Beliefs and perceptions that influence utilization of HIV/AIDS services by newly HIV diagnosed men in rural Mbashe Sub-District in the Eastern Cape Province of South Africa.

# By

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# Declaration

I **Clever Mubuyayi** declare that this research report is my original work. Any work done by other person has been properly acknowledged in the text. The report is submitted in partial fulfilment of the requirements for the degree of Master of Public health, in the field of Social and Behaviour Change Communication with university of Witwatersrand, Johannesburg. It has not been submitted for any other degree or examination in this or any other university.

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#### Abstract

## Introduction

HIV/AIDS services are now given freely at public health facility level. They have been decentralized to the formal primary health facilities in the rural areas. Despite the efforts by the South African government, the utilization of those services remains a challenge. There are gender disparities in utilisation of HIV/AIDS services as females utilize the services in greater numbers compared to their male counterparts. The newly diagnosed seropositive men tend to disappear soon after HIV testing, only to appear in a formal health system when their immune system is seriously suppressed and at a more advanced WHO stage of disease. Therefore, the overall aim of this study was to explore the underlying perceptions and beliefs that influence utilization of HIV/AIDS services by newly diagnosed HIV positive men in Mbashe Sub-District of the Eastern Cape between January 2010 and March 2011

#### Methods

The study was conducted in the rural Mbashe Sub-District of the Eastern Cape Province and utilized a qualitative methodology. This qualitative approach relied on semi-structured indepth interviews with newly diagnosed HIV positive men of 18-49 years of age who were either accessing or not accessing the HIV/AIDS services during January 2010 and March 2011. The participants were recruited through purposive sampling and 18 interviews were conducted in 6 different facilities at three different service levels. Interviews were audio-recorded and transcripts were subjected to thematic content analysis based on the Health Belief Model.

#### Results

The results show that both groups of men reacted negatively to HIV positive status. The experiences during HIV Counselling and Testing were not linked to whether men could access services. The barriers to utilizing the available HIV/AIDS services included fear of stigma and discrimination, need for an alternative quick cure which delayed utilization of the services, the clinic as gendered space, compromised Provider-Initiated Counselling and Testing (PICT) model implementation, shortage of food, physical fitness and alcoholism. The facilitators for access included the need for survival, disclosure and social support, and cues to action like witnessing a relative dying due to HIV/AIDS related illness. However, the HBM model could not squarely explain the trends in accessing HIV service since few constructs were found to be relevant and also some issues that are outside the HBM model emerged.

#### Conclusions

The study demonstrates that newly diagnosed men's utilization of the subsequent free HIV/AIDS services at the primary health care level is influenced by many factors . There are those factors that trigger men to utilize the services and those that deter them from accessing necessary HIV/AIDS services. The factors that influence their access to services are mainly within the multilevel framework which ranges from individual, family, community and societal factors. Therefore, the targeted interventions to address the issue should focus on addressing stigma and discrimination, policy change on training, recruitment and deployment of male nurses, integration of traditional/spiritual interventions within the mainstream of health services, correct implementation of the PICT model and encouraging couple

counselling and testing. The Health Belief Model constructs, especially perceived severity, were not strongly linked to whether men accessed services or not.

# Dedication

I dedicate this work to my family, especially my wife (**Nomkitha**), son (**Tanaka**) and daughter (**Atipa-Ishe**) for allowing me to sacrifice their time to complete this research project. Your love and support made this research project possible. Thank you very much for being there and not giving up.

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# List of Abbreviations

Acquired Immune Deficiency Syndrome
Antenatal Care
Antiretroviral Therapy
<b>Community Health Centre</b>
Eastern Cape Department of Health
Fixed-Dose combination
Health Belief Model
HIV Counselling and Testing
Human Immune Virus
Human Research Ethics Committee
In-Depth Interviews
National Department of Health
Provincial Eastern Cape Department of Health
Primary Health Care
Provider Initiated Counselling and Testing
People Living with HIV
Pre-Antiretroviral Therapy
Pre-Treatment Lost to Care
Tuberculosis
United Nations program on HIV and AIDS
Voluntary Counselling and Testing
World Health Organization

#### **CHAPTER 1**

# INTRODUCTION, LITERATURE REVIEW, AIMS AND OBJECTIVES

# **1. Introduction**

# **1.1 Background**

The HIV and AIDS epidemic remains a major global public health challenge with a total of 33.3 million people living with HIV worldwide (WHO, 2011). In 2009 alone, 2.6 million people were newly infected with HIV and about 1.8 million people died of AIDS (WHO, 2011).

South Africa specifically carries the world's greatest burden of HIV infection, with estimates that it is home to approximately 17% of the world's HIV population (UNAIDS., 2008). The Eastern Cape Province is one of the most affected areas in South Africa with 28% of HIV prevalence in 2007 (DoH, 2008b). The Eastern Cape Department of Health (ECDoH) went further to show the HIV prevalence per district, in which Mbashe sub-district recorded 28.3% among women attending antenatal care (ANC)<sup>1</sup> (DoH, 2008a).

A growing body of evidence suggests that men are far less likely than women to access HIV services including testing, treatment and other care and support services (Hudspeth et al., 2004). Data from South Africa indicates that men account for only 21% of all clients receiving HIV counselling and testing (HCT) (Magongo et al., 2002). Men's underutilization of HIV services significantly undermines prevention and treatment efforts since the HCT

<sup>&</sup>lt;sup>1</sup> Antenatal clinic is the visit to the health care facility by pregnant women. In South Africa women are mandated to test for HIV through Provider-Initiated Counseling and Testing.

approach in South Africa is regarded as the entry point to HIV treatment and care (Magongo et al., 2002). Forty-five per cent of those accessing antiretroviral therapy (ART) are men, despite roughly equal HIV prevalence rates among men and women (Uganda, 2008). These gender discrepancies in ART uptake reflect men's beliefs that seeking health services is a sign of weaknesses (Nachega Jean et al., 2006).

Similarly, research on the uptake of ART shows that uptake is higher among women, In Khayelitsha, 70% of those accessing ART were women (Coetzee et al., 2004). In Johannesburg General Hospital, women accessing ART outnumber men by a ratio of two to one (Hudspeth et al., 2004). In other studies men have been found to seek care when symptoms are far advanced (Biber et al., 1999). The consequence is that men access ART with more compromised immune systems, resulting in poorer health outcomes and a greater cost to the health care system (Hudspeth et al., 2004). The evidence suggests that delayed health care seeking may result from male socialization where health seeking behaviours are often taken to be a sign of weakness (Pearson and Makadzange, 2008). The results of a 2004 survey of 566 Khayelitsha residents showed that two-thirds of respondents agreed or agreed strongly with statement that men think of ill-health as a sign of weakness which is why they go to a doctor less often than women (Natrass, 2006)

There are barriers to men accessing HIV/AIDS management services. Initiating early and comprehensive HIV management of patients can reduce mortality and impact on morbidity associated with HIV/AIDS. It is therefore imperative to better understand men's perceptions and beliefs following a positive HIV diagnosis.

The HIV Counselling and Testing HCT Policy Guideline stipulate that a person, upon consent, will be tested for HIV through either Client Initiated Counselling and Testing (CICT) or Provider-Initiated Counselling and Testing (PICT). The CICT is initiated by the client who wants to know their HIV status whilst the PICT is initiated by the health care providers when the patient is in the consulting room in order to maximize HCT coverage (DoH., 2010) If a client tests positive then blood has to be taken for CD4 count, and the patient is screened for Tuberculosis (TB), enrolled in wellness program during the Pre-Antiretroviral Treatment (Pre-ART) period or enrolled into the Antiretroviral Treatment (ART) program if the CD4 count should be 350m/g(DoH, 2008b). For HIV positive individuals to initiate ART as early as eligibility criteria allow, a specific sequence of events should be completed, starting with HIV testing to diagnose the infection, a baseline CD4 cell count and enrolment in a care programme with regular CD4 monitoring, and ending with initiation of ART (Larson et al., 2010).

In conclusion, HIV/AIDS services are available in most public health facilities i , but data shows that men are lost to follow up after testing HIV positive and re-emerge later when their condition is at a more advanced stage of disease (Losina et al., 2010).. Therefore, this research aimed to explore how the beliefs, perceptions and experiences of newly HIV diagnosed men influences their access to HIV/AIDS services drawing on the Health Belief Model (HBM) as a conceptual framework.

#### **1.2 Literature Review**

This section will give an overview of the literature relating to men's uptake of HIV services after a seropositive HIV test and the utilization of subsequent services. The main purpose of the section is to situate the current study in the framework of the previous studies. The presentation will start with the inhibiting factors to HIV/AIDS service utilization and lastly the facilitating factors to the HIV/AIDS service utilization.

## 1.2.1 Determinants of non-utilization of HIV/AIDS services by men

## 1.2.1.1 Hegemonic masculinities and HIV service Access

Hegemonic masculinity is defined as enactment of an idealized form of masculinity (being the real man) in a particular time and place (Connell and Messerschmidt, 2005). Masculinities that promote notions of toughness has been identified as one of the key features that influence gender disparities in the access of HIV/AIDS services (Nyamhanga et al., 2013). The delayed health care seeking is caused by male socialization where health seeking behaviours were often associated with a sign of weakness and less resilient (Pearson and Makadzange, 2008). Research has shown that men's non-access of HIV/AIDS services is influenced by socio-culturally rooted perceptions of 'real men' as strong, emotionally independent, tough, and fearless as a barriers associated to access and adherence to HIV treatment (Skovdal et al., 2011a). These types of masculinities are the hegemonic masculinities which tend to influence men's access to HIV/AIDS services including counselling and testing (Hounton et al., 2005). The study by Skovdal in Zimbabwe found that men's enactment of social constructed versions of manhood can also have a subordinating role, by preventing them from taking advantage of life-saving HIV services (Skovdal et al.,

2011a). Similarly, South African men who are participating in ART programmes are discouraged by societal expectations and local constructions of masculinity from disclosing their HIV status and seeking treatment in fear that they would be perceived as failing sons, husbands or breadwinners (Fitzgerald et al., 2010). On the same token, a growing number of studies highlighting that due to beliefs about masculinities, men are significantly less likely to get tested for HIV (Chirawu et al., 2010) or to enrol and adhere to antiretroviral treatment services (Kipp et al., 2010). In this case, men are not accessing HIV/AIDS services because they believe that as they are biologically men, they should not be cowards like women who always visit the health care facilities (Skovdal et al., 2011a). In a different research, a systematic peer review of 21 articles found that 60% more women enrolled onto ART compared to their male counterparts; a trend which they argue is not explained by the higher prevalence among women compared to men, but an indicator of gendered health-seeking behaviours (Skovdal et al., 2011a)

However, the findings of most studies did not explain neither how masculinities directly affect men's access to HIV/AIDS services nor account for the reasons why some men, with similar masculinity beliefs are accessing HIV/AIDS services. This research engages with these issues in the discussion in order to add to the discourse.

# **1.2.1.2 Public health facilities as gendered spaces**

Another barrier for men is that they perceive health care facility as a gendered space which therefore deters them from accessing the HIV/AIDS services. Men view clinic as women's space as many clinics are run mainly by women, holding positions as nurses and counsellors,

and are also primarily attended by women and children, therefore men may find visiting the clinic cumbersome and embarrassing (Mills et al., 2009). This was confirmed in the study, where men felt that they are supposed to be seen as or actually be stronger than women and seeking care would belie this supposed strength (Pearson and Makadzange, 2008). To further substantiate this, a study in South Africa found that 70% of people who managed to stay on and adhere to HIV treatment were women and in Uganda, just over twice as many women managed to keep viral suppression high after six months of treatment (Kipp et al., 2010). The two studies show that more men are outside the HIV treatment programme hence they are dying more than women. To confirm this, the study in Uganda found that men are about 1.5 times more likely to die than women (Mills et al., 2012). The same study also found that lower CD4 status at baseline was associated with mortality.

#### 1.2.1.3 Stigma and discrimination: a barrier to accessing HIV and AIDS services

Another barrier to accessing services is the stigma and discrimination. In the literature, Stigma was recently defined as "typically a social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation that result from experience, perception or reasonable anticipation of an adverse social judgment about a person or group. This judgment is based on an enduring feature of identity conferred by a health problem or health-related condition, and the judgment is in some essential way medically unwarranted ((Weiss et al., 2006). Since the early days of the HIV/AIDS epidemic until today, stigma and discrimination still remain central and have been recognized as obstacles to both prevention programmes and uptake of services (Nakigozi et al., 2013). Stigma as perceived barrier to using HIV care services is consistent with findings from other studies that implicated HIV-related stigma and discrimination toward people living with HIV (PLWH) as a barrier to HIV care services (Bogart et al., 2008, Russ et al., 2012)A study in Brazil found that higher stigmatizing attitudes were correlated with lower HIV services utilization as well as unwillingness to tell anyone about an HIV-positive diagnosis (Pulerwitz et al., 2008).

Similarly, a study by Fitzgerald and colleagues revealed that stigmatising beliefs about AIDS and their associated fears of discrimination influenced decisions to seek HIV testing and HIV treatment services (Fitzgerald et al., 2010). Fox and colleagues found that HIV positive men who have not disclosed their status were less likely to adhere to their treatment because they do not want to be seen taking ARVs out of fear of negative treatment from those around them (Fox et al., 2010). The authors further highlighted that the fear of telling spouses and friends about their HIV positive status as well as fear that people would laugh at them and look down upon them for being HIV positive in the society affected outcomes (Fox et al., 2010). Contrary to this findings, a study by Cloete and colleagues found that HIV and AIDS related stigma was more intense among women than men due to women's subordinate role in society (Cloete et al., 2010). They conclude that stigma is less likely to be a factor that hinders men's access of HIV and AIDS services.

#### 1.2.1.4 Access to HIV and AIDS services

Access is described in the literature as a complex concept that requires the assessment of at least four aspects (Gulliford et al., 2002). These aspects include financial, organizational and social or cultural barriers that limit the utilization of services. This means that access measured in terms of utilization is dependent on the distance and affordability of services and not merely adequacy of supply (Gulliford et al., 2002).

Men perceived distance from the primary health care facility as a barrier that influences their non-access to HIV/AIDS services (Posse and Baltussen, 2009). The distance from home to the health facility was often cited as one of the most important barriers to the initial uptake of ART and to patient adherence (Rosen et al., 2007, Posse et al., 2008). However, Steinberg found that the issue of distance was not the only influence to not accessing HIV/AIDS services since people were dying who stayed within a walkable distance to a clinic (Steinberg, 2008). This highlights the importance of cultural or social barriers.

#### 1.21.5 Perception of poor quality of services at public health facilities

Lastly, men's perception that services offered by the public health facilities are poor and of low quality emerged to be a barrier to HIV/AIDS service access. A study in South Africa confirmed that poor quality of care is endemic in South Africa's public health sector, which reaffirms other studies that documented qualitatively the lived experiences of clients attending HIV care and treatment (Orner et al., 2008). To further substantiate that, queues and poor privacy at health centres increase the worry that bystander may discover the reason for men's visit (Pearson and Makadzange, 2008). However, in the same token there was no

discussion of the health care providers' attitude towards men which also poses a great challenge among men. Barriers such as provider attitudes have been found to contribute to delayed presentation at hospitals and clinics as well as adherence failure (Ilongo, 2004). It is clear that the literature review shows that there is a missing discourse that should be considered when exploring factors that influences men's access to HIV/AIDS services.

#### 1.2.2 Determinants of HIV/AIDS service utilization by HIV positive men

There are also different factors that influence newly HIV positive men to access the available HIV/AIDS services. There is limited literature on factors that motivate men to access HIV/AIDS services as well as accessing general health services.

# 1.2.2.1 Perceived severity of health out-come increases health seeking behaviour for HIV/AIDS services

People in general, are influenced to access services due to their perception of the severity of the disease. The more they feel threatened with a serious disease the greater the likelihood of accessing health services. In a qualitative study in Tanzania perceived severity of HIV was determined by the presence of physical symptoms, with severe illness which compelled HIV positive clients honour and adhere to their clinic appointments (Wringe et al., 2009). Some patients who perceived their illness as serious overcame obstacles to clinic attendance, including embarrassment and being seen to be attending services (Wringe et al., 2009). However, the same study also found that some clients defaulted on treatment when their condition improved until their condition deteriorates again, while others decided to defer ART due to absence of symptoms, despite having very low CD4 count (Wringe et al., 2009).

This implies that men utilize HIV/AIDS services when they are feeling sick or have symptoms and then stop when they feel better. Feeling healthy is likely to be major reason for not seeking HIV medical care. Seven study participants (14.6%) felt that seeking medical care only became necessary when one felt sick or had symptoms and signs of HIV disease (Nakigozi et al., 2013). The absence of physical symptoms diminished the need to seek care. Many clients that are on ART programme might have been enrolled late when they were at advanced disease progression. This point was made by Losina and colleagues who found that nearly half of the HIV patients had pre-treatment loss to care (PTLC) as defined by not following up CD4 count which is critical for entry into care (Losina et al., 2010).

#### **1.2.2.2 Beliefs about treatment**

HIV positive men were motivated to utilize the available services due to their beliefs in efficacy of drugs and their faith in the treatment, specifically on ART treatment (Curioso et al., 2010). Additionally, men took ARVs because they wanted to extend their life and to be with their family and friends (Curioso et al., 2010). Men sometimes accessed the available HIV services due to their belief that they still need to be with their families as well as to be physically healthy. Wringe and colleagues found that positive social aspect such as the ability to spend time with family and friends, or raise young children were perceived as important benefits of improved health (Wringe et al., 2009). These beliefs and perceptions that improvements in physical well-being are associated with returning to daily activities which many patients had suspended, enabling some to regain feelings of independence motivated some patients to access HIV/AIDS services (Wringe et al., 2009).

These finding highlight why some men attend HIV/AIDS support groups. The studies allude to the main reason why men would access HIV/AIDS services after being diagnosed HIV positive.

# 1.2.2.3 Experiences after being diagnosed HIV Positive

With HIV Counselling and Testing as the entry point to HIV/AIDS management, men's experiences during counselling and testing influences their access to HIV/AIDS services after testing positive. Male clients who had positive experiences during counselling and testing tend to access the available services. The study by Garland found that few clients who were satisfied with their counselling and testing experiences were basing on the level of comfort and support provided by the person conducting the HIV test (Garland et al., 2011). These men tend to end up joining the support groups that are operating at facility or community level. However, clients who were not satisfied with Counselling and Testing are likely not to access the preceding services after testing HIV positive. The same study found that the most of dissatisfaction stemmed from a perceived lack of counselling, or poor quality of counselling led to men's disappearance after testing HIV positive or sometimes visits another facilities (Garland et al., 2011). This means that the positive experiences with the tester or counsellor determines the further seeking of HIV/AIDS services.

However, the above study is limited as it did not discuss whether the men that access HIV/AIDS services late were satisfied or not by their HIV testing experiences. A study found that men who access HIV/AIDS services after becoming severely ill are remaining in the ART program (Skovdal et al., 2011a). This means a lot has to be explored in order to establish what compliments men to access HIV/AIDS services whether earlier or late and remain in the program.

### **1.2.2.4 Social support systems**

Interpersonal relationships are another factor that facilitates men's utilization of HIV/AIDS services. These relationships are embedded within the individual's family members, intimate partners and other friends. All of these people forms the social support system and it this social support system that might influence newly diagnosed HIV positive men to access HIV/AIDS. Social support system has been found to have a bearing in influencing the decisions to access HIV care among men (Muula et al., 2007). In the same token, a different research confirms that social support plays an important role in influencing men to access HIV/AIDS services after testing HIV positive (Amberbir et al., 2008). They found social support as a consistent ART adherence predictor as patients who reported social support were more adhering to ART than those who did not.

However, through analysis of the social support in influencing men's access to HIV/AIDS service, it is clear that while the concept of social support is more relevant, it is limited in showing the other side of social support due to stigmatisation and fear of losing a partner.. Thus, the interest of the research is to seek an understanding how this social support also causes non utilization of HIV/AIDS services by men.

# **1.2.3 Concluding Remark**

This literature review highlights an important knowledge gap that, if addressed, could contribute to the Department of Health's strategies to improve men's access to HIV/AIDS services.

#### **1.3 Statement of the Problem**

The literature shows that newly HIV diagnosed men have low rates of accessing the freely available HIV/AIDS services as compared to females (Hudspeth et al., 2004). They only enrol into HIV/AIDS management when their CD4 counts are very low and at an advanced stage of disease progression (Biber et al., 1999). Recent research conducted in South Africa reported that 34% of patients who were lost to follow up died prior to ART initiation (Losina et al., 2010). Patient record reviews in Durban show high rates of mortality among those men considered lost to follow up, 27-59% mortality in patients (Losina et al., 2010). In a separate study, South African evidence indicates that men are 1.47 times more likely to die from HIV/AIDS than women (Boulle et al., 2010). High mortality rate among HIV positive males was also supported by two studies in Malawi which found a heightened mortality among males regardless of clinical features as well as increased to follow-up. Therefore, the question of what factors influence men's non-utilization of HIV services remains critical.

#### **1.4 Justification for the Study**

This study intends to fill several gaps in the literature. First, there is little research in the reasons that HIV positive men do not access HIV/AIDS services at the same rate as women. Most studies that have been conducted examining the utilisation of HIV services by women and men tend to be quantitative, and offer little insight to the social processes that contribute to men's relative disadvantage in HIV service uptake and retention. The study intends to explore what influence men's utilization of HIV/AIDS services after testing positive in order to understand how to provide a comprehensive HIV/AIDS management. This is in line with

the findings of Mills that targeting men in prevention and treatment may have large impact on mortality, new infections, and the economic impact of HIV/AIDS (Mills et al., 2012). The study will also contribute towards the implementation of the new developments on ARV-the Fixed-Dose Combination (FDC) for men. The enhanced understanding of men and their beliefs, perceptions and experiences will help public health practitioners in government, civil society, business and policy makers in combating and management of HIV/AIDS.

# 1.5 Study Aims and Objectives

The overall aim of this study was to explore the underlying perceptions and beliefs that influence utilization of HIV/AIDS services by newly diagnosed HIV positive men in Mbashe Sub-District of the Eastern Cape between January 2010 and March 2011

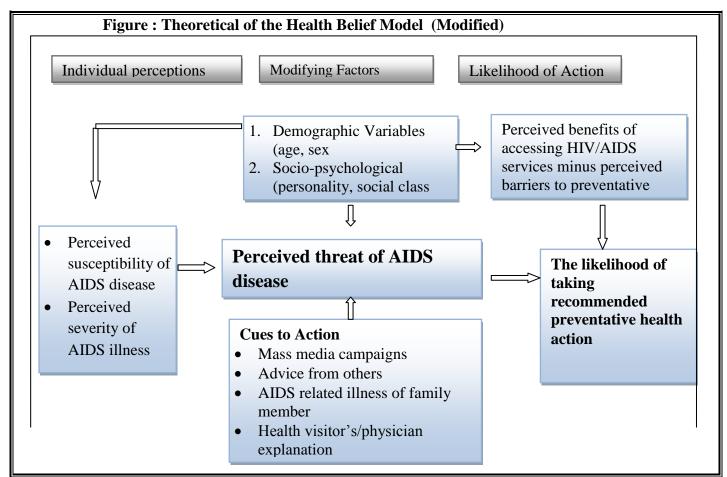
# Specific Objectives

- 1. To explore men's perceptions, beliefs and experiences of their HIV positive diagnosis in Mbashe Sub-District of the Eastern Cape between January 2010 and March 2011
- To explore men's health-seeking behaviour patterns after a positive diagnosis between January 2010 and March 2011.
- To explore men's perceived barriers to accessing HIV/AIDS services after a positive HIV diagnosis
- 4. To explore perceptions and beliefs that influence HIV positive men to access HIV/AIDS services at public health care facility in Mbashe Sub-District.

#### **1.6 Conceptual Framework**

While the role of biomedical interventions for the prevention and management of HIV remains critical, the role of social and behavioural factors to support these needs to be better understood. This study will draw on the constructs of the Health Belief model which is based on the premise that people are most likely to take health-related action if they feel that by so doing they can avoid a negative health condition (Hazavehei et al., 2007). The Health Belief model is based on the constructs of perceived susceptibility (to disease) and perceived severity (perceived threat), perceived barriers, perceived benefits, cues to action and health action (Hochbaum et al., 1992). If perceived susceptibility and perceived severity is high, one is likely to take action to address health problem (Hounton et al., 2005). Perceived barriers are those issues that if they are higher than the perceived threat health seeking is not prioritized for example the transport cost to go to the public health facility to access HIV/AIDS services. The perceived benefits will lead a person to taking action if they outweigh the barriers. Lastly, cues to action are triggers such as bill-board that motivate a person to seek health pertaining to a particular disease (Hochbaum et al., 1992). The relationship between perceived threat of a disease or health outcome and uptake of a health behavior is not always linear. Hounton and colleagues in Uganda found that men who perceived that the severity of HIV/AIDS was high (87%) had low condom usage (Hounton et al., 2005).

# The Health belief model is represented diagrammatically below:



**Source:** Stretcher, V., & Rosenstock, I.M., (1997). The Health Belief Model. In Glanz ik, Lewis F.M., & Rimer, B.K., (Eds). Health Behaviour and Practice. San Fransisco: Jossey-Bass.

In the results section of this study, the constructs of the model will be explored and analyzed to see the extent to which they explain the influence on men accessing HIV/AIDS services after being diagnosed HIV positive.

# **1.7 Summary of the Chapter**

Men's health in the HIV/AIDS era has been lagging behind. Focus has been directed to the most vulnerable groups which are mainly women and children as defined by WHO. This influenced the gender disparity in the access of HIV/AIDS services. Males are accessing HIV/AIDS services in their low numbers as compared to women. Those few men that have enrolled in different HIV/AIDS service programme especially ART came at a later date when they were more advanced in disease prognosis. This late access of HIV/AIDS services is disturbing the expected positive results of ART programme in Sub-Saharan Africa. This study will therefore help to understand what influences men's access to HIV/AIDS services in order to strengthen the available intervention.

### **CHAPTER 2**

# **RESEARCH METHODOLOGY**

# **2.1 Introduction**

This section describes the methodological approach used to investigate the research question. The section describes the procedure and sequence and the nature in which planned actions were executed in this study. In addition, the section also gives motivation for the execution of different actions and processes.

#### 2.2 Research Design

This research is qualitative in nature as it explores the perceptions and beliefs of HIV positive men who both access and do not access the available HIV services after testing positive. Qualitative approach emanates from an interpretive paradigm where the emphasis is on more meaningful social interaction. This approach argues that reality is constructed by the people as they interact in their environment and therefore the interest of researchers should be about how people make sense of their interaction within the environment (Neuman, 2006). The qualitative research approach aims to seek deeper understanding with no intention of predicting the futures issues (Merriam, 1998). The qualitative approach has been extensively used in the study of HIV/AIDS due to the sensitivity of the topic. Qualitative research allows flexibility during the course of the research process. Due to complexity and sensitivity of the topic unexpected events and unanticipated insights, which may divert the study to different direction, may arise. Therefore, the qualitative approach is more appropriate as it allows the researcher to be 'bricoleurs' meaning having the ability to adapt and draw from various skills and techniques as they are required during research process (De Vos et al., 2002). In addition, this research used a qualitative approach because of the need for in-depth information that engages with the voices of the respondents towards the issue under study.

#### 2.3 Study Site

The research was conducted in the rural Mbashe Sub-District of the Eastern Cape Province. The Sub-District is a sparsely populated area with a more subsistence way of life. The area is rural and the people are frequently unemployed and mainly survive through subsistence farming or remittances from family members working elsewhere, social grants and pensions from the government (Fitzgerald et al., 2010). The public health facilities are points of health access within the area and the furthest people travels between 8-10 kilometres to access health services. The smaller health care facilities affiliates to a Community Health Centre.

The study was done at two (2) Community Health Centres (CHCs) that are located in the peri-urban areas and offer 24 hour services. The other two (2) were the clinics that are located in the rural areas and offer fewer services and for only eight (8) hours of the day and the last two (2) were the clinics that offer less service with confined HIV counselling rooms.

#### 2.4 Study Population

The study population is men aged 18-49 years old who were newly diagnosed HIV positive during the period of January 2010 and March 2011. These men were residents in the selected areas and were diagnosed HIV positive from the local public health facilities. The population was also constituted of both men who were accessing and those who were not accessing any HIV services from the public health facilities after a positive HIV diagnosis.

#### 2.5 Pilot study

A pilot study was carried out to inform the main study. In this study, the pilot study was conducted with four participants: two HIV positive men who have not accessed HIV/AIDS services as well as two HIV positive men who were accessing HIV/AIDS services during this study. The HIV positive men accessing or not accessing HIV/AIDS services were recruited from the support groups from two different health care facilities. For the purpose of pilot study HIV positive men who delayed utilization of HIV/AIDS services were engaged. The main purpose of the pilot study was to test whether the questions were understandable and whether the interview guide would elicit responses that would answer the research question. The feedback from the pilot study effected changes to the tools like adding more probing questions to get deeper information as well as rephrasing of questions that were not clear to the respondents.

# 2.6 Sampling Strategy

The study used a purposive sampling strategy to select the respondents for the study. This approach is useful when selecting members of difficult-to-reach, specialized population for

an in-depth investigation (Neuman, 2006). The prospective respondents selected from the HCT registers and followed by the health care providers with whom they had established a rapport. Health care providers explained the study and asked whether the potential respondent could be contacted by a researcher. The researcher then called the prospective respondents for an appointment at a place of their choice.

Men were eligible to be selected for the study if they had tested HIV positive within the six months period prior to the start of the study. Men who had accessed as well as those who had not accessed HIV services were eligible for selection.

Clinic Level		Brief description	
			Participants
Community	Health	These are public health facilities that offer wide	5
Centres (CHCs)		range of services including HIV-TB services. One	
		of them has a laboratory where blood tests are	
		done. They open for 24 hours and 10 smaller	
		health facilities affiliates to one CHC.	
Level 2 Clinics		These are Middle public health facilities with	6
		slightly bigger structures and higher monthly head	
		count than level 3 clinics. They offer more	
		services because they have more nurses (4 and	

Table 1: Number of respondents from different levels of PHC who participated in this study

Level 3 Clinics	above) and with designated HIV counselling room. These are the smallest clinics with very small structures. They operate from 08:00 am-17:00pm. They offers fewer services due to less number of professional nurses (2-3 nurses)	7
Total Participants		18

# 2.7 Data Collection

In order to comprehensively understand the problem statement identified, this study used primary data sources through in-depth interviews. The interviews were recorded as both field notes as well as electronic recording in order to be sure that most information is gathered. In all the interviews, consent forms for both verbal interview (**Appendix G and H**) and recording the interview (**Appendix E and F**) were signed to guarantee the acceptance of the respondents. The respondents who declined to sign the two consent forms were not included for the study.

#### 2.7.1 In-Depth Interviews (IDIs)

The study utilized primary data collected through one-to-one in-depth (IDIs) interviews with the selected respondents. This type of data collection method is generally used to gain a detailed picture of a participant's beliefs about, or perceptions or accounts of, a particular topic (De Vos et al., 2002). He went further to allude that the semi-structured interviews especially suitable where one is particularly interested in complexity or process, or where an issue is controversial or personal. Interviews were more appropriate for this particular study since it gives the researcher the leverage to observe non-verbal communication and connect with the verbal communication. The face to face contact with the respondents' facilitated the responses and quality information as well as no need for literacy (Joubert, 2007). However, the interviews have their own limitations; it creates an artificial environment that may intimidate the respondents. In addition, interpersonal factors (e.g. respondent's suspicion) may interfere with data collection processes (Joubert, 2007).

The collected data was recorded as both field notes and tape records. The record allows a much fuller record than notes taken during the interviews (De Vos et al., 2002). Most of data missed when taking notes was added from the tape records. However, some of the clients were not comfortable with being recorded as they wanted to maintain their anonymity. After assurance to confidentiality and anonymity was given, the participants agreed to be recorded during the interviews sessions. The interviews took between forty-five (45 minutes) to one (1) hour per individual session.

#### 2.7.2 Data Collection Procedure

All the respondents were contacted telephonically by either the professional nurse or community care worker who conducted the HIV Counselling and Testing to that particular client. The research brief was given to the prospective respondents and if agreed to participate an appointment was made with the researcher. The interviews were conducted by the researcher with all the respondents. The researcher is a young man who at the time of the study was working as a project manager for HIV-TB integration project. He did not have a prior relationship with any of the study participants. He did know the health care providers who assisted with the recruitment of the study participants. It was easier to contact and meet with respondents who were accessing HIV/AIDS services than those that are not accessing services after testing HIV positive which led to extended period of data collection process. All of the males who were accessing services agreed to meet with the researcher at the health care facility whilst those that are not accessing services only two were interviewed at the health care facility. The rest were not comfortable with health care facility and were interviewed in their homes. An interview guide (Appendix I and J) were used for both men accessing HIV/AIDS services and those that are not accessing HIV/AIDS services.

#### 2.8 Data Analysis

A range of approaches to qualitative analysis have been developed (Miles and Huberman, 1984). There are no fixed rules for the analysis of qualitative data as there are some key processes that need to be noted (Kalekin-Fishman, 2001). Data collected in this study was in form of texts and interview transcripts from the IDIs and audio recordings respectively. Data

was analysed inductively, however there were a few deductive codes that were based on some constructs from the Health Belief Model. The audio-taped data was transcribed in English maintaining the verbatim meaning for easy analysis. The same line of thinking that taped material has to be transcribed (typed or written out) as the written word is the basic medium of analysis (Joubert, 2007). Data was analysed qualitatively through the use of firstly; codes, categories and then the emerging themes were drawn from both the field notes and audio-taped interviews. The thematic analyses of verbatim transcriptions of the interviews were then done using the technique of (Miles and Huberman, 1984). They defined data analysis as consisting of three concurrent flows of activity: (1) Data reduction, (2) Data display, and (3) Conclusion drawing/verification. Deductive analyses with codes that emerge from the data were used in order to better organize the findings of the study. The analysis of data was done in comparison of both groups of men that are not accessing HIV/AIDS services and those that are accessing same services based on the themes in line with the Health Belief model and also outside the framework. However, data analysis started early during the data collection process. The data collection and analysis are tightly interwoven processes and must occur alternately, because the analysis directs the sampling of data (De Vos et al., 2002).

# 2.9 Ethical Consideration

The ethical issues in this study were given a great priority. The study ethical clearance was requested and issued by the University of Witwatersrand Human Research Ethical Committee (HREC) with clearance number: **M 120283** (**Appendix A**). The permission to conduct the research in Mbashe Sub-District was issued by Provincial Eastern Cape Department of Health

(PECDH) before the study was conducted (**Appendix B**). In addition, the recruitment of the participants was done by the health care providers who had already established the rapport with them during HIV counselling and testing session. The prospective respondents were then briefed about the study and participation was voluntary as consent forms for both interviews and recording were completed before participating (**Appendix E, F and G, H**). Lastly, the necessary pre-arrangements were in place with the medical social workers for follow-up in the case of highly distressed participants after the interviews. However, none of the participants engaged the services of the medical social workers after the research.

## 2.10 Summary of the Chapter

This chapter clarified the processes used in conducting this study in the field and off the field. The qualitative approach was engaged in this study due to the nature and sensitivity of the topic understudy. In addition the sampling strategy used was carefully selected in order to appropriately suit this study particularly. The study needed more detailed information about the beliefs and perceptions that influence men's utilization of HIV/AIDS services, therefore in-depth interviews proved to be the most appropriate approach to use. Many ethical considerations were prioritized in this study since human subjects are at the centre stage of investigation. Lastly, data analysis conducted was in line with the qualitative research design.

#### **CHAPTER 3**

## RESULTS

# **3.1 Introduction**

This chapter presents the results of the study. The data analysis started during data collection and extended in this chapter in which further in-depth content analysis was carried out in order to deduce categories and common themes. As highlighted in chapter 2, analysis of data was done through thematic analysis of verbatim transcriptions of the interviews using technique of (Miles and Huberman, 1994). The analysis of data is also situated within some few constructs of the Health belief model (HBM) to explore beliefs and perceptions that influence utilization of HIV/AIDS services after diagnosed sero-positive.

#### 3.2 Socio-demographic characteristics of respondents

All the respondents in this study were residents of the poor rural areas and the surrounding peri-urban areas in the Eastern Cape and were not formally employed. Among the eighteen respondents, three were married with children. The majority while not married had partners with children who were not living with them in the same house. The age range of the respondents was 29 years to 49 years.

#### 3.3 Men's reactions to testing HIV positive

All the 18 respondents highlighted good experiences during the process of HIV counselling and testing. This was described by both the men that are accessing HIV services as well as those that are not accessing the same services. The men that were not accessing the services confirmed having a positive experience during the HIV testing and counselling process.

## 3.3.1 Nurse/ Counsellor-Patient Empathy

All of the respondents spoke about their positive experiences with nurse/counsellor-patient empathy either during or after taking an HIV Counselling and Testing. The men that were accessing services indicated that this good experience with the health care providers led them to quickly link with the health care services as they managed to get more information about HIV/AIDS as well as service access.

"I was happy about the experiences during and after testing. The nurse showed me great care and I felt encouraged as I was given more information on treatment and the benefits of treatment." [Man accessing HIV services, 29 years]

The responses were not different from those men that tested for HIV and never returned to access the HIV services. They also revealed that they had a very good experience with the health care providers who showed care and also the counsellors who took enough time during counselling. :

"I had good experiences at the clinic. Those people showed me care and support, especially sisters (Nurses). The counsellors took their time as counsellors during

counselling and advised me that if I'm not happy with the result it is my right to go test somewhere." [Man not accessing services, 33 years]

However, for some of the newly diagnosed HIV positive men, their positive experience of the HCT process did not lead directly to accessing the freely available HIV services. This phenomenon highlights that there were a more complex set of reasons that went beyond their individual first contact with the health care providers and the referrals that they received.

## 3.3.2 Negative feeling after testing HIV positive

When asked about their feelings after testing HIV positive, the majority of the respondents felt shocked.

"I had TB in Joburg and was on treatment for six (6) months. I felt bad about being HIV positive since I have no parents." [Man accessing HIV services, 37 years]

In addition, self-blame was accompanied by guilt and regret for not using protection when having sex:

"It was useless of me for not using protection at the first place. I wouldn't be in this mess. I will never forgive myself because today I would have been taking of something else not this incurable disease." [Man accessing HIV services, 44 years]

However, despite feelings of shock, guilt and self-blame, most of the men who were accessing HIV/AIDs services admitted that they accepted the HIV positive status since there was nothing they could do to change it except seeking help:

"I was shocked but as a man I told myself that illness is similar. If there is help I will go for that help. So I just accepted as it is." [Man accessing services, 40 years]

There were also few respondents from the non-accessing cohort that indicated that they also accepted their HIV status. However, they made peace with the disease but it was not enough to push them to access the freely available HIV/AIDS services.

"I was shocked but just accepted it since I told myself that I have this disease that is without cure and I made peace with it." [Man not accessing services, 35 years]

## 3.4 The perceived severity of HIV/AIDS related illness

The majority of the respondents highlighted that they were aware of the severity of HIV/AIDS. This was from both the men that are accessing HIV/AIDS services and those that are not accessing the same services.

## 3.4.1 Fear of death due to HIV

Men who were not accessing HIV/AIDS services expressed beliefs and perceptions that HIV was a death sentence as there is no cure. They understood well how severe and dangerous the disease can be, as they even witnessed their neighbours dying due to this disease. A 33 year old man spoke of his sense of fatalism that being diagnosed HIV positive would lead to his death. He also expressed fear of death:

"There is nothing I can do because now ultimately I am going to die. They say that this disease kills and I have seen my neighbours dying, I don't want to die too." [Man not accessing services, 33 years]

Other respondents revealed their fear of death due to HIV/AIDS. They blamed themselves for testing for HIV since they were stressed about knowing their HIV status for they are not prepared to die. They preferred not knowing their HIV status as they could not accept the impending death associated to HIV/AIDS:

"It was difficult for me to accept it because HIV related illness will lead to AIDS which has no cure but just death. I don't want to die now. I cried and asked myself many questions...why did I go there to test now I'm stressed." [Man not accessing services, 44 years]

Contrary, men that are accessing services confirmed that they understand the severity of HIV/AIDS related illness and it helped them to demand the necessary HIV/AIDS services at public health facility. They became to understand the infection as more individualistic hence an individual had to seek help. The most motivating aspect was their responsibility as the head of the family that caused them to defy all odds and access HIV/AIDS services:

"This is my life and if I ignore the nurses, I will die and leave my children struggling without someone to help them since their mother is not working. I was one of those who did not want to hear about treatment but when I thought about my children the following day I was at the clinic in the morning [Man accessing services, 33 years]."

In addition, some of the men that are accessing HIV/AIDS services combined the fear of severity of HIV/AIDS and their masculine roles as family heads as the most factors behind their accessing the HIV/AIDS services:

"The feel of my children and my life led me to access HIV services (treatment) even though they say it won't cure HIV but lowers it. There was no other way than accessing treatment because HIV is dangerous to people as it kills." [Man accessing services, 40 years]

### 3.5 Need for quick alternative cure

Respondents confirmed their desperation for quick alternative cure to HIV. Most of the men that are not accessing the HIV/AIDS services revealed that they tried other alternative treatment and cure for HIV instead of the formal health system. The alternative cure was mainly the traditional medicine and religious intervention. Religious intervention involved prayers for healing and taking holy water:

"I once went to buy a bottle of traditional medicine and drank because I heard someone saying if I go to re-test I was going to be negative but when I went to re-test I was still positive then I left the traditional medicine. I then went to church for the priest to pray for me." [Man not accessing services, 29 years]

Another respondent echoed same sentiments of searching quick alternative cure:

"I went to church and given holy water which was for epilepsy but used it also to help me for this HIV that the nurses said I have. I also went through the traditional healer's cleansing ceremony which was supposed to strengthen me within the family

but I had the hopes that the powers of the ancestors will defeat this HIV [Man not accessing services 37 years]."

It was not only men that are not accessing HIV/AIDS services who tried quick alternative cure. Even those that are accessing HIV services had tried religious interventions either prior to accessing treatment or during their treatment at the clinic. However, interestingly, they didn't stop their current treatment:

"I went to church and the priest used to pray for me but I didn't leave treatment. Someone even said had HIV but is now negative because he was saved. But I said it was against what I was told at the clinic and I left." [Man accessing services, 34 years]

The respondents confirmed that what they went to the pastor in search of quick HIV negative status. The only hopes for that were pinned on the holly prayers as they did not want to be associated with the deadly disease:

"I went to church for the first time. I wanted the pastor and all the people to pray for me as I wanted to be HIV negative but it did not help." [Man accessing services, 39 years]

Over the counter Western medicine was also tried as the respondent did not trust the effectiveness of the nationally available treatment. The desire for being HIV negative among the men accessing HIV/AIDS services led to the acquiring of over the counter medicine:

"I once felt that the treatment was not enough then I went to buy different medication from a chemist. I just wanted to be HIV negative." [Man accessing services, 37 years]

## 3.6 Barriers to HIV/AIDS Service utilization

There are different barriers and challenges that are influencing HIV positive men's nonaccess to HIV/AIDS services. More of the barriers reported were personal barriers more than health system related barriers or hindrances. These vary from stigma and discrimination, shortage of food physical fitness etc. These are presented as sub- themes below:

## 3.6.1 Stigma and discrimination

The most common barrier was the fear of stigma, discrimination and even rejection especially from the other patients at the health care facility, family members or friends and community at large. This was a serious issue among the respondents that are not accessing HIV/AIDS services highlighted stigma and discrimination as their major barrier. One respondent eloquently remarked:

"If you are known to be HIV positive, people will end up not accepting you because they will look down upon you as if you are a person who doesn't leave with people or end up giving you names." [Man not accessing services, 32 years]

In addition, due to same fear of stigma, some respondents' preferred accessing HIV/AIDS services where they remain anonymous. They preferred places that are far away from their areas of residence and even prepared to migrate across the provinces in order to maintain

their anonymity due to fear of community and local stigma. This is illustrated by the following extract:

"I need to go there at the clinic and take transfer to Cape Town so that I take treatment in Cape Town than here. It is better there because I will be free and no-one knows me." [Man not accessing services, 36 years]

Another source of stigma that deterred men from accessing HIV/AIDS services was perceived from the local health care providers like community care workers who are doing HIV Counselling and Testing as well as offering Community Home-Based Care services [CHBC]. The issue of them being recruited from the communities and are part of the large community was raised as a challenge that men decided not to frequent and access the available HIV/AIDS services. One respondent commented:

"The volunteers are children of this area and they grew up whilst watching them. They give me respect as an elder community member and now if I go there for treatment that respect will be neutralized and eroded." [Man not accessing services, 37 years]

Another respondent echoed the same sentiments as they fear that their HIV status will be known by the community:

"The presence of local health care providers intimidates me because we become very afraid that they will move around and talk about it to other people and tomorrow I will be known by the whole community." [Man not accessing services, 42 years]

## 3.6.2 Public Health clinics as a gendered space

Apart from stigma and discrimination, clinic as gendered space emerged as an important barrier in the study. This was revealed by four men that are not accessing HIV/AIDS services. They revealed how they try to visit the public health facilities to seek help but sometimes they quit whilst in the queue or they do not visit at all. Their main challenge is that at public health facilities there are more women and children than men which pose a challenge when suggesting to visit these health points. This was captured by one of the respondents:

"Queues are always more females at the clinic and they cause me to leave before meeting the nurse and think of another day. But when you come another day it is the same then I decided to stop visiting the clinic." [Man not accessing services, 44 years]

Same sentiments were clearly expressed as the issue of masculinity comes in. It was difficult for men to be in the queue with women and children instead of being with other men:

"I become shy at the clinic because all people are women-nurses are women and in the queue they are all women and young children. How do I look at them? I'm a man and should be with other men out there. It was better if there were more man." [Man not accessing services, 42 years]

Due to the need and desire to maintain masculinity, conversely, man preferred to be visited by the health care providers than them visiting the women and children infested public health facilities. One respondent eloquently puts it: "I wouldn't mind treatment but only if it is delivered at home not me go there and mingle with women and children at the clinic. That place makes me sick as I feel out of place among women." [Man not accessing service, 35 years]

#### 3.6.3 The Implementation of PICT model as a barrier to service utilization

Most clients who are not accessing the HIV/AIDS services voiced their concern on the issue of Provider-Initiated Counselling and Testing (PICT). They felt as if they were involuntarily tested for HIV at the health care facility when they had actually visited for other health services like TB treatment and collection of epilepsy treatment not specifically for HIV testing. Actually these patients were overwhelmed to the extent that they even stopped treatment:

"Dual attention of both HIV and TB was too much for me then I decided to drop even the TB treatment that I had started. After all I did not want the HIV test yet but the sisters at the clinic said I should test for HIV as the two normally goes together. I was hesitant at first but I just said let me do it but after it was too much pressure on me." [Man not accessing services, 37 years]

Another respondent who is epileptic also echoed the same issue of testing for HIV when he had gone to collect his routine monthly treatment:

"When I tested for HIV, I had gone there for my epilepsy but they told me that I should test for HIV. I tested and they told me I tested HIV positive, they also said I

should come back for that HIV. I didn't go back there, even the epilepsy treatment I stopped at once. I will go there when I feel sick not now." [Man not accessing services, 39 years]

## 3.6.4 Perceived food shortage as a barrier to access HIV/AIDS treatment

A perceived food shortage emerged as an important factor that prohibits or affects the access of free HIV/AIDS services offered at public health facility in the rural areas. About six of the respondents highlighted the food shortage as the main barrier to accessing HIV/AIDS services at the public health facilities. One responded remarked:

"We don't have enough food to eat before taking treatment. They say this thing needs a lot of food and if you take them without food you die now. So I need to be sure first that I have enough food before using this treatment." [Man not accessing services, 33 years]

Another respondent highlighted the issue of food and also alluded how government should be supportive on the issue of additional food in order to boost the access to HIV/AIDS services by men:

"We are suffering here at home. We don't have something to eat as this is rural area. I cannot go to clinic and collect HIV treatment that I will never use. It is better if someone who will use it to take it. It is difficult because we don't have enough food. I have to eat first before I take treatment. Where is the food? Government should give

us food parcels or porridge first and I can collect the treatment." [Man not accessing services, 34 years]

However, the issue of perceived food shortage was not only the concern of the respondents that are not accessing HIV/AIDS services as the issue was also raised by the respondents that are accessing the HIV/AIDS services. They noted that they are also struggling to get food before taking treatment. This is shown by the interpretation of one respondent below:

"We need food before taking treatment but we are poor and very poor, so sometimes it is difficult when there is nothing to eat. No wonder you see there is no adherence to treatment. Some people take treatment this month but next month they delay because they still have that treatment for the skipped days." [Man accessing services, 29 years]

This issue again intimidated some of the respondents to enrol on ART programme since they did not know where to get the necessary food nutrients before taking their treatment on daily basis which led to delay in treatment:

"I was afraid that I did not have a job yet I should eat healthy before taking treatment. Where was I going to get the food? As a result the nurses were calling me to go to the clinic but I delayed because I was afraid of starting treatment then default on the way." [Man accessing services, 35 years]

## 3.6.5 Perception of being healthy (absence of symptoms of sickness)

The feeling of being health emerged to be a more barrier than advantage to access HIV/AIDS services among the respondents that are not accessing the services. Most of the respondents used the absence of sickness to perpetuate their denial of HIV status and could not see the reason of visiting the health facility for different HIV/AIDS services. One of the respondents echoed his belief about physical fitness and positive HIV status:

"They told me I'm HIV positive but I never have cough or any sickness soon after their test. This is what causes me not to believe it. I'm strong and not sick myself. May be later then I can call the sister (Nurse) and go there." [Man not accessing services, 37 years]

However, another respondent affirmed the same notion that he can only visit the health facility for assistance if he feels that his body is weakened by the disease. Without that, he does not see the reason for seeking any help:

"I'm still feeling healthy so I don't see the reason for that (Visiting the facility for help) but if you are becoming weakened it is a must that you go there because you will be feeling that something wrong and you will be encouraged to go." [Man not accessing services, 44 years]

## 3.6.6 Alcohol use and smoking as a barrier to utilization of HIV/AIDS services

Alcoholism and smoking was affirmed as one of the barriers that are influencing nonaccessing HIV/AIDS services by the HIV positive men. This factor affected these men as they are not in a position to quit the two in favour of HIV treatment as well as other complimentary services. However, they understand the dangers of alcoholism whilst on treatment. This was captured by one of the interviewees:

"Especially for me, Alcohol and smoking affects me because I still need to drink before I start treatment as they say treatment should not be mixed with drinking and smoking." [Man not accessing services, 49 years]

Some of the respondents rather extended further the issue of alcoholism and smoking by exposing that they engage on alcoholism and smoking as a way of shunning away the deep thinking and psychological effect of being HIV positive. They revealed that their main issue of concern was the fear of HIV/AIDS as incurable diseases that is associated with death:

"I'm just like other men, we like alcohol and smoking more than anything else. If you take alcohol you forget about the HIV that said to be no cure and but dying. So let me drink for now and the HIV I will see it later." [Man not accessing services, 40 years]

In addition, some respondents highlighted that they understand that alcohol and smoking is not good for their health especially as HIV positive. Their belief was that they could not mix alcohol and treatment at the same time but rather stop alcohol and smoking first before starting treatment. The respondents confirmed that they are even trying to stop taking alcohol and smoking even though it is proving to be very challenging. This is however, causing them not to respond to phone calls from the nurses. One respondent expressed as shown below:

"My main problem is drinking and smoking. I have tried to stop but hey...it is difficult. If I can manage to stop alcohol and smoking, then I will be at the clinic whenever the

nurses call me. But for now I cannot even answer their calls because they will force me to take the treatment whilst I'm still a smoker and likes alcohol." [Man not accessing services, 49 years]

### 3.7 Factors facilitating men's access to HIV/AIDS services

The respondents who are accessing different HIV/AIDS services claimed that they were motivated by different factors to access HIV/AIDS services. These facilitating factors motivated them in different ways. The main facilitators were need to survive, Disclosure and social support and need to fulfil masculine roles.

## 3.7.1 Benefits of treatment (Need for survival)

Most men that are accessing HIV/AIDS services confirmed that their desire to be healthy and survive like other men whose HIV status is negative is the major driver to their utilization of services. They remarked that they wouldn't want to die of HIV/AIDS related illness yet there is available treatment. One respondent clearly put it:

"I just want to live long like any other person. I don't want to die early because of HIV/AIDS yet the treatment is available." [Man accessing services, 42 years]

They further highlighted the issue of masculinity roles as a motivation to access HIV/AIDS services. They felt that as the head of the families, they desired to see their children progressing through all the ranks of education whilst they are still alive. This was more common among the men that are married or cohabiting with their partners yet having kids they sired together:

"The need to do my duty as a father to my children of making sure they have acquired education like other well off children was the most push to access treatment." [Man accessing services, 37 years]

The greatest wish for children growing up with their father as the advisor emerged prominently as respondents highlighted the need to guard and practise good parental roles to his children so that they won't fall in the same trap like him of being HIV positive:

"I want to fulfil my wishes of seeing my children growing up with their father and also giving them advice about life so that they won't make similar mistakes like mine in life. I have started to teach them about HIV and how dangerous it is." [Man accessing services, 40 years]

## 3.7.2 Disclosure and availability of social support

All respondents that are accessing the HIV/AIDS services confirmed that they have disclosed their status to someone and the support they got led them to access services freely without fear. This also made the easily honour their clinic appointments without failure:

"If you disclosed your status, there is no fear of stigma so you access your treatment freely and not miss any clinical appointment." [Man accessing services, 33 years]

All the married or cohabitating men revealed that they disclosed to their partners or wives as well as their mothers and got unwavering support through until today. The support they got includes the financial support for transportation to the health care facility to access treatment as well as in form of food parcels. However, the praised the support from immediate family members as more important than any support from a friend:

"I disclosed my status to my mother and my partner. They told me to be strong as they were going to help me. It is good to be supported by family members more than friends. They used to give me money for transport to go and access treatment in Butterworth which is 50km away as well as food parcels." [Man accessing services, 33 years]

Conversely, the unmarried respondents highlighted the important role played by a friend if one discloses to them. It was noted that as per the advice from the nurse, one was supposed to have someone to act as treatment supporter who reminds them on treatment times. These friends also assured them long survival if treatment is taken properly:

"I told my friend because the sister (nurse) told me to bring a person who could support me. My friend always supports me by reminding me the treatment taking time. He even made me strong as he assured me that if I take my treatment properly will survive for a long time." [Man accessing services, 37 years]

# 3.7.3 Witnessing relatives', neighbours' and friends' sickness and death due to HIV/AIDS

The respondents who are accessing the services confirmed that they witnessed relatives and friends who died due to HIV/AIDS because of non-access to HIV/AIDS services. This was a strong factor that influenced them to quickly visit the health facility to access services. This is clearly illustrated below:

"I saw my best friend when he was sick and died due to HIV/AIDS because he never accessed any treatment. I then decided that as they say treatment is available, I will go and collect it." [Man accessing services, 40 years]

Another respondent echoed the similar sentiments that they have buried a number of people due to HIV/AIDS as it is now told openly during funerals. That influenced him to access the HIV/AIDS services and even to adhere to the treatment as he never missed any treatment collection date:

"We have buried a lot of people due to this disease and they are even saying it at funerals. So I decided myself to access and keep on accessing HIV treatment. There is not even a single month that I did not access the treatment." [Man accessing services, 44 years]

## 3.8 Summary of the Chapter

The study has presented major qualitative findings that emerged from the in-depth interviews in the entire study. It has raised interesting issues basing on the few constructs of the HBM and others outside the theory on how they either motivate or could not sufficiently motivate men to access HIV/AIDS services. The other issues outside the HBM that influenced men's utilization of HIV/AIDS services needs a close attention. The study focused on the factors that influence men's utilization of HIV/AIDS services after testing positive. It is clear from this study that there is a dire need for the department of health and other stakeholders to address the number of barriers that in order to motivate the newly diagnosed seropositive men to access the freely available HIV/AIDS services

#### **CHAPTER 4**

## DISCUSSION

# **4.1 Introduction**

This study aimed to explore the beliefs and perceptions of men that influence their access to HIV/AIDS services soon after the sero-positive diagnosis. The literature review revealed that some HIV positive men disappear from formal health system and only to re-emerge when they are at a more advanced disease with a poorer prognosis. The study was designed to explore the different reasons why HIV positive men delayed accessing HIV/AIDS services. The Health Belief Model was used as a theoretical framework to guide the analysis and interpretation of the study findings.

The results show that some of the HBM constructs were supported in influencing newly diagnosed HIV positive men's decision to access HIV/AIDS services. These included perceived benefits of attending services, and perceived barriers. However, the HBM proved not to be the most appropriate framework to explain why some men accessed the services or not. For example, the threat of HIV and AIDS was very high among some men not accessing services. Instead of these motivating men to access services, they felt paralysed and responded by wishing that they had never tested as not knowing their status was considered preferable. There were interesting pathways that men followed in order to access the HIV/AIDS services that could not be fully explained by the health belief model. One of the phenomena revealed by this study was that some men delayed accessing the formal health

system consulted other alternative institutions like traditional healing and religion. This section therefore discusses the constructs of the HBM as well as other issues that emerged from the research findings.

## 4.2 Experiences with HIV Counselling and Testing

The study found that experiences during the HIV counselling and Testing (HCT) are not enough to motivate men to access HIV/AIDS services after their new sero-positive status. The men interviewed in this study reported a positive nurse/counsellor-patient relationship regardless of whether they accessed HIV services or not. Findings from a qualitative study conducted in United States of America (USA) found that experiences during HIV counselling and testing can motivate men to access subsequent HIV/AIDS services (Garland et al., 2011). Similar findings were reported that the experiences and quality of counselling was the first determinant of accessing HIV/AIDS services after testing positive (Chersich et al., 2008, Obermeyer et al., 2009). However, this study contradicts the findings of Skovdal and colleagues where good patient-nurse empathy was applauded as effectively influenced access to HIV/AIDS service (Skovdal et al., 2011b). This implies that it is not only good HCT experience and rapport between the client and the counsellor that leads to access to services. There are different factors that are beyond mere experiences during HCT that influences that decision.

#### 4.3 Perceived Severity of HIV/AIDS related illness

In this study, the high perceived severity of HIV/AIDS illness to some extent triggered health-seeking behaviours among some newly diagnosed HIV positive men but the majority

were not enough motivated. Both groups of men confirmed the severity of HIV/AIDS illness, associated with death if services are not accessed but it was not all of them who accessed services. However, This is in line with the findings of another research that perceived severity about HIV/AIDS may not be sufficient to induce HIV/AIDS service access by newly diagnosed men (Hounton et al., 2005). Even the men that were accessing the HIV/AIDS services acknowledged the severity of the disease but could not link it to their motivation to access HIV/AIDS services. However, these findings are in contrary to the findings of a research in Tanzania that perceptions of illness severity influenced HIV clinic attendance especially changes in physical symptoms and sickness (Wringe et al., 2009). This study therefore shows that it is not only the threat that motivates men to access HIV/AIDS services but it goes beyond the HBM constructs where issues like beliefs and experiences accounts for negative health access behaviour.

## 4.4 Health-seeking behaviour of newly diagnosed HIV positive men

Participants frequently spoke about the search for quick cure as an alternative to the available bio-medical ART in the public health facilities which led to delays and non-utilization of HIV/AIDS services. In another research, preferences to traditional medicine were explained as a result of cost of accessing the services, familiarity with the methods, perception of treatment efficacy, and lower levels of associated stigma in using the services (Plummer et al., 2006, Fairfield et al., 1998). However, in this study use of alternative either traditional herbs, religious intervention or over the counter purchase was in search of quick cure to the HIV/AIDS disease. Men either accessing or not accessing HIV/AIDS services had searched for quick cure as their first point of health concern to their HIV positive status. However,

some of these men were frustrated by failure of alternative quick cure as they expected and ended up in the mainstream of health for treatment, care and support. This was also found that denial of HIV status was associated with using alternative healers, and could occur prior to, during or after starting ART (Wringe et al., 2009).

### 4.5 Perceived barriers to HIV/AIDS service access

This is the section that was fairly explained by the HBM in this study. There were different perceived barriers to men's access to HIV/AIDS services. These barriers were more both institutional and personal in nature. The emerged barriers include stigma and discrimination, implementation of PICT, perceived shortage of food, clinic as a gendered space and alcohol use and smoking.

In this study, the results showed that stigma is still a challenge that influences HIV men's access to relevant services. Stigma was manifested as expression of fear of being seen by other people at the HIV clinic, hence in advently disclosing their HIV status (Nakigozi et al., 2013). Entry into HIV care was associated with fear of exclusion from participation in community social and political events or falling out with a social or peer group. The results are in line with the recent research in Zambia that found that even access to care has become more common; stigma has not disappeared and continues to play a strong role in the decision-making process around ART (Fox et al., 2010). Interestingly, in this study fear of the community stigma was perpetuated by the fact that community care workers were from the

same community with the men as the DoH policy encourages community care workers to be from the community served by the Primary Health Care centre (PHC).

Men viewed the Primary Health Care centre as a gendered space which is mainly flooded by women and children. These spaces perceived as affects their dignity within the family and community at large. One of the participants stressed that the presence of the local community care workers at the facility discouraged him to access services because they used to respect him but now they were going to disrespect him. These findings concur with the literature and also with findings in Zimbabwe that men fears that their dignity will be compromised if found to be HIV positive and opt to ignore services (Skovdal et al., 2011a).

In addition, PICT came out strongly as a barrier to accessing HIV/AIDS services which is contrary to its global mandate. Men who had visited the public health facility for other health issues and were offered PICT ended up not accessing HIV/AIDS services. However, the problem is with the way the model was implemented at facility level more than the policy itself. It was revealed that the PICT was implemented as the entrance to access services rather than a patient having a choice of voluntarism and could deny it but still access services as stipulated in the policy. If PICT not implemented with caution and with fundamental respect of the key principles in which it is based, it affects the access of the preceding HIV/AIDS services. A study in Kenya, Tanzania and Zambia confirmed similar results as they found the very low numbers of people offered treatment after exposed to Provider-Initiated Counselling and Testing of HIV (Njeru et al., 2011). This means that most of the people who tested HIV positive did not enrol to treatment programme lost after their HIV test. The findings of this study therefore confirms that clients were not given the chance to deny the HIV test during

PICT which left others shocked, stressed and overburdened. Therefore, the challenges faced when implementing the PICT opt-out approach to HIV testing calls for a renewed resources and right-based momentum (Njeru et al., 2011).

The study also found out that alcohol use and smoking led to delays in accessing HIV/AIDS services after testing positive. This aspect is very serious in the rural set up where alcohol is cheap and readily available due to the availability of traditionally brewed bear. Men reiterated that their non-access to the preceding HIV/AIDS services was due to their interest in both alcohol and smoking. The men not accessing HIV/AIDS services spoke about fear of mixing alcohol and ART which the service provider warned them not to do. The findings of Morojele and colleagues has same sentiments that service providers' advised their clients to refrain from using ART while consuming alcohol and also warned them on the actual effects of alcohol on memory causing them to forget to ingest doses of their ART (Morojele et al., 2013). It was also found in this study that men had enough knowledge about the relationship between HIV/AIDS treatment and alcohol as they thought of quitting alcohol and smoking in order to start treatment. These findings correlate strongly with the results where several men described how, knowing that the ART programme discouraged alcohol use, and they had waited to start treatment until managing to stop or reduce alcohol use (Fitzgerald et al., 2010). In another study, individuals who drank alcohol delayed seeking initiating ART services due to misperception that alcohol abstinence is a pre-requisite for ART enrolment (Morojele et al., 2013). However, some constructions of masculinity that promotes alcohol use and selfreliance may indirectly play a role in men's late presentation to treatment and the uptake of ART services.

This study also found out that shortage of food or additional nutrition hinders newly diagnosed men from accessing HIV/AIDS services. This issue was highlighted by both men that are accessing and those that are not accessing subsequent HIV/AIDS services. The situation was more glaring because the rural Mbashe is generally dry and there is high percentage of unemployment. Most of the men were not employed and staying with a relative who is also unemployed. This poses a great challenge on bringing food on the table, hence men decided not to access HIV/AIDS services including ART. These results are in line with the findings that ART is difficult to take on an empty stomach, travel to a health facility may become impossible because of weakness and lethargy and adverse effects of treatment like dizziness and nausea (Ivers et al., 2009). The study went further to allude that lack of access to appropriate food and the direct effect that HIV has on impaired metabolic functions in absorption, storage and utilization of nutrients can translate into compromised immunity, nutrient deficiencies, and increased vulnerability to infectious diseases (Ivers et al., 2009). In another study in Ethiopia, unstable food security had an influence in the access of HIV/AIDS services especially the ART since men were afraid of chemical reactions that affect their health (Rawat et al., 2010). However, in two different studies, food aid found to delay HIV disease progression in Uganda (Rawat et al., 2010) and a separate study in Zambia found that food assistance associated with better adherence to ART (Ivers et al., 2009).

### 4.6 Facilitating factors to access HIV/AIDS services after sero-positive diagnosis

The study finding confirms that there are different exceptional factors that highly motivate men to access the HIV/AIDS services in the Mbashe sub-district. These factors range from

social support, need of being healthy and also masculinity roles as head of the family especially among those men who were either married or cohabiting with children.

The main aspect that emerged to be strongly motivating these men into accessing HIV services are the availability of social support. The social support was mainly from either the mother or the intimate partner. The study results showed that most of the men who stayed with their mothers and intimate partners easily confided their HIV status with the two. The results concur with another study in Ethiopia, disclosure of HIV positive status by patients was high and that relatives were the first ones to whom patients disclosed their status to (Posse and Baltussen, 2009). This shows that this type of social system is more necessary in the battle against HIV/AIDS.

The disclosure of ones' HIV status to these important family components ensured social support that men ended up into accessing HIV/AIDS services including enrolling into ART programme. The findings are in line with the research in Mozambique that most of the factors in family support cluster refer to confidentiality, discrimination and disclosure, with an exception of encouragement of relatives to access ART (Posse and Baltussen, 2009). In another study, self-efficacy or confidence in being able to sustain clinic attendance was determined by patient's experiences of family support (Wringe et al., 2009).

There was also monetary support from social family structure which motivated men to end up accessing HIV/AIDS services. This money could be used for transport especially before the decentralization of the ART services to the public health facility as well as buying food for

these HIV positive men. The issue of food specifically was highlighted as a massive challenge among the HIV positive people as it delays the access of the available services including ART.

Perceived benefits of accessing HIV/AIDS services were not more at individual level but at family level were men were motivated to access and honour clinic appointments due to their parental obligation to their children. In this study this type of benefit was echoed by married men with children. The study in Tanzania correlate the same findings as positive social outcomes such as the ability to spend time with the family and friends or raise young children perceived as benefit of improved health (Wringe et al., 2009). Conversely, unmarried men and not having children did not see being health as a benefit as they cited being healthy only. These results concur with the findings that male gender, no children and never having married were associated with late presentation to formal health system for HIV/AIDS services (Parrott et al., 2011).

Lastly, this study also found that the mere fact of being healthy was very important benefit; however, it was perpetuated by the self-efficacy of defying stigma and ownership of individual's health to access the HIV/AIDS services. The study in Tanzania shared the same results as they found that improvements in physical well-being and returning to daily activities which were suspended and gaining feelings of independence (Wringe et al., 2009). This goes with a lot of renegotiating men's belief of masculinity and challenge the values attached to it.

#### 4.7 The application of HBM to HIV/AIDS service access

In this study, perceived barriers emerged as the main and powerful HBM constructs that could predict the access of men to subsequent HIV/AIDS services followed by few point on perceived severity of HIV/AIDS and lastly the benefits of accessing HIV/AIDS services. The balance between the perceived barriers and perceived benefits were very significant and useful as men had more barriers in accessing the HIV/AIDS services. Even the men that were accessing HIV/AIDS services highlighted facing same barriers before enrolling on ART program. The cues to action construct motivated men to access HIV/AIDS services mainly due to the availability of supportive social support system within the family as well as witnessing sickness and death of a relative or neighbour.

However, HBM was reported to be one of the most widely used behavioural frameworks for more than five decades but has been criticized for its inability to efficiently predict people's behaviour (Glanz et al., 1990). The results in this study concur with this finding since not all the constructs of the HBM were able to predict the HIV/AIDS service access by the newly diagnosed HIV positive men. In addition, all men were aware and confirmed the high magnitude of HIV/AIDS disease severity and their fear of death but that threat construct alone could not sufficiently motivate and trigger the individual men to access HIV/AIDS services. This is also in line with the findings in one of the studies in Benin where perceived severity and adequate knowledge about HIV/AIDS was not sufficient to induce condom usage (Hounton et al., 2005). In this particular study, the participants that managed to access HIV/AIDS services highlighted other different factors that motivated them to access HIV/AIDS services like disclosure to either mother or intimate partner and also masculinity roles for those ones that are married with children which are not related to the HBM at all. These finding confirms that the driving force in human behaviour change is more than the restrictive boundaries of the HBM.

## 4.8 Summary of the Chapter

The overall conclusion of this chapter is that HIV/AIDS services access is influenced by factors in array. These factors are not only within the framework of the HBM model. This showed that there are deeper factors more than the constructs of the HBM that influences the prediction of HIV/AIDS service access. However, there are few powerful constructs that managed to predict the human behaviour in the field of accessing HIV/AIDS services.

#### **CHAPTER 5**

## CONCLUSIONS AND RECOMMENDATIONS

#### **5.1 Introduction**

The study explored the beliefs and perceptions that influence the utilization of HIV/AIDS services among the newly diagnosed sero-positive men in rural Mbashe sub-district. The study had four specific objectives which are: (a) to explore the perception, beliefs and experiences of men about their HIV positive status, (b) men's health-seeking behaviour after HIV positive diagnosis, (c) barriers to accessing subsequent HIV/AIDS services and lastly, perceptions, beliefs and (d) experiences that influence HIV positive men to access HIV/AIDS services in rural Mbashe sub-district.

#### 5.2 General concluding remarks

The results of this study demonstrate that newly diagnosed men's utilization of the subsequent free HIV/AIDS services at the primary health care is influenced by factors in array. There are those factors those that trigger men to utilize the services and those that deter them from accessing necessary HIV/AIDS services. The factors that influence their access to services are mainly within the multilevel framework which ranges from individual, family, community and societal factors.

Perceived severity of HIV/AIDS illness found to be less motivating men to access the services as well as their documented good experiences during counselling session could not trigger them to access HIV/AIDS services. Their belief and perception revolves around the alternative cure e.g. traditional health, religious intervention and over the counter medication

as their first point of health service access. However, there were many barriers to HIV/AIDS services access revealed in this study. The barriers hinder the health-seeking behaviour of these men to the extent that those that ended up accessing services were at a more advanced disease prognosis. The main barrier that delayed men was the search of quick cure that is alternative to ART (traditional healing, divine intervention and over the counter purchase). In addition, fear of all forms of stigma and discrimination at all levels played a pivotal role in deterring men from utilizing HIV/AIDS services. This was mainly from family, community as well as facility level in which men described as a gendered space, infested with women and children. Structurally, the implementation of PICT policy, instead of positively influencing men to access HIV/AIDS services, it distanced these men from accessing the services. However, this was mainly due to the fact that PICT was implemented as a mandatory approach, without giving a client choice to decline. On the other hand, factors that triggered men to access HIV/AIDS services were the availability of social support system which was also made easier by disclosure of one's HIV status to either mother or intimate partner. Another factor was the witnessing of relatives or neighbours' illness or death due to HIV/AIDS and the eagerness of fulfilling the family leader roles and responsibilities like sending children to school as well as seeing their children grow.

## 5.3 Recommendations of the research

#### 5.3.1 Address stigma

Stigma and fear of discrimination has been a challenging issue in the field of HIV/AIDS for more than a decade now. The HIV/AIDS strategies should address this stigma and discrimination from grassroots level since its adverse effects are delays in accessing HIV/AIDS services which compromise health of people especially men. Community

leadership should be on the forefront in order to encourage diffusion of innovation which will make it easier for the multitudes to appreciate.

## 5.3.2 Advocacy for better proportion of male nurses

When asked about ideal situation that can motivate men to access HIV/AIDS services after a positive status, almost all the respondents highlighted the need for men friendly clinic with more males as nurses. High level of advocacy for a policy that stipulates better portion of males to be trained and deployed as nurses is recommended in order to complete the male friendliness of the clinics. This policy should be implemented in all academic institutions that offers nursing program.

## 5.3.3 Designing Community-Based programmes

Hegemonic masculinities have been found to be a barrier that influences non-access of HIV services by men. It is therefore recommended that there should be community-based programmes that give space to stimulate dialogue among men in order deconstruct masculinity complexities that affects men's access to health services like HIV/AIDS. These social spaces might be community-based support groups that encourage involvement of traditional leadership, supportive of the engagement and reflection of the barriers that affects man.

#### 5.3.4 Integration of traditional medicine into main-stream of health services

Traditional health should be recognized and integrated into the main-stream of health with strong referral system to avoid both delays and non-access of HIV/AIDS services by HIV positive men. The traditional healing practise emerged to be the first health shop that the HIV positive men consult due to their beliefs and readily availability of the service. This proved to be an important first point of health that if strengthened and well recognized by department of health may make a difference in the fight with HIV/AIDS.

#### 5.3.5 PICT implementation

PICT should be implemented as stipulated within the guidelines not otherwise without giving the clients chance of either consenting or not consenting HIV testing. This should not be like mandatory because some of them felt that they were tested when they were not ready to testing. If well implemented at primary health care level it will definitely motivate men to access HIV/AIDS services early.

## 5.3.6 Encouraging Couple counselling and Testing

Partners should be encouraged to test for HIV as a couple as this will help to overcome fear of HIV seropositive disclosure to sexual partners. Since most men either delayed or never accessed HIV/AIDS services due to fear of disclosure, the approach will help both as prevention strategy in case of discordant couples as well as quickly linking them to treatment program.

# **5.4 Further research required**

Research still required in order understand how PICT is implemented at facility level in order to have clear answers on why the men are finding it difficult to access HIV/AIDS services after a positive HIV status. More quantitative research is also required to establish the magnitude of the non-access of the HIV/AIDS services after a positive diagnosis.

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# APPENDICES

# Appendix A

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UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG Division of the Deputy Registrar (Research)			
HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL) R14/49 Mr Clever Mubuyayi			
CLEARANCE CERTIFICATE	<u>M120283</u>		
PROJECT	Beliefs and Perception that Influence Utilization of HIV/AIDS Services by Newly HIV Diagnosed Men in Rural Mbashe sub-District in the Eastern		
	Cape Province of South Africa		
INVESTIGATORS	Mr Clever Mubuyayi.		
DEPARTMENT	School of Public Health		
DATE CONSIDERED	24/02/2012		
+DECISION OF THE COMMITTEE*	Approved unconditionally		
Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.			
<u>DATE</u> 04/05/2012 <u>CHAI</u>	(Professor PE Cleaton-Jones)		
*Guidelines for written 'informed consent' attached where applicable cc: Supervisor : Tinswalo M Hlungwani			
research and I/we guarantee to ensure compliance w contemplated from the research procedure as approv Committee. <u>I agree to a completion of a yearly p</u>	am/we are authorized to carry out the abovementioned ith these conditions. Should any departure to be ved I/we undertake to resubmit the protocol to the		

# **Appendix B**



#### Dear Mr C. Mubuyayi

RE: Beliefs and perceptions that influence utilization of HIV/AIDS services by newly HIV diagnosed men in rural Mbashe Sub-District in the Eastern Cape Province of South Africa.

The Department of Health would like to inform you that your application for conducting a research on the abovementioned topic has been approved based on the following conditions:

- 1. During your study, you will follow the submitted protocol with ethical approval and can only deviate from it after having a written approval from the Department of health in writing.
- You are advised to ensure, observe and respect the rights and culture of your research participants and maintain confidentiality of their identities and shall remove or not collect any information which can be used to link the participants.
- The Department of Health expects you to provide a progress on your study every 3 months (from date you
  received this letter) in writing.
- 4. At the end of your study, you will be expected to send a full written report with your findings and implementable recommendations to the Epidemiological Research & Surveillance Management. You may be invited to the department to come and present your research findings with your implantable recommendations.
- Your results on the Eastern Cape will not be presented anywhere unless you have shared them with the Department of Health as indicated above.

Your compliance in this regard will be highly appreciated

W Y DIRECTOR: EPIDEMIOLOGICAL RESEARCH & SURVEILLANCE MANAGEMENT



#### Appendix C

#### Information Sheet: Men who are not accessing HIV/AIDS services

Hello and welcome. I sincerely thank you for giving me your time. My name is **Clever Mubuyayi.** I am a student at the University of Witwatersrand. I am conducting research looking at beliefs and perceptions that influence utilization of HIV/AIDS services by newly HIV diagnosed men in rural Mbashe Sub-District in the Eastern Cape Province of South Africa. I will come to any place you regard convenient to meet you and explain the study to you, and the managers of the clinic will not be involved in this process.

#### Invitation to participate:

I would like to invite you to volunteer to participate in the research study which will be conducted in Mbashe sub-district. You should agree to participate in the study only if you fully understand what will be asked and are completely happy with the procedures that will be involved. If you do not understand the information or have any questions, please feel free to ask me. Your treatment will not be affected if you choose not to participate in this study.

#### What is involved in the study:

If you would like to take part, you will be interviewed by me at a time and place that is easiest for you to get to. The interview will last for about 60 minutes. With your permission this interview will be recorded so that I can make sure that I can gather the right information. Taking part in this is entirely voluntary and up to you, and no person will receive any benefits or be disadvantaged in any way for choosing to participate or not to participate in the study. You may refuse to answer any questions you do not feel comfortable answering and you may choose to pull out from this study at any point without any negative consequences.

### **Risks:**

The interview will be conducted in a private room of your choice. The potential risks you may face from participating in this study are:

- You may feel uncomfortable answering some questions that may be addressing some sensitive and personal issues
- You will have to spare at least an hour to participate hence may lose time for doing your routine household chores.

You are however informed that you are free not to answer questions that make you uncomfortable.

# **Benefits:**

You will not get direct benefits from this study. The information collected in this study will be helpful in supporting government efforts to improve HIV services.

### **Confidentiality**:

All the information collected in this study will be strictly confidential. No information that identifies you will be included in this report. The interview material (tapes and transcripts) will not be seen or heard by any person besides for myself and my supervisor. The material

will be kept in a locked cupboard that only myself and my supervisor will have access to. All material will be kept for two years and then destroyed.

Once I have the results, and the final report has been written up, the report will be seen by members of the University of the Witwatersrand. If you choose to participate in this study please fill in your details on the attached consent form. I will return to collect the forms within the next three weeks. Alternatively Once you have read this information sheet and understood everything in it, please take care with it, as the information on this sheet could disclose your HIV status if it is seen by anyone else.

### Information and contact person:

If you have any questions regarding this study, you can contact:

#### Clever Mubuyayi

I can be contacted by telephone at (043) 726 0216/ 071 6870 620 or by email at clever@tsamail.co.za.

#### Contact details of researcher/s:

In the event that you want further information regarding your rights as a researcher or complaints regarding this research, you may contact the Chairperson of the University of Witwatersrand, Human Ethics Committee at this number (+27) 11 717 2230/1

#### Appendix D

#### Information sheet: Men who are accessing HIV/AIDS services

Hello and welcome.

I sincerely thank you for giving me your time. My name is **Clever Mubuyayi.** I am a student at the University of Witwatersrand. I am conducting research looking at beliefs and perceptions that influence utilization of HIV/AIDS services by newly HIV diagnosed men in rural Mbashe Sub-District in the Eastern Cape Province of South Africa. I will come to your health care facility or anywhere you are comfortable to meet you and explain the study to you.

### Invitation to participate:

I would like to invite you to volunteer to participate in the research study which will be conducted in Mbashe sub-district. You should agree to participate in the study only if you fully understand what will be asked and are completely happy with the procedures that will be involved. If you do not understand the information or have any questions, please feel free to ask me. Your treatment at this public health facility will not be affected in any way by participating in this study.

#### What is involved in the study:

If you would like to take part, you will be interviewed by me at your health care facility. The interview will last for about 60 minutes. With your permission this interview will be recorded so that I can make sure that I can gather the right information. Taking part in this is entirely

voluntary and up to you, and no person will receive any benefits or be disadvantaged in any way for choosing to participate or not to participate in the study. You may refuse to answer any questions you do not feel comfortable answering and you may choose to pull out from this study at any point without any negative consequences.

#### **Risks:**

The interview will be conducted in a private room of your choice at the health care facility. The potential risks you may face from participating in this study are:

- You may feel uncomfortable answering some questions that may be addressing some sensitive issues.
- You will have to spare at least an hour to participate hence may lose time for doing your routine facility program work

You are however informed that you are free not to answer questions that make you uncomfortable.

### **Benefits:**

You will not get direct benefits from this study. The information collected in this study will be helpful in supporting government efforts to improve HIV services.

### **Confidentiality**:

All the information collected in this study will be strictly confidential. No information that identifies you will be included in this report. The interview material (tapes and transcripts) will not be seen or heard by any person besides for myself and my supervisor. The material

will be kept in a locked cupboard that only myself and my supervisor will have access to. All material will be kept for two years and then destroyed.

Once I have the results, and the final report has been written up, the report will be seen by members of the University of the Witwatersrand. If you choose to participate in this study please fill in your details on the attached consent form. I will return to collect the forms within the next three weeks.

### Information and contact person:

If you have any questions regarding this study, you can contact:

### Clever Mubuyayi

I can be contacted by telephone at (043) 726 0216/ 071 6870 620 or by email at clever@tsamail.co.za.

# Contact details of researcher/s:

In the event that you want further information regarding your rights as a researcher or complaints regarding this research, you may contact the Chairperson of the University of Witwatersrand, Human Ethics Committee at this number (+27) 11 717 2230/1

### Appendix E

#### Consent Form (Audio-taping): Men who are not accessing HIV/AIDS services

I hereby confirm that the person seeking my informed consent to participate in this study has given me information to my satisfaction. He/she explained to me the purpose of the study and procedures involved, risks, benefits and my rights as a participant in the study.

I am aware that my voice will be recorded. I have been informed that only the research team and unless otherwise required by the Human Ethics Committee and other human rights organizations will access the tapes and hear my recorded voice. I have been informed that the recorded voices will be kept in a lockable cabinet and destroyed by shredding after 3 years

I am aware that it is my right to withdraw my consent in this study without any prejudice. I hereby freely and voluntarily give my consent to be audio-recorded in this study.

Respondent:	
Name:	
Signature:	
Date:	
Researcher:	
Name:	 _
Signature:	 _
Date:	 

#### Appendix F

#### Consent Form (Audio-taping): Men who are accessing HIV/AIDS services

I hereby confirm that the person seeking my informed consent to participate in this study has given me information to my satisfaction. He/she explained to me the purpose of the study and procedures involved, risks, benefits and my rights as a participant in the study.

I am aware that my voice will be recorded. I have been informed that only the research team and unless otherwise required by the Human Ethics Committee and other human rights organizations will access the tapes and hear my recorded voice. I have been informed that the recorded voices will be kept in a lockable cabinet and destroyed by shredding after 3 years.

I am aware that it is my right to withdraw my consent in this study without any prejudice. I hereby freely and voluntarily give my consent to be audio-recorded in this study.

Respondent:	
Name:	
Signature:	
Date:	
Researcher:	
Name:	 _
Signature:	 _
Date:	 

### Appendix G

### Consent Form (Interview-Men who are not accessing HIV/AIDS services)

I \_\_\_\_\_\_\_ agree/disagree to being interviewed by Clever Mubuyayi for his study on beliefs and perceptions that influence utilization of HIV/AIDS services by newly HIV diagnosed men in rural Mbashe Sub-District in the Eastern Cape Province of South Africa. He explained to me the purpose of the study and procedures that will be followed to collect data. He has also explained to me the risks and benefits and my rights as a participant of the study.

I have received the information for the study in isiXhosa and have had enough time to read it on my own and ask any questions where I was not clear. I feel that I am comfortable to take part in this study having all the questions I had answered to my satisfaction.

I am aware that the information that will be gathered from this study and from all participating people will be processed with confidentiality into a research report that may further be published. I am aware that this report and any publications from it will be shared with other academics and provincial Department of Health officials

I am aware that it is my right to withdraw my consent from the study without any prejudice. I hereby freely and voluntarily give my consent to participate in the study.

Respondent:

Name:		
Signature:		

Date:

Researcher:

Name:\_\_\_\_\_

Signature: \_\_\_\_\_

Date:\_\_\_\_\_

Signed \_\_\_\_\_

### Appendix H

### Consent Form (Interview-Men who are accessing HIV/AIDS services)

I \_\_\_\_\_\_\_ agree/disagree to being interviewed by Clever Mubuyayi for his study on beliefs and perceptions that influence utilization of HIV/AIDS services by newly HIV diagnosed men in rural Mbashe Sub-District in the Eastern Cape Province of South Africa. He explained to me the purpose of the study and procedures that will be followed to collect data. He has also explained to me the risks and benefits and my rights as a participant of the study.

I have received the information for the study in English and have had enough time to read it on my own and ask any questions where I was not clear. I feel that I am comfortable to take part in this study having all the questions I had answered to my satisfaction.

I am aware that the information that will be gathered from this study and from all participating people will be processed with confidentiality into a research report that may further be published. I am aware that this report and any publications from it will be shared with other academics and provincial Department of Health officials

I am aware that it is my right to withdraw my consent from the study without any prejudice. I hereby freely and voluntarily give my consent to participate in the study.

Respondent:

Name:		
Signature:	 	
Date:		

Researcher:

Name:\_\_\_\_\_

Signature: \_\_\_\_\_

Date:\_\_\_\_\_

Signed \_\_\_\_\_

# Appendix I

# Interview Schedule: (Men who are not accessing HIV/AIDS services)

# **1. Biographical Information:**

Tell me a little about yourself

Probe: - age

- marital status

- children

- employment

# 2. Beliefs and Perceptions of Testing HIV positive

Tell me about when you came to the clinic for an HIV test?

- What was your diagnosis?
- What did the counsellor tell you after you were diagnosed?

How did you feel when you left the clinic/health care facility that day?

-[probe on severity of non-access of HIV/AIDS services]

What did it mean to you to find out that you are positive?

# 3. Health-Seeking behaviour after a positive HIV diagnosis

Where have you gone to for help after testing HIV positive, if anywhere at all?

- Traditional healer
- Over the counter medication
- Church/religious institution

Who have you talked to about your diagnosis, if anyone at all?

- What have they advised?

Tell me about any experiences with health care since you had your HIV test?

What are the next steps for you in the management of your HIV?

# 4. The perceived barriers to HIV/AIDS service utilization

What do you think affect men going to HIV/AIDS services after their HIV positive test?

Probe [Do concerns about quality of care/treatment by health care providers prevent use of services? Do cost or travel distance limit use of services? Lack of knowledge about when to seek care?

What would make it easier/harder for you to go to health facilities for the on-going management of your HIV?

Probe [For suggestions to increase men's access to HIV/AIDS services]

# Appendix J

# Interview Schedule: (Men who are accessing HIV/AIDS services)

# **Biographical Information:**

Tell me a little about yourself

Probe: - age

- marital status

- children

- employment

# 2. Beliefs and Perceptions of Testing HIV positive

Tell me about when you came to the clinic for an HIV test?

- What was your diagnosis?
- What did the counsellor tell you after you were diagnosed?

How did you feel when you left the clinic/health care facility that day?

-[probe on how severity HIV/AIDS led to access of available services]

What it meant to you to find out that you are positive?

# 3. Health-Seeking behaviour after a positive HIV diagnosis

Where have you gone to for help after testing HIV positive?

- Traditional healer
- Over the counter medication
- Church/religious institution

Who have you talked to about your diagnosis, if anyone at all?

- How their advice influenced you to enrol on HIV/AIDS management programme?

Tell me about your experiences with HIV-related health care since you had your HIV test?

- Probe on how these can influence access to HIV/AIDS services

### **4** Facilitating factors to HIV/AIDS service access

Tell me more about factors that motivated you to access HIV/AIDS services at a public health facility?

Probe: Is this different for some men?

What do you think should be done at this health care facility to increase men coming for services, if anything at all?

[Probe [elaborate more on that]