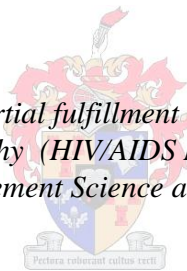


**PATIENT AND PRACTITIONER PERCEPTIONS OF PROMOTERS AND
INHIBITORS OF HEALTH SEEKING BEHAVIOUR AMONG AFRICAN MEN
ACCESSING HIV HEALTH SERVICES IN KWA-ZULU NATAL**

by

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degree of Master of Philosophy (HIV/AIDS Management) in the Faculty
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Declaration

By submitting this assignment electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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Abstract

Men might benefit from opportunities specific to their needs in improving access to HIV care. This is a group vulnerable to higher morbidity and mortality than their female counterparts, due not only to poor or delayed health seeking behaviour and the culture of blame for the transmission of HIV, but probably due to neglect, inadequate or poor support by the current policies, by a gender biased research agenda, by the international research community and global health funders.

Objectives

The objectives of this current study were:

- to explore the reasons for poor health seeking behaviour amongst African men seeking HIV care in KZN;
- to establish the health care practitioners' views about the reasons for the perceived poor health seeking behaviour amongst African men accessing HIV services in KZN;
- to inform guidelines in improving access to HIV services by African men

Methodology

In-depth interviews were employed as the method of obtaining lived experiences, perspectives and opinions of men living with HIV and that of their health care practitioners.

Results

It was found that men still feared the diagnosis of being HIV positive, even with the advent of highly active anti-retroviral therapy (HAART) and the advances in managing this disease.

Several reasons for this fear emerged with the common theme being the doom of impending death, social stigma and fear of abandonment as well as social marginalization.

Conclusions

We cannot expect to attract men to predominantly female orientated settings within health faculties. Special attempts need to be made to reach out to men in places they are comfortable being in. Messages should be clear and concise about the effectiveness of low cost, available treatment for HIV; and that early diagnosis improves health outcomes. Cultural sensitive interventions are needed that are suitable, in generating a clearer understanding of health management options and motives.

Opsomming

Mans kan baat vind by geleentede wat op hulle spesifieke behoeftes met betrekking tot beter toegang tot MIV-sorg afgestem is. As 'n groep, is mans met MIV méér kwesbaar vir siekte en sterfte as hul vroulike eweknieë – deels weens hul geneigdheid om laat of glad nie om gesondheidshulp aan te klop nie en die kultuur van beskuldiging vir MIV-oordrag, maar waarskynlik ook weens verwaarlosing sowel as onvoldoende of swak steun deur huidige beleid, deur die geslagsbevooroordeelde navorsingsagenda, deur die internasionale navorsingsgemeenskap en deur wêreldgesondheidsfinansiers.

Oogmerke

Die oogmerke van hierdie studie was:

- om vas te stel waarom Afrikamans in KwaZulu-Natal wat MIV-sorg benodig, geneig is om laat of glad nie om gesondheidshulp aan te klop nie;
- om te bepaal wat gesondheidsorgpraktisyns beskou as die redes waarom Afrikamans in KwaZulu-Natal wat MIV-sorg benodig, oënskynlik geneig is om laat of glad nie om gesondheidshulp aan te klop nie; en
- om riglyne vir beter toegang tot MIV-dienste vir Afrikamans te rig.

Metodologie

Diepte-onderhoude is gebruik as metode om die werklike ervarings, beskouings en menings van mans met MIV sowel as dié van hul gesondheidsorgpraktisyns te bekom.

Resultate

Die studie bevind dat mans steeds 'n MIV-positiewe diagnose vrees – dít ondanks die bekendstelling van hoogs aktiewe antiretrovirale terapie (HAART) en vooruitgang in die bestuur van dié siekte. Verskeie redes vir hierdie vrees het aan die lig gekom, en die algemene tema blyk te wees die onheil van die naderende dood, sosiale stigma en vrees vir verwerping sowel as sosiale marginalisasie.

Gevolgtrekkings

Dit is onrealisties om te verwag dat mans die oorwegend vrouegerigte omgewings in gesondheidsfasiliteite sal besoek. Daar moet 'n spesiale poging aangewend word om na mans uit te reik op plekke waar hulle op hul gemak is, en om kort en kernagtige boodskappe oor te dra oor die doeltreffendheid van beskikbare laekoste- MIV-behandeling en die belang van vroeë diagnose vir beter gesondheidsuitkomst. Toepaslike kultuursensitiewe intervensies is nodig om 'n duideliker begrip van gesondheidsbestuursmoontlikhede en -motiewe te skep.

Acknowledgements

To the ever committed work of the Health Care Practitioners,

Who in the face of so many adversities,

Strive on.....

And the affected men,

Whose voices are seldom heard.....

Thank you for sharing with me

Ngiyabonga

Acronyms and abbreviations

ART	Anti-retroviral Therapy
ASSA	Actuarial Association of SA
HAART	Highly Active Antiretroviral Therapy
HCP	Health care practitioner
HIV	Human Immune Deficiency Virus
IDU	Injectable drug users
KZN	Kwa-Zulu Natal
MDG's	Millennium Development Goals
MMC	Male medical circumcision
MSM	Men having sex with men
MTCT	Mother to child transmission
OI	Opportunistic infections
PICT	Provider initiated counselling and testing
PLHIV	People living with HIV
SSA	Sub Saharan Africa
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
VCT	Voluntary counselling and testing
W H O	World Health Organization

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Chapter 1: INTRODUCTION

1.1 Introduction

After 20 years of relentless frontline clinical work in primary care contexts, this research is borne out of the following concerns: Are current policies and global funders doing enough in focussing their efforts towards male targeted interventions in order to curb female acquisition of the disease? Should we consider the needs of men in planning and policy development and to what extent? Do we recognise the gender disparities in access to HIV services?

These questions are relevant when working within the World Health Organization (WHO) Treatment 2.0 guidelines (WHO/UNAIDS, 2011) and South African National Strategic Plan (National Strategic Plan 2011-2016, 2011) for HIV in its prevention campaign of zero (0) new HIV infections. Men might benefit from opportunities specific to their needs in improving access to HIV care. This is a group vulnerable to higher morbidity and mortality than their female counterparts, due not only to poor or delayed health seeking behaviour and the culture of blame for transmission of HIV, but probably due to neglect, inadequate or poor support by the current policies, by research agenda, by the international communities and globally funded projects.

This qualitative study attempts to fill a gap in the knowledge about the possible barriers and triggers inhibiting or facilitating men from accessing public HIV services, be it initial testing to know your status or to remain in continued care and treatment. It will provide insight in creating valuable systems or adjusting policies to promote and improve the utilization of HIV services by men in KZN.

1.2 Background

South Africa, considered as the most developed country within Africa, can also boast of having the largest number of people living with HIV (PLHIV) in the world, approximately 5.6 million in 2009 (UNAIDS, 2010). Contextually, one in every six PLHIV in the world, live in South Africa.

The Sub-Saharan Africa (SSA) region carries the greatest burden of the epidemic. The recent statistics of the global HIV and AIDS epidemic published by UNAIDS (UNAIDS, 2011) estimates people living with HIV globally at 34 million. As 23 million of all people living with HIV reside in SSA, it bears 68 % of this global burden. The province of KwaZulu-Natal bears the brunt of the disease burden within South Africa itself, at 39.5%.

Fifty percent of this burden of disease is amongst women, both globally and in SSA, making HIV infections amongst women higher than in men. Consequently, more focussed treatment, research and human rights advocacy are directed towards women and girls, resulting in less attention being given to men and their particular needs. Most of the relative successes in treatment, screening and prevention campaigns have been documented in females rather than in men. In South Africa, a common entry point for HIV screening and care is via the antenatal clinics as part of their routine care for pregnant women. No such opportunity exists for men.

Traditionally, females and children access health care more readily than their male counterparts, (Galdas, 2005). This is of particular interest in KZN, as it has the highest prevalence in SSA, and has health seeking practices entrenched in culture and tradition (Helgeson, 1987). According to Ward, Metens, & Thomas, (1997), men delaying or not accessing HIV services timeously, poses a threat to incidence and prevalence data

monitoring as well as to efficacy of interventions. It has been observed that men access HIV services, either for initial testing or for care and support, only when they are seriously ill mostly with HIV associated opportunistic infections (Skovdal, Campbell, Madanhire, Mupambireyi, Nyamukapa, & Gregson, 2011). This presentation correlates to very low CD4 counts (Street, 2009) resulting in poor outcomes and high mortality, (Mills, Bakand, & Birungi, 2011). The availability of highly active antiretroviral therapy (HAART) is insufficient to mitigate the epidemiological cost of delayed access to case identification and comprehensive care.

Although a possible explanation could be attributable to poor health seeking behaviour amongst men, there might be a culture of blame, female oriented programs and the Millennium Development Goals Global (MDG's) that creates a programmatic bias toward maternal and child health programs. Is there much known about the experiences or specific issues that men have to endure in order to access care? No, not much is known pertaining to this. Subsequently, this hinders any efforts on how to involve men with focussed efforts to change either their health-seeking or risk-taking and behaviours. If we intend to improve the vulnerability of women from acquiring HIV infections, directed efforts at improving male orientated access to HIV services encompassing testing, care, support and treatment, is tantamount and critical with regards to preventing new infections both in men and women, and reducing morbidity and mortality in men.

1.3 Purpose

The purpose was to investigate the possible factors that either inhibit and or promote the utilization of HIV services by African men in KZN.

The specific objectives were:

- to establish the perceived inhibitors in accessing HIV services by African men in KZN;
- to establish the perceived promoters in accessing HIV services by African men in KZN;
- to establish the health care practitioners' views about the reasons for the perceived poor health seeking behaviour amongst African men accessing HIV services in KZN;
- to explore the reasons for poor health seeking behaviour amongst African men seeking HIV care in KZN and
- to inform guidelines in improving access to HIV services by African men

1.4 Significance

It is common knowledge that men tend to seek help later than women. Help seeking for health problems is no different. These reasons range from a multitude of cultural, social, economic and masculinity issues. Since KZN bears the brunt of the HIV burden of disease within SA and that although women out-number the men in HIV incidence, at least they are traditional attendees of health care and programs are generally geared towards women and child health; little is known on what or why men are reluctant to access care. The proposed study will focus on the subjective views and experiences of men already seeking HIV health care, thereby elucidating perspectives, inhibitors or promoters or supporting criteria in seeking HIV health care within the public health care system, in KZN. By addressing the specific needs of men in accessing care, morbidity and mortality might improve amongst HIV positive men

1.5 Rationale

I chose to conduct this study based on my long term clinical experience and the constant questioning on “*why did you not come earlier for testing and treatment*”; and the constant heartache of not able to do much more when men present for the first time being critically ill; when you see women and their children on treatment and care and living healthier for longer with the obvious absence of their partners; or the unknown status of their partners. We know historically and from literature available that men universally, delay in seeking help. I needed to know from the actual men utilizing these facilities about their experiences, the possible barriers, the facilitators and their specific needs in order to make accessing care more amenable to men. To make them feel that what they need and say matters; that program leaders and funders need not develop generic plans; that all designs need not match all people; that culture, social beliefs and attitudes matter.

This dissertation is divided into 5 chapters:

Chapter 1: Introduces background information into the topic, the purpose, rationale and significance of the study

Chapter 2: Reviews available literature pertaining to the topic and highlights the knowledge gap and the relevance of this study.

Chapter 3: Describes the study design in which this study adopted a qualitative paradigm and also presents the procedures for data collection, the ethical issues and data analysis.

Chapter 4: Discusses the qualitative study findings and the sample description.

Chapter 5: Analyses, summarises and presents conclusions and recommendations and implications for possible research, policy and practice reviews.

Chapter 2: LITERATURE REVIEW

2.1 Introduction

This study seeks to understand the reasons, gain knowledge and determine the context pertaining to men and their health seeking behaviour with regards to accessing HIV health services within KZN. This vital information is necessary to influence both policy makers and the approach of health workers to men and their idiosyncrasies, so as to reduce morbidity and mortality from delayed access to HIV health care. Although, it has been observed by both myself (following 20 years of experience in clinical practice within rural KZN) and fellow health care practitioners, within the public health sector; and supported by various studies, that men have poor health seeking behaviour, documented by the likes of Cheatham, Barksdale and Rodgers (2007), it is still necessary to explore the views of key role players, who will be the best narrators of perceived and experienced barriers and triggers, promoters and inhibitors to men accessing HIV services within the public health sector in KZN.

Prior to discussing the literature, a few concepts and definitions require clarification and some discussion. The concept of health seeking behaviour has become an important tool to understand possible delays or positive actions in accessing care across various conditions. Sometimes the term is interchangeably used with 'help seeking behaviour' (Cornally & McCarthy, 2011). A defined help seeking behaviour for a health problem can therefore be a planned action or a focussed behaviour involving interpersonal interaction with a health care practitioner. Seeking help is a process in response to a problem, and involves an active pursuit of help from health care personnel, since the issue cannot be resolved on its own.

Additionally, health seeking can infer seeking health options in the absence of an actual health problem, and this might include health promotion involving lifestyle changes in

preventing diseases. So, health seeking can occur in healthy states, and does not always involve an external source for help. In this instance, we will agree that health seeking/help seeking is a process involving a focussed planned action with the assistance of a health care professional. Hence a health problem needs to be recognised, and sometimes self-help or alternative assistance sought out prior to formal health care; or others seek it as first response. Then the planned action of actually selecting the source of help is an essential step to health seeking behaviour. This individual is acting with agency. Consequent to this is the interaction with the third party itself, the health care professional, where the actual problem needs to be verbalised and disclosed. The key here is exchange of personal information and willingness to share and of disclosure.

There are potential barriers that can act negatively at these steps of the process. The following variables are crucial in determining health seeking behaviour particularly in men:

- Recognising and defining the problem (Arnault, 2009): largely determined by the cause; the perceived significance and severity, duration and the perceived consequences. Appraisal and evaluation of these variables are tantamount in the mode of action to follow (Lauver, 1992).
- Decision to act: (Eiraldi, 2006) this is largely influenced by demographics, perceived knowledge, social and cultural norms, attitudes and expectations. These factors are innately dependent or influenced by historical events like past health seeking experiences, attitudes and beliefs of others about health services or health problems and gender norms (Barker, 2007). Nelson -Le Gall (1985), states that the willingness to seek help is influenced by the cost to person of seeking this help and the motivation or desire to get help.

- Selection of source of help: choosing an agent (Jordan & Oei, 1989), either whom or where to for help. This often is the unknown and little choice over health care provider (within the public health system). This again can be influenced by various extraneous factors, historically and socially, economically, traditional and culturally. Here barriers and facilitators influence choices.

A normal outcome from seeking help for a health problem would be a resolution of the problem and a sense of wellbeing. However, this is not always true and a non-resolution can often occur with a realization of no cure sometimes (as in the situation of having been infected with HIV). This dissatisfaction can lead to resentment of the system and anger. Negative outcomes of health issues, can lead to delayed health seeking in the future or seeking alternative sources of help. In addition, this might impact on others seeking similar help for similar health related problems, via social networks.

This literature review hones in on the following concepts:

- Social associative aspects underpinning behaviour patterns in seeking health care amongst men
- Economical dispensation of the health seeking needs of men as in health vs poverty issues
- Health systems elucidating attitudes and systems needs for male friendly access, including funding and program prejudices

2.2 Social aspects

2.2 .1 Social norms and masculinity

It has been intimated that masculine ideologies and the resulting socialization of men has had an effect on men's health seeking behaviour (Galdas, 2005). This has been substantiated further by a study undertaken by (Rabiee, 2001), using semi structured interviews of men between 15-19 years of age, where he concluded that health was equated to physical fitness and was dictated by social norms and that these responses were dictated by powerful notions of masculinity and their masculine identities. Men who were interviewed by Chapple, Ziebland & McPherson (2004) about delayed health seeking behaviour, also confirmed the fear of appearing weak or that they lacked masculinity. In the context of HIV and its status as an engendered epidemic, particularly in SA where it is predominantly heterosexual, the feminization of the disease stems from racial and gender inequalities and the inferior socio-economic status of women. These notions result from gender norms and practices around sexuality and barriers against prevention of HIV, imposed by men. Although cultural practices can be modified or contested, risky sexual practices still exist among men, even in the face and knowledge of the HIV pandemic. Brown, Sorrel and Raffaelli (2006, p. 594), quote Namibian reflection that *"if you do not die of AIDS you are not a man"*.

Although messaging around sexual practices and risky behaviour in HIV prevention is public knowledge it still seems that manhood remains tied to control and dominance in sexual relationships, typical of patriarchy. In a survey in a South African township (Magruder, 2006) two thirds of the participants agreed with a statement that *"men think of ill health as a sign of weakness which is why they go to the doctor less often than women"*. Hence the assumption that men will less likely access HIV care than their female counterparts, or delay in seeking treatment for any ailments for as long as possible, ensuring not admitting to

weakness and the parading of their masculinity. This assumption can be supported by a study performed by Nachega, Hislop, Dowdy, Lo, Omer, Mensberg, Chaisson and Maartens, (2006) where it was found that the CD4 of men initiating ART were much lower than females, intimating that men are sicker and much later in their disease process than women when starting ART. This is also illustrated by work done by Bekker, Myer, Orrel, Lawn, and Wood (2006), where he found that South African men, on average, are sicker than women, when presenting for ART initiation, suggesting delays in getting tested or in care seeking if already tested positive. Beck (2004), corroborated this by suggesting that constructs of masculinity fostered this denial of illness and that illness showed signs of physical weakness and conflicted with the norms of men being strong(er) and the family protector and provider.

HIV positive men also saw clinics as places for women and that the whole HIV and AIDS is a 'women's issue'. This makes the concepts of gender norms and masculinity difficult for men to relent to medical illness as it is seen to be a sign of weakness, thus delaying any medical attention. Within the context of HIV, this means that men will access care late or never, making their survival from HIV much lower than their female counterparts. These issues of masculinity and gender norms are often implicated in the delay and reluctance of men accessing care (Peacock, Redpath, & Weston, 2008). Poor access to HIV care is already an observed problem. In many societies, cross cultural based evidence shows that men need to be seen as invulnerable and self-reliant, not supposed to show emotion, and seldom in need of help and attention. This delay and reluctance to seek either health care or health advice has also been noted in a qualitative study involving men with severe chest pain and with prostate cancer (Greene, 1999). It has been intimated by Doyal, Hunt and Payne (2001) that delay or reluctance in seeking help and utilising health care services may be associated to their cultural beliefs in masculinity, traditions and social norms.

In a study in the UK, on men with cancer of the testes, these male respondents regarded seeking help as not a masculine trait and defined the “male” approach as being stronger, independent enough to take care of their problems, (Pulerwitz, Barker, & Segundo, 2004).

Masculinity and patriarchy were evident in the study by Skovdal, Campbell, Madanhire, Mupambireyi and Nyamukapa, (2011, p. 2) “*informants reported a clear and hegemonic notion of masculinity that required men to be and act in control, to have know-how, be strong, resilient, disease free, highly sexual and economically productive*”. This patriarchal mind set creates a distinct problem to accessing care when male patients are now supposed to follow a rigid set of instructional type rules to follow if one is found to be HIV positive. The reluctance of men accessing health-care is further fuelled by the health systems and services that are not geared or specifically set up to deal with and address the needs of men. Furthermore these instructions are given by predominantly female nurses to engage in ‘the good patient’ behaviour which conflicts with the local culture of manhood.

Are these the reasons for poor access to HIV services by men? Should there be more enabling conditions for men to access HIV services that are more supportive of their masculinity? Skovdal *et al.*, (2011) concluded in the same study, that HIV service providers should consider the various barriers that prevent male users from accessing these types of services and provide more enabling conditions to improve access. There is a lacuna in the literature leaving these questions unanswered.

2.2.2 Culture and tradition

The research evidence confirms that health seeking behaviour is influenced by multiple factors namely gender, age, cultural background, socioeconomic status and their own attitudes behaviour and values. One also needs to consider an alternative to the power of

masculinity, that of cultural norms. This refers to attitudes to biomedicine. Shisana, Rehle, Simbayi, Parker, Zuma and Bhana (2005) found in a survey done nationally, that twenty five percent of the participants said that if they were found to be HIV positive, ART would not be accessed by them as they did not believe in the concept of AIDS and that the side effects of the drugs will harm and even kill them. Although not disaggregated into gender, almost fifteen percent believed that the HIV can be reduced by traditional medicine. It is in Beck's study (2004), where it was reported that more SA men than women held this belief surmising that men will have relatively low uptake of care related to HIV. In the South African Demographic survey of 1998, the question asked "*during the last month have you been to any of the following health services for medical care for yourself*", the analysis verified that men accessing government facilities was 25% lower than women, since men are traditionally unlikely to ask for help or health care .

The use of traditional medicine could explain for the difference in the numbers seeking western medicine. Especially in HIV related signs and symptoms, where the signs of wasting, diarrhoea and skin lesions can typically be associated with witch craft (Ashcroft, 2005). This is further supported by Beck's qualitative study (2004), where he quotes a male participant, "*I believe in the tradition, in sangoma. Few men believe in drugs, in treatment, but all men believe in the sangoma because our fathers believed in the sangoma*" A study of mine workers (Campbell, 1997) also reported scepticism about biomedical claims on HIV and AIDS and believed in the power of traditional healers.

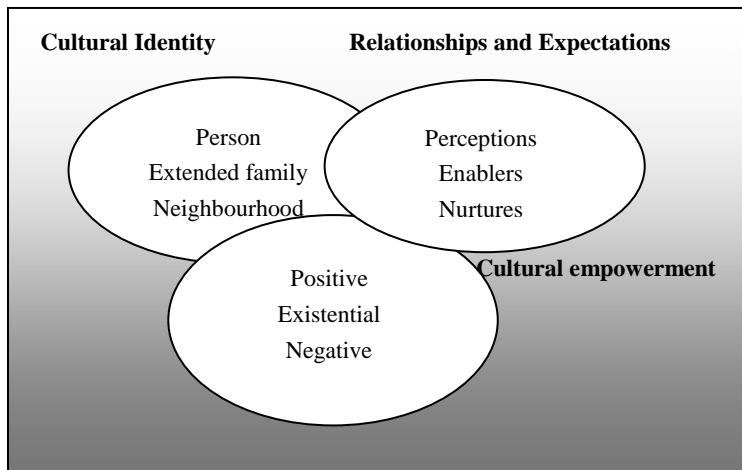
A study was done in Malawi, guided by a model based on health behaviour and culture (Hatchett, Kaponda, Chihana, Chilemba, Nyando, & Levy, 2004). This was undertaken to identify the health seeking behaviour amongst Malawians, through their unique cultural

experiences. It was shown that both western medical and traditional forms of health care and treatment are significant for individuals and their families affected by AIDS. Respondents reported that seeking healthcare occurs in three stages: (1) the initial form of traditional family care and treatment; (2) traditional remedies from cultural healer; (3) finally westernised medical treatment. The various choices and interchanges between these stages are prompted by symptom progression or deterioration. As is universal practice, when any of the remedies fail and symptoms become more difficult to manage, rural Malawians will try treatment from alternative sources. Westernised interventions, in order to improve access to treatment and health care, should consider utilizing the role of traditional forms of care used by the community. Understanding their role in why there is considerable delay in health seeking into traditional health care facilities. Their involvement can reduce the suffering caused by HIV and AIDS. Activities and interventions that provide information, education and skills for HIV and AIDS prevention and care, should include the traditional family caregivers. Modern health professionals could collaborate more closely with traditional healers to provide information on AIDS and the recognition of HIV and AIDS signs and symptoms. Healers can therefore assist in referring patients for western medical treatment and thereby reduce the delay in health seeking and progression of the disease. These interventions have been done successfully in other African countries. In rural Kenya, traditional healers are often used as initial point of care prior to entry into modern medical facilities like hospitals or clinics (Madu & Baguma, 1997) and in South Africa, some projects undertook to train traditional healers to diagnose and provide information about HIV and AIDS (Wilson, 2000). In Uganda, integration of modern medical care with traditional, has proven to be an effective intervention (Kipp, 2002).

Culture in the African population, is often shown to be an important factor impacting HIV/AIDS. It influences behaviour both positively and negatively. These factors include, the number of sexual partners, values and beliefs around sexual practices, timing of sexual debut, the uptake and use of condom and health seeking behaviour (Simbayi & Shisana, 2002). Culture can be described as *'a system of interrelated values active enough to influence and condition perception, judgment, communication, and behaviour in a given society'*, (Mazrui, 1986). When ill, relationships and social roles are influenced by cultural belief systems. In the health care environment, especially in a multicultural society that we function in, it is common knowledge that tradition and cultural practices form the foundation and backbone and on which health seeking behaviour, in particular with HIV and AIDS is expressed. This is how health is defined and understood.

In African culture, the issues around HIV has eroded and threatened and placed pressure on many previously positive traditional responses to disease prevention. An example is discrimination and social isolation a consequence of stigma, and of the sick or HIV-infected person. This is where culturally and traditionally; the sick are cared for by their immediate families and caring communities. It is therefore important and crucial that we understand that culture influences behaviour, moreover health seeking behaviour and HIV in particular.

Within the context of determining health seeking behaviour of men, we are trying to solve health problems in Africa by evaluating strategies and interventions mostly developed for western countries. We need to recognise the fact that many behaviours, moreover health seeking behaviour patterns, occur in the context of unique cultural norms and traditional practices, (figure below) is a cultural model that was developed by Airhihenbuwa (1989) to guide a cultural approach to HIV/AIDS in Africa.

Figure 1: Adapted from (Airhihenbuwa, 1989)

2.2.3 Stigma and denial

Peter Piot, an Executive Director of UNAIDS, stated: *“HIV stigma comes from the powerful combination of shame and fear. HIV is transmitted through sex and so is surrounded by taboo and moral judgment... giving in to HIV/AIDS by blaming others for transmitting HIV creates the ideal conditions for the virus to spread: denying there is a problem, forcing those at risk or already infected underground, and losing any opportunity for effective public education or treatment and care”* (Piot, 2001, pp. 4-5).

One of the most stigmatised medical conditions in the world is most likely HIV and AIDS. In 2006, in UNAIDS facilitated discussions, interested parties in 122 countries time after time acknowledged HIV-related stigma and discrimination to be one of the five main obstacles to attaining worldwide access to HIV prevention, treatment, care, and support (UNAIDS, 2008)

One of the consequences of stigma experienced by PLWHA is the decline in health seeking behaviour that can consequently serve as a barrier in accessing voluntary counselling and testing (Daftary, Padayatchi, & Padilla, 2007). Stigma, isolation and discrimination all interfere with HIV strategies involved with HIV prevention, diagnosis and treatment. This can subsequently become internalized by people living with HIV and AIDS (UNAIDS, 2006).

Although AIDS stigma is still prevalent, at a national level, it appears to be somewhat on the decline in South Africa, as shown by the findings of the 2005 National HIV household survey by Shisana *et al.*, (2005). A survey among 1054 HIV positive individuals, recently conducted in Cape Town, still found significant levels of internalized stigma. A large number of respondents did not disclose their HIV-positive status for fear of stigma and discrimination (Simbayi, Kalichman, Strebel, Cloete, & Hendl, 2007). Attitudes and misconceptions are still keeping HIV under wraps. Being infected with HIV is still perceived as having low moral standards and an outcome of risky sexual behaviour, despite the knowledge that HIV can be acquired during normal sexual acts. PLHIV fear isolation, rejection and discrimination by all that know and surround them, resulting in a perpetuated culture of silence amongst them (Johnston, 2001).

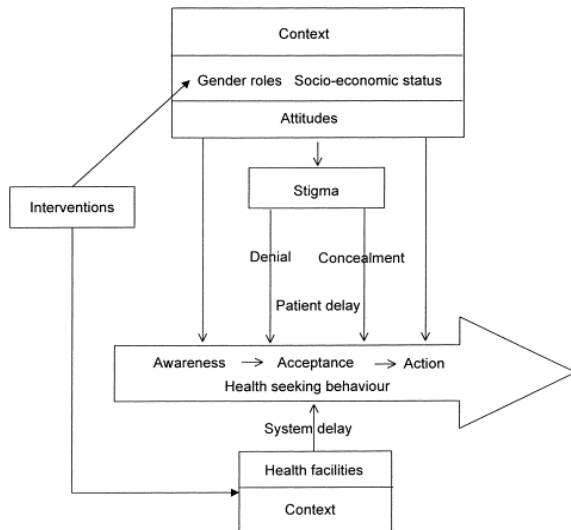
The stigma associated with HIV and AIDS is shown to be more severe for women than for men. Sometimes, also shown to be associated with traditional beliefs that AIDS is caused by supernatural forces or spirits (Simbayi, 2004). A negative consequence of stigma is denial. If you deny the possibility of being infected, surely the consequence would be delayed in health seeking? This denial, associated with fear of stigma and discrimination forces PLHIV to hide their condition. This behaviour has dire consequences as the continuing denial of the

possibility of being infected or the silence about HIV/AIDS can prove lethal since it subsequently prevents people from accessing care and thereby accepting their role in infecting their sexual partners,(Qwana,(2000);Strydom(2000).This also limits the possibility of living a healthy life with HIV.

Concealing of the disease and the denial of its existence, results in stigma. This phenomenon seems to be more common amongst men, which then leads to delay. These delays can take various forms: non-disclosure or denial of disease, accounting for patient delay; delays due to the health systems, health service delivery and other contributing system-related factors. Similarity in findings is also described in Mexico by (Rubel & Carro, 2003), of how social stigma of having TB and concealment of the illness, caused prolonged delays in seeking health care. This study done in Mexico, illustrated how family relationships are affected by stigma and that expected rejection by their families were up to fifteen percent, when they returned home from hospital. In an unpublished study by Rubel, among immigrants in California, it was also found that many patients avoided disclosure about their disease to people they lived with. They feared that their spouse would discover the disease, thereby sever their relationship by not eating or sleeping with them

In another study done in Vietnam, by Johansson, Long and Diwan (2000), looking at factors that influenced health seeking behaviour, with specific reference to gender differentials in delays in health seeking, the following was evident- typically described health seeking behaviour of men was that they “*neglected symptoms until the disease reached a serious stage*”. Factors attributable to this are shown in their conceptual framework below:

Figure 2: Conceptual framework: direct and indirect influences of contextual factors (here assumed to be gender roles and socio-economic status). Adapted from (Johansson, Long, & Diwan, 2000)



2.3 Economic

It is by now widely accepted that this epidemic, caused by HIV/AIDS, is the reason its people; their households; their communities and enterprises are all impoverished. Households that are already compromised, become poorer as a result of the long term illness and death of many members, many of whom are income-earning adults. Poverty is not only about income and economics but includes:

- Poverty of service, where services such as health and education are inaccessible or are not provided for;
- Poverty of resources, where their rights to representation or governance is denied.

Rabiee (2001) found that socioeconomic factors influenced men from differing economic status, whereby men from poor socio economic sectors tend to 'normalise' their symptoms

resulting in delays in help seeking, and that how these symptoms of illness are perceived are influenced by both cultural and social factors and not by gender or masculinity alone. Blocker, Smith and Romocki (2006) using focus group discussion, elucidated a different perspective by female counterparts as to the plausible reasons that men considered themselves providers and hence put their own needs (of health care) after the needs of their spouses and or children. It was determined that it was unlikely for money to be utilised for their male health care needs if it was needed to care for their families.

An observed fact by Lienhardt and Rowley (2001) showed a striking difference in health seeking behaviour patterns between rural and urban areas and between the young and old individuals. As in Botswana, Ghana, Kenya and Korea, residing in rural areas was a risk factor for late diagnosis. This can be explained by several factors, including poorer access to health care in rural areas in term of transport and infrastructure, lack of updated training and mentoring of village health workers, lack of supervision of health staff at rural peripheral level and differences in general education and knowledge levels between rural and urban areas.

Poverty works through a host of dependent related issues, including unequal income distribution (Gie, 1993), inequalities in economics between men and women which promotes transactional sex (Halperin, 2001), relatively poor or substandard public health education and dysfunctional or inadequate public health systems (Mitton, 2000). Other stressors related to poverty in poor rural townships such as informal housing, poor public transportation, sanitation, insufficient food, HIV and AIDS discrimination, poor education, unemployment leading to violence and crime have also been shown to be associated with HIV transmission risks (Kalichman, Simbayi, Kagee, & Toefy, 2006).

The historical role played by labour-related migration, namely of mine workers over decades in fuelling the spread of HIV and TB within South Africa, is a now widely accepted fact (Okee-Obong, 2001). Migration, singularly, is an important risk factor for transmission of HIV because migrant workers are more likely than non-migrants to have additional sexual partners away from home (Lurie, 2000). This migration, between the mines and places of residence by migrant mine workers, has helped to facilitate and propagate the spread of HIV infection back into their rural places of abode found by Lurie, Zuma, Williams, Mkaya-Mwamburi, Garnett and Sturm (2005). Apart from miners, a study by Shisana has also shown migration of educators, to be a major risk factor for HIV (Shisana, Rehle, Simbayi, Parker, Zuma, & Bhana, 2005).

2.4 Health systems and attitudes

The health systems and its health care practitioners can influence this issue if they are suitably informed and understand the nature of their masculinity, beliefs, their attitudes and differing background and culture. A study by Plowden, John, Vasques and Kimani, (2006) involving black men as key informants using semi structured interviews, identified a positive patient provider relationship as key factor in facilitating better health seeking behaviour in men. Rose (2000) supported this by concluding that men valued providers that they thought were caring in nature and that they appreciated their concerns about other personal and social issues and not just restricted to their health care needs. In response, health care practitioners described several ways that they could be more accessible to the men in the communities that they serviced elucidated by Plowden *et al.*, (2006) for example providing them with their pager or phone numbers, coming in without an appointment and addressing matters telephonically.

Sometimes, even after the patient has willingly sought help by gaining access into the health system, the communication that follows between the HCP and patient may not always lead to expectations or the desired outcomes (Page, 2005). This problem is roots in both cultural and structural beliefs. The structural issue might be that of lack of access to health care or limited education, One's health beliefs, which are cultural or traditional and maybe learned in situations of poverty, may influence against accessing medical care or adhering to care and medication. One common and basic practice of this kind is that if you do not have symptoms, there is no reason to take further medication. In early diseases such as asymptomatic HIV, this belief can have devastating consequences for the patient. Any intervention or awareness to improve these health disparities should include both structural and cultural components. The most desirable structural intervention would be naturally be access to health promotion prevention messages and education , which would provide the foundation necessary to influence an effective cultural intervention, including modification of previous beliefs about treatment of asymptomatic disease.

Some research done by Leichliter, Paz-Bailey, Friedman, Habel, Vezi and Sello, (2011) has identified additional barriers to accessing care and the associated delays in seeking health care in South Africa, being that of attitudes where it was reported that experiences with some female nurses were rude or judgmental of the men. Situation where this occurs and some of the factors associated with delay in seeking care include the perceptions of the seriousness of symptoms and whether or not self-treatment occurred (Reddy, 1999).In addition to this, for HIV-positive men, the public service daytime clinic hours; and a belief that clinics were for women; as they typically have mostly female staff, were barriers to care (Orner, 2008).

World Health Organization (WHO) in 2007 published a global strategy for STI control and prevention (WHO, 2007). One recommendation was '*male involvement, male motivation, and services for men*' (WHO, 2007). In order to encourage men to access health care services and receive appropriate treatment, public health services must reflect and respond to men's needs (Pearson, 2003). In a study to explore sexual health care access and seeking behaviours in men 5 years after implementation of free ART in the public sector in South Africa (Young, 1981), they examined the sexual health care-seeking practices of South African men and sought to understand the factors (including STI/HIV knowledge and attitudes) that may drive men's health-seeking decisions in a culture with a pluralistic health care system. This study found that their lack of knowledge about STI/HIV and ART appeared to be related to their decision not to seek HIV testing, and their lack of awareness of STI symptoms may influence their sexual health care-seeking behaviours. In addition to this, several men also tended to avoid HIV testing because they found the current VCT process within the public health system to be lengthy, time consuming and judgmental. It may be possible that a more streamlined, client-centred approach to VCT would be more acceptable to men. Provider-initiated testing could also be a useful approach to increasing testing by men and should be explored and documented. The most important finding from this study is related to the quality of available sexual health care and its role in health care seeking among men. A study done in Uganda (Nuwaha, 2006), found that several men believed that they could receive a higher quality of sexual health care services at private doctors; however, this contention would not appear to be supported in the literature. The quality of care and the use of syndromic management for STI are doubtful in private sector. Of note in this study is that finding also suggests problems with the quality of care in the public sector.

In order to increase and facilitate health care-seeking behaviours among men, it is obvious that it is important to make public clinics a more comfortable and conducive place for men to seek care. Generally men perceived clinics as a place for women given the large number of female patients' usage and the predominance of female staff. There is also a perception that female nurses in public clinics were rude and judgemental toward men. Issues need to be discussed with current nurses and health care providers so they could be trained to more effectively communicate with male patients in a sensitive, non-judgmental way and to develop a rapport prior to a physical exam. A possibility is that having some male health care providers, in addition to female providers, may aid in making clinics a more comfortable place for men.

There is a need for strategies that are more gender sensitive, in order to address issues causing these delays in seeking health care (Johansson, 2000). Accessible, affordable, comprehensive services at all levels of the health systems are of utmost importance in order to reach both genders equitably, including the poor and those that live in remote rural areas .

Factors related to individuals or factors related to systems influences the ones behaviour in seeking help. Meaning that delays can be caused by individuals own behaviour or due to the health system's inadequacies. These factors can be changed by various interventions such as decentralisation of services, improving health education, reducing the costs of treatment, and improving the working conditions for staff, incentives and encouraging retention and recruitment by improving salaries. These interventions can be implemented anticipating a change in context and thereby improving health seeking behaviour.

Family structure and gender roles also influence health-seeking behaviour. Women, who are traditionally dependent on their husbands and in laws, are concerned about rejection. Men worried about financial issues and loss of income. These concerns amongst men and women differ as their roles in society differ.

The clinical competence of staff in combination with caring and nurturing attitudes is a vital component of quality of care. This influences the accessibility for the chronically ill. Public health services deficiencies will only serve to fuel the reluctance of the ill to seek help when needed. This could be from previous personal experiences or via social network of experiences of others.

Positive interaction between patients and staff is beneficial for the both the trustworthiness and confidence in health care and treatment and of the health institutions. The behaviour of staff, poor attitudes and lack of sensitivity are deficiencies reported by many (Vlassoff & Morena, 2002). Patients often report that they are reluctant in seeking care because of the way they are treated by the health system, often in an inferior manner. It describes both callous and less than desirable attitudes of staff where, health care workers often reacted with aggression to patients who presented for treatment in the late stages of their disease. The conclusion is that it is this behaviour often makes the patients afraid, uncomfortable, and unwelcome. This threatening attitude deters them from returning for help. It is therefore important to consider the consequences of poor attitudes and care into consideration. Donabedian (1988) reported in his study that, poor care is wasteful and harmful to patients. The consequence of wastefulness is depletion of resources which could have been utilised more profitable in treating patients better.

When teaching and training health workers, it is tantamount that there is a greater need for better understanding of both gender, behavioural and sociological aspects of disease, and not concentrate only on the technical aspects. The process of quality improvement must involve self-reflection; awareness of own limitations, ownership and responsibility for their own processes of change. This involves a continuous process of engagement; of assessing and reassessing to improve the cycle of caring. This needs to be integrated into the whole setting of achieving quality of care such as ensuring a working environment, proper functioning equipment and facilities, open communication, good management and leadership.

Although these barriers identified in literature could apply to other groups, research is needed to enlighten us further to the specific reasons for poor access to HIV care amongst men within KZN. A South African perspective on male health seeking behaviour seems to be lacking in the research literature. This study may contribute to reducing this lacuna.

2.5 Summary

There is a paucity of accurate data, by the South African government, on the number of people accessing antiretroviral therapy for HIV and AIDS. It is reported that 42 per cent of PLHIV eligible for ART are receiving treatment. Data from independent civil groups argue that this is over estimated. It is shown that women are more likely to access testing and care for HIV and AIDS, than men. According to the World Health Organisation, 68 percent of those accessing ART are female; knowing that almost equal number of male and female require treatment. In Khayelitsha, Cape Town, a study on the uptake of ART showed that 70 per cent of those accessing treatment were women (Coetzee, Hildebrand, & Boule, 2004). Another study in Johannesburg General Hospital, found that women: men accessing ART were 2:1. In a wellness clinic in North West Province, a similar situation was found in a

survey of 5757 patients (Hudspeth & Venter, 2004). Men also access care in a rather immune compromised state as they more often delay initial access to care much later than women (Hudspeth & Venter, 2004).

It is apparent that discrepancies in uptake of ART between genders do not result from the higher infection rates amongst women. In fact the ASSA (2003) found that out of all the patients eligible for ART, 46% were men, however on 36% accessing treatment were men.

These findings tend to support the suggestion that the socialisation of men and the concepts of masculinity affect behaviour, where health seeking behaviours are seen taken to be a sign of weakness and something women indulge in. In a study by (Nattrass, 2006), 566 Khayelitsha residents were surveyed and two-thirds of the participants either agreed or strongly agreed with the statement that, “*men think of ill-health as a sign of weakness which is why they go to a doctor less often than women.*” In 1998, the Demographic and Health Survey (DHS) showed significant differences in the utilization of health services between men and women. This low usage of health services by men mirrors their low utilization of HIV services as well.

A renowned clinician of the South African HIV/AIDS Clinician’s Society, Dr Francois Venter, stated that government needs to play a critical role in improving access and utility of the use of HIV services by men. He says “*The work being done by NGOs... is making a difference in terms of how men now relate to the pandemic, but this exercise should not fall squarely on the shoulders of civil society groups.*”. *The government seriously needs to consider new approaches if it is to attract more men to its ARV program*” (Venter, 2006).

The factors that influence the severity and pattern of the pandemic caused by HIV and AIDS are multifaceted. These include several social, cultural and economic factors. According to ABT Associates Incorporated (2000), these factors include: social norm and cultures that accept and condone many sexual partners for men, the non-affirmation of women in society and within their own personal relationships; lack of open dialogues about sex and sex education amongst children; reluctance in condom use based on traditional and culture; high mobility and migration allowing for easy movement of the virus into new communities; disruption of family life due to apartheid and labour issues; frequency of other sexually transmitted diseases and high levels of poverty in the region.

It is therefore irrelevant and inappropriate to focus on specific aspects in an attempt to curb this disease, when it is evident that combinations of social inequalities have played a role in shaping the pattern and the steady un-abating growth of HIV and AIDS. This translates the need to address all elements using the psycho-socio-environmental model, requiring a multi-sectorial approach using true interdisciplinary team efforts. It also requires concerted effort, commitment as well as strong political will.

Chapter 3: RESEARCH METHODOLOGY

3.1 Introduction

This chapter provides a detailed discussion of the methodology used to investigate the study titled Patient and Practitioner Perceptions of Promoters and Inhibitors of Health Seeking Behaviour amongst African Men accessing HIV health services in Kwa-Zulu Natal. A research design is a general strategy for solving a research problem. It provides the overall structure for the procedure the researcher followed, the type of data the researcher collected and how she went about getting such data, how such data was analysed and interpreted. The chapter also gave further exposition on the justification of the methods utilized, the study setting and the ethical considerations involved in the study. Finally the possible limitations encountered in the course of the study were highlighted.

3.2 Research design

The study has made use of qualitative methods. This qualitative paradigm enabled the researcher to understand the day to day experiences and the perspectives of the target population being investigated. Given the time, skill and resource constraints, this was best achieved by narratives, describing what was experienced, within their rich cultural, traditional backgrounds, and their specific social norms', thus using an insider-perspective rather an outsider-perspective. Creswell (1998) and Patton (1990) inferred that quantitative data by itself often produced an incomplete picture and that there was an added value in incorporating qualitative data element to research for an added level on understanding. Qualitative research believes people to be complex language users, who have an ability to interpret and understand their own social worlds and experiences (Brown & Locke, 2008). It was therefore suitable for this research as a way of understanding the individual's conception

of their behaviour and experiences. It is located in the interpretative phenomenological study, as this paradigm looks at a comprehensive investigation of individual lived experience, and how the individual makes sense of that experience (Eatough & Smith, 2008). This applies to this research, as all the research questions look at health seeking behaviour and experiences from the individual's point of view.

The study was both descriptive and exploratory in design. In qualitative research it is expected that people's experiences will differ, hence allowing the process to evolve as the researcher explores and discovers new perspective (Cresswell, 1998). This study makes no claim that the findings may be replicated or generalised, as this is not a descriptor of qualitative research, and is a predominantly used to generate theories from understanding particular or local situations. It rather concerns itself with comparability and translatability.

The qualitative methodology is based in a critical paradigm. A critical paradigm is particularly interested in issues such as social justice, and seeks to assess subjugated knowledge and the unique viewpoints of oppressed groups (Benatar, 2011). Critical research provides an opportunity to forefront the voices of role players whose views and opinions may traditionally be neglected when developing health policies, guidelines and strategies.

Unlike quantitative research, a qualitative study does not seek reliability; but anticipate that people's opinions may be unique, varied and changeable.

Validity considers whether findings from the study are plausible and qualitative research employs differing validity constructs than quantitative research. To ensure validity, the researcher has used direct quotations from my interviews to provide 'true' description of a given reality.

3.3 Sampling

3.3.1 Study site (Appendix L)

The study was carried out in the province of KwaZulu-Natal (KZN), South Africa, which is the second most populous province with a population of 10.8 million people, 21.4% of the total population in South Africa, Statistics, South Africa, (2011). Half of the population (54%) reside in rural areas (KwaZulu-Natal Provincial Government). The designated hospitals, where participants were chosen and permission was granted, were predominantly rural health care facilities (district level hospitals) within KZN.

These were within health districts DC27 and DC 24 (Appendix L); deep rural hosting one of the furthest of all KZN hospitals being Manguzi Hospital, bordering on Mozambique and the other facility being in Tugela Ferry.

Although the researcher is not directly involved or currently working in these facilities, these facilities were both known and accessible to the researcher, as she travels there (from her home in EThekweni- Durban) to supervise medical students during their rural attachment in final year of study. This study was undertaken during the period August 2012 to October 2012.

3.3.2 Selection of participants

The study employs purposive sampling methods and participants are regarded as potentially information-rich sources of data (Patton, 1990). This type of purposive sampling was employed for its appropriateness and purpose of rich description and experiences. These individuals were assumed to be the best to reveal and share information regarding the subject

discussed in this study. The requirement was that they would be HIV positive African men already accessing care at a public health facility, within KZN. The recruitment process adhered to the following steps:

- Contacted the health care workers at the 2 ARV clinics at the 2 hospitals I had permission to conduct the study at, informing them of my study (Appendices B,D,E)
- Drawing up an information sheet and a consent form for the participants (Appendices H,F,G)
- Made appointments to visit the designated ARV clinics
- The recruitment of male participants was assisted by the professional nurse in charge of the ARV clinic
- Information was given to the possible participants, with time for frequently asked questions. (Appendix H)
- The availability of qualified HIV lay counsellors for additional counselling if required for any of the participants, during or post interviews, was ensured.
- The participants reviewed and signed the informed consent. (Appendices F,G)
- The interviews then followed, using the semi structured interview questionnaires (Appendices I)
- An additional series of semi structured interview questionnaires, using convenience sampling, were administered to Health care practitioners working at these HIV service sites. (Appendix J)

3.3.3 Sample size

As qualitative research focuses on in depth interviews and finding information rich cases, a definite number of participants was not specified at the beginning, as cases will be continually be located until saturation. Generally qualitative researchers do not have hard rules regarding sample size. It mainly depends on the research question to be addressed, what will be useful and what will be credible. What is important is to reach the point of redundancy or saturation, meaning no more relevant emerging data.

3.3.4 Inclusion criteria

The participants were HIV positive African men, over 18years of age, either already on treatment or newly diagnosed and awaiting treatment. They were both either Zulu but English or isiZulu speaking patients. Health care professional included professional nurses, doctors and HIV counsellors caring for HIV positive patients within these facilities.

3.3.5 Exclusion criteria

Women who were HIV positive were not included in this study group. Other health care professional workings in other disciplines within the facility (other than the HIV ART clinic) were excluded. Men under the age of 18 were excluded. Any participant that was unable to speak either English or isiZulu was excluded, or if informed consent was not granted or there was reluctance to discuss process details.

3.3.6. Demographic descriptions

For this small study, simple demographic data was collected consisting of:

- Age, marital status, number of children, number of sexual partners, living arrangements, employment history, income source, hobbies and habits

(See TABLE 1: PLWHA)

- Professional designation, age, gender, years in service, experience in HIV care

(See TABLE 2: HCP)

3.3.7 Challenges to recruitment

The hospitals (two of the five) that granted the researcher permissions were the furthest away from home and work, the furthest being 550kms away. The researcher often did not find the time to interview participants, after supervising and mentoring students and still being on time to travel back home.

3.3.8 The interviewing process

The data collected in this study relied on the face to face interviews conducted by me and an interpreter, sometimes this being an isiZulu speaking medical student or the ARV clinic counsellor. The advantages of this were the participants ability to provide information based on own experiences and views and the researchers power to control the process. However, the disadvantage was that the participants' sometimes included biased information knowing I was a medical doctor or when in the presence of an ARV counsellor.

3.3.9 Data collection instrument

Data tools used in this study were the semi structured interview guide for both practitioners and patients; HIV positive men attending HIV services and health care practitioners caring for these men. Both of these interview questionnaires were original and administered face to

face and sometimes with an interpreter if deemed necessary depending on language preferences. These questionnaires went through iterative changes as deemed necessary according to the directions of the in-depth interviews. However, the themes that the researcher wanted to cover for the HIV positive participants included: demographics, timing of testing in relation to getting ill, was testing voluntary or not, use of traditional medicine, the cultural and gender issue with regards to accessing care, belief systems, stigma and disclosure, role of HCW attitudes and current health systems.

3.4 Ethical considerations

The nature of my research, involving face to face interviews with participants, required ethical consideration to ensure that a balance of the potential risks to the participants and potential benefits of this pilot study. The necessary approval letters were obtained sequentially from the different levels and bodies of authority. The protocol was first approved by the Africa Centre for HIV/AIDS Management, and then reviewed by the Ethics Research Committee University of Stellenbosch (REC), Appendix K. Permission with stipulations was obtained in August 2012, HS823/2012. Applications for permission to conduct the study were also submitted to the KZN Department of Health Provincial office, (Appendices A; B); and the CEO of the individual hospitals (Appendices C; D; E)

Rights to privacy and confidentiality were ensured during recruitment. This was through anonymity of the demographic details of the participants. No personal identifiers were used on the questionnaires. They had a choice of using code names. The participants autonomy were preserved in that all participants were informed that this is for research purposes only and have the right to decline or terminate the interview at any point. Participants were informed that they could withdraw from the research process at any time without adverse

consequences. They were also informed that non-participation would not affect the services they receive from the health facility.

Informed consent was also obtained from every participant interviewed for the study. Verbal consent was obtained from all participants who were interviewed during recruitment, and prior to selection to participate in the study. Participants were being fully informed of the nature of the study through a study information sheet. Written consent was sought from all participants, both from the HIV positive men themselves and the health care practitioners. Participants only signed a consent form, following a clear interpretation and understanding of its content (Appendix F; G). The consent form was a separate document on a University of Stellenbosch.

Beneficence of this study will be in the outcome achieved in informing guidelines on male specific needs for health care. Potential risks to participants were that these interviews could raise disturbing or emotional issues. Risks and non-maleficence as to minimize the probability of harm to the participant and appropriate counselling of any harm envisaged was offered to participants that required it. The counsellors that would have been utilized were fully qualified counsellors already working at the ART clinics, who had agreed to assist the researcher in the event of counselling being necessary. None of the respondents required additional counselling as a consequence of any emotional trauma caused by the interview process.

3.5 Data collection

3.5.1 The researcher as a research instrument and author

The researcher although, currently working at the University of KwaZulu Natal and is no longer involved in clinical practice at any of the provincial district hospitals, she has had more than twenty years clinical experience at rural district hospitals and is regarded as an ‘insider’ to understanding the unique challenges that exist in managing such illnesses as HIV and AIDS. As such, more objective views were taken as the researcher had no direct influence on any of the participants. The researcher also has adequate second language fluency in Zulu, thus had a good understanding of the language content of the interviews and verified the translation versions.

3.5.2 Data collection

Data was collected through face to face semi structured interviews. All participants meeting the criteria for inclusion agreed to be interviewed, and to have their voices recorded. The demographic form was filled and was found to be helpful to the researcher in building rapport with the participants. Participants were asked to choose a name for the purpose of the study, aimed at protecting their identity. These names were linked anonymously to the consent form they signed, demographic form, interview voice recording and field notes documented by the investigator. The protocol included basic data on background information, the aspect of attitude and perception on possible inhibitors or promoters to accessing HIV services within their community. The interview also solicited demographic, socio-economic and cultural information, (See Appendices I; J)

3.5.3. Data management

All written and electronic data collected were securely stored. Written data that includes the signed consent forms, demographic forms and filed notes were stored in the investigator's file kept in a secure lockable cupboard with restricted access. Besides the consent forms, no other records were available linking the participants study numbers to their identity. The voice recordings were conducted using an Olympus digital voice recorder. Data was transferred from the voice recorder onto a personal computer using the supplied software. This transfer allowed for a secure password-protected electronic storage of data. The transcribed and translated data were also stored on a back-up disc in case of any unintended and unforeseeable damage or loss of electronic data on the computer occurred.

3.6. Data analysis

Due to the small number of participants enrolled in this study, content analysis of the transcripts from semi structured questionnaires was undertaken manually. This process commenced immediately following each interview. Emerging themes, thoughts and other observations were written down immediately after interviews in the field notes journal. The investigator listened to the voice clips repeatedly for immersion and familiarization with the data collected. Field notes were also read several times during data collection and analysis. The content was transcribed, coded and themes established. Categories were compared to find connections between themes. The eventual goal in this analysis was to integrate themes to conceptualise into some theoretical base for interpretation to inform guidelines and assist with local policy development at facility level.

3.6.1. Validity concerns

Validity is a process whereby the researcher gains the confidence of the reader as having achieved a credible explanation of the phenomenon studied. The following strategies were used by the researcher to maintain validity of the study: 1) Taking copious notes during the interview process; 2) making verbatim transcriptions. The use of respondents own words was used when coding and summarising these responses, thus maintaining the credibility of the data set. However, the qualitative process using interviews cannot be completely devoid of researcher bias. There could have been participants bias in the responses received knowing that I was a medical doctor and had some history with these hospitals.

3.6.2. Trustworthiness

In qualitative research, credibility is the criteria for trustworthiness. This was ensured by direct contact and engagement with each participant during the interview process, verifying interpretation by a peer and assistant interpreter, and tape recording all interviews which enabled the researcher to transfer detailed transcriptions, direct quotations and contextual descriptions provided by the participants.

Chapter 4: STUDY FINDINGS

4.1 Introduction

The aims of this qualitative study were to establish an understanding of the day to day lived experiences of men needing to access HIV care at public facilities, thereby surmising probable promoters and inhibitors in achieving this. The main questions guiding this study were:

- What does it mean to a black South African man to have HIV? How do gender, culture and traditional medicine impact on your choices to seek help? Impact on daily life? Discourses about HIV? Is the present health care system conducive to men seeking help? What is your message to other men out there in your communities?
- What are your experiences treating HIV positive men and women? What are your opinions about men seeking care, especially related to HIV? What promotes or inhibits men accessing care? What is the way forward?

Data was collected via face to face interviews, using a semi structured interview schedule. Copious notes and audiotapes were used to record information, with the written consent of each participant.

4.2 Sample description

There were two types of participants, HIV positive men (PLWHA Group 1) and the Health Care Workers (HCW Group 2). In total, the researcher interviewed 6 HIV positive men and 3 HCWs, between the 2 facilities. All participants were interviewed at the health care facilities, where they either sought care or worked at. The interviews with PLWHA took approximately 45-60 minutes each. The interviews with HCW took 30 minutes each

Group 1: n = 6. All were HIV positive men already in care, support and treatment for HIV.

Group 2: n = 3. All were health care workers, employed by the KZN DOH, and worked at the ART clinics within their facilities.

Table 1: Demographics: PLWHA

Pseudonyms	Age	Marital status	Number of Children	Employment/previous occupation	Income	Duration of infection
Sipho	34	Single/never married	nil	Part-time/previous migrant 8yrs	State grant	8 years
Themba	39	Single/never married	4	Employed/no migrant	State grant	3 years
John	63	Married x2	8	Unemployed/previous migrant 21 years	State grant	8 years
Ocean	35	Single/never married	3	Unemployed/previous migrant >5yrs	State grant	12 years
Emmanuel	39	married	3	Unemployed/Previous migrant, duration?	State grant	3 years
Bongani	44	Single/never married	4	Employed /previous migrant x 10 years	Wage	3 years

Of note in the demographics of these respondents is that: only 33% of them are married; 83% of them have 3 or more children; only 33% are employed; 83% are on state grants; 83% were previously migrant workers and 67% of these worked 5 years or more away from home and family.

Table 2: Demographics: HCP

Pseudonyms	Age	Gender	Designation	Number of years' experience/ (HIV care)
Portia	37	Female	Professional nurse	6 months in HIV
Eunice	46	Female	Lay counsellor	12 yrs. in HIV
BB	48	Female	Professional nurse operational manager	8 yrs. In HIV

4.3 RESEARCH FINDINGS

The process of data analysis was to firstly read and re-read all transcripts from the audio tapes, together with the copious field notes taken during the interviews. Themes emerged from the experiences of both these men and HCW that were interviewed.

PLWHA

Themes	Categories
Knowledge about HIV	Clarity of messages Types of messaging Mode of communication
Culture and gender	Traditional medicine Masculinity Attitudes
Stigma and discrimination	Fear of dying Fear of isolation
Health system and attitudes	Female nurses Hours of service
Impact on life	Work and Income Partners and relationships Friendships

HCP

Themes	Categories
Gender and culture	Masculinity issues Traditional medicines
Health seeking behaviour of men	Reluctance Denial Delays

Attitudes and Health system	HCW attitudes Vertical systems
Knowledge and messaging	Mode of communication Special needs

4.3.1 PLWHA: Themes

4.3.1.1. Knowledge about HIV

The PLWHA described having tested positive for HIV as being very difficult and overwhelming initially, but once in the system, they have no doubts that this was the best decision they had made - to test and know your status, thereby receiving appropriate care and support. They all agreed that they feel like normal healthy men again, and that their minor ongoing symptoms of recurrent flu, rashes, gastroenteritis, lethargy, general malaise are now a thing of the past. They expressed a wish that other men would follow suit and come in for testing and appropriate care. When asked why are men reluctant to volunteer to test for HIV?

The responses were as follows:

Themba: *“Like me, I was first very scared...scared of dying, we are all scared of dying and this thing has killed many people. When we talk about this thing...we think about dying”*

And **John** added: *“You know, these men don’t know all the truths about HIV, only when you are here at the clinic, and can see how many people are coming for help and how many people are living for long... long time, then we can see that this thing, this HIV, we don’t have to die from it, it’s just like having BP and sugar”*

When I reiterated that messaging around HIV and AIDS were abundant and on all social media networks and freely available, there was again agreement on the wide availability of

such information however **Sipho's** opinion was *“that is not enough, just having it on billboards, posters about condom usage, and to know your status and to be faithful. This thing is getting boring now, the men see the same thing and they don't listen anymore. It's like any advert on TV now. You have to talk to them face to face”*.

When the researcher inquired about how should this be achieved then, if the usual or current method is not effective? To which **Themba** responded, *“You have to get the men together in the same place and give them information, like in a tavern, or their workplace, or even at schools; but you have to get the men separately. You see they don't like to be with the women, to hear the same thing. If they are alone as men and you talk to them as men, then they will listen”*. **John**, the older of the men interviewed, and who is also part of the support group said *“we as HIV positive men, on ART, need to go house to house...door to door and tell these men to get tested. We need to let them know that they can live for long and be healthy for long, look at me-I'm fit now, in fact I want to have another baby. We are planning on our male support group to do this door to door, as we can see that our men are still dying outside, as they are hiding from this HIV”*

Bongani suggested the use of current community care givers (CCG-nompilos), *“we have these care givers that come to our community, the nonpilos. Why are they not testing? They come right to your door, and if are able to test for HIV, it will sort out many problems especially if she sees someone is ill. This also takes less time than the trip to the hospital and the long queues there is not good for a sick man”*

4.3.1.2. Culture and gender

According to literature, masculinity and culture especially with regards to Africanism play an important role in health seeking behaviour amongst men. The PLWHA that were interviewed for this study, were culturally black African men of rural background and their responses to what role did being black African men with HIV mean to them were corroborated by both the literature and experience. **Sipho**, the youngest of the respondents, also unmarried and childless, appeared to be rather disconcerted and accepting of his predicament more readily by saying *“I accepted it and found no problems with the test results, as I was lucky that I was not very ill and had a minor problem when I got tested. Some people are very ill and have no hope. I know that I can survive long and have a normal life with HIV. Although I am a Zulu, I did not use any Zulu muti, as I can see others using it with no help. I believe in ART”*.

Whilst **Themba** added: *“it was very difficult at first, as you supposed to be strong and beat this thing, it was hard to accept, but then about 2 weeks later, when I attended my classes, I knew that this is where I will get help. I did use Zulu muti first when I had my shingles, like we all do as Zulu people- we always try out home medicines first. Then I heard about the problems of ART and Zulu medicines, and I wanted to get better so I left using the Zulu medicines”*

The concepts of masculinity and Africanism (explained in the literature) were corroborated by **John**'s response: *“Zulu man with HIV may die with this secret. They are afraid to know or afraid to disclose. It was painful but I accepted it as I found out that my late wife was positive (after she died). So I expected to be positive too. But I am lucky that my 2nd wife is still negative now.*

The issues around utilization of alternative remedies, or traditional medication and repeated visits to private practitioners, initial methods of accessing care for symptoms related to HIV infection, thereby delaying the need to test for HIV were explained by **Bongani**: *“I had to quickly accept this and carry on, although it was very hard to know but there was nothing to do now but to take treatment and live my life. I can see many that are doing well on treatment. Hey but it is very hard for Zulu men to test...sssh! Lots and lots...they are too scared, then there is the problem between the man and the woman, about who had it first, and who to blame. This makes the man not wanting to know their status and just live. I also used Zulu muti when I started to get ill and weak, and it cost me money...lots of it! It was very difficult to take this, although we are used to it. It makes you ‘palaza’ (vomit) and you get weaker and you lose the weight and you look sicker. I say ‘no’ to Zulu muti if you have HIV”*

Ocean explained why he thought that men do not test early on, prior to getting seriously ill: *“You see we men can spend lots of money going to the private doctors, but if we have to come to hospitals it has to be a major problem, we have to be dying. Men don’t come for minor things since they are supposed to cope with minor things so testing for a Zulu man is not an option unless he is dying”*. However **Emmanuel** had a sobering personal stance: *“It is very difficult for most men to test, not for me. It’s my choice if I want to live or not whether I have HIV or not, I have to live with it. These men are scared, I have plenty of friends too and I don’t know why they don’t come- maybe they do not trust where they going for help”*.

4.3.1.3. Stigma and discrimination

The issues of stigma and fear of discrimination have been widely documented as one of the worse drivers of the pandemic. Not only does it serve to perpetuate the disease transmission

but also plays a key role in delaying health seeking behaviour. The responses by the men interviewed, about their reluctance to test for HIV revealed the fear of discrimination by both family and their community and of being ostracized.

Themba: *“We don’t want to test because when we test positive then our girlfriends leave us. It is better that we don’t know. It’s a problem using condoms as well. As soon as you want to use a condom, they know you are HIV positive and then the problems start.”*

Bongani *“In our community, when they know we have HIV, they stay away and talk about us to others. They don’t visit you or use our cups or dishes anymore.”*

On the contrary **Emmanuel** did not seem to have any issues around stigma and disclosure: *“I have no problem at home, or at work. Everyone knows that I am HIV positive and they support me. I need the support and help.”*

Related to the issues of stigma the researcher probed if the cause of them acquiring HIV stigmatised them at all? Did they know how they acquired HIV? To this the responses were:

Sipho: *“Yes of course, it’s through women”*

Bongani: *“I was a naughty man and had many girlfriends and never used a condom”*

John: *My wife was HIV positive and I didn’t know her status”*

None of the respondents suggested any other reasons for them acquiring HIV other than heterosexually. There was no mention of witchcraft as elucidated in some of the literature discussed in the literature review. However they were aware about other methods of acquiring the HI virus (contact via infected blood, MTCT, IDU).

4.3.1.4. Impact on life

The impact that HIV has had on their lives was a direct question to all of the participants. This followed the narrative about having tested positive and is now on the care and treatment program. This question required some explanation as the responses were not forthcoming. The researcher assumed that the understanding of the question was poor. The responses varied from behaviour changes to financial constraints.

Sipho: "there are no negative problems with my HIV; it's not like TB where you can get it from someone near you. My family knows about my status and they are careful".

Themba: "it affected me by changing how I live now. I was a 'joller' but now I am more careful"

John: "I find it very difficult with money. Lots of money is used up for healthy food now. We are told to eat healthy and when you have a big family, it is very hard".

Themba: "it does cost money going up and down for tests and treatment. Especially if the clinic near you cannot help you and you have to go to the hospital every time. It would be nice if we had an injection for HIV... or even a once a day tablet. It's not easy to take so many tablets twice a day. We are still praying for a cure"

All the participants still had partners, and all had disclosed to their families. No mention was made about disclosure to their close friends though. When probed directly in a question about discussion about HIV with friends, this was a topic that was not discussed openly or part of normal social discussions. Like the response from Themba: "We don't talk about HIV with friends like we talk about soccer..... (Giggles)

Sustaining a full time job was an issue that affected most of the participants. This was the result of time spent away from work for appointments at the hospital for blood tests, then blood results, TB screening and results, literacy sessions to commence on ART. Two of the six PLWHA were hospitalised for HIV related illnesses as well, which also contributed to time away from work. The men expressed frustration in holding onto to either a part time or full time job if it did forced them to spend full days at the health facilities for the HIV related processes.

4.3.2 HCW: Themes

4.3.2.1. Gender and culture

Literature has evidenced that culture plays a significant role in the Black African men's belief system on causation of diseases, especially with regards to HIV, some believing it is due to witchcraft or that the concept of AIDS does not exist. In addition to this the masculinity role that influences behaviour patterns influences health seeking when needed. The health care workers had opinions that did not vary from these:

BB: "You see it's the mind of the man, he is the man. You see it's the cultural thing, you cannot change the way he thinks...that's the role of the man, they don't take the initiative, and they don't come for help. We must realise that this won't change so we must work around it and must understand this cultural issues and explain to the men that diseases are diseases and your culture is there to stay but we need to sort this disease out, to alleviate it or prevent it."

Portia: *“unfortunately in our Black community, the numbers of men coming to the clinics are fewer than females, even when the women have disclosed to their partners and ask them to come along to be tested; they refuse, and get very angry. They either are scared to know their status or they already know but are in denial and using cultural/Zulu muti to help him (but has not disclosed to his partner). I have men that have refused their babies from taking ART and prefer taking them to the Inyanga, until the baby gets so sick and needs to be admitted and then it is revealed to the doctor that they defaulted on ART because the father refused to give the child the ART.”*

4.3.2.2. Health seeking behaviour of men

Historically, men are known to have poor help seeking behaviour. It is related to gender and masculinity and the patriarchal society we function in. With the negativity associated with having HIV, its stigma and discrimination contributes greatly to the delays in seeking help. The HCW's responses to this end are:

Eunice: *“females come for help for anything, even for fever or anything, and then they are counselled about testing and the importance of knowing your status. Men ignore their early symptoms (like a rash, shingles, fever) and say they will see the next time, while they are getting sicker with more OIs. Then these OIs kill them and it's the same OIs that killed many others that they see in their communities, and it's this that are making the scare to test”*

Portia: *“men deny their status and stay at home, they also refuse to use a condom because then they have to disclose their status to their partner. They then get sicker but still stay at home until seriously ill and we cannot do very much, even if started on ART, but he has too many OIs, so he dies and the other men see that he was not helped even when he did come to*

hospital, but they don't understand in what state he came and how much we can do to help. So the problem goes on and on."

4.3.2.3. Attitudes and Health system

In order to encourage men to access health care services and receive appropriate treatment, public health services must reflect and respond to men's needs (Pearson, 2003). Are the barriers to access by men influenced by the current health system or the human resource factor?

In the health facilities that the researcher utilized, the health care workers did agree with fact that men are influenced by health system issues, however solutions were forthcoming as well. **Portia** said *"our system works well now as we have included other things within the ART clinic, and we do see more men coming to test. TB screening and TB treatment is also here, and now the male medical circumcision (MMC) counselling and booking also happens here. So the stigma of being in the ART clinic is slowly disappearing. It helps to integrate services.*

BB added that *"sometimes this environment is not conducive for men to be seen at, because of the stigma issue. They don't want to be seen separately like referred to the ART clinic. It is better that we include HIV care and treatment into the normal general outpatient care, like we do for all other chronic diseases. Men might feel more comfortable, since they are not separated and the stigma of being in an ART clinic is no more a problem."*

The issue of being trained and experienced enough to deal with problems associated with HIV disease was then directed to the HCW. All of them were confident to deal with clinical, social and spiritual need of these patients as there were processes in place within their system. They did not see it as an issue of concern. Regarding attitudes of being female nurses and the responses of men being comfortable being seen predominantly by female staff?

***Eunice**, an ART counsellor of many year of experience assured the following: “as a counsellor, men are always given a choice if they preferred a male counsellor to deal with them. Not often do they request for this. I personally feel comfortable dealing with men and I think they feel the same way”.*

***Portia** thought that men were more comfortable talking to female health care workers: “I am very comfortable in my job, and men always open up to me, they even feel free to cry in front of me, especially older men when they are tested positive and ask me ‘my child how did I get this thing at my age?’ I find men ask more questions than females. They are not shy to ask about reproduction (having more babies), seeing that they are asked to use condoms. Females don’t often ask this question”.*

The issues of personal upbringing and respect for the elders were mentioned by **BB**: “most men feel free with female nurses, depends on the upbringing of these nurses, that they have respect. There are a few (a small percentage, like a 1/4%) that have no respect and don’t know how to communicate with older men.”

PLWHA:

Bongani: *“Prefer female nurse generally as they are mother figures, they care more and they have time to listen to your problems, male seem to half listen and have not much patience with us”.*

Ocean: *“I have no problems being treated by female or young nurses; they are trained to do this”.*

John: *“Sometimes it is difficult to listen to young female tell you about sexual things and about condoms at my age”.*

4.3.2.4. Knowledge and messaging

There was consensus about the issues around HIV messaging and knowledge about HIV; that although it is widespread and freely available on most media networks, there are shortcomings or rather special needs with regards to men and the communication of these messages. There were various recommendations made with possible solutions to assist this process in order to get more men to test and enter care and support earlier in their disease process or just to be aware of their negative status and how to remain negative.

PLWHA: *“Yes there is a lot of information about HIV, everywhere, but men look at it like an advert, like on TV when they are advertising something to buy, some people are interested and others are not. Men need to be talked to face to face. Even if it’s many times, each time someone new will listen”*

HCW: *“there are many places to get a pool of females to educate and counsel and test, since females come for contraception, to antenatal clinics, bring their sick babies. We do not have*

the same situation for men. You will see that even at public awareness's, there more females and children present, men will walk away. For men, there must be special ways and times and places to educate them. There must be peer support groups to encourage them to come for care. We need to go to taverns, football matches, workplaces, schools (and separate the male students), and talk to them about their needs and why they need to test, know their status and what help can be expected if tested positive."

4.3.3. What are your suggestions if any, to improve this situation?

Recommendations and suggestions

At the end of each interview, both with the PLWHA and the HCP, the researcher's closing question was what their recommendations or suggestions were in improving any of the issues that they deemed could be righted. To this end, the researcher noticed similar opinions between the groups of respondents: that of positive messaging.

PLWHA:

- *"we have to get them to come early for testing and we need to go from house to house to teach them about living positively with HIV"*
- *"You know they really don't listen to the messages on the radio and TV anymore. We have to go door to door and spread the gospel as positive men living normal lives with HIV"*
- *"It's not only the job of the health worker to spread this message; we in the community need to help bring these men to the clinics to get tested. They are our friends, brothers and fathers that are dying"*

HCP:

- *“We need to bring the men together, not the women and children...just the men, in places where they are comfortable and talk to them as individuals”*
- *“You see we can easily get the women in the health facilities to educate and test them since we have pools of them here. This is not the case for men. We need to go find them in taverns, football matches, at their workplace”*
- *“Peer education will work, I mean that we must match the education and age levels and these men will feel comfortable. Sometimes they get intimidated by others”*
- *“We also need to tell them about the first signs of HIV, the simple things that happen (like fever, rash and sores) that our men got to the inyangas for...thinking it's nothing and it is a simple thing and it will go away. These simple things add up and then time passes and you get very sick and very thin. Then who will help...?”*

Chapter 5: DISCUSSION, RECOMMENDATIONS AND CONCLUSION

5.1 Introduction

This chapter discusses the themes identified within the existing literature and the lived experience of the men interviewed about their health seeking behaviour with regards to HIV care. It also discusses the implications on health policy and practices. This study involved interviewing PLWHA specifically black South African men (n=6), and HCP working in ART clinics (n=3). These interviews were based on semi structured guides to elicit both lived experiences and opinions of both groups of respondents.

5.2 Summary of findings and discussion

5.2.1 HIV diagnosis - Getting tested

HIV testing was not considered until the onset of ill health. Although a small but saturated sample, all of the men interviewed only tested for HIV when they were ill. Out of the six men, only one voluntarily tested for HIV, following the death of his wife, who was found to have died of AIDS. All the others were referred to and recommended for an HIV test by a HCP. When asked if they would have tested without being prompted by a HCP, none of them would have tested for HIV, if they were not ill. The period described between onset of symptoms and getting tested for HIV varied between a few months to a few years, with the seeking of alternate health care during periods of minor illnesses. Two of the participants had AIDS on first diagnosis and was hospitalised with complications and OIs, prior to starting on ART.

The issues around delays in men seeking any health care were reiterated by the narratives from the HCPs interviewed, and corroborated with the fact that men ignore several of their less serious symptoms (which could be early signs of HIV infection and HIV related OIs) until very late stages when they are being investigated for other serious medical complications (mostly AIDS related).

A salient fact that a senior HCP pointed out was the fact that females are always more accessible to the HCP to offer testing, or education or counselling. By this she meant “*that there is always a pool of women to talk to, at the family planning clinics, at ante natal clinics, even at baby clinics as it’s mainly the women that seek health care or bring their children for immunizations or treatment. We can catch them all over; this is not the case with men. We have to find them and this is usually too late... when they are already too ill and have to come to the hospital for admission and treatment*”.

Are men less likely than women to seek health care? What are the implications of these gender differences in help seeking? Over the past few decades, studies have been consistent in their findings that men, of differing social backgrounds, ages, ethnicities and nationalities, are less likely than women to seek health care. But why do men have such difficulty in seeking help; or how can we understand these societal norms and masculine ideologies in analysing their help seeking behaviour? As narrated by the men interviewed in this study, the initial decision to seek help was fraught with anxiety, fear and uncertainty which resulted in delays. However, when within the health care system and realised the improvement in personal wellbeing, their perceptions about masculinity and social norms changed and advice on ways to encourage the same behaviour change amongst other men were forthcoming.

In the event of available treatment and the many advances in managing HIV, testing is paramount for early diagnosis and entry into management and also heralded as the single most important HIV prevention strategy. However, delays in voluntary HIV testing, especially amongst men, and the several reasons thereof has been cited. These include barriers to seeking general health care to actual barriers to HIV testing faced by men. This is supported by the survey conducted by Kellerman; Lehman & Stevens (2002), showing high risk untested persons; and the reasons varied from perceptions of risks to fear and lack of knowledge of available treatment. This phenomenon of recognition of risky behaviour and that of early warning signs of possible infection with HIV is still poorly understood with the sample population of this study as well. This phenomenon is again supported by a study in England and Wales during 2000-2004, (Chadborn, Delpech, Sabin, Katy, & Evans, 2006) where out of the 15 523 new late diagnoses (CD4 lower than 200), 74% of diagnoses were among black-African heterosexual individuals, with men making up 49% of these cases. This translates to the short-term mortality associated with late diagnosis being over nine times higher than that among individuals diagnosed earlier. Unfortunately, there is seems to be a lack of perceived benefit of HIV testing the benefits; of significance early diagnosis and low cost access to treatment are still not common knowledge not widely known. This is compounded by the perceived risks of testing; the risks of compounded stress and worry, stigma and associated discrimination with social marginalization.

5.2.2 Perceived Barriers/Facilitators

The array of barriers discussed included those relating to individual, structural, social issues. These varied from experiences of 'others' in their community, low risk perceptions, migratory work patterns, and delayed health seeking behaviours; lack of opportunities for

testing as a routine health promotion strategy at local or community based settings; fear, stigma, discrimination and cultural and masculinity.

One of the most common and crucially cited barriers to testing and accessing care for HIV was 'fear'. This fear was mostly of death. "*I didn't want to know that I was positive because this meant I was going to die*". The other reason for fear was of the possible reactions from partners, discrimination and stigma associated with being HIV positive. "*My girlfriend will definitely leave me and accuse me of being unfaithful*" It is therefore clear that there is a culture of secrecy and silence around HIV, possibly because HIV transmission is associated with sexual promiscuity, negative and stigmatised behaviours and unfaithfulness. This stigma of the mode of HIV transmission is then transferred to HIV testing itself.

In a qualitative explorative study identifying barriers to HIV testing, Schwarcz, Richards, Frank and Wenzel (2011) identified the concept of fear as being the most common deterrent to voluntary testing. Of the sample of 41 participants, 68% of the respondents cited fear as one of the main barriers to testing. This fear included the reactions of family, friends and the quality of their lives if tested positive for HIV. In Leichliter, Paz-Bailey, Friedman, Habel, Vezi and Sello's study (2011), fear was cited as being born out of lack of knowledge of and about HIV and ART; and that it meant a death sentence. This same study also reported the possibility of abandonment by the family on disclosure, thus perpetuating stigma associated with being HIV positive. Stigma and fear surrounding HIV is further supported by studies conducted by Kalichman & Simbayi, (2004); Kalichman, Simbayi, Cain, Jooste, & Skinner (2006) and ASSA (2003); despite all the efforts put into media and educational programs across the nation.

HCP often discovered denial or undisclosed status of positive men to their partners until their female partners are tested positive and asked to bring their partners along only to find that they were tested positive a while ago but have not disclose and have not entered into the continuum of care. The negative consequences of this situation is that if men are in denial/or have not disclosed, then there is poor or non-usage of condoms leaving the females totally vulnerable.

Another barrier voiced by the men in accessing care was the issue of ART clinic times. They were disgruntled with the fact that the ART clinics functioned between office hours only. This meant that if they have temporary jobs, time away from work to access care is not an option, as sick leave is not a benefit. They had to weigh up the need for an income or accessing care, which normally took several hours in a public facility. The non-availability of ART outside office hours at public facilities and the belief that these facilities are for women, is quoted as a further barrier and is supported by a study done in SA((Omer, Cooper, Myer, Zweigenthal, Bekker, & Moodley, 2008), where it was reported that thought services including HIV/STI and reproductive health should accommodate the different needs of men and their work commitments.

PLWHA also commented on the poor integration of HIV care into the normal functioning of the general outpatient departments in hospitals. *“It is not easy to be sent to another section and wait at a park-home which says HIV clinic to be tested or pick up your pills”*. *Everyone then knows why you are there. This thing must be same as any other disease, like BP (hypertension) or sugar (diabetes)”*. This concern talks to the issues around stigma again and the exceptionalism around HIV and AIDS, perpetuated by the current public health policies and systems.

One of the HCP supports this concept of integrating vertical systems, that she “*found that integrating TB and MMC within the ART clinic has improved access and the number of men testing has increased*”, explaining that men feel more comfortable that people now do not guess that they are HIV positive but could be there for either TB or for MMC. She sees this as a facilitator in improving access to testing and care. It has been suggested that integration of HIV/AIDS services is likely to be beneficial, if not crucial, for quality of care and sustained improvement for people living with HIV/AIDS.

Economics and financial constraints also came into this discussion about the need to be referred from their local clinics to the hospitals for further care relating to HIV, as the nurses are sometimes not well equipped to cope with some issues related to HIV, so they find themselves going to and fro from clinic to hospital-costing them money they often do not have. Consequently, this causes delays in them getting to the hospital timeously. In the rapid appraisal mostly qualitative study titled “Hunger, waiting times and transport costs: Time to confront challenge’s to ART adherence in Africa”, (Hardon, Akurut, Comoro, & Ekezie, 2007)it was found that although many of the treatment plan and policies could be free or low cost, the related costs to accessing care and adhering to care is a major obstacle especially in low income societies. These ranged from transport costs, lost wages due to frequent visits to lengthy waiting times.

A literature review undertaken by Cheatham, Barksdale and Rodgers (2007) although identifies barriers to other groups of people, they were still viewed as unique to Black men; that being issues including employment and sources of income-these issues being jobs, which are difficult to come by, transient or very low paying, making health care unaffordable.

Groups at high risk of late diagnosis should be targeted for health promotion activities, opportunistic screening, and removal of any barriers to testing.

HIV testing in a variety of settings would reduce missed diagnoses and costs. Routine checks on new patient in primary care may provide the earliest opportunity to diagnose HIV infection.

5.2.3 Health care prior to diagnosis

Five of the six PLWHA, attended either a traditional healer or used traditional medications for symptoms experienced prior to diagnosis. The participant that did not utilize traditional medication was the youngest of the six and seemed to be the most knowledgeable about HIV and also sought medical care and HIV testing within weeks of first being symptomatic. He coincidentally does not have any children at 34 years of age.

Although all respondents agreed that the use of traditional medicine is part and parcel or their innate culture, and that using it for minor complaints will still go on (even by them); they were adamant that it should never be used as a possible treatment for HIV per se. There was a concern that more education is needed in their communities about the use of traditional medicine as alternate medical care for HIV, more concern was about the extravagant financial implications. *“These inyangas charge big money...like 1.5 thou...” Mostly they give us muti to palaza (emetic) or to ikishwa isisu (purgative).”*

The opinions of the HCW on the use of traditional medication was that the men were definitely using traditional more often and longer than women, and it is one of the reasons

for delays in help seeking behaviour amongst men as they wait for this to work until seeking western medical care, consequently getting sicker.

In the study done in Northern KZN, UMkhanyakude district, (Case, Menendez, & Ardington, 2005) where some of my study respondents resided, 1282 post death cases were retrospectively examined, on their health seeking behaviour prior to death. The findings support the common generalised use of traditional medicines by over half of the cases, with the average costs of each treatment being high. Whilst chronically ill patients seek western medical care, others are more likely to seek more traditional healers and take more non-prescribed medications which have implications for the chronic management of HIV and AIDS.

5.3 Limitations of the study

Although providing some insight on barriers and or triggers to accessing HIV care amongst African men within KZN, this study has its limitations. As with any qualitative research study, decision on the sample size and whether saturation was achieved, depends wholly on the researcher. This study sample size was fairly small and represents only a fraction of the number of men requiring to access health care, either to initially test for HIV or to continue on chronic care program; noting that the issues raised by both PLWHA and the HCP, may not be representative of all men and therefore cannot be generalizable. However, it is shown that however small this research was, the use of qualitative methodology was useful to identify possible inhibitors /barriers or triggers to men accessing HIV care in public health facilities, possible assisting with workable solutions both at policy and facility level of care. Both policy planners and local implementers need to acknowledge the value of these small studies and encourage more of the same to improve outcomes of the Global HIV program.

5.4 Conclusion

This qualitative study was exploratory in nature and was undertaken to ascertain the experiences, opinions and views of African men accessing health care with regards to HIV in particular. It attempted to verify barriers and triggers to accessing care by African men, some of these factors have been reported on by other studies and either verified here or added some new value to the already existing pool of knowledge.

The salient findings from this study were that men, although considered the dominant sex, still experience great amount of fear regarding the state of their health regarding testing positive for HIV. Fear dominates as the major obstacle to knowing their HIV status thus avoiding the need to seek care. This fear is related to the doom of pending death!

Although culture and the use of traditional medicine was prevalent, either as the initial means of treatment or as an adjunct, the issue of gender and masculinity did not feature as a deterrent to accessing health care, amongst the PLWHA. However the HCP thought differently.

Current Health systems within the public sector is not conducive to the needs of men, especially employed men and arrangements need to be planned to involve private public partnerships to assist with this.

This study also elucidated the issue around disclosure and stigma around partners and the fear of abandonment and isolation from friends and family.

HCP concerns about not having a captive pool to access men per se, to educate and encourage them to test and know their status in order to live long healthy lives; as is the case with accessing women and children. This fact answers the question in the introduction about programs being female or child orientated, with disregard to the issues of men and their needs and their role in preventing this pandemic rather than always been viewed as the perpetrates and the vectors for its transmission. We, within public health systems, need to take cognisance of the definite gender disparities and the structures that influence and aid the promulgation of poor or delayed access to care and treatment by men.

While treatment guidelines change iteratively with new research, and both family and community participation are encouraged in order to facilitate the support of program implementation, little engagement and guidance is sought related to gender specific needs. More is required in examining the issues relating to how men understand or experience seeking health care with regards to actually getting treatment or acquiring knowledge on either health promotion/prevention. Therefore, by listening to men who have accepted the need for help, and who are in the process of changing, we might better understand the evident paradoxes of being male and adapting in an African society. A fuller understanding of the processes that might facilitate changes in men's individual concepts of masculinity to include seeking help could provide important insights for help providers and community health outreach programs as they seek to effectively communicate with and treat male clients.

5.5 Recommendations

Based on the findings of this study, the following recommendations are offered:

5.4.1 Issues around testing

- Introduce home testing- by nompilos (CCG), to avert delays in knowing your status
- Encourage couples counselling to ease the issues of fear of disclosure and domestic violence
- Incorporate opt out mandatory testing/routine testing in health care, to avoid missed opportunities
- Facilitate PICT to avoid long queues at specific lay counselling offices,
- Offering HIV testing in a range of venues, from schools, workplace, GP surgeries to community- or faith based organisations, could increase the opportunity for testing.

5.4.2 Issues around messaging

- Messages need to be more directed, personal, non-political;
- Clarity and explanation of the importance of testing and commencing care;
- Impart clear knowledge of signs and symptoms of possible early infection and associated OIs
- Emphasize that HIV is a chronic manageable disease
- Include peer education and door to door information
- Reiterate that early diagnosis improves health outcomes
- Confirm the availability of cost effective treatment to manage the disease

5.4.3 Health systems

- Integrate systems within the health facilities incorporating holistic point of care
- Ensure open/suitable hours for access to ART for employed PLWHA within health facilities or alternate pick up at health centres e.g. private GP's or private pharmacies; as in a Private Public Partnership

- Ensure HCW understanding of peculiarities around men and their behaviour patterns and specific needs
- Collaboration with traditional healers in educating them on the need for timeous referral for further testing and care within the western medical facilities; thus reducing delays and progression of disease.
- Development or adaptation of interventions to reduce social, personal and cultural barriers,

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APPENDIX A



AFRICA CENTRE FOR HIV/AIDS MANAGEMENT

14 June 2012

District Manager
KZN Department of Health

Dear Sir / Madam

Re: Intention to conduct a research project at the ART clinics at any/all of the following District Hospitals within KZN: Church of Scotland, Manguzi and Wentworth.

Dr N Moodley, a Master of Philosophy student in HIV and AIDS Management (Student Number: 17457173), at the Africa Centre for HIV/AIDS Management at Stellenbosch University intends to conduct research at the abovementioned ARV clinics at District hospitals within KZN.

This research is on Perspectives of Patients (HIV positive men) and Practitioners about promoters and inhibitors to accessing HIV services at public health facilities in KZN. The target group will be HIV positive men attending ART clinics and Health practitioners working within the ART clinics. Selected participants will be interviewed/audio-taped by the researcher and an interpreter if so required. These will be anonymous and will ensure complete confidentiality. The completed transcripts will be collected and all necessary precautions will be taken to ensure that they are not accessible by any other person.

The research is primarily academic but the results of the study will be submitted to the Department of Health, if requested. We therefore kindly request permission for Dr N Moodley to carry out this study at the above mentioned facilities. The study should run over a 3 month period, August 2012 - November 2012. Her research supervisor is Dr T Qubuda and his contact details are as follows: tqubuda@sun.ac.za, Africa Centre, Stellenbosch University. 021 808 3999/3006. Feel free to contact us if you have any further questions.

Kind Regards,

Burt Davis
Lecturer
Africa Centre for HIV/AIDS Management
STELLENBOSCH UNIVERSITY | Private Bag X1 | Matieland 7602 | RSA
T: +27 21 808 3006 | F: +27 21 808 3015
E: burt@sun.ac.za | W: www.aidscentre.sun.ac.za



Appendix B



health

Department:
Health
PROVINCE OF KWAZULU-NATAL

Health Research & Knowledge Management sub-component
10 – 103 Natalia Building, 330 Langalibalele Street
Private Bag x9051
Pietermaritzburg
3200
Tel.: 033 – 3953189
Fax.: 033 – 394 3782
Email.: hkrkm@kznhealth.gov.za
www.kznhealth.gov.za

Reference : HRKM 115/12
Enquiries : Mr X Xaba
Tel : 033 – 395 2805

Dear Dr N. Moodley

Subject: Approval of a Research Proposal

1. The research proposal titled '**Patient and practitioner perceptions of promoters and inhibitors of health seeking behaviour amongst African men accessing HIV health services in KwaZulu Natal**' was reviewed by the KwaZulu-Natal Department of Health.

The proposal is hereby **approved** for research to be undertaken at Church of Scotland and Manguzi Hospitals.

2. You are requested to take note of the following:
 - a. Make the necessary arrangement with the identified facility before commencing with your research project.
 - b. Provide an interim progress report and final report (electronic and hard copies) when your research is complete.
3. Your final report must be posted to **HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200** and e-mail an electronic copy to hkrkm@kznhealth.gov.za

For any additional information please contact Mr X. Xaba on 033-395 2805.

Yours Sincerely



Dr E Lutge

Chairperson, Health Research Committee
KwaZulu-Natal Department of Health

Date: 21/08/2012.

uMnyango Wezempilo . Departement van Gesondheid

Fighting Disease, Fighting Poverty, Giving Hope

Appendix C



AFRICA CENTRE FOR HIV/AIDS MANAGEMENT

14 June 2012

The Chief Executive Officer
Manguzi Hospital

Dear Sir/Madam

Re: PERMISSION TO CONDUCT RESEARCH AT: Manguzi Hospital

Dr N Moodley, a Master of Philosophy student in HIV and AIDS Management (Student Number: 17457173), at the Africa Centre for HIV/AIDS Management at Stellenbosch University intends to conduct research at the ARV clinics at District hospitals, within KZN.

This research is on Perspectives of Patients (HIV positive men) and Practitioners about promoters and inhibitors to accessing HIV services at public health facilities in KZN. The target group will be HIV positive men attending ART clinics and Health practitioners working within the ART clinics. These participants will be asked to volunteer to be interviewed. These will be anonymous and will ensure complete confidentiality. The research is primarily academic but the results of the study will be available to the Department of Health, and relevant hospitals, if requested.

We therefore kindly request permission for Dr N Moodley to carry out this study at your hospital. The study should run over a 3 month period, August 2012-November 2012. She wishes to start collecting data (conducting interviews) as soon as permission is granted to do so. Her research supervisor is Dr T Qubuda and his contact details are as follows: tqubuda@sun.ac.za, Africa Centre, Stellenbosch University, 021 808 3999/3006. This research will be conducted at no cost to the hospital. I hope that this request will be considered favourably.

Kind Regards,

Burt Davis
Lecturer
Africa Centre for HIV/AIDS Management
STELLENBOSCH UNIVERSITY | Private Bag X1 | Matieland 7602 | RSA
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Appendix D



Private Bag X301
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3973
Tel. No. 035 5920150 Ext. 205
Fax No. 035 592 0144/0158
E-mail: sipho.vumase@kznhealth.gov.za
www.kznhealth.gov.za

Enquiries: Dr SB Vumase

Date: 07/08/ 2012

Dr Neeri Moodley
Department of Rural Health
UKZN (Howard College)
DURBAN

Re: Research for masters studies

Your request as above is acknowledged.

Provisional approval is hereby given for you to conduct research at Manguzi Hospital.

Our approval is however based on three conditions as follows:

1. The research does not interfere or has minimal interference with the routine patient care provision;
2. The final approval by the KZN Provincial Health Research Committee is sought by you; and
3. The hospital is provided with a copy of your dissertation/ thesis on completion of the project.

Yours Sincerely,

Dr SB Vumase
CEO: Manguzi Hospital

Appendix E



Health
Department
Health
PROVINCE OF KWAZULU-NATAL

CHURCH OF SCOTLAND HOSPITAL
Private Bag A 502, Tugela Ferry 3810
Tel: 033 495 1000 Ext: 4075/4002 Fax: 033 493 1121
www.churchofscotland.co.za
E-mail: enquiries@kznhealth.gov.za

Enquiries: B. Dlomo
Date: 06 August 2012

The Principal investigator
Dr Neeri Moodley
Department of Rural Health
UKZN (Howard College)
George Campbell Building
4th floor
ext 3084

RE: PERMISSION TO CONDUCT RESEARCH AT CHURCH OF SCOTLAND HOSPITAL

I have pleasure in informing you that permission has been granted to you by the Church of Scotland Hospital to conduct research on research for master's studies.

Please note the following:

1. Please ensure that you adhere to all policies, procedures, protocols and guidelines of the Department of Health with regards to this research.
2. This research will only commence once office has received confirmation from the Provincial health Research Committee in the KZN Department of Health.
3. Please ensure this office informed before you commence your research,
4. Church of Scotland Hospital will not provide any resources for this research.
5. You will be expected to provide feedback on your findings to the Church of Scotland Hospital.

Thank you

Sincerely

Mrs. B. Dlomo
Deputy Manager Nursing
Church of Scotland Hospital

Appendix F



UNIVERSITEIT•STELLENBOSCH•UNIVERSITY
jou kennisvennoot • your knowledge partner

STELLENBOSCH UNIVERSITY CONSENT TO PARTICIPATE IN RESEARCH

Patient and Practitioner Perceptions of Promoters and Inhibitors of Health Seeking Behaviour amongst African Men accessing HIV health services in Kwa-Zulu Natal

You are asked to participate in a research study conducted by Dr N Moodley (MBCHB) from UKZN, Natal and Dr T Qubuda, from the Department of Economic management, at Stellenbosch University. The results of which will contribute to my required thesis for my MPhil HIV Management degree. You were selected as a possible participant in this study because you fulfill my inclusion criteria for this study being an HIV positive man over 18 years of age and attending a public facility in KZN.

1. PURPOSE OF THE STUDY

The purpose of this study is to ascertain the perceived reasons for the health seeking behaviour amongst African men accessing HIV services within public health services in KZN.

2. PROCEDURES

If you volunteer to participate in this study, we would ask you to do the following things:

- Read and understand the participant information sheet and sign a consent form, allowing yourself to be interviewed by the researcher
- You and the researcher, will be located in a private, confidential room to undertake the interview
- A interpreter will be provided if you so prefer, or the interview will be recorded in the language of your choice (English/IsiZulu)
- The interview process should last approximately 20-30 minutes
- This will take the form of a conversation only. No physical examinations or invasive tests will be performed during the consultation
- This will be a once off interview, no follow up participation will be necessary
- You would be asked and encouraged to be as sincere and honest as possible when answering the questions. The success of this study depends entirely on your contribution.
- There is NO right or wrong answers. This is not a test. You will NOT be jeopardized in any way by the answers provided for this study

3. POTENTIAL RISKS AND DISCOMFORTS

If you experience any minimal risk of discomfort during the interview, whilst you narrate any of your experiences and your illness, you will be provided with appropriate counseling. If you wish to discontinue with the interview following any discomfort, then you will be excused from participating. We do not foresee any significant or potential dangerous psychological risks or harm during this interview process.

1. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

There are no direct benefits to the participants of this study, however, the recommendations made following the completion of this research, might have an influence on health system modifications in managing HIV positive male patients in KZN

2. PAYMENT FOR PARTICIPATION

There is no payment for participation in this study.

3. CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means not using any personal identifiers on your interview sheets, no personal information will be recorded or shared publicly. All information obtained during your interview will be audio recorded/written and kept as a hard copy in a locked cupboard in the researcher's office, and an electronic copy of written notes on a personal computer with a secret password for the researcher's personal computer with access to the researcher only. Recorded interviews will be played back to you for clarifications and any possible edits. These tapes will only be used for transcription purposes and will also be locked up in a cupboard

This information will, however, be made available to the University of Stellenbosch, as a report written for my thesis, as a requirement for my Master's degree. The DoH and the hospital management do have the privilege to have the recommendations obtained from the analysis on completion of the research.

4. PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so

5. IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact:

- Dr N Moodley: 0842291745. neeri.moodley@gmail.com
Department of Rural Health
George Campbell Building
4th floor
UKZN (Howard College)
031 2603084
- Dr T Qubuda: 021 808 3999/3006 tqubuda@sun.ac.za
Africa Centre,
Industrial Psychology Building
Ground Floor, Room 1029
Stellenbosch University

6. RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact MsMaléneFouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE

The information above was described to [me/the subject/the participant] by [name of relevant person] in [Afrikaans/English/Xhosa/other] and [I am/the subject is/the participant is] in command of this language or it was satisfactorily translated to [me/him/her]. [I/the participant/the subject] was given the opportunity to ask questions and these questions were answered to [my/his/her] satisfaction.

[I hereby consent voluntarily to participate in this study/I hereby consent that the subject/participant may participate in this study.] I have been given a copy of this form.

Name of Subject/Participant

Name of Legal Representative (if applicable)

Signature of Subject/Participant or Legal Representative

Date

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to _____ [name of the subject/participant] and/or [his/her] representative _____ [name of the representative]. [He/she] was encouraged and given ample time to ask me any questions. This conversation was conducted in [Afrikaans/*English/*Xhosa/*other] and [no translator was used/this conversation was translated into _____ by _____].



Signature of Investigator

Appendix G



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STELLENBOSCHUNIVERSITY CONSENT TO PARTICIPATE IN RESEARCH

Patient and Practitioner Perceptions of Promoters and Inhibitors of Health Seeking Behaviour amongst African Men accessing HIV health services in Kwa-Zulu Natal

You are asked to participate in a research study conducted by Dr N Moodley (MBCHB) from UKZN, Natal and Dr T Qubuda, from the Department of Economic management, at Stellenbosch University. The results of which will contribute to my required thesis for my MPHil HIV Management degree. You were selected as a possible participant in this study because you fulfill my inclusion criteria for this study being an HIV positive man over 18 years of age and attending a public facility in KZN.

1. PURPOSE OF THE STUDY

The purpose of this study is to ascertain the perceived reasons for the health seeking behaviour amongst African men accessing HIV services within public health services in KZN.

2. PROCEDURES

If you volunteer to participate in this study, as a Health Care Practitioner, you would be requested to ask you to:

- Read and understand the participant information sheet and sign a consent form, allowing yourself to be interviewed by the researcher
- You and the researcher, will be located in a private, confidential room to undertake the interview
- The interview process should last approximately 20-30 minutes
- This will be a once off interview, no follow up participation will be necessary
- You would be asked and encouraged to be as sincere and honest as possible when answering the questions. The success of this study depends entirely on your contribution.
- There is NO right or wrong answers. This is not a test. You will NOT be jeopardized in any way by the answers provided for this study

3. POTENTIAL RISKS AND DISCOMFORTS

No potential risk or harm is envisaged during this interview with a Health Practitioner

4. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

There are no direct benefits to the participants of this study, however, the recommendations made following the completion of this research, might have an influence on health system modifications in managing HIV positive male patients in KZN

7. PAYMENT FOR PARTICIPATION

There is no payment for participation in this study.

8. CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means not using any personal identifiers on your interview sheets, no personal information will be recorded or shared publicly. All information obtained during your interview will be audio recorded/written and kept as a hard copy in a locked cupboard in the researcher's office, and an electronic copy of written notes on a personal computer with a secret password for the researcher's personal computer with access to the researcher only. Recorded interviews will be played back to you for clarifications and any possible edits. These tapes will only be used for transcription purposes and will also be locked up in a cupboard.

This information will, however, be made available to the University of Stellenbosch, as a report written for my thesis, as a requirement for my Master's degree. The DoH and the hospital management do have the privilege to have the recommendations obtained from the analysis on completion of the research.

9. PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

10. IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact:

- Dr N Moodley: 0842291745. neeri.moodley@gmail.com
Department of Rural Health
George Campbell Building
4th floor
UKZN (Howard College)
031 2603084
- Dr T Qubuda: 021 808 3999/3006 tqubuda@sun.ac.za
Africa Centre,
Industrial Psychology Building
Ground Floor, Room 1029
Stellenbosch University

11. RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms Maléne Fouché [mfouché@sun.ac.za; 021 808 4622] at the Division for Research Development.

SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE
--

The information above was described to [*me/the subject/the participant*] by [*name of relevant person*] in [*Afrikaans/English/Xhosa/other*] and [*I am/the subject is/the participant is*] in command of this language or it was satisfactorily translated to [*me/him/her*]. [*I/the participant/the subject*] were given the opportunity to ask questions and these questions were answered to [*my/his/her*] satisfaction.

[*I hereby consent voluntarily to participate in this study/I hereby consent that the subject/participant may participate in this study.*] I have been given a copy of this form.

Name of Subject/Participant

Name of Legal Representative (if applicable)

Signature of Subject/Participant or Legal Representative

Date

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to _____ [*name of the subject/participant*] and/or [*his/her*] representative _____ [*name of the representative*]. [*He/she*] was encouraged and given ample time to ask me any questions. This conversation was conducted in [*Afrikaans/*English/*Xhosa/*other*] and [*no translator was used/this conversation was translated into* _____ by _____].



Signature of Investigator

Date

Appendix H: Information sheet

Dear Respondent/Participant

Re: Patient and Practitioner Perceptions of Promoters and Inhibitors of Health Seeking Behaviour amongst African Men accessing HIV health services in Kwa-Zulu Natal

In partial fulfillments of the requirements of the Master Philosophy Degree in HIV/AIDS Management from the Africa Center of HIV/AIDS Management at Stellenbosch University. I am carrying out a study with the above title. The information you will supply is for academic purposes and will be treated with confidence. The purpose of this study is to gather information through the interviews with the selected participants (HIV positive men) I intend to ask the following research question- **what are the perceptions of both the HIV positive men and the health care workers on the possible promoters and inhibitors of seeking HIV services at public district hospitals in KZN?** The aim of the study is to establish if there are possible issues that could be addressed in enhancing men accessing HIV care within the Public health system in KZN, in order to inform guidelines in improving care and decreasing morbidity and delaying mortality associated with HIV.

The study objectives are as follows-

1. To establish the perceived inhibitors in accessing HIV services within public health systems in KZN
2. To establish the perceived promoters in accessing HIV services within public health system in KZN
3. To establish the health care practitioners' views about the reasons for the perceived poor health seeking behaviour amongst men
4. To explore the reasons for poor health seeking behaviour amongst African men seeking access to public HIV services within KZN

Please feel free to contact me should you have any questions or you need clarification. Thank you.

Yours sincerely



Dr N Moodley

Department of Rural Health

George Campbell Building

4th floor

UKZN (Howard College)

neeri.moodley@gmail.com

0312603084(W); 0842291745(mobile)

Appendix I: Interview schedule for selected HIV positive men**Opening**

After selecting HIV positive men at the ART clinic, information about the research will be imparted, and volunteers will be asked to participate by signing an informed consent form. I shall then conduct the interview with the volunteer participants in a private room. During the interview I would like to ask some questions about the participant's experiences as a HIV positive male within his community, work situation, family and friends and within the Health system, his expectations of health care he receives/should receive.

The interview should take 20 to 30 minutes.

The interview will be semi-structured, guided by the following kinds of questions:

Demographics:

Age:	
Living arrangements:	
• Alone	
• Lodging home/boarding home/group home	
• with family	
• with friends	
• with partner	
• other	
Marital status:	
• single, never married	
• divorced	
• married	
• widowed	
• common law	
• separated	
Children:	
• none	
• 1-3	
• >3	
Employment/occupation	
• student	
• part time	
• full time	
• unemployed	
• state grant	
• migrant worker (past/present)	
Hobbies/practices	
• church	
• sport	
• smoker	
• alcohol/drugs	
• income generation	

A. Initial illness narrative

Tell me about your first experience /problems with your health OR when you got ill? (Probe -did you suspect HIV?)

1. When did you realize you actually had HIV (tested Positive)? Establishing time delay
2. Did you test for HIV voluntarily (whilst you were well) or recommended when you were ill? By whom?
4. Was there a delay in getting diagnosed for HIV? Why? Who caused the delay? (You or a HCW/healer) (If delay established) -do you think getting tested earlier would have been better?
5. Describe how you felt following this positive diagnosis

.....

B. System and attitude:

Tell me about your experience coming to the hospital for care

6. Did you receive all the information and treatment that you had expected from the hospital/clinic after you were diagnosed? if no why and what else did you need/expect?.
7. Was the experience of being tested and getting your results an easy or painful experience?
8. What could have been better? Or what made it easy?
9. The treatment from staff acceptable/or not? What would have been better?
13. Do you manage to keep you appointments? Why?
14. Do you manage to take your drugs? Why?
15. Does the present system at the hospital work for you (with regards to testing and getting your treatment)? Why?

.....

C. Culture and tradition

How does it feel being a Black African man having HIV?

16. Was it difficult to get tested? Does culture play a role in getting tested or taking treatment? If yes what can/should be done to assist with this
17. What caused your HIV (your opinion). Could anything else have caused it
18. Did you visit your healer or use other medication when you were ill? How long? Which do you prefer and why?
19. Do you think that traditional medicines play a role in treating HIV?

.....

D Impact:

How did having HIV affect your life?

20. Have you disclosed? To whom? (if no-)Why? Response
21. Do you talk about HIV freely (home, family, Friends)?
22. Are you aware of men delaying being tested or coming for treatment for HIV? Why do you think this happens? What can/should be done to make this right?
23. What else would you like to add to this interview that you think is important for the HCW/ system to know

Appendix J: Interview schedule for Health Practitioner

Opening

After information about the research is given to the Health Practitioners (HP) within the ART clinic, volunteer HP will be asked to participate by signing an informed consent form. I shall then conduct the interview with the volunteer participants in a private room. During the interview I would like to ask some questions about the participant's experiences as a HP working in the ART clinic; opinion on health seeking behaviour of men compared to women; possible reasons for this and suggestions to improve the situation if need be. The interview should take 20 to 30 minutes.

The interview will be semi-structured, guided by the following kinds of questions:

Demographics:

Designation	
Years of service	
Age	
Sex	

Tell me about your experience working in the ART clinic.

1. How long are you working in the ART clinic? Do you enjoy working in the HIV unit?
Explain (are you well equipped to deal with HIV)
2. In your experience working here, is there a difference in the number of males and females coming for care? Explain/why do you think this is so?
3. Who do you think are sicker when you first see those, males or females patients? Why?

Describe your current system of care here at the ART clinic

4. Does your current system of providing HIV care (testing and support and treatment) work equally well for both male and female patients? If yes, explain
If no, what would improve the current situation?
5. (Female HCW) Are you comfortable caring for HIV positive male patients regardless of age
6. (If female) Are male patients comfortable being treated by you?

What is your experience on Health seeking behaviour amongst men?

7. Do you think black men find it easy coming for HIV care and treatment?
If no, why do you think that is so? If yes, why do you think that is so?
8. If you were a HIV positive male patient, would you use these services? Explain
9. Do you think male have different needs compared to females in accessing HIV care and treatment? Explain
10. What are main factors that influence/facilitate men to use your facility?
11. What factors inhibit/restrict them from using your facility?
12. What would/can change these attitudes?
13. What would you change in your current system to improve access by men?

Appendix K: Ethics approval: HS823/2012

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Approved with Stipulations
New Application

07-Aug-2012
 MOODLEY, Neermala

Protocol #: HS823/2012

Title: An Investigation into Patient and Practitioner Perceptions of Promoters and Inhibitors of Health Seeking Behaviour amongst African Men accessing HIV health services in Kwa-Zulu Natal

Dear Dr Neermala MOODLEY,

The **New Application** received on **16-Jul-2012**, was reviewed by Research Ethics Committee: Human Research (Humanities) via Committee Review procedures on **26-Jul-2012**.

Please note the following information about your approved research protocol:

Protocol Approval Period: **26-Jul-2012 -25-Jul-2013**

Present Committee Members:

Theron, Carl CC
 Somhlaba, Ncebazakhe NZ
 Viviers, Suzette S
 Van Zyl, Gerhard G
 Fouche, Magdalena MG
 Van Wyk, Berte B
 Hansen, Leonard LD
 Horn, Lynette LM
 De Villiers-Botha, Tanya T
 Newmark, Rona R
 Prozesky, Heidi HE
 Beukes, Winston WA

The Stipulations of your ethics approval are as follows:

Letters of Permission:

1. The applicant is requested to submit copies of letters from the KZN Department of Health and the CEO of the five district hospitals granting formal institutional permission for the research to the REC once they are received.

Consent Form:

- 1. The applicant has acknowledged that there is a slight possibility that HIV positive African men visiting ARV clinics participating in the research might be traumatized by the interview. The applicant indicated that risk in this regard will be mitigated by making provision for counselling if this would be desired by participants. The applicant is requested to submit details on the nature of the contingency measures to the REC once the arrangements have been finalized. The applicant must also in a short note to the REC confirm whether the counsellor/counsellors is/are suitable qualified.**
- 2. The applicant visits the five district hospitals monthly in his capacity as a lecturer at the University of KZN to mentor medical students doing practical work in the hospitals. Potential research participants visit the ARV clinics to see health practitioners working at the clinic. Despite the fact that the applicant is a registered medical practitioner, the REC will nonetheless regard it as inappropriate if the researcher would directly approach individuals visiting the clinic to invite them to participate in the research. The invitation should be extended by an individual that the patient normally would have interacted with when visiting the ARV clinic. The applicant must, in a short note to the REC, clarify the recruitment process to be followed.**
- 3. The informed consent formulation should be edited to accurately reflect the applicant's academic affiliation. The applicant will be conducting the research under the banner of the Africa Centre for HIV/AIDS Management within the Faculty of Economic and Management Sciences and not in his capacity as lecturer at UKZN.**

Information Sheet:

1. The portfolio of evidence accompanying the application for ethical clearance includes a short participant information sheet over and above the two formal informed consent forms based on the SU informed consent template. The participant information sheet is redundant and should not be used in the research project

Standard provisions

1. The researcher will remain within the procedures and protocols indicated in the proposal, particularly in terms of any undertakings made in terms of the confidentiality of the information gathered.
2. The research will again be submitted for ethical clearance if there is any substantial departure from the existing proposal.
3. The researcher will remain within the parameters of any applicable national legislation, institutional guidelines and scientific standards relevant to the specific field of research.
4. The researcher will consider and implement the foregoing suggestions to lower the ethical risk associated with the research.

You may commence with your research with strict adherence to the abovementioned provisions and stipulations.

Please remember to use your **protocol number (HS823/2012)** on any documents or correspondence with the REC concerning your research protocol.

Please note that the REC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review:

Please note that a progress report should be submitted to the Committee before the approval period has expired if a continuation is required. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

National Health Research Ethics Committee (NHREC) number REC-050411-032.

This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility permission must be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 483 9907) and Dr Helene Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant parties. For approvals from the Western Cape Education Department, contact Dr AT Wyngaard (awyngaard@pgwc.gov.za, Tel: 0214769272, Fax: 0865902282, <http://wood.wcape.gov.za>).

Institutional permission from academic institutions for students, staff & alumni. This institutional permission should be obtained before submitting an application for ethics clearance to the REC.

Please note that informed consent from participants can only be obtained after ethics approval has been granted. It is your responsibility as researcher to keep signed informed consent forms for inspection for the duration of the research.

We wish you the best as you conduct your research.
If you have any questions or need further help, please contact the REC office at .

Included Documents:

Consent to participate 2
Interview schedule 2
DESC app
Research Proposal
Admin review
REC app
Consent to participate
Participant information sheet
Interview schedule

Sincerely,

Winston Beukes
REC Coordinator
Research Ethics Committee: Human Research (Humanities)

Appendix L: Manguzi Hospital ← ; Church of Scotland ←

