



FACTORS INFLUENCING DELAYED HIV TESTING: A CLIENT PERSPECTIVE

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DECLARATION

I, Siziwe Teresa Chonco, do affirm that this is completely my own work and not anyone else's. Where the works of other authors have been used, this is appropriately referenced and acknowledged. This work has not been submitted in any form for any other degree or professional qualification to the Durban University of Technology or other institutions for examination purposes or any other purpose.

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ABSTRACT

BACKGROUND

South Africa, especially KwaZulu-Natal remains heavily burdened with HIV and AIDS. Timely HIV testing is the cornerstone to HIV prevention in terms of early diagnosis and access to treatment, care and support services. Factors that influence delayed HIV testing must be investigated and reported to inform plans that are directed at improving implementation of HIV testing services and access to care, treatment and support services for people living with HIV.

PURPOSE OF THE STUDY

This study was aimed at identifying factors that lead to delayed HIV testing in a sample of people attending a Primary Health Care clinic in KwaZulu-Natal, South Africa.

METHODOLOGY

A descriptive qualitative design was used in this study. The population in this study was HIV positive patients who had recently tested for HIV and received their first CD4 count result of 350 mm³ or less. Purposive sampling, which is a type of non-probability sampling, was used to select the study participants from the population. Semi structured interviews using an interview schedule were used to collect data. Data was collected until data saturation was reached.

RESULTS

The data was analysed by means of content analysis and raw data was coded and sorted into sub categories and categories. The underlying meaning of categories was formulated into one overarching theme: *Testing for HIV is daunting and embedded with issues of stigma, denial and a fear of knowing one's positive status.*

CONCLUSION

To encourage early HIV testing before HIV positive people become noticeably ill requires efforts directed at change of attitude and improvement of support for HIV positive people in families, communities and health service institutions. Community forums to be actively involved in eliminating the stigma and discrimination associated with HIV positive people by creating awareness of these matters and encouraging community and family support for people with HIV.

DEDICATION

I DEDICATE THIS DISSERTATION TO THE ALMIGHTY GOD, MY FATHER IN HEAVEN, WHO HAS PROVIDED ME WITH WISDOM AND STRENGTH TO GO ON THROUGH ALL HARDSHIPS AND HAS WALKED WITH ME UNTIL THE END. THANK YOU LORD YOU ARE WORTHY TO BE PRAISED. I CAN DO ALL THINGS THROUGH CHRIST WHO STRENGTHENS ME (PHILLIPIANS 4: 13).

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OPERATIONAL DEFINITIONS

Antiretroviral therapy (ART): - Antiretroviral therapy refers to the use of three or more antiretroviral drugs to achieve viral suppression and is usually given for a lifetime.

Viral suppression: - Refers to the state of maintaining the viral load at undetectable levels, which is below 50 copies/ml.

Sero-discordant: - A couple where one partner is living with HIV and the other is HIV negative.

Continuum of care: - A coordinated and integrated system of care which guides and follows up on clients over time, offering comprehensive health services from HIV screening, diagnosis and management of HIV, ART initiation, psychosocial support and retention in care.

Eligible for ART: - People who are living with HIV who qualify for ART initiation.

Health service provider: - Anyone who renders a health care service including nurses, doctors and counsellors.

Delays in HIV testing: - Delays in HIV testing in the context of this study is positive HIV tests with a CD4 count of 350 cells/mm³ and below at diagnosis.

LIST OF ACRONYMS

Acronym	Full term
HIV	Human Immunodeficiency Virus
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral therapy
PHC	Primary Health Care
KZN	KwaZulu-Natal
WHO	World Health Organisation
UNAIDS	Joint United Nations Programme on HIV/AIDS
STI	Sexually transmitted infections
TB	Tuberculosis
MSM	Men who have Sex with Men
HCT	HIV counselling and testing
CD4	T-lymphocyte cell bearing CD4 receptor

CHAPTER 1: INTRODUCTION

1.1 BACKGROUND

Human immunodeficiency virus (HIV) and Acquired immune deficiency syndrome (AIDS) remain the world's most serious health challenge since it was first discovered more than four decades ago. According to the Joint United Nations Programme on HIV/AIDS (UNAIDS) the world's HIV prevalence is estimated at 35.3 million, the majority of people living with HIV are in the low to middle income countries especially in the sub-Saharan Africa (UNAIDS 2013: 4). Since 2005, the world has seen a rise in new HIV infections, which have risen by 7% in in the Middle East and North Africa and by 5% in Eastern Europe and central Asia (UNAIDS 2013: 13). Although there is a general decline in new HIV infections globally, sub-Saharan Africa has the highest HIV prevalence and accounts for 70% of people living with HIV worldwide (UNAIDS 2013:12). Despite efforts to expand access to antiretroviral therapy (ART) there is still low treatment coverage due to barriers to accessing treatment and care services (UNAIDS 2013: 6).

In 2014 South Africa was declared as a country with the highest HIV epidemic in the world with an estimated 5.51 million people living with HIV (South Africa 2014a). Human immunodeficiency virus prevalence in South Africa (South Africa 2014a) is estimated to be 10.2% with an estimated 16.8% of the adult population between the ages of 15 - 49 years living with HIV.

KwaZulu-Natal (KZN) is the second largest province in South Africa with an estimated population of 10 694 400 (South Africa 2014b) and the highest HIV incidence in the country according to Strauss *et al.* (2015: 1). The authors found that KZN is heavily burdened with both HIV prevalence and incidence, which is 24.7% and 2.3% respectively. Out of the 52 districts in South Africa, UMgungundlovu district in KZN has the highest HIV prevalence of 40.7% (South Africa 2012).

In response to the HIV burden in South Africa, the South African National Strategic Plan (NSP) on HIV, Sexually transmitted infections (STI) and Tuberculosis (TB) 2012-2016 was launched by the SA president in December 2011 (South Africa 2011a). The NSP outlines South Africa's response to HIV and is aligned with the negotiated service delivery agreements of all government departments and forms the strategic direction for the national response for the next five years. Through the NSP, the South African Government invites all sectors of society to come together and take part in the fight against the HIV epidemic. The primary goal of the NSP is the reduction of new HIV infections by at least 50%. Other goals include initiation of antiretroviral therapy (ART) to at least 80% of eligible patients and reduction of stigma and discrimination related to HIV and TB by 50%. The aim of the National Department of Health (NDoH) was to have zero new infections, zero discrimination and zero AIDS related deaths by the year 2015 (South Africa 2012).

In December 2014, the NDoH published the National Consolidated Guidelines for the Prevention of Mother to Child Transmission of HIV (PMTCT) and the Management of HIV in Children, Adolescents and Adults (South Africa 2014a). This guideline increases the eligibility criteria for starting lifelong ART with effect from January 2015. The World Health Organization (WHO) clinical staging of HIV/AIDS is also another method that is used to measure clinical signs that have been agreed upon by a team of experts in health care, to be associated with HIV/AIDS (WHO 2005). Clinical staging identifies diseases that are associated with immune suppression and gives a clinical picture of HIV disease progression. It is used when HIV is diagnosed and to monitor the clinical status of patients on follow up visits to guide ART decision-making.

When more people access ART there will be increased viral suppression and a reduction in the community pool of HIV infection, leading to decreased new infections (South Africa 2015), and decreased HIV mortality (South Africa 2015). ART eligibility includes:

1. Adults and adolescents with a CD4 cell count of 500 cells/mm³ or below;
2. Pregnant and breastfeeding women regardless of CD4 count or World Health Organisation (WHO) clinical staging and;
3. Children under the age of five years;
4. Tuberculosis (TB) and Hepatitis B co-infection; and
5. HIV positive partners in sero-discordant couples.

1.2 PROBLEM STATEMENT

According to the UNAIDS 2013 report, one in four people living in low and medium income countries has a CD4 count of 100 or below at diagnosis, which indicates late diagnosis. This increases the rate of mortality and morbidity due to HIV and increases the rate of HIV transmission by people who do not know their status (UNAIDS 2013: 52). An estimated 36% of people living in sub-Saharan Africa do not know their HIV status (UNAIDS 2013: 51).

It has been established that HIV is the third leading cause of death in South Africa; the percentage of deaths attributed to HIV in 2014 was 31.1% (South Africa 2014). According to the interim report of the Committee on Morbidity and Mortality in South Africa which looks at all deaths of children under the age of five, over 50% of children's deaths that occur in South African hospitals are AIDS related (South Africa 2012). The majority of children who were HIV positive presented in an advanced HIV disease stage: 68% presented in WHO clinical stage four and 20% presented in WHO clinical stage three (South Africa 2012).

To provide an entry point to the HIV continuum of care, South Africa has implemented an HIV Counselling and Testing (HCT) policy which was launched in 2010 and revised in 2015 (South Africa 2015a). In 2011 the South Africa Minister of Health launched an HCT campaign that was implemented throughout the country with 13 million people being tested within the first 18 months. The campaign was reported as a success, though the results were

below the set target of 15 million. During this campaign people were tested at different sites, which included community sites and homes. However, analysis revealed that there was poor linking of people to care and treatment once diagnosed with HIV. The HCT policy was revised in 2015 to address the gaps identified during the HCT campaign (South Africa 2015a).

The HCT policy is implemented in different ways including client-initiated counselling and testing, provider-initiated counselling and testing, couple counselling and testing, home-to-home HCT, infant and children HCT. The revised policy's aim is to improve HIV testing throughout SA, in communities, workplaces, health facilities and homes. It provides HCT health service providers with standardised guidelines to provide HCT services and mitigate the gap that was found to exist between HIV testing and linkage to care. The objective is to test people early and those who test positive must be supported and entered into a treatment plan according to their stages of disease while those who are HIV negative are encouraged to stay negative by giving them health education and advice on HIV prevention. Thus, HCT provides different approaches to HIV prevention and serves as a point of entry for ART initiation. Chimoyi *et al.* (2015: 2) argued that HCT has become increasingly available in SA, but the state of HIV counselling and testing remains low. Testing is avoided by a majority of South Africans due to negative opinions regarding testing and the stigma associated with being HIV positive (Chimoyi *et al.* 2015: 2).

1.3 PURPOSE OF THE STUDY

The aim of this study was to identify factors that lead to delayed HIV testing in a sample of HIV positive people attending a Primary Health Care Clinic in KwaZulu-Natal, South Africa. To achieve better outcomes in HIV/AIDS health service providers at all levels must be aware of factors that cause delayed HIV testing which in turn delay HIV/AIDS management. The root causes need to be identified and managed.

1.4 OBJECTIVE OF THE STUDY

- To explore factors influencing delayed HIV testing.
- To describe factors influencing delayed HIV Testing.

1.5 RESEARCH QUESTION

- What are the factors influencing delayed HIV testing?

1.6 SIGNIFICANCE OF THE STUDY

In spite of the burden of HIV/AIDS in South Africa, especially in KwaZulu-Natal, early diagnosis of HIV infected people is not sufficient. A cross sectional study conducted in four outpatient clinical sites in Durban, South Africa (Drain *et al.* 2013: 6) found that among participants who tested HIV positive and had a CD4 test done, 33.6% presented with late stage HIV disease at the time of diagnosis. Delayed HIV testing is referred to as late HIV diagnosis, which occurs one year or more after being exposed to HIV (Nelson *et al.* 2010: 652). Drain *et al.* (2013: 4) report that late stage HIV disease with a CD4 count below 100 mm³ is associated with high mortality, poor response to treatment and onward HIV transmission, which negatively impacts on the HIV epidemic.

1.7 CONCLUSION

Human immunodeficiency virus and AIDS have been the most challenging health problems throughout the world for more than four decades, with the largest number of people living with HIV residing in sub-Saharan Africa. South Africa has the largest HIV epidemic in the world. The Province of KwaZulu-Natal accounts for the highest HIV incidence and prevalence in the country. In spite of efforts to improve HIV testing, delayed diagnosis of HIV is still a

problem in South Africa. Research on HIV provides evidence based practices to inform initiatives to improve early HIV testing, thereby improving the process of linking eligible people to treatment and care which will result in improved HIV management to reduce the burden of disease as well as mortality and morbidity associated with HIV/AIDS.

CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION

It is estimated that in 2012, 35.3 million people were living with HIV in the world, 2.3 million were newly infected and 1.6 million died of AIDS related causes (UNAIDS 2013: 4). In spite of the world's HIV epidemic journey in the past four decades, 19 million out of the 35 million people living with HIV in the world have not been diagnosed and therefore are not on treatment (UNAIDS 2015: 5). The UNAIDS has developed a set of targets to prevent new HIV infections and to end the HIV epidemic by 2020, which state that; 90% of people living with HIV will be diagnosed, 90% of people living with HIV will be on lifelong ART and 90% of people receiving ART will have undetectable viral loads (UNAIDS 2015: 4). The first step towards achieving these targets is to get people to test and know their status. South Africa has one of the best ART programmes in the world; regardless of this fact, over 40% ART eligible South Africans are still not on treatment (Drain *et al.* 2013: 1). Mortality rates due to late presentation for HIV diagnosis is still high, especially in rural areas where there is poor access to health care (George *et al.* 2013: 2). In order to eradicate the HIV epidemic, HIV screening must be increased to facilitate early diagnosis and access to HIV prevention, treatment and care (Musheke *et al.* 2013: 2).

This literature review included a critical review of current literature. The focus of the review was to gather information on what factors influenced people who are at risk of HIV to choose not to test for HIV until they experience significant ill health. To conduct this literature review, the researcher used multiple sources of information that were accessed through a variety of data bases and journals including: Proquest, EbscoHost, African Journals Online (Open Access), Oasis Open Journals, Bioline International, PubMed Central, Plos ONE, Science Direct and Oxford Journals. The information included, professional peer reviewed journals, books, Internet sources and dissertations. The search was conducted using the following search terms:

delayed HIV testing, HIV testing behaviours, HIV prevalence in South Africa, sub-Saharan Africa and the world. The literature review discussed and critically analysed nine barriers that contributed to delayed HIV testing.

2.2 DELAYS IN HIV TESTING

Early HIV infection has no identifiable symptoms; people who do not feel sick may not readily present themselves for HIV screening (Nakigozi *et al.* 2013: 50). Delays in getting tested for HIV in at risk individuals occur where there is lack of education on risk factors (Aziz and Smith 2011: 232) therefore it is important to raise awareness on the importance of testing even in the absence of symptoms of disease (Aziz and Smith 2011: 235). Research confirms that the clinical outcomes of timeous commencement of ART does not only have an impact on improved quality of life for HIV positive people and reduction of mortality due to HIV; people living with HIV who are on ART are less likely to transmit HIV to others (Meade *et al.* 2014: 187). A range of factors have been associated with barriers to HIV testing, including: HIV related stigma, denying AIDS, health service provider as a barrier to testing, low health literacy, poor access to health care, perceived low risk of HIV infection, perceived high risk of HIV infection, HIV testing behaviour according to gender and conspiracy beliefs about HIV (Musheke *et al.* 2013: 2; Ntsepe *et al.* 2014: 141).

2.2.1 HIV related stigma

Stigma refers to the social isolation of an individual known to have a particular disease, which is socially unacceptable (Mburu *et al.* 2014: 2). HIV related stigma is associated with feelings of shame and unworthiness for a person living with HIV, which is further compounded by negative community attitudes towards HIV positive people (Tsai 2015: 276). Stigma acts as deterrent to HIV testing among those that do not know their status; leads to delayed HIV testing and barriers to access treatment and care as people who suspect possible stigma try to avoid stigmatizing conditions (Treves-Kagan *et al.* 2016:

2). In addition to these effects of stigma is the association of young people who practice sex with being immoral and committing a sin and the belief that HIV is a punishment for this sin (Campbell *et al.* 2005: 808). Fear of being stigmatized has a negative impact on the uptake of HIV testing in sub-Saharan Africa and has been cited as the driver of the HIV epidemic; people with HIV are not liked, the treatment they receive from their families and communities suddenly changes the moment they are known to be HIV positive; people start to discriminate against them and isolate them (Treves-Kagan *et al.* 2016: 5). This is supported by Musheke *et al.* (2013: 6) who report that the public perceive HIV positive people as promiscuous; this makes people afraid of being seen attending an HIV testing site. The authors go on to say that people who are HIV positive are subjected to amongst other things: isolation, violence, losing a partner, divorce, hardship in their marriages and difficulties in finding a partner; these factors lead to barriers in accessing health care for HIV testing and significantly contributes to low HIV testing rates (Musheke *et al.* 2013: 9). Stigma prevents the disclosure of an HIV status to a partner; HIV positive people who do not disclose their status to partners contribute to delayed HIV testing of HIV exposed partners, as they will not be aware that they are at risk. In some instances people get to find out about the status of a partner after the partner has died; this contributes to HIV transmission and HIV related deaths (Yakob and Ncama 2016: 15). There is a need to overcome stigma and encourage disclosure of HIV status to allow early testing of those at risk (Yakob and Ncama 2016: 12). Community attitudes towards people living with HIV and the perception that they are to blame for being infected because they did not listen to advice makes people avoid disclosing their status because they fear discrimination and rejection (Stangl *et al.* 2013: 1). This is consistent with the findings of Golub and Gamarel (2013: 12) who state that non-disclosure of HIV status is linked to stigma and this stigma will also lead to denial of HIV to avoid dealing with the state of being HIV positive. Expressions of stigma directed at people living with HIV have been found to be affecting the uptake of HIV testing since these take place where the people reside; within families and communities and make it difficult to cope with being HIV positive (Campbell *et al.* 2005: 808). People who anticipate discrimination from families and sexual partners are not

only unlikely to test for HIV; they would also not disclose their HIV positive status (Abdool Karim *et al.* 2008: 362).

A study conducted on African men living in the United States revealed that participants did not get tested for HIV because they perceived that no one will want them once they are known to have HIV and attending an HIV testing site will create suspicions that they are HIV infected; this translated into lower testing rates amongst these men (Bova *et al.* 2016: 189). Similarly, Golub and Gamarel (2013: 622) report that people who are likely to be HIV positive avoid testing to protect themselves from rejection by partners, families and the community. Individuals try to disassociate themselves from HIV because they think it is stigmatizing, they keep thinking they are not at risk and disregard their predisposition to HIV, this results in a decreased likelihood to test for HIV (Golub and Gamarel (2013: 622). Abdool Karim *et al.* (2008: 361) also reveal that the impact of anticipated HIV/AIDS related stigma and discrimination results in barriers to access health care, HIV prevention and support. A report on a study conducted on Nigerian youth points out that young people dislike testing for HIV due to fear of testing positive and the resultant stigma (Yahaya *et al.* 2010: 163). At the same time, stigmatizing people with negative attitudes towards people living with HIV who are also unwilling to get tested for HIV also delay themselves from knowing their status; low testing rates can be improved by a change of attitudes that will reduce HIV stigma and discrimination (Meade 2014: 190).

Failure to visit the health facility for follow up care after an HIV diagnosis is also strongly linked to stigma (Aziz and Smith 2011: 232; Sprague and Simon 2014: 4). Receiving HIV prevention information and taking condoms from condom containers that are placed at clinics is seen as stigmatizing, because to other people it implies that a person who is taking condoms is engaging in risky sexual behaviour, this impacts negatively on HIV prevention (Henrickson 2015: 35). The social impact that HIV has makes the subject of HIV not easy to talk about in social gatherings with friends, the topic is simply avoided, when it does get brought up, it is usually gossiped about and jokes are made of it (Hall *et al.* 2015). People avoid being known as having HIV, those with a

history of substance abuse will resort to returning to drugs and alcohol abuse because they don't want to accept the HIV diagnosis, they worry about how they will be viewed by other people more than worrying about HIV (Sprague and Simon 2014: 4).

Stangl *et al.* (2013: 2) argue that people who experience internalised stigma fear the response they will get from other people if their HIV positive status becomes known – they anticipate being negatively judged by others. This is similar to findings of a study conducted by Sprague *et al.* (2014: 6) who found that these fears contribute to late HIV testing as well as delayed entry into HIV treatment, care and support programmes. People who have witnessed stigmatizing actions and criticism directed at people living with HIV avoid testing to protect themselves from being stigmatized (Golub and Gamarel 2013: 625).

A study conducted in Kenya discusses denial and other negative emotions that are brought about by HIV related stigma, which could be eliminated by a change in community attitude (Ntoh *et al.* 2014: 582). Chimoyi *et al.* (2014: 2) acknowledge that AIDS related stigma impacts negatively on efforts to fight the HIV epidemic. This is due to the fact that where there is increased stigma and discrimination, the likelihood to test for HIV is very low therefore inhibiting uptake of HIV counselling and testing services and increasing the rate of HIV transmission.

2.2.2 Denying a possible HIV positive diagnosis

Denial is a common psychological response to something that is unpleasant to a person (Kamen *et al.* 2012: 1328). Denial is when a difficult situation that is perceived as a threat is regarded as not true; denial assists an individual to adjust to the undesired situation and reduces the feelings of anxiety (Kalichman 2009: 3). Late HIV diagnosis is often a result of not wanting to know the truth, some people decide to live without knowing their HIV status. Unknown HIV status makes them live more freely by believing they are HIV

negative mainly because they have never tested and being HIV positive will not concern them; they decide not to test to avoid worrying about HIV (Hall *et al.* 2011: 8). Those that do not want to change their risky behaviours prefer not to know their HIV status to avoid an obligation to change their risky behaviours (Hall *et al.* 2011: 12). Fear of knowing a diagnosis of HIV has been identified as the most prominent barrier to HIV testing, people who are at risk fear testing because they do not know what impact being HIV positive will have on their lives and relationships with families and friends, therefore they choose not to think about HIV (Schwarcz 2011: 896).

Aziz and Smith (2011: 232) observe that people who are at risk of HIV often delay testing because of denial of the risk factors or they lack education that will help them identify their risk. This delay in testing and seeking treatment results in opportunistic infections and contributes to AIDS mortality (Aziz and Smith 2011: 234). When there is perceived stress, denial becomes a useful mechanism to assist an individual to cope with the stress of living with HIV but there are negative effects of denial too (Kamen *et al.* 2012: 1328). Examples of these negative effects include deprivation of social support and poor adherence to treatment, both of which have a negative impact on the health of an individual with HIV (Kamen *et al.* 2012: 1334). According to Kalichman (2009: 3) prolonged denial is harmful because it makes some individuals disregard medical advice and follow-up because they do not want to accept an HIV positive diagnosis. Health service provider counselling must promote access to care and HIV prevention strategies to facilitate retention in care. Denial of an HIV positive status can be prevented by improving support to patients with HIV through listening to their concerns, giving them factual information about the disease, and clearing up any misconceptions to facilitate acceptance and compliance to HIV prevention and care programmes (Nakigozi *et al.* 2013: 5).

2.2.3 Health service provider as a barrier to testing

Late HIV diagnosis is a public health concern, provider initiated HIV counselling and testing (PICT) is an important measure that is implemented to

improve early diagnosis and timeous treatment of HIV infected persons (Loos *et al.* 2014: 82). Provider initiated HIV counselling and testing refers to the health care provider giving HIV related information and offering routine HIV testing at the point of care even if the patient did not come for the test. Routine HIV testing limits stigma and discrimination against HIV as HIV testing gets included into routine screening, all patients who attend a health care service are offered an opportunity to test for HIV (Basset and Walensky 2010: 78). Timely HIV testing improves access to HIV related services to reduce transmission; timeous initiation of ART reduces AIDS related morbidity and mortality (Drain *et al.* 2013). According to studies conducted by Bokhour *et al.* (2015: 5); Hallmark *et al.* (2014: 4); Basset *et al.* (2010: 78), a number of barriers to HIV testing are health service provider related. These studies report that pre- and post-test counselling and the process of obtaining consent for HIV testing takes too long, since this task is added onto the existing staff workload and there are not enough staff to provide testing as well as post-test counselling for those patients who do test positive. For these reasons staff do not like to conduct pre-test counselling; they feel it would be better to screen patients for HIV as part of routine screening without having to go through the process of pre-test counselling and obtaining written consent (Bokhour *et al.* 2015: 5). A study conducted by Hallmark *et al.* (2014: 4) showed that low staff numbers to deal with the workload and lack of staff knowledge in HIV counselling and testing skills is a barrier to HIV testing. Some health service providers experienced discomfort and felt that asking their patients to test for HIV will be stigmatizing and feared discussing HIV and sexuality related matters with their patients (Hallmark *et al.* 2014: 4; Loos *et al.* 2014: 86). Health service providers tended not to offer testing when they thought HIV prevalence was low amongst patients they see (Hallmark *et al.* 2014: 8). Offering the HIV test to older patients above the age of 50 years was viewed as unnecessary according to health service providers perception that older patients do not have multiple sexual partners and don't use drugs and therefore are unlikely to be HIV positive (Bokhour *et al.* 2005: 7). Fear of health service provider gossip is also seen as a barrier to HIV testing, which is the case in rural areas and smaller communities where everyone knows each other, testing is avoided even when offered, if there is fear that the health

service provider will disclose the status and subject the HIV positive person to stigma (Leta *et al.* 2012: 8; Treves-Kagan *et al.* 2016: 7). Unwelcoming and uncaring staff attitudes hinder access to HIV services as such reactions make people lose trust in the health service as a whole and avoid attending health facilities (Yakob and Ncama 2016: 9). Despite health service provider barriers to testing, it is important to recognise that routine testing is accepted by patients and has improved the rate of HIV testing in settings where such testing is routinely offered (Loos *et al.* 2014: 82; Bassett and Walensky 2010: 79).

2.2.4 Low health literacy

Health literacy is the ability to receive, read, understand and make use of health related information, which allows an individual to make informed decisions regarding their health, and to follow treatment related instructions (Barragán *et al.* 2005: 422). Inadequate education and low health literacy is associated with a poor response to HIV testing and follow-up care, mainly because of poor understanding of verbal or written information presented (Hunter 2011: 3). Jean *et al.* (2012: 7) found low levels of knowledge of HIV to be linked to delayed HIV testing in a study on barriers to HIV testing. Another study conducted in the rural areas of eight countries situated in sub Saharan Africa noted that older sexually active adults above the age of 50 had poor HIV knowledge which led to low rates of HIV testing amongst this group of people (Negin *et al.* 2011). According to Ciampa *et al.* (2012: 5), low health literacy in women is associated with low HIV knowledge, which might have negative effects on the choices they would make on the use of health care services for their own health and that of their children. Sasaki *et al.* (2010: 4) report that amongst mothers who visited antenatal clinic at least once in their pregnancy and received HIV related health information, not all of them were able to answer questions regarding HIV correctly. Mothers who failed to answer questions related to HIV information that was taught to them had low levels of testing in comparison to those who answered evaluation questions correctly (Sasaki *et al.* 2010: 4). The authors conclude that health literacy

increased the rate of HIV testing and low health literacy was associated with non-acceptance of HIV testing (Sasaki *et al.* 2010: 5). This conclusion is similar to a study conducted in rural Tanzania in which the authors report; increased acceptance of HIV testing was seen more often in people who had a good knowledge of HIV, the mode of transmission and how ART works (South *et al.* 2013: 12). Men in this study were more knowledgeable about HIV transmission than females, hence in this community; more men than females tested for HIV. Only five% of women knew about transmission of HIV from a mother to her child; this was seen as mainly due to females staying at home and their source of information being limited to family members and radios. This resulted in poor uptake of prevention of mother to child transmission (PMTCT) in HIV positive women of this rural community (South *et al.* 2013: 12). In contrast, a study conducted in Johannesburg, South Africa summarizes, females were more knowledgeable about HIV than males and had high numbers tested compared to men (Johnston *et al.* 2011: 4).

According to Kumar and Arya (2015: 27), doctors do not initiate HIV counselling and testing with their patients; instead, they wait for the patients to request the test. If the patient is not well informed about HIV and the importance of testing, a request for an HIV test will be unlikely and the patient will miss the opportunity to get an HIV test. Kumar and Arya (2015: 27) also suggest that health service provider initiated counselling and testing would address the gap in HIV knowledge and the importance of testing. Providers should make use of the opportunity to educate patients and should request them to test when they present themselves for health services. Health education and community wide communication on recent HIV information and the promotion of HIV testing, giving priority to low socioeconomic groups who are undereducated, will improve HIV knowledge and testing (Jean *et al.* 2012: 8). In contrast to the above studies, a study conducted by Barragán *et al.* (2005: 425) report that patients with low health literacy were more willing to undertake HIV testing than those who are literate in health related matters. Barragán *et al.* (2005: 425) conclude by saying that low health literacy is not necessarily a barrier to HIV testing if a health service provider recommends testing.

2.2.5 Poor access to health care

For health care to be accessible it has to be of an acceptable quality, be responsive to the needs of health service users, meet and exceed their expectations and result in users satisfaction (Yakob and Ncama 2016: 2). Yakob and Ncama (2016: 2) further report, satisfied clients are likely to adhere to a treatment plan and advice given by health service providers, satisfaction lead to trust in the health system which will have an impact on individual patient's health which will result in positive health outcomes for HIV. The long distance to the clinic and the associated cost of transport has been reported as another cause for late stage HIV test as well as an inability to keep clinic appointments (Drain *et al.* 2013: 6; Yakob and Ncama 2016: 10). In support of this argument, Aziz and Smith (2011: 233) argue that access to health care consists of client factors as well as health facility factors. Client factors include lack of transport to a health facility due to low income or unemployment, which makes money limited to basic needs such as food and shelter rather than paying for transport. There is a need to increase access to HIV testing and follow up of patients who test positive especially in sub-Saharan Africa and South Africa where a number of people are unable to access health care services due to low socio economic conditions. Aziz and Smith (2011: 233) point to a health facility factor when they write that some people who want to access health care may not be able to do so due to the health facility only being open during working hours, which makes it impossible for them to access health care services because they cannot take time off work to attend the clinic. This is confirmed in a study conducted by Yakob and Ncama (2016: 10) which reports, there is limited access to health care after hours and on week-ends with some of the services such as HIV services not available after hours and on week-ends, which limits access for those people who are unable to access these services during the day.

According to Luseno *et al.* (2010: 262) it is of utmost importance for people to know their HIV status, be linked to care and to remain in care, but this is only possible if they have access to health care services. Prolonged waiting times to see a health professional also contributes to individuals testing late when

they have signs of AIDS (Drain *et al.* 2013: 6). Taking HIV services to where the people are will not only assist in improving access to health care and early HIV diagnosis, it could eliminate stigma attached to HIV (Mantell *et al.* 2014: 466).

2.2.6 Perceived low risk to HIV infection

HIV counselling and testing services are widely available free of charge but it is noted that a number of individuals come for an HIV test during the late stage of HIV disease because they never thought they were at risk of contracting HIV (Cherutich *et al.* 2012: 3). A study conducted by Nunn *et al.* (2011: 233) reveal that individuals who have multiple sexual partners, who engage in unprotected sex and have a history of sexually transmitted illnesses, did not perceive themselves as being at risk of getting HIV. The authors suggested that HIV prevalence is high amongst individuals who perceive themselves as not at risk. Basset and Walensky (2010: 78) report that there is a particular concern regarding HIV risk, which may not be recognised in sero-discordant couples, people who test negative may think their partners are also negative whereas there might be a risk if there is sero-discordance in couples.

In a study conducted in China, Men who have Sex with Men (MSM) thought they were not at risk and did not see a need to get tested for HIV even though they engaged in risky behaviours (Zhao *et al.* 2015: 7). Stephenson *et al.* (2015: 5) also report that MSM who are in relationships with a single partner whom they have entered into a sexual agreement with, thought of themselves as not at risk of ever contracting HIV, even though these men practice unprotected anal sex; asking a partner for HIV testing is seen as a sign of distrust and is avoided to keep the partner happy.

Musheke *et al.* (2013: 6) found that individuals who are not in a sexual relationship and who have abstained from sex regard themselves as not at risk of HIV infection, which makes them think there is no need to get tested.

Routine offering of HIV testing will encourage individuals to test and know their status irrespective of their perception of whether they are at risk or not (Hoffman *et al.* 2015: 4). Perceived low risk of HIV has profound effects on high-risk individuals who will not access HIV testing, treatment and prevention services (Basset and Walensky 2010: 78). Evidence suggests that two thirds of individuals who perceived themselves as not at risk tested HIV positive; these individuals were engaging in risky sexual behaviours which reinforces the importance of continuously informing individuals of HIV risks (Nunn *et al.* 2011: 233). According to Straus *et al.* (2015: 3) perceptions about low risk is strongly linked to lack of knowledge about HIV. Therefore, it is important to spread HIV testing messages to assist individuals make the right choices about testing and prevention of transmission of HIV.

2.2.7 HIV testing behaviour according to gender

In some African countries men are regarded as the head of families and men make important family decisions. Studies conducted in Ethiopia and Lesotho have shown that in some community's decisions for women to have HIV tests are made by men (Leta *et al.* 2012: 2; Mantell *et al.* 2014: 462). In the case of gender inequality and gender-based violence women are at risk because they anticipate abuse should they test HIV positive, therefore they do not test (Gari *et al.* 2013: 1). According to a study conducted by Obermeyer and Osborne (2007: 1766), men and women have different perceptions of HIV testing. Men perceived themselves as being at low risk for HIV infection compared to women irrespective of the high risk sexual behaviours that men engage in (Obermeyer and Osborne 2007: 1766). Mburu *et al.* (2014: 6) report that less men than women access and use HIV services including testing because they do not want to be known as having HIV. Masculinity makes men want to be in control and powerful; the thought of being sick makes them feel invaluable so they prefer not to take the sick role (Mburu *et al.* 2014: 4). Mburu *et al.* (2014: 4) state that fewer men attend HIV support groups because if they do this will make their status known, however they often continue having multiple partners and do not disclose their status. The few that attended support

groups for HIV positive patients hid their identity because they feel ashamed and less of a man, they want to keep their status a secret (Mburu *et al.* 2014: 4). In a study conducted in South Africa, women are known to be regular users of health facilities, which has become a norm in their communities; when men are seen attending the health service regularly, especially if they are young, their visits easily become labelled as HIV related; this makes men associate clinics as belonging to women and they avoid attending clinics (Treves-Kagan *et al.* 2016: 10).

Evidence shows that more women will agree to have a HIV test if it is offered to them at antenatal clinics than in any other setting (Obermeyer and Osborne 2007: 1766). Jean *et al.* (2012: 6) found that HIV testing is higher in women who underwent antenatal care than the ones who did not. There are greater opportunities of being offered an HIV test in an antenatal setting. A study conducted in Zimbabwean clinics showed that 99% of antenatal women were tested in comparison to 65% of women who came for other reasons; routine HIV testing was offered to pregnant women whereas the other group of women voluntarily requested testing (Sasaki *et al.* 2010: 4). The scaling up of routine HIV testing needs to include all genders. Mantell *et al.* (2014: 465) suggest that men's low levels of testing could be overcome by the implementation of Home Based Testing, which provides an opportunity for couple counselling and testing and increased family support.

2.2.8 Fear of unintentional disclosure

Studies have identified that some people fear that the clinic based HIV test is not confidential and they fear they might meet someone they know at the clinic or the health service provider at the clinic may divulge their HIV status to others, therefore, people prefer a home based test (Musheke *et al.* 2013; Gari *et al.* 2013: 1; Leta *et al.* 2012: 8). Testing sites based outside health facilities seem to have high utilization rates (Musheke *et al.* 2013: 6). Conversely Njau *et al.* (2014: 7) found that testing for HIV at a mobile site or home affects the confidentiality of a test, the community will know about it and this will give rise

to stigma and gossip, testing in a large hospital is believed to provide some anonymity and therefore preferred. Low testing rates are attributed to the lack of confidentiality that is perceived by people attending health facilities and include; designated waiting areas and treatment rooms for HIV positive people, designated HIV patient files. These practices lead people to opt to use health facilities that are away from their communities where no one would recognize them, this poses a challenge because of the distance that has to be travelled to reach the next health facility, and therefore many people would just not test (Treves-Kagan *et al.* 2016: 8). Long waiting time to have an HIV test at the clinic is believed to negatively affect confidentiality as it gives more time for other people to walk in and recognize those that are waiting to see the counsellor (Njau *et al.* 2014: 5). Hall *et al.* (2014: 4) attribute low levels of HIV testing to a fear that the results of the test will not be confidential. When a lack of confidentiality is perceived, the rate of HIV testing is reduced (Musheke *et al.* 2013: 2).

2.2.9 Conspiracy beliefs about HIV

In a study conducted in the United States, African American women who participated in the study held a belief that HIV is a virus that was purposely created by “the white people” in government to eliminate the disadvantaged Black people. (Aziz and Smith 2011: 234). Similarly another United States study conducted by Gillman *et al.* (2013: 43) in MSM found that there is a belief that drug companies and the government have discovered a cure or vaccine for HIV but are withholding it from the black minorities. These conspiracy beliefs result in avoidance of HIV testing, which hinders efforts made towards prevention and treatment of HIV (Musheke *et al.* 2013: 10). This study further reports that in some African countries HIV testing was viewed as a strategy used by Western countries to dominate and therefore people were resistant to test once they had this belief. Gari *et al.* (2013: 2) conducted a study in the Southeast United States, the results of which reveal that African Americans believed that HIV was created by the White people to kill all Black people and that the United States government is exploiting the

Black people by testing the efficiency of ARVs on them. Aziz and Smith (2011: 234) found that some African Americans also believed that HIV was produced by their government in an attempt to eradicate them and that there is a cure for AIDS but it is not given to them and the government uses those who take ARVs as subjects for experiments. This study focused on the use of health care services by the African Americans in need of health care, and it identified under-utilization of health services by this community, which was, amongst other reasons, due to this conspiracy belief (Aziz and Smith 2011: 234). Studies conducted in Mali and Zambia concur; HIV was a game plan by white people to stop the multiplication of black people, make money on selling condoms and medication, while using blacks for their drug experiments. These conspiracy beliefs were brought about by earlier research projects that were done in Africa on drug trials and marketing of HIV testing by the western researchers on African patients. These activities were seen as a secret plan to eliminate black people and achieve the interests of western countries (Musheke *et al.* 2013: 10).

Fakoya *et al.* (2012: 621) report that some Africans living in London who attend some charismatic churches believe that HIV and other illnesses are associated with being possessed by demonic spirits. People attending these churches trust that praying vigorously will protect those who believe in God from contracting HIV and those with the HIV disease will be healed; this in turn delays HIV testing. In contrast, there are positive effects of religion and spirituality for patients who believe in God; positive religious coping is used by patients when they look for a deeper relationship with God and acknowledge God's love, this has been found to be an important factor that assists people with HIV cope better with the disease and contribute in rational decision making when managing the disease (Cotton *et al.* 2006: 11).

According to Ntsepe *et al.* (2014: 143), one main reason for the reduced uptake of HIV testing amongst White and Indian people in South Africa is the perception that HIV does not affect them as their communities have low HIV prevalence. In order to improve HIV testing, the benefits of knowing ones HIV

status must be emphasized to all communities irrespective of their HIV prevalence rates (Aziz and Smith 2011: 236).

2.2.10 Strategies to improve HIV testing

HCT is an important prerequisite for the control and management of the HIV epidemic, evidence shows that where there is increased HCT there is reduced HIV incidence (Strauss *et al.* 2015: 2). The World Health Organisation has developed a Framework to guide service delivery approaches to HCT; this framework provides a guide for different countries to choose a combination of accessible and acceptable approaches that best suit their communities, and implement these approaches to improve access to HIV testing. Some of these approaches include but not limited to expanding community based testing options and innovation to extend HIV testing services beyond health facilities (WHO 2012).

Community based HCT has resulted in increased HIV testing rates around the world, in both developed and developing countries (Kenya *et al.* 2015: 358). Multiple studies that were conducted in the USA, Europe, United Kingdom and Spain agree that the initiative of testing people at mobile sites rather than in community clinics has a far better success rate as a large number of people tested at mobile sites in comparison to those that tested in the clinics (Spielberg *et al.* 2011: 111; Thornton *et al.* 2012: 418; Kenya *et al.* 2015: 358). This is affirmed by a study conducted in South Africa which states that mobile testing services attracted more young adults and men compared to clinics, testing in a site outside of clinic provide some convenience especially to men (Basset *et al.* 2012: 372). A study conducted in rural Luganda on HIV home testing show an increase in the level of first time testing amongst men, this strategy proved to be feasible and acceptable to men who never accessed HIV testing services (Hensen *et al.* 2015: 14).

Another HIV testing promotion strategy to improve early HIV testing that was successfully implemented in the USA is the routine offering of HIV testing in a variety of health care settings including emergency rooms, STI clinics and

community based centres to all adults, adolescents, pregnant women and children even when their risk is perceived to be low (Fenton 2007: 219).

Improving and maintaining good provider-client relationship encourages testing, strong relationships between the provider and the client make it easy for clients to test when they know that the provider cares (Aziz and Smith 2011: 235). Creating awareness of HCT and the benefits of testing encourages testing, people who have knowledge of HCT and how they will get help should they test positive are likely to test (Chimoyi *et al.* 2015: 7). Pharmacy based HIV testing has been used as a successful strategy to normalise HIV testing and reduce barriers in testing by using a comprehensive based approach where pharmacy staff provide HIV testing together with other health screening tests such as, hypertension and diabetes (Crawford *et al.* 2016: 140). Inclusion of HIV testing in other health screening tests improve the rate of HIV testing uptake, this makes testing as part of wellness screening rather than a perception that HIV is a disease that is exceptional from other diseases. The newly developed South African school health policy with a focus on offering youth friendly services to adolescents, which includes health screening and HIV testing has had a contribution in the improvement of HIV testing and access to treatment care and support services by the youth in need of this support (Strauss *et al.* 2015: 12).

In addition to the provider support, people need support of the people that they live with, support from the community especially family and friends. Research conducted in South Africa provides insights on the improved willingness to undergo HIV testing when support from the family is present (Strauss *et al.* 2015: 2012). Elderly people play an important role in encouraging the younger generation to test HIV, where older people are educated on HIV, they have higher general knowledge of HIV and a more positive attitude towards HIV, which will make them test HIV and in turn encourage the younger generation to test (Negin *et al.* 2011)

2.3 CONCLUSION

It is evident from the review of the literature that the uptake of HIV Testing is hindered by barriers as reported, including: HIV related stigma, denying AIDS, health service provider barriers to HIV testing, low health literacy, perceived low risk of HIV infection, poor access to health care, HIV testing behaviour according to gender, fear of confidentiality of an HIV test and conspiracy beliefs about HIV. Stigma came up as a major barrier out of which other barriers emerge. Few studies have assessed denial on its own but it has come up as part of other barriers, for example, fear of knowing ones HIV status brings about denial and the perceived low risk of HIV infection relates to denial. People who perceive themselves as low risk for HIV infection appear to be in denial, because the literature has revealed that some of them will be sick but will choose not to associate their illnesses with HIV even when they know they engage in behaviours that put them at risk.

CHAPTER 3: RESEARCH METHODOLOGY

3.1 INTRODUCTION

The purpose of this chapter is to describe the research design methodology that was used to explore the factors influencing delayed HIV testing in a sample of HIV positive newly diagnosed patients who had a first CD4 count of 350 mm³ and less. The phenomenon of “delayed HIV testing” was explored using a qualitative content analysis design. The researcher chose the qualitative methodology because it allowed for exploration of meanings, which assisted in uncovering factors influencing delayed HIV testing according to the research participant’s perspectives (Polgar and Thomas 2008: 84). Exploratory qualitative research is used when the researcher has little or no information about the topic under study and is usually selected to achieve clear and precise information on the research problem (Naoum 2001: 40). In this study, the researcher set to explore factors, which influence people to delay testing for HIV, through interviews with the participants and exploration of what study participants have said as well as the description of the results after data analysis.

3.2 SETTING DESCRIPTION

The study was conducted in a public Primary Health Care (PHC) clinic, Clinic A, in the West Sub-District of eThekweni Metropolitan, KwaZulu-Natal. This PHC clinic is under the management of eThekweni Metropolitan Health Department. The most senior official and accounting officer in the Metropolitan is the City Manager, below the city manager is the Deputy City Manager, the Head of Health, the Deputy Head of the West Sub-District, the Primary Health Care Senior Manager and lastly the Nursing Services Manager who has the responsibility of managing the clinic operations. Primary Health Care is an integrated, comprehensive health care system that

is designed to provide promotive, preventative and curative health services that are affordable. (de Haan 2009: 23). In South Africa, PHC is provided free of charge by PHC Clinics and Community Health Centres (CHCs); accessible at community level and is the first point of contact for the public health sector. If the management of a patient requires expert intervention, the decision will be made at PHC or CHC to refer the patient to the next level of care, which would be: the District hospital, Regional hospital or a Tertiary hospital. The decision will depend on the condition of the patient and the required intervention according to the Essential Drug List and Standard Treatment Guidelines. (South Africa 2000: 4). Clinic A belongs to eThekweni Municipality Health Department and is situated in a suburb five kilometres from Pinetown. Primary Health Care services that are offered in this clinic include: treatment of minor ailments, nutrition, child and women's health services and chronic disease management. All PHC services at this clinic are provided by Professional Nurses; the clinic has a doctor who visits once a week to attend to complicated non-emergency patients whose conditions require medical management from a doctor. Clinic A was chosen as a study site because the diversity in the patient population meant that there were opportunities for a rich and varied sample. The clinic is in a suburb but there is a semi-rural area that is situated about one kilometre away from Clinic A, which consists of informal dwellings and shacks. The suburb where Clinic A is situated consists of formal houses, tarred roads and yards with gardens. The nearby informal dwellings and shacks consist of informal houses, which are either built with mud, corrugated iron, wood, old bricks or stones. The majority of people from these informal dwellings and shacks use this clinic.

3.3 POPULATION

The population in the research context is defined as humans, objects or substances that meet certain criteria for inclusion in the study according to the researcher's area of interest (Botma *et al.* 2010: 200). The population in this study was HIV positive patients who had recently tested for HIV and received their first CD4 count result of 350 mm³ or less. The patients who attend Clinic

A come from high to low socioeconomic backgrounds. The majority of the patients are labourers who are unskilled and dependent on public health facilities, mostly Africans with a few Indians. There are a lot of immigrants and migrants that are seen in this clinic as it is near the New Germany industrial area where many immigrants from neighbouring African countries and migrants from rural areas within South Africa work. Due to high mobility, immigrant and migrant workers have increased risk of HIV infection especially if their sexual risk behaviours are high (Coffee *et al.* 2007: 344).

3.4 SAMPLING

Convenience sampling, which is a type of non-probability sampling was used to select the clinic A from other clinics. The researcher chose clinic A because it was convenient and accessible since the researcher knew the clinic manager and staff of this particular clinic through working with them in her job as a quality assurance co-ordinator for a group of clinics, which clinic A falls under. Clinic A was also chosen because of its population diversity since it serves people from low to high socioeconomic backgrounds, which was going to make the collection of rich data possible.

Purposive sampling, a type of non-probability sampling, was used to select the study participants from the population. Purposive sampling allows the researcher to pick the research participants who are likely to have the knowledge necessary to address the study purpose (Botma *et al.* 2010: 201). This type of sampling was chosen because pre-determined criteria were used to find participants that would be able to provide information about themselves and their circumstances to assist the researcher achieve the objectives of the study.

Prior to the sampling process, the researcher set appointments with the Clinic Nursing Services Manager and the HIV/AIDS Counsellor to explain the research and its objectives and agreed on the date when the study would commence. The researcher then developed a relationship with the HIV/AIDS

Counsellor in the clinic. The Counsellor was given information about the research and was requested to refer patients who met the selection criteria and who were willing to participate in the study to the researcher. The Counsellor's role ended after she had referred participants to the researcher. An information leaflet containing a short description of the research purpose and the selection criteria was given to the Counsellor to give to patients or read it to them, this was done to assist them to make an informed decision. The Counsellor approached the patients on an individual basis to ensure privacy and dignity. The Counsellor personally took patients who agreed to participate to a consulting room where the researcher was conducting the interviews.

The selection criteria were:

- HIV positive patients who are testing for HIV for the first time with a first CD4 count of 350 mm³ and below at diagnosis of HIV and
- Above 18 years of age.

The sample size was determined by data saturation. Botma *et al.* (2010: 200) define data saturation as the situation where the data is not bringing in any new information. When a total of 18 participants had been interviewed in this study the researcher came to a stage where no new information was obtained from the data and it was decided that it was time to terminate the process of data collection. The data was collected over a period of two months.

3.5 RESEARCH INSTRUMENTS

Semi structured interviews using an interview schedule were used to collect data. Semi structured interviews were used to gain an in depth knowledge about the subject under study according to the beliefs, opinions and views of the research participants (Botma *et al.* 2010: 209). The interview schedule was made up of demographic information and guide questions, which were formulated using the information that emerged from the literature review (appendix 5a and b). Polgar and Thomas (2008: 108) define an interview as

an interaction between the researcher and the research participants with the aim of gaining information from the participants to achieve the objectives of the study. The themes that emerged from the review of literature provided information that was used to form guide questions to test the common themes in the literature such as perception of HIV risk, denial of an HIV positive status, that were relevant in the population that was studied.

A semi-structured interview method of data collection was chosen for this study because of its potential to allow the researcher to extract deep descriptions about the factors influencing delayed HIV testing and to probe and get more information from the participants. Probes that emerged from the initial interviews following data analysis were also used during subsequent interviews.

3.6 DATA COLLECTION

According to Polgar and Thomas (2008: 89) data collection refers to the collection of accurate and objective information on the research participants to find answers to the research questions. Data was collected from the 4th of November 2014 to the 9th of January 2015. Interviews took place on a one to one basis in a consulting room at the clinic. This room is located next to the counsellor's room and it was allocated for use by the researcher during the time the research took place. The room was a fully equipped clinic consultation room with air conditioner, one desk, two chairs and an examination couch. The windows had blinds, which were slightly closed, and the door of the room was kept closed during each interview process. To ensure confidentiality, there were no group interviews.

The counsellor introduced participants to the researcher. They were warmly welcomed, thanked for agreeing to participate and invited to take a seat and make themselves comfortable. The interviews opened up with the researcher introducing the research topic, the purpose of the research and why the interview was important for the study. The researcher explained how the interviews would be conducted and approximately how long it would take.

Once the participants had been made to feel at ease and expressed a willingness to participate in the study they were asked to sign informed consent (appendix 4a and b).

The interviews ranged from ten to fifty six minutes and were recorded using a voice recorder. The interview was guided by an interview schedule, which consisted of a set of predetermined open-ended questions arranged in a sequence according to how sensitive they were (appendix 5a and b). This arrangement of questions was done to allow participants to get used to the interview by the time sensitive questions were asked (Botma *et al.* 2010: 209).

The advantage of conducting interviews is that it allowed for observation and interpretation of non-verbal responses, which assisted with data analysis and reporting of findings (Polgar and Thomas 2008: 108). Baumgartner, Strong and Hensley (2002) also identified some of the advantages of interviews such as that the interviewer can be in control of the situation and is able to collect complete information, the ability to clear misconceptions and to follow-up on some responses. However there are some negative aspects to interviews such as some people finding it difficult to talk openly about sensitive issues, which may hinder their openness (Polgar and Thomas 2008: 109). To overcome this the researcher developed a good rapport with the participants prior to the interview process by showing respect and understanding of what the participants said and listened with interest (Botma *et al.* 2010: 208). All participants participated willingly and talked freely, their body language did not show any signs of distress.

The participants granted consent for voice recording; a cell phone voice recorder was used to record the interviews and later downloaded onto a password-protected computer. Voice recording allowed the researcher to concentrate on the interviews and transcribe the recordings after the interview was completed. Non-verbal communication that was observed and experienced by the researcher was recorded in the field notes – for example a sigh, a pause and nodding.

3.7 DATA ANALYSIS

The researcher listened and re-listened to all voice-recorded interviews and transcribed them verbatim, firstly in the language they were recorded in, that was in isiZulu, and then translated the interview transcripts into English. The researcher did the translation of interviews from isiZulu to English since she is bilingual, can speak, read and write both English and isiZulu. The researcher then read the transcribed interviews several times and listened to the voice recorded interviews again to make sure they were correctly transcribed and this gave her an opportunity to immerse herself in the data which resulted in understanding what the data was representing and assisted with the interpretation of data.

The data was analysed manually using descriptive content analysis to extract meanings from the data. Content analysis refers to the analysis of what the text says and gives interpretation to the words and phrases; the unit of analysis must be chosen when content analysis is used (Graneheim and Lundman 2003: 106). The unit of analysis selected for use in this study was the information from the interviews that were held with the participants. The unit of analysis refers to every word or phrase in the transcript (Graneheim and Lundman 2003: 106). The data was extracted from the interview transcripts and displayed in a manageable format on flip charts, which made analysis and interpretation possible.

Words, sentences and paragraphs, which shared the same concept through their context and content, were referred to as meaning units (Graneheim and Lundman 2003: 106). All text that contained information that related to reactions or feelings were highlighted using coloured marker pens. All highlighted words, sentences and paragraphs, which contain information that related to each other, were classified as meaning units and were coded the same.

Following the identification and classification of meaning units condensation was used to shorten texts while retaining the meaning; these meaning units were classified as condensed meaning units and labelled sub categories. Graneheim and Lundman (2003: 106) define condensation as the process of shortening text without changing the main idea.

Following the identification of condensed meaning units further abstraction of condensed text descriptions were given to the sub categories to create categories (table 4.1). Abstraction is defined as a higher level of description and interpretation of categories (Graneheim and Lundman 2003: 106), categories led to the formulation of a theme.

3.8 TRUSTWORTHINESS

Trustworthiness refers to the ability of the researcher to critically appraise every decision made during the entire research process. Evidence of the researcher's integrity was demonstrated by her ability to continuously check if the procedures followed in data collection were adequate and that data was accurately analysed. Measures to achieve trustworthiness in this study are described in the following: credibility, confirmability, dependability and transferability, according to Lincoln and Guba (1985) as cited by (Botma *et al.* 2010: 292).

3.8.1 Credibility and Confirmability

Lincoln and Guba as cited by (Botma *et al.* 2010: 233) explain that credibility focuses on the assurance that adequate relevant quality data was collected, the correct method to collect data was applied and the research participants were appropriate for the study based on their experience. Pre-determined criteria were used to select participants in this study according to their specific attributes in relation to the research question. The selected participants; HIV positive patients with a first CD4 count of 350 mm³ and below at diagnosis of HIV were able to relate their own reasons for delayed HIV testing, which

contributed to a generous description of the factors influencing delayed HIV testing. Confirmability was applied in peer debriefing when the supervisor and the co-supervisor evaluated some of the interview transcripts and illustrations, which showed how data categories and themes were formed, objectively.

The researcher collected complete and accurate data, which was transcribed verbatim, and quotations used in this dissertation are drawn from that raw data (appendix 7). Full and accurate field notes, which are interpretive, were recorded and were used for data verification purposes to support the theme that emerged.

3.8.2 Dependability

Dependability refers to the process of determining the quality of data by measuring its consistency over time and clear explanation of the study process and report (Botma *et al.* 2008: 292). The researcher carefully documented and kept a record of interview transcripts and field notes to enable tracking of data to its origin. The research methodology was well described to enable replication of the research in similar settings.

3.8.3 Transferability

Transferability means the degree to which the results of the study can be transferred to other individuals and groups and the findings of the study used in other studies as well (Baumgartner, Strong and Hensley 2002: 221). The study has been described in enough detail to be able to be replicated by another researcher. This was made possible by clarifying and defining descriptions according to the participant's perspectives.

The researcher has given a detailed description of the study setting, the participants, observations made during the study, the methodology that was followed during data collection as well as data analysis and reporting to allow other researchers to test it in similar settings.

3.9 LIMITATIONS OF THE STUDY

Reporting bias was a concern should the participants fail to respond in a way that would answer the research question. To minimise this, the interviews started with a broad question, which was open ended. The researcher established a good relationship with participants and used communication skills such as listening, paraphrasing, clarifying and probing, to uncover the participants perspectives on factors influencing delayed HIV testing.

3.10 ETHICAL ISSUES

In order to adhere to ethical principles and to protect the rights of the research participants, Ethics must be applied and adhered to throughout the research process (Botma *et al.* 2010: 4). The principle of respect for persons, beneficence and justice were adhered to at all times. The researcher commenced the study after ethics approval from the Durban University of Technology Ethics Committee (appendix 1) and the eThekweni Municipality Health Unit Research Committee (appendix 2b).

Participants verbally confirmed their thorough understanding of what the study was about prior to their inclusion. Complete information regarding the research purpose and objectives was given to participants in the form of a letter of information (appendix 4a and b), which was in the participants' language to enhance understanding. Before interviews commenced, a written informed consent (appendix 4a and b) was obtained from each participant after thorough explanation of all the details regarding their participation in the study.

Notwithstanding the fact that it was anticipated that there would be no serious threats to the welfare of the participants, this study made provision for referral to an experienced social worker at the clinic should any of the participants have experienced emotional breakdown and needed counselling.

All information concerning the participants was handled confidentially and no names were used to identify participants, pseudo-names were given to protect the identity of participants. Research related information was kept confidential in a password-protected computer.

3.11 CONCLUSION

This chapter provided a detailed account of this study's research methodology. A descriptive qualitative study method was used to analyse and represent the factors influencing delayed HIV testing according to clients' perspectives. The sample consisted of 18 purposefully selected participants who met the predetermined criteria according to the study objectives. Semi structured interviews using an interview schedule was used to collect data. Content analysis was used to analyse the verbatim transcriptions. The data was coded and grouped into sub categories and categories that led to identification of a theme. To protect the rights of the participants ethical principles were adhered to. Trustworthiness was assessed to ensure reliability and validity of the qualitative findings.

CHAPTER 4: RESULTS

4.1 INTRODUCTION

This chapter presents the results of the study, which were obtained from 18 in-depth interviews with participants. The researcher intended to understand the phenomenon of delayed HIV testing so as to be able to inform initiatives to improve the health system's approach to HIV testing and to enrol more eligible people onto ART.

In demographic terms, 12 participants were female and six were male whose ages varied between 23 and 64. Two thirds of the participants were unemployed. A majority achieved high school education with only two participants who did not receive any education at all. Few participants were married in comparison to the majority who were not married but living with their partners. Despite a large number of immigrants in this population no foreign nationals were part of the sample. This was not intentional.

4.2 PRESENTATION OF FINDINGS

To ensure the confidentiality of all participants during the presentation of the results, participants were given pseudo names. The illustrative quotations taken from the interview transcripts consist of multiple participant perspectives, which are represented as spoken by participants in their own words and translated into English as they spoke in isiZulu. On completion of data analysis, eight sub categories; three categories and a theme emerged from this study. The codes, subcategories, categories and the theme that emerged are presented in Table 4.1.

Table 4.1 The meaning units, codes, sub categories, categories and the theme extracted from content analysis of the Qualitative data

Meaning unit	Codes	Sub categories	Categories
Clinic is attended due to illness. Refused to test when asked by nurses at each visit. Lies about having tested HIV negative [Peter]	Never tested but lied about it to nurses. Pretending to be HIV negative but lied to avoid testing	Denial related to a positive HIV status	Stigma and Discrimination
No HIV risk perception before testing and being HIV positive does not mean anything [Maggie]	Perceived no risk of HIV and HIV is not a problem		
Felt fine and she kept telling herself she is fine [Toto]	Testing was delayed because of perception that nothing was wrong		
Previous partner got sick and died of HIV, never thought he had HIV even though they were not using condoms every time, she guesses he had been lying to herself [Prisca]	No risk perception of HIV although partner died of HIV		
Changed previous clinic trying to run away [Peter]	Avoided being seen by people at the clinic		
I did not want to test because I did not want to know I am positive [Yvonne]	Protected self from knowing about HIV status		
He did not want to be known as having HIV, he was scared of being different to other people [John]	Felt ashamed of having people know of his status	People like to gossip	
In the clinic people who have HIV are seen separately and are treated in a container outside the clinic. HIV testing is done in the same container. I was scared of people gossiping about me when they see me in the container [Vanessa]	Separation of HIV testing from other services and separation of HIV positive people make others know and talk about you		

I did suspect I might have HIV before I tested because I was unwell, lost a lot of weight and I was previously admitted to hospital but I was scared to test [Margaret]	Scared of testing HIV positive because I could see the signs	Fear of knowing HIV status	Stigma and Discrimination
He had thought of testing HIV when his wife kept on bringing it up but he was very scared to test so he kept on pushing the thought aside [Jack]	He did not want to think about testing because he was scared to test HIV		
Became aware of risk when her partner's girlfriend disclosed they were HIV positive [Toto]	Did not test HIV when she became aware she was at risk	Judgement	
He only talks to his wife about his status, he is scared of talking to other people because he thinks they will discriminate him, in his community, they do not accept HIV positive people well [Luke]	Fear of disclosing to other people other than his wife because of fear of being discriminated		
People undermine people who are HIV positive and think they are intellectually incompetent and will instruct their children not to come near them [Neil]	Fear of being mistreated by people in the community		
He thought of testing for HIV because one of his partners became ill, but he was scared of being seen by people who knew him at the clinic because they were going to gossip about him and treat him as someone who is worthless [Neil]	Scared of being judged and bad treatment from other people		
There is a problem with talking about HIV with the in-laws, I fear they will isolate and judge me if they get to find out about my HIV status because they are the type of people who judge [Cindy]	Fear of being isolated and judged by in-laws		
Talks about HIV with friends because most of them have it but scared of talking about it with a partner [Precious]	Scared to disclose to a partner	Non-disclosure of HIV status	
Scared of telling her mother because her sister had died of HIV [Judy]	Protecting her mother by not telling her about her status		

I knew I was at risk because my partner was taking ARVs since year 2010, I have been with him since 2008 and we did not use condoms [Margaret]	Having a partner on ARVs and not using condoms made HIV infection likely	Unprotected sex and risky lifestyle	High risk behaviour
She knew she was at risk because her partner has lots of other women, she kept on getting sexually transmitted illnesses because they were not using condoms [Vanessa]	Frequent sexually transmitted illnesses and unprotected sex		
He thinks he was at risk of having HIV because of the life he was living, he liked women a lot and used to have one night stands, he used to have seven different women in seven days [Luke]	Slept with a lot of women		
She did not consider taking an HIV test, herself and her friends were ignorant, they kept on sleeping around and never used condoms [Precious]	Had multiple partners		
HIV testing was considered but avoided because in the clinic there are long queues and delays [Vanessa]	There are long queues and long time spent at the clinic	Long queues and delays at the clinic	Long waiting time

Theme: ***Testing for HIV is daunting and embedded with issues of stigma, denial and fear of knowing ones HIV positive status***

4.3 PRESENTATION OF THE SUBCATEGORIES, CATEGORIES, AND THE THEME

The sub categories and categories will form the basis for the presentation of the results.

4.3.1 Stigma and Discrimination

This category emerged from the following sub categories: denial, gossip, fear, judgment and non-disclosure of HIV status.

4.3.1.1 Denial related to a positive HIV status

An overwhelming majority of the participants did not want to believe they were HIV positive even though they were sick for a long time. Fourteen participants indicated that they delayed taking an HIV test because they did not want to know their status. Some study participants avoided testing HIV because they did not think they had HIV. The advice to test that some of them received from the nurses made them eventually take the decision to test. The participants did not suspect that they were HIV positive even though they were chronically ill. At times they associated the symptoms they had with other reasons apart from the possibility of being HIV positive to avoid HIV testing. According to the descriptions given by the participants, signs that indicated they might be HIV positive were ignored and they decided to carry on with their lives – they thought there was nothing wrong with them. Most of them tested because nurses introduced testing to them and they were asked to test. Some did not think they could have HIV but decided to test to rule it out. Some participants felt that they had to be emotionally ready before they could test for HIV and they delayed testing while they prepared themselves. Others avoided testing because they did not want to face the fact of being HIV positive. This view is illustrated in the following comments:

Luke

... Sickness never stopped, I kept on going in and out of doctors, until really my situation got worst and I realised that I will die if I don't do anything about it... When I finally tested, I was ready.

Maggie

I did not suspect I have it. I told myself that even if I have this thing, it will not kill me, I would only die when my time comes.

Toto

No I did not suspect but I told myself that I might be positive since that other women said she is HIV positive. Also I was gradually losing weight but I did not associate it with HIV.

Peter

I was sick and each time I attended the clinic nurses were always asking me to test. I kept lying to them several times, telling them I have tested before and was negative but the truth is, I had never tested... I even changed my previous clinic to this one because I was trying to run away.

George

I went to the clinic and they advised me to test. I ignored them and refused. I was losing weight, I was progressively losing weight in an unusual way, and it was even noticed by my sisters. My pants were no longer fitting me. I thought it was because I had worries due to my divorce.

Mandy

I did not think I would have it sister because I'm not a person who is fast with men. I thought that people who get it are those that are fast.

Prisca

The person I was with was too fast and he liked women a lot. I think I got it from him because we were not using condoms. He died and I think he died of

AIDS because he was having TB and taking tablets. I was no longer with him when he died.

4.3.1.2 People like to gossip

Participants in this study voiced their fears about social damage that occurs as a result of their HIV status becoming public knowledge. Such public knowledge produced gossip that occurred once people become aware of one's HIV status. Most participants were running away from clinics that were within their communities because they did not want to be seen by people, who knew them, attending HIV services in their local clinic. They preferred to attend a clinic where hardly anyone knew them for fear of gossip about them in their community, which could have led to them being discriminated against and isolated. Four participants stated that if people who know you see you attending the clinic for HIV services, they gossip about you to others. The following quotes are in support of this view:

Neil

Yes, I thought about it because one of my partners also became ill. I did not test sooner because I was scared, I was scared of being seen by the people that know me, (took a deep breath), (eyi-ya) when they see you attending for HIV in the clinic they gossip about you and once people know you are HIV positive they treat you as if you are worthless.

Vanessa

I was really scared to come to the clinic because at the clinic there are separate queues and all people who are HIV positive are placed separately and are treated in a container that is outside the clinic. If you go to the container everybody will know that you are HIV positive. Even testing is done in the same container, I was scared to test because people who know me would see me and start gossiping about me. Even the files of HIV patients are not the same as others, they are green and are written HCT... Even people that you did not want to know your status will end up knowing.

Luke

HIV patients have different files from others; they carry a green file, so if you are carrying a green file everybody knows you are a HIV patient, which is embarrassing. I did not want people to know I have HIV. If everyone can have the same file people will be free. In the community so many people like to gossip.

4.3.1.3 Fear of knowing HIV status

Some participants did suspect they might be HIV infected before they tested, because of their illness history, others had been admitted to hospital with symptoms that they associated with HIV, but they were scared to test. The thought of testing HIV brought fear and was always ignored even when they were asked to test by their relatives or the health service providers at the clinic. Some fears were associated with uncertainty as to how they would cope with being HIV positive. The negative experiences of HIV positive people in their communities contributed to their fears of knowing their status. Some participants feared the lack of confidentiality in the clinic and that by coming to the clinic to test for HIV they would unintentionally disclose their status to others because they perceive there to be no privacy at the clinic. The clinics have separate queues and areas for rendering different services including a queue for people who want to have an HIV test. Five participants expressed their fears of testing for HIV; here are some of the quotes:

Peter

Deep down I suspected I might have the disease. I saw many things happen to others when they discover they have the disease, some commit suicide before even taking the pills, that made me scared.

George

I was scared to test. I refused to test when asked by nurses ... people are very scared of being told they have the disease. It happened recently in my

community that a young man hanged himself and tried to commit suicide when he was told he had the disease.

Yvonne

I was sick ... I was not getting better. I suspected I had HIV because I heard on the radio and they were talking about the signs like diarrhoea and weight loss, I always had diarrhoea. I also had lost a lot of weight. I was scared of testing because I did not want to know I had HIV.

George

Another problem here at the clinic once you have HIV you are separated from other people that does not have it, we are directed to this park home and all other people remain in the main clinic. If they can stop separating people and treat everyone the same and give them the same card.

John

I did not want to be known as having HIV. What can I say; I was just scared of being different to other people.

Jack

I had thought of testing HIV when my wife kept on bringing it up but I was very scared to test so I kept on pushing the thought aside.

Margaret

I did suspect I might have HIV before I tested because I was unwell, lost a lot of weight and I was previously admitted to hospital but I was scared to test.

4.3.1.4 Judgement of people living with HIV

The majority of participants indicated that they were concerned about being mistreated by their family and other people in their community and therefore did not want to test for HIV. Stigma attached to an HIV positive result made nine participants avoid an HIV test. Some of the reasons they brought up

were that they do not want others to know they have HIV because they anticipated that they would be treated badly and lose the respect they got from people. Some participants felt embarrassed to test for HIV; they wanted to keep it to themselves. Others felt that if they knew they were HIV positive, they would feel different to other people. Some participants were scared of testing for HIV and knowing their status because they did not want to be judged by their families and the community. People avoided testing for HIV because they did not want to be seen at the clinic by people who knew them; they feared they would be judged. Others just did not think they could be HIV positive, they thought people who get infected with HIV are those who are promiscuous; they did not want to be associated with being HIV positive. Talking about HIV was perceived as not accepted and would result in isolation of an HIV positive person. Judgement is captured in the following excerpts from some participants:

Cindy

With my in-laws there is a problem, I can't tell them because if they find out they will gossip about me and they won't allow me to touch their things and they will isolate me because they are the type of people who judge.

Peter

I have seen people with AIDS and have heard people judging them. I asked myself, if it was me what would people say, what will my children say? No I did not want to know... I did not want my family to judge me.

Luke

... It was scary to test HIV because of the way people associated HIV with people who sleep around, I will be labelled as that as well.

Sylvia

I don't talk about HIV with my family because they are always criticizing people who are sick and who are taking medication. I know if they can find out my status they will discriminate me, so I have decided not to talk to them about it.

George

People even tell their children to be scared of HIV positive people and not to come near them.

4.3.1.5 Non-disclosure of HIV status

Non-disclosure of HIV status had an effect on some participant's delay in HIV testing. Failure of the partner to disclose their HIV positive status was reported by some participants to delay them testing for HIV. They would sometimes hear from other people that their partner had HIV, sometimes after breaking up or only after the partner had died. One participant felt that it was better to keep his HIV status a secret because he felt that if you told one person they would tell other people. For one participant, testing HIV would mean he has to tell his family, he was scared to tell his mother and he was not prepared to do that. Non-disclosure of HIV status is represented in the following participant's responses:

Peter

I know my mother must know my HIV positive status because even if I die she will have to bury me but I don't know how to tell her... Even to this day I'm scared of how I will tell my mother.

Mandy

... My ex-boyfriend got very ill and lost a lot of weight, he had skin rashes and was always scratching himself. He eventually died. I suspected he had HIV although he did not tell me.

Luke

About this disease you are more free if you keep it to yourself and don't tell other people ... someone once said HIV is an evil that you can live with, I think that's true. I don't talk about HIV to anyone except my wife.

Judy

One of my sisters had HIV and died that's why I am scared of telling my mother, my sister refused to take ARVs until she died.

4.3.2 High-risk behaviour

High-risk behaviour emerged from the following subcategory: unprotected sex and risky lifestyle.

4.3.2.1 Unprotected sex and risky lifestyle

A majority of participants cited that the presence of risk factors for being HIV positive made them avoid testing because they did not want to know the truth. One participant stated how he was warned by his mother about getting HIV because he was putting himself at risk by changing partners frequently, he felt sad that he did not listen. Eleven participants perceived that being at high risk for HIV contributed to their avoidance of HIV testing. Knowledge of a possible HIV positive status due to risky sexual behaviours and having an HIV positive partner or a partner who died of AIDS made some participants scared of knowing the truth. Some feared they would not be able to cope with knowing the truth, this discouraged HIV testing and knowledge of their status. This is reflected in the following comments:

Vanessa

I frequently suffered from sexually transmitted illnesses and I also had vaginal warts. I was advised at the clinic to test... I knew I was at risk when I had unprotected sex with him and I kept on getting sexually transmitted illnesses.

Margaret

I knew I was at risk because my partner is taking ARVs and he started in 2010. I have been with him since 2008 and we did not use condoms all the time before but now we are using condoms every time.

Luke

I think I was at risk because of the life I was living. I liked women a lot. I had so many girlfriends when I was younger... I used to have one-night stands and I used to sleep with seven different women in seven days.

Peter

My mother always gave me advice about things that will make me get HIV, she warned me about changing girls frequently... There is an element of trust involved; you just feel you can trust the person ... so yes we did not use condoms... I have eight children with different mothers.

Precious

No I did not think of testing. My friends and myself were so ignorant we just lived life and we just wanted a nice time and we were totally ignorant, we slept around and never used condoms.

4.3.3 Long waiting time

Long waiting time emerged from the following subcategory: Long queues and delays at the clinic.

4.3.3.1 Long queues and delays at the clinic

Two participants attributed their delayed HIV testing to long queues and delays while waiting for a service at the clinic. They believed the waiting time to be too long and they did not have time to wait. One participant mentioned that he preferred attending a private doctor because there the service was quicker, the waiting is shorter and if you do not have medical aid the private doctor hardly checks you for HIV. Some participants stated they were aware that their sickness might be due to HIV but they did not want to wait in a long queue at the clinic to get tested. This is reflected in the following comments:

Luke

... Really I had all the signs. I wanted an easy way out, so when I was sick I kept on going to doctors surgery because you don't sit there for too long, ... everything is done quickly and you are given medicine or injection and off you go... Maybe it's better when you have medical aid because when you are poor like us, the doctors don't check things like HIV, and only the clinics check all things and HIV. Here in the clinic there is so much delay, you sit in a long queue to be seen, so that's another reason why I did not test for a long time.

Vanessa

Yes I did consider testing HIV but I was just lazy to come; you know the laziness of young people. I was just lazy to hold the queue at the clinic waiting for pills.

The following overall theme emerged out of the three categories identified:

Testing for HIV is daunting and embedded with issues of stigma, denial and a fear of knowing ones HIV positive status.

4.4 CONCLUSION

The findings discussed in this chapter have allowed a description of the factors that influence delayed HIV testing according to the perspectives of participants in this study. Data collected from participants was analysed, coded and classified into sub categories, categories, the underlying meanings of categories were tied to formulate a theme.

Importantly the most common reason for not testing early as cited by a majority of participants in this study was denial and high-risk behaviour. Stigma, judgment, discrimination and fear of the unintended disclosure of an HIV positive status due to poor confidentiality at the clinic were identified as major barriers to testing. The fear of negative social outcomes of a positive HIV test can impede some persons from getting tested for HIV and therefore

contributes to challenges in delayed HIV testing and reduction of HIV disease burden.

CHAPTER 5: DISCUSSION OF RESULTS

5.1 INTRODUCTION

Early testing for HIV is an important measure that can be used to control the HIV epidemic. It is hoped that the findings of this study will provide insights into how to improve early HIV testing and therefore timeous diagnosis of HIV disease, which in turn will lead to early access to lifesaving ART before complications of HIV set in. Since the availability of ART, HIV has changed from being a terminal illness to a manageable chronic illness (Kamen *et al.* 2012: 1327). Timeous testing and diagnosis of HIV infection is the cornerstone of a successful ART programme, which will improve the quality of life and prolong the lives of HIV infected people. Delayed HIV testing refers to testing more than one year after HIV exposure and is referred to as a late HIV diagnosis (Nelson *et al.* 2010: 652).

5.2 OVERVIEW OF THE RESEARCH DISCUSSION

This study aimed to address the following objective:

- To explore factors influencing delayed HIV testing.
- To determine and describe factors influencing delayed HIV testing.

The results of this study have shed some light on the factors influencing delayed HIV testing. The findings in this study revealed that participants were sick but sickness did not make them seek HIV testing at the outset, instead delays took place. What was common amongst all participants in this study was that they all took a decision to test for HIV when they had serious illnesses that they associated with HIV. The discussion of the findings of this study will be based on the three categories and seven sub categories that emerged from the study, namely:

➤ **Category 1: Stigma and discrimination**

Sub categories: Denial related to a positive HIV status, People like to gossip, Fear of knowing HIV status, Judgement of people living with HIV, Non-disclosure of HIV status

➤ **Category 2: High risk behaviour**

Sub category: Unprotected sex and risky lifestyle

➤ **Category 3: Long waiting time:**

Sub category: Long queues and delays at the clinic

5.2.1 Stigma and Discrimination

Participants in this study demonstrated an awareness of the negative social consequences that follow a HIV positive diagnosis, where they had either heard of or witnessed social isolation and discrimination of people who had disclosed their status. However, when people anticipate that they will be discriminated against should it become known that they are HIV positive, the probability of accepting or opting for an HIV test is reduced (Ramirez- Avilla *et al.* 2012: 4). Stigma results in discrimination, which can be personalised by HIV positive people (dos Santos *et al.* 2014: 1).

Anticipated stigma due to an HIV positive status may explain why participants in this study feared taking an HIV test which resulted in delays in accessing health care. This is confirmed in a study conducted in China by Xiao *et al.* (2015: 80) who report that HIV positive individuals are stigmatised and blamed for getting themselves infected with HIV due to the public's beliefs that the HIV positive person's status is due to immoral acts such as having sex with different partners as well as drug abuse. These findings are substantiated by Moshabela *et al.* (2011: 80) who report that participants in their study reported that they were scared of testing for HIV because they did not want to

be treated badly and unfairly by their families, which resulted in delays in seeking care. This is in contrast to a study conducted by Ndida *et al.* (2007: 100), which found that families are supportive and sympathetic towards their HIV positive family members.

Stangl *et al.* (2013: 10) report that refusal of HIV testing and non-disclosure of HIV status to partners is due to stigma, people who have not disclosed their status to their partners are unlikely to practice safe sex and therefore they contribute to the spread of HIV. As Odimegwu *et al.* (2013: 2) explain, fear of stigma leads to low HIV testing rates for people who are in danger of HIV infection.

Discrimination due to being HIV positive was anticipated by participants in this study, which prevented them from testing for HIV timeously. The negative social impact of discrimination was perceived by some participants, which made them opt not to test. This is affirmed by a study conducted in Malaysia which found that positive social attitudes that are not discriminating towards HIV are associated with high levels of HIV testing, whilst discriminating attitudes are associated with low levels of HIV testing (Wong 2013: 1360).

Lack of confidentiality and privacy during HIV testing negatively affects HIV testing uptake (Ntsepe *et al.* 2014: 146). Participants in this study feared that the HIV test at the clinic was not confidential because there is a lack of privacy due to the systems that are being used by the clinic to sort patients, which make people who come for HIV services identifiable to others. The participants' interpretation was that if they came to the clinic for an HIV test, the result could be unintended disclosure of their HIV positive status that would subject them to isolation and discrimination. There are stigmatizing attitudes from health care staff that discriminate against HIV positive patients such as separating HIV patients from other patients and not respecting their rights to privacy (Philip *et al.* 2014: 1236). This is substantiated by a study conducted by French *et al.* (2015: 1043) in South Africa who explain that forced disclosure for patients who visited health facilities for HIV treatment was an unavoidable experience because HIV positive patients were issued a

black file, this identified them from other patients and predisposed them to stigma in the community.

5.2.1.1. Denial related to a positive HIV status

The first interview question aimed to determine how the participants came to a decision to test for HIV and whether they suspected they could be HIV positive before they took the test. Denial was found to be a strong indicator for delayed HIV testing. The main reason for HIV denial is the stigma that is associated with being HIV positive, it is possible that denial comes as a result of stigma, which can be real or anticipated (Ntoh Yuh *et al.* 2014: 582).

According to Livneh (2009: 44) denial is a coping mechanism, which assists the individual to adjust to a stressful situation, but prolonged denial can have a negative impact on health when it causes delays in necessary interventions. Denial helps people to psychologically adapt to unpleasant situations and it lowers stress levels and leads to better coping when the diagnosis is finally accepted (Livneh 2009: 44). Participants in this study used denial when they refused to accept that something was wrong with them and ignored the signs of their ill health.

The thought of testing produces fear in people when they think about the possibility of being HIV positive so they prefer to suspend the idea of testing. The fear of testing positive leads to denial where people keep telling themselves it can't be HIV that is causing them to be sick (Nelson *et al.* 2010: 652). When the risk of HIV infection is perceived to be low, for example in a person with a single partner and who does not engage in sex with that same partner often, HIV is the last thing to suspect and therefore even when such a person gets sick they do not associate their illness with HIV (Nelson *et al.* 2010: 653).

The absence of physical symptoms also contributed to some delays in testing by some participants, who reported that they had no signs of illness and therefore thought they were fine even when they discovered that they have

been with an HIV positive partner. This is consistent with research on delayed entry into HIV medical care conducted in the United States of America by Robertson *et al.* (2015: 7) who suggest that people delayed HIV testing for reasons such as feeling healthy, unwillingness to accept test results and not wanting to know about being HIV positive.

Some participants in this study avoided HIV testing; avoidance of HIV testing is strongly linked to denial because those participants who thought they were not sick and those who were at high risk for HIV infection avoided HIV testing. In contrast, people who regarded themselves as low risk for HIV infection are likely to avoid HIV testing and knowing their status (Lekalakala-Mokgele 2014: 72). Research conducted in Thailand to assess HIV testing behaviours of intravenous drug users concluded that avoidance of HIV testing amongst this group was due to fear of discrimination, feelings of shame and stigma (Ti *et al.* 2012: 2475). Avoidance of being stigmatised due to being HIV positive makes people who visit clinics hide their interest in HIV testing; they request services other than an HIV test and avoid having an HIV test, which unnecessarily increases the cost of health care (Young and Zhu 2012: 739) Wachira *et al.* (2014: 4) report, people do not want to attend dedicated HIV clinics since they find this stigmatizing as everyone will associate them with HIV if they get seen in these clinics by the people who know them. This is consistent with a study conducted in South Africa by Borgat *et al.* (2013: 845) which gives an account of distress and fear to accept an HIV positive status due to imagined stigma and anticipated community gossip when one's status gets known. Mothers who are HIV positive fear taking their children for an HIV test, they keep believing their child is negative and would only take the child for an HIV test only when they suffer from a severe illness; their actions are brought about by fear of being blamed for infecting the child and rejection following disclosure to family (Yeap *et al.* 2010: 1104).

5.2.1.2 People like to gossip

Participants in this study were concerned about being seen by people who knew them when they attended for HIV services, they feared they would be gossiped about in the community which would lead to discrimination against them. This contributed to delayed testing. Research suggests that HIV positive people reported incidents of gossip and verbal abuse due to the fact that they were HIV positive, some avoided going to the clinic when they needed to, because of fear of gossip about them (dos Santos *et al.* 2014: 8). A study conducted by Tom (2013: 5) reveal that some participants experienced domestic violence, relationship break ups and gossiping after they disclosed their HIV status.

5.2.1.3 Fear of knowing HIV status

Participants in the current study expressed fear of being diagnosed with HIV, this fear seemed to underlie denial, anticipated stigma and questionable confidentiality around the HIV test. There are two dimensions of fear that were experienced by participants in this study; the first one is their own personal fears towards being told they have HIV. As stated by Wong (2013: 1360), one of the reasons people avoid getting tested is the fear of testing positive. This is confirmed by Ntsepe *et al.* (2014: 143), who report that some people who are at risk for HIV infection fear testing HIV positive because they are afraid to accept a positive HIV status. Fear of testing HIV positive results in poor treatment seeking behaviour even when people see that they are sick (Seyoum and Legesse 2013: 8).

The second dimension of fear is strongly linked to the social effects of being HIV positive. It seems that fears of loneliness and rejection influence decisions to test for HIV; this was significant in some participants. Chimoyi *et al.* (2015: 2) propose that the decision to test HIV is strongly influenced by the perception of the impact of the results of the test, which bring about psychological threats associated with being HIV positive; people who expect ill treatment from family, friends and community when their status gets known are unlikely to test.

5.2.1.4 Judgement of people living with HIV

The findings of this study suggested that fear of being judged, isolated and discriminated against by family and the community made participants avoid early HIV testing. This shows that HIV positive people are subjected to judgement and discrimination in their communities. Similar findings were reported by Urgate *et al.* (2013: 170) who reveal that most participants thought HIV positive people should be ashamed of themselves and blamed them for getting themselves infected with HIV. Ugarte *et al.* (2013:170) also report that the community had insufficient knowledge of HIV, which the researchers thought to be an underlying reason for external stigma and discrimination by this community. Judgeo and Moalusi (2014: 81) state that HIV positive people are perceived by society as dirty and immoral and therefore must be avoided; little respect is given to HIV positive people.

5.2.1.5 Non-disclosure of HIV status

Participants in this study expressed the fear of disclosure of their status to families and significant others and as a result did not test for HIV when they thought about it. They waited and only took the test when their health was deteriorating due to illness. The reasons for non-disclosure as given by most participants were fear of the consequences of such disclosure; fears of being judged and isolated were seen as the most significant barriers preventing early HIV testing. This perception persists after knowledge of an HIV positive status, with some people not disclosing to their partners which results in poor engagement in care (Nakigozi *et al.* 2013: 6). This suggests that there is stigma attached to being HIV positive, which might be preventing people from disclosing their HIV status to significant others (French *et al.* 2015: 1043). This is consistent with the literature, which indicated that non-disclosure of HIV status is a useful way of controlling stigma, for some HIV positive individuals (Judgeo and Moalusi 2014: 81). Paintsil *et al.* (2015: 18) expand on the issue of disclosure; parents who are HIV positive fear disclosing their status to their children because they want to keep their status a secret and

they fear that children will reveal their status to other people and they will be subjected to isolation and rejection. Most people perceived discriminatory reactions from partners, neighbours, friends, colleagues, employers, if they were to disclose their HIV status to them (dos Santos *et al.* 2014: 9). Single and divorced people find it hard to disclose their status to partners because of lack of security in their relationships and uncertainty of how the partners will react to such news; disclosure is higher in those who are married and those cohabitating (Tom 2013: 5).

HIV positive patients will in the course of their lives require ART; HIV and AIDS stigma adversely affects adherence to ART when patients default on taking their medication because they fear disclosure if they are seen taking medication (Katz *et al.* 2013: 19). Stigma and discrimination can hamper disclosure of HIV status to families and significant others and can prevent access to health care services (Rispel *et al.* 2015: 16).

5.2.2 High risk behaviour

Conroy (2015: 11) found that timing of an HIV test was influenced by fear of testing HIV when a positive HIV status was suspected. Participants who knew they were at high risk of HIV feared an HIV test and knowing their status. A study conducted in Malawi concluded that men who identified themselves as likely to be HIV positive reported low levels of HIV testing (Conroy 2015: 11). Perceived high risk to HIV infection seems to cut across other categories; participants who perceived themselves as at risk for HIV also experienced denial and stigma.

5.2.2.1 Unprotected sex and risky lifestyle

It was clear that a majority of participants feared HIV testing because they suspected they were HIV positive due to previous risky sexual behaviours, they recognised the symptoms of illness that they had could be due to HIV or they became aware that their partners had AIDS or had died of AIDS. In

keeping with the literature, HIV testing rates are low in individuals who perceive themselves at risk, such as those who engage in sex with multiple partners and those with a history of sexually transmitted illnesses (Lee *et al.* 2015: 6). This is consistent with the study conducted in Ethiopia on HIV testing behaviours of students aged between 15 and 24 years (Sisay *et al.* 2014: 9). This study report that students who perceived themselves as high risk reported low levels of HIV testing. Historically high-risk sexual behaviour does not encourage HIV testing (Johnston *et al.* 2010: 928).

5.2.3 Long waiting time for service in the clinic

Reducing waiting times through the management of queues is one of the priority areas of the South African Health National Core Standards (Department of Health 2011b: 7). Long waiting times in clinics result in patient dissatisfaction and decreased compliance to HIV treatment (Deo *et al.* 2012: 5; Muchedzi 2010: 5). Some of the participants cited long waiting time and long queues in the clinics waiting to have an HIV test as contributing to delayed testing. Waiting too long for a service at a health facility contribute to patients leaving without a service or postponing the elements of a service which they think could cause even more delay. In some cases this meant leaving without the HIV test. This is consistent with the findings of the studies of Kwapong *et al.* (2014: 8) and Atnafu *et al.* (2015: 1) which report long waiting time for services as a barrier to people accessing HIV services including HCT and follow up care. In pregnant women the lengthy waiting period made them feel exhausted and compromised the chances of having an HIV test (Kwapong *et al.* 2014: 8).

5.2.3.1 Long queues and delays at the clinic

Efficiency of the health service depends on how quickly the health service providers attend to patients; participants in this study expressed their dissatisfaction caused by long queues, which resulted in delays at the clinic. Insufficient staff that is unable to cope with the large numbers of patients that

visit health facilities contributes to patient dissatisfaction due to delays in accessing health care (An *et al.* 2015: 15; Yeap *et al.* 2010: 1103). Some people who do not present themselves for health care services do so to avoid being absent from work and losing their jobs due to spending hours at the clinic, this leads to missed opportunities for early HIV testing (Fox *et al.* 2012: 1243). There is a need to train and support staff on clinic organization and management of queues to prevent patients from sitting in long queues for lengthy periods (Yeap *et al.* 2010: 1105). Integration of HIV services into routine care of patients could limit the time patients spend in the clinic and would encourage early HIV testing (An *et al.* 2015: 2). Queue minders must be made available at clinics to assist patients where to sit in the queues and to keep informing them how long they can expect to wait in queues this would avoid time wasted while in a wrong queue and allay anxiety to patients (Borgat *et al.* 2013: 852).

5.3 CONCLUSION AND SUMMARY

This study has identified some factors influencing delayed HIV testing. All the participants saw HIV testing as important although going through with it was avoided and taken only in desperation due to ill health. As reported in this study HIV related stigma remains a barrier to efforts to prevent new HIV infections and affects optimal access to HIV intervention services. HIV positive people are confronted by a less welcoming world, they experience rejection by families, friends and community. This contributes to the non-disclosure of an HIV status, engagement in unsafe sex, self-isolation and poor health care seeking behaviours.

Health is a basic human right, everyone should be afforded an opportunity to receive health care in an environment that does not pose any psychological threat to one's privacy; this calls for improved efforts to limit stigma and discrimination experienced by people living with HIV. A safe and supportive environment that allows people to freely access HIV testing without fear of being discriminated against must be created both in the home, community

and health service institutions. HIV testing messages, which contain adequate information about the disease, must be continuously accessible to everyone as part of encouraging people to test and limit stigma directed at HIV positive people. Adequate knowledge can eliminate fear and the psychological consequences of being HIV positive through education and empowerment of communities. Continuous engagement with communities at community forums and through their leaders on HIV related matters must take place to improve community support and acceptance of people living with HIV.

Timeous HIV testing and HIV disclosure to partners and safer sex will lead to success in the management of HIV and AIDS and reduce new HIV infections when HIV transmission is prevented and the pool of HIV positive people in communities is reduced. All participants in this study had the correct information on how HIV is transmitted but the importance of addressing sexual risk behaviours was ignored. In this regard, health education on prevention of transmission and behavioural change must continue.

The decision to test for HIV appears to be strongly reliant on the support that people have or anticipate to have, and the perceptions of other people around them regarding HIV and the health status of the individual. In other words the absence of fear of stigma and discrimination is important to prevent HIV denial and encourage people who are at risk to test HIV, know their status and access lifesaving ART.

5.4 RECOMMENDATIONS

5.4.1 For individuals

For every individual to access the necessary HIV prevention, care and treatment, they need to test HIV and know their status. Good health status is personal wealth; individuals have a personal responsibility to take care of their own health for the benefit of themselves and the benefit of those that they care about. It is a responsibility of an individual to seek health care screening

before sickness sets in, and continue to monitor own status at least once a year. HCT services are accessible at all health care settings, including pharmacies and mobile points. Individuals must use the HIV information they receive from different sources to make decisions to test HIV. Self-HIV testing can also be done if preferred and provides convenient testing at a place and time the individual prefers. Stigma directed to self must be dealt with to overcome fear of testing and knowing HIV status. The benefits of knowing HIV status must overcome perceived threats of knowing HIV status. To overcome fear of disclosure of HIV status, couples can opt to access HCT together to enable partners to learn their status at the same time, which encourages partner support.

5.4.2 For families

This study has explored different roles that families play to facilitate or discourage HIV testing. Discrimination and judgment of family members who are living or suspected to be living with HIV must be eliminated to encourage HIV testing. Families must engage in talks about HIV and these talks must be in a constructive manner that does not discriminate and encourage each member to know their own status. Each individual must be made to feel free to talk about their HIV status with family members without fear of being gossiped about and judged. Families must accept and provide support for family members who are HIV positive and avoid blaming them. People who feel accepted by the people they care about are likely to take care of their own health, adhere to treatment and prevent infecting others.

5.4.3 For communities

People fear being judged and isolated in their communities should they be known or suspected to be HIV infected. Community members must aim at reducing stigma and discrimination against people living with HIV. Gossiping about people with HIV must be avoided, communities must treat HIV not differently to any other chronic disease that require treatment to be kept under control. Community dialogues must take place either in the health facility or at

community levels at regular intervals and HIV must be included in the discussions to allow opportunities to share information about HIV, mode of transmission, prevention, treatment and care and to encourage community members to test and know their status. HIV positive people must be made to feel accepted in their communities and be treated the same as any other individual, isolation of people living with HIV must be avoided. Community members must stand against any discrimination directed to anyone because of their HIV status. Individual rights and privacy must be promoted through community education to encourage people to respect each other's privacy.

5.4.4 For traditional leaders

Traditional leaders can play an important role in dealing with AIDS related stigma and to encourage people to test HIV. People respect their traditional leaders and are likely to listen to advice from them. Traditional leaders should encourage HIV testing in their communities and support the department of health initiatives that are directed at HCT, such as mass HIV testing campaigns. Traditional leaders must support these campaigns by promoting them to their people and encouraging people to attend. HCT should form part of the agenda and discussion during community meetings that are facilitated by traditional leaders. Health care workers must be invited to attend meetings called by the traditional leaders and be given a slot to talk on HCT, benefits of testing and give information on how to access HIV prevention care and treatment services

5.4.4 For health care workers

To fight stigma and discrimination individual privacy and human dignity must be preserved at all times. Health service institutions must eliminate separate queues for HIV infected people and implement a similar client record folder for every client to avoid unintended or forced disclosure of HIV status.

Scaling up of home testing will reduce the need to come to the clinic for HIV testing and will improve HIV testing of people who live far from the clinic and

make HIV testing accessible even to people who are not seeking medical care. Health care workers must form teams that regularly go to communities to offer home HIV testing as well as HIV testing at mobile sites based at community levels, to reach out to individuals that cannot access clinics. AIDS stigma affects utilisation of HIV services. To eliminate stigma HIV testing must always be included and offered to all individuals who come for general health screening for disease such as diabetes, hypertension and cholesterol. Strengthen health education to improve HIV knowledge and discourage social isolation of HIV positive individuals.

Reduce waiting time and delays in receiving care, which has a negative impact when people do not access HIV testing if they are unable to wait for a long time in the queues. Facilitation of screening and fast tracking of patients when they visit clinics and the maintenance of fast queues for services that do not require people to wait for long must be strengthened; this is a requirement by the Department of Health i.e. health service reorganization using the ideal clinic model (Department of Health 2015b). Promote and maintain good relationships with client to make it easy for clients to discuss sensitive issues pertaining HIV. Good provider- client relationship will facilitate acceptance of HIV testing in a welcoming stress free environment.

5.4.5 For health service managers

Health service managers have a duty of managing resources allocate to them, this includes human resources. It is a duty of health service managers to analyse working conditions and facilitate equal distribution of staff in such a way that all areas of the health facility are covered, which will promote teamwork and prevent some staff from being more overworked than others. In-service training of staff must include implementation of HIV policies and the role that staff should play in promoting and improving access to HIV testing. This will overcome health service provider barriers to HIV testing, staff should be made to understand, through in-service training that HCT services form part of their work and is not an added burden. Staff is the driver of HCT in health care settings, motivation and staff retention strategies must be utilised

to make sure that competent staff are available to offer HCT services. Staff involvement and input must be taken into consideration when planning the rollout HCT services to promote staff commitment and satisfaction. Services must be available to offer support of staff who care for people living with HIV should they become emotionally affected

5.4.6 For policy developers

The overarching theme that emerged in this study pertains to how clients perceive HIV testing. Anticipated consequences of testing HIV make people fear testing and choose to avoid taking the HIV test until they realise they have no option but to test in order to access treatment, in some cases this decision is taken too late and death from HIV related complications becomes unpreventable. To inform policy review on HIV testing without violating human rights, it could be considered to make HIV testing part of health screening for every individual that seeks health care when the individual gives a verbal consent. The health care system requires more human resources to meet the requirements of testing everyone, the future policy can look at training and retaining more counsellors that will be responsible to provide HCT this could make HCT services sustainable at facility and community levels.

5.4.7 Closing remarks

In summary, to encourage early HIV testing before HIV positive people become remarkably ill requires efforts directed at a change of attitudes and behaviours as well as improving support of HIV positive people in the families, communities and health service institutions. Individuals must be motivated to become responsible for their own health. Stigmatising activities must be avoided at health care service institutions. Communities must play a more active role to fight the HIV epidemic. Community forums and community organisations must be actively involved in eliminating stigma and discrimination directed towards HIV positive people by creating awareness of HIV related stigma and encourage community and family support for people with HIV. Health care policy developers must use the latest evidence to inform

the review of HIV policies. It is hoped that these efforts will encourage more people to test for HIV and know their status, which will reduce HIV/ AIDS related mortality and morbidity and the HIV disease burden in the country.

5.5 LIMITATIONS OF THE STUDY AND SUGGESTIONS FOR FURTHER RESEARCH

This study sample only included people who delayed HIV testing, other HIV positive people outside these criteria were excluded and therefore factors that influence early HIV testing were not identified. The exclusion of this group of people might have denied the study some insights that could be important in identifying other factors related to delayed HIV testing. The study has identified factors influencing delayed HIV testing according to the client perspective and did not include identification of factors according to the perspective of health service providers; there might be valuable input that could have been obtained should the research have included health service providers as well.

Further studies are needed to identify factors that influence HIV testing in all groups of people to encourage a holistic approach to the improvement of HIV testing for all.

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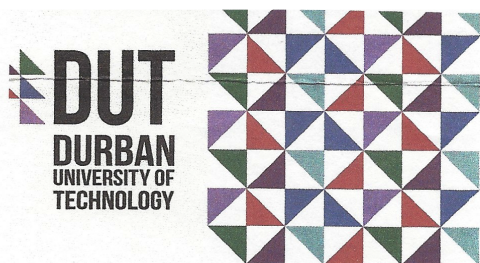
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APPENDICES

Appendix 1: University Ethics Clearance



Institutional Research Ethics Committee
Faculty of Health Sciences
Room MS 49, Mansfield School Site
Gate 8, Ritson Campus
Durban University of Technology

P O Box 1334, Durban, South Africa, 4001

Tel: 031 373 2900
Fax: 031 373 2407
Email: lavishad@dut.ac.za
http://www.dut.ac.za/research/institutional_research_ethics
www.dut.ac.za

26 September 2014

IREC Reference Number: **REC 52/14**

Ms S T Chonco
13 Rose Crescent
New Germany
3610

Dear Ms Chonco

Factors influencing delayed HIV Testing: A Client Perspective

I am pleased to inform you that Full Approval has been granted to your proposal REC 52/14.

The Proposal has been allocated the following Ethical Clearance number **IREC 069/14**. Please use this number in all communication with this office.

Approval has been granted for a period of one year, before the expiry of which you are required to apply for safety monitoring and annual recertification. Please use the Safety Monitoring and Annual Recertification Report form which can be found in the Standard Operating Procedures [SOP's] of the IREC. This form must be submitted to the IREC at least 3 months before the ethics approval for the study expires.

Any adverse events [serious or minor] which occur in connection with this study and/or which may alter its ethical consideration must be reported to the IREC according to the IREC SOP's. In addition, you will be responsible to ensure gatekeeper permission.

Please note that any deviations from the approved proposal require the approval of the IREC as outlined in the IREC SOP's.

Yours Sincerely

Prof J K Adam
Chairperson: IREC

Appendix 2a: Permission letter to the eThekweni Municipality Health Unit

13 Rose Crescent

New Germany

3610

25 March 2014

The eThekweni Health Unit Research Committee and Management

9 Archie Gumede Place

Durban

4000

Dear Sir or Madam

**RE: REQUEST FOR A PERMISSION TO CONDUCT A RESEARCH STUDY
AT WYEBANK CLINIC**

I hereby kindly seek permission to conduct a research study at Wyebank Clinic. Presently I am registered as a Master of Technology student at the Durban University of Technology in the Department of Community Health Studies, Nursing Programme. The proposed title for my study is: **Factors Influencing Delayed HIV Testing: A Client Perspective.**

This study is aimed at identifying factors that lead to delayed HIV testing in a sample of patients who are newly diagnosed HIV positive who have a first CD4 count of 350/mm³ and below. The main objective of this study is to identify barriers to HIV testing which will inform plans to improve implementation of HIV Counselling and Testing Policy Guidelines. Descriptive qualitative study using content analysis will be applied. Semi structured interview method of data collection using an interview schedule will be conducted. I have attached with this letter my research proposal for your review.

I look forward to your favorable response.

Thank you.

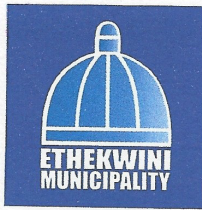
Yours Sincerely

Student: Ms. Siziwe Chonco

Supervisor: Ms. Penelope Margaret Orton (M Nursing)

Co-Supervisor: Dr. Ayisha Razak (PhD)

Appendix 2b: Approval letter from the eThekweni Municipality Health Unit



HEALTH UNIT

9 Archie Gumede Place, Durban, 4001
P O Box 2443, Durban, 4000
Tel: 031 311 3523, Fax: 031 311 3530
www.durban.gov.za

Dear Mrs S. Chonco

20 October 2014

Subject: Approval of a research proposal.

The research proposal titled: **Factors Influencing Delayed HIV Testing: A client perspective**, was reviewed by the eThekweni Municipal Health Unit Research Committee and the **approval is hereby given**.

The following to be noted:

- Submission of the indemnity form obtainable from the eThekweni Municipality Health Unit before commencement of the study.
- Prior arrangements to be made with the facility and an assurance that all services will not be disrupted.
- No staff member should be used for collecting data for the researchers.
- **Progress reports to be provided and the final report of the study to the eThekweni Municipality Health Unit or emailed to: grace.mufamadi@durban.gov.za**
- Obtain permission from the eThekweni municipality Health Unit for press releases and release of results to communities/stakeholders.
- The Unit has to receive recognition for the assistance given.
- Any amendment to the study to be communicated with the eThekweni Municipality Health Unit and the relevant amendment form obtainable from the unit to be submitted.
- Withdrawal of permission to conduct research will be left to the discretion of the eThekweni Municipality Health Unit.

Yours faithfully

[Redacted Signature]

Signature: [Redacted Signature]

Deputy Head for Health Unit

Date: 20.10.2014

Appendix 3a: Letter of indemnity from the eThekweni Municipality Health Unit

No. M.1/1/2

Director : Health
Box 2443
DURBAN
4000

Researcher- Name: Siziwe Chonco
Institution- Name: DUT
Institution- Address: Steve Biko Campus,
Dept. of Nursing, Durban

Research Subject: Factors Influencing
Delayed HIV Testing! A Client Perspective

Dear Sir/Madam

RESEARCH SITE : ETHEKWINI MUNICIPALITY HEALTH DEPARTMENT

I, the undersigned, hereby wish to apply for permission to attend the eThekweni Health Department to undertake research on Council property.

I understand that any permission granted to me will be subject to:

- (a) there being no additional cost to the Council; and
- (b) the exigencies of the eThekweni Health Department, and provided that no interference with its programme will ensue.

In consideration of the facilities given and to be given to me by the eThekweni City Council, as aforesaid, I hereby indemnify the said Council and its officers and hold it and them harmless against and hereby waive, renounce and abandon any claim for damages or compensation arising from injury or loss which I may sustain whilst on Council property or transport or on the way to or from any Council property or place of research or which I may sustain in any way whatsoever whilst conducting research.

I further indemnify the eThekweni Council and its officers against any claim whatsoever which may in any way result from the facilities afforded to me and be brought against the said Council or its officers.

Date: 24. 10. 2014

[Redacted Signature]
Researcher's Signature

Witness: [Redacted Signature]

[Redacted Signature]
Researcher's Name (in capital letters)

Permanent Address:

13 Rose Crescent, New Germany, 3610

Period

From: November 2014 to January 2015

Appendix 3b: Acknowledgement of research conditions from eThekweni Municipality Health Unit



Health Unit

ACKNOWLEDGEMENT OF RESEARCH CONDITIONS:

I _____ undertake to comply to

EThekwini Municipality Health Unit's conditions for the study, as stipulated in the permission letter.

Name and signature of principal investigator:

Name [REDACTED] Signature: [REDACTED] Date 24.10.2014

Name and signature of other researchers:

Name: _____ Signature: _____ Date: _____

Name: _____ Signature: _____ Date: _____

Name: _____ Signature: _____ Date: _____

Name: _____ Signature: _____ Date: _____

Appendix 4a: Letter of information and consent



LETTER OF INFORMATION

I greet you and thank you for participating in this study

Title of the Research Study: Factors influencing delayed HIV Testing: A Client Perspective.

Principal Investigator/s/researcher: Siziwe Chonco (Bachelor of Nursing Science)

Co-Investigator/s/supervisor/s: Penny Orton (M Nursing) & Dr Ayisha Razak (PhD)

Brief Introduction and Purpose of the Study: You are invited to participate in a research study that explores the reasons behind delayed HIV testing.

Outline of the Procedures: Your participation in this study requires an interview during which you will be asked your experiences regarding HIV testing and what brought you to test when you did. The interview will take approximately 45 minutes to an hour. With your permission the interview will also be audio taped and transcribed with the purpose of gathering accurate information on the interview.

Risks or Discomforts to the Participant: I do not anticipate any harm or discomfort to come to you.

Benefits: The results of this research will hopefully improve the practices in health care to benefit patients. The researcher will get an opportunity to publish an article based on the results of the study to benefit other health care professionals.

Reason/s why the Participant May Be Withdrawn from the Study: Your participation in this research is voluntary. You may withdraw at anytime during the research if you wish to do so and your care will not be jeopardised because of such decision.

The researcher may withdraw you at any time from the research at her professional discretion.

Audiotaping is part of this research. Your signature means that you agree to participate in this study.

Remuneration: There will be no remuneration or financial benefits for

participation in this study.

Costs of the Study: They will be no cost to you as a participant in this study.

Confidentiality: The interview will be kept strictly confidential and your name will not be used anywhere in the recordings, a code will be allocated to identify information, for data analysis purposes only and the data will be securely stored. The information obtained will be used for study and professional purposes only.

Research-related Injury: There are no anticipated risks to you as a person. However if it happens that during the interview you experience emotional discomfort, counselling by a trained counsellor will be arranged for you.

Persons to Contact in the Event of Any Problems or Queries: Please contact the researcher (tel. no. 0313113536), my supervisor (tel. no. 0313732537) or the Institutional Research Ethics administrator on 031 373 2900. Complaints can be reported to the DVC: TIP, Prof F. Otieno on 031 373 2382 or dvctip@dut.ac.za.



CONSENT

Statement of Agreement to Participate in the Research Study:

I hereby confirm that I have been informed by the researcher, Mrs Siziwe Chonco, about the nature, conduct, benefits and risks of this study - Research Ethics Clearance Number: _____, I have also received, read and understood the written information regarding the study. I am aware that the results of the study, including personal details regarding my sex, age, date of birth, initials and diagnosis will be anonymously processed into a study report. In view of the requirements of research, I agree that the data collected during this study can be processed in a computerised system by the researcher. I may, at any stage, without prejudice, withdraw my consent and participation in the study. I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study. I understand that significant new findings developed during the course of this research, which may relate to my participation will be made available to me.

Full Name of Participant Date Time Signature / Right Thumbprint

I, S.T Chonco herewith confirm that the above participant has been fully informed about the nature, conduct and risks of the above study.

Siziwe Chonco

Full Name of Researcher

Date

Signature

Full Name of Witness (If applicable)

Date

Signature

Full name of Witness (If applicable) _____

Date

Signature

Isandiso 4b: Incwadi yokunika ulwazi nesivumelwano



INCWADI YOKUNIKA ULWAZI

Sawubona,

Ngiyabonga kakhulu ngokuthi ube ingxenye yalolucwaningo.

Isihloko socwaningo: Izizathu ezingaba nomthelela ekwephuzeni ukuhlololwa igciwane lesifo sengculazi.

Umcwaningi omkhulu: Ms S. Chonco (Bachelor of Nursing Science)

Ababheke Umcwaningi: Ms P. Orton (M Nursing) noDokotela A. Razak (PhD)

Isingeniso: Ngicela ukukwazisa ngocwaningo engizolwenza kulomtholampilo olumayelana nokukhulumisana nabazobamba iqhaza kulolucwaningo ngenhloso yokuthola izimo ezibangele ukuthi ukuhlololwa kwabo igciwane lengculazi kubambezeleke.

Inhloso yocwaningo: Inhloso ngqangi ukuba ngithole ukuthi kungani izinga lokuhlololwa igciwane lengculazi lingafinyeleli kulelo elifunwa uhulumeni wezempilo. Ekugcineni ngizosebenzisa imininingwane engiyitholile ukuqwashisa ozakwethu kwezempilo ngalokho okutholakele ukuze nabo bathole ulwazi oluzobasiza lapho benza izinhlelo zokuhlola abantu igciwane lengculazi.

Uhlaka lokuzokwenziwa: Ukuhlala nawe sikhulume kabanzi ngalesihloko ngenhloso yokuthola ulwazi kuwena. Isikhathi esingasichitha singaba phakathi kwengxenye yehora nesigamu kuya kwihora elilodwa. Ngicela ufunde lencwadi uyizwe ubuze kumcwaningi uma ungaqondi kahle bese ushicilela isivumelwano sokuvuma ukuthi uyathanda ukuba ingxenye yocwaningo ngokuba kukhulunywe nawe futhi kuqoshwe inkulumo phakathi kwakho nomcwaningi.

Amathuba okungaphatheki kahle: Awekho amathuba okuzizwa ungasaphathekile kahle, ngoba ngizokhuluma nawe kuphela ngeke ngikwenze lutho.

Inzuzo: Ayikho inzuzo ngaalolucwaningo ezotholwa nguwe kodwa imiphumela yalolucwaningo ingasiza abasebenzi bezempilo nabaphathi babo ngolwazi abangalusebenzisela ukuthuthukisa izinhlelo zokuhlolwa kwalabo okumele bahlolwe igciwane lengculazi.

Isizathu sokuhoxiswa kulolucwaningo: Ungakwazi ukunqaba ukukhuluma nami noma ukuqoshwa kwenkulumo. Futhi lokho ngeke kube ngemiphumela engaba mibi kuwena.

Iholo: Ayikho imali etholakalayo ngokuba ingxenye yocwaningo.

Izindleko zocwaningo: Zonke Izindleko zocwaningo zibhekene nami njengomcwaningi, akukho lutho obhekeke ukuthi ulukhokhe wena.

Imfihlo: Amagama awuzusetshenziswa kulolucwaningo. Ngizoba nendlela eyimfihlo yokukhombisa ukwehlukana kwababambe iqhaza kulolucwaningo njengokubhala inombolo esikhundleni segama.

Ukulimala okungenziwa ucwaningo: Akukho kuhlawulwa ukulimala okungenziwa ucwaningo njengoba ngizobe ngikhuluma nawe kuphela kungekho lutho oluzokwenziwa kuwena. Uma uzizwa uba nokuphazamiseka ngokomoya emva kokuphendula imibuzo nokukhuluma nami nizozama ukukweluleka , uma kunesidingo ngizokwedlulisela kumeluleki oqeqeshiwe ukuze akusize

Ongabathinta uma kunenkinga noma kukhona ofuna ukukubuza:

Thintana nami uNks S. Chonco kulenombolo yocingo 031 3113536 noma abaqaphi bocwaningo u Ms P. Orton kulenombolo (0313732537) Dokotela A. Razak kulenombolo (031 2691322) noma ikomidi eliphakeme lokubhekele ukuvikeleka kocwaningo kulenombolo 031 373 2900.

Okuvulelekile: Uma uvuma ukuba ingxenye yocwaningo ngicela ukuthi usayine imvume.



ISIVUMELWANO

Isivumelwano sokuba yingxenye yocwaningo

- Nginyaqinisekisa ukuthi ngitsheliwe Umcwangingi u_____ (igama lomcwangingi), ngendlela yokuqhutshwa kocwaningo, inzuzo nokuphathelene nokungaphephi kwalolucwaningo – Inombolo yemvume yekomiti:_____.
- Ngitholile futhi, ngafunda ngazwisisa incwadi yolwazi engaphezulu (Incwadi yabazongenela ucwaningo) ngalolucwaningo.
- Ngiyazi ukuthi imiphumela yalolucwaningo, kanye nakho konke okuqondene nami njengobulili, iminyaka, usuku lokuzalwa, iziqalo zamagama ami kuzogcinwa kuyimfihlo embikweni kulolucwaningo.
- Ngokubhekelela izidingo zalolucwaningo, ngiyavuma ukuthi ulwazi oluzoqoqwa kulolucwaningo luqoshwe ukuze lulalelwe umcwangingi lapho esebhala. Umcwangingi angalufaka ku khomputha ukuze athole imiphumela.
- Ngingaphuma kulolucwaningo, ngigodle imvume, nokuba ingxenye yalolucwaningo noma kunini ngaphandle kokuthola ukungaphatheki ngendlela.
- Ngibe nethuba elanele lokubuza imibuzo (ngokuzivumela mina ngingaphoqwanga) ngiyazinikela ukuthi ngikulungele ukuba ingxenye yalolucwaningo.
- Nginyaqonda ukuthi imiphumela ezotholakala ngenxa yalolucwaningo ephathelene nokuzinikela kwami ukuba yingxenye yalo ngiyokwazi ukuyithola.

Amagama omhlanganyeli	Usuku	Isikhathi Ukusayina

Mina _____ (umcwaningi) ngiyaqinisekisa ukuthi umhlanganyeli obhalwe ngenhla wazisiwe mayelana nohlelo lwalolucwaningo, nendlela oluzokwenziwa ngayo ngokunjalo nobungozi obungaba khona

Amagama omcwaningi	Usuku	Ukusayina

Amagama ofakazi (Uma bedingeka)	Usuku	Ukusayina

Amagama ofakazi (Uma bedingeka)	Usuku	Ukusayina

Appendix 5a: Interview schedule



Interview Schedule with the aim of exploring Factors influencing delayed HIV Testing: A Client Perspective

The following questions will be used to guide the interview

Demographic information:

Gender:	Age:	Employment status:	Level of school education:	Married, Single, Living with a partner or Widowed (choose the applicable)

- Tell me about how your decision to test for HIV came about?
- Did you suspect that you might be HIV positive before taking an HIV test?
- If the above answer is yes, what was it that made you think that you might be HIV positive?
- Have you considered or thought of testing for HIV before now?
- If the above answer is yes, what made you not to test then?
- Are you comfortable speaking about your HIV status with your family or partner? If not, why?
- What are your beliefs about HIV / AIDS and its transmission from one person to another? Did these beliefs stop you from testing for HIV until now?
- Did you consider yourself at risk of having HIV? What made you think you were or not at risk of HIV infection?

The opening question may provide all the answers to cover scheduled questions that will follow, however probes will be used depending on the patient's response to questions. As the participant answers, the researcher will note coverage of the scheduled questions.

Appendix 5b: Uhlelo lokuxoxisana



Uhlelo lokuxoxisana ngezizathu ezingaba nomthelela ekwephuzeni ukuhlolwa igciwane lesifo sengculazi.

Lemibuzo elandelayo izosetshenziselwa ukuqondisa inkulumo

Ulwazi ngendabuko yakho:

Ubulili:	Iminyaka:	Isimo ngokomsebenzi owenzayo:	Izinga lemfundo esikoleni:	Ushadile, awushadile, unomasihlalisane, umfelwa noma umfelokazi (khetha okuyikona)

- Kungabe ufike kanjani kulesinqumo sokuza uzohlola igciwane lengculazi?
- Ubuke waba nako ukusola ukuthi unalo leligciwane?
- Uma impendulo engenihla ivuma, yini ekwenze wacabanga ukuthi unalo igciwane lengculazi?
- Uke wakufikela umcabango wokuhlola leligciwane ngaphambilini?
- Uma impendulo engenihla ivuma, yini eyakwenza wazindela?
- Ukhlulekile ukukhuluma ngengculazi nomndeni wakho noma ohlekisana naye? Uma kungenjalo, kungani?
- Ngokwazi kwakho ingabe igciwane lengculazi lithetheleka kanjani lisuka kumuntu liya komunye? Inga lezinkolelo onazo zikwenze wazindela ukuhlolwa leligciwane?
- Uke wacabanga ukuthi kungenzeka ukuthi unalo igciwane lengculazi? Uma kunjalo noma kungenjalo, kungani?

Umbuzo wokuqala ungenza imibuzo elandelayo iphenduleke ,noma kunjalo imibuzo ingahlolisiswa ukuze kutholakale ulwazi olunzulu. Ngesikhathi umhlanganyeli ephendula umcwangingi uzobe ecubungulisa ukuphenduleka kwayo yonke imibuzo.

Appendix 6: Editing certificate

DR RICHARD STEELE

BA, HDE, MTech(Hom)

HOMEOPATH and EDUCATOR

Registration No. A07309 HM

Practice No. 0807524

Freelance academic editor

110 Cato Road

Glenwood, Durban 4001

031-201-6508/082-928-6208

Fax 031-201-4989

Postal: P.O. Box 30043, Mayville 4058

Email: rsteele@telkomsa.net

EDITING CERTIFICATE

Re: **Siziwe Teressa Chonco**

Master's dissertation: **FACTORS INFLUENCING DELAYED HIV TESTING: A
CLIENT PERSPECTIVE**

I confirm that I have edited this dissertation and the references for clarity, language and layout. I am a freelance editor specialising in proofreading and editing academic documents. My original tertiary degree which I obtained at UCT was a B.A. with English as a major and I went on to complete an H.D.E. (P.G.) Sec. with English as my teaching subject. I obtained a distinction for my M.Tech. dissertation in the Department of Homeopathy at Technikon Natal in 1999 (now the Durban University of Technology). During my 13 years as a part-time lecturer in the Department of Homeopathy I supervised numerous Master's degree dissertations.

Dr Richard Steele

31 January 2016

electronic

Appendix 7: Transcribed interview

**RESEARCH TOPIC: FACTORS INFLUENCING DELAYED HIV TESTING: A
CLIENT PERSPECTIVE**

QUALITATIVE INTERVIEW TRANSCRIPT

PETER (PSEUDO NAME)

DATE OF INTERVIEW: 04. 11. 2014

GENDER: MALE

AGE: 26 years

EMPLOYMENT STATUS: Unemployed

LEVEL OF EDUCATION: Matric

MARITAL STATUS: Single

METHOD USED: Semi-structured interview

Researcher: Tell me about how your decision to test HIV came about?

Peter: I was sick and each time I attended the clinic nurses were always asking me to test, I kept on lying to them several times, telling them I have tested before and was negative but the truth was, I had never tested. I even changed my previous clinic (named the clinic) to this one because I was trying to run away.

Researcher: What made you lie to the nurses about knowing your status?

Peter: I did not want to test because I did not want to know if I was positive. I was scared of what people will say when they know I am HIV positive. I have seen people with AIDS and have heard people judging them. I asked myself, if it was me what would people say, what will my children say, no, I did not want to know. I was scared of knowing and also of telling my family especially my mother. I did not want my family to judge me. My mother always gave me advise about things that will make me get HIV,(a sigh), she warned me about changing girls frequently. I know my mother must know my HIV positive status because even if I die she will have to bury me but I don't know how to tell her, even when I get sick she will help me. My biggest fear was being judged by

people once they know I am HIV positive so I did not want to know. Even to this day I'm scared of how I will tell my mother.

Researcher: Have you disclosed your status to anyone?

Peter: Yes my girlfriend knows what is going on, she is the one who forced me to test after she had tested positive. She did test the first time and was negative, after a while she tested for the second time and she then tested positive, that's when she insisted I must also test.

Researcher: Did you use condoms?

Peter: There is an element of trust involved, you just feel you can trust the person. I can say she got the disease from me because it wasn't long after we stated dating that she got tested and discovered that she had nothing so yes we did not use a condom. After a long while she went to check and found that she had the disease, which is when she asked me to go and test.

Researcher: Did you suspect that you might be HIV positive before taking an HIV test?

Peter: (Uhm..) No I did not suspect anything and at the time when I checked I did not think I had it, it's just that I was sick. I decided to check so I can clear my mind; I finally accepted I might have HIV. I then tested as suggested repeatedly by others; I stopped being scared. Deep down I suspected I might have the disease. I saw many things happen to others, when they discover they have the disease some commit suicide before even taking pills that also made me scared. You know, recently in July at my neighbourhood, gentlemen hanged himself with an electric kettle cord after being told he is HIV positive at the clinic and committed suicide.

Researcher: What do you think make people kill themselves after knowing they are HIV positive?

Peter: I wouldn't know it must be that they are not brave. I would never kill myself even now when I know my status, I will think about my children. I have eight children with different mothers and I don't get along well with their mothers.

Researcher: What are your beliefs about HIV /AIDS and its transmission from one person to another? Did these beliefs stop you from testing for HIV until now?

Peter: I think its sex and no other. It's this trust issue, I used to trust them and when your partner is pregnant she will definitely check and when they say they have nothing you also tell yourself you also have nothing.

Researcher: How do you if know your partner is telling you the truth?

Peter: When they go get tested and they tell me their results came back negative I believed them. They would not hide it because of the pregnancy, obviously if they are pregnant and have the virus, the baby will also get it, that's what I told myself and I knew that if the baby is born and they give it something for the virus, I would notice.

Researcher: Did you ever consider yourself at risk of having HIV? What made you think you were or not at risk of HIV infection?

Peter: Yes I did, as I grew up as a person who liked women a lot, I don't wanna lie to you. I used to be with three different women in one week. Other women were so annoying, rude and so lazy, they would not even prepare my bathwater and prepare my food when I come back from work, I had to prepare my own bath water and my food. I kept on getting more women trying to find a better one. Each time I found someone, they will do exactly the same, so I realised it was pointless.

Researcher: What made you not to use condoms?

Peter: I don't wanna lie to you, I really did not like condoms but I have started using it now because I'm forced to. When there is no condom I do nothing, I now have no problem with the use of condoms (laughs).

Researcher: We have come to the end of the interview, is there anything else you would like to talk about?

Peter: No, but I am worried about the skin lesions that I have all over my body (showing his arms with a rash), its embarrassing for me when people look at me but I hope that when I start ARVs it will be better.

Researcher: I hope so too, you must talk to the nurse about it, I will refer you to her now. I appreciate you speaking openly with me, thank you.

END OF INTERVIEW