of a medical professional they are taught to and begin to view and refer to their bodies and illness in sophisticated and complicated technical terms (Williams and Bendelow, 1998:161). As a result, the body and the disease are then viewed as concrete and material products by the bio-medical industry which prioritises 'disease' over 'illness' (Williams and Bendelow, 1998:161).

Secondly, medical treatment may in fact reinforce and increase the awareness of an individual's physical well-being which may end up with the individual increasing or altering his drug intake or dietary plans (Williams and Bendelow, 1998:161). Some of these treatment methods such as renal dialysis, chemotherapy, and ARVs may just be as expensive, time consuming and painful as the illness itself (Williams and Bendelow, 1998:162). In some cases the sufferer may become dependent on the treatment.

During illness it is "normal" for the body to seek restoration to its former place of good health and avoid mortality (Frank, 1995:85). This restoration of good health according to Frank (1995:85) is facilitated by the use of "an agency outside the body: medicine operating through either surgery or drug". Frank (1995:85) believes that the body is returned to functionality only through dependency on an agency (medicine) that is separate and distinct from the body. The idea of the sufferer becoming dependent on medicine is supported by de Swaan (1990:220, cited in Fox, 2012:82), who states that "illness is marked by increasing dependency". Therefore, it can be inferred that men

living with HIV and/or AIDS can become dependent on the medical treatment available to them such as ARV's. Therefore, an important question to ask would be: what does this dependency on medication/treatment do for the construction of these men's masculinity?

Consequently, Williams and Bendelow (1998:161) believe that "medicine is both a fountain of hope", which gives people the opportunity to heal and restore their good health as well as a "fountain of despair" which, when you consider the pain, suffering, dependency and medical expenses, may be an odious, tiresome, painful and long process. However, medicine does in some cases help bring relief by bringing the physical and emotional, as well as the body and society, together even if it's not to the previous optimal level (Williams and Bendelow, 1998:162).

In the event that bio-medicine does not bring the much needed relief, the sufferer can choose to surrender and give in to the illness. According to Charmaz (1995:272) surrendering means to "stop pushing bodily limits, to stop fighting the episode or the entire illness. The quest for control over illness ceases and the flow with the bodily experience increases". The sufferer no longer sees the self as being independent of the ill body but at this point acknowledges that they are one entity, and accepts that victory over the illness is no longer certain (Charmaz, 1995:272).

Surrendering is an internal, conscious process that the sufferer adopts which is different from being overtaken by the illness which is done without choice (Charmaz, 1995:272). When the sufferers surrender to illness, they lose hope, become passive, depressed, incapacitated, fearful, and they lose interest in living (Charmaz, 1995:273). Charmaz

(1995:273) believes that when a sufferer is very sick the only plausible action to take is to surrender to the illness as this brings unity to the diseased body. Charmaz (1995:273) states that surrendering is better as this can be equated to fighting “for” oneself, instead of fighting the illness and fighting “against” oneself. Thus, through surrender, the sufferers gain themselves and lose their bodies to the illness, which according to Charmaz (1995:273) “leads to a deeper awareness of self, situation, time and place with others”.

HIV and/or AIDS is an incurable disease which greatly affects the bodies of those living with it. Hence, as the illness worsens and becomes unbearable, it would not be surprising to find men living with this chronic illness surrendering and losing hope because of the perceived inevitable loss of life that is to follow. In the event that the ARV treatment does not bring relief or restore the men to their previous healthy status, they may find themselves giving up and surrendering to the illness as suggested by Charmaz (1995). However, if the treatment seems to work and improve their health, the men may become dependent on the treatment as a source of restoring good health. This may have significant implications on their masculinity constructs.

## **2.11 Culture, Gender and Illness**

### **2.11.1 Culture and Illness**

Cultural diversity has a significant impact on how individuals view, understand as well as respond to illness (Williams and Bendelow, 1998:164). Reactions to illness take place within different social and cultural contexts and, as a result, responses differ from sufferer to sufferer, with some sufferers voluntarily seeking methods to relieve their illness. However, some contexts may not allow a sufferer to seek relief or may

rationalise or normalise the illness (Williams and Bendelow, 1998:165). Helman (1990) cited in Williams and Bendelow (1998:165) believes that expressing illness or keeping it hidden is primarily dependent on the context, beliefs and values of the social and cultural group of which the sufferer is a part.

In other words, one's ability to express illness or feelings related to an illness is culture-dependent. It depends on how the individual's cultural group expresses, views, understands and accepts illness and the expression of illness. If illness and/or the expression of illness is shunned within a cultural group, individuals may be forced to hide their ill-health for fear of being negatively judged by their cultural group. But, if a cultural group accepts and acknowledges the expression of ill-health individuals are more likely to express their ill-health and gain sympathy and support from their cultural group. In the same way that the expression of illness is culture-dependent, it is also gender-dependent.

### **2.11.2 Gender and Illness**

Gender also plays a key role in how men and women experience and respond to illness. According to Williams and Bendelow (1998:166) men react differently to illness when compared with women. Men, as a rule, tend to suppress and refuse to admit to and acknowledge illness because they fear that admitting to ill-health will result in a loss of their masculinity (Kaufman, 1994, cited in Courtenay, 2000:1389). Charmaz (1995:268 cited in Courtenay, 2000:1389) argues that illness "can reduce a man's status in masculine hierarchies, shift his power relations with women, and raise his self-doubts about masculinity".

Morris (1991) cited in Williams and Bendelow (1998:166) argues that “since the advent of history women’s illness has been viewed using a patriarchal lens, set upon male power and dominance against female fragility, tenderness and weakness”. Bendelow (1993) cited in Williams and Bendelow (1998:167), in a study aimed at exploring the meaning and experience of illness, found that both men and women credited females with an ability to cope with illness lacking in men. Some of the reasons the respondents gave as to why women coped better with illness were that they experienced child birth, menstruation and child-rearing and they could not afford the luxury of giving in to the illness.

Therefore, there is need to realise that the body is indeed a complex and fragile entity which deals with illness in different ways. It is important to note that the response to illness is both gender-specific as well as context/culture-specific. Therefore, people react and deal with illness differently depending on their location, culture and gender. It is also essential to note the possible effects and impact of bio-medicine on the body when it comes to dealing with illness, particularly HIV and/or AIDS. Thus, the best way to understand the sickness people living with HIV and/or AIDS endure is through their narratives. That’s why this study utilises the collection of illness narratives from men living HIV and AIDS to better understand their experiences.

## **2.12 Illness narratives**

During the 18<sup>th</sup> century, before the advent of bio-medicine, at the height of doctor-patient relationships, the doctors placed great emphasis on the narratives of their patients, requesting information such as the patient’s “lifestyle, moral stance and broader environment” in order to give a diagnosis and treatment regimen (Bury,

2001:265). With the rise of bio-medicine, the emphasis on the patient's illness narrative and experiences has been greatly reduced as the study and treatment of disease has become more and more separated from the individual (Bury, 2001:266).

In order to avoid isolation, loneliness and despair, patients need to find meaning for their suffering (Williams and Bendelow, 1998:163). According to Williams and Bendelow (1998:163) "sufferers frequently report that it is fellow sufferers who can really understand their pain (i.e. audit their experience empathetically)". Therefore, if you do not suffer from a similar illness as a sufferer you will not fully understand what they are going through and experiencing. The best tools that can be utilized to better understand the suffering and pain are stories and narratives told by the sufferers themselves (Williams and Bendelow, 1998:164).

According to Frank (1995) cited in Williams and Bendelow (1998:164), the sufferer through story telling or narratives, can turn the negative illness into a meaningful and positive story. Through narratives, the sufferers can add shape and weight to their lived experiences, combining feelings, thoughts, emotions, social and bodily processes in a coherent manner that highlights continuity and change (a lived life) (Kleinmann, 1988, cited in Williams and Bendelow, 1998:161). Therefore, narratives are central to the way we view, analyse and understand illness and our lives (Williams and Bendelow, 1998:164). Chapter Three offers further discussion of illness narratives, but for the remainder of this chapter, discussion turns to two important issues relevant to any discussion of HIV and/or AIDS, namely socio-economic effects of living with HIV and/or AIDS, and stigmatisation.

## **2.13 The Socio-Economic effects of living with HIV and AIDS**

There are many social, economic, cultural and political factors around the world that seem to exacerbate the spread of HIV and AIDS. These factors are frequently inter-linked and are sometimes ingrained in societies. As such, it becomes difficult to recognize them as well as to do away with them. For the purpose of this research I will pay specific attention to poverty and its effects on HIV and/or AIDS, and how it is closely linked with gender constructs, particularly masculinity.

### **2.13.1 Poverty and HIV and AIDS**

It is believed there is a strong, but not simple causal relationship between poverty and the spread of HIV and/or AIDS (Whiteside, 2002). Stillwagon (2000) cited in Whiteside (2002:317) found that “HIV prevalence is highly correlated with falling calorie consumption, falling protein consumption, unequal distribution of income, and other variables conventionally associated with susceptibility to infectious diseases, however transmitted”. Whiteside (2002:318) goes further to highlight that all poverty conditions such as protein-energy malnutrition, iron-deficiency anaemia and vitamin-A deficiency decrease the body’s ability to fight off diseases.

HIV and/or AIDS has adverse effects on the socio-economic well-being of an individual and an entire household and these are often more severely felt by the women and children within a family (Taraphadar et al., 2011:251). Poorer households are the most likely to be severely affected because they have high dependency ratios – often having many children and a spouse who depend on the bread winner - with the bread winners often being the victims of HIV and/or AIDS (Isaksen et al., 2002:75). Poorer households are also most likely to see a reduction in income and resources as they care for the working family members and as their expenses increase due to medical bills and funeral

costs (Isaksen et al., 2002:75; Whiteside, 2002). As a result, the household may resort to a number of coping mechanisms which may include the selling of assets, as well as sending children out to work which in turn will affect the education of the children (Isaksen et al., 2002:75).

As well as making people vulnerable to the pandemic, poverty makes them more susceptible to contracting HIV (Isaksen et al., 2002:75). Whiteside (2002:317) suggests that the spread of HIV and/or AIDS is exacerbated by high levels of poverty, for example, commercial sex workers who are driven by poverty and the need to feed their families.

This pandemic also has severe consequences at community level with agricultural production and food supply levels dropping (Isaksen et al., 2002:75). A case study in Zimbabwe showed that agricultural production dropped by 40-60% for households which had lost a family member due to AIDS (Isaksen et al., 2002:77). The effects of HIV and/or AIDS are not confined to the agricultural sector, however. Across the economic board, higher rates of absenteeism from work due to illness or caring for ill family members results in a decrease in productivity (Isaksen et al., 2002:28). Also in some companies, healthier employees end up working longer hours to cover for their sick colleagues. This results in companies paying more for overtime as well as in these employees being overworked and exhausted (Isaksen et al., 2002:28).

The psychological stress of looking after ill family members, friends or colleagues, mourning the death of loved ones as well as living through the grieving period, also results in employees taking more time off work and therefore being less productive

which has a significant impact on the GDP of a country (Isaksen et al., 2002:28). In a study of the South African economy, it came to light that the country would lose 8% GDP per capita due to HIV and/or AIDS, with the decrease being attributed to a decline in total factor productivity and a shift in government funding due to more resources going towards healthcare (Isaksen et al., 2002:76).

An International Labour Organization (2000) study cited in Isaksen et al., (2002:26) forecast that the labour force by the year 2020 will be an estimated 10-22% smaller – about 11.5 million people fewer – than it would have been had HIV and/or AIDS not been a factor. With this reduction in the labour force, production levels will decline and healthcare funding will need to increase. This means that government would have to spend more on its citizens' healthcare needs from a very limited fiscus. All this will have knock-on effects on other industries and may also lead to an increase in taxes in order to sustain this kind of economic model.

The most severe psycho-social impact of HIV and/or AIDS is felt by women and children. The women care for their ill spouses, and, in the event of death, are often forced to marry a brother of the deceased as part of the inheritance customs in many African cultures (Foster and Williamson, 2000). This means that the children are often malnourished, orphaned, forced to live with relatives and in most cases receive poor to little education, due to either poverty or forced migration, as the deceased property is often grabbed by family members (Foster and Williamson, 2000)

Whiteside (2002) also highlights that although poverty is one of the biggest catalysts in the spread of HIV, an individual's sexual behaviour choices are also an important factor.

For example, a truck driver who drives long distances across countries may find himself engaging in sex with a commercial sex worker because he is away from his wife for long periods at a time, is bored, or may feel he needs some compensation for his dangerous and onerous job. His sexual behaviour is not led by poverty because he can afford to pay the sex worker, but is guided by his need to satisfy his sexual and/or emotional needs.

Research by Campbell (1997) supports Whiteside's argument above. In a study conducted on the sexual practices and levels of HIV in the South African gold mining area of Carletonville, it was found that the mineworkers were involved in risky sexual behaviours such as having multiple sexual partners, having sex with commercial sex workers as well as no condom use (Campbell, 1997). In this study the participants reiterated the 'pleasure' derived from unprotected sex and also that it was 'something that men needed' (Campbell, 1997). These men believed that sex was essential and that it was the most easily available form of recreation after a long and dangerous shift underground in the mine (Campbell, 1997). They also believed that sex played a key part in the regulation of a balanced supply of blood and sperm, and also that frequent sexual intercourse was essential for the maintenance of a man's good health. Effects of prolonged celibacy such as depression, short-temperedness, violence, inability to think clearly, recklessness and impulsive behaviour were stated (Campbell, 1997). Thus, Whiteside (2002) and Campbell (1997) show that although poverty is one of the accelerants of the spread of HIV, individual behaviour as well as relative economic prosperity can also be linked to the spread of HIV.

The issue of economic prosperity and the spread of HIV is evident in Botswana. According to Whiteside (2002:317) Botswana has the highest per capita income rate in Africa and also has one of the highest HIV infection rates. Whiteside (2002:317) suggests that rapid economic growth also carries negative consequences, such as deprivation, disease and death. Consequently, when a person has money they can afford to pay for sex as a way of satisfying their sexual desire if they need to. This increases their likelihood of contracting HIV.

This is supported by Youde (2001, cited in Whiteside, 2002:317) who argues that individuals become accustomed to the economic growth and cannot deal with the decay. Thus, it is evident that with both economic growth and decline there is the risk of an increase in the spread of HIV. However, with economic growth there is a better chance of coping with the disease because of the increase in resources (Whiteside, 2002:319).

## **2.14 The Stigma attached to HIV and AIDS**

One final issue that requires attention in any discussion on HIV and/or AIDS is that of stigmatisation. HIV and/or AIDS as a pandemic has brought about immense physical pain and suffering to those living with the virus and the people around them who are affected by this pandemic. However, it has also brought added pain to those infected because of social and psychological suffering in the form of stigmatisation and discrimination.

### **2.14.1 What is Stigma?**

It is difficult to find complete consensus concerning a definition as the term is used differently in different disciplines like psychology, sociology, anthropology, political

science and social geography (Link and Phelan, 2001:365). However, the most consistent and referred to definition is the one given by Goffman (1963) in his book *Stigma: Notes on the Management of Spoiled Identity*. Goffman (1963:3) as cited in Link and Phelan (2001:364) defines stigma as an “attribute that is deeply discrediting” and that reduces the bearer “from a whole and usual person to a tainted discounted one”. This definition was formulated long before the discovery of AIDS, from research with people who suffered from mental illness and possessed physical deformities, and those whose behaviour was classified as socially “abnormal” for example homosexuals and criminals (Parker and Aggleton, 2003:14).

Therefore, an alternative definition would be useful taking into account the presence of the AIDS pandemic. Cracker et al., (1998:505) cited in Link and Phelan (2001:365) note that “stigmatised individuals possess (or are believed to possess) some attribute, or characteristic, that conveys a social identity that is devalued in a particular social context”.

Irrespective of different definitions of stigma, what is clear is that it has negative connotations, can be viewed as a mark of disgrace and is closely linked to stereotyping and rejection (Link and Phelan, 2001:365). According to Link and Phelan (2001:375) stigma is dependent on power, be it social, cultural or political power. They believe that for stigma to be present some form of power relation is at play between the ‘labellers’ and the ‘labelled/stigmatised’. In this regard, those family members or community members who do not live with HIV perceive themselves as having the social power to stigmatise those living with HIV and/or AIDS. The issue of stigma is considered to be highly relevant to the HIV and AIDS pandemic.

Indeed, Parker and Aggleton (2003:13) cite the founding director of the World Health Organization's Global Programme on AIDS, Jonathan Mann, who spoke of three epidemics related to HIV and AIDS. The first related to the contraction of HIV – an epidemic which entered communities silently and about which people knew very little. It would take years to be detected and understood. The second, related to the progression from HIV to AIDS. This Mann (cited in Parker and Aggleton, 2003:13) argued would also take many years but would occur if the virus went undetected and untreated. The third was considered the most explosive by Mann. This epidemic Mann identifies as the economic, political, social and cultural responses to AIDS. He argues that this epidemic is characterised by very high levels of stigmatisation, discrimination and collective denial. Thus, he felt that the stigmatisation and discrimination which accompanied HIV and/or AIDS infection was an epidemic on its own and was central to the fight against HIV and/or AIDS just like the disease itself (Parker and Aggleton, 2003:13).

Stigmatisation is also largely perpetrated against those communities which are viewed as being greatly affected by HIV. These distinctions could be based on physical criteria such as skin colour, gender, (Parker et al., 2002, as cited in Skinner and Mfecane, 2005:159); sexual orientation, (Crewe, 1991, as cited in Skinner and Mfecane, 2005:159); and type of work such as sex work (Wojcicki and Malala, 2001, as cited in Skinner and Mfecane, 2005:159). Even geography could be used as a distinguishing characteristic, with entire continents, such as Africa, being stigmatised (van der Vliet, 1996, as cited in Skinner and Mfecane, 2005:159).

There is also a high risk of some groups of people suffering multiple stigmatisations especially those living with HIV and AIDS who are also seen as being different in other aspects by their communities (Skinner and Mfecane, 2005:159). For example, a black gay male who is living with HIV or a physically challenged black female living with HIV, or a mentally challenged young boy living with HIV are all likely to face multiple stigmatisations as a result of their differences from the norm. Each point of difference isolates them from a particular segment of their community (Skinner and Mfecane, 2005:159). Therefore, work against HIV-related stigmatisation should inter-link with other stigmatisations that people experience within their communities (Hospers and Blom, 1998, cited in Skinner and Mfecane, 2005:159).

HIV and/or AIDS stigma also has numerous consequences which could be avoided were de-stigmatisation to take place. Some of the consequences of this stigma are that it acts as a hindrance to early voluntary counselling and testing (VCT) and is a barrier to the effectiveness of prevention, treatment and care services (Kalichman and Simbayi, 2003). According to a study conducted by Kalichman and Simbayi (2003) of HIV testing attitudes, AIDS stigma and HIV counselling and testing in a black township in Cape Town, South Africa, individuals who had not been tested for HIV held significantly greater AIDS related stigmatic attitudes than those who had been tested. Those who had not been tested were significantly more likely to agree that people living with AIDS were dirty, should feel ashamed and should feel guilty (Kalichman and Simbayi, 2003; Genberg et al., 2009).

In addition, the stigma associated with a positive HIV diagnosis may weaken a man's masculine role performance (Duck, 2009, 303). A study by Skovdal et al., (2011) of men

and their behaviours with regard to healthcare in Zimbabwe, found that men diagnosed with HIV did not feel comfortable going to clinics and queuing for treatment and joining support groups as these environments were largely made up of women. It emerged that often the medical providers were women (nurses) and the men were too shy or embarrassed to be helped by women as this weakened their masculinity.

### **2.15 Conclusion**

This chapter has presented critical and relevant literature around the phenomenon of HIV and/or AIDS around the world and in South Africa. It has also highlighted the social and economic factors that continue to hinder attempts at curbing the spread of the HI virus. These factors are largely influenced by social and cultural constructs of masculinity.

A greater understanding, in particular of men's sexual health, needs to be sought because men tend to have higher mortality rates due to AIDS, lower HIV testing rates and poorer adherence to treatment compared with women. In addition, men find it harder to acknowledge and disclose illness because they believe doing so would weaken their masculinity constructs. However, this only weakens their chances of recovery and returning to optimum health.

This study utilises a narrative analysis approach to gain insight into the lives of men living with HIV and/or AIDS in the hope of understanding their experiences better and the way in which these experiences shape their masculinity with regard to the chronic illness they suffer.

In concluding, work still needs to be done if we are to meet the MDG's by 2015 and particularly a lot of work if men and their sexual behaviours are to be understood and interpreted so as to formulate programmes that may assist in behaviour change. As a result, this study aims to add to that body of knowledge of men's sexual behaviours, and life experiences of living with HIV while adhering to the guiding policies which are the Millennium Development Goals and the Negotiated Service Delivery Agreement. This study's findings may aid in the formulation of policies for men and their sexual behaviours as well as their experiences of living with HIV and/or AIDS. Together with other studies, this may mean that effective manuals for men's programmes will be able to be designed.

## **Chapter 3**

### **Research Methodology**

#### **3.1 Introduction**

This chapter provides details regarding the research design, methods of data collection, research instruments, population under study, sampling and sampling procedure, data collection process and ethical issues that were adopted and applied. With the intention of understanding and explaining the experiences of men living with HIV and AIDS, this study will make use of the masculinity theoretical framework explained in Chapter 2 in an attempt to elicit and analyse the illness narratives of the participants.

#### **3.2 Methodology**

According to Terre Blanche and Durrheim (2006:6), the term methodology “specifies how researchers may go about practically studying whatever they believe can be known”. Therefore, methodology can be understood as being the theory of the research methods, in terms of what, who and where the researcher decides to study. Methodology also includes theory of what or whom to include and exclude and the consequences of this on the research, ethical concerns as well as how to write up the findings of the research. Neuman (2011:163) states that these methods can either be qualitative or quantitative. Alternatively, they may be the triangulation of both qualitative and quantitative methods. This study adopted a qualitative methodology which meant that the data was collected by the researcher in written or spoken language, as opposed to the systematic empirical investigation of quantitative research which uses numeric data. According to Ritchie and Lewis (2003:3), qualitative research is defined as research “directed at providing an in-depth and interpreted understanding of the social

world of research participants by learning about their social and material circumstances, their experiences, perspectives and histories”. This method is useful in trying to understand the experiences of men living with HIV and/or AIDS.

In addition, qualitative research has many different data collection and data analysis methods. For the purpose of this research, a narrative approach was adopted. A narrative approach involves the study of a person and his/her experiences as told in the form of a story (Creswell, 1998). Day-Sclater (2004:115) suggests that narrative analysis is “a way of finding out how people frame, remember and report their experiences”, in this case, the experiences of men living with HIV and/or AIDS, as a “way of generating knowledge that disrupts old certainties and allows us to glimpse something of the complexities of human lives, selves and endeavours”.

The narrative approach is the best approach to use for this research design because through the use of language and story-telling, it offers the researcher the opportunity to better understand the emotions, thoughts and perceptions the narrator places on specific life events. Crossley (2000:136) states that an HIV-positive diagnosis can have devastating effects on the way an individual views ‘time’ and this may have a crucial “psychological and social impact affecting one’s sense of identity, self-concept and moral responsibility”. People usually take the issue of time and life for granted, a positive diagnosis may shake and disrupt all this and as a result throw the person’s well-being into sharp relief (Crossley, 2000:136). This means that the individual no longer takes the time they have left for granted because of the realisation that death is now inevitable due to the chronic illness from which they suffer. The biggest challenge for the person is rebuilding and re-ascribing meaning to their life.

This is made possible through the cathartic process of story-telling or narrating which makes it possible for the person to make sense of their experience (Crossley, 2000:135). Because Crossley's method of narrative analysis allows individuals to project into the future, it provides them with a sense of basic security as it encourages the belief that events and actions can be influenced and controlled by the individual (Crossley, 2000:136). This belief encourages individuals to look forward to the future with hope and optimism, and not to view the future with pessimism as an inevitably dark and miserable time. Another benefit of Crossley's (2000) narrative method is that it utilises narratively sequenced interview questions which allow for participants' internal and social world to be entered into as similarly as possible across participants.

### **3.3 Research Design**

According to Durrheim (2006:34), "research design is a strategic framework for action that serves as a bridge between research questions and the execution or implementation of the research". The descriptive research design of this study was formulated in order to meet the objectives and to fulfil the aims of eliciting, analysing and understanding the narratives of men's experiences of living with HIV and/or AIDS.

The principal aim of the study was to elicit, explore and describe in detail the narratives of men living with HIV and/or AIDS. Therefore, the research design translates into the systematic framework for action because it is guided by concrete research questions from which coherent and plausible conclusions will be drawn through systematic observation of the data collected (Durrheim, 2006:34). The intended description of the lived experiences of men living with HIV and/or AIDS was aided by the use of a semi-structured interview questionnaire (see Appendix A).

### **3.4 Method of Data Collection**

This section of the study explains the procedures and or processes that were adopted in collecting data. It looks at the population under study, the unit of analysis, the sample size, the sampling procedure, and the research instruments.

#### **3.4.1 Population under Study**

The population under study is the entire group from which the researcher draws samples (Neuman, 2011:246). The researcher drew a sample of 8 participants from a population of an estimated 76 000 men living with HIV and/or AIDS in the municipality (StatsSA, 2013:7). The criteria used for participants' involvement in the study were that they resided within Buffalo City Municipality in the Eastern Cape Province of South Africa, were male, of any economic class, racial group and/or cultural group, and of any sexual orientation (heterosexual or homosexual).

### **3.5 Sampling and Sampling Procedure**

#### **3.5.1 Sample Selection**

The study made use of non-probability sampling in selecting its participants. According to Durrheim and Painter (2006:139), non-probability sampling refers to “any kind of sampling where the selection of elements is not determined by the statistical principle of randomness”. In other words, this sampling technique does not afford all the individuals in the population a chance to be sampled. Thus, only certain men living with HIV and/or AIDS were sampled.

Convenience sampling and snowball sampling techniques explained below were utilised (Elam, Ritchie, & Lewis, 1997). Convenience sampling lacks a clear strategy and is used because of the ease of access of the participants to the researcher (Elam, Ritchie, & Lewis, 1997). In other words, participants were selected because they were easily

accessible to the researcher, which resulted in lower costs and less time spent trying to access the participants. Snowball sampling is a technique for developing a research sample where existing study participants recruit future participants from their acquaintances or friends until the desired sample size is reached (Salganik & Heckathorn, 2004:196).

I was able to use databases and networks of organisations that work with people living with HIV and/or AIDS to access the participants. I had established working relationships with some of the organisations during the time I worked for a local non-governmental organisation prior to this study. I contacted the directors of these organisations which included the Samaritan Care Centre, Empilisweni Masimanyane AIDS Education and Training Centre and AGAPE. All of them either house or treat men living with HIV around the Buffalo City Municipality region. I asked the directors and care workers to set up a meeting with me in order for me to explain to them the details of the research as well as what I would require of them to assist me. After meetings with the directors, permission was granted. Following this, I requested their organisation set up interviews with participants. This was done efficiently and the times and venues of the interviews were communicated to me.

Most of the interviews were held at the different organisations' offices. Only one interview took place at the participant's residential home as he was too sick to meet me at the organisation's offices. Consent for this to happen had been granted by the participant. I was able to find more participants from the organisations I had used as entry points into the communities as they made use of their existing links within these communities.

Thus, convenience sampling was employed in that I simply went to organisations with which I had established a working relationship. This made it convenient and time saving for the researcher. In terms of snowball sampling, I also utilised this method in that some of the participants as well as organisations referred me to other people who could assist me in gathering the relevant data. This, in turn, was cost effective and time saving.

### **3.5.2 Sample Size or Unit of Analysis**

A sample can be defined as a smaller selection of the total population from which investigations will be conducted (Neuman, 2011:240). The sample size or unit of analysis is the focus point of investigation (Neuman, 2011:263). The sample size's attributes and characteristics or the actual number from each category of participants that will be included in the research, validate the study (Neuman, 2011:263).

This study sampled and interviewed 8 men living with HIV and/or AIDS. This sample size was considered appropriate during the research as it became clear that including new participants would not add new knowledge. The aim of the study was to explore and seek greater understanding of men's life experiences of living with HIV and/or AIDS, and the effect the illness had on these men's masculinity constructs. Therefore, it was not deemed appropriate to have a large sample size as the researcher did not seek to generalise findings to the total population. Marshall (1996:523) supports the idea of small samples. He argues that qualitative researchers tend to focus on large samples and fail to realize the usefulness and effectiveness of small samples. Marshall (1996:523) states that "an appropriate sample size for a qualitative study is one that adequately answers the research question". Thus, the number of participants ought to

increase only when the study progresses but with no new themes, categories and points emerging as the study reaches its saturation point (Marshall, 1996:523). In other words, small samples are useful and relevant for as long as they fulfill the research objectives and answer the research questions.

Paton (1990) cited in Coyne (1997:627) also supports the idea of small samples, arguing that the focus of qualitative research is largely in-depth using small samples, sometimes using even one case/participant who is selected purposefully. Crouch and McKenzie (2006:492) even go as far as referring to a small sample size as “beautiful” because the labour employed in the modelling of the project is an integral part of the research and thus “deepens understanding and builds breadth into the investigation through mindfulness of other work in the field”.

So, as argued above, even a small sample can bring about new insight into phenomena and experiences (Frank, 1995, cited in Crouch and McKenzie, 2006:493). Indeed, Crouch and McKenzie (2006:496) argue that small samples are the best way to conduct inductive, analytic, and explorative studies. However, Crouch and McKenzie (2006:496) also acknowledge that explorative research should not be allowed to be “stand-alone acts”. Small sample research should be pursued with the sharing of information and findings amongst researchers, and follow-up studies are needed. This may lead to good work which will enrich and liven up the discipline as well as the methodology of small samples (Crouch and McKenzie, 2006:496).

### 3.6 Participants

Pseudonym	Age	Sex	Sexual Orientation	Race	No of years living with HIV/AIDS
1. Mike	56	Male	Heterosexual	White	16
2. Thabo	37	Male	Heterosexual	Black	8
3. Sipho	59	Male	Heterosexual	Black	19
4. Phillip	28	Male	Homosexual	Coloured	1 yr 10mnth
5. Vuyo	45	Male	Heterosexual	Black	17
6. Roger	54	Male	Heterosexual	Coloured	8
7. Thando	35	Male	Heterosexual	Black	9
8. Zweli	47	Male	Heterosexual	Black	8

As indicated in the chart above, 8 participants were interviewed from a population of about 76 000 men living with HIV and/or AIDS in the Buffalo City Metropolitan Municipality. The participants were all males, 7 out of the 8 were heterosexual and only one participant, Phillip, was homosexual. The oldest participant was Sipho who was 59 years old at the time of the interviews and the youngest participant was Phillip who was 28 years old at the time of the interview. The average age of the participants was 45 years old.

One participant, Mike, was white, two participants, Phillip and Roger, were coloured and the remaining five participants were black. Sipho had been living with HIV for the

longest period. He had been living with HIV for 19 years and Phillip had recently contracted HIV, and had been living with the virus for nearly 2 years.

### **3.7 Data Collection**

Data was collected through the use of in-depth interviews. This research method was utilised because of its applicability and usefulness in investigating small samples. It is also useful in gathering 'rich' data.

#### **3.7.1 In-depth Interviews**

The study utilised in-depth, semi-structured interviews for individual participants. According to Kvale and Brinkmann (2009:27), semi-structured interviews attempt "to understand themes of the lived everyday world from the subjects' own perspective".

Kvale and Brinkmann (2009:130) define semi-structured interviews as "an interview guide" and the "guide will include an outline of topics to be covered, with suggested questions". Semi-structured interviews are guided by questions focused on certain themes which may include suggested questions from the participant's responses (Kvale and Brinkmann, 2009:27).

The interviews were scheduled in advance, at a designated time and suitable environment outside of everyday life (that is away from their homes, work places or neighbourhoods). The interviews were organised around an area of particular interest which focused on the everyday experiences of men living with HIV and/or AIDS (Dicicco-Bloom and Crabtree, 2006:315). The interviews were also centred on a set of open-ended questions with other questions arising from the responses given by the participants (Dicicco-Bloom and Crabtree, 2006:315).

The semi-structured interview format was particularly useful to this study because it encouraged the participants to respond freely and enabled the researcher to explore issues at greater depth. The process of collecting information using this method involved presenting the participant with a warm and welcoming environment that was comfortable (Kelly, 2006:301). This was achieved through formal introductions as well as offering the participants refreshments such as tea and coffee.

The use of semi-structured interviews also enabled the participants to develop interest and bring in other emergent but relevant issues the researcher did not know (Greeff, 2011:343). Proper attention was given by the researcher to avoid boredom, repetition and to keep the interview focussed.

The participants were given the chance to do 90% of the talking, with the researcher asking brief open-ended questions using as easy-to-understand English as was possible. The researcher also began with general/broad questions leading to specific/narrow questions. For example, the interviews began with the researcher asking general questions about the participant's name, place of residence, marital status and gradually shifted to more specific and personal questions about the participant's sexual practices and behaviours and perceptions of HIV.

The participants were allowed "free rein" to talk about whatever they felt in response to the questions asked. The researcher also avoided interrupting the participants as they talked and instead jotted down key points to probe later during the interview.

A number of verbal prompts were used by the researcher. These techniques included verbal responses such as, "okay, yes, I see" to show that the researcher was paying

attention and was interested in what the participants were saying. In some instances the researcher asked for clarity so as to better understand what the participants were talking about (Greeff, 2011:345). Paraphrasing and summarising of the participants' stories were used by the researcher, using different words from those of the participants, so as to show understanding (Greeff, 2011:345).

The researcher also paid particular attention to the participants' stories and avoided the common interviewing pitfalls highlighted by Greeff (2011:346). These pitfalls include interrupting the participants while they were talking - therefore cell phones were switched off - asking questions in an illogical order, teaching and preaching to the participant, counselling the participants, and the use of translators. However, a translator was used in one interview where it was absolutely essential as the participant could not speak fluent English but had expressed his desire to be interviewed. The interview was translated from Xhosa to English.

### **3.8 Data Collection Process**

A tape recorder was used to capture data as it would have been impossible to write everything down in such an interview setting without missing important nuances and losing focus (Greeff, 2011:359). After the interview, the recorded interviews were transcribed. This was done by a professional transcriber, and simply meant reproducing on paper the interview material recorded on the tape recorder (Crossley, 2000). According to Crossley (2000:73) "it is a laborious procedure which involves sitting down with the tape, playing and replaying, stopping and starting, until you have an 'adequate' copy". Also all the interviews were conducted in English except for one interview where a community field worker filled in as an interpreter because the participant was a first

language Xhosa speaker and was not fluent in English. The field worker was male, and was employed by the organisation which provided the interview participant. The participant was asked if he would be comfortable with the field worker being present to interpret and he consented to the idea. Permission to collect data was sought from all participants before the interviews commenced.

### **3.9 Data Presentation and Analysis**

Data were analysed using in particular Crossley's (2000) narrative analysis approach where the researcher highlighted and explored seven key areas of inquiry which were: 1. key events, 2. significant people, 3. imagery, 4. tone, 5. emerging themes, 6. future plans/script and 7. identification or symbolism of phases. The researcher asked participants to narrate any significant positive or negative events that stood out in their memory, to list significant people in their lives and why they were significant, to narrate their plans for the future, as well as to narrate a highlight or a turning point in their lives.

According to Crossley (2000:67) "the personal narrative is a special kind of story that every one of us constructs to bring together different parts of ourselves into a purposeful and convincing whole". Like other interpretive approaches, narrative analysis attributes a central role to language, but more specifically to 'stories', which help in one's self-construction (Crossley, 2000). Therefore, through the type of language we use, we construct our identities; we narrate events, and express our feelings, emotions and thoughts about these events. From this perspective, the stories participants in this study narrated about their experiences as men living with HIV and/or AIDS, worked in helping the researcher better to understand the type of masculinities they possessed and how the participants constructed these masculinities through their stories.

Narrative analysis requires the researcher to be involved in a sustained interpretive relationship with the interview transcripts in order to discover the meanings related to the social and psychological realities in the personal narratives of others (Crossley, 2000). Crossley (2000) outlines the main steps to be followed in the analysis of personal narratives. Firstly, I was involved in the repeated reading of and familiarisation with the transcripts, in order to begin to identify emergent themes. Then I identified important concepts which were to be looked for in the personal narratives of participants (Crossley, 2000).

According to McAdams (1993, cited in Crossley, 2000:89), there are three principles to look for, and these are “narrative tone, imagery and themes”. Narrative tone is the most pervasive feature in adults’ personal narratives and is conveyed in both the content and form or manner of the story. For example, it could be pessimistic or optimistic (Crossley, 2000). Imagery is both discovered and made up through the use of language, it is contained in every personal narrative (Crossley, 2000). In other words, imagery is used by the participants, for example, ‘I felt pain, like I had needles underneath my feet’. This gives the reader a picture/image of needles literally under the narrator’s feet, pricking and causing pain. Finally, themes underlie many events or stories told and hence similar patterns may emerge when similar stories are told.

The final step saw the researcher weaving the identified themes and images which emerged during the interpretation of the transcripts into a coherent story. It is linked to previous literature and is expanded on in the discussion section of this paper.

### **3.10 Validity and Reliability in Qualitative Research**

According to Lewin (2011:221) validity refers to “whether or not the measurement collects the data required to answer the research question”. Janesick (2003:69) supports Lewin’s idea, she states “validity in qualitative research has to do with description and explanation and whether or not the explanation fits the description. In other words, is the explanation credible?” Validity can also be distinguished into two parts: internal and external validity.

Lincoln and Guba (1985) cited in Whitemore et al., (2001:523) translated internal validity into credibility, and external validity into transferability. Seale (1999:44) believes credibility is attained “through prolonged engagement in the field, persistent observation and triangulation exercises, as well as exposure of the research report to criticism by a disinterested peer reviewer and a search for negative instances that challenge emerging hypotheses and demand their reformulation”. Furthermore, Seale (1999:45) believes external validity or transferability is achieved “not through random sampling and probabilistic reasoning, but by providing a detailed, rich description of the setting studied, so that readers are given sufficient information to be able to judge the applicability of findings to other settings which they know”.

Thus, a researcher must emphasize validity as a process of checking, questioning, and theorising, not as a strategy for establishing rule-based correspondence between the findings and the ‘real world’ (Kvale, 1996). Therefore, validity in this study was ensured by the selection of an appropriate methodology for answering the questions, selection of appropriate instrumentation for gathering the type of data required, and by selecting and using an appropriate sample (Cohen, Manion, & Morrison, 2007).

Other principles of validity are commitment and rigour, transparency and coherence as well as a paper trail (Yardley, 2008:243). Commitment and rigour are achieved through the thoroughness of this study, with respect to appropriateness of the sample to the research question being answered (Yardley, 2008:248). Although the sample size may be viewed in some quarters as small, the depth of the questions as well as the data gathered reflects that unique insights into the experiences of men living with HIV and/or AIDS were obtained through a detailed and theoretical interpretation of the data (Yardley, 2008:248). Rigour was also achieved through the researcher's commitment in the gathering and analysis of the data. An extensive and methodical engagement with the data, the participants, and the reader highlights the rigorous effort applied in this research (Yardley, 2008:248).

According to Yardley (2008:248), coherence of a study means "the extent to which it makes sense as a consistent whole". Transparency and coherence were enhanced through the description of how participants were selected through a clear inclusion criterion, as well as through justification of the interview schedule used and the manner in which interviews were conducted, as explained in the beginning of this chapter. The way in which the data has been analysed and the findings written up, supports Yardley's view on coherence and transparency. Polkinghorne (1988, cited in Crossley, 2000:104) suggests that this concept and the concept of validity in general mean being 'well-grounded and supportable'. In addition, transparency was enhanced by the availability of a paper trail. According to Yardley (2008:243) "it should always be possible to provide evidence linking the raw data to the final report". The researcher has kept a 'paper trail' of the documents used during the research as well as electronic and hard copies of the

raw data. This increases the transparency and validity of the research should other researchers request to see this information.

### **3.11 Ethical Issues**

Ethical issues and principles in social research are present in both qualitative and quantitative research even if the actual details involved may differ greatly (Flick, 2011:225). According to Booth et al., (2003:285) the issue of ethics has two broad concepts which involve moral or immoral behaviour and actions by the researcher as well as the construction of bonds and ties with the participants and communities involved in the study. These bonds and ties could be useful in future. Ethical issues should always be considered in research so as to ensure the safety, dignity, rights, integrity, feelings and perceptions of participants and communities (Clough and Nutbrown, 2007:173).

#### **3.11.1 Permission**

In complying with ethical standards, a letter seeking permission was sent to the organisations I used as entry points into the communities because, as suggested by Miller and Bell (2002, cited in Miller, 2012:61), control over decision-making around access to participants is not always up to the researcher. If the proper channels are not followed the entire project may be jeopardised.

#### **3.11.2 Confidentiality and Anonymity**

According to Clough and Nutbrown (2007:96) “all research must be interrogated for the means by which it ‘protects’ the interests of the participants”. As a result, all the participants in this study were assured of confidentiality and anonymity (Terre Blanche et al., 1999). As the researcher, I did everything in my power to protect the data gathered, as well as the identities of all the participants involved in the research

process. Pseudonyms were used in the reporting of the findings and only the researcher knows the identity of the participants.

### **3.11.3 Informed Consent**

The participants received clear explanations of the task expected of them so they made informed decisions to participate voluntarily in the research (Terre Blanche et al., 1999). The most significant concern within professional research guidelines is often that none of the participants is coerced into participating in the study and that any involvement should be voluntary (Miller and Bell, 2002, cited in Miller, 2012:56). Furthermore, according to Miller and Bell (2002, cited in Miller, 2012:64-65) obtaining written consent from participants has become increasingly important to researchers and poses new ethical considerations. Providing the participants with the full details of the study, as well as obtaining their written consent before the interview commences, is very important (Miller and Bell, 2002, cited in Miller, 2012:65). In accordance with this, participants in this study were asked to sign a consent form before the interview took place. This research design did not involve any form of deception as, as highlighted by Bulmer (1982) cited in Denzin and Lincoln (2005:145), “deception is neither ethically justified nor practically necessary, nor in the best interest of sociology as an academic pursuit”.

### **3.11.4 Transparency**

Participants were given full details as to how to contact the researcher, and about the aims and objectives of the research. They were also made aware that the research findings would be published in the University of Fort Hare research report.

### **3.11.5 Human Dignity and Human Rights**

Participants were treated with respect at all times and were also assured of their freedom to withdraw from the research at any time and for any reason.

### **3.12 Limitations**

In qualitative research the researcher is an integral part of the research process. The researcher acknowledges that the methodology used in this study is not perfect and has limitations. First, the researcher realises and acknowledges that he is central to the research. Thus, it is difficult for the researcher to go through the process without exerting some form of influence through the researcher's bias or idiosyncrasy. Being aware of this, the researcher consciously made an effort to try and maintain integrity and objectivity when designing the research, collecting and analysing the data, and in the writing of the research paper.

The second limitation is that the findings produced (as a result of a small sample) from the qualitative methodology cannot always be generalised to the entire population. Even though this method was useful in getting rich data on the phenomena of men's experiences of living with HIV and/or AIDS and the effects this illness has on their masculinity constructs, these findings cannot be used to generalize the experiences of all men living with HIV and/or AIDS.

### **3.13 Conclusion**

This chapter discussed the methodology component of the study. It provided details of how data was gathered and analysed. It was strongly guided by the research problem and research objectives as it aimed to answer the research questions. The following chapter discusses the findings of the research and subsequent analysis of the data.

## Chapter 4

### Findings and Data Analysis

#### 4.1 Introduction

This chapter presents the findings from and the interpretation and data analysis of the data collected from men living with HIV and/or AIDS in the Buffalo City Municipality in the Eastern Cape Province of South Africa. Crossley's (2000) narrative analysis methods and techniques, as explained in Chapter 3, were used to analyse and interpret the data with particular emphasis on recurring themes as well as on narrative tones and imagery.

Understanding the experiences of living with HIV and/or AIDS and how these experiences impacted on the construction of the participants' masculinities was crucial to the study. In addition, gaining insight into sexual practices, emotions and the meanings attached to events in their lives from their narratives was crucial to fulfilling the objectives of the study. The participants were asked questions ranging from their thoughts and perceptions of HIV before acquiring the virus to their most notable experiences and events, including the challenges they faced. They were also asked about their current sexual practices which helped to understand and interpret their narratives as well as to shed light on the practical implications of these practices for their masculinities. One of the main findings was that the participants all had similar stories about their sexual experiences and practices, the challenges they endured, as well as similar emotions and perceptions of their chronic illness.

## **4.2 Illness Trajectory**

The storylines of the participants tend to follow a similar illness trajectory. These include their contracting of the HI virus, how they found out they were living with HIV, the emotions, thoughts and perceptions that followed the realisation that they were living with HIV and, finally, the experiences they went through in their lives regarding their sexual practices and behaviours after diagnosis.

## **4.3 Masculinity**

As stated in Chapter 2, masculinity is a socially constructed phenomenon which is constantly redefined by men's relationships with other men and women. Masculinity is also context and culture specific. The two distinct types of masculinity, hegemonic and subordinate masculinity, as mentioned by Connell (1995) will be used as theoretical departure points when analysing the data in this chapter

## **4.4 The negative perceptions of an HIV positive diagnosis**

HIV, like any chronic illness, is closely associated with reduced life span, sickness, pain, ill-health and the fear of impending death. Thus, a recurring theme that was evident in the participants' narratives, when asked about their feelings and thoughts about their HIV diagnosis, was that they viewed the diagnosis as a death sentence. They had very little or no positive outlook and felt that death due to the virus was inevitable. Their perception of impending death showed how powerless and vulnerable they were to the virus. This is in sharp contrast with the ideals of hegemonic masculinity constructs which view masculinity as being in control of everyday life situations and illnesses. This perceived lack of control weakens the hegemonic masculinity construct (Duck, 2009:300).

The chapter content has been organised according to each participant's narrative following their illness trajectory, with close attention paid to similar and recurring themes in participants' narrative experiences. In the presentation of extracts from the narratives, particular emphasis has been placed on the verbatim narrations of the narrators. However, at times, the narrator's interjections appear in brackets. Very little to no emphasis was placed on grammatical errors and grammatical accuracy, thus very limited editing of the transcribed narratives was done.

The following section will briefly introduce the interview participants to the reader. The section will also highlight each participant's sexual practices, before contracting HIV, how each participant discovered he was living with HIV, and each participant's experiences of living with HIV. The analysis will aim to provide in-depth insight into the experiences men living with HIV and/or AIDS face, and the emotions, thoughts and perceptions they attach to those experiences and how these experiences shape their understanding of masculinity.

## **4.5 Participants and their Narratives**

### **4.5.1 Mike**

Mike, at the time of the interview, was a 56 year-old white, single, heterosexual male. He had once been married but was now separated from his wife. He had been living with HIV for 16 years. Mike worked as a mechanic at a panel beating garage. In 2011 Mike was diagnosed with TB which he believes was caused by the "dust and fumes" he inhaled while working at the car shop. He fell ill for a long period of time. During his severe illness his co-workers discovered his HIV status and not long after that he was laid off work.

Mike found out he was living with HIV after his girlfriend had been diagnosed with HIV. Initially, when he was tested his results came back negative, but after 6 months he went back for a second test and was subsequently diagnosed with HIV. He narrates:

*“Well this woman I was going out with, she went to the hospital and she was diagnosed HIV, and then they said I must have a test. I tested came back negative, six months later I went back and had it checked and they found me positive”*

*(Mike, Page 3, Line 20-23)*

Mike had no idea that he was suffering from HIV prior to his girlfriend's being diagnosed. He had not shown any signs of illness so he had no reason to believe that he could be living with HIV. Although Mike acknowledges not using condoms, he maintained that he always had one partner at a time:

*“Well I only had single partners (at a time)... I never used condoms.... Condoms used to hurt me, because of my foreskin (uncircumcised).”*

*(Mike, Page 14, Line 8-14)*

Mike admits to having one partner at a time, and to not using condoms consistently because they hurt his penis during sex. This risky behaviour put him in danger of contracting HIV. The extract contains imagery of ignorance towards the possible negative effects of not using a condom. Furthermore, Mike's narrative supports the ideals of hegemonic masculinity constructs which are characterised by risky sexual behaviour (Foreman, 1999:22). During the interview, Mike admitted to not being

circumcised, and as a result the use of a condom during sexual intercourse caused discomfort. This suggests Mike was more concerned with sexual pleasure and comfort than he was with protecting himself from unwanted sexually transmitted diseases such as HIV.

When asked to describe himself as a man, and if living with HIV had in any way shaped his understanding of being a man, Mike responded to these two questions as follows:

*“I was virtually the bread winner in the house and now I am nothing..... I used to look after my mother and my little brother.”*

*(Mike, Page 17, Line 7-8)*

*“No, I am still a man, don’t you worry..... I am still the person I used to be I will never change.”*

*(Mike, Page 19, Line 4)*

In his response Mike clearly feels his manhood was determined by his ability to provide for his family financially. This bread-winner ideal supports the notion of a hegemonic masculinity construct as put forward by Duck (2009:287) who suggests that men believe their masculinity is largely defined by their ability to earn an income and provide for their families. Mike’s narrative also supports Connell and Messerschmidt’s (2005, cited in Duck, 2009:288) belief that economic access ranks highly for men who adhere to the ideal constructs of hegemonic masculinity.

However, from the time he was diagnosed with HIV, Mike had not been able to work and therefore could longer provide for his family. This suggests a negative impact or weakening of his masculinity buttress and this is shored up when he says, “I am

nothing” although a contradiction emerges when he says, “I am still the person I used to be”. In so doing, he insists that his lack of employment and income does not make him any less of a man than he was before.

When Mike was asked what his perceptions towards his future were after his HIV diagnosis, he narrated a story containing images of surrender, and loss of interest in life. He points out that he “just didn’t care no more” and that everything “had no meaning at all”. This suggests that he perceived HIV as a deadly disease which would kill him quickly. He narrates:

*“Argh well, I just didn’t care no more, I just thought no well this is the end of it..... Ja, everything like took, had no meaning at all.”*

*(Mike, Page 4, Line 23-25)*

The tone of Mike’s extract is sad. This is so because he thought the end of his life was near and for that reason there was nothing to look forward to or to be happy about. In the narrative above Mike shows lack of control over and uncertainty about his future due to his HIV diagnosis. This outlook is inconsistent with and in contrast to hegemonic masculinity constructs which are characterised by control over the future and never giving in or surrendering to ill-health (Charmaz, 1995:272; Edwards, 2006:2).

Mike’s most negative experience while living with HIV is the stigmatisation he has had to deal with. He feels he has been let down by his family and friends as he narrates:

*“Well I got shunned by everybody. The minute they knew that I was HIV they all pulled away..... Like I said I have lost all my friends. Really, I don’t care at all, there is nothing left now.”*

*(Mike, Page 5, Line 1-2 and Page 6, Line 10-11)*

The above narrative extract suggests a tone of dejection. The imagery is filled with isolation because Mike has no friends or family he can depend on and turn to in times of need. Thus, he believes this to be the most negative experience he has had to go through while living with HIV. Goffman (1963:3) defines stigma as an “attribute that is deeply discrediting” which reduces the stigmatised person “from a whole and usual person to a tainted discounted one”. With stigma comes untold psychological, social and emotional suffering for the stigmatised individual or group. Mike feels “there is nothing left now” for him. This admission of hopelessness, and a lack of control caused by the stigma he faces, weakens his masculine role performance. This according to Duck (2009:303) deviates from the ideals of hegemonic masculinity. Therefore, it can be inferred that the isolation and neglect Mike suffers due to his HIV status largely weaken his masculinity construct.

Mike reported being on ARV treatment. He takes four pills a day and reported having no side effects from the antiretroviral treatment. When asked about the treatment and its effects on his body he simply replied:

*“I am on ARVs. I take four tablets once in the evening.... Nothing, no effects”*

*(Mike, Page 5, Line 25)*

From the extract, it seems Mike is content with the treatment and this is so because he suffers no ill effects at all from the treatment. The imagery Mike portrays is of a satisfied individual who is happy with the treatment he is receiving. Although, Mike's narrative does not suggest an addiction to the ARV treatment because he takes it regularly, it does however suggest a dependency on the treatment. Mike noted religiously taking 4 pills a day in order to maintain good health. This dependency is inconsistent with notions of hegemonic masculinity. The theory of the hegemonic masculinity construct suggests that men who adhere to this masculinity construct believe their bodies are independent and do not need medicine or treatment to restore and retain good health (Duck, 2009:300; Courtenay, 2000:1389). Thus, in this case Mike does not sufficiently fall under the hegemonic masculinity construct because he seems to rely on an external factor for optimum health.

#### **4.5.2 Thabo**

At the time of the interview Thabo was a 37 year-old black, heterosexual widower who had been living with HIV for 8 years. Thabo had been in the navy and had been posted to Cape Town from the late nineties until he left the navy around 2004. While Thabo lived and worked in Cape Town his wife and family lived in the Eastern Cape. He was the third of five siblings to contract HIV. The other two siblings had passed away because of this pandemic.

Thabo lost his wife to suspected AIDS-related ailments in 2009. He found out he was living with HIV in 2005. In 2007, he discovered that his wife was also living with HIV. He unknowingly read her hospital charge sheet where he found she was being given

nevirapine. He admitted to knowing what the drug was for and realised then that his wife was living with HIV. He found out his HIV status when he fell ill and went to hospital:

*“I also was not feeling well. I believed that I had TB at the time and then I was advised there (at the clinic) by the sisters to do an HIV test that is when I saw that I am HIV positive.”*

*(Thabo, Page 4, line 12-16)*

Like Mike, Thabo had no idea that he was HIV positive until tested. His contracting of the virus happened, in all probability, as a result of unprotected sex. In the extract below Thabo acknowledges having multiple partners while working in Cape Town and not consistently using condoms. He describes his sexual practices while in Cape Town:

*“But you see as a teenager you always had one girlfriend before, you see, because I left for Cape Town in 1997. So I had a couple of girls but at the time I usually had one girlfriend. But when I went to Cape Town you see, there were many locations there maybe you have a girlfriend on this side, so that when you go to that location you meet that person or if you go to another location. Ja. So it was not that we did it very often mainly on weekends when we are going to have a good time then we decide to go to another location then I know that I have got a partner there..... I would say, I did not use it every time (condom) that I slept with a girl or something. Basically, I had that mentality that hey, you see, you don't feel this woman you see. Sometimes even when she gives you, you take it off maybe while she is not aware.”*

*(Thabo, Page 11, Line 9-32)*

It is clear from Thabo's narrative above that he was more interested in the sexual pleasure of unprotected sex, which he believed was more intimate. He had numerous sexual partners in and around Cape Town's high density suburbs (locations). He had

casual sex with these partners from time to time depending on which area he and his friends went to for “a good time”. This put him at great risk of contracting HIV. The imagery portrayed in the narrative extract above is of a young man, enjoying life away from home, seeking sexual pleasure and possibly influenced by his peers. He appears oblivious to the dangers of having numerous sexual partners and also of having unprotected sex. His behaviour in seeking numerous sexual conquests, the consumption of alcohol and inconsistent condom use is in line with the dangerous behaviours of the hegemonic masculinity construct. Lindegger and Quayle (2009:43) cite “multiple sexual partners, unprotected sex, use of alcohol before sex and, in some cases sexual violence” as characteristic of the hegemonic masculinity construct.

When Thabo was asked if he thought his family and friends considered him to be a man and what made him feel like a man he responded by saying:

*“Well, by my friends I am accepted for who I am but in terms of family, I think I still have to prove, I don’t know what I should prove, I still have a lot to do to prove to them that I am this man, you see, maybe they can share the same thing. .... No, my partner was my wife, you see, so definitely I was her man, ja. We had a child together.”*

*(Thabo, Page 13, Line 31-34)*

In the narrative above Thabo indicates that among his peers he is considered a man, and this could be attributed to his sexual conquests. However, he doubts that he is considered a man within his family. He is puzzled as to what he needs to do for them to consider him a man but with his late wife he felt very confident that she considered him a man because they shared a child together, for him his masculinity construct is reinforced by the fact that he was able to father a child. This supports Duck’s (2009:287)

notion which believes hegemonic masculinity constructs emphasise marriage and children among other things.

When asked if living with HIV had in any way shaped his understanding of being a man Thabo responded:

*“Well, being HIV positive I would say – I look at the different relationships in a different way now, you see, because in the first place that I have HIV it’s because of these relationships that I had. Now I tend to, most of the time, to abstain, rather than go and experience and experiment. I tend to just live by me I am that person who would just like to be alone you see.”*

*(Thabo, Page 14, Line 32-36)*

Thabo’s response highlights his behaviour change after being diagnosed with HIV. He no longer seeks sexual pleasure and sexual gratification which are ideal constructs of hegemonic masculinity. Now he analyses the different relationships he mentions in a different way and, as a result, abstains from any sexual activity, choosing to spend time alone and in isolation. The illness has caused him to isolate himself from people in order to avoid possible stigmatisation (Williams and Bendelow, 1998:161).

Thabo’s response when asked about his perceptions of his future after being diagnosed with HIV is similar to Mike’s. Thabo expresses imagery of sadness - he reiterates and emphasises this three times in the extract. The extract also contains images of depression and melancholy because Thabo had lost two siblings to the HI virus. As a result, he felt that he was inevitably going to die “quickly” and that the virus was a death sentence.

*"You know, I was sad, you know. In previous years I had an elder brother who was also living, who had passed away already due to the illness. My sister, the one before me, she also passed away..... That is why I also thought maybe it's the way, that I am going to die quickly. I was sad, I was very sad to know that."*

*(Thabo, Page 5, Line 17-25)*

The tone in Thabo's extract is also very sad, with no glimmer of hope because of the experience he had when his two siblings passed away because of AIDS. He felt that he would take the same route and that he would "die quickly". Thabo's extract shows his belief in his inevitable and impending death and his lack of control over this. In this way, his masculinity construct is weakened and doubts about his manhood are raised (Charmaz, 1995:662), because he has no power to control and avoid death from the virus (Edwards, 2006:2).

Thabo's most negative experience of living with HIV, like Mike's, is the stigma and discrimination that accompanies this disease. Thabo narrates how his own family members and community gossip about and spread news of his HIV status without his consent:

*"I would say that it was that I know that I was HIV positive. Maybe a member of the family, an old person for that matter, maybe tells other people straight to other people behind your back, you see, that so and so is HIV positive or even if you get a cold or something, automatically, even if it is a cold or a cough or something, automatically it is that disease, it has got that big stigma there and that person is not coming to confront you in your face, tells other people, you see. Even now when I was on this wheelchair, I heard people saying. They would come to me some of them and they would say when*

*they come and visit that they spread in the location that you will never walk again, you see, you are bound to the wheelchair”.*

*(Thabo, Page 8, Line 17-26)*

Thabo's narrative tone is filled with disappointment at the way people spread word of his HIV status in his community. He feels that whenever he falls ill, people quickly associate that particular illness with HIV and as a result they are pessimistic about his health improving. The narrative imagery is disheartening. The stigmatisation he faces seems to affect Thabo greatly and possibly weakens his masculinity construct, as he is wheelchair bound and gossiped about, about which he can do nothing (Duck, 2009:303).

Thabo reported being on ARV treatment. He reported taking three ARV tablets twice a day. He also reported encountering side effects from the ARV treatment. Thabo narrates his treatment regimen and pain below:

*“Yes I am on ARV's and early this year (2013) I got what do you call it, spinal TB, abdomen TB basically due to the fact that I defaulted on the tablets last year..... I take three tablets twice a day”.*

*(Thabo, Page 7, Line 18-22)*

*“But the problem I always encounter is with my feet they become sore but they say that it is the side effects related to being HIV positive. When I lie on the bed when I want to step down, I had something like needles underneath my feet. My legs got stiff sometimes. I can't just stand up and walk. I had to stretch first, you see..... I asked*

*recently when I went for the check-up they said no, it is also the pills that made that, so I shouldn't bother much."*

*(Thabo, Page 8, Line 4-11)*

From the tone of his narrative, Thabo is plagued with pain. The imagery is plagued with pain, with images of needles piercing the soles of his feet. The narrative also includes imagery of uncertainty as to what causes the pain he feels. Is the pain caused by the fact that he is living with HIV or is the pain caused by the pills he takes to treat the HI virus? Thabo does not seem to know why he feels this pain but takes comfort when he is told that the pain is caused by the pills. He concludes by saying "so I shouldn't bother much". Thabo's dependency on medication as well as his lack of control over his illness and pain suggests a contrast in hegemonic masculinity beliefs, that he should possess unrestricted control and authority over his body (Duck, 2009:300). Thus, Thabo's narrative extract shows signs of a subordinate masculinity.

#### **4.5.3 Siph**

At the time of the interview Siph was a 59 year-old black, heterosexual male. He was a widower, whose wife had died of suspected AIDS-related ailments. Before being diagnosed with HIV, Siph was a builder. Siph was diagnosed with HIV in 1994. Because of his declining health, Siph had to stop working soon after his positive diagnosis and has never been able to hold a steady job since. At the time of the interview, he had been living with HIV for 19 years. Siph found out he was HIV positive after visiting the doctor because of stomach pains:

*“I had a problem in the stomach, pains in the stomach. Then I went to the doctor and the doctor started to test me and he told me I had HIV.”*

*(Sipho, Page 3, Line 2-4)*

So, like Mike and Thabo, Sipho was not aware of the illness he had, he thought that it was simply stomach pains. He never thought that he could be living with HIV. It was only after further blood tests were done that his HIV status was revealed to him. Sipho’s narrative extract above shows imagery of ignorance, unawareness and to an extent naivety, in that he did not believe he could be HIV positive, despite his risky sexual practices which he details as follows:

*“I had only two partners, my wife and someone else. I did not use condoms with both women. I did not know about condoms or the disease before I got it”*

*(Sipho, Page 7, Line 28-29)*

Considering Sipho contracted the virus in 1994, it may be understandable that he had no prior knowledge of the virus or condoms as he claimed, as there was significantly less awareness and education around the subject matter then than there is now. Sipho’s narrative suggests he sought sexual gratification and experience more than he sought information and knowledge about the dangers of unprotected sex. His extract contains imagery of ignorance, risky sexual behaviour and infidelity. Sipho’s behaviour supports Rao Gupta’s (2000:3) analysis of hegemonic masculinity. Rao Gupta believes gender socialisation leads men to believe from the age of adolescence that multiple sexual partners will bring about experience and knowledge and this prevents them from actively seeking information on the dangers of unsafe sex. Men adhering to constructs

of hegemonic masculinity do not seek information about health-related dangers such as risky sexual practices. As a result, they place themselves at risk of contracting the HI virus (Rao Gupta, 2000:3).

Sipho was asked to describe himself as a man, and responded as follows:

*“I was a family man. I worked and brought money. Now the relationship is not the same as before when I was still working. After I stopped working my family found out about my HIV status and I have not worked for over two years now.”*

*(Sipho, Page 11 Line 17-19)*

Sipho felt that being able to support his family financially made him feel like a man (Duck, 2009:287). When this was taken away from him he began to doubt his manhood. His family found out that he was living with HIV because he was retrenched from his place of employment and had not been able to work “for over two years now”. This seems to have created a huge strain for him and his family and this has severely weakened his masculinity.

When asked if living with HIV had in any way shaped his understanding of being a man, Sipho responded:

*“I still have strong sexual desires, but I now control them because I know my status”*

*(Sipho, Page 12, Line 6)*

It seems Sipho is now forced to be more disciplined and in control of his sexual desires and urges because of his HIV status. This is in sharp contrast with the constructs of hegemonic masculinity which indicate that men seek sexual pleasure and sexual

conquest at every available opportunity (Courtenay, 2000:1389). Siphon realises the need to control his sexual desires and abstain so that he does not further spread the virus or weaken his CD4 cell count.

Siphon also perceives his HIV status as a death sentence and feels powerless because he cannot do anything to change his situation. He narrates:

*“When I found out, my morale dropped, I felt down and angry. But there was nothing that I could do about it.”*

*(Siphon, Page 4, Line 10-11)*

Siphon’s narrative tone and imagery is sorrowful. He acknowledges he felt “down and angry” at the revelation that he was living with HIV. He goes further to state that “but there was nothing I could do about it”. This shows how helpless Siphon feels about his situation because there is nothing he can do to change his HIV status. This again, is in contrast with the ideals of hegemonic masculinity which prescribes that men always have the power and control to shape their future and destiny (Edwards, 2006:2). Thus, Siphon feels his hegemonic masculinity is greatly weakened by his HIV status as there is nothing he can do to change this status.

Siphon did not mention of having endured any negative experiences because of his HIV status. This maybe because he did not tell his extended family or his community of his status:

*“I only told my wife who died, and my brother who does not live with me. I never told the community of my status”*

(Sipho, Page 5, Line 1-2)

Sipho's decision not to tell his community or his family about his status suggests a fear of stigmatisation and discrimination. He possibly fears the negative impact such a revelation would have on the way the people would perceive, judge and treat him. The fear of being harshly judged and stigmatised encourages Sipho to keep his status a secret. This is possibly in the hope of maintaining his manhood and masculinity construct intact, as any negative response could weaken this masculinity construct (Duck, 2009:303). Sipho's narrative imagery portrays a theme of secrecy and fear. His narrative tone is ambiguous with regard to why he decided to keep his status a secret. During the interview, he never did give a direct answer as to why he chose to keep his status a secret which, in all fairness, is his choice and right.

Sipho acknowledges taking treatment for TB and for HIV. He also reports feeling no side effects from the treatment:

*"I use ARV's. I take half a pill for TB in the morning and two ARV pills in the evening. I feel right when I take them, no side effects".*

(Sipho, Page 3, Line 8-10)

Sipho's narrative tone is cheerful and the imagery implies he is satisfied with his treatment regimen. Sipho highlights his comorbidity as he acknowledges suffering from TB and HIV. His narrative suggests he is heavily dependent on treatment for both the diseases from which he suffers. This dependency also highlights the lack of control Sipho has over his health, and the weakening of his masculinity construct as a result (Duck, 2009:300). Courtney (2000:1389) believes hegemonic masculinity constructs do

not allow for men to be dependent on any external factor which seems to contradict Siphos position.

#### **4.5.4 Phillip**

At the time of the interview Phillip was a 28 year-old coloured, homosexual male. He had never been married. Phillip had dreamed of becoming a nurse but said that his dreams had been interrupted by his HIV status. He had been living with HIV for close to 2 years. Phillip, like Mike, had been sick for three weeks and was advised by friends to go to the clinic:

*“I was sick for three weeks, and my friends told me to go to the nearest clinic to check for TB, check for AIDS or Asthma. I test myself all the testers and the test results told me I had HIV.”*

*(Phillip, Page 1, Line 24-26)*

Phillips narrative extract above shows that he did not think much of his illness prior to the HIV diagnosis. Phillip openly admits to having had multiple male sexual partners and not using protection frequently or consistently enough. Regardless of his risky sexual practices, which he narrates below, he had no suspicion that he might be diagnosed with HIV:

*“I had multiple partners, and I would say I didn’t use condoms because I hated them. Condoms are not strong enough they burst, that is why I don’t do, with them.”*

*(Phillip, Page 9, Line 5-6)*

Phillip is openly gay and admits to not using condoms with his partners because he had had bad experiences with condoms where they “burst” and because of that bad experience he no longer found condoms to be reliable. Thus, for Phillip the issue is not

about his knowledge of condom use but his lack of trust and faith in the quality of the condoms. The imagery portrayed in Phillip's narrative is of distrust with the product (condoms), which he possibly uses as a convenient excuse not to use condoms.

It is widely believed that gay men adhere to characteristics of a subordinate masculinity (Lusher and Robins, 2010; O'Neil and Hird, 2001:211). The imagery of Phillip's narrative suggests that condom use during a sexual encounter was at his discretion. This may suggest that Phillip could have been the dominant, power-wielding and decisive partner in his relationships. This may then imply that within homosexual relationships there are partners who adhere to hegemonic masculinity constructs of decision-making, control and leadership as supported by Moodie (2001). Those individuals may wield influence over the subordinate partner.

Phillip when asked to describe himself as a man responded:

*"I would say Phillip is a good person, he knows what he is and he lives with that and before I have sex with my multiple partners I talk to them before I do it. I convince them about myself."*

*(Phillip, Page 10, Line 17-19)*

Phillip describes himself as a man in terms of his personal characteristics. He views himself as "a good person". He also feels he is a man because he is gentle, charming and he is able to "convince" his sexual partners into having intercourse with him. It is important to note that Phillip is openly gay and theoretically adheres to the constructs of a subordinate masculinity because of his sexual preference (Groes-Green, 2008). This could be the reason why he describes his masculinity in terms of personal attributes and

not physical or material attributes like men adhering to constructs of hegemonic masculinities. Phillip supports the notion put forward by Groes-Green (2009) that subordinate masculinities do not put emphasis on dominance or control over others but rather are compassionate while striving for equality. This is evident when Phillip says “I talk to them (his partners) before I do it, I convince them about myself”.

When asked if living with HIV had in any way shaped his understanding of being a man, Phillip responded:

*“Yes, because everybody knows me. I am a gay person, and they know I do everything with a man, that is why. Men know me, they said: “let’s go to Phillip”. Then the boy will ask, “Who is Phillip?” Then he will say “let’s go to the person with the nice ideas, images, looks, thoughts and everything in himself, he will tell you what to do”.*

*(Phillip, Page 11, Line 6-9)*

It seems Phillip’s understanding of his manhood is based on his character, personality, appearance and on how other men perceive him as being the person with the “nice ideas”. It also suggests Phillip may be the ring leader amongst his peers and this is supported by the phrase in the narrative when Phillip says, “he will tell you what to do”. This could also suggest that his manhood is based on his being the leader of his clique. Thus, it seems that Phillip amongst his peers, adheres to hegemonic masculinity constructs because of his influence based on his leadership, power and decisive authority (Courtenay, 2000:1388).

When asked what his perceptions towards his future were after being diagnosed with HIV, Phillip replied that getting sick, even with a chronic disease like HIV, is a “natural thing in life”. His narrative tone and imagery are optimistic as he narrates:

*“I was thinking if I have it, I have to live with it. I mustn’t be scared. I mustn’t be afraid of it because it is a natural thing in life.”*

*(Phillip, Page 3, Line 9-10)*

Because Phillip is gay, he is believed to adhere to subordinate masculinity constructs (O’Neil and Hird 2001; Duck, 2009; Lusher and Robins, 2010). He does not seem to be overly concerned by the fact that he is living with HIV. Men who adhere to subordinate masculinity constructs understand that they do not possess authority for decision-making nor do they possess power to change or influence behaviour (Duck, 2009:300). Thus, Phillip is quick to accept and understand that he has “to live with it”. He has to tolerate and accept his HIV status. The interesting thing to note about his narrative is that he believes having this disease “is a natural thing in life”. This suggests that his subordinate masculinity construct which is theoretically tolerant, empathetic and compassionate makes him more understanding and accepting of his situation (Charmaz, 1995:664). Phillip acknowledges that his situation is beyond his control and is a “natural” occurrence controlled by the universe. This is in contrast with the participants conforming to descriptions of hegemonic masculinity who believe that every situation is/should be controlled by the male (Edwards, 2006:2).

Phillip reported never having experienced any form of stigmatisation or discrimination due to his HIV status. He seems to have a care-free attitude towards life and therefore does not pay much attention to the outside world's opinions about him. He narrates:

*“Negative experience? I have to believe in myself, if I can't believe in myself who is going to believe in me and I have to live with it and I have to carry on with life. Don't think about it”*

*(Phillip, Page 4, Line 21-23)*

Phillip does not seem worried about what other people think of his HIV status. He is solely focused on living his life regardless of what other people may think about it. O'Neil and Hird (2001) would characterise Phillip as falling into the category of a subordinate masculinity construct because he is gay. In this instance, this notion could hold water as Phillip's narrative extract above also supports Groes-Green (2009) characterisation of subordinate masculinity as being compassionate, free-thinking, liberal and striving for equality and success in all spheres of life. Phillip's narrative extract does not suggest a deviation from the attributes of a subordinate masculinity construct but rather is aligned to these attributes which in no way weaken his masculinity construct.

Phillip acknowledged taking ARV treatment every evening. He also reported experiencing side effects from taking the anti-retroviral treatment. In his narrative he explains the different kinds of pain and symptoms he suffers:

*“Yes, I am on treatment. Like ARV’s. I do take them at night at half past six and it is four tablets. It gives me hot flushes and it makes me like vomiting but I try to keep it in my body so it must not get out.....and I see like stars, like blurring.... Sweating as well...”*

*(Phillip, Page 3, Line 22-24)*

Phillip’s narrative tone is also beset with suffering caused by the treatment but it is made lighter when he acknowledges that regardless of the pain he experiences from the treatment, he tries to keep the medication in his body “so it must not get out”. This highlights the presence of mind that Phillip has, because he knows the only way the treatment will help him is if it stays in his body. The imagery conveyed in Phillip’s narrative is of suffering as well as of some optimism that the medication will work and improve his health.

Phillip resigns himself to accepting the illness as a “natural thing in life” which he has “to live with”. Thus, with regard to his understanding of his manhood, illness and his sexual orientation his narrative suggests that he adheres to the theoretical constructs of a subordinate masculinity (Lusher and Robins, 2010). Because Phillip adheres to subordinate masculinity constructs, he understands that he cannot dominate or effectively control his ill-health (Groes-Green, 2009). Phillip, like the others, is dependent on his treatment in order to maintain good health. Thus, Phillip’s subordinate masculinity construct does not seem to be weakened by his illness or his dependence on treatment.

#### 4.5.5 Vuyo

At the time of the interview Vuyo was a 45 year-old, single, black heterosexual male. He was the oldest of five siblings, and he grew up in a very religious home. Vuyo was diagnosed with HIV in 1996 and had been living with the virus for 17 years at the time of the interview. Vuyo narrates how he found out he was living with HIV:

*“I was sick, okay, then I was hospitalized and then the doctor, you know, said to me that I was having appendicitis and then they operated me and then I was still sick, okay..... Then he said to me he wanted to do the procedure and I said to him: “as long as the procedure is going to make me feel better” then he took some blood from me. These rapid tests were not available then and the blood usually took about seven to fourteen days to come out..... So I was discharged and then the doctor said to me I must go to my GP. So when I went back to the GP to go and get my result I could see the reaction on his face when he saw me waiting, you know. He said to me: “I phoned the laboratory more than two times and I couldn’t believe what I saw” and I said to him: “Please tell me, what did you see?” He said: “You know what? You have got AIDS”.*

*(Vuyo, Page 6, line 1-16)*

Vuyo’s narrative shows that he did not think he could have HIV. He assumed that it was appendicitis but when the pain persisted he decided to visit his general practitioner in the hope of finding out what the problem in his body was in order to alleviate his suffering through pragmatic (attempt to rid the body of pain) and hermeneutical means (seeking meaning and understanding of the pain). (Williams and Bendelow, 1998:160).

Unlike Mike, Thabo and Sipho, Vuyo had one sexual partner at the time he contracted the virus but, similar to the other participants, Vuyo did not use protection during his one

and only sexual encounter. His first ever sexual encounter led to his contracting HIV. He narrates:

*“It was my first sexual intercourse, no protection at all okay, since I grew up in a charismatic church okay, and then you know, as I said to you before my father instilled some values in us. He said to us: “Okay, I am telling you, you must study first okay”..... It was just a one night stand.”*

*(Vuyo, Page 12, Line 3-6)*

Vuyo had one sexual partner, with whom he had sexual intercourse only once, and on that one night he did not use a condom and he contracted HIV. Vuyo’s narrative tone when he describes this experience is sorrowful, because he felt as if he had let his father and his family down. His father tried to “instil values” in him and this meant that he was to abstain from sexual intercourse until after he had finished his studies and got married. However, Vuyo was not able to meet these expectations and at his first time of having sex, he did not use a condom and contracted HIV. Vuyo’s narrative raises some suspicion as to how a young man raised in the church and whose father was strict and instilled good values in him could be reckless enough to endanger his life by having unprotected sex in his first sexual encounter, or indeed, whether his insistence that he had only one sexual encounter is correct.

Irrespective, an image of ignorance as to the use of condoms is evident in the above extract. Vuyo’s narrative suggests that he did not seek adequate information about sex and the importance of condom use prior to his becoming sexually active, which placed him at great risk of contracting HIV (Rao Gupta, 2000:3). Vuyo’s risky sexual behaviour and lack of condom use is consistent with the ideals of hegemonic masculinity which

Lindegger and Quayle (2009:42) are posited as being characterised by “multiple sexual partners, unprotected sex, use of alcohol before sex and, in some cases sexual violence”. Vuyo’s narrative suggests he may have been more concerned with sexual conquest and navigating his first sexual experience, which was “just a one night stand”, with ease than with protecting himself from unwanted sexually transmitted infections. Furthermore, images of disappointment and failure are present as he feels he let down his father and his family.

Vuyo, when asked how he would describe himself as a man, responded by saying:

*“Yeah especially my family, you know, they believe in me and then they trust me. And also my friends, you know, and also the community, especially my community, when there is something they don’t understand they know where to go. They always ask me we need something like this you know, because we don’t understand this.”*

*(Vuyo, Page 16, Line 23-26)*

Vuyo seems to take great pride in the fact that his family as well as his community believe in and trust him, and that they come to him for advice and guidance. Vuyo feels that his knowledge and wisdom shape his manhood. It can be said then, that Vuyo adheres to the ideals of hegemonic masculinity because he prides himself on being a leader, being knowledgeable and being able to direct and advise his family and community in times of need. This supports Courtenay’s (2000:1388) notion that hegemonic masculinity includes “leadership, strength, power and authority”.

Asked whether living with HIV had in any way shaped his understanding of being a man, Vuyo replied:

*“No, nothing, nothing, nothings has changed. I am still the same man that I was before”*

*(Vuyo, Page 17, Line 7)*

Vuyo is adamant “nothing, nothing” at all has changed. He feels that he is still the same man he was before he contracted HIV. This indicates that he feels he still holds the same place in, respect and adoration of both his family and his community. His family and community continue to hold him in high regard because they continue to seek guidance from him. This reinforces his manhood and hegemonic masculinity construct. However, Vuyo’s response was negative when asked about what his perceptions towards his future were after his HIV diagnosis. He feels he is useless because he contracted HIV. His narrative tone and imagery contains a lot of anger directed at himself. He narrated:

*“I hated myself, you know, I hated myself, you know. You know, I saw myself as so useless and then also not being a man enough.”*

*(Vuyo, Page 6, Line 31-32)*

Vuyo is not happy with himself for contracting HIV. He feels his masculinity is weakened by his contracting of the HI virus. Men, who adhere to hegemonic masculinity construct ideals, consider their bodies to be machines and therefore believe that they can never fall sick or be in bad health (Edwards 2006:14). Hence, Vuyo’s realisation that he is living with HIV - which may result in his falling sick from time to time as well as having to change his sexual practices – leads him to feel that his hegemonic masculinity will be weakened. Also, Vuyo says he feels “useless”. This shows his subtle admission to the fact that he cannot be ‘useful’ enough to control his health, life and future. This supports the notion by Charmaz (1995:268) that illness “can reduce a man’s status in masculine

hierarchies, shift his power relations with women, and raise his self-doubts about masculinity". Vuyo's admission to being powerless over his health is in sharp contrast with the theoretical ideals of hegemonic masculinity constructs which espouse the idea that men who adhere to hegemonic masculinity constructs possess power and control over their lives (Courtenay, 2000:1388; Duck, 2009:300).

Vuyo narrated his most negative experience of living with HIV as the stigmatisation and discrimination he faced at work every day. He narrated his experience:

*"Everybody, everybody, you know. I was victimised emotionally, physically and psychologically and you know, can you imagine, you know, when you end up having your own toilet..... and people started to say nasty things, you know and then I had this thing that was inside of me that I couldn't tell anyone".*

*(Vuyo, Page 3, Line 11-13 and Page 4, Line 6-7)*

Vuyo's narrative extract above contains imagery of pain and his tone is filled with embarrassment. He is ashamed of and embarrassed by the way his colleagues treat him in the workplace. They allocated him his own toilet and gossiped negatively about him, which made him a victim of stigmatisation and discrimination. This experience greatly affected Vuyo as he says he "couldn't tell anyone" about what was happening to him in the workplace. This negative experience suggests a weakening in Vuyo's masculinity construct as he could not do anything about it, and he could not perform his masculine roles because he was disregarded in the workplace (Duck, 2009:303). The lack of power, control and authority to deal with his stigmatising situation contradict the

traits of hegemonic masculinity constructs and as a result weaken Vuyo's manhood (Duck, 2009:300).

Vuyo is the only participant who indicated that he was not on any treatment for the HI virus. He also gave reasons as to why he was not on any treatment:

*"Fortunately, I am not even on treatment..... because my CD4 count is still very high."*

*(Vuyo, Page 7, Line 10-12)*

Vuyo's narrative tone seems very joyful, because even though he lives with HIV, his CD4 cell count is still very high. Hence he does not need to take antiretroviral treatment. This may suggest a reinforcing of Vuyo's masculinity construct because he does not take treatment. He feels proud that his health is still very good without the aid of external factors such as treatment. Thus, he feels he is in control which in turn reinforces his hegemonic masculinity construct (Courtenay, 2000:1389). The imagery portrayed in the narrative is that of appreciation of his good health.

#### **4.5.6 Roger**

At the time of the interview Roger was a 54 year-old, coloured, heterosexual male. It was not clear from his narrative whether he had ever been married but he was father to two children. Roger was diagnosed with HIV in 2005 and had been living with the virus for 8 years at the time of the interview. Roger narrates how he found out he was HIV positive:

*"It was in 2005 then I went to the Day Hospital to check because I was coughing, to check if I have got flu something like that and when they tested me, they counselled me before they tested me. They tested me and they found that I am HIV positive."*

*(Roger, Page 1, line 18-21)*

From the extract above, it is clear that Roger had no idea he was living with HIV. When he fell ill he went to the hospital confident that he had flu and nothing as serious as HIV. His narrative started off with a lot of optimism that the visit to the hospital would not bring bad news but quickly turned to gloom with the thoughts of impending death and severe pain as a result of being HIV positive.

Roger admits to having multiple partners and to not using condoms. His reason for not using condoms is that he did not think that he would contract the HI virus. He narrates his story as follows:

*“I had multiple partners.”*

*(Roger, Page 9, Line 24)*

*“I didn’t use condoms that time. I started using condoms when I was diagnosed..... I didn’t think I would catch HIV.”*

*(Roger, Page 11, Line 9-13)*

Roger was clearly naive and ignorant about contracting HIV. He did not think that having multiple sexual partners as well as not using condoms would lead to him contracting the deadly virus. He did, however, learn his lesson after being diagnosed with HIV and during the interview he reported to now using condoms. Roger’s experience of not using condoms and assuming that he would never catch HIV supports Edward’s (2006:14) notion that men who adhere to the ideals of hegemonic masculinity constructs view their bodies as machines that are invincible and indispensable. Thus, Roger adheres to the qualities of hegemonic masculinity construct as described by Lindegger and Quayle (2009:42) who characterise this masculinity construct as being

involved with “multiple sexual partners, unprotected sex, use of alcohol before sex and, in some cases sexual violence”.

During his narrative Roger gave a description of what he felt made him a man. This description centred on material possessions and social institutions such as marriage and fatherhood. He narrated:

*“I am a man, ja, because why I do the same as what other men do..... To have a wife, children, a house, everything.”*

*(Roger, Page 13, Line 3-5)*

Roger describes and feels he is a man because he does “what other men do”. He uses the example of his having a wife, children and a house as contributing to his manliness. Thus, his understanding of his masculinity is rooted in his ability to marry and have a wife, procreate and to own property. This is in line with hegemonic masculinity constructs (Duck, 2009:287).

When asked if living with HIV had in any way shaped his understanding of being a man Roger responded:

*“No, no, nothing has changed..... I feel also the same as I felt before.... I still feel like a man.”*

*(Roger, Page 13, Line 21-23)*

Roger feels he has not changed a single bit and his masculinity construct has not changed either since being diagnosed with HIV. He is still married, has children, and owns a house, all of which give him a sense of entitlement and reassurance about his manhood. This is in accordance with Duck’s (2009:287) attributes of a hegemonic masculinity construct which emphasise “marriage, children and jobs”.

Roger's feelings and perceptions of HIV were based on the information he had received about the virus. As he narrates, he believed that living with HIV automatically resulted in a quick death which could be avoided by the consistent use of treatment:

*"I felt bad, because why, they said the people that are HIV positive they die quick. But I said to myself if I use the treatment then I am going to last long"*

*(Roger, Page 5, Line 12-13)*

Roger's narrative tone is negative and the imagery is pessimistic at the beginning. However, it ends on a more positive and optimistic note with Roger's realisation that the use of treatment could have a positive impact on his life. He "felt bad" about contracting HIV and he believed that he would die quickly. This suggests that Roger is aware that he does not have the power, authority or control over his health or his life now that he is living with HIV. Roger's narrative defies the traits of a hegemonic masculinity construct as stated by Courtenay (2000:1388) who believes that hegemonic masculinity includes "leadership, strength, power and authority".

Furthermore, Roger states, "if I use treatment then I am going to last long". Roger acknowledges that he now has to depend on his treatment for the possibility of a long life. This dependence goes against the characteristics of the hegemonic masculinity construct – of being in full control of their bodies – as Roger now has to depend on biomedicine for long life which limits/weakens his masculinity construct (Duck, 2009:300).

Roger felt he had not had any negative experience as a result of his HIV status. He states that nothing has changed with the relationships he has with family and friends.

He narrates his good fortune:

*“To tell you the truth, none, nothing, negative experience I had. I am just like the same as I was. My family they don’t even worry, they are just the same as before. My friends also same as before. They don’t treat me different. They treat me the same, maybe even better than before”.*

*(Roger, Page 8, Line 5-8)*

Roger’s tone in the narrative extract above is content. He is happy with his support system and the way they still support and stand by him. The imagery is filled with notions of support and a strong support structure. Roger feels that his family and friends, if anything, treat him better than they did before he was diagnosed with HIV. He is very happy that he does not face any form of stigmatisation or discrimination from those who know his status. This may reinforce his masculinity construct and manhood as he does not feel undermined, belittled or discriminated against because of his HIV status.

Roger acknowledges being on ARV treatment which he takes twice a day. He also says that he suffers from no real side effects because of the anti-retroviral treatment. Roger narrated his experience with the treatment as follows:

*“I am just using ARV’s. I take two in the morning and two in the evening. No, there is no after effects..... I don’t feel sick, I don’t feel drowsy, I just feel normal.”*

*(Roger, Page 6, Line 9-11)*

Roger's narrative tone is one of relief and elation because he does not feel any further pain due to medication which may have compounded his worries. The narrative imagery used is of relief because he does not have to worry about the medication causing him more pain and discomfort. Although Roger does not suffer any side effects which could negatively impact upon his masculinity construct, he does imply a dependency on the treatment. He acknowledges taking his treatment twice a day, every day, which suggests the suggestion that he may be dependent on his treatment in order to maintain his good health. This dependency on treatment strongly weakens Roger's masculinity construct. Duck (2009:300) believes that any deviation from the ideals of a hegemonic masculinity construct such as sickness which results in a lack of control over one's body is associated with weakness and is viewed as not being manly and masculine.

#### **4.5.7 Thando**

At the time of the interview Thando was a 35 year-old, black, heterosexual male. Thando was married and lived with his wife and 5 year old daughter. His daughter was born HIV negative. Thando is the only participant who reported having found out his HIV status after voluntary testing, even though it was influenced by his work, it was not a requirement:

*"I went for testing. I volunteered by myself to go for testing. The reasons behind that, I was working for an NGO called (name withheld). I was one of the educators, people were around dispersing the information about HIV but it was unfair for me, unfair to others if I can tell them to go for testing whereas I didn't know my status. So I said I must go and know my status first so that I can tell them about the things that I went through. So unfortunately or fortunately I was HIV positive."*

*(Thando, Page 1, Line 20-25)*

Thando went for voluntary testing so that he could know his status and as a result encourage other people to test also. The tone of the narrative extract is positive, and it indicates that Thando was aware of his prior behaviour hence he wanted to know his status. The imagery is optimistic, with Thando stating that he needed to know his status and so that he would be able to make wise and informed decisions about his life in the future. Although Thando tested voluntarily, his sexual practices prior to the testing were very risky and dangerous.

Thando admits to having multiple sexual partners and no condom use even though he had knowledge of the dangers of not using a condom since he had contracted an STI prior to his HIV diagnosis. He narrated his experience:

*“I had a partner but I used to change ladies. Like if I am, let’s say, I am not married and on a date until such time when there is no importance of having this relationship anymore, I would have another partner and I won’t wear a condom and I won’t go for testing. I still remember when I had an STI twice in two months. The nurse told me: “This is not good for you. You need to wear a condom.” I said: “Wow! What do you mean, I am too young for those things?” I didn’t know that I was creating an entry point.”*

*(Thando, Page 13, Line 3-8)*

*“I was very young at the time condoms didn’t make sense to me.”*

*(Thando, Page 13, Line 29)*

Thando had prior knowledge about HIV and condoms. One of the nurses to whom he went for help when he contracted an STI suggested to him that he use condoms but the use of condoms “didn’t make sense” to him . Had he taken heed of the advice he

was given, things could have turned out differently. However, as a result of not following the advice, he contracted HIV. The imagery in Thando's narrative extract is of a man who believed he would not be infected with HIV.

Thando tested voluntarily (with some influence from his work) in contradiction with the notion put forward by Duck (2009:285) that men do not consistently and voluntarily go for HIV testing. Thando shows characteristics consistent with the constructs of hegemonic masculinity in that he was promiscuous, indulged in the risky sexual practice of inconsistent condom use, and twice caught STI's and did not take heed of the advice given to him by the nurses. Thando's defiance of professional advice, coupled with social pressures to fulfil gender stereotypes of promiscuity (Lee and Owen, 2002:45), were possibly an effort to preserve his masculinity construct (Kauffman, 1994, cited by Courtenay, 2000:1389; Rao Gupta, 2000:3; Charmaz, 1995, cited by Courtenay, 2000:1389). By continuing to take part in risky sexual activities regardless of the previous infections he had contracted, Thando placed himself at subsequent risk of contracting HIV.

Thando describes his manhood in accordance with the way his family treat him even after his positive diagnosis. He goes on to say:

*"I am responsible. I said no one can berate or no one can be infected. I will always safeguard the ones that are younger than me and I am living my life as an example. I am living my life to educate others. I have been there I know how it is to be there. My family, according to my family, my family supports me very well and I am happy to have that kind of a family."*

(Thando, Page 16, Line 10-14)

*“Nothing will happen (in the family). I am the youngest, nothing will happen in the house unless, if they didn’t call me. They have to tell me first, we are now frightened to do this or what are your inputs, what role do you want to play.”*

*(Thando, Page 16, Line 23-25)*

Thando takes pride in being responsible and being a social change agent. He believes his masculinity is shaped by the way he treats others. He makes mention of how he refuses to be belittled and of his discipline in the way he refuses to infect other people, as well as the way he strives to protect the younger generation. His manhood is therefore shaped in the way he views himself as the guardian and mentor of others, old or young, male or female. He also makes reference to the way his family is supportive of him and refrains from making serious family decisions without his input. The fact that his family consults him and values his contributions as the male figure and last born reinforces his manhood. Thando’s need to safeguard others and his desire to be involved in important family decision-making processes as part of the patriarchal system suggests that he adheres to the ideals of a hegemonic masculinity construct (Duck, 2009:287).

When asked if living with HIV had in any way shaped his understanding of being a man, Thando replied:

*“Yes!! First of all, as I have said one of the turning points when I got diagnosed HIV positive is it enlightened me in so many different ways. I remember from an organisation called the men’s sector, they had broadened my knowledge of becoming a man. If you go to a younger guy like me in the township and ask him about men’s sector he won’t tell*

*you because he doesn't have the knowledge but because I am HIV positive I have broadened my mind thinking and so many people, okay they know me because I have been infected for such a long time. They will tell you that there is this organization who wants you, can you come and give us your input, and can you come and give us what to do. So I am that kind of a person. I say: "okay, there is a need what about myself, do I have a role to play?" So it has built me as a man, a person who is so responsible, a person who knows that the community needs me more than I need them now."*

(Thando, Page 17, Line 1-11)

Thando agrees that living with HIV has indeed shaped his understanding of being a man. Now he feels he has received a lot of training and education around HIV and/or AIDS and is in a better position to impart this knowledge to young people as well as to his community. He has become more responsible and has built stronger and closer ties with organisations and his community. In the last sentence of the narrative, Thando says he has become more responsible and has realised that "the community needs me more than I need them now". This statement hints of an adherence to the constructs of hegemonic masculinity which, according to Courtenay (2000:1388), includes "leadership, strength, power and authority". This suggests that he feels he has become an asset to his community who needs him within it more than he needs to be there, reaffirming patriarchal dominance beliefs particularly of leadership and authority within his community (Connell, 1995; Groes-Green, 2009; Duck, 2009; Courtenay, 2000).

Thando's perception of the HIV virus was that it was deadly. This was largely based on the fact that there was no cure or treatment available when he contracted the virus in 2004. Thando shared his thoughts:

*“First of all I thought that it was the end of the world..... I thought it was the end of the world, and you can imagine because at that time there were no anti-retrovirals..... and I have seen so many people that were dying in front of me. I thought it was the end of the world.”*

*(Thando, Page 2, Line 9-13)*

In Thando's narrative above he indicates that he feels that the diagnosis signals “the end of the world”. The imagery in the extract is one of hopelessness. He felt hopeless and helpless because at the time that he contracted the virus, in 2004, anti-retroviral treatment was not widely available and affordable. Therefore, he felt that because of the limited availability of treatment, nothing could help cure the HIV virus or even prolong his life. Thus, without treatment Thando had no faith in being able to live a long, fulfilled life. This suggests that Thando felt biomedicine was his only chance to live a long life (Frank, 1995:85). This is supported by de Swaan (1990:220, cited in Fox, 2012:82) who states that “illness is marked by increasing dependency”. However, drug dependency weakens the entrenched ideals of hegemonic masculinity constructs as being independent and in control of their health (Duck, 2009:300) and never admitting to illness (Courtenay, 2000:1389).

The tone of Thando's extract above is sceptical and pessimistic which is influenced by his experiences of seeing others die from the incurable nature of the HI virus. This lack of power and control over the disease that Thando exhibits weakens and undermines his masculinity construct. This is also in direct contrast with the ideals of the hegemonic masculinity construct which believe that the individual possesses power, authority, dominance and control over his life (Courtenay, 2000:1388).

Thando has faced numerous challenging and testing negative experiences as a result of HIV status. He tells of the stigmatisation he has experienced at his church and within his family:

*“Within the churches, you know what, church is one of the places where they can build you or they can tear you apart. Once you have got this kind of illness they think that you are already dead. You will find that you aren’t even a part of the congregation anymore. You are just here, each and every time. Sometimes you have got bad days like every human being has. Sometimes you have flu, sometimes I will have things, once they see something: “Are you okay? Are you going to die?” They think of arranging the funeral and everything, but being a part of a church is something very challenging most of the time or being part of the family sometimes because family level you are not always the same. Some people, I still remember when I first found out about my status, some family members they even want my ID so that they can take insurance for me.”*

*(Thando, Page 7, Line 15-25)*

Thando narrates the negative experiences he has had to endure as a man living with HIV and being part of a church congregation and an extended family. He feels the church actually stigmatises the sick instead of uplifting them. He tells of how any illness or “bad day” could be misinterpreted as a potential near-death experience. He goes further to narrate how even his own family members are quick to assume he is dying and try to make insurance claims on his behalf every time he falls ill. His narrative tone is filled with disappointment at the way the very institutions that are supposed to help and support him further victimise him. The imagery is filled with disappointment in the family and church institutions and how they negatively affect him. This negative

experience may have a negative impact on Thando's manhood and masculinity construct because he is powerless and cannot do anything to effect change in the negative treatment they afford him. This suggests a deviation from the characteristic constructs of hegemonic masculinity which emphasise strength, control and influence over one's life, health and illness (Duck, 2009:300).

Thando, like most of the participants, acknowledges being on ARV treatment. He takes five pills per day. He says that he does not suffer from any side effects because of the antiretroviral treatment but acknowledges he is addicted to some other forms of medication:

*"I am taking anti-retrovirals. Two in the morning and three in the evening. Fortunately, I have never had any bad side effects. I never experienced such things. I am fine but the funny thing is that I am not sure if I am fine about it. I am addicted to Grandpa, I started when I used to have slight headaches, I used to take Grandpa a lot. I have been hospitalised, especially this year, three times."*

*(Thando, Page 6, Line 11-15)*

As seen in the narrative above, Thando's tone is very grateful that he has never suffered any side effects from the antiretroviral treatment. He acknowledges, however, that he is addicted to "Grandpa" - which is a powder-form medication used to treat headaches. He has been hospitalised on numerous occasions because of this addiction. The imagery in the narrative extract above is of gratitude because he suffers from no side effects but, on the other hand, there is also imagery of addiction and dependence on Grandpa. Thando has been hospitalised several times which is evidence of the way in which he has jeopardised his life. Thando's narrative supports de

Swaan's (1990:220, cited in Fox, 2012:82) assertion that "illness is marked by increasing dependency". Thus, Thando's masculinity construct is greatly weakened by his dependence on ARV treatment and his addiction to "Grandpa" medication. He has no control over his treatment in-take or his health and lack of control of his body and his sickness is associated with weakness and is viewed as unmanly and contradicts the ideals of a dominant masculinity according to Duck (2009:300).

#### **4.5.8 Zweli**

At the time of the interview, Zweli was a 47 year-old, black heterosexual male. Zweli is married and has been living with HIV for 8 years. He found out he was HIV positive in 2005 through what seemed to be a regular visit to the clinic with what he perceived as a minor illness:

*"No, I was here (clinic), I was sick because I had got the flu so I had to test. They forced me to do the test. So I allowed it and then they found (HIV)... I was so shocked."*

*(Zweli, Page 2, Line 2-3)*

Zweli's narrative tone begins positively with the belief that he suffered from a minor illness and that his visit to the medical professionals would be routine with no life threatening news. The narrative extract ends with the sad and shocking revelation that he was living with HIV.

There is also a hint of contentment and complacency in that despite his risky sexual behaviour which he narrates below, he did not ask for an HIV test but was "forced" into taking one. Zweli narrates his sexual practices before being diagnosed with HIV:

*“After, as I said in 2000, I started to get my responsibility. I started to have one partner at a time and I didn’t use condoms. I tried to use condoms but there is no interest as such in condoms.”*

*(Zweli, Page 11, Line 16-18)*

*“Sometimes, it depends to the person. Yes I used it but sometime I didn’t use it. We used it twice a night maybe before twelve or before eleven in the night and then in the morning we forget about the condom, we didn’t use it, skin to skin.”*

*(Zweli, Page 12, Line 5-7)*

Zweli reported having one sexual partner at a time but that he did not consistently use condoms. For him, condom use was all dependent on the woman with whom he was involved. If she insisted on using a condom then he would use a one, if she was open to the idea of unprotected sex, and did not see the need for condoms he would not use them. When it came to the issue of condom use, Zweli was very easy going and left the decision to use or not to use a condom to his female partner. It seems he was not particularly concerned about his own health but was more concerned about the sexual pleasure derived from “skin to skin” sexual intercourse. The imagery used is in line with the constructs of hegemonic masculinity, more concerned with self-pleasure, ignorant of the dangers of not using a condom (Rao Gupta, 2000:3; Edwards, 2006:2). In addition, Zweli contradicts himself because he says he began to get more responsible, but his sexual behaviour was irresponsible and put him at high risk of contracting HIV.

Zweli believes unprotected sex, “skin to skin” makes him a man and makes him feel manly. He described his masculinity as being shaped by:

*“Unprotected sex, when you are doing sex using no condoms, you are doing sex, flesh to flesh and you feel your body attaching to each other there is great sexuality but a good sexual situation. But when you are going to use condoms there will be no such contact. When you are skin to skin you get the good results than when you are using condoms. At the same time if you do sex without a condom, really, really, it is marvellous, it is fantastic. It is good !!! ”*

*(Zweli, Page 15, Line 23-29)*

Zweli believes the pleasure derived from “flesh to flesh” sexual intercourse makes him feel like a man. He describes the feelings of this intimacy as being “marvellous”, “fantastic”, and “good”. Thus, for Zweli his manhood is to an extent reinforced by his ability to have unprotected sexual intercourse. Zweli’s risky sexual behaviour is consistent and closely related to the typical high risk behaviours of a hegemonic masculinity construct branded by multiple sexual partners and unprotected sex (Lindegger and Quayle, 2009:50).

When asked if having HIV had in any way shaped his understanding of being a man, Zweli responded:

*“Your confidence is slowing your self-esteem, yes, it is slowing your self-esteem... Because I can’t do this. When my mind is on a bed, let me use a condom and then the penis will not function properly because of that. Because the aim (to have sex) and the organ they are connecting to each other. Your aim tells you this then the body will follow that communication of the body. Ja, so you are not feeling right unless you just forget about all these things and the first thing is use a condom and then you will feel free.”*

*(Zweli, Page 16, Line 28-33)*

Zweli, from the extract above, tries to explain how his confidence and self-esteem are lowered because of the need to use condoms as a result of his HIV status. He describes how his male organ does not respond to his desire to have sex if he is to use a condom. This suggests that Zweli is aroused much more by the thought of unprotected sex and is “turned off” by the thought of having to use a condom. Thus, Zweli’s manhood is reinforced by his ability to get aroused, get his male organ working and take part in unprotected sex which in turn suggests that Zweli’s masculinity construct is consistent with the ideals of hegemonic masculinity which is characterised by risky sexual behaviour (Lindegger and Quayle, 2009:50).

After the positive diagnosis, Zweli’s first impression of his HIV status was that it was a death sentence. Zweli’s narrative imagery below indicates pessimism. His tone is filled with doubt as he narrates:

*“I thought it was the end of the road for me because there was no cure or ARV’s at that time”*

*(Zweli, Page 2 Line 19)*

Zweli acknowledges that he thought it was “the end of the road” for him after finding out he was living with HIV. His feelings of impending death were made worse because in 2005 when he contracted the virus, ARV treatment was not as readily available and as affordable as it is today. Thus, without treatment he felt death was inevitable.

Because “there was no cure or ARV’s at that time”, Zweli’s narrative pinpoints his self-admission to being powerless over his HIV status and over his health. Zweli’s acceptance of being powerless over his health is associated with weakness, which is

viewed as unmanly, and deviates from the ideals of hegemonic masculinity constructs (Duck, 2009:300).

However, ARV's are now more readily available than they were when Zweli first contracted HIV. Zweli narrates of his experiences with the antiretroviral treatment. He acknowledges taking 4 ARV'S everyday as well as TB treatment. He narrates his experiences with the treatments' side effects:

*“Well, I am using ARV's now. I take two ARV's in the morning and in the evening. And I also take two pills for TB at the same time. Before, before was so sad because there are effects that you are upset with the stomach, or yes, let's say stomach - you want to vomit you want to do something. But they are going to give you something that can calm those effects. They avoid the side effects”*

*(Zweli, Page 6, Line 6-10)*

Zweli's narrative tone indicates with some concern because these side effects cause him discomfort. The narrative ends with a hopeful tone because the medical professionals give him more pills “that can calm those effects”. As a result of the lessening of the side effects from the treatment, his tone changes from being negative to slightly more positive. Zweli is happy about the availability of medication that lessens the pain caused by the side effects but, as a result, his dependency on medication increases in order to lessen the pain and as De Swaan (1990:220, cited in Fox, 2012:82) states “illness is marked by increasing dependency”. Therefore, Zweli's resulting dependency on medication to ease his pain also deviates from the ideal constructs of hegemonic masculinity stated by Duck (2009:300), and it is viewed as a weakening of his masculinity construct and as unmanly behaviour.

Zweli reports not having had any negative experiences as a result of his HIV status. This is the case because Zweli did not disclose his status to anyone except his wife. He narrates:

*“No because they didn’t know me, they don’t know me that I am HIV.... I didn’t tell anyone. It is my wife and me only”.*

*(Zweli, Page 7, Line 11-13)*

Zweli has not informed anyone except his wife of his HIV positive status. This may suggest a fear of stigmatisation which might have resulted had he told his family and his community. The imagery in the narrative extract above is filled with secrecy. The tone is fearful. He is fearful of the response his revelation could evoke and therefore he keeps his status a secret. Zweli possibly fears that if his family and community know of his status they would react and act negatively towards him. This could also negatively impact his manhood. The revelation and possible negative response from people could weaken his masculinity construct, causing a deviation from the ideals of power, authority, control and influence of a hegemonic masculinity construct which he Zweli adheres to.

#### **4.6 Discussion**

The way all the men interviewed behaved with regard to their sexual practices and behaviours is largely in line with the constructs and ideals of hegemonic masculinity as defined by Connell (1995), Courtenay (2000), Rao Gupta (2000), Moodie (2001), Edwards (2006), Duck (2009), Lindegger and Quayle (2009) and numerous other authors. All 8 men largely exhibited behaviours closely linked to the ideals of hegemonic masculinity. These behaviours included having multiple sexual partners, inconsistent

condom use, lack of sufficient sexual and HIV knowledge, and inconsistent testing patterns. All these put them at great risk of contracting HIV.

It is important to note that a large number of the men interviewed - Mike, Thabo, Vuyo and Thando- reported having experienced some form of stigmatisation and discrimination at work, at church or within the family because of their HIV status. Sipho and Zweli reported that they did not disclose their HIV status to either their family or community, and, as a result, had not faced any form of stigmatisation or discrimination. Their fear of being stigmatised perhaps resulted in their unwillingness to disclose their HIV status. Phillip and Roger are the only two who reported that they had disclosed their status to their communities but had never been stigmatised or discriminated against as a result. For those men who experienced some form of stigmatisation, their masculinity constructs were greatly affected and weakened which seems to have brought emotional, psychological and physical suffering.

The research findings highlight how masculinity is socially constructed. The findings show how men constructed, viewed and understood their manhood and masculinities through social factors – such as being the bread-winner, being involved in family and community matters and decision-making processes – material possessions - such as a job, a car, a house - and through social institutions like having a wife and children (family). In addition, they expressed their masculinity through their sexual practices such as being able to have multiple partners and being able to have unprotected sex.

Research also suggests that gay men, who are believed to have subordinate masculinities, view themselves as men through their personal attributes and

characteristics and not through physical or sexual conquest and material possessions as suggested for men who adhere to hegemonic masculinity ideals.

The research findings also show that the participants who adhered to the ideals of a hegemonic masculinity construct shared similar attitudes and perceptions towards their future prospects after being diagnosed with HIV. They viewed living with HIV as weakening their masculinity as they struggled to fulfil the cultural and societal masculinity stereotypes of promiscuity and risky sexual behaviours (Lee and Owen, 2002:43). In addition, in some instances participants suggested the need for or dependence on bio-medicine for good health (Williams and Bendelow, 1998:161). These behaviours demonstrated by the participants deviate from the goals of hegemonic masculinity constructs. Adherence to hegemonic masculinity constructs are believed not to need help from any external factor to maintain or restore their good health as they perceive themselves as machines that are immune to illness (Edwards, 2006:14). Therefore, this suggested a deviation from the ideals of hegemonic masculinity.

It is also interesting to note that although a significant number of the participants adhered to the constructs of hegemonic masculinity when it came to their sexual practices and behaviours, they also exhibited subordinate masculinity constructs in other areas. For example, a significant number of participants were dependent on treatment for optimum health and this dependence on an external factor is in adherence with constructs of subordinate masculinity. Thus, it was important to note that even though participants adhered to constructs of hegemonic masculinity in some aspects of their life, they also simultaneously adhered to constructs of subordinate masculinity in

other aspects of their lives. Therefore, it can be noted that hegemonic masculinity constructs vary depending on the situation. And there can sometimes be an interchange between hegemonic and subordinate masculinity depending on the situation. This supports the notion that masculinity is situation and context specific.

#### **4.7 Conclusion**

The study findings suggest that a significant number of the participants adhered to the ideals of a dominant hegemonic masculinity construct which was identified by the participants' descriptions of their manhood, sexual practices and behaviours. The participants found sexual conquest, promiscuity, patriarchy, employment, marriage and family, and ownership of property to be factors that defined their manhood. All these factors make up the characteristics and ideals of hegemonic masculinity. But, within the same breathe it is important to note that the participants also exhibited constructs of subordinate masculinity. This suggests that subordinate and hegemonic masculinity are intertwined and interlinked. Therefore, the emergence of a masculinity type is largely dependent on the context or situation the man is faced with.

Because masculinity is socially constructed (Connell, 1995), the way a man understands and conceives a chronic illness such as HIV and/or AIDS is closely tied to his masculinity concept. From the narrative analysis in this chapter, it was brought to light that a significant number of the participants displayed characteristics in line with the ideals of hegemonic masculinity constructs (Connell, 1995). This type of masculinity construct is the most dominant and widely accepted form of masculinity. Even Phillip, who is gay and is theoretically classified within the subordinate masculinity construct because of his sexual orientation, was involved in the risky sexual behaviour of no

condom use and multiple sexual partners - behaviours similar and consistent with the ideals of hegemonic masculinity construct according to Connell (1995).

Therefore, in the same way that masculinity is constructed, it can also be deconstructed – socially. The participants' masculinity constructs were brought into question and, at times, greatly weakened because of their experiences of their HIV status. This disease greatly weakened their perception of their manhood because of the physical, emotional and psychological suffering they went through due to a lack of control over their bodies and their health (Duck, 2009:300). For the participants, dependency on treatment, which was perceived as aiding in the restoration of their optimum health, was also seen as weakening their manhood.

Thus, in conclusion, the findings highlight the need for a continued understanding of masculinity constructs. With the emergence of HIV, masculinity constructs, primarily hegemonic masculinity construct, will need to be reconfigured to take into account the effects of this chronic illness on men and their social and cultural roles and expectations. The findings of this research support Edwards' (2006:3) idea that change and continuity are factors which influence the discourse of historical and contemporary masculinities and identities. Therefore, after analysing the effects of HIV illness on men, new social and cultural constructs of masculinity need to be posited to encourage safe and responsible sexual behaviours for young boys and men. Because without these social and cultural changes in masculinity constructs, the HIV and/or AIDS pandemic will be most likely to continue to spread unabated.

## **Chapter 5**

### **Summary and Conclusion**

#### **5.1 Introduction**

This chapter reflects on the main issues raised in this research. The aim of the research was to elicit, investigate, explore and understand the illness narratives of the life experiences of men living with HIV and/or AIDS in the Buffalo Municipality Region of the Eastern Cape Province in South Africa.

#### **5.2 Chapter Summaries**

##### **5.2.1 Chapter One**

This chapter describes the background of the study, states the problem, the research aims and objectives and poses the research questions. This chapter also highlights the theoretical framework that will be used as a reference for understanding masculinity and its social constructivism. This theoretical framework centres on Connell's work on masculinity.

As a result, the dominant form of masculinity, that is, hegemonic masculinity, and its ideals is featured in this chapter. It briefly notes that masculinity is a socially and culturally constructed phenomenon. The ideals of this form of masculinity differ from author to author but one constant expressed in this chapter is that hegemonic masculinity is the most notorious, popular and exalted form of masculinity.

The second type of masculinity, subordinate masculinity, is also discussed briefly. This form of masculinity is also socially and culturally constructed and represents a deviation from the goals and ideals of the more dominant hegemonic masculinity. It is made clear

in this chapter that masculinity, primarily the hegemonic masculinity framework will be used as a concept which will help to better understand the experiences of men living with HIV and/or AIDS.

Chapter 1 considers the limitations of the study, the study's significance and it outlines each chapter of the research.

### **5.2.2 Chapter Two**

This chapter introduces and discusses the history of HIV and/or AIDS. Details of how HIV was discovered and opposing theories of where HIV originated from are briefly explored in this chapter. The global and regional statistics, demographics and trends of HIV and AIDS according to UNAIDS are considered.

Chapter 2 focuses on the body, pain and illness. An overview of the body and illness is presented and the way sociological approaches understand and conceive illness is discussed. It is noted that people who suffer from HIV and/or AIDS are not only in physical pain, but they also suffer and feel the emotional, psychological and psycho-social effects of such a disease and illness. Some of the psycho-social effects of HIV and/or AIDS discussed include, but are not limited to, isolation, loneliness, stigmatisation, discrimination due to an HIV positive diagnosis and/or a dependency on anti-retroviral medication. Thus, the body, during illness, becomes the "central aspect of experience". This results in the sufferer trying to alleviate this pain through two components – hermeneutical and pragmatic means.

The consideration of dependency on medication results in a discussion of bio-medicine, the bio-medical model and illness. Williams and Bendelow argue that dependency on

treatment reinforces the split of emotional and physical dualism instead of acting as a healing catalyst. This is said to be the result of two factors, the first is that when individuals seek medical help they are taught to view and refer to their bodies and pain in sophisticated and complicated terms. As a result, the body and disease are viewed as concrete products by the bio-medicine industry and this then places greater emphasis on disease over illness. The second factor is that medical treatment may reinforce and increase the awareness and pain of the sufferer which may result in the patient increasing or altering their drug intake. As noted in the research, some participants suffered unpleasant side-effects from the ARV treatment, which added to the already present pain of the illness within their bodies. Therefore, as William and Bendelow put it, “medicine is both a fountain of hope” and a “fountain of despair”.

Another important point discussed in Chapter 2 is the importance of illness narratives. These accounts of “insider” perspectives of the illness experiences through narratives are an important tool in understanding how sufferers understand, explain and rationalise their pain and illness. The sufferer, through narratives, can turn the negative illness into a meaningful and positive story. In this way, the eliciting and collection of narratives is an important feature of this research.

Also of great importance are the effects of cultural and gender differences as they affect how people view, understand and respond to illness. Therefore, an individual’s expression of pain and illness is primarily dependent on the context, beliefs and values of the social or cultural group of which the sufferer is part. Gender plays a significant role in the expression or suppression of pain and illness. Men suppress and deny the presence of pain or illness because they fear that admitting to ill-health will result in a

loss or weakening of their masculinity construct. Thus, it is important to note that an individual's response to pain is both gender-specific and context-specific.

This chapter also highlights through the literature that HIV and/or AIDS is a gender-based disease which affects men and women differently. Women and young girls are twice as likely to contract the disease as males of the same age. However, although the rate of HIV infection is lower in men than in women, men have higher mortality rates due to HIV and/or AIDS. This, the UNAIDS suggests, is because gender norms of masculinity discourage men from seeking medical attention, such as voluntary testing, admitting to ill-health and adhering to treatment.

The masculinity framework is further discussed in this chapter, with authors defining what they believe masculinity to be and what characteristics or ideals each type of masculinity adheres to. Also discussed is Edward's three-phase model of the evolution of masculinity studies from the mid 1900's to date. This illustrates how masculinity constructs and understanding have evolved over time due to a number of different social factors. Because HIV is spread through sexual contact, it is crucial to understand what roles masculinity constructs as well as male sexuality play in the spread of this pandemic. The research findings also highlight how the participants understand and construct their masculinity in terms of their sexual practices and social experiences.

The socio-economic impacts of poverty, domestic violence, gender-based violence and alcohol abuse and their effects on HIV and AIDS are also discussed in Chapter 2 as these factors play a part in exacerbating the spread of the pandemic or in making the lives of those living with the virus a little more difficult to live.

Chapter 2 also discusses the political position of the global and national communities with regard to their response to HIV and/or AIDS. Legislation and policies, which aim to help in the fight against HIV, are featured. These policies include the Millennium Development Goals set up by the United Nations and the Negotiated Service Delivery Agreement set up by the South African government to combat the scourge of the HIV and/or AIDS pandemic. These policy documents aim to reduce new infections and the spread of HIV. They help to guide and provide better understanding of the responses and measures adopted to understand the experiences of men, as well as their sexual behaviours which place them at high risk of contracting HIV.

### **5.2.3 Chapter Three**

This chapter provides more evidence as to why the selected research method was the most suitable to meet the research's aims and objectives. The collection and analysis of "insider" accounts/narratives of the experiences of living with HIV and/or AIDS offer a better way of understanding men and how they experience and deal with illness, particularly a chronic illness such as HIV and/or AIDS.

This approach is ideal because it offers "insider", first-hand illness accounts of personal experiences which are richer and thicker than medical and sociological theories of illness which offer "outsider" perspectives. While utilising descriptive narrative research techniques, the qualitative data collected in the form of narratives from the participants is interpreted in order to make sense and to configure the information so as to generate observable outcomes with regard to the experiences of living with HIV and/or AIDS.

Utilising a descriptive narrative research design made it possible to analyse and interpret the narratives in a homogenous manner, identifying themes that were unique

as well as themes that were recurring across the participants' narratives. These themes included issues such as risky sexual practices, the lack of voluntary testing, a strong dependence and religious adherence to treatment, The aim of this was to recount, interpret and describe social and cultural depictions used by the participants to express their experiences of living with HIV and/or AIDS, and the effects this had on their masculinity constructs.

Chapter 3 indicates that the findings of this qualitative research design cannot be generalised to the entire population. However, qualitative research findings achieve external validity or transferability, which allow the findings to be recognised if studied under similar contexts or settings.

#### **5.2.4 Chapter Four**

This chapter presents the findings of the descriptive narrative research design. It shows that understanding the experiences of individuals living with HIV and/or AIDS and the way in which these experiences impact on the construction of their masculinities is crucial to the study. In addition, it gives insight into their sexual practices, emotions and the meanings attached to these events, through their narratives. It is noted that the storylines of most of the participants, although individual and unique, tend to follow a similar illness trajectory with similar emotions and thoughts occurring at various points.

This chapter provides findings that suggest that most of the participants adhered to the ideals of hegemonic masculinity. Their risky sexual behaviours and practices were in line with the sexual behaviours of men who adhered to hegemonic masculinity constructs. In addition, the participants' understanding and description of their masculinities and manhood highlights that masculinity is socially constructed. They

constructed their masculinity in relation to whether or not they owned property, were married, had children, had a job, and financially provided for their families. All these are social factors which contribute to their understanding and perception of what masculinity is. Even Phillip, who is theoretically considered to adhere to the ideals of a subordinate masculinity construct, exhibited behaviours in line with the hegemonic masculinity ideals of having multiple sexual partners and inconsistent condom use.

The participants shared similar emotions of pessimism and despair when they were diagnosed with HIV. They all felt as though this diagnosis was a death sentence which signalled an inevitably quick death. Participants also reported that living with such an illness was difficult because they had to endure different forms of stigmatisation and discrimination because of their status. Some of this stigmatisation was very degrading. Hence, they did not disclose their status to anyone.

However, some of the participants, like Phillip, have learnt to accept and embrace the fact that they are living with HIV and/or AIDS, and as a result, experience the need to live life and enjoy it to the fullest. Thando also learnt to accept his illness and manage it in the best way he could for the sake of his wife and daughter who were both HIV negative. Thando's joy comes from the knowledge that he could father a child who is HIV negative.

What is of importance to note, is that most of the participants indicate having changed their sexual behaviours from before their diagnosis and became less promiscuous and risk-taking. The participants indicated that they found it easier to abstain from sex now, be involved with one partner at a time and to use condoms more consistently. This

sexual behaviour change suggests that the illness somehow brought about a mind-set shift more in line with safe sexual practices.

The lack of control of and sickness from the disease, as well as the treatments' side-effects which some men reported experiencing, significantly weakened the men's masculinity constructs as they deviated from the ideals of hegemonic masculinity. The men reported having to spend long periods of time in hospital because of their ill-health which resulted in family members and their communities gossiping about their health and impending death. Because the participants could do nothing about this they felt weak and vulnerable, which had negative effects on their manhood and masculinity constructs.

In summary, this chapter describes the unique and similar experiences the participants encountered as reflected in their narratives. The illness trajectory for most of the participants followed a similar path, beginning with how they were unsuspectingly diagnosed with HIV after a short illness. This was followed by the emotions, thoughts, perceptions and experiences they underwent because of their HIV status and the effect these experiences had on their masculinity constructs and understanding of their manhood.

### **5.3 Conclusion**

This research sought to highlight the important role that narrative exploration plays in the understanding of illness experiences. Narratives are an important tool which help to provide first-hand accounts of illness experiences from the narrators/sufferers themselves.

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## Appendixes

### Appendix A – Semi Structured Interview Questionnaire

1. How old are you, and where are from?
2. **When** and **How** did you find out about your HIV status?
3. **How** did the results make you feel, and **why**?
4. Tell me about your life before you were diagnosed with HIV?
5. **What** were your hopes, plans and dreams for your life? And has being diagnosed with HIV interrupted any of these? In what way/s ?
6. **What** were your perceptions, beliefs, attitudes and thoughts towards HIV before you were diagnosed as being HIV positive?
7. Are you currently on any medical treatment for the illness and **what** are the effects?
8. **What** negative experiences have you gone through since being diagnosed with HIV?
9. **What** positive experiences have you gone through since being diagnosed with HIV?
10. Have you experienced any form of stigma as a result of being HIV positive and if so please tell me about it?
11. **What**, if any would you classify as a turning point/highlight in your life since being diagnosed with the HIV virus?
12. **How** do your family and friends feel about your HIV status?
13. **Who** can you say has played a significant role in your life since being diagnosed with HIV? b) **How** and **why** would you say they have been significant in your life?

*Now I am going to ask you questions that are a little more personal. If you feel uncomfortable you can decline to answer the question and we can move on to the next question. But it would be of great importance if you answered the questions and would mean a great deal to me I once again would like to assure you that the information shared will be confidential and your identity will remain anonymous.*

14. **What** was your sex life like before being diagnosed with HIV, **how** often did you have sex and did you have a single or multiple partners?
15. **What** were your sexual practices like before being diagnosed with HIV? Did you use condoms, if yes **how** often. If No **why** not? b) Have your sexual practices and sex life changed since being diagnosed with HIV? If yes,**how**?
16. When you contracted HIV were you in a stable relationship?
  - a) If yes is the partner you were in a relationship with the same person you contracted HIV from? b) If no do you know from whom you got the virus?
17. How would you describe yourself as a man, and do you think you were accepted as a man before by family, friends and partners?
18. Do you think being HIV positive has in any way shaped your understanding of being a man? If yes **how**? If no, **why** do you feel this way?
19. Imagine you were to write a book about your experiences of living with HIV/AIDS, what would be important to you, to include in the book? Are there any messages you might like to include in such a book? Is there any advice you would include in the book, particularly advice to other men?
20. From your experiences, would you say there are any misconceptions about HIV and AIDS? Are we made to believe things about HIV and AIDS that you think are not true, given your experiences? Are there things that are true and we should believe? What are these things?

## Appendix B – Consent Form



University of Fort Hare  
*Together in Excellence*

University of Fort Hare  
DEPARTMENT OF SOCIOLOGY  
**AGREEMENT BETWEEN STUDENT RESEARCHER &  
RESEARCH PARTICIPANT**

Updated 31 October 2013

I agree to participate in the research project of Tendai Gumbie entitled “**Men living with HIV and AIDS**: A narrative study of males experiences of living with HIV and AIDS in Buffalo City Metropolitan Municipality in the Eastern Cape Province of South Africa”.

I understand that:

1. The researcher is a student conducting the research as part of the requirements for a Master’s degree at the University of Fort Hare. The researcher may be contacted on 079 940 1442 or [t\\_gumbie@yahoo.co.uk](mailto:t_gumbie@yahoo.co.uk). The research project has been approved by the Research Projects and Ethics Review Committee, and is under the supervision of Ms Penny Jaffray in the Sociology Department at the University of Fort Hare, who may be contacted on 043 704 7013 or [pjaffray@ufh.ac.za](mailto:pjaffray@ufh.ac.za)
2. The researcher is interested in the narratives of men diagnosed as HIV positive or living with AIDS and how this has impacted on the construction of their masculinities.
3. My participation will involve my answering questions in an interview setting which will take about 60 minutes.
4. I will be asked to answer questions of a personal nature but I can choose not to answer any questions about aspects of my life which I am not willing to disclose.
5. I am invited to voice to the researcher any concerns I have about my participation in the study, or consequences I may experience as a result of my participation, and to have these addressed to my satisfaction.
6. I am free to withdraw from the study at any time - however I commit myself to full participation unless some unusual circumstances occur or I have concerns about my participation which I did not originally anticipate.

7. The report on the project may contain information about my personal experiences, attitudes and behaviours, but that the report will be designed in such a way that it will not be possible to be identified by the general reader.

8. If possible, our organisation would like to come back to this area once we have completed our study to inform you and your community of what the results are and discuss our findings and proposals around the research and what this means for people in this area.

**INFORMED CONSENT**

I hereby agree to participate in research regarding ..... I understand that I am participating freely and without being forced in any way to do so. I also understand that I can stop this interview at any point should I not want to continue and that this decision will not in any way affect me negatively.

I understand that this is a research project whose purpose is not necessarily to benefit me personally.

I have received the telephone number of a person to contact should I need to speak about any issues which may arise in this interview.

I understand that this consent form will not be linked to the questionnaire, and that my answers will remain confidential.

I understand that if at all possible, feedback will be given to my community on the results of the completed research.

.....

**Signature of participant**

**Date:**.....

I hereby agree to the tape recording of my participation in the study

.....

**Signature of participant**

**Date:**.....

## **Appendix C – Reflections**

Reflecting or reflexivity is thinking about something after the event, and it involves immediate, dynamic and continuing self-awareness (Finlay and Gough, 2003). It requires critical self-reflection of the ways in which the researcher's social background, assumptions, positioning and behaviour impact on the research process (Finlay and Gough, 2003). According to Finlay and Gough (2003:3), reflexivity in qualitative research is when "the researcher turns a critical gaze towards themselves". In the following section I will detail the problems that affected me as a researcher in conducting this study, even though I eventually felt and believed that I had done my best to collect, analyse and interpret the data without being biased or bringing my own opinions into the study.

Firstly, my religious beliefs played a significant role in my mind. I am religious and as a religious individual, I feared that the topic of sexual narratives and behaviours was going to be difficult for me. The findings and some of the information the participants gave about their sexual experiences and practices somewhat contradicted what I believe and also went against some of the values I hold. However, I eventually realised that this was a research project and I had to stay as objective as possible so as to try and attain my goals, thus I eventually distanced my religion from the project.

Secondly, because of my personal opinions about sex and safe sexual behaviours, I constantly had to remind myself to stay objective and simply to analyse the data without being judgemental of the responses of respondents. At first this was difficult as my own morals seemed to shape my analysis of the data, but with time, I withdrew my personal

feelings, thoughts, ideas, views and beliefs about the topic and the study and continued with the research project without being personally morally involved.

Thirdly, I share the same cultural, economic and social background as the participants and this was both negative and a positive for my study. It was positive in that I could easily relate to some of the experiences the participants had been through. However, relating to these experiences was also negative because in my analysis I then tended to put in my personal views and thoughts about the experiences as they had affected me at a personal level but eventually I learnt to take a step back and analyse the data objectively as a social researcher.

I believe that having had the experience of conducting a project on my own I have learnt many things about how researchers can easily influence or bias their projects. Thus, I have learnt valuable first-hand lessons which I hope to carry with me into future research projects so as to make them as transparent and bias-free as possible.