AN EXPLORATION OF CLINIC BASED INFLUENCES THAT SUPPORT OR HINDER THE RETENTION OF HIV POSITIVE CLIENTS IN PRE- ART CARE AT A CLINIC IN JOHANNESBURG, SOUTH AFRICA FROM JANUARY 2010 TO JULY 2014

Research Report submitted to the School of Public Health University of the Witwatersrand in partial fulfilment of the requirements for the degree Master of Public Health

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Declaration

I **Shelter Mushipe** declare that this research report is my original work. Any work done by other persons has been properly acknowledged in the text. The report is submitted in partial fulfilment of the requirements for the Degree of Master of Public Health (MPH) with the University of the Witwatersrand, Johannesburg, South Africa. It has not been submitted for any other degree or exam in this or any other University.

Signature: 

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Date: 26 September 2017

Dedication

Dedicated to my mother and my three adorable children for their love, endless support, encouragement and sacrifices.

Abstract

Background:

Retaining people living with HIV in the continuum of care (CoC) is a major challenge internationally and in South Africa. However, health care providers can play a role in strengthening retention at different points in the continuum. Understanding the perceptions of health care providers regarding barriers to retention of HIV positive pre-antiretroviral therapy (pre-ART) clients can productively inform pre-ART patient retention programmes.

Objective

To explore health care worker perceptions on factors associated with retention of pre-ART clients at a clinic in the city of Johannesburg, South Africa.

Methods:

A cross sectional qualitative study was conducted using semi structured interview guides with a total of 11 health care providers who were comprised of the facility manager, six professional nurses and four lay counsellors in the ART programme. The respondents were purposively sampled. One-on-one interviews were conducted and audio recorded. Field notes were collected during the interviews and the recordings were transcribed after the interviews. Thematic content analysis was conducted using MaxQDA software.

Results:

The major finding of the research was that there is a lack of understanding of the scope and extent of pre-ART care and not all health care providers seem to get adequate preparation for tracing potential LTFU clients or retaining them in care. Informants in the study indicated as particularly problematic the late return for care by pre-ART clients, which usually occurs when clients are already very sick. Other factors that were identified as challenges include fear of disclosure, shortage of designated health care professional for pre-ART clients, lack of work space in the clinic, inadequate record keeping of patient information, concerns of disclosure and negative attitudes from staff. Clients not returning for their CD4 results, in part due to non-availability of the results or infrequent health care visits, also led to a loss of care even before eligibility for pre-ART or ART could be determined.

Conclusions:

This study highlights some of the causes of non-engagement or loss to follow up (LTFU) in the HIV CoC among pre-ART individuals based on the health providers' perceptions. The research thus provides an impetus for future research involving both health care providers and the pre-ART individuals to explore best practices that will enhance retention of pre-ART individuals in the continuum of care to attain optimal public health services.

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Nomenclature/List of Abbreviations and Symbols

AIDS	Acquired Immune Deficiency Syndrome
AIC	AIDS Information Center
ART	Antiretroviral Therapy
ARV	Anti-retroviral
ARTAS	Antiretroviral Treatment Access Study
CAC	Community-based Adherence Clubs
CBD	Central Business District
CDC	Centers for Disease Control & Prevention
CD4	Cluster of Differentiation 4 (T4 'helper' lymphocyte)
CoC	Continuum of Care
HCT	HIV Counselling and Testing
HIV	Human Immunodeficiency Virus
HREC	Human Research Ethics Committee
IDI	In Depth Interview
IPT	Isoniazid Preventive therapy
KAP	Knowledge, Attitudes and Practices
LTFU	Loss to Follow Up
NHLS	National Health Laboratory Services
NIMART	Nurses Initiated Management of Antiretroviral Therapy
PICT	Provider Initiated Counselling and Testing
PLHIV	People Living with HIV
Pre-ART	Pre-antiretroviral Therapy
PMTCT	Prevention of Mother-to-Child Transmission
RCT	Randomised Control Trial

SCT	Social Cognitive Theory
SPH	School of Public Health
TnT	Test and Treat
UNAIDS	United Nations Programme on HIV/AIDS
WHO	World Health Organization

Chapter 1: INTRODUCTION, STUDY OBJECTIVES AND LITERATURE REVIEW

1.1 Introduction

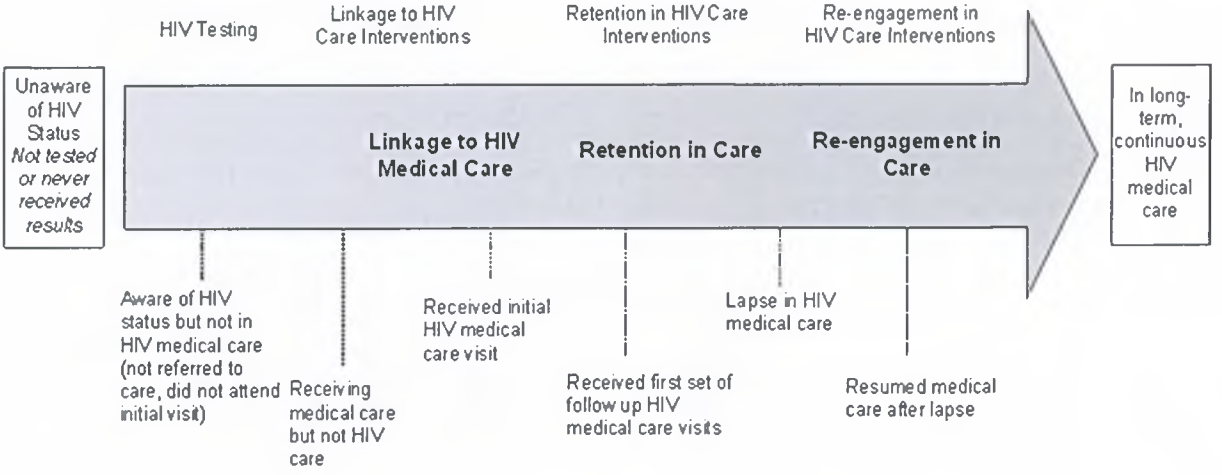
Human Immunodeficiency Virus (HIV), which causes Acquired Immune Deficiency Syndrome (AIDS), is one of the world's most serious health and development challenges with 35 million people living with HIV globally (1). The vast majority of people living with HIV (PLHIV) reside in low and middle income countries, particularly in sub Saharan Africa (2). South Africa has the largest number of PLHIV in the world, estimated to be around 6.4 million (3). The World Health Organisation (WHO) estimates that only 39% of HIV Positive individuals are aware of their status; the majority of people are hesitant to test for HIV, despite the fact that more countries in sub Saharan Africa have adopted policies on provider initiated testing and counselling (PICT) and the number of facilities providing HIV Counselling and Testing (HCT) continue to increase (4) sub Saharan Africa, among clients who know their HIV Positive status, just 57% complete assessment of antiretroviral therapy (ART) eligibility(5). Very late initiation of ART for PLHIV is a major concern, especially at a time when the WHO is advocating for earlier ART initiation at a CD4 cell count of 500 cells/μL (6).

Globally, ART is the single most effective biomedical intervention developed to prolong and improve the quality of life of PLHIV (7). Other key strategies include health system re-engineering, behaviour interventions, testing with immediate results, and peer support, which have increased enrolment into HIV care (8) . The success of ART roll out in low and middle income countries has been remarkable, and almost 9.7 million people initiated ART by 2013 compared to 300,000 in 2000 (9). Expanded access to antiretroviral treatment in South Africa and other sub Saharan countries has dramatically improved the quality of life of millions of PLHIV (10). Despite these advances, many PLHIV commence ART at advanced stages of infection, resulting in high rates of early mortality even while on treatment (11).

Early initiation of ART services during the asymptomatic phase of HIV-infection can greatly reduce the risk of progression to clinically symptomatic HIV disease and death (12). PLHIV infection can achieve viral suppression if they receive a sustained combination of ART services (13, 14) and reduce the risk of sexual transmission of HIV infection by more than 90% (9).

The focus of the health care sector has been on ART, while other components of the continuum of care (CoC), such as pre-ART care, have received little attention in practice or scholarship (15). The concept of the CoC was developed as a response to the many needs of PLHIV and their families over the course of their lives and the difficulties they face in accessing treatment and psychosocial services (16). CoC was developed by the WHO and later adopted as a strategy by UNAIDS and national HIV/AIDS programmes in Africa and Asia (17). Retention in the CoC is considered a requirement for health care workers and clinicians for optimal clinical outcomes in PLHIV. It has been established that once an individual has been diagnosed HIV positive, they go through several steps before they are initiated on ART, and this is known as the "HIV cascade" (18). The HIV cascade steps move from HIV diagnosis to linkage to HIV care, ART eligibility, and ART initiation (18). Studies have shown that PLHIV who engage in HIV care before being eligible for ART to have a lower risk of mortality (19), and this finding forms a central concern of this project. The sequential stages of CoC function as a monitoring tool for the UNAIDS "90-90-90" strategy to reach three targets by 2020: diagnosing 90% of PLHIV globally, putting 90% of people with diagnosed HIV on sustained ART services and achieving viral suppression in 90% of people receiving ART services (20).

Figure 1.1 Pathway of care for HIV positive individuals



While global public health scholarship recognises the importance of enrolment within the ART programme, similar research and policy attention to the pre-ART enrolment component of the CoC is not as robust. It is a key area, therefore, that needs further academic focus in order to retain PLHIV in care and to enhance optimal clinical outcomes (21). It is important to

encourage and assist PLHIV to seek treatment management of HIV during the pre-ART stage before it progresses to AIDS. Rosen and colleagues (22) explain that,

> *without effective retention in pre-ART care, beginning with HIV testing and continuing until the first antiretroviral drugs are dispensed, even clients who have long been aware of their HIV status will access care only when seriously ill which is often well after treatment eligibility.* (p.8)

Achieving universal access to treatment in sub Saharan Africa is hampered by loss to follow up (LTFU) during the preparation stage of ART (23). Although universal ART coverage has not been achieved in South Africa, it has been estimated that 80% of people in need of ART were receiving the WHO recommended ART regimen by October 2012 (24). However, South Africa has poor retention in pre-ART care, which prevents ongoing immunologic and clinical evaluation, and this increases the risk of late initiation of ART when the immune system has already been severely compromised and some opportunistic infections have begun to surface (19).

WHO has defined pre-ART as the interval between enrolment in the ART programme and the time ART is started. However, for this study, pre-ART care will be defined as the phase between an initial HIV positive diagnosis and before ART initiation. Pre-ART care involves retaining HIV positive clients in clinical care until they are eligible for and enrolled on ART (25). Because the pre-ART stage receives little attention from the health sector or the public (26), there are currently no definitions of pre-ART care at the national level in South Africa, nor are there policies in many sub Saharan countries that support the implementation of pre-ART care services (18). This results in difficulty for programs to address the challenges faced in retaining clients in care and implementing best practices (21). However, it is essential that PLHIV should make regular follow up medical visits during the early stages of HIV infection so as to monitor disease progression and ensure timely initiation of ART (27). Importantly, retention in pre-ART care also allows for the provision of prophylactic medications for opportunistic infections, ongoing staging, prevention of mother-to-child transmission (PMTCT), and prompt initiation of ART once indications arise (28). Thus, the focus of the study is mainly for people who are HIV positive, but not yet eligible for ART.

1.2 Background

Concerns around ART and pre-ART care form a central point of politics and policy in South Africa. In December 2009, the president of South Africa announced a massive campaign to mobilize all South African citizens and residents to get tested and know their HIV status. To date, this is the largest HIV testing campaign ever undertaken by a single country (29). The HCT campaign has increased the number of people who know their HIV status in South Africa, with over 18 million people having been tested since the launch of the campaign (30, 31). However, a significant portion of those who tested positive failed to be linked to the CoC because of supply and demand barriers. The supply side constraints can be described in terms of service delivery, such as clients experiencing several barriers to accessing CoC once they receive their first HIV positive test result (32). The barriers to accessing CoC might include the non-availability of care to all clients along the full cascade of care due to an insufficient number of qualified health care providers to provide treatment and care to all PLHIV (33). While some individuals who do not perceive themselves to be at risk of HIV infection and less likely to seek HIV testing (34), some clients do perceive their risk of HIV infection, but simultaneously face significant barriers to access HIV testing services (32), which may be a mix of both supply and demand factors.

Demand-side constraints, such as stigma and limited knowledge about HIV, also have a negative impact on the implementation of the HIV treatment and care strategies (33). Late presentations for pre-ART care tend to be more prevalent among marginalized groups of people, such as migrant population due to fear of harassment and stigma at the health care facilities (35). Fear can also be a significant barrier to CoC, including fear of the disease itself, fear of disclosure and fear of subsequent social stigma, discrimination and criminalization of risk behaviours (36). A study conducted in Zambia and South Africa suggests that HIV related stigma may impede the successful implementation of HIV prevention and treatment programmes (37).

More than two-thirds of people who tested positive for HIV but were not yet eligible for treatment when diagnosed were lost from care according to a systematic review of pre-ART care in sub Saharan Africa (25). Studies included in the review reported a substantial loss of clients at every step of care, starting with clients who do not return for their initial CD4 count results and ending with those who do not initiate antiretrovirals (ARVs), despite eligibility (25).

South Africa has seen major changes in the required CD4 count to initiate PLHIV on ART, from 200 cells/mm3 to 350 cells/mm3 and currently 500 cells/mm3 (38). Stages of persons living with HIV on pre-ART were categorized as follows:

- Stage 1: from HIV testing to receipt of CD4 count results or clinical staging
- Stage 2: from receipt of CD4 count results or clinical staging to ART eligibility
- Stage 3: from ART eligibility to ART initiation (25).

PLHIV are considered lost to care if they are more than three months late for a scheduled consultation; however, some studies in South Africa used different definitions, ranging from one to six months late for a scheduled consultation (25). Poor engagement in care entails that a patient is initially linked to health care services, but along the CoC, the individual misses clinic visits and subsequent retention in care (28). However, in this study, poor engagement of newly diagnosed HIV positive persons is associated with non-engagement in the pre-ART phase, which may lead to an inferior CD4 count of <500 cell/ uL, WHO disease stage III or IV, and consequently delayed ART receipt and non-adherence (39). The poor engagement of newly diagnosed HIV positive persons substantially decreases the optimal care required to offer clinical and biological monitoring, which in turn increases morbidity and mortality among PLHIV (40). Several other studies have shown the importance of the CoC for PLHIV and focus on several steps of HIV service delivery, including diagnosis, linkage to care, and retention in care until eligible for ART (39).

Pre-ART guidelines do exist; however, they are embedded in other documents that are not specific to pre-ART such as the "Clinical Guidelines for the Management of HIV/AIDS in adults and Adolescence and the HIV Counselling and Testing (HCT) Policy guidelines. Pre-ART care data in South Africa are not routinely collected and are considered by some studies to be a "broken link" in the monitoring of many health care programs (41, 42). Although loss to follow-up after ART initiation is increasingly recognized by researchers, little is known about pre-treatment loss to care (PTLC) after an initial positive HIV test (42). In a large public health care clinic in Johannesburg, 69% of clients who were registered in pre-ART care did not return to follow-up medical appointments within one year, impeding monitoring disease progress to initiate eligible clients on treatment in a timely manner and improve clinical outcomes (27) Better health information systems that allow clients to be tracked between service delivery points are needed to properly evaluate pre-ART loss to care (27).

Few studies have focused on the pre-ART stage in South Africa, hence the researcher sought to explore clinic based factors that support or hinder the retention of pre-ART clients in the CoC. By exploring factors that contribute to retention in the CoC for PLHIV who are not eligible for ART, the researcher sought to contribute to scholarship on retaining PLHIV in the CoC. The researcher expands such knowledge by analysing real life data on where the gaps are and making recommendations on how to reduce the factors that hinder the process and how to promote factors that support retention in HIV care.

1.3 Statement of the Problem

Focus on loss to care after ART initiation is increasingly recognized, little is known about pre-ART careafter an initial positive HIV test (43). Pre-ART care as a stopgap measure of HIV progressing to AIDS is needed urgently to reduce HIV-related morbidity and mortality globally (21). With changed eligibility criteria (22), strategies on how to encourage clients to return for test results and remain in the CoC continue to be important, particularly for clients that may not be experiencing negative health symptoms (16). If major progress towards universal access to ART is to be attained, there is an urgent need for HIV programmes to strengthen the existing HIV CoC pathway and to ensure that increased access to HIV testing is accompanied by improved linkage and retention to HIV care (8).

1.4 Justification for the Study

PLHIV who enter the health care system is lost at every step along the CoC, particularly in the period between HIV diagnosis and before initiation of ART (27). It is now recognised that poor retention of clients in care, especially in the pre-ART period, is a major driver of increased morbidity and mortality among PLHIV (44). This study follows the events at a health care facility in Johannesburg, where PLHIV are missing appointments and not following up to the expected HIV care for various reasons ranging from individual perceptions of susceptibility to HIV (27) to social issues such as stigma (27). This study seeks to identify clinic based factors that support the retention in care of PLHIV during the pre-ART period and further enlighten the health care professionals on the importance of retaining PLHIV in care. The facility based services and other factors are important as their variability enhances or hinders the retention of PLHIV in different health care facilities. Insights from healthcare providers would be useful to identify factors associated with enhancing patient retention in pre-ART care. For the purpose

of this study, the terms clients, HIV positive persons, HIV positive individuals, persons who tested HIV positive & PLHIV were used interchangeably.

1.5 Study Aim and Objectives

Study Aim

To explore clinic based factors at a primary health care clinic in Johannesburg, South Africa that support or hinder the retention of HIV positive people in the CoC, if they are not ART eligible.

Study Objectives

1. To explore HIV-related services offered through the facility based wellness programme at a primary health care clinic in Johannesburg, including allocation of human resources from January 2010 to July 2014.
2. To describe retention practices and resources allocated to tracing and bringing clients back into care who are lost to care during the pre-ART phase at the same local primary health clinic in Johannesburg from January 2010 to July 2014.
3. To explore clinic staff perceptions on how their practices support or hinder the retention of PLHIV who are pre-ART at the same primary health clinic in Johannesburg.
4. To recommend how to reduce the factors that hinder retention in CoCand to promote those factors that support retention of PLHIV in the CoC.

1.6 Literature Review

1.6.1 Loss to follow up in the pre-ART phase

Within public health scholarship, the pre-ART period has shown significant levels of patient attrition, particularly before HIV testing and when clients are being assessed for ART eligibility. Globally, 20–33% of those initially identified as HIV positive is known to have been retained in pre-ART care before initiating ART. However, these results need to be interpreted with caution due to various definitions of "pre-ART" (22). A study from South Africa found that 63% of people who tested HIV positive at clinical and voluntary counselling and testing facilities were linked to initial HIV care (45), but a significant LTFU in the pre-ART phase has been reported in other sub Saharan African countries (46).

The starting point for being in the pre-ART stage is the moment of HIV transmission or from the perspective of the public health system, an HIV positive diagnosis. In 2010, the South African government's policy on HCT expanded to include PICT, which placed an obligation on health care providers to explain to clients the importance of knowing one's HIV status and of testing habitually for HIV as part of normal health seeking behaviour (6). The HCT campaign has dramatically increased the number of South Africans who know their HIV status with an initial testing of 10 million people at the end of 2010, while 18 million knew their HIV status between 2010 and 2013 (47). Dr Aaron Motsoaledi who is the Minister of Health of South Africa reiterated the government perspective that "the HCT campaign has proven to be a powerful vehicle for the social mobilisation of the awareness of HIV/AIDS" (48).

1.6.2 Knowing one's HIV status and HIV care

A major challenge of HCT campaigns is that a significant number of those who are tested and are found to be HIV positive are not being linked to the CoC (49), reinforcing critiques that knowing one's status is not enough to change individual outcomes or national prevalence rates (50). A pattern of loss to care after HIV testing is replicated globally, albeit at different rates (22). For instance, the treatment cascade in South Africa has shown that there are two main leakages of people who are lost between a positive HIV test and the CD4 test, and persons who test HIV positive but who are lost between a CD4 test and the return visit for the CD4 test result (31). A study conducted in Rwanda also indicated that 50% of known HIV-infected individuals are not engaged in regular HIV care, which results in these individuals not having a sustained access to ART, prophylactic medications, or other medical services (49).

HIV CoC before and after the initiation on ART is vital so as to reduce individual HIV mortality and morbidity rates and also to deliver positive interventions aimed at reducing ongoing transmissions (28). LTFU has negative repercussions among HIV positive individuals, thus an analysis of existing clinical services, such as adherence clubs, is necessary (51). Adherence clubs were first introduced in Khayelitsha, South Africa in 2007 to reduce the burden of health services and entailed that stable clients were grouped into "clubs" (52). These were led by non-clinical staff (counsellors), who have previously been trained in facility-based patient preparation and support, and who receive additional training and mentoring (53). The areas

where adherence clubs were implemented highlighted a significant improvement in the retention of stable clients and supported better adherence (54). These club meetings also acted as support groups for HIV positive individuals and a mechanism to provide clients with healthy lifestyles (55).

1.6.3 Push and pull factors for the retention in pre-ART care

There are several reasons for the poor retention of pre-ART care clients which have not been looked into by various studies (16). It is important to note that retention in a particular health care facility is not synonymous to retention in care (56). Some clients who are labelled as lost to follow up may, in fact, be accessing care from a different health care facility (45). Studies in South Africa also articulated to barriers to HIV CoC which include not feeling well enough to come to the clinic, feeling well but not perceiving the need for regular HIV care, alcohol abuse, and mental health problems (57). Some of the highlighted barriers cited by health care providers include perceived stigma and discrimination by HIV positive individual at health care facilities and other competing priorities, such as work (57). Limited access to transportation services, language barriers, and long waiting times also inhibit clients' abilities to access health care in various facilities (58).

Some of the barriers to retention in pre-ART care, which are discussed in detail below, are healthcare system accessibility, long travelling distances, models of care, social support, stigma and disclosure, length of waiting period for another CD4 count, higher CD4 count and some clients not perceiving the need for regular HIV care (59).

1.6.3.1 Models of care

Certain models of HIV care and programme strategies have been associated with poor or greater retention in care, especially those related to the centralisation or decentralisation of care (60). It was found that groups that received adherence counselling, home visits, and community health worker involvement had LTFU of 1% - 5% compared to 14% of the control group (8). In a township in South Africa (Khayelitsha) several service adaptations were implemented to relieve pressure on clinics by moving towards a nurse based, doctor supported decentralised model of care by developing out of clinic approaches to adherence support for stable patients (61). This resulted in a total of 776 adherence clubs initiated in Cape Town, with 18,700

patients initiated and enrolled on ART, a representation of one in five (19%) of all ART patients in care in Western Cape (61). In Malawi, Massaquoi et al (62) demonstrated that a centralised "hub" lost clients faster than a decentralised "spoke" site for the same group (63). A study conducted in seven sub Saharan countries among 122,405 clients in 216 health care facilities concluded that better retention was associated with the presence of peer support groups and outreach services (64).

1.6.3.2 Health care system accessibility and clinic visits

Health care system inaccessibility has been identified as a major factor influencing retention in care in a wide variety of settings in sub Saharan Africa (65) and relates to the distance clients have to travel to clinics and the high cost of transportation (66). Access to the HIV CoC is a key issue which determines the frequency of visits made to health care facilities, particularly in rural areas (67). In a study in Uganda, 44% of pre-ART clients who were eligible for ART but did not start treatment cited transportation as the major reason for failure to initiate (68). A multi-site study conducted in Western, Eastern and Southern Africa, using a month absence as a criterion, found that if travel time was to exceed two hours, the risk of non-retention would double (63). This is less a factor in an urban environment in South Africa, where many health care facilities are within a 5-km radius from residential areas.

More relevant are current HIV care approaches that require several clinic visits to enable individuals to provide a blood sample for the CD4 count and return a week or weeks later to receive the results (22). This scenario might provide an excuse for many clients not to return for further care, as they risk losing employment by taking time off work on several occasions (22).

1.6.3.3 Lack of communication and coordination at a health system level

Better communication and understanding between patients and healthcare providers facilitates better retention in HIV care (69). Poor coordination and failure to communicate with patients was identified as one of the main barriers for healthcare providers to offer optimal services to patients (69). Several studies have reported similar results of dropouts and missed appointments due to communication and coordination problems. This also included weak information systems, poor follow-up and tracking of patients and failure to effectively communicate rapidly changing treatment protocols and referral procedures throughout the health system (70).

1.6.3.4 Shortage of human resources and training

Long waiting times was the most frequently cited barrier to accessing HIV care and has been one of the most common complaint from pre-ART patients which is stemmed from wider resource constraints and poor management of patient flow in clinical settings due to persistent human resource shortages (71). One study conducted in South Africa found that shifting HIV testing to lay counsellors complicates the HIV care considering they also have other duties to fulfil (72). The results of the study further showed that there was limited counselling skills for specific groups (such as pre-ART patients), and a lack of standardised training policies (72). The healthcare providers often did not have the requisite skills or knowledge of current treatment protocols or referral procedures for providing pre-ART care to HIV-infected patients, and were unprepared to provide further emotional support to their clients (61).

1.6.3.5 Social support, stigma and disclosure

Social support systems and interpersonal relationships are predictors that often facilitate persons living with HIV's utilization of HIV care (27). In resource limited settings, social determinants of retention in care have been found to be important (63) as noted by one of the largest qualitative studies in Africa, conducted by Ware et al. on patterns of accessing care by PLHIV. They established that social relations helped in overcoming barriers to care through encouraging others to visit the health care facilities, people are given money by family members so as to visit the health care facilities and in some instances accompanying individuals to the facilities (63).

Stigma regarding HIV status and fear of disclosure to family members was identified as a major barrier to uptake of HIV CoC (73). Although human rights instruments and legal prohibitions can protect PLHIV against discrimination in health care services, the same human rights and legal prohibitions cannot protect against stigma, which is social rather than structural (73). Non-disclosure of one's HIV status deterred PLHIV from not attending an HIV clinic in Tanzania and not taking treatment in South Africa, Zimbabwe and Zambia or from seeking or administering prophylaxis in one study (74). Further studies have highlighted that some women are scared to disclose their HIV status because of negative reactions they face from their partners such as refusal to test for HIV, abandonment and violence (73). The emphasis that has been placed on non-disclosure for PLHIV might be counterproductive as non-disclosure is increasingly difficult to maintain as immune deficiency progresses (73). Instead of breaking

the destructive silence around HIV, non-disclosure instead promotes it, which is often detrimental to the individual's health (75).

Negative and stigmatizing attitudes of nurses and doctors has also been documented as a common patient complaint in many settings (76). Compounded with self stigma, discrimination and stigma from healthcare workers makes access to health services challenging to many PLHIV (76). In instances where health workers use verbal abuse and claim that clients default deliberately, patients report feeling unwelcome and fearing the possibility of confidentiality being breached by nurses (intentionally or unintentionally about their HIV status to others in the clinic or community) (77). In one study in South Africa, the healthcare providers minimised the effects of patient barriers as they believed that patients should take responsibility for overcoming such barriers (69). In contrast, a study conducted in Limpopo, South Africa, illustrated that a good clinic and good carers especially non-judgemental and empathetic supportive staff contributed to the well being of the clinets and improve patient retention (77).

1.6.4 Patients' age and higher CD4 count

HIV care retention was found to be poor, particularly for younger individuals with higher initial CD4 cell count in a study in Kwa-Zulu Natal, South Africa (28). In a purposively selected study in Soweto, South Africa, participants who tested HIV positive, described feeling "too healthy" to start treatment (78). This subjective view of being too healthy might be framed within the context of treatment being reserved for the sick as further established by a study in sub Saharan Africa which cited that clients with a low CD4 count (who are likely to be symptomatic) are more likely to be retained in pre-ART care than clients with a high CD4 count (who are likely to be asymptomatic) (57).

CHAPTER 2: METHODOLOGY

2.1. Design

A qualitative exploratory design was conducted with the use of semi-structured interview guides. This approach was used to collect data from health care providers who attended to PLHIV but are not yet eligible for ART in the health care facility under study. Participants freely expressed their opinions on the services offered in the wellness programme, retention practices and resources allocated to tracing and bringing clients back into care, and how health care providers' practices support or hinder the retention of HIV positive pre-ART person.

2.2. Study Setting

The study was conducted at an urban primary health care clinic in Hillbrow, Gauteng province, Johannesburg, South Africa. Hillbrow is in one of the most densely populated suburbs in the city. The clinic serves at least 5 000 clients a month who reside around Johannesburg central business district (CBD) and the suburb (79). Some migrant populations from as far as Zimbabwe find the facility easily accessible from Park Station, which is the main bus terminus for both internal and cross-border migrants. The reason for choosing the facility is its location and easy accessibility by many people. It was also convenient for the researcher to access the facility as the researcher once worked there, thus already had a working relationship with the staff. However, the facility is not meant to be representative of all public clinics in South Africa.

2.3. Study Population

To be eligible, personnel had to have been at the health care facility since the HCT campaign of 2010 or prior, following the principle of information-rich participants (80). There were 15 health care professionals who had been working at the site from January 2010 or prior to that, according to staff registration records. Their ages ranged between 25 and 60. There were only female employees at the facility, working as the facility manager, professional nurses, and lay counsellors, thus limiting the study population to female participants.

2.4. Study Sample

Given the small number of the study population, all 15 health care providers were invited to participate in the study. This study is based on results obtained from eleven health care

professionals, including lay counsellors, professional nurses, and the facility manager. The remaining four participants (three professional nurses and one lay counsellor) were unable to participate due to personal and work-related challenges that disrupted the interview appointments. The researcher produced and showed an approval letter from the Wits Human Research Ethics Committee (HREC number M140384) and Johannesburg Health District Research Committee (see Annex 2 and Annex 3) which gave the researcher permission to conduct the research at the facility. After obtaining approval and permission from the facility manager, the researcher, under the facility manager's guidance, drafted a work plan on when to conduct the interviews with the lay counsellors, professional nurses and the facility manager.

2.5. Data Collection

Data collection included semi structured interview guides with 11 of the health care providers. The two semi structured interview guides (Annex 4 and 5) were developed for different health care cadres, which included lay counsellors (Annex 4), professional nurses and the facility manager (Annex 5). The semi structured interview guides solicited information on current opinions on care practices pertaining to PLHIV who are on pre-ART care. Interviews with the facility manager and professional nurses focused on information on pre-ART care, which included clinical evaluation such as physical examination, WHO HIV disease clinical staging and CD4+ cell count enumeration done at National Health Laboratory Services (NHLS) as well as support services. The semi structured interview guide for lay counsellors focused more on health information was given to pre-ART clients to encourage them on the continuum pathway. Appointments were made by the researcher, through the facility manager, for interviews which were conducted by the researcher from February to August, 2015.

In qualitative research, the interviewer is also part of the research instrument. Considering that the researcher has worked at the facility as a project coordinator under an NGO, some participants might have viewed the researcher as someone sent by management to monitor their work performance. Due to the Hawthorne effect, some participants feared that the information they provide during the interview could potentially be relayed to the Department of Health. This resulted in a withdrawal of non-communication of what was really happening at the facility and a lot of fidgeting and impulsive movements by participants. This led to non-commitment to the research by some participants. However, before the interviews, the

researcher explained clearly to the participants that the research was for degree purposes and their names will be kept confidentially.

Due to series of personal and work-related events by the participants and activities at the health care facility, it was difficult by the participants to abide by the appointments. Interviews lasted between 20 to 45 minutes as the health care providers wanted to attend to clients since the interviews were conducted during working hours. All interviews were conducted in English and were audio-recorded. The interview with the facility manager was very short due to a personal event that had previously taken place at the facility, which she shared in confidence with the researcher. The manager was willing to have a follow-up interview at a later date. However, this did not take place due to time constraints. Lay counsellors faced some difficulty in expressing themselves in English, however, the semi structured interview guides continued in English. This was due to language barriers between lay counsellors and the researcher as English is not the lay counsellors' first language, thus they had difficulties expressing themselves fully during the interviews. All interviews were conducted at the health care facility in a private room to minimize additional cost to participants. As such, no monetary or other compensation was provided to these individuals. Audio consent also was taken (see Annex 6) to ensure that the interviews were electronically audio-recorded by the researcher so as capture information verbatim. A reflective journal was also kept by the researcher to capture some of the non-verbal cues demonstrated by the respondents. After each interview, the field notes were documented by the researcher electronically in MS Word.

2.6. Data Management and Analysis

Data were collected by the researcher through audio-recorded in-depth interviews and transcribed electronically by professional transcribers (Top Transcribers) into Microsoft Word. Each of the IDI received an identification code. The researcher reviewed and verified the transcriptions against the recordings. The new project was created by uploading and labelling raw data (transcripts). A mix of inductive and deductive analysis was used to develop codes, thus a coding structure and assignment were established. This entailed that initial coding of the transcripts was performed according to the study objectives, but new codes and themes were established based on the data. Coding of the contents of the interview and identification of key themes was carried out by the researcher using the MaxQDA software. These were developed

into a code book by the researcher. Through a constant comparison approach, sub themes were highlighted within each theme. Statements were coded with a specific context in order to avoid data fragmentation. Quotations, memos and observations with regards to each study objective (topic) were evaluated to identify common themes and variant views using a thematic analysis approach.

2.7 Ethics

This study received ethical approval from the Wits Human Research Ethics Committee (HREC number M140384) (See Annex 2). The researcher also received permission to conduct the study from the regional health manager and facility manager of the clinic (See Annex 3). Participation in the study was voluntary. Participants had a choice to participate or refuse to participate and could stop the interview at any point. After receiving an explanation from the researcher and going through the information document (See Annex 7), each informant provided written consent to an interview and recording by signing an informed consent form for an interview and for recording (See Annex 8 and 6). The identity of the interviewees was kept confidential by not capturing identifying information, such as names and addresses. Data, including audio recordings, will be stored securely for a minimum of two years after publication or six years in the absence of a publication, after which recordings will be destroyed. No unauthorized person will have access to these files.

Ethical issues emerged during the study, such as lack of privacy. The interviews were done during working hours, which made it difficult to attain complete privacy with the participants, however, the researcher assured the participants that their confidentiality would be protected. The researcher also ensured that she was available at flexible times, taking advantage of slow times, as participant time was limited and it was important that the interviews did not disrupt the clinic operations.

CHAPTER 3: RESULTS

Eleven female health care providers (four lay counsellors, six professional nurses and one facility manager) were interviewed for this research on clinic based factors which support or hinder the retention of PLHIV in the CoC at the pre-ART stage. All the participants had been working at the facility during and before the 2010 HCT campaign. The main themes and sub-

themes that emerged through inductive and deductive analysis were explored for each objective.

3.1 Facility-Based Wellness Programme Services

Having interviewed professional nurses and counsellors on the wellness services that are offered to pre-ART persons at the facility under study, participants perceived that counselling was an essential component for all persons who test for HIV with a special focus on post counselling for those who test HIV positive. During the post counselling sessions, issues discussed between the patient and health care providers included disclosure, prevention from further re-infections, health literacy (that is ensuring clients have obtained and understood basic health information to enable them to make appropriate health decisions), psychosocial and other supportive services. Although participants noted that adherence should be combined into wellness programmes that have been situated in primary health care facilities, the facility under study did not offer this service to pre-ART clients. The implication of the absence of a wellness programme was that among the health care facility staff the concept of adherence for clients has not yet expanded beyond treatment to include adherence to clinical care.

Table 1 below summarises the post-HIV counselling that health care providers, including counsellors and professional nurses, described offering to PLHIV

Table 1: Post-test HIV counselling provided by Health Care Providers

Services Provided to PLHIV	**Main Provider**
Voluntary HIV Counselling (Pre and Post): This also includes emotional and psychosocial support	Counsellors
HIV Disclosure and Prevention	Counsellors / professional nurses
Health Education: This is the provision of health information, such as ways to live a healthier lifestyle, safe sex and any HIV related topic.	Counsellors/ professional nurses

3.2. Importance of Counselling

At the health care facility under study, the role of HIV counselling was talked about by lay counsellors while the nurses did not mention it. Lay counsellors highlighted the importance of counselling with one lay counsellor explaining that it helps clients cope with their situation in terms of accepting their HIV status. Another lay counsellor specifically linked counselling to health literacy in terms of receiving information, which can be done through information and educato materials encouraging PLHIV to live a healthy lifestyle and assist with a patient's emotional wellbeing (being able to disclose and accept their status). As one lay counsellor stated:

> *Why I am counselling the people who are not yet on treatment because you can still live a longer life. It depends on how you, firstly, have to accept the status, secondly disclose and follow the right procedure and then live a normal life, a healthy lifestyle and then accept who you are on the case. Especially when you are not on ARV, you must take care of yourself.* ~ **lay counsellor 01**

Lay counsellors in this study noted that there are various issues discussed during the HIV counselling and testing session such as the importance of drawing blood for the CD4 count, knowing one's CD4 measurement, and TB testing. A sub-theme that emerged was that they provided clients with health information at two separate points of counselling: pre-counselling and post counselling.

Pre-Counselling

All four lay counsellors referred to the health education and counselling services which they offer to clients who attend pre-counselling sessions. Importantly, they emphasized the rights of clients to get tested or not. According to the counsellors, they give clients a choice of whether or not to proceed with the HCT process. Two lay counsellors also mentioned that pre - counselling is intended to give clients direction and advice, such as knowing one's HIV status. During the pre-test counselling, the participants mentioned that they are preparing the clients before they receive their HIV test results. This was important, regardless of the test outcome:

The pre-counselling is before she gets the results and then to be ready for the results, the outcomes of the results and then to make it a point that it's a good decision the client has done by coming to know his or her status. ~ **lay counsellor 02.**

Post Counselling

After the pre-counselling session, when the clients are tested for HIV and their results are disclosed, clients are further counselled (post- counselling). Although the two counselling sessions occur at different times during the patient's overall testing process, the participants in this study noted that they form two integral components of a continuous counselling session. The pre-test counselling and post-test counselling sessions are done by the same counsellor, as mentioned below by one of the lay counsellors who had been working at the facility for almost seven years.

I do counselling, HIV counselling, HCT and then now testing, pre-and post-counselling. I do pre-and post-counselling and then testing for HIV and then do the follow ups for and the adherence classes. **~lay counsellor 03**

Participants indicated the importance of a post-test counselling session, which could be used as a form of intervention to prevent a future situation where a counsellor should give the client a positive HIV test result. The four lay counsellors agreed on the processes undertaken during the counselling of an HIV negative patient, which included encouraging clients to live a healthy lifestyle and advice on how to maintain an HIV negative status. As one participant stated, this aspect of the counselling session becomes critically important for the following reason: *"...and they must know if they are HIV negative how you can stay negative, I further educate them on the consistence of using condoms (showing a doodle and condoms)."* ~ **lay counsellor 02**

3.3. Giving hope and encouraging disclosure

The four counsellors agreed on the importance of giving hope during the post-test counselling after receiving an HIV positive result. They all highlighted that it helps to encourage people who have tested HIV positive to continue with their lives. One study participant emphasised that an HIV positive status was not a death sentence and that counsellors should encourage those clients testing HIV positive not to lose hope. One articulated this importance by saying:

We give hope to people who are HIV positive, this now a day's people who are living with HIV positive there is no more that stigmas like before and that you have to accept yourself and disclose as it is a very important part and afterwards proceeding with the recommended treatment. ~ **lay counsellor 01**

The importance of giving hope to newly diagnosed patients and the importance of disclosure were not raised by other study participants.

3.4. Receiving full clinical assessment

The health care providers also explained that clients receive full clinical assessments. The participants explained that a full clinical assessment for PLHIV includes a variety of health care services, such as the CD4 count measurement and physical assessment. CD4 cell count measurements have been central to understanding HIV disease progression and making important clinical decisions. Both lay counsellors and professional nurses described changes of the CD4 limits to determine client's eligibility for ART.

Immediately a person is found to be reactive, blood is drawn on the same day for CD4 count measurement. The CD4 count is done. Unfortunately, we don't do [the pap smear] immediately; they have to book for Pap smear. And then, when the results come we also do the, when the results come, it's only then when we take a step if it happens, that's the CD4 count is between 500 cells/mm3 *and 550* cells/mm^3*, they should come back in three months again. But if it's 500* cells/mm^3 *or below, they should have the Hepatitis B test done and crypto antigen ratio and the haemoglobin is also checked.* ~ **professional nurse 01**

The professionally experienced and Nurses Initiated Management of Antiretroviral Therapy (NIMART) trained nurse further explained the specifics of the physical assessment done on newly diagnosed HIV positive persons. Although other professional nurses touched on this aspect, they were not as elaborate as compared to the NIMART trained nurse:

Well, the general physical appearance is done whereby patients is assessed from head to toe we check the scalp... We do ear, nose and throat. We check the mouth. We check the skin, any rashes, any discolorations. Sometimes you find that even we check the legs because sometimes maybe the legs may be sore. We check all that. General physical

examinations that, and we also to chest examination, abdominal examination and genital. **~professional nurse 02**

Other health care providers also described the clinical assessment, which is conducted for all newly diagnosed HIV Positive persons. This includes an initial TB test. Thereafter, clients who tested positive were also required to be tested for STIs such as Hepatitis B, liver problems, kidney problems and pap smear tests.

3.5. Inconsistency on return dates for CD4 results

After the CD4 count measurement and the sputum tests were conducted, respondents noted that newly diagnosed HIV positive persons are requested to come back to collect their results. The dates given to the clients differed among individual workers, with some counsellors and professional nurses informing clients to come back after three days to up to two weeks.

You know, it depends on……. we have had people who would come on Monday, then they would have the results back by Thursday. And it varies. Sometimes they come in a week. Maybe we do it and then give them a week to come. You find that we still have to phone for the results. It varies. **~professional nurse 03**

Participants were asked to describe how a patient receives CD4 test results. One lay counsellor highlighted that clients would get their CD4 count results after two weeks and that the primary interest was whether the patient was above 500 cells/mm3. Thereafter, clients would be notified that their CD4 count is too high to start initiating ARV treatment.Participants were also asked to describe the procedure for clients who did not qualify for ARVs whereas the CD4 count was above 500 cells/mm3. A different lay counsellor mentioned that clients were advised to be monitored for six months if they did not qualify for ARVs and clients were also given the necessary vitamins such as Bactrim. However, the amount of time clients should come back for another CD4 count test varied, as a Lay counsellor advised for clients to come back only after three months. Such clients would fall into the pre-ART group of interest to this study.

3.6. Lost CD4 count

In the study clinic, there were occasions when patient's CD4 count results were either lost or inconclusive. Overall, three lay counsellors reported that they would usually phone the lab if

clients CD4 count results were lost. The facility manager also stated that due to the delay of CD4 count measurement results from the NHLS (laboratory), it was advisable to inform clients to come back for their results after two weeks to avoid inconveniencing the clients. Two lay counsellors explained further about the procedure of lost CD4 count results:

> *Oh, we use the phone. I phone the lab. We've got barcodes. We put a barcode on the file. Then you phone the laboratory then give them the barcode and the name and the surname and ID number. So, that's how we get their results. Then after... maybe after 3 days, we got the...they give us copies if we phone them.* **~lay Counsellor 04**

> *You tell them that they are HIV positive and they should come back after two weeks and then they come and the results are not here. Usually, sometimes, it takes up to two weeks. Sometimes we phone the lab and they say that the results are not there and when that happens and we have to do another blood.* **~ lay counsellor 01**

Delayed or missing CD4 results discourage patients from coming back to the health care facility to enquire about their CD4results which results in many PLHIV lost from HIV care.

3.7. Pre-ART Retention Challenges

Research participants mentioned that many of the pre-ART retention challenges had to do with structural issues, such as lack of space, deficiency in human resources, inconsistent record keeping, inactively following up with clients, negative attitudes from professional nurses, stigma clients experience and the lack of disclosure.

3.7.1 Human Resources Requirements for managing pre-ART clients

Participants were asked to state the human resources requirements for managing pre-ART clients as compared to a patient being initiated on ART. The services offered to persons living with HIV and on treatment are different from those that are on pre-ART as stated by participants in the study. The four professional nurses stated that one of the main challenges they faced was a shortage of designated health care provider in order to offer the required services to pre-ART persons. The facility manager also reported that "there is a need for a designated nurse who would solely work for TB-HIV collaboration for pre-ART clients.

3.7.2. Inadequate space for privacy

In addition to the urgent need for professional nurses who will focus on the pre -ART clients, there was also working space challenges related to where professional nurses conducted consultations. Furthermore, participants noted that clients have complained that there is inadequate space for privacy and felt that they were not being respected which is a major concern. For example, there was a consensus on the lack of space in the facility by the professional nurses who mentioned that:

> *"You know we have a problem with rooms. We don't have space here. Ja. So, in as much, whether it would be nice that we have a dedicated nurse, there is no room, ja,."* **~ professional nurse 04.**

Inevitably, the space constraints and overcrowding translated to increased clinic congestion thus affecting patient waiting times in the queue. Furthermore, one lay counsellor had reported that longer waiting times would discourage clients from seeking health care services, as the typical waiting times was three hours.

3.7.3. Record keeping of pre-ART clients

According to the professional nurses interviewed, documentation of pre-ART clients, which includes the keeping of individual records of pre-ART clients (medical charts) and collective records for collecting data (pre-ART register, Isoniazid Preventive therapy (IPT) register, etc.) were not properly done, maintained and in some instances, unavailable. The quality of the record keeping has implications for the ability to trace pre-ART clients who do not come for follow-up visits. This, in turn, impacts the ability of a health care facility to improve their service provision for pre-ART clients. Based on the professional nurses' opinion, the key gap with regard to record keeping was the registers and clinical charts being poorly completed. This gap meant that data would be excluded from monitoring and evaluation tools. One professional nurse explained:

> *All information should be recorded in the clinical chart as the source of the information because if the patient clinical chart is not well recorded the register will also not have correct information... The pre-ART register... still needs to be strengthened in terms of recording.* **~professional nurse 04**

Another nurse also highlighted the magnitude of the challenge by stating what is being done in other facilities pertaining to pre-ART as a programme:

> *"Most of the facilities are not using data for planning their programs. This is something that the district M&E and Information Unit is trying to instil in facility managers."* ~ **professional nurse 01**

Mismanagement of records was also highlighted amongst the study participants. It was further mentioned by one professional nurse that there was no designated register, therefore records are not kept well. However, the facility manager disagreed on the availability and non-availability of the pre-ART register. The facility manager stated that in some instances the register is hidden in another room.

The professional nurses had shared ideas on how they document and keep records of clients under the wellness programme. More specifically, one professional nurse explained that there is a designated box for patient files that fall under the wellness programme.

Attitudes about documenting clients' information were also mentioned as a major challenge which hindered the record keeping process and maintenance of the clinic patient database. This was reflected in reluctance to record information and the hiding of registers. For example, one nurse said:

> *On Pre-ART, there is just an issue of recording; they keep on saying they are not being trained. The pre-ART register sometimes disappears from the consulting room ... because it is not well filled."* ~ **professional nurse 05**

Professional nurses had different opinions regarding the importance of recording of pre-ART for pre- ART clients. According to one nurse:

> *Health care workers just do it for the sake of collecting data. There is no evidence to show that it is used for planning. ... I don't think they are using them for planning for change.* **~professional nurse 01.**

3.7.4 Following up clients at home

Health care providers explained the importance of tracing the pre-ART clients and retaining them in HIV care before their immune systems are further weakened. However, all the study participants admitted that only clients eligible for ART were actively followed-up. Health care providers alluded to the fact that pre-ART clients only come back to the clinics when they felt sick and adopted self-care behaviours by getting over-the-counter medications. Therefore, this type of behaviour results in the inconsistency in the continuity of treatment as explained by the participant below:

> *Patients do not come back to the clinic for continuity of care. They wait until it is too late when they are then sick. When clients' CD4 count is high, they do not come back for check-ups; some clients even opt to buy their vitamin tablets at pharmacies over the counter. They only come back when they are very sick and when their CD4 count would have dropped tremendously.* ~ **professional nurse 06**

All the professional nurses and lay counsellors highlighted challenges in tracing pre-ART clients. Before health care providers trace clients, they need to get prior permission from the clients to trace them. One of the lay counsellors who worked at the health care facility for the past 10 years explained:

> *We get permission; oh, it must indicate that they have agreed that they want to be visited at home. So, lay counsellors ask them on that form, there is space where it says, "Do they want to be visited?" Because some people still have not disclosed their status and do not want health care workers to visit them at home.* ~ **lay counsellor 04**

Additional considerations that impact the ability of the health care providers to trace clients or provide service include client-related factors (as perceived by the providers), which participants noted usually manifest as a combination of multiple factors. This includes the fear of disclosure and any actions that could have a stigma effect on patient confidentiality (e.g. CHWs doing home visits) as highlighted from the facility manager. Resultantly, clients would deny their health status and refuse to seek medical care. One lay counsellor further explains:

> *There is still a challenge on disclosure whereby people are not willing to disclose to family members except to the home-based carers. We try to make use of the social*

worker to inform the clients on the significance of disclosure. Many people deny that they are sick / HIV positive, but bewitched. However, it is not like before [i.e. had improved]. ~ **lay counsellor 01**

According to the study participants, clients used different strategies to remain anonymous and 'untraceable' because of stigma, denial and lack of knowledge. Respondents noted that some clients are reluctant to comply with appointments and give wrong contact details or use different facilities for testing and re-testing. The facility manager and one lay counsellor reported that clients would not stay at one facility but rather change to different facilities until they are satisfied with the clinic. This was due to clients locating themselves to clinics further away from their place of residence thus being able to avoid being recognised by community members.

3.7.5. Healthcare workers' negative attitudes towards clients

The participants indicated that the healthcare workers' negative attitudes towards clients remained a major issue: *"Sometimes they do complain about our attitudes. Patients mention that we are not confidential we are not treating them with respect."* ~ **professional nurse 02.**

One lay counsellor further mentioned that health care providers' attitudes played an important factor in regards to retaining clients in care. She reported that one of the clients refused to be helped by one of the health care providers because of her attitude. This emphasises that clients who have a negative perception about health care providers due to their attitude are less willing to accept health care services which could be vital. She said that:

...the last time there was a patient here that was arguing with another lady who use to be a [inaudible 0.20.49] counsellor here and he ends up saying to me that this lady is not going to treat me because of her attitude. I think that the attitude counts. ~ **lay counsellor 02**

3.7.6 Healthcare providers' perception of clients' stigma and disclosure

Most of the study participants agreed that stigma and discrimination was one of the challenges when clients wanted to get follow up medical assessments and treatment. Clients did not want

to be seen in the queues or with testing equipment such as blood collection bottles as this has been perceived to have negative connotation with being HIV positive.

> *Others are afraid of other people. If it's somebody sees them at the clinic, with that plastic and the bottles of blood. They know what is happening to me. So, they are afraid of that.* ~ **lay counsellor 04**

> *The other challenges are that they are scared to come to the clinic, people will see me and say "Oh you are positive" so that is the problem but it is up to them to want to come back.They only come back when they are very sick and when their CD4 count would have dropped tremendousl.* ~ **lay counsellor 02**

Gender differences with regards to retention practices were also raised during an interview with a professional nurse. This was further explained that men were more afraid of stigma and did not want to be seen at the clinic as compared to their female counterparts.

> *And he is, she, he is not well. But he says he tested somewhere, he doesn't want to come to the clinic. But I'm sure they are afraid of the stigma, sometimes, the men. Yes. They don't want to be seen at the clinic.* ~ **professional nurse 04**

Two lay counsellors reported that clients have difficulty disclosing their status to their partners due to the fear from family members and partners. In addition, one Lay counsellor had mentioned that this was due to the fear of rejection. With regards to clients who are working, they also found it difficult to disclose their status and maintaining their work life separately.

> *Others say it's a work because if you tell someone's come to the facility she asks at work, you give her the sick note and then you tell that person to come after two weeks. It's another thing at work it's going to be hassle that you, constantly you are not coming to work what's happening and the other thing she didn't disclose you see. So-, and then they'll say, "what's wrong with you'" and then it's become a bad end for that person because number one she didn't disclose at work and she must come to the clinic.* ~ **lay counsellor 03**

> *So, those are the challenges that we get the people they talk about their partner, some will say that I did not tell my partner I am scared. So, I think it is the fear from mostly from the family.* ~ **lay counsellor 02**

3.8. Additional service provision challenges

Most of the gaps identified about service provision could be ascribed to administrative and logistic factors such as congestion at the clinic, which affect the flow of clients. Misconceptions about treatment were also identified as one of the main challenges which affected the retention in pre-ART care. Some of the service provision challenges are described below.

The major gap discussed by the study participants was the fragmentation of services and the absence of a one-stop service. At the study facility, clients were referred to different units or rooms for other forms of care such as for sexually transmitted diseases (STIs) or family planning. The facility organisation, set-up and availability of work space can contribute to the breaching of confidentiality as mentioned above. The effects of not having a one-stop service include unsatisfactory patient flow, clients not arriving at their destination (after being referred) because of poor communication between referral points and long waiting times. The lack of integration of services is still visible in the separate operation of units, which influences the patient flow and the ability to identify pre-ART clients timeously:

> *We have our HIV and TB units. We do not have a STI-specific unit; clients come like anyone. The TB and HIV Units are separated. But there is referral system from one unit to the other. We have noted the two units are very apart; we identified that as a problem. There is no plan in place to make them closer to each other.* ~ **facility manager**

Both lay counsellors and nurses highlighted that all chronic conditions were treated in one place and there was no designated area for clients who were on pre-ART care. As a result, this has created longer queues due to the bottlenecking.

> *This is not well for HIV/AIDS, e.g. patient flow becomes a challenge like queuing and being referred to another. There is no one-stop service. There seems to be a bottleneck in terms of the service flow at the facility. E.g. those who are stable will be able to get care from another cadre of professionals within the health care facility. Waiting and sitting for longer duration in the facility is not user-friendly.* ~**professional nurse 02.**

CHAPTER 4: DISCUSSION

The aim of the study was to explore clinic based factors at a primary health care clinic in Johannesburg, South Africa that support or hinder the retention of HIV positive people in the CoC if they are not ART eligible. This was to be achieved through exploration of services offered through the facility based wellness programme at the clinic, identifying the retention practices and resources allocated to tracing and bringing clients back into care who are lost to care during the pre-ART phase and exploring the clinic staff's perceptions about how their practices support or hinder the retention of HIV positive pre-ART persons. The major finding from the study was that there was a lack of understanding of the scope and extent of pre-ART care and not all health care providers seemed to get adequate preparation for tracing potential LTFU clients or retaining them in care. Research participants in the study indicated as particularly problematic the late return for care by pre-ART clients, which usually occurred when clients were already very sick.

Studies such as this one are important for identifying clinic based factors that influence retention in pre-ART care and could be used for making evidence-informed decisions to improve patient care, promote lasting retention in care and bolster programmatic outcomes. This would further help to attain the goals of the UNAIDS 90-90-90 targets in sub Saharan Africa, which are challenged by a weak care cascade, with poor linkage to care and retention in care (81). While the scaling-up of access to ART care has been evaluated in several studies, little has been written on HIV COC in the pre-ART phase (53). Integration of HIV services along the CoCfrom HIV testing to ART initiation has been programmatically poorly implemented in South Africa with different funding streams, personnel, monitoring tools and indicators (53). This discussion considers how lessons from one clinic speak to the larger issues facing South Africa and the region regarding pre-ART care.

4.1. Pre-ART care VS ART care services

This study found that health care providers lacked an understanding of the scope and extent of pre-ART care and not all seemed to get adequate preparation for tracing potential LTFU clients or retaining them in care. The health care facility under study showed a breakdown in the continuum of HIV care between HCT and ART. This supports findings of a systematic review

conducted by Rosen and Fox in 2011 on retention in HIV care between testing and treatment in sub Saharan Africa, which reported that only one third of the pre-ART clients were retained in care (33%) (22). Kranzer et al. review of four studies in South Africa similarly found low retention in pre-ART care, ranging between 41% and 46% (16) unlike the ART care which has a retention rate of almost 85% (5). As in most other middle and low-income countries, the focus of interventions has been mainly on improving the testing rates for HIV, as is evident in the HIV testing campaign in South Africa and on preventing losses in the ART care period (16), with a gap in the middle. The lack of sufficient linkages between the various stages of HIV care and a focus on the initiation of ART and the long-term retention of clients on ART contributes to the twice as high LTFU of pre-ART clients in the HIV care programme compared to clients eligible for ART (82). At the facility-level, when viewed through the lens of a single clinic, this lack of attention manifests in multiple ways.

4.2 Package of care for pre-ART individuals

According to the study participants, the package of care for pre-ART individuals was limited to vitamins B complex and Bactrim (co-trimoxazole). Updated national guidelines in South Africa recommend that individuals not yet eligible for ART are transferred to a "wellness programme" for regular follow up and repeat clinical assessment every six months (83, 84). The framework for the wellness programme at the facility under study was not consistent with this guideline, as some participants informed pre-ART individuals to come after three months, while others suggested six months. Inconsistency in the advice given to clients was common when comparing interviews.

The facility's wellness package of care for pre-ART mainly revolved around counselling and focused on health education and positive living. Given that counsellors are already employed for pre- and post-test counselling, this is hardly surprising. Other literature on retention has also noted a high reliance on providing health education as a means of encouraging clients to return for care (85) Retention programs have also placed a high value on providing health education, as timely health information is considered essential for behaviour modification and informed decision making (28). Of importance to note during the relay of health information is the appropriate time and context and emotional state of the individual.

At the study facility, counsellors were not able to do follow up counselling to offer further information about relevant health services beyond post-test counselling. Counselling support should be available to the client in the weeks and months following the positive test results to avoid overloading the client with information about HIV and to allow time to adjust to their diagnosis (86). Furthermore, besides verbal information stated by the participants, no handouts were given to client which proved to be a gap. Interventions proposed by WHO for HIV prevention, treatment and care include an approach based in health facilities, such as including information and education materials for preventing HIV transmission by people living with HIV, preventing the progression of HIV to AIDS, and any health related information (87). Further intensive education is supported by a randomised control study which stated that intensive patient education significantly improves clients compliance to treatment or HIV CoC (88), although this did not look at pre-ART. However, other studies have noted that educational efforts had made little impact on service used due to multiple factors that range from illiteracy to the fear of being seen with pamphlets containing HIV related information (73).

The post counselling that was explained by the participants might not be effective, as one study stated that when a patient learns that he or she is HIV-positive, the psychological shock prevents an effective transfer of information (89). It is well documented that clients become less receptive to the post test information and less aware of care (such as pre-ART care) required to prevent further reinfections after learning their status (90). This phenomenon justifies giving clients comprehensive pre-testing counselling so that they perceive the issues before they are screened and confirm that they have the physical and psychological capacity to understand the risks and benefits inherent in taking the screening test.

In addition to counselling, another aspect of the wellness programme was a clinical assessment. This included CD4 count measurement, physical assessment, liver tests, TB and STI screening. As with other advice, clients were given inconsistent instruction to return and collect their results anywhere from three to fourteen days after testing after the CD4 count measurement and the sputum tests. If the CD4 count measurement results were delayed by the NHLS (laboratory), this waiting period could be postponed further, with serious repercussions for the clients' access to optimal HIV care. A study has shown that clients are less likely to return to care when several clinical visits are required (91), leading to LTFU. This is due to clients not

having enough resources for transport which has been reported by several studies in South Africa (27).

4.3. Pre-ART Retention challenges

4.3.1. Confidentiality and nurse attitudes

Challenges faced by pre-ART persons based on health worker perception at the facility under study is confidentiality and professional nurses' attitudes, which had a negative impact on offering the required services to pre-ART persons. Study participants mentioned that nurse attitudes discouraged clients from accepting health care services from them as well as not having enough trust in terms of confidentiality issues. Some clients would rather wait until they are very sick to seek HIV care. The health care workers also blamed patients for not coming back as was evident in the quotation. "they wait until it is too late." The judgmental attitudes and victim blaming attitudes and beliefs are hard to change, and studies have shown that clients prefer to travel long distances just to be attended to by sensitive, non-judgmental health care providers who will provide support and optimal care (91, 92). The study results have extended previous literature that negative attitudes of health care providers contribute to the poor quality care and can contribute to LTFU by pre-ART clients (20, 92).

4.3.2. Data collection of pre-ART individuals

Timely health information is an essential management tool to deliver an effective health service especially at the early implementation stage of a programme (53). According to the professional nurses interviewed, documentation of pre-ART clients included the keeping of individual records of pre-ART clients (medical charts) and collective records (pre-ART register, INH register, vitamin B complex register and Bactrim/ co-trimoxazole register). While information pertaining to individuals' health helps in the successful management of their health, registers create additional administrative work load for the health cadres who are already overburdened which in turn might affect their service towards the clients (93). It is therefore essential to document the clients' clinical information in a consolidated patient or clinical chart/file which also contains sections for pre-ART care. The participants' highlighted scenarios where the pre-ART register is not properly completed or in some instances "disappear" from the facility because it is paper based, there is, therefore, a need to use an electronic register to resolve this issue. As noted in one study that record keeping could become

a major challenge considering that some facilities do not have an adequate or existent computer system to handle large patient loads, which could lead to clients having longer waiting times (94).

The quality of record keeping had implications for the ability to trace pre-ART clients who do not come for follow-up visits. Resultantly, the inconsistency in data collection of patient information impacted on the ability of the health care facility under study to improve their service provision for pre-ART clients either by tracing them or identifying those lost to care. Similar issues were highlighted in a study conducted to assess women's perceptions of health system weaknesses relating to ART retention in the Eastern Cape, South Africa, which reported a high frequency of incorrect counting, duplication of information and inconsistent indicators (95). This suggests that more research is needed to evaluate the introduction of quality improvement systems in a South African context at a clinic and national level which will be discussed in more detail in the recommendations section.

4.3.3. Case management of pre-ART individuals

While structures exist that would enable case management of pre-ART clients, it was not happening at the clinic under study. In a randomised control trial (RCT) by centers for disease control and prevention (CDC) known as Antiretroviral Treatment Access Study (ARTAS), pre-ART individuals who received a case management-based intervention were facilitated to HIV care linkage within six months (96). The case management intervention ensured that a newly diagnosed HIV positive person received at least five case manager contacts to ensure linkage to HIV care (96). A cautionary note is that even with a pre-ART care system in place, as had been done in the case of a clinic in Cape Town, there could still be implementation issues due to weaknesses in the continuity and quality of service delivery (53).

4.4. HIV stigma and fear to access health care

The context of stigma in the community contributed to LTFU issues in the clinic. A study by Maartens and colleagues showed that stigma can lead to clients avoiding accessing care from facilities within their communities, thus leading to LTFU (97). The study results show that health care providers believed that clients currently experienced stigma and discrimination

within the community, thus affecting their willingness to access and remain in care. Similarly, a study that aimed to evaluate the experiences of social stigma and implications for health care among a diverse population of HIV positive adults revealed that early negative experiences with the health care system may also result in individuals delaying medical care for HIV, thus posing a higher risk of HIV among the community (98).

Facility specific issues that were raised in this study were that there are specific queues and specific equipment that is being exclusively used for HIV-positive clients. Moreover, one study that was conducted in Botswana reported that HIV-related stigma was associated with decreased likelihood of utilising routine HIV testing and of planning to test among people not previously tested. This was done due to the introduction of a policy in 2004 which made HIV testing part of the routine testing. The main objective was to increase uptake of HIV testing and treatment and to reduce HIV-related stigma by treating the HIV test like any other routine medical procedure (99). This highlights the need for context-specific or facility based studies to better understand the social processes that shape stigma as experienced by persons living with HIV/AIDS. As highlighted by a study in South Africa on gender and access to ART, it was established that gender norms are some of the causes that make it difficult for men to accept their ill health condition and also impede their health seeking behaviour (100).

4.5. Men's unwillingness to engage in HIV care

Men's delay in seeking health care leads to a likelihood of late HIV diagnosis and lower their chances of remaining in HIV CoC and eventually leads to higher odds of morbidity and mortality (28). In this study, gender affected both access to care and retention in HIV care. Participants at the facility highlighted that gender relations and masculinity deterred men from receiving HIV care at the health care facility under study. It was further explained in the study that men were more afraid of stigma and did not want to be seen at the clinic as compared to their female counterparts. One study that was conducted in Zimbabwe had reported that the main reasons why men were less likely to use HIV health care services were due to the perception of masculinity whereby men were expected to be disease free, be strong, economically productive, be in control and be highly sexual within society (101). This societal norm has put more men at risk of HIV infection and seeking the information related to safe sex in order to prove their manhood (78).

4.6 Lack of integrated services

The fragmentation of services and the absence of a one-stop service for PLHIV were identified by health care providers pertaining to the services offered to pre-ART clients. Some studies that were conducted in South Africa have reported that the main challenges to the implementation of a one-stop service were the lack of policy guidance on integrated care and weak referral systems (35) which were also the case at the facility under study. It should also be noted that while facility staff favoured one-stop services, this is not always true of clients. One study conducted in Sub Saharan Africa that aimed to assess the prevalence and factors associated with clients lost in the programme between HIV diagnosis and the start of ART indicated that participants preferred to retain sub-specialist groups of health care providers whilst strengthening the referral system (102). In addition, a study in Mwanza, Tanzania, that measured the proportion of HIV-positive pregnant women who underwent the antenatal HIV diagnosis assessment further supports the idea that the successful rollout of integration of ANC and HIV care is highly dependent on the buy-in of providers (acceptability and feasibility of integration interventions) and the available support provided (74). The ability to provide one-stop HIV integrated services is possible and has the potential to increase retention in pre-ART care. Due to conflicting results, the researcher suggests tailored interventions for the facility as more ideal and would lead to the success of the implementation of the pre-ART programme. More studies are needed to evaluate the effectiveness of standalone models and integrated health services within a South African context as well.

4.7. Limitations

A key limitation of this study is that clients who were labelled as lost to follow up may, in fact, be accessing care and treatment from a different facility. Thus, the perceptions of LTFU by staff at the clinic may be misguided by this phenomenon. Additionally, the researcher's role as a former employee at the health care facility might have influenced the results of the study, as participants may have responded in the way that reflected a social desirability or a Hawthorne effect, whereby participants may have responded in the way that reflected what they thought. This might have resulted in information bias or skewed results to an extent which the responses could potentially be underestimated.

The researcher is a foreign national, study participants might not have been interested in the study and viewed it suspiciously, hence the participants might have lacked the commitment to participate in the study. The researcher was forced to rebook appointments on several occasions. As highlighted in the methodology section, lay counsellors faced some difficulty in expressing themselves in English, thus there is a potential for information bias and mistranslation of information. The researcher did not make arrangements for translations which limited some interviews with the lay counsellors.

The study did not involve interviewing PLHIV due to ethical, logistical and time constraints. However, health care providers who work directly with clients at community level provided information pertaining to PLHIV and AIDS. These were their own perceptions and cannot be construed as those of PLHIV. This study also focused on one health care facility, hence the findings cannot be generalised in other health care facilities.

CHAPTER 5: CONCLUSION AND RECOMMENDATIONS

5.1. Conclusion

In addition to the major challenges related to the lack of emphasis on pre-ART care in scholarship and practice, associated problems regarding record keeping and the provision of integrated services, and several other hindrances at this facility were also identified. The facility under study had an influence on pre-ART care, due to what it provides or supplies. The services are available but they are not provided for in a CoC fashion, thus hampering the optimal utilisation of the health care services by PLHIV. Some of the factors that are affecting the supply of pre-ART services are insufficient post-test counselling for newly diagnosed patients on the importance of CoC, and ineffective linkage to further CoC. There is an inability to provide services according to the defined standards for health establishments due to insufficient space for private consultations at the health care facility, which in turn causes clients to wait for long period of time. This is a major source of dissatisfaction with care and consequently a barrier to the CoC. Fragmentation of services at the facility also increases the likelihood of clients falling through the cracks and not reaching their designated points, which results in LTFU. Negative attitudes of health care providers contribute to poor quality care, resulting in suboptimal patient care. Conversely, positive encounters within the health-care system can motivate patients to seek ongoing medical assessment and treatment for their drug dependency and other health related problem.

5.2. Recommendations

Improving pre-ART retention

Based on this study, the following recommendations have been made for improving retention, the first being a change in organisational culture. The health care facility needs to adopt an HIV treatment guideline that underscores the importance of pre-ART care. Emphasis should be placed on the importance of adherence to HIV care as a whole, rather than solely on ART. Improved attention to retaining clients that are on pre-ART in the HIV CoC requires a multi-pronged approach that will not only strengthen the pre-ART phase of HIV care at the facility level (99). Other recommendations to strengthen the focus on pre-ART care could be divided into recommendations for the policy, provincial, district, facility and community level. Doing a root cause analysis at different levels of some of the gaps identified could also contribute to

providing the necessary information to devise improvement in services or pre-ART-specific interventions. A few facility-specific suggestions follow:

Patient and health care provider relationship

Patient and health care provider relationships need to be improved through a facility system level implementation of sensitive education and training activities for health care providers and staff members. In order to improve health care provider positive or negative relationships with clients, it is essential to understand the factors that influence the relationship. The study results have established that negative staff attitudes were one of the main challenges to retention in pre-ART care. According to literature, patient provider relationship is a crucial element as this is associated with patient satisfaction, patient self-management and treatment adherence (85). Thus, it has been recommended that a workshop aimed at improving patient provider communication skills, which could be taught at all levels, is a crucial skill that has gone unnoticed. A similar study was conducted to evaluate this intervention which included a full-day training, optional workshops to reinforce strategies for engaging the patient and personal feedback on video-taped interactions with simulated clients (role playing exercises). Overall, those that received the training had improved in their patient-centered communication and communication behaviours immediately post-training, however, it has been suggested that longer training or follow ups are preferred as this reinforces original training compared to brief training (85).

Tailored support for pre-ART individuals

As previously mentioned in the study results, there is no support tailored for pre-ART individuals that could help address their fears and other social challenges such as stigma. Uganda implemented a similar tailored support system known as the 'Post Test Clubs'' by AIDS Information Center (AIC) that provided long-term support to individuals who have been tested for HIV regardless whether the person was positive or negative. This brought about positive experiences for the individuals during the pilot testing of the intervention as some individuals reported that the support from the clubs brought new social relationships (friendship) and comfort before initiating ART. There are similar support mechanisms such as the post-test club in South Africa offered by non-governmental organisations that cater for pre-

ART individuals which can be adopted by the South African government so as to offer it as a public health intervention where social support structures are limited.

Implementation of men, masculinity and engagement in HIV care as intervention

Policy makers need to implement a men and masculinity intervention to address men's barriers to HIV testing, care and treatment. There is a need for HIV health promotion programmes that specifically target males in terms of increasing the knowledge about the importance of pre-ART retention. More specifically, such programmes need to challenge the behaviours and beliefs associated with the ideology of masculinity which males are portrayed as dominant and have relationship control (78) which translates to health risks for men themselves and their partners. For example, the "One Man Can" programme initiated by Sonke Gender Justice Network in South Africa, involves community participatory workshops that provide an open space to discuss social issues and encourage men to reflect upon social norms , definition of masculinity, and how masculinity norms can be challenged in relationships, communities, and broader society (78). These workshops should be replicated in communities such as Hillbrow since men who have attended these workshops have reported having increased capability to overcome masculinity related behaviours associated with testing, care and treatment. In addition, men have reported having an increased willingness to be tested for HIV as they were able to discuss HIV openly. Interventions that challenge masculinity norms provides a promising new approach to address male retention in pre-ART care (78).

Introduction of quality improvement system in the clinic setting

Accurate and reliable health data has been an essential component to monitoring health and improving the delivery of health care programmes and services. As previously highlighted in the study results, there is poor documentation with incomplete or missing pre-ART registers. It has been recommended that a quality improvement initiative that involves data training to health care providers should be introduced in a clinic setting and at a national level. This training highlights the importance of patient information, data collection and feedback, regular data audits (carried out by data clerks in the health facility) and monthly data reviews thus increasing the completeness of the clinic database. One study was conducted to evaluate the effectiveness of a similar programme on the accuracy and completeness of data in PMTCT

services in KwaZulu-Natal, South Africa. After the intervention was implemented in 58 clinics, it has been reported that the level of data completeness increased by 38% (16).

Point of care CD4 count testing

Study results have highlighted that one of the main challenges to retain clients in care was due to the clients being required to collect their CD4 count results at the clinic between three to fourteen days depending on whether there was a delay in results at the laboratory. In order to reduce the amount of time taken to receive these results, it has been advised to implement the point of care CD4 count testing. This intervention aims to ensure timely completion of ART eligibility assessment by clients receiving their CD4 count results at the time of HIV diagnosis. It is used to overcome the main challenges of delayed results in the laboratory, reduced the time of HIV testing to ART initiation, reduce LTFU and increase the chances of infected individuals having their CD4 T-cell count measured and receive the results on the same day (27).

This intervention was implemented in Johannesburg, South Africa (Esselen Clinic). Results showed that providing CD4 results at HIV diagnosis increases the likelihood of reporting for ART compared with standard of care. A number of clients LTFU dropped significantly and the influence of returning to collect CD4 results was diminished thus reducing the clinical visits (103).

Further research on pre-ART care among the most at risk population

Barriers to pre-ART care were not explored among any other specific populations such as sex workers and migrants, and this represents a potential area of further research. Males were considered to be less likely to remain in pre-ART care however, there are limited studies that evaluate interventions that cater for men who are constantly travelling due to work purposes (46). As previously discussed, language was one of the limitations to the study. Therefore, it has been recommended that future studies should be conducted in the study participant's local language in order to prevent any information bias.

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Appendices

Annex 1: Senate Plagiarism Policy

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG | FACULTY OF HEALTH SCIENCES

PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS

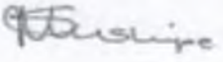
SENATE PLAGIARISM POLICY: APPENDIX ONE

I **Shelter A. Mushipe** (Student number: **749403** am a student)

registered for the degree of **Master of Public Health** in the academic year **2017**

I hereby declare the following:

- I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the original source) is wrong.
- I confirm that the work submitted for assessment for the above degree is my own unaided work except where I have explicitly indicated otherwise.
- I have followed the required conventions in referencing the thoughts and ideas of others.
- I understand that the University of the Witwatersrand may take disciplinary action against me if there is a belief that this is not my own unaided work or that I have failed to acknowledge the source of the ideas or words in my writing.

Signature  Date: **31 March 2017**

26/04/2015
1

Annex 2 HREC certificate

R14/49 Mrs Shelter A Mushipe

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M140384

NAME: (Principal Investigator)	Mrs Shelter A Mushipe
DEPARTMENT:	School of Public Health Joubert Park Clinic Department of Health Rehion F
PROJECT TITLE:	An exploration of clinic based influences that support or hinder the retention of HIV positive clients in Pre ART care at Joubert Park Clinic, Johannesburg, South Africa from January 2010 to July 2014
DATE CONSIDERED:	28/03/2014
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Sara Nieuwodt
APPROVED BY:	Professor P Cleaton-Jones, Co-Chairperson, HREC (Medical)
DATE OF APPROVAL:	20/06/2014

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House, University.
I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**

Principal Investigator Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Annex 3: Approval Letter from Johannesburg Health District

GAUTENG PROVINCE
REPUBLIC OF SOUTH AFRICA

Joburg
a world class African city

Enquiries: C Fraser
Tel +27(0) 11 407 7437
Tel +27(0) 11 407 6340

PO Box
Braamfontein
South Africa
2017

21 May 2014

Dear Ms Mushipe

APPROVAL TO CONDUCT RESEARCH WITHIN THE JOHANNESBURG HEALTH DISTRICT

Permission has been granted to you to conduct research within the Johannesburg Health District.

Topic: An Exploration of clinic based influences that support or hinder The retention of HIV positive clients in Pre ART care at the Joubert Park Clinic, Johannesburg, South Africa

Please contact the following person(s) before you commence with your project and to gain access to the clinics:

Region	Regional Health Manager	Contact No.	Cell phone
F	Mr Oupa Montsioa	011 681 8130	082 467 9423

Should you have any queries please do not hesitate to contact our department.

We look forward to your Final Research Report.

Thank you

DR. R. BISMILLA
Executive Director
City of Johannesburg
Health Department

21/5/2014

Annex 4- Semi structured interview Guide – Lay Counsellors

A. IDI Preparation Checklist

The following preparations should be completed before each IDI;

- ☐ 1 extra copy of study information sheet
- ☐ 1 extra copy of consent form
- ☐ 2 copies of audio-recording consent form
- ☐ Digital audio-recording equipment (tested for working condition)
- ☐ Backup batteries for audio recorder(s)
- ☐ Notebooks for interviewer
- ☐ Private room
- ☐ Food and drinks for interviewee

Name and Signature of Study Staff: _____ *Date:* _____

B. Checklist for Interviewer

The IDI shall only progress once the following are confirmed:

- ☐ Interviewee has been working at Joubert Park Clinic since 2010
- ☐ Study ***consent form has been signed*** and ***copy given to interviewee***
- ☐ Interviewee has ***signed audio-recording consent form***

Name and Signature of Study Staff: _____ *Date:* _____

C. Introduction Exercise

Note: Start recording

Once the consent process is complete, to build rapport, the interviewee introduces a little bit about himself/ herself without using his/ her name, e.g. age, number of siblings and what he/ she does for pleasure

Note: Check that recorder is working before proceeding

D. IDI guide

Note: Start recording

1. Could you tell me a little bit about your current position
    a. How long have you been doing this job?

2. May you please explain the purpose of counselling to PLHIV who are not yet eligible for ART but in care.
    a. Can you describe what you talk about
    b. Do you feel like you have any influence over the decision they make? Explain.

3. Can you describe how a patient receives CD4 test results from the time the blood is drawn
    a. How long do they wait to get a CD4 test?
    b. What happens to the patient if the results are not available?
    c. How long do pre-ART Persons living with HIV/AIDS wait at the facility to get other services?

4. Can you explain some of the reasons pre-ARTpatients may not to come back to health care facility for scheduled appointment or a clinical review
    a. In your view, what is the most important reason why clients do not return?
    b. What measures do you use to encourage attendance and compliance to scheduled appointments? Explain.
    c. Can you explain some of the challenges pre-ART clients have described to you

5. Can you describe how persons living with HIV/AIDS are documented? Explain.
    a. Probe specifically about documentation of pre-ART clients. Explain

6. From your experiences, how are resources allocated to activities targeting PLHIV before ART is initiated?
7. Can you describe services offered to PLHIV who are not yet eligible for ART

Is there anything else you would like to add before we finish?

Annex 5: Semi structured Interview Guide – Facility Manager and Clinic Nurses

A. IDI Preparation Checklist

The following preparations should be completed before each IDI:

- ☐ 1 extra copy of study information sheet
- ☐ 1 extra copy of consent form
- ☐ 2 copies of audio-recording consent form
- ☐ Digital audio-recording equipment (tested for working condition)
- ☐ Backup batteries for audio recorder(s)
- ☐ Notebooks for interviewer
- ☐ Private room
- ☐ Food and drinks for interviewee

Name and Signature of Study Staff: _____ *Date:* _____

B. Checklist for Interviewer

The IDI shall only progress once the following are confirmed:

- ☐ Interviewee confirms he/ she has worked at the facility since 2010
- ☐ Study ***consent form has been signed*** and ***copy given to interviewee***
- ☐ Interviewee has ***signed audio-recording consent form***

Name and Signature of Study Staff: _____ *Date:* _____

C. Introduction Exercise

Note: Start recording

Once the consent process is complete, to build rapport, have the interviewee introduce a little bit about herself without using her name, e.g. age, number of siblings and what she does for pleasure

Note: Check that recorder is working before proceeding

D. IDI guide

Note: Start recording

1. May you describe your work pertaining to people living with HIV/AIDS?
    a. May you explain the main focus area (wellness/ ART)

2. Can you describe how clinical assessments are done to newly diagnosed HIV positive persons
    a. When is the blood drawn for CD4 test for the newly diagnosed HIV positive person?
    b. Please explain how long it takes to get the results back.

3. Can you please explain how clients access pre-ART services in the facility?

4. Can you describe the human resource requirements for managing pre-ART clients?
5. Can you describe how clients that are lost to care for pre-ART services are identified
    a May you explain the tools used for the identification purposes.

    b How do you track clients that are lost to care from pre-ART services?

    c Are there any available resources for this purpose?

6. Can you describe how the facility uses pre-ART data?

7. Can you describe your own perceptions pertaining to pre-ART?
    a. Are persons living with HIV turn up in large numbers for clinical and wellness services before ART initiation? Explain the reason for this huge or low turnout.
8. May you explain any differences in attendance between men and women for pre-ART services

9. Can you describe your feelings about offering services to Persons living with HIV/AIDS on pre-ART care
    a. Do you feel you have an influence on their turn out?
    b. Can you describe health information that is provided to persons living with HIV/AIDS about pre-ART?
    c. Can you describe how the clinic may improve loss to care among HIV positive clients on pre- ART

Is there anything else you would like to add before we finish?

Annex 6 Audio-recording Consent Form – Interview

The reason for audio-recording the interview has been explained to me.

I am aware that I may choose whether to participate or not to participate in the interview and to be recorded.

I am aware that I may stop the interview at any point.

- The researcher will take measures to ensure that audio recordings of the interview will be stored in locked and/or password protected files and will be stored securely for a minimum of two years after publication or six years in the absence of a publication, after which recordings will be destroyed

I consent to having the interview audio recorded.

Interviewee:

Name: _____

Signature: _____

Date:_____

Researcher

Name: _____

Signature:_____

Date:_____

Annex 7 Information Document

Study title: An exploration of clinic based influences that support or hinder the retention of HIV positive clients in pre- ART care at a clinic, Johannesburg, South Africa from January 2010 to July 2014.

1. Introduction

Good Day, my name is Shelter Mushipe. I am a student at the University of Witwatersrand and an employee of Howard University in Pretoria, South Africa. I am doing a research on exploring clinic based influences that support or hinder the retention of HIV positive clients in pre-ART care. Research is a process of getting data and information which gives answers to a question. This is a study that only involves research and not routine care. This study is being conducted by me in my capacity as a student, in partial fulfilment of the Masters in Public Health at Wits University.

Invitation to participate:

I am inviting you to take part in a pre-ART research study. In this study, pre-ART care will be defined as the phase between an initial HIV positive diagnosis and before ART initiation. Before participating in this study, it is important that you read and understand the following explanation of the purpose of the study, the study procedures, benefits, risks, and your right to withdraw from the study at any time.

This information leaflet is to help you decide if you would like to volunteer. You should fully understand what is involved before you agree to take part in this study. If you have any questions, do not hesitate to ask me.

What is involved in the study;

The study design will be a qualitative exploration of clinic staff perceptions of the quality of services offered to pre-ART patients, the retention practices and resources allocated to tracing and bringing back patients into care and other practices that may influence the retention of pre-ART patients. It will also comprise exploratory qualitative face to face in-depth interviews (IDIs) with you.

If you take part in this study, I will interview you in English language. With your permission, the interview will be audio-recorded so that I do not miss anything that you say. I will explore with you a series of open ended questions. Your responses to the questions will be used to help me:

- Learn about your experience of having HIV positive persons being retained in care before ART enrolment
- Understand how you feel about pre-ART based on your experience
- Understand how you communicate with clients about pre-ART

I am inviting all 15 staff from the clinic whose work relates to pre-ART to participate, including management, professional nurses and lay counselors.

The total amount of time required for your participation in this study is between forty-five to no more than one hour. The interview will take place in a private room and is a one-time event. No other

interviews are required. I am mainly interested in this information because I want to learn how I can improve retention in care for persons living with HIV who are not yet eligible for ART.

Risks of being involved in the study:

The interviewer may ask questions or raise issues that are personal and of a sensitive nature that may make you feel uncomfortable or upset. There are no wrong answers in this type of interview. I am interested in your experiences and thoughts. However, you may skip any questions that you don't want to answer or discontinue the interview at any point. There may be other discomforts that are not known at this time.

6. Costs and Benefits of being in the study:

There is no cost to you for being part of the study. You will not benefit directly from taking part in this study. Information gathered from this study may help me learn more about how to improve Pre-ART care in South Africa, better considering the experience of health workers, like you.

Participation is voluntary:

It is important that you understand the following:

- Taking part in this study is completely voluntary.
- You may refuse to take part in this study or leave it at any time. By doing so, you will not lose any benefits you receive now or have a right to receive.
- Your decision will not affect your ability to take part in other research studies.

This consent form may contain words that you do not understand. Please ask me to explain any words or information that you do not clearly understand. If you agree to take part in this study, I will ask you to sign this form to show that you want to take part. I will give you a copy of this form to keep.

8. Right as a Participant in this Study to refuse to take part

Taking part in the study is your choice. If you decide to take part, you can always change your mind. You can stop taking part at any time.

9. Ethical Approval

This study protocol has been submitted to the University of the Witwatersrand, Human Research Ethics Committee (HREC) and written approval has been granted by that committee. The Health Regional Manager (Region F) and facility manager of the clinic have also granted written approval for the study.

10. Confidentiality

Anything that you share in the interview will be kept confidential in the following ways:

- Your rank as a participant will not be mentioned in the study
- We will use a code instead of your name for any quotes, which will be transcribed directly from the audio recording.
- Audio recordings and transcripts of the interview will be stored in locked and/or password protected files and will be stored securely for a minimum of two years after publication or six years in the absence of a publication, after which recordings will be destroyed
- All information obtained during this study, including personal data and research data will be kept strictly confidential. Data that may be reported in scientific journals will not include any information that identifies you as a participant in this study.
- This information will be reviewed by authorised representatives of the study team
- The information might also be inspected by the University of the Witwatersrand, Human Research Ethics Committee (HREC).

11. Sources of Additional Information

If you have any questions about this study, you may contact Ms. Shelter Mushipe (Cell: 073 839 7226) the principal investigator.

If you have any questions about your rights as a participant or for reporting of complaints/ problems, you may contact: HREC Medical chairperson Prof P Cleaton-Jones on 011 717 2302, email address peter.cleaton-jones@wits.ac.za, HREC Secretariat, Ms Z Ndhlovu on 011 717 1252, email address, Zanele.ndhlovu@wits.ac.za ,or Ms A Keshav on 011 717 2700, email address, anisa.keshav@wits.ac.

Annex 8 Informed Consent:

- I hereby confirm that I have been informed by the study staff (_____) about the nature, conduct, benefits and risks of the Pre-ART care Study.

- I have also received, read and understood the above written information (Participant Information Leaflet and Informed Consent) regarding the study.
- I am aware that the results of the study, including any personal details such as those regarding my age and residential area will not be included 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 interviewer.
- 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.

PARTICIPANT:

Printed Name Signature / Mark or Thumbprint Date and Time

I, _____herewith confirm that the above participant has been fully informed about the nature, conduct and risks of the above study.

STUDY STAFF:

Printed Name Signature Date and Time

Annex 8 Informed Consent:

- I hereby confirm that I have been informed by the study staff (_____) about the nature, conduct, benefits and risks of the Pre-ART care Study.
- I have also received, read and understood the above written information (Participant Information Leaflet and Informed Consent) regarding the study.
- I am aware that the results of the study, including any personal details such as those regarding my age and residential area will not be included 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 interviewer.
- 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.

PARTICIPANT:

Printed Name	Signature / Mark or Thumbprint	Date and Time

I, _____herewith confirm that the above participant has been fully informed about the nature, conduct and risks of the above study.

STUDY STAFF:

Printed Name	Signature	Date and Time