

# **UNIVERSITY OF THE WESTERN CAPE**

Faculty of Community and Health Sciences

## **LOSS TO FOLLOW UP FROM HIV CARE AMONG WORKERS IN THE SOUTH AFRICAN CLOTHING AND TEXTILE WORKERS UNION IN ETHEKWINI DISTRICT, KWAZULU NATAL**



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## KEYWORDS

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Antiretroviral therapy program

Qualitative study

People living with HIV



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# ABSTRACT

## BACKGROUND AND AIM

**Background:** Human Immune Deficiency Virus (HIV) is a public health challenge worldwide. Antiretroviral therapies (ART) are medications that treat HIV virus infection by suppressing the virus and stopping progression of HIV disease, and that improve quality of life. People initiated on ART need to adhere to their treatment for the rest of their lives.

In 2016, there were 7,1 million people (age 15-49) in South Africa living with HIV, representing 19 % of the global HIV burden, with 56% of the adults on ART. Life expectancy of South Africans for both males and females improved between 2009 and 2011 because of ART treatment. People lost to follow up while on ART compromise their own health and the long term positive benefits of the ART regimen, and hence there is a growing emphasis to improve the retention of people who are already on treatment.

**Aim:** This study was conducted examining HIV positive South African Clothing and Textile Workers Union (SACTWU) members who are currently on ART treatment and had previously been lost to follow up (LTFU) from ART care. The study aimed to explore factors associated with LTFU of clients on ART treatment and care among the South African Clothing and Textile Union members living with HIV and attending the SACTWU Worker Health Program Clinic.

## METHODOLOGY

An exploratory qualitative study design method was used to explore the reasons why the SACTWU union members who are HIV positive and on treatment from their clinic get LTFU. For participant selection, purposive sampling was used to recruit the ten patients that had been LTFU and traced back to the clinic. These patients had to have been SACTWU members who are HIV positive and on ART attending the SACTWU Worker Health Program clinic. Seven service providers employed at the SACTWU Health Clinic were also selected for participation in the study. Data was collected through a focus group discussion with the service providers, and through in-depth interviews with the patient participants. The interviews were transcribed and the content analysed. Data was coded and categorized using manual coding. The content of the transcribed and translated interviews was analysed thematically and arranged into appropriate themes to generate explanations.

## FINDINGS

The study findings showed that factors influencing LTFU were complex and interlinked. The most common factors identified as contributing to SACTWU union members getting lost to follow up were individual related factors, socio economic factors and health system related factors. The most common patient related factors contributing to the SACTWU ART patients being LTFU is non-disclosure of their HIV status. Non-disclosure resulted in lack of support which led to LTFU. Other individual related factors included physical health, lack of treatment literacy, and impact of alcohol use, travelling and use of herbal medication as an alternative to ART. Socio economic factors which contributed to the SACTWU ART patients being LTFU were cost and logistics, food shortages, stigma, discrimination, living conditions of overcrowding and lack of privacy and work related pressures. Health system factors that contributed to LTFU among the SACTWU ART patients were mostly the required frequent clinic visits and the long waiting times at the clinic. This made a noteworthy contribution to the SACTWU union members on ART being LTFU because their income was negatively affected by these clinic visits. Other health system related factors included health worker attitudes and stand-alone clinics which placed them at risk of potentially being identified by others as being HIV positive.

## CONCLUSIONS AND RECOMMENDATIONS

Strategies need to be implemented that address patient related factors, socio economic factors and, most importantly, health system factors. It is hoped a more accepting work environment has the potential to make it easier for the SACTWU members living with HIV and on ART to stay adherent to the ART treatment and thus reducing LTFU. Engaging the employers will also assist in increasing their awareness to HIV/AIDS and will result in special consideration of their employees on ART when they have their clinic appointments. Ways to encourage and deal with the possible need for the disclosure of HIV status should be pre-emptively discussed with patients before the lay counsellor performs an HIV test so that should the patient test positive, potential plans for disclosure have been developed. Patients should be encouraged to be accompanied by the person to whom they have chosen to disclose their HIV status when they attend their second scheduled appointment at the health facility. They should also be counselled not to stop taking ART if they have been drinking but to rather continue even if they have missed some medication doses. They should also be counselled not to stop taking ART if they have been drinking but to rather continue even if they have missed some medication doses. ART services should be offered at both SACTWU clinics (the stand-alone ART clinic and the general PHC clinic) so that a patient who did not wish to be seen as living with HIV has the option of obtaining their ART without having to collect this from the ART clinic.



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## ABBREVIATIONS AND ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral therapy
ARV	Antiretroviral
CCMDD	Central Chronic Medication Dispensing and distribution
DOH	Department of Health
FDC	Fixed Dose Combination
HCW	Health Care Workers
HIV	Human Immunodeficiency Virus
LTFU	Lost To Follow Up
PLWH	People Living With Human Immunodeficiency Virus
SACTWU	South African Clothing and Textile Workers Union
TB	Tuberculosis
UNAIDS	Joint United Nations Programme for HIV/Acquired Immune Deficiency Syndrome
USAID	United States Agency for International Development
WHO	World Health Organisation

## DECLARATION

I, **Sibusisiwe Noluthando Ziqubu**, declare that *Loss to follow up from HIV care among workers in the South African Clothing and Textile Workers Union in Ethekwini District, Kwazulu Natal* is my own work, which has never been submitted for any degree or examination in any other institution. All the sources used or quotations used have been acknowledged by complete references.

**Full name:**

**Signature:**



**Date:**

10 November 2018





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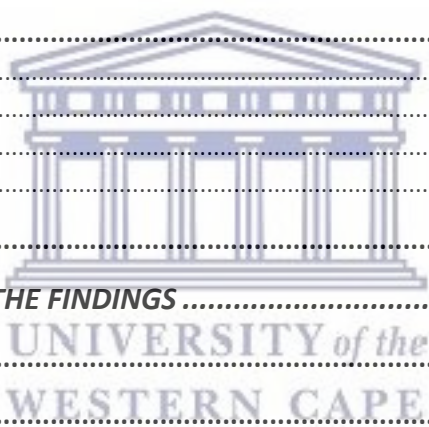
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# CHAPTER 1 - INTRODUCTION

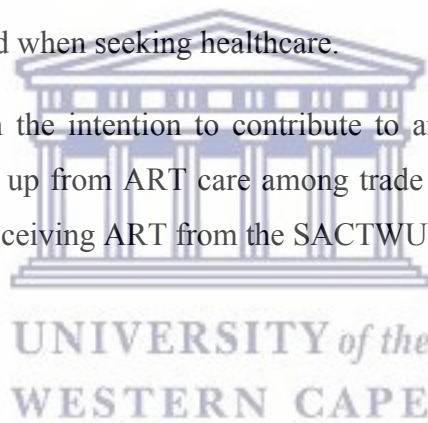
## 1.1 INTRODUCTION

Human Immunodeficiency Virus (HIV) is one of the major contributors to morbidity and mortality worldwide. UNAIDS (2015) global statistics estimate that there are approximately 36.7 million people currently living with HIV globally. Sub-Saharan Africa, and particularly Southern and Eastern Africa, is the region most affected by HIV. Sub-Saharan Africa has approximately 25.6 million people living with HIV (PLWH) comprising 70 % of those living with HIV worldwide (UNAIDS, 2015). Globally, as at July 2017, 20.9 million PLWH were initiated on antiretroviral therapy (ART).

Antiretroviral therapy (ART) comprises a combination of medication that provides treatment to people living with HIV (PLWH). The drugs do not kill or cure the virus but control viral replication within a person's body and allow the individual's immune system to strengthen and regain capacity to fight infections. When taken in combination, ART significantly reduces mortality and improves the life expectancy in PLWH. When virus replication is slowed down, so is HIV-related disease and transmission (World Health Organisation (WHO), 2013). Africa is the leading continent in expanding access to ART therapy, with Sub-Saharan Africa having approximately 11 million PLWH on treatment, and with South Africa having the largest ART treatment program (UNAIDS, 2016). South Africa has the largest global ART treatment program with an estimated 3.4 million PLWH initiated on ART treatment by mid-2015 (Johnson et al., 2017). Despite the greatly improved coverage with ART, significant numbers of people drop out of care at various points of the treatment pathway. This reduces the individual and public health effectiveness of provision of ART care programs. In 2014, UNAIDS launched a campaign called '90-90-90' for 2020 with the aim of controlling and ending the HIV epidemic by the year 2020 (UNAIDS, 2014). This means that by the year 2020, 90% of all those who are HIV positive should be diagnosed and know their status, 90% of all those who are diagnosed with HIV should be initiated on ART, and 90% of all those on ART should be virally suppressed. The currently accepted defines LTFU as a patient having not been seen at the clinic either by a nurse or doctor or having collected ART medication at the pharmacy for "90 days after the last scheduled appointment" (WHO, 2011: 26).

While the access to ART rate has increased in the low resource settings, the retention of patients on ART care has become an increasing challenge (Fox & Rosen, 2010). Because of poverty, care to not disrupt a person's employment is frequently prioritized over their own healthcare. Hence, working class people may be among those commonly LTFU from ART care (KI, social worker). Many strategies have been developed in order to initiate as many people living with HIV (PLWH) as possible on ART and reduce the number of PLWH who become LTFU from ART treatment. In South Africa, these include free public sector healthcare provision of lifelong ART upon diagnosis with HIV since 2016 (Cornell et al., 2017). Other initiatives include increasing availability and access to local clinics in the rural areas, ART adherence promoting clubs in the communities and establishing Central Chronic Medicine Dispensing and Distribution (CCMDD) programmes and workplace programmes. In the case of the latter, those employed can receive medical care at the workplace healthcare facility or near their employment (National Department of Health, South Africa (DOH, 2015). The trade union South African Clothing and Textile Workers Union (SACTWU) has also established clinics where the union members can seek medical services closer to their workplace. These clinics were established for the convenience of union members so that their employment is not greatly affected when seeking healthcare.

My research was conducted with the intention to contribute to an improved understanding of the factors influencing loss to follow up from ART care among trade union members living with HIV, belonging to the SACTWU and receiving ART from the SACTWU clinics.



## **1.2 PROBLEM STATEMENT**

LTFU of PLWH on ART presents a serious problem for an individual's health and public health initiatives to control the HIV epidemic. Interruption of ART can lead to an individual's health deteriorating and a person may become more infectious as his or her viral load will be high. The lives of those living with HIV are at greater risk as they are more likely to contract opportunistic infections as their CD4 count decreases. From a public health perspective, poor ART adherence can lead to both individual and group resistance to ART medication and greater risk of HIV transmission. Data for 18 countries collected in 2013, including a cohort of approximately 200 people on ART in each country reviewed, indicated that the average retention rates decreased from approximately 86 percent at 12 months on ART to 82 percent at 24 months to 72 percent at 60 months from starting ART (WHO, 2013).

As a result, there is a growing emphasis on improving the retention of people already initiated on ART. Ensuring good adherence will decrease the HIV incidence rates as PLWH are less infectious when on ART. Known barriers to adherence to treatment include having to travel long distances to the health facilities, long waiting times at these facilities, shortage of clinic staff, PLWH having difficulty taking time off work to attend healthcare, inadequate understanding of their ART treatment plan and fear of HIV-related stigma, discrimination and death (WHO, 2013). It is therefore important to investigate the reasons for LTFU from ART care in order to address problems associated with poor ART adherence.

SACTWU members have their own health facility established closer to the workplace where they can collect their ART and receive appropriate specialised HIV care. This means that they do not have to attend at their overcrowded local clinics where they could also be seen by other members of their community. Nevertheless, some SACTWU members living with HIV on ART are LTFU from ART care. Exploring in greater depth the reasons for this will assist SACTWU in developing further strategies for retaining and linking their ART clients in care and support the promotion of greater treatment adherence.



### **1.3 STUDY RATIONALE**

Expanding access to ART brings positive changes to the global HIV epidemic in numerous ways. Key areas of improvement include PLWH becoming healthier, AIDS related morbidity and mortality showing substantial declines, risks of drug resistance being reduced and HIV transmission risks for an uninfected partner becoming minimal (WHO, 2013; UNAIDS, 2014). The UNAIDS report (2014) emphasises that exploring the reasons patients are LTFU from ART care will help highlight care and treatment gaps that need to be addressed so that once initiated on treatment clients are encouraged to continue with ongoing treatment. Exploring the reasons patients are LTFU from ART care at the SACTWU health clinics may specifically assist healthcare workers at these facilities to develop strategies to improve patient ART retention as well as provide lessons for work-place based ART programs, more broadly. This will include improving our knowledge of health services related factors, patient related or drug (ART) related causes or a combination of causes to LTFU from ART care. Better understanding of these reasons causing barriers to retention in care will contribute to interventions implemented to ensure that the goal of 90-90-90 is achieved (WHO, 2015).



## 1.4 RESEARCH AIM

The aim of this study was to explore factors associated with having been lost to follow up of clients on ART treatment and care among the South African Clothing and Textile Union members living with HIV and attending the SACTWU Worker Health Clinic in Durban, South Africa.

## 1.5 OBJECTIVES

The objectives were:

- 1 - To describe the demographic profile of SACTWU Union Members living with HIV and attending the union health clinic.
- 2 - To explore among the SACTWU members attending at the clinic and on ART, factors that may influence LTFU such as economic factors, social and cultural factors and health systems factors that may hinder ART care attendance
- 3 - To explore facilitating factors that improve retention of members on ART and in care.

## 1.6 RESEARCH QUESTION

The aim of conducting this research study was to answer the following questions:

What are the reasons of loss to follow up of SACTWU Union members living with HIV from ART care?

What are the healthcare providers' views of the issues clients face in ART adherence leading to possible LTFU from the SACTWU ART care?

## 1.7 CONCLUSION

The mini thesis consists of six different chapters. In *chapter one* the background of the research study, its context, the research problem, research question and its aim and objectives have been discussed. *Chapter two* reviews literature on the reasons for LTFU from ART care among patients on ART. This will assist in informing the exploratory causes for SACTWU members becoming LTFU in ART care. *Chapter three* describes the methodology used. This includes describing the research settings, study population, study design, the type of sampling strategy, data collection and analysis,

study rigor, research ethics considerations and the study's methodological limitations. *Chapter four* presents the research findings. *Chapter five* interprets the research findings and compares the findings of the study with those of other studies. In *chapter six*, I summarize the study implications and suggest recommendations, based on the findings. This may assist in developing strategies to decrease the number of PLWH in this setting who become lost to follow up.



# CHAPTER 2 - LITERATURE REVIEW

## 2.1 INTRODUCTION

Chapter two examines the literature in the field focusing on research evidence on factors contributing to loss to follow up of people living with HIV while on antiretroviral therapy (ART). In this review, I focus particularly on the following influencing factors that have been researched: patient related factors and socio-economic and health system related factors.

## 2.2 DEFINITION OF LOSS TO FOLLOW UP

A successful HIV program is measured by the lower prevalence of the AIDS-related opportunistic infections and mortality rates. This is because of the high morbidity and mortality rates associated with the illness, if the person living with HIV is not on ART. In sub-Saharan Africa, services for HIV care and treatment have expanded rapidly and have provided life-saving ART to over 2million infected adults and children (Chi et al., 2011). It has therefore become imperative to measure retention in care, which is measured by loss to follow up (LTFU) to determine the program effectiveness (Brinkhof et al., 2009).

Retention in HIV care can be defined as continuous engagement in care from initial diagnosis with HIV in a package of prevention, treatment, support and care services (WHO, 2011). Retention can be defined from the moment of initial engagement in care of being diagnosed with HIV and linked successfully to services, to assessment for eligibility, initiation of ART and remaining lifelong in ART care. This entails patients remaining linked to a facility and religiously adhering to their clinical appointments or pharmacy pick up of their ART medication. This is because ART prevents and very substantially reduces the risk of opportunistic infections and mortality. LTFU may include people who have self-transferred to another facility, unascertained deaths as well as true losses to follow up (WHO, 2015; Onoka et al., 2002). For clinical purposes, a shorter period of time has been considered as LTFU for patients who have missed clinic appointments, for either a consultation with a nurse or doctor or collection of ART medication, as this can lead to ART non-adherence creating individual drug resistance. This may result in a broader public health drug resistance problem for the ART program. Patie (2015) explains that taking ART is a lifelong commitment that requires the individual's consistent adherence to the prescribed treatment. This is in order to prevent disease progression and to promote optimal health. Good adherence to ART prolongs life and improves

quality of life so that fewer opportunistic infections are experienced. It is important to establish why and how people become LTFU after starting ART. If there is no retention in care of patients on ART, then it may be an indication of the failure of the program.

A challenge to ongoing research on program attrition (absence of retention in care) has been a lack of standardised definitions of LTFU. A standardised definition of LTFU is required for comparative reviews of data on patient retention to be possible from various ART programs. LTFU and retention to care are two different entities that are used to monitor the ART program. These are a direct opposite of each other because when you know the retention rate, you indirectly know the LTFU rate in a program. In many programs providing ART, clinicians report substantial patient attrition; however, there was a lack of clear consensus or uniformity in criteria for defining patient to LTFU in studies in the past (Chi et al., 2011). LTFU was often described as “lateness” for scheduled appointments, but the actual time intervals used varied greatly among programs (Chi et al., 2011)

A number of time measures were proposed in the medical literature which included late for one’s last scheduled appointment, or the time elapsed since the last clinical appointment which was a consultation with either a nurse or doctor or pharmacy visit to collect medication. In a cohort study conducted in Lusaka, Zambia, patients who were lost to follow up were classified according to the following definitions: late for scheduled clinical encounter, which refers to the patient going to the clinic to be in consultation with a doctor or nurse or to pick up their ART at the pharmacy (>30, >60, .90,>180 and > 365 days) and time since last clinic encounter with either a health care worker or medicine pick up at the pharmacy (>90 and > 180 days) (Li et al., 2013). Other literature, for example from Medecins Sans Frontieres (Doctor Without Borders’), has defined LTFU from ART care as being more than 2 months late for a scheduled appointment, which was when a patient did not return to care for 2 months or longer from their last clinic visit. Yu et al. (2007) in northern Malawi, used a 3 month interval from the time of a missed appointment for a clinic visit. Kaloustian et al. (2006) describe LTFU as 3 months without the patient being seen from the last clinic visit. In an analysis of 19 countries in 2011, Chi et al (2011:10) researchers recommended that the definition of LTFU from ART care should apply to a patient who has not been seen by a health care provider or has not collected ART medication for 180 days or more since their last clinic visit. While these studies added to the field of knowledge in promoting a focus on the importance of retention of patients on ART, the differences in their definition make it possible to compare their outcomes and to use in other studies.

The current WHO definition of LTFU for a patient on ART, which reaches a consensus on its definition, defines LTFU as a patient having not been seen at the clinic either by a nurse or doctor or

having collected ART medication at the pharmacy for “90 days after the last scheduled appointment” (WHO, 2011: 26). Hence, this definition indicates that it is only after this period of time has elapsed that a patient should be considered LTFU for the purpose of monitoring and evaluation classifications (WHO, 2014). This is now the standard definition for assessing LTFU on ART. Monitoring and evaluation of data allows program evaluation and is critical for informed decision making for the progress and impact of any program.

### **2.3 REASONS FOR LOSS TO FOLLOW UP**

Particularly given the rapid expansion of universal access to ART in Sub-Saharan countries it is important to conduct studies examining LTFU to care in ART programs. Rosen & Fox. (2011) conducted a study examining ART programs in different countries in Sub-Saharan Africa including South Africa and Botswana. The study revealed retention rates to be between 46% and 85%. Among the causes of poor retention, LTFU was a significant cause at 56% and then death at 40%. South Africa had the lowest LTFU rate of 13% and Botswana had the highest LTFU rate at 36% (Rosen & Fox 2011). Among the causes of LTFU, death was seen as the major contributor to LTFU. A cohort study conducted in Malawi revealed that 50% of the patients that were classified as LTFU had died and only 23% were alive and had stopped treatment. The reason for 27% of those LTFU was unknown as they could not be traced. Some clients who were LTFU in one facility had collected their treatment at another facility. This meant that they were not truly LTFU but rather that there was a gap in communication between facilities in the transfer or movements of patients. Similarly, a study in South Africa showed that out of the patients LTFU, 25% of those assumed LTFU were in fact accessing their treatment at other ART centres (Dalal et al., 2008). In contrast, the United Kingdom has had lower rates of clients LTFU due to death. In a cohort study conducted in the United Kingdom, only 3% of the patients were classified as LTFU due to death (Gerber et al., 2010).

The findings of the above studies reveal that death contributes a lot to the incidence of LTFU. These figures of those classified as dead could be more if those truly LTFU were found. I can conclude that other reasons causing patients to be LTFU could be known, if all the patients who are LTFU are found. This still shows gaps in the ART programs.

## 2.4 INDIVIDUAL AND PATIENT-RELATED CHARACTERISTICS AND FACTORS ASSOCIATED WITH LOSS TO FOLLOW UP

Research shows that most of the discontinued care in ART occurs within the first year of initiation. Retention of people on ART, and ensuring adherence to treatment are critical determinants of successful long term health outcomes for PLWH (Berherto et al., 2014). Despite the proven benefits in being on an ART program, patients LTFU remains a major problem. It is therefore important to establish why and how people become LTFU after starting ART.

Research on LTFU of patients in ART care highlights individual characteristics that act as potential risk factors associated with LTFU. Analysing the patient characteristics of those LTFU can assist in directing the focus to where interventions are needed in ART programs. Most studies conducted in the Sub-Saharan African countries have estimated that 20-40% of patients on ART are LTFU due to certain characteristics (Berherto et al., 2014). These characteristics include a younger age group category (Age 11-19), those who have had a substituted regimen because of regimen failure or severe adverse effects, a lower WHO clinical staging, a lower CD4 count and non-isoniazid prophylaxis which is used for the prevention of acquiring tuberculosis. A cohort study conducted in Ethiopia examining predictors of LTFU in patients on ART revealed that the risk of LTFU increased with a decreased CD4 count. In contrast, in Switzerland and Zambia an opposite pattern is seen in which risk of LTFU increased among the patients with a higher CD4 cell count (Berheto et al., 2014; Li et al., 2013). LTFU among those in Ethiopia with the low CD4 count could be from death, whereas those in Switzerland and Zambia with the increased CD4 count might have been healthy and decided to stop coming to collect their ART because maybe their CD4 had increased drastically. Several studies have shown that men are more likely to become LTFU due to morbidity and high risk of drug abuse (Li et al., 2013). In a study conducted in India male gender was associated with LTFU (Alvarez-uria et al., 2013). Similarly, with Li et al.'s 2014 study in Zambia, men were most likely to be LTFU. This was because men tended to fear stigma and were more likely to be involved in habits like consuming alcohol which contribute to them being LTFU. Age of the patient also plays a significant part. The younger the patient the more likely for them to be LTFU. Li et al. (2013) agreed that one of the patient characteristics associated with LTFU was that of a young age. Patients with advanced clinical stages (III and IV) were less likely to be LTFU as there was an increase in health seeking behaviour. This was because their CD4 count was low and exposed them to feeling sick frequently. However, a study conducted among the French showed a history of AIDS defining illnesses being associated with greater LTFU (Rosen & Fox 2011). This is because the patients had become so ill that they were not able to go seek assistance at health facilities, or it may be because of death. Unlike those patients who become worried that they might get ill due to their low CD4 count,

others have become already so ill that they do not even have the energy to seek medical assistance. Regimen substitution due to adverse reactions to new drugs is also associated with LTFU (Rosen & Fox 2011). This is maybe because patients become concerned about the side effects of the new drugs, causing them to become LTFU and perhaps seek other treatment options or stop treatment. LTFU is also found to be associated with the length of engagement in care. This is an occurrence seen globally. Berheto et al. (2014) state that, generally, the possibility of dropping out from care gradually increases with being longer in care.

The studies mentioned above highlight some of the most common patient characteristics of those who are LTFU. This could assist ART programs in focussing their efforts particularly on those individuals with those characteristics, once initiated on ART and retain them in care thus decreasing the rate of LTFU amongst them. Educating the community, especially those prone to LTFU, would improve or decrease the rate of LTFU (Berheto et al, 2014). One also needs to take into consideration when looking at these studies above, the difference in their settings. Africa and Europe have very different circumstances and therefore the health provision will differ. This will inevitably influence their LTFU statistics and the outcome of the studies conducted.

Patient-related factors involve individual influences that affect behaviour towards an illness. These include an individual's access to resources, knowledge, and beliefs towards their health or illness or their expectations based on prior visits to health services (Mathebula, 2014). Ahmed et al. (2013) state that patients with a better immune status or less advanced disease stages could result in self-assessment that they are healthy and therefore not in need of health care. In the recent South African national 'test and treat' guidelines, large numbers of those testing HIV positive are initiated immediately on ART, regardless of their CD4 count and clinical staging (DOH, 2015). This means that some patients are initiated on ART while still having a very high CD4 count and may not have experienced any illnesses related to their HIV status. This could contribute to patients being LTFU, as they may see no need to take their ART while their CD4 count is high and they do not feel ill. Maskew et al. (2007) mention that patients' lack of understanding that ART needs to be taken life-long may contribute to individual ART discontinuation. Mugisha et al.'s (2014) quantitative study conducted in Northern Uganda examining 41 health institutions, found that 31 033 of patients who had discontinued ART and who were traced through the study, reported they were unaware that ART involved life-long treatment adherence. This highlights the need for health providers to emphasise the importance of taking life-long ART and the negative consequences of non-adherence to treatment once initiated.

Side effects of ART have also been found to promote LTFU from ART, especially among those who have a tuberculosis (TB) co-infection. Complaints of having a heavy ‘pill’ burden when taking combined treatment for TB and HIV have emerged as a negative factor to adherence among co-infected patients (WHO, 2014). Some drugs cause side effects in patients such as severe diarrhoea caused by the Alluvia. This side effect may lead to patients not returning for their medication refill. In a study conducted at the Immune Supress Syndrome clinic in Uganda, among 78 interviewed patients initiated on ART in the period between January 1, 2004 and September 30, 2007, one of the commonest patient-related reason reported for LTFU included ‘feeling too sick’ from medication side effects. Miller et al.’s (2010) qualitative research study conducted in Themba Lethu Clinic in Johannesburg, South Africa reported similar findings, as one respondent reported: “As soon as I was started on ARTs I became so ill and weak and developed a running stomach” (Miller et al., 2010:50) This highlights the need for patients to be properly informed about the side effects of their medication, so that that they are better prepared for what to expect when starting ART. Some patients might be reluctant to start or to continue with their ART because of side effects they have heard about from other people. For example, they might have heard of or seen people they know whose body shape changed due to taking certain ART medication in the past. During health education and counselling emphasis needs to be placed on explaining that newer ART drugs have been developed, with less such side effects and that a patient can switch to other medication if they experience side effects on those prescribed for them, rather than discontinuing treatment. Patients moved to a fixed dose combination (FDC) regimen of ART medication, involving stopping an older drug regimen, could also lead to patients’ concern about developing side effects on new regimen, if they do not have clear information may contribute to LTFU (Geng, et al.2010).

## **2.5 SOCIO-ECONOMIC FACTORS**

Socio-economic factors influencing our health attitudes and behaviour are underpinned by the social and economic experiences and realities. These mould our personality, attitudes and lifestyle (Mathebula, 2014). Economic factors include inability to pay for health service visits, lack of food and broader financial difficulties. In a qualitative study conducted in Johannesburg South Africa, one female respondent reported “One of the reasons I stopped coming for treatment was because of transport cost” (Miller et al., 2010: 51). While South African primary healthcare facilities services are free, patients incur costs in public transport travel to get to health facilities. This may hamper those who are unemployed or earn low salaries from attend health service. In addition, those who are employed may not want to risk losing a day’s pay by having to attend health facility. In Miller et



al.'s (2010) study, employed respondents reported difficulties in being able to take off working time to attend the clinic during regular operating hours. This was, particularly if they had newly started working at a company. Therefore, some patients would be likely to rather miss their clinic visits, for fear of losing employment or a partial wage loss.

Mugisha et al. (2014) adds that food shortages and food insecurity at household level have a great impact on adherence and LTFU in the ART program. People who have a chronic condition like HIV are routinely advised to practise living a healthy lifestyle, including having a healthy diet. Those who are unemployed or without good levels of income cannot afford the expense of healthier food. Patients are also informed that they should take their medication after food (KI, pharmacist). This may be an additional cause for patients to discontinue their medication, as on certain days they may be without food and therefore do not take their medication.

Stigma is a major barrier to accessing HIV/AIDS services and treatment. Real or perceived HIV/AIDS related stigma is a negative response to a person because of their HIV status (Mugisha et al. 2014). HIV-related stigma may prevent some HIV patients from disclosing their status to their family, friends and employers because they fear rejection or discrimination. They may also avoid going to local health facilities for their treatment because they are afraid of being seen by members of their communities or families. Some patients fear being questioned by their families about why they need to visit a health service on a regular monthly-basis, when it is time for them to collect their medication, and this may cause them to become LTFU.

In some geographical areas, community members adopt alternative therapies and medicines as an alternative to starting ART, as they do not feel sick. Remien et al. (2007) suggest that when alternative therapies are popular among PLWH, more patients are likely to become non-adherent to their ART. These alternative therapies include herbs or spiritual therapies. Peltzer et al.'s (2011b) study conducted in KwaZulu-Natal South Africa revealed that ART non-adherence was associated with the use of herbal treatment (Remien et al, 2007).

Lack of family support is also a contributor to LTFU among ART patients. PLWH who do not have family support may feel unloved and isolated, posing a challenge in ART adherence (Bongololo et al., 2005). Support can be closely related to disclosure. PLWH may fear discrimination from their spouse, social network, and other family members and therefore not disclose their HIV status and end up with no support. Moomna's (2012) study in Zambia among PLWH similarly showed that patients who disclosed their HIV status to families and friends experienced support and fewer challenges in adherence to ART, in contrast to those without social support.

## 2.6 FACTORS RELATED TO THE HEALTH SYSTEM

Health institutions' service delivery problems, such as long waiting times, may contribute to patients becoming LTFU from HIV care in developing countries (WHO, 2009). A lack of understanding on the part of the patient and/ or the inadequate provision of information by healthcare workers can contribute to clients being LTFU. The newly introduced 'test and treat' HIV guidelines in South Africa have led to a much larger number of patients being enrolled in ART programs. This could exacerbate overcrowding in health care centres, which would mean that the health care providers have limited time available to attend to patients. Health provider illness due to high burden of patients for whom they need to care may have led to more staff falling ill or becoming fatigued and having to take time off work (Mugavero et al, 2010). This in turn means that facilities are often short staffed and not all patients can be attended to. This may lead to some being turned away without their tablets. Mugavero et al. (2012) report that workforce shortages have increased due to insufficient numbers of qualified clinicians specialised in HIV care and treatment to accommodate caring for the growing numbers of patients on ART.

Miller et al' s. (2010) study reported health service related factors for discontinued clinic attendance. As one woman reported: "I lost my card and I was afraid to come to the clinic...isn't it that at the reception when you have no card they tell you to go back" (Miller, 2010:50). If the procedure had been properly explained to her, she may not have assumed she would have been chased away and became non-adherent to treatment. An India study showed that some patients were LTFU because of fears of harsh treatment they may receive from health care workers (Alvarez-uria, et al., 2013). Training of quality of care in health care providers' attitudes is vital, as negative attitudes can contribute to clients being LTFU.

Inflexibility in clinic hours to accommodate work schedules and domestic care activities may also serve as barriers to consistent HIV care attendance (Mugavero et al., 2012). Adherence to ART means regularly keeping all HIV care scheduled appointments. Health facilities often function only during weekdays, when most people are at work and may find it inconvenient to attend services during the week. This may be a contributing factor to LTFU of some patients, as they need to choose remaining at work over attending the clinic.

With major increases in patients initiating ART in South Africa, there have been drug shortages or stock outs in some health institutions. For example, Themba Lethu clinic at Helen Joseph Hospital in Johannesburg sees more than 800 HIV/ AIDS patients weekly. This may be partly due to collecting

ART medication at a hospital being preferred by some patients because of a number of local clinics experiencing drug stock outs and shortages. One patient cited “sometimes they say there are no pills and send me to the hospital” (Miller, 2010:51). This could contribute to patients becoming LTFU, because they may be discouraged from going to the same health facility again if they find they have to return home without their medication because of drug shortages.

From the reasons that contribute to LTFU mentioned in the studies above, one can conclude that all the influences on becoming to LTFU are interlinked. A public health approach which needs to be employed in order to manage a successful ART program. A public health approach focuses on preventing health problems in a way that extends better care and safety to the entire population rather than individuals. An ART program should not only focus on the ART drugs, side effects, stock available, resistance and retention rate, but also take into consideration the issues around the individual which could make it difficult for them to commit to care.

## **2.7 CONCLUSION**

The increasing proportion of patients’ LTFU while on ART compromises their own health and the long term success of the ART program. It impacts negatively on the immunological benefits of ART and increases the probability of AIDS-related morbidity, mortality and hospitalisation for individuals. The broader consequences of treatment failure due to poor adherence also lead to ART drug resistance at a population level (WHO, 2014). Based on the literature I have reviewed, a complex diversity of barriers has been found to contribute to becoming LTFU among patients on ART.

# CHAPTER 3 - RESEARCH METHODOLOGY

## 3.1 INTRODUCTION

This chapter describes the methodology used in this study. It details the study setting, study population, study design and the sampling technique used. It describes the data collection methods used and the analysis of the data, efforts to address credibility, rigour and trustworthiness, and also the methodological limitations of the research and the research ethics considerations.

## 3.2 THE STUDY SETTING

The South African Clothing and Textile Workers Union (SACTWU) is one of the largest unions in South Africa. It has developed health facilities for its members in various parts of the country. This study was conducted in one of the SACTWU clinics in KwaZulu-Natal, in the Ethekewini district. The clinic is in an industrial area of the Durban metropolitan area where most of the clothing and textile factories are situated. It was established in an industrial area so that SACTWU members would be able to receive medical assistance not too far from work. This allows them to collect their medication during their lunch hour. Some factories have allowed their employees a certain amount of time off to go to the clinics and still get their full working day's pay. SACTWU also has a number of panel doctors distributed around Ethekewini, to whom those members who work outside of the Durban metro can go to seek health services. They obtain care at selected practitioners, at no extra cost. The clinic offers HIV care including ART treatment, tuberculosis screening and treatment and primary health care services to SACTWU members from areas around the Durban metropolitan area. Currently, the clinic has 1560 clients on ART and this number has been increasing rapidly since the introduction of the South African 'test and treat' national guidelines. The majority of the population attending the clinic is Zulu speaking, with a minority group, English-speaking. The SACTWU members earn a low income via weekly wages but have access to free health services throughout the union clinic facilities as long as they remain union members and pay the SACTWU levy. The clinic operates from Mondays to Fridays, between the hours of 6:30 and 15:30. The clinic opens as early as possible so that patients are attended to before going to work. This allows the clinic to attend to as many of the members as possible, so they can get to work on time and not lose their day's pay. The clinic has a medical practitioner, two professional nurses, two lay counsellors who do HIV counselling and testing and conduct ART literacy classes for those who have tested HIV positive, a

social worker, two pharmacists and two pharmacy assistants. It also has a home based care program in which community carers go out to the patients' homes to conduct home visits when necessary. The community carers together with the social worker also do the tracing of clients that are LTFU. In addition, the clinic has a team of lay counsellors involved in an outreach program, who periodically visit all factories which are serviced by this clinic. During the outreach program, they offer HIV testing and counselling to the workers and refer those who are HIV positive to the clinic for HIV care.

### **3.3 THE STUDY DESIGN AND METHODS**

The study used exploratory, flexible qualitative design. This type of study is useful to generate in depth insight into barriers that lead to clients becoming LTFU and to potential facilitators to remaining in care. A qualitative research approach helps uncover concepts which can help in understanding the perceptions, experiences or behaviours of people and their social meanings (Pope & Mays 1995). According to Black (1994), qualitative research assists in exploring issues in depth rather than in measuring them or associating them with other variables, as is the case in quantitative research. Qualitative research is especially effective in obtaining culturally specific information about people's values, opinions, behaviours, relationship-related and the social contexts of that particular population (Mack et al., 2011).

The strength of qualitative research methods in exploring the reasons for LTFU from ART care is its ability to provide complex textual description of how people experience or feel about their being LTFU or discontinuation on ART. It is suited to the research objectives of revealing the individual, socioeconomic and health service related aspects of LTFU of patients on ART, and investigating client and providers' feelings and perspectives on health care centre services, including those provided at the SACTWU worker health clinic. It asks the questions why and how events occur. According to Mack et al. (2005), qualitative methods are also effective in identifying intangible factors such as social issues which may not be readily apparent in the type of questions asked in quantitative research. Qualitative methods allow flexibility, meaning that they allow greater spontaneity and adaptation to the interaction between the researcher and the study participants. Participants have the opportunity to respond more elaborately and in greater detail and depth.

Its use of open ended questions and probing gives participants the opportunity to respond in their own words, rather than restricting their choice to fixed responses, as would be the case in quantitative methods. Open ended questions have the ability to evoke responses unanticipated by the

researcher (Brink 2006). Qualitative research is therefore well placed to seek to understand the factors underpinning the problems of patients becoming LTFU from ART, from the perspective of those affected.

### **3.4 POPULATION AND SAMPLING**

#### **3.4.1 The study population**

The study population in this research comprised SACTWU members on ART attending the SACTWU Worker Health Programme Clinic in Durban, South Africa. This included men and women working in the clothing and textile industry and aged of 18 years and above. The study population work and live in different parts of the Ethekewini Municipality. It included 12 SACTWU members that were previously LTFU from ART from the SACTWU clinic for more than six months and had since been traced or returned for treatment. This group of patients was considered as an appropriate study population from which draw the sample as they would provide rich information on why they were lost to follow up. They had not returned voluntarily but has been followed up by clinic staff and agreed to return. It would have been very difficult to locate members who had permanently been lost to follow up from ART care as many moved from their original address and were often no longer working in the industry. 6 Key informants were also interviewed in the research study. Key informants consisted of health care providers who work at the SACTWU ART clinic. The SACTWU clinic has a total number of 14 health care providers. They included a nurse, lay counsellors, the social worker, a pharmacist, a pharmacy assistant and community carers who dealt with those SACTWU members who were previously lost to follow up.

#### **3.4.2 The Sample selection and methods**

According to Robson (2010), a sample is a selection of a group from a population. Sampling is important as it is difficult in research to obtain a whole population for interview. Purposive sampling, conventionally used in qualitative research, was used. Robson (2010) mentions that the principle of selection in purposive sampling is that the researchers' sampling judgement should take into account typicality or those most likely to provide well informed views on a topic, such as key informants.

This study sample consisted of ten clients who had been LTFU and subsequently located and had returned to care and ART after initially being classified as LTFU. The clinic has a good data base system in which clients who are on ART are flagged for attention if they have missed their

appointments. After explaining the purpose of the study and the criteria for patients eligible for the study to the social worker, the lay counsellors and the community carers, they used the clinic data base to help the researcher to identify those patients who were eligible as potential study participants. Follow up appointments were made for patients for their collection of ART, but who had previously missed appointments in the past as per criteria for LTFU, were identified so they could be approached to participate in the study. Those who were interested were provided with a study information sheet (Appendix 2A and Appendix 2B...) and those consenting to participate in the study were asked to give written consent (Appendix 1A and Appendix 1B) as proof of their agreement to participate in the study.

The researcher also approached potential key informants for study participation. The aim of the study was fully explained to them and written consent obtained from those who agreed to participate in the study.

### **3.4.2.1 Inclusion criteria-patients**

Patients eligible for inclusion in the study were:

SACTWU members who:

- 1 - Had been lost to follow up from ART care for more than three months and found again and returned for HIV care and ART. This is because the recognised definition of LTFU stipulates that these are clients who have not been seen for three months or more.
- 2 - The participants had to be 18 years or older. This is because people who are employed are usually 18 years or older and hence it would be rare to find participants younger than 18 years in employment. In addition, caregiver permission would be needed for participation of those younger than 18 years, which would have been difficult to obtain because of issues related to confidentiality and disclosure of a person's HIV status.
- 3 - Participants had to be SACTWU members. This is because the clinic is only available to SACTWU members.
- 4 - Participants must have been receiving ART from the SACTWU clinic.

### **3.4.2.2 Exclusion criteria**

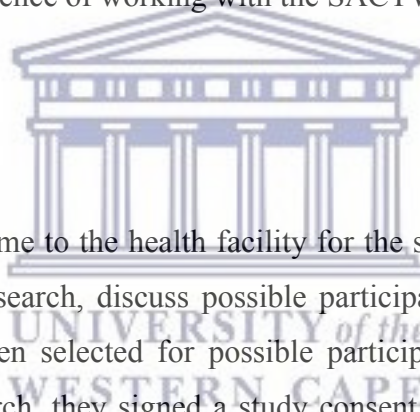
Patients excluded included those:

- 1 - Less than 18 years of age.
- 2 - Not a SACTWU member.
- 3 - Had been LTFU less than 3 months.
- 4 - Not yet on ART.
- 5 - Too ill or incapacitated to be able to be interviewed.

### **3.4.2.3 Inclusion criteria-key informants**

#### Key informants

- 1 - Had to be employed in the SACTWU worker health program clinic, as this would mean they would have knowledge and experience of working with the SACTWU members.



### **3.4.3 Participant recruitment**

When the selected participants came to the health facility for the scheduled appointment, I then had the opportunity to explain the research, discuss possible participation with the patient and inform them on what basis they had been selected for possible participation in the study. If the patient agreed to participate in the research, they signed a study consent form and an appointment for the interview was set up. If the patient was not rushing away at the time of their consultation, the interview was conducted on the same occasion as their consultation visit.

Those invited to be potential key informants study participants were provided with participant information sheet (Appendix 4A and Appendix 4B) and a confidentiality binding form (Appendix 3A and Appendix 3B) as these interviews were conducted in focus groups. Health care workers who agreed to participate in the study were then given consent and confidentiality binding forms to sign (appendices 4A and 4B).



## **3.5 DATA COLLECTION**

### **Study instrument piloting and data collection**

A pilot study was conducted with people who would have been eligible as participants in order to determine whether the questions in the interview guide were structured in an appropriate manner for responses. The pilot study interviews were excluded from the main study.

Data for patient participants, who have been LTFU in the past, were collected through semi-structured individual in depth interviews. Focus group discussions were held with the key informants comprising health care workers working at the SACTWU worker health programme clinic. Individual interviews were conducted in the language that the participants were most comfortable in, which was mostly in isiZulu. This was to ensure that participants could easily express themselves comfortably and fluently. The focus group interviews were conducted in English to accommodate the non Isi-Zulu speaking individuals. Those health care workers who were not completely fluent in English were advised to inform the researcher if any questions were unclear, so that they could be translated into isiZulu. They were additionally informed that if they felt unable to express themselves well enough in English, they could express themselves in isiZulu as the researcher is fluent in both isiZulu and English. This proved not necessary after all as they could all respond appropriately in English. The interviews were conducted by myself, as the researcher, and were audio taped with the consent of the participants. This was to ensure that no information was missed and the researcher would be able to go back and listen to the recordings again after the interviews were transcribed. My own personal research journal was kept and used while collecting the data to note down ideas and themes that emerged.

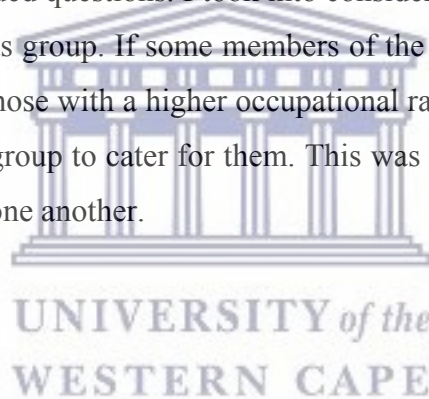
#### **3.5.1 Individual Interviews**

This is one of the most common qualitative exploratory research methods instruments. They are effective in giving a 'human face' to research problems, especially when they are used in dealing with sensitive issues like HIV (Mack et al., 2005). The interviews were conducted face-to-face individually by me as the researcher, to ensure that each participant felt comfortable and free to express their views and individual reasons for having been LTFU. This technique was intended to elicit a vivid picture of the participant's perspective on the research topic. The client was able to enlighten the researcher as to why they became LTFU after they started their ART. The client was in

a close one-on-one conversation with the researcher during the interview, so the researcher could pose questions in a casual manner, listen attentively to the participant's response and be in a position to ask follow up questions and probe the responses. The interviews were conducted at the SACTWU clinic in one of the consulting rooms.

### **3.5.2 Focus Group Discussions**

A focus group discussion involves one or more researcher and several participants meeting as a group to discuss a topic (Mack et al., 2005). Focus group discussions are appropriate when a researcher can gather together approximately eight to ten participants who feel free to share their views on a non- personal topic. In this study, the focus group included the healthcare providers mentioned in section 4.3 table 2. They were not asked personally sensitive questions, but rather asked about their clients' experiences. I approached potential providers in a group to ask if they would be willing to participate in the focus group discussion and led the discussion, asking the informants to respond to open-ended questions. I took into consideration the different ranks of health care workers involved in the focus group. If some members of the group appeared to be constrained or intimidated to talk in front of those with a higher occupational rank, I had made contingency plans to conduct a separate discussion group to cater for them. This was not needed as the group members were comfortable engaging with one another.



### **3.6 DATA ANALYSIS**

In qualitative research studies, data analysis is ongoing, with insights emerging through an interactive process during research (Henning, van Ransburg & Smit, 2004). Data analysis started in parallel with data collection. The thematic analysis was used analyse the data. The five steps of thematic analysis described by Pope, Ziebland and Mays (2000) were followed, namely familiarisation, identification, indexing, charting, mapping and interpretation. Familiarisation included listening to the recorded interviews, reading my transcripts and studying my notes. Identification included identifying concepts and themes and identifying the key issues from the data. Indexing was applying the thematic framework by creating codes on the transcript. Charting involved rearranging data to fit into appropriate themes to which they relate to and forming charts. Mapping and interpretation includes using the charts to define concepts and finding association between themes. Once interviews had been conducted the researcher spent time transcribing and translating the individual in depth interviews from isiZulu into English. During transcription,

pseudonyms were given to each participant rather than their proper names being used. Time was also spent listening to the tape recordings several times to ensure all information was properly documented and nothing was missed. This also assisted in further familiarising me with and immersing me in the data.

Data was coded manually using a coding list that I developed, based on the questions in the question guide (see Appendix 5 and 6). The coding list is lists of codes that are I had generated that include data with similar extracts. Themes were then identified from the coded data. This involved arranging data according to appropriate themes to help generate explanations or interpretation of the data. I used the emerging themes to highlight the contributing factors to clients LTFU from ART care and potential facilitating factors that may have helped them return to ART care. My research journal was reviewed during data analysis to make me aware of my own ideas and beliefs in complementing the interview data.

### 3.7 RIGOUR

Rigour was ensured during the research process, including data collection and analysis.

As part of ensuring rigour, a **Member checking** technique was used to achieve trustworthiness. In this method, the validity process shifts from the researcher to the participants in the study (Cresswell & Miller, 2000:127). This involved, in addition to recording interviews, summarizing from memory what participants had said during the interview at the end of each session and checking that they agreed with what I had heard. My MPH mini-thesis supervisor independently coded a few interviews to compare her extraction of themes with mine.

**Triangulation** of data and resources was carried out. This consists of using more than one method of data collection during the research process (Robson, 2010). In this study, data was collected from two sources through in-depth interviews from the participants who were LTFU and from the key informants in a focus group discussion. In addition, as explained, I augmented this data with my journal notes. Hence, source triangulation of data also increased the rigour of my study.

**Transferability** involves describing the background, setting, population, selection and characteristics of participants and the themes that emerged from a qualitative study in rich detail,

using thick descriptions (Cresswell and Miller, 2000). The thick descriptions of the study methods and findings aim to provide the reader with a sense of the exact methods used and events described and experienced in the research. This may enable insights to be gained if other settings and similar studies were to be conducted for comparability.

**Reflexivity:** I am a medical officer by qualification, and while I acknowledge the importance of HIV cares, I am aware that I have certain perceptions and that clients may have had particular perceptions of me as one of their healthcare providers while I conducted this research. While conducting the research I kept a notebook of feelings, ideas, personal thoughts, problems and frustrations throughout the research process. I referred to these during the write ups of the research and also for monitoring my personal ideas, feelings and how I perceived participants to have interacted with me. Nevertheless, my position as a healthcare provider at the clinic raises issues of possible bias in patient participant responses and reactions to me in my role as a medical officer, as well as the healthcare providers' responses to me as the clinic manager. This may have biased the way they answered questions, as they may have wanted to answer in a socially desirable way. The participants previously LTFU could also have felt constraints in making comments to me on how they felt about the services provided by the facility and could therefore not be a true reflection.

### 3.8 RESEARCH ETHICS CONSIDERATIONS

Research ethics approval was granted by the University of the Western Cape Biomedical Ethics Research Committee (Appendix 7). Permission and clearance to conduct the research was obtained from the SACTWU as well as permission obtained to use their clinic data-base in order to identify potential participants for the study (Appendix 8).

The three fundamental principles of human research ethics were followed. These included that the aim, objectives and purpose of the study were fully explained to the study participants before data collection began. Participation in the study was voluntary for clients that were LTFU and the key informants. I emphasized that potential participants could choose not to participate at all, withdraw from the study at any point or decline to answer specific questions. They were assured that a decision not to participate or to withdraw from the study would not affect their care at the clinic or affect them negatively in any other way. An information sheet explaining details of the study, including the benefits and risks was provided to the participants and translated into isiZulu for those who were non-English speaking (See Appendices 2A and 2B). Written informed consent was obtained from all

the participants and interviews were not conducted without them signing an informed consent form (See Appendices 1A and 1B). I included an additional confidentiality binding form for the service providers involved in the focus group discussion (FGD) to sign and these too were translated into isiZulu (See Appendices 3A and 3B). The participants were assured of confidentiality through their consent form being stored separately from the interview data in a locked cabinet and would only be seen by the researcher. Anonymity was maintained in reporting of results. Study participants were given a study identification number rather than their name being recorded, and pseudonyms have been used in writing the reports. General findings reflective of themes that emerged are reported rather than findings attributable to specific individuals.



## CHAPTER FOUR – PRESENTATION OF FINDINGS

### 4.1 INTRODUCTION

This chapter presents the findings, from the in-depth interviews with the SACTWU clinic patients who had become lost to follow up on ART and from the focus group discussion with the SACTWU clinic healthcare worker key informants. I provide details on the socio-demographic characteristics of the patients interviewed and the background and the details of the health care worker key informants. I describe the factors that hindered patients in remaining in ART care. These factors are grouped into individual related factors, socio-economic factors and health system factors.

### 4.2 SOCIO-DEMOGRAPHIC CHARACTERISTICS OF PATIENT PARTICIPANTS

A total number of 12 patient participants who met the study inclusion criteria were interviewed. Their socio-demographic characteristics are described in Table 1 below.

**Table 1 - Socio-demographic profile of patient participants**

Characteristics	Variables	Freq. n	
Sex	Male	5	
	Female	7	
Age	18-25	1	
	26-30	2	
	31-40	7	
	41-50	2	
Marital Status	Single	7	
	Married	4	
	Divorced	0	
	Partner died	1	
	None	0	
Level of education	Primary school	Completed	2
		Not completed	0
	Secondary school	Completed	8
		Not Completed	2
	Tertiary school	0	

### 4.3 DESCRIPTION OF THE KEY INFORMANTS (KIs)

A total number of seven health care workers participated as key informants in the focus group discussions. Table 2 below shows their socio-demographic profile.

**Table 2- Socio-demographic profile of key informants (KIs)**

<b>Characteristics</b>	<b>Variables</b>	<b>Freq. n</b>
<b>Occupation</b>	Professional nurse	1
	Lay counsellors	1
	Social	1
	Pharmacist	1
	Pharmacy assistant	1
	Community carers	2
	<b>Gender</b>	Male
	Female	6
<b>Race</b>	Black	5
	White	1

### 4.4 INDIVIDUAL RELATED FACTORS

The key individual, or patient, factors which were reported as influencing SACTWU ART patients in becoming lost to follow up were non-disclosure of their HIV status; not experiencing ill health; poor understanding of their ART treatment regimen; alcohol use; alternative use of traditional herbal treatment rather than ART; and unplanned or unanticipated extended travel. These factors frequently interacted with each other in impacting on patients' ability to adhere to treatment and continue attending the SACTWU ART clinic.

#### 4.4.1 Disclosure

##### Lack of disclosure of HIV status hindered ART adherence

There was consensus among the health care workers interviewed that patients' non-disclosure of their HIV status to close family/friends or a partner acted as a barrier to ART adherence. This contributed to SACTWU clinic patients becoming lost to follow up from ART. They were unable to call on the support from significant others in their lives in taking their medication or to enlist their support in collecting their medication at the clinic if they were unable to collect it themselves. As one KI informant expressed this:

*'Having not disclosed their HIV status to anybody caused a lot of the patients to get lost to follow up because it eventually becomes difficult for them to collect their medication all the time without support and led to some of them being lost to follow up'* (KI, lay counsellor).

Participants frequently found disclosing their HIV status to others difficult, either due to being reluctant to disclose their status altogether or fearing that if their status became known, this would become common knowledge outside of their immediate circle of colleagues. This made it difficult to openly adhere to their ARV treatment and hindered them from attending the ART clinic to collect their medication. As some participants stated:

*'I stopped coming to the clinic because my mom was asking me why do I have to go to the clinic all the time. I have not told her about my status. I realised that this was affecting me so decided to stop going to avoid all these questions'* (Participant 4, 38 year old male).

*'I stopped coming to the clinic because there was a lot of people (work colleagues) who knew me (at the clinic) and they would have told others that we work with that I am also HIV positive and so decided to stop coming to the clinic because I was not ready for people to know that I also attend the SACTWU ART clinic'* (Participant 7, 41 year old female).



#### 4.4.2 Not yet experiencing physical illness can affect perceptions on the need to be on ART

Lack of experience of physical illness increases the likelihood of patients becoming lost to follow up

Individuals who had not yet experienced physical illness as a result of their HIV infection found it difficult to accept their diagnosis of being HIV positive. This emerged as an important ‘disincentive’ to continue with, and be consistent in, ART adherence. Patients felt reluctant to continue taking ART when they were not feeling any of the effects of ill health. This in turn influenced clients in becoming LTFU from the ART clinic. As one client expressed this:

*‘Mina (me) HIV positive? Hai I did not believe cos (because) I wasn’t sick at all. I took amaARVs anyway cos (because) I was told my CD4 results are too small. Sometimes I take the medication and eventually stopped going to the clinic because I didn’t have time and I don’t believe I need them. I stopped going to take my ARVs because I wasn’t feeling sick at all’ (Participant 3, 39 year old male).*

A participant who had undergone an HIV test because the opportunity to do so had presented itself but had not experienced ill health from being HIV positive and on diagnosis was initiated on ART stated:

*‘I was told I have to take ARVs for life, I stopped because I was not sick and taking amaphilisi (pills) every night is not nice so I stopped taking them and stopped going to collect them’ (Participant 10, 52 year old male).*

#### 4.4.3 Treatment literacy

Lack of treatment literacy hindered adherence

During literacy ART classes, before the patients are initiated on ART, sufficient information appears to be provided to the patients with regards to ART treatment. However, lack of understanding and knowledge among some of the patients was still seen to be a problem, despite the view that adequate information had been provided. Lack of understanding as to why ART should not be discontinued once initiated and needed to be taken for life, made it more likely that patients would become LTFU.

*'Work was very very busy and my supervisor shouts cos (because) I have to come to the clinic and collect my tablets. So since I was healthy and my last CD4 count was high, I stopped attending at the clinic'* (Participant 4, 38 year old male).

*'I did not know that ARVs were taken for life and I did not get affected on the days I did not take them so eventually I should not continue taking the ARVs because im fine'* (Participant 8, 31 year old female).

Key informants added that some patients had asked them when they would be able to stop taking their medication and be discharged from ART. Hence, misconceptions related to lack of understanding were seen as a reason why a number of patients became LTFU.

*'This one client said he thought you stop ARVs when you feel fine and get discharged'* (KI, professional nurse).

#### **4.4.4 Alcohol abuse**

##### Excessive alcohol use hindered adherence

Consuming excessive alcohol emerged as a factor that led to patients forgetting to take their medication, and contributed LTFU from treatment. Those who consumed alcohol reported that they found they did not have time to think of issues such as taking their ART medication on a number of occasions due to alcohol consumption; they began to miss taking their medication as they did not see the point of continuing to take ART. As a result, they stopped attending the clinic to collect their medication.

*'Angeke ngiqambe amanga (I won't lie)....on weekend I drink and have party with my friends and forget to take my medication and in the end I had missed so many tablets I decided to stop because I did not get sick since I was not taking them'* (Participant 7, 42 year old female).

*'Drinking I would say contributed a lot in me deciding to stop my ARVs'* (Participant 12, 25 year old female).

Key informants concurred that patients who consumed excessive amounts of alcohol, deprioritised coming to the clinic for their ART, and had been more likely to have become lost to follow up from the clinic. As one key informant reported:

*‘Majority of the patients that were normally traced (due to having become lost to follow up from the clinic) have drinking as problem that contributes to them being lost to follow up’ (KI, Social worker).*

#### **4.4.5 Travelling**

##### Unplanned or extended travel due to work or visiting relatives hindered adherence

Participants whose work involved frequent travelling that was often unpredictable in terms of the time it would take to cover the required distance, reported that this resulted in them having difficulties with ART adherence. This made it more likely that they might become lost to follow up from ART clinic.

*‘I am a driver at work and so sometimes I travel long distances and find myself not back on time for my clinic appointment and my ART run out eventually it made me get used to not having the ARVs and ended up not going back to collect’ (Participant 1, 34 year old male).*

*‘Travelling eventually made me forget about my clinic appointments’ (Participant 10, 52 year old male).*

Some participants reported that travels to visit family or friends that were either unplanned, or planned but extended unexpectedly, led to them running out of ARV treatment and missing their clinic appointments for a medication refill.

*‘I had to go to the farms because my mother-in-law was sick and had to go look after her and ran out of medication and since I was not going back I just decided to stop and not go back to the clinic and beside my mother-in-law would question me all the time I have an appointments at the clinic’ (Participant 3, 51 year old female).*

Key informants stated that patients who travel a lot were informed of their in case of extended travel. They could seek treatment at the nearest clinic where they were located and receive their supply of ART instead of discontinuing treatment and eventually becoming LTFU.

*‘It is always explained to the patients that if they happen to be travelling and they run out of their medication they can go to the nearest clinic where they are and request for ART. They can just take their empty containers and their carrier cards as proof but instead they just give up and forget about coming back to the clinic when they are eventually back for a short while’ (KI, pharmacy assistant).*

However, there seemed to be a continuous disjuncture between the information that healthcare providers reported providing to clients in this regard and clients' actions while away from their usual medication pick up services.

#### **4.4.6 Alternatives to ART**

##### Traditional herbal medication use

The use of traditional herbal remedies to treat illnesses is very common among some segments of African society. Traditional herbal medications have been advertised to communities and sold and promoted as alternatives to ART in treating HIV. Herbal medication is believed by those who promote the medication to have the capacity to boost the immune system of the body. Most of the participants in the study who had become lost to follow up because of circumstances such as being unable to take time off work used traditional herbal medication as an alternative. Traditional medicine became more convenient to use than ART because of easy accessibility and because the need for collection was less frequent.

*'I was told that the muthi is for all diseases and HIV and it heals it so there was no need for me to collect the ARVS'* (Participant 10, 52 year old male).

*'I can go to the traditional healer over the weekend when I am not working to get my medicine, akuhluphi (it's not a problem) I am not affected at work and the muthi does heal HIV so I forgot about the clinic'* (Participant 9, 55 year old female).

#### **4.5 SOCIO-ECONOMIC FACTORS**

In this study, key socio-economic factors which emerged as contributing to clients becoming lost to follow up from the ART clinic included: costs and logistical issues, food shortages, stigma, discrimination, living conditions and workplace attitudes.

##### **4.5.1 Costs and logistics**

###### Cost and logistical problems contributes to loss to follow up from ART

Costs incurred when workers became unemployed, and logistical issues related to workers taking time off work were identified as some of the reasons why the SACTWU clinic patients became LTFU from treatment. The SACTWU clinic is situated near the clothing factories. This is aimed at

assisting workers in decreasing their costs in reaching the clinic and easing any logistical problems they may face when having to seek medical help. When an individual becomes unemployed they are given a period of six months to continue attending the clinic without paying a fee before they are transferred out to their local public sector clinic. This is to allow for the individual to have continuity in where they attend healthcare in case they find employment again at another factory in the clothing and textile industry. Should this be the case, they would then be allowed to continue using the SACTWU ART clinic services. However, when an individual continued unemployed it became difficult for them to incur the cost of travel to the SACTWU clinic as they had no income over this period and were also constrained by having to spend time trying to find new employment.

*'While I had no work, I had no money and I stopped coming to the clinic because I was looking for job in the other factories'* (Participant 12, 25 year old female).

Key informants concurred, saying:

*'Most of the factories are near the SACTWU clinic and so those who become unemployed find it hard to come to the clinic because they cannot afford bus fare to get to the clinic'* (KI, social worker).

Some participants complained that even when employed, because they are paid on the basis of the number of hours worked, taking time off work to go to the clinic meant they earned less income, placing a strain on their financial situation. It therefore became difficult for them to lose out on part remuneration in order to keep their clinic appointments. This acted as a deterrent to maintaining their regular ART clinic appointments.

*'I cannot afford to keep taking time off to come to the clinic ngoba (because) I will be paid less hours, meaning less money all the time I come here. That's why is stopped going because they won't even allow me to send someone to collect on my behalf [Meaning that the clinic does not always allow patients to send someone else to collect their treatment on behalf due to the need to review their clinical status or for their routine bloods tests to be conducted.]'* (Participant 6, 47 year old male).

#### 4.5.2 Food shortages

##### ART medication needing to be accompanied by food intake may hinder adherence

Clients were advised at the clinic to take their ART medication after eating. Food shortages that occurred as a result of temporary unemployment, proved one of the barriers to clients' adherence to ART, and hence leading to becoming LTFU from ART care. As one participant shared:

*'The factory I was working for closed down and I did not have a job for a while, so sometimes I do not have food to eat in the house and so couldn't take my ARVs .I decided to stop collecting them because I sometimes don't have food to take with the medication'* (Participant 7, 41 year old female ).

A clinic key informant also indicated that this was a problem affecting ART adherence:

*'A patient told me she had no food and was not going to waste her time collecting ARVs because she wasn't going to take them anyway'* (KI, pharmacist).

#### 4.5.3 Stigma as a result of inadvertent disclosure

##### Fear of rejection and emotional abuse

The SACTWU ART clinic only services those members who are HIV positive, therefore everyone who is seen at the SACTWU clinic leads to inevitable disclosure of their HIV status to work colleagues who attend the same HIV clinic. HIV related stigma resulting from inadvertent disclosure of their HIV status was reported by both the participants and the key informants as one of barriers causing loss to follow up from ART. Some participants feared coming to the SACTWU ARV clinic because they feared they would experience HIV-related stigma as a result of being known by other fellow workers and employers to be attending the SACTWU clinic.

*'I didn't want people to know I go to the SACTWU ARV clinic because people always talks bad about people who are HIV positive that's why I stopped going to collect'* (Participant 12, 25 year old female).

One participant said she stopped going to the SACTWU ART clinic because she began to see many of her work colleagues going to the same clinic she attended. She feared that these work colleagues would then share with others at work that they had seen her attending the same ART clinic as they did. Even if her work colleagues did not have a problem with being known to be living with HIV, she still did not feel comfortable with them disclosing her status to other fellow workers.

*'I stopped coming to the SACTWU clinic to collect my medication because there are a lot of people from work that I saw who go there too. I mean I know that they go there too because they are on ARVs, it's just that.....the thing is I do not like it when they talk at work and telling everyone I also go with them to the clinic'* (Participant 8, 31 year old female).

One key informant mentioned that she had advised clients to seek medical services at another health institution if they wanted to avoid an inadvertent disclosure instead of resorting to stop coming to the SACTWU clinic.

*'I have always advised patients to consider being transferred out to their local clinic if they do not want to be seen by the people they work with, then they will not have to worry about being stigmatised at work by their fellow colleagues'* (KI, pharmacist).

#### **4.5.4 Discrimination**

##### Isolation and gossiping about PLWHIV

One participant expressed that she had seen that there was discrimination towards individuals who were known to be living with HIV by other fellow employees at her workplace. This made her unwilling for her HIV status to be known, as she feared she would receive similar discriminatory treatment as with others known to be living with HIV at her workplace.

*'I sometimes don't like the people at work to know that I attend the SACTWU clinic because they will start talking about me at work and excluding me during lunch hours or in anything that they do so that's why I decided to just pretend to be like them and stopped coming for my treatment cos in any case I'm not sick'* (Participant 7, 41 year old female).

#### 4.5.5 Living conditions

##### Overcrowding and lack of privacy hinder adherence

Many people leave rural areas and seek employment in the urban areas. They rent accommodation near work, which they share with colleagues, friends and/or family. When people had not disclosed their HIV status to the people with whom they were living, it became difficult to adhere and to remain on their ART treatment. This could lead to them becoming LTFU. Participants reported:

*'There are four of us sharing a room and no one knows my HIV status so it becomes difficult for me to keep my pill containers so eventually I decided to stop going to collect them'* (Participant 8, 31 year old female).

*'I stopped going to the clinic because I have no privacy where I stay so even if I wanted to carry on its difficult'* (Participant 5, 59 year old male).

A key informant commented:

*'Because of poverty people live in crowded household and so a person who does not want to disclose their status would rather give up on coming to collect. It's so sad because if communities would see HIV like any other illness we would not have so many people dropping out from treatment'* (KI, lay counsellor).



#### 4.5.6 Work related pressures

##### Being unable to take time off work acts as a barrier to adherence

Patients who participated in the study expressed fears that if they often took too much or too frequent time off at work, this could result in them losing their employment. They were concerned that if they were constantly absent from work on a regular basis to attend clinic appointments and to refill their ART prescriptions this could place strain on the employer and employee relationship and jeopardise their employment situation. As a result, some decided to stop attending the clinic for their treatment and rather focus on retaining their job. Some of the participants reported that:

*'My supervisor always shouts at me when I have to attend the clinic, say work needs to be done and he would say I must stay at home if I am sick. I got tired of my supervisor shouting*



*at me all the time I had to go to the clinic so I just decided to quit the clinic'* (Participant 7, 41 year old female).

*'I had to choose between my job and the clinic'* (Participant 3, 39 year old male).

*'We were too busy at work, so I could not come to the clinic'* (Participant 11, 42 year old female).

*'I had just started at a new job and I could not ask every time I needed to go to the clinic'* (Participant 12, 25 year old female).

Clinic staff interviewed reported that they believed more needed to be done to educate employers, because this would decrease the numbers of patients LTFU because of work pressures:

*'We need to go out to the factories and give more educational talks to the workers and more especially to the employers as well because their lack of knowledge and putting work first causes clients to be lost to follow up'* (KI, lay counsellor).

## **4.6 HEALTH SYSTEM FACTORS**

Health systems factors relate to the way health services are organised and provided. This includes the accessibility of the facility, the overall environment of the facility, patient-provider relationships and support services offered at the facility.

Health service factors that were reported as barriers for clients and that could lead to them becoming lost to follow up included long waiting times while seeking a clinic consultation, over-crowding, the isolation of ART clinic from other health services, and poor health worker-patient relationship. These were factors that were reported as influencing patients in not coming to the clinic, and thus becoming lost to follow up.

### **4.6.1 Poor healthcare provision**

#### Long waiting times at the clinic can contribute to lost to follow up

Participants complained about long waiting times waiting to be attended to by healthcare providers at the SACTWU clinic. This became problematic as they were only allowed a limited time within a day

by their employers to go and seek medical care at the SACTWU ART clinic. Thereafter, they were paid per the number of hours worked or not paid at all if they did not make it to work on time if the limited time given to them to seek healthcare had been surpassed. Missing a whole day or a few hours of work had a negative impact on the workers financially, who would then rather stop attending the clinic. Participants expressed that:

*'I never make it to work on time, at the pharmacy they make us wait nje (just) for long. The pharmacist is very slow and she knows we need to get to work. This ended up affecting me at work and[i] got paid less every time I have to go to the clinic. I wish they could deliver the tablets at our factory otherwise I would not have stopped going'* (Participant 3, 38 year old male).

*'The nurses come late in the mornings and they go make their tea first while we wait I could not do it every month to go back there'* (Participant 8, 31 year old female).

One of the key informants who had worked at the SACTWU clinic for a lengthy period explained that the SACTWU ART programme had expanded over the years, initiating a much larger number of clients onto ART. Some of the patients were unaware of the increase in patient numbers on ART. Having to wait much longer than previously to be attended to caused frustrations among patients and an increase in the number of ART patients who did not feel they could wait for such a long period to receive care. This was likely to have contributed to them becoming LTFU.

*'When we started the ART roll out programme we had very few patients and they were all seen in the morning and they all used to make it to work on time. Patients forget that the programme has grown and is still growing, having a lot of patients than before so patients cannot compare the days when the clinic was starting and now, of course the waiting time will increase! Not everyone will get to work on time unfortunately and this has caused patients to drop out of care and become LTFU'*(KI, pharmacist).

#### **4.6.2 Health worker attitudes**

##### Negative attitudes and lack of support from healthcare workers

Some clients complained of being disrespected when spoken to by the healthcare workers (HCW). These negative attitudes were seen as factors that discouraged patients from returning to the SACTWU clinic for their treatments.

*'Sometimes I forget my clinic card at home, but go to the clinic ngoba (because) I know my file number but the lady who gives us the files shouted at me in front of all the other patients ethi yena akasebenzi kanje (telling me this is not how the clinic operates) and sometimes would make me wait and gives those who have their clinic cards first, then mina (me). The attitude from the receptionist is always bad. I just left and never returned and that's what I told them when they came looking for me' (Participant 7, 41 year old female).*

Many of the participants mentioned that the negative attitude they received at the SACTWU clinic from the HCW contributed a lot to causing delays in being attended to by the HCW at the clinic. They felt that the HCW did not take into consideration that patients were given limited time off work to attend the clinic.

*'I sometimes go to the clinic during my lunchtime and ask for a pass out because the clinic is close to my work. The nurse would shout at me and say this is also their lunchtime. Why do I choose to come to the clinic at this time, as they all leave for lunch leaving us sitting on benches until their lunch hour is over'. I cannot come in the mornings because I would never make it for work and if I come during my lunch breaks the attitude and the treatment is even worse so I just didn't bother coming back to collect the ARVs' (Participant 1, 34 year old female).*

*'It was so much better when the old workers were still working at the clinic they knew we were rushing to work. These young nurses do not want to work. It really became difficult to return there' (Participant 9, 55 year old female).*

One key informant concurred that some of the poor HCW attitudes towards patients could have contributed to the SACTWU clinic patients becoming LTFU. She stated:

*'Nurses attitude contributes a lot to clients being lost to follow up, I have seen the way they treat patients and shout at them especially for coming just before they knock off work' (KI, Social worker).*

#### **4.6.3 Frequent clinic appointments**

##### Monthly ART clinic appointment seen as an inconvenience by patients

Clinic appointments are scheduled monthly for patients to visit the clinic for a medication refill and health review by a clinician. Participants reported that these monthly visits to the SACTWU clinic

required them to take too much time off work over the course of a year. The frequency of clinic visits needed was inconvenient and deterred them from keeping all their appointments.

*'Why can't they give us pills for 3 months like I heard they do at government clinic? Here we have to come every month. I left for the clinic that my cousin gets his treatment so I don't have to miss work so many times'* (Participant 12, 25 year old female).

#### **4.6.4 Isolation of the ARV clinic**

##### Isolation of the ARV clinic from other health services hindered adherence

Having stand-alone clinics for those who are HIV positive was seen to be a barrier to clients' clinic attendance and as contributing to becoming lost to follow up. The SACTWU ARV clinic was separated from the PHC clinic due to the growing number of patients having been initiated on to the ART program. This was to avoid too extensive overcrowding. Key informants concurred that this made a lot of the patients to become lost to follow up. They commented:

*'With the clinics separated the clinic has lost a lot of patients on the ARV clinic side because the workers didn't like the other workers knowing that they attend the ART clinic'* (KI professional nurse).

Participants also admitted that they stopped coming to the SACTWU ART clinic because they did not understand why the two clinics had to be separated.

*'Especially on a Friday when we finish early at work, I do not like to come to the clinic cos (because) a lot of people go on a Friday and the people not on ARVs will see me going to the ART clinic'* (Participant 2, 38 year old female).

#### **4.7 CONCLUSION**

This chapter has presented the main findings of the study. The findings show that a range of individual related, socio-economic and health system factors contribute to patients becoming lost to follow up from ART care at the SACTWU clinic. Socio-economic factors and health systems factors were most commonly mentioned as barriers to remaining in ART care. These included unemployment, food shortages, frequent clinic visits and stand-alone clinics for ART care.

The following chapter discusses the findings of the study, relating them to the comparative literature in this area.



# CHAPTER FIVE – DISCUSSION OF THE FINDINGS

## 5.1 INTRODUCTION

This chapter discusses the main study findings presented in the preceding chapter as factors contributing to LTFU among SACTWU Union Members on ART care. I will discuss these in conjunction with comparative literature in this area of study.

The findings in this study revealed that the factors contributing to LTFU could be categorised into: individual (patient)-related factors, socio-economic factors and health system related factors. This is in line with the study findings of Bauleth (2013), Mathebula (2014) and Mwale (2016) and others, in which they also showed that the main contributing factors to ART patients' poor adherence leading to LTFU fell into these categories.

## 5.2 INDIVIDUAL FACTORS

Patient-related factors influenced attitudes and behaviour towards consistent ART adherence and attending ART care. Themes that emerged related to patient-related factors that contributed to LTFU included: non-disclosure of HIV-positive status, not experiencing ill health, poor treatment literacy, alcohol abuse, travelling schedules and delays and alternatives to ART being available in the form of herbal medication.

### 5.3.1 Disclosure

The findings of the study revealed that the lack of disclosure of a person's HIV status hindered adherence and was a noteworthy contributor to LTFU of the SACTWU union members from the ART clinic. HCW expressed the view that self-disclosure of a patient's HIV-positive status to close family or friends could assist those on ART in adherence and keeping ART clinic appointments. They stated that having someone to remind them when it was time to take their medication daily could help. It could also assist by a person to whom they had disclosed their status being willing to attend the clinic on their behalf to collect medication if they were unable to make their clinic appointments. HCW reported always encouraging their clients who were initiated on ART to seek out close friends and family to whom they felt comfortable disclosing their status, and from whom

they could seek support. Bauleth (2013), who conducted a study in Oshakati Hospital in Namibia looking at factors associated with poor adherence amongst patients receiving antiretroviral therapy, reported that lack of disclosure of HIV status acted as a barrier to ART clinic attendance. Findings from Bauleth's (2013) showed that, sometimes, when HCW were zealous in encouraging HIV-positive clients to disclose their status to relatives, the clients were reluctant to do so as they feared the reaction and treatment they were likely to receive from relatives upon disclosure. This prompted them to rather stop attending the clinic for treatment than disclose their HIV status to relatives. A further contributory factor to LTFU from ART care to emerge from this study was that more participants feared that attending the ART clinic would lead to their HIV status becoming common knowledge amongst their colleagues and family. Bauleth's (2013) study had similar findings.

### **5.2.1 Not yet experiencing physical illness can affect perception of the need to be on ART**

The latest national ART treatment guidelines adopt a 'test and treat' strategy, which stipulates that all individuals that test positive for HIV must be initiated on ART immediately, regardless of their clinical staging or CD4 count (DOH, 2014). This guideline has increased the number of people being initiated on ART who have not yet experienced any physical illness from HIV. In this study, this emerged as a factor contributing to poor adherence and LTFU among patients who are on ART. The study found that participants who had not as yet experienced ill health were less motivated in taking their ART and tended to have poorer adherence and were more easily LTFU. In Bauleth's (2013) qualitative study, a participant also mentioned that she stopped taking her ARVs because she was feeling better and thought it was not necessary for her to continue taking ART treatment.

### **5.2.3 Poor treatment literacy**

Poor treatment literacy related to the taking of ART medication emerged in the study as a contributing factor to LTFU. For example, there were instances reported in which patients asked when they would be discharged from ART as they were feeling better. This indicated that some patients lacked the knowledge that it was essential that ART be seen as a lifelong treatment. Bauleth's (2013) qualitative study found similarly that some participants stopped taking their ARTs because they felt better and thought it was unnecessary to continue with treatment. In both studies, participants clearly didn't fully understand that the ART is lifelong treatment even when an individual is not experiencing physical illness. Patients who decided to stop taking their ART showed insufficient knowledge of the dangers and consequences of defaulting on ART treatment;

that includes greater individual vulnerability to a recurrence of HIV related illnesses and problems related to individuals and population resistance to particular ART medication due to interrupted treatment.

#### **5.2.4 Impact of alcohol use**

The study findings showed excessive alcohol intake having a negative effect on ART adherence, contributing to them becoming LTFU. This is in keeping with Mwale's (2016) findings from a qualitative study conducted in Zambia that examined factors affecting retention in care of patients on ART in the Kadwe District in Zambia. Mwale's (2016) study also found that excessive consumption of alcohol (in the form of beer drinking) caused patients to forget to take their ART medication, ultimately leading them to stop taking their medication altogether. Cramn et al. (2010) also found that consuming alcohol when on treatment had negative consequences for treatment adherence, with patients forgetting when to take their ARV treatment.

#### **5.2.5 Travelling**

All the participants in this research study were working class, with some of their jobs requiring them to travel extensively, which negatively affected their ART adherence. Mugisha, et al. (2007) conducted a study in Northern Uganda examining the reasons for LTFU among the ART clients, and they found that 7% of the participants were LTFU due to travelling and migration. In Mugisha et al.'s study (2007), some of the participants had permanently emigrated from the country for economic reasons. Mugisha et al. (2007) cite a study participant in a focus group discussion who reported that many patients found business opportunities in Southern Sudan and did not ever return.

In our study, participants who were company drivers, whose job was to travel making deliveries and collections, frequently found that their travel was extended making it difficult to keep scheduled clinic appointments. This negatively impacted on their treatment adherence and visits to the clinic. Zulu's (2009) qualitative study conducted at Murchison Hospital in KwaZulu Natal province in South Africa investigating factors associated with default of scheduled drug pick-ups and clinic visits by patients on ART, found that truck drivers were some of the patients most vulnerable to missing their ART treatment and one of the main groups of people affected by work schedule leading to LTFU. This shows that patients who were in job categories that involved extensive travel tended to become more likely to become LTFU from ART care. Other participants in our study reported travel



for social or family reasons, for example when someone was unwell back at home, and extended visits away from the usual residence, lead to them staying longer or moving permanently to another area. In Zulu's (2009) study, some patients reported moving from the usual place of residence to an area where they didn't usually attend ART care, because they preferred to die closer to home, placed them at greater risk of becoming LTFU from ART care.

### **5.2.6 Alternatives to ART**

#### The impact of herbal medication on ART use and adherence

The study established that even though the participants came to test for their HIV status and were enrolled on the ART program, a substantial number reported having tried using herbal to cure themselves of HIV medication. This is mostly influenced by seeing community members or colleagues advertise and encourage the use of herbal medication as a cure for HIV. A study conducted at Thembaletu Clinic Helen Joseph Hospital in Johannesburg that investigated LTFU of patients on ART also found that a decision to try the use of traditional medicine was one of the major reasons why some of the clients became LTFU (Maskew et al., 2007). In this research study, one participant reported having stopped taking ART due to being unable to collect their ART treatment and as a result adopted what they saw as a more practically feasible behaviour. This involved them opting for the use of traditional medicine, which their colleagues reported as having helped them in slowing down HIV progression, or as offering HIV cure, rather than missing treatment altogether. Peltzer et al.'s (2011b) study results concurred that use of herbal medication was associated with decreased ART adherence, leading to patients becoming LTFU from ART care. Antiretroviral therapy not providing a cure for HIV encouraged patients to seek other alternatives to ART such herbal remedies. This was in the hopes that these might provide a cure for their condition.

### **5.3 SOCIO ECONOMIC FACTORS**

Socio economic factors have a great influence on the health of communities. Themes that related to socio economic factors that emerged from this study included cost and logistics, food shortages, stigma, discrimination, living conditions and work related pressures.

### 5.3.1 Cost and logistics

Unemployment, even if this was temporary, contributed considerably to LTFU amongst the study participants. The SACTWU ART clinics are situated near members' workplaces for the members' convenience, in terms of transport and time costs. However, if members became unemployed, they were faced with cost and logistical problems in travel from their communities to one of the SACTWU ART clinics for consultations. Participants emphasised the financial difficulties incurred when they were either permanently or temporarily unemployed. Some clothing and textile industry factories employ a strategy of temporarily closing their factories during their 'off-peak' seasons, leaving their employees unemployed and without an income during the closure period. When unemployed, some workers moved back to their homes such as farms in rural areas. Study participants reported experiencing problems with cost of travel to get to the SACTWU ART clinics during times of unemployment, since the clinics were located closer to their previous workplaces than to their homes. The need to pay travel costs, particularly in the context of non-receipt of income, played a leading role in clients with HIV becoming LTFU. The Miller et al. (2010) cohort study showed similar findings, namely that financial difficulties experienced by clients meant that they did not have sufficient money for the transport costs to reach their usual health facility. This contributed to them becoming LTFU from treatment. Gelmanova et al.'s (2007) research findings also found unemployment to be associated with low socio-economic status that had negative impact on treatment adherence. Two of the KI in the current study commented on this subject by saying that patients who were unemployed were most commonly among those who would find it difficult to keep their clinic appointments and adhere to their treatment. They attributed this to the travelling costs involved in reaching the SACTWU clinic for care.

### 5.3.2 Food shortages

Food shortages also were reported to be a contributing factor for study participants becoming LTFU. Zvavamwe et al. (2008) mentions that successful completion of treatment in a patient is closely associated with the availability of food. Some participants reported that when they attended the clinic to obtain a re-issue of their monthly supply of medications HCW, in providing them with instructions on how to take the medication, stressed that they should take their medication after food. Hence, some study participants reported making a decision to stop collecting their treatment if they didn't have sufficient food to take with their medication. This had an influence in their becoming LTFU from treatment. Mathebula's (2014) study conducted in Thekganang ARV clinic in Pretoria, South Africa that similarly examined reasons for LTFU from HIV care, had similar findings that food

shortages (having nothing to eat) hampered patients' ART adherence and clinic attendance. Murray et al. (2009) and Weiser et al. (2003) in their findings, also concurred with this study's findings that food shortages impacted negatively on patients' determination to take and adhere to ART. Even though their appetite improved after initiating ART treatment, continued adherence was hampered by having no food, and thus contributed to them becoming LTFU from care.

### **5.3.3 Stigma**

HIV associated stigma is associated with poor knowledge, fear of the disease and death and unsafe sexual behaviour (Theron, 2005). The study participants all reported that they felt that living with HIV was for the most part stigmatised. They feared disclosing their HIV status because of fears of rejection. This included fears that they would be abandoned by an intimate partner if they disclosed their HIV-positive status, as well as fear of stigmatisation or being subject to gossiping at work if they were seen attending the HIV/ART clinic. Hardon, et al.'s (2006) cohort studies conducted in three different countries (Botswana, Uganda and Tanzania) had similar findings. In Hardon et al. (2006), participants reported feeling that they had to hide the fact that they were taking ART medication, due to fears that this would create gossiping about them. Charurat (2010) also found that, although the number of treatment facilities had been increased and made more accessible to communities, patients still continued to avoid accessing care at facilities within own communities because of their fear of stigma. Wasti et al. (2012) also found that PLWH avoided seeking treatment at their nearest clinic because of fears of stigmatisation. The WHO (2006) reported that HIV stigmatisation remained a major problem hindering HIV treatment and care.

### **5.3.4 Discrimination**

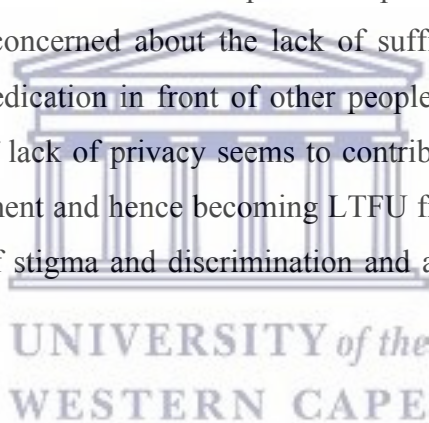
In this current study, discrimination contributed to patients becoming LTFU as patients feared that it being known that they were living with HIV would create a situation of isolation and rejection from partners, relatives or colleagues. Due to poor knowledge of HIV and AIDS, communities often have misconceptions about this condition. When a person tests positive for HIV they therefore find it difficult to disclose their status because of what they have heard or seen people around them say about people living with HIV. In the current study, most participants feared for their status to become known, or taking their medication in front of their families, friends or work colleagues, due to fears that they would experience discrimination as a result. In Bauleth's (2013) study also found that

participants feared experiencing isolation by friends, who would keep a distance from them if they discovered their HIV positive status.

### **5.3.5 Living conditions**

#### **5.3.5.1 Overcrowding and lack of privacy**

Some study participants reported sharing rooms with colleagues or relatives as they were not originally from Durban, but residing in the city for work purposes. They shared rooms to save on rent money so they would have money to send back home every month. The participants concurred that this overcrowding (sharing of rooms) contributed to their non-adherence and eventually contributed to their becoming LTFU. These findings are compatible with those of Mathebula (2014). A participant in his study reported that as he lived in a hostel sharing a room with his other colleagues, he feared taking his ART medication in front of them and therefore became non-adherent. Wasti et al. (2012) also mention that most patients reported being embarrassed about their HIV status and being therefore concerned about the lack of sufficient privacy to take their ART alone. Having to try and take medication in front of other people led to their skipping their ART doses. This experience of lack of privacy seems to contribute to patients not going back to clinics to collect their ART treatment and hence becoming LTFU from care. Overcrowding and lack of privacy cross-cut with fears of stigma and discrimination and act as deterrents to some patients remaining on ART.



#### **5.3.6 Work related pressures**

Being on lifelong ART, like any other chronic illness, requires dedicated time for clinic visits, which means taking time away from work. The SACTWU workers work daily and for long hours and sometimes on weekends without rest. Many SACTWU employees are contract workers. Their employment can therefore be particularly jeopardised if they take too much time off work. Some employers view taking substantial amounts of time off work for healthcare visits as making an employee unfit for their job. This could result in termination of a worker's employment. Those participants who were contract workers were paid per number of hours worked. Therefore, the more hours they spent at a health facility, the less they got paid. This created difficulties, as each time workers took time off to work to go to the clinic they were faced with being paid less at work due to the number of hours they lost working while at the clinic. These financial difficulties contributed to

them becoming LTFU. Maskew et al. (2007), who conducted a similar study to this one elsewhere in South Africa, also highlighted financial difficulties as a leading cause of LTFU among the ART patients. Similarly in Zulu's (2009) study some participants reported that they felt they had to choose between their jobs and attending the clinic. In both the Green (2004) and Bauleth (2013) studies, participants reported stopping taking their ART treatment in order to retain their employment.

## **5.4 HEALTH SYSTEM ORGANISATIONAL FACTORS**

Health system organisational factors examine how the health services are managed and delivered, the health facility environment, health care provider-patient relationships and medication (Mukumbang et al., 2017). During the interviews with the participants, the four subthemes related to health system organisational factors contributing to patients from the SACTWU clinic being LTFU were: inadequate service quality, which included long waiting times; frequency of clinic visits; clinic structure and operational issues such as stand-alone clinics separated from other services that could then be easily identified as catering to HIV care and treatment; and in the case of some HCW, poor health worker attitudes to patients.



### **5.4.1 Long waiting times**

The long waiting times for consultations with healthcare provider, and at the pharmacy to collect medication, were cause of much frustration for study participants. These affected their willingness to keep clinic appointments and had a negative impact on their earnings as it meant fewer hours worked in a day. This contributes to LTFU from care. Zulu's (2009) study concurs that a loss of working time comprises a pressing and immediate concern for patients, as long waiting times at healthcare facilities cause them financial harm. In Bauleth's (2013) study, similar complaints were reported, namely that patients faced long waiting times at clinics. These findings were also common in the studies conducted by Miller et al. (2010) and Mathebula (2014), who also reported that clients complained about the long waiting times at healthcare facilities.

### **5.4.2 Frequent clinic appointments**

Clinic appointments are determined by a number of factors, which include availability of drug supply at the clinic, adherence issues that a patient might be having and whether a patient is clinically stable

or not. The SACTWU clinics collect their ART drug supply from King Edward Hospital, which sometimes does not supply a sufficient amount of the drugs required for the number of patients the SACTWU clinics cater for. If the patients have other co-morbidities like hypertension or diabetes which are insufficiently controlled and need attention from a clinician, then the patients will be seen more often than if there are no co-morbidities. Most of the patients did not seem to receive sufficient information on, or did not understand, the processes causing delays. This added to their sense of frustration and acted as a deterrent to them attending the clinic. Complaints of only receiving one month's supply of ART treatment from the SACTWU clinic instead of three months' supply, as was the practice at most government public sector clinics, acted as an additional hindering factor in remaining on treatment. This complaint was linked to problems related to the financial costs of having to attend the clinic on a monthly basis. In Mwale's (2016) study conducted in Kabwe District, Zambia, participants had similar concerns about receiving only one month's instead of three months' drug supply.

#### **5.4.3 Stand-alone clinics**

In government hospitals and clinics, for operational reasons, the ART clinics or sections are usually separate from the general outpatient departments, and in some hospitals the ART department has its own pharmacy. These ART clinics are often assigned their own special name that is different from that of the hospital or other clinic. Initially, the SACTWU health facilities were not separated into two separate general primary care and ART clinics. However, with an increase in the number of SACTWU members enrolled in its ART program, the facilities were separated, as more space was needed and having two clinics situated opposite each other in one road. One is solely for ART treatment and care, and the other is a general primary health care clinic. This emerged as a source of unhappiness among participants and contributed to some of the ART patients who did not want to be seen using the ART clinic, to stop attending the clinic for fear of their HIV status being known.

#### **5.4.4 Health worker attitudes**

Poor health worker attitudes towards ART patients can lead to a poor patient-health worker relationship, which can have a negative effect on adherence, eventually and potentially leading to LTFU from care. In the current study, many participants expressed concern about the negative attitudes they sometimes experienced from some of the health care workers. This took the form of being reprimanded or shouted at. Some participants complained that some HCW were not

sympathetic if they complained about losing pay because of long waiting times at the clinics and were unhappy if they attended the clinic over lunch time when HCW wanted to take their lunch break. One participant singled out staff working in reception as being particularly uncaring in their attitudes towards the patients. Similar sentiments were expressed in Zulu's (2009) study conducted in Murchison Hospital in KwaZulu Natal province in South Africa, looking at reasons for default follow up of ART, where reception staff at the facility clinic from which they collected their treatment were perceived as being short tempered. In Miller et al.'s (2010) study conducted in South Africa, similar findings emerged, with a participant who had lost his clinic card reporting that he was reluctant to go back to the clinic as staff at the reception routinely turned patients away if they were not in possession of their clinic cards. In Bauleth's (2013) over-critical attitudes from some HCW were also seen as deterring patients from attending healthcare facilities.

## **5.5. STUDY LIMITATIONS**

This qualitative study was not aimed at being generalizable to all LTFU patients from HIV care. The study only included those clients who were LTFU but returned to care, and did not include those who were permanently LTFU in care.

The study only focused on patients attending a clinic for the trade union members, which kept the study limited geographically to the urban area of Durban in KwaZulu Natal, and therefore the findings may not be reflective of the situation in other urban centres or in rural areas.

Nevertheless, the findings provided insights that are useful to the SACTWU clinic in its efforts to better retain its union members on ART into care, and can provide valuable insights on which to base research in other similar settings.

## **5.6 CONCLUSION**

The study findings discussed were interlinked, and mostly influenced by the socio-economic status of the workers and their difficulty in disclosure of their HIV status. Despite the trade union's efforts to ensure easy accessible health services to their members, these factors are still an issue. Reasons for LTFU among the SACTWU union members on ART appeared to resonate with those in a number of other studies in different countries.

The next chapter outlines the overall conclusions of the study, and recommendations are discussed with respect to addressing some of the factors causing LTFU of ART patients at the SACTWU ART clinic.





# CHAPTER 6 - CONCLUSION AND RECOMMENDATION

## 6.1 INTRODUCTION

In summary, this study's aim was to explore factors associated with loss to follow up of clients on ART treatment among the South African Clothing and Textile Union members living with HIV and attending the SACTWU Worker Health Clinic in Durban, South Africa.

## 6.2 SUMMARY OF CONCLUSIONS

This exploratory study demonstrated that the reasons that the SACTWU ART patients are LTFU are interlinked and complex. In implementing this research, participants who had been LTFU but subsequently returned for treatment were selected and interviewed using in-depth interviews. Health-care workers also provided their opinions on this topic through focus group sessions. The purpose of the study was to provide insights on the causes for patients becoming LTFU so as to assist the SACTWU clinic management, health care workers, the trade union SACTWU and the employers to develop strategies to decrease the incidence of LTFU at the SACTWU ART clinic. Adherence of individuals and retention to ART care of PLWH will not only improve the ART programme but prolong the life for PLWH.

The study demonstrated that the reasons that the SACTWU ART patients are LTFU are interlinked and complex. The main contributing factors to LTFU identified were: individual- related factors, socio economic-factors and health-system related factors. Key individual factors included non-disclosure of HIV status, not yet experiencing physical illness as a result of living with HIV, poor antiretroviral treatment literacy, the impact of excessive alcohol use, travelling away from the clinics clients routinely attend for ART services, and use of alternatives to ART.

Economic factors primarily related to the costs to individuals of reaching the ART clinics, particularly when the clients were unemployed, and food shortage. Social factors deterring ART adherence included: stigma, discrimination, overcrowded living conditions that created lack of privacy, and work-related pressures.

Dominant health-system factors included poor health service provision, difficulties created by the need for monthly clinic appointments, stand-alone clinics leading to potential inadvertent disclosure of their HIV status and negative attitudes by some health workers.

## **6.3 RECOMMENDATIONS**

As loss to follow up remains a problem amongst the SACTCWU clinic ART patients despite the SACTWU union's initiative of offering health services specifically for union members close to their place of employment, key areas identified as contributing to LTFU could assist in addressing some of the factors promoting loss to follow up. Below, I outline a set of key recommendations:

### **6.3.1 RECOMMENDATIONS REGARDING INDIVIDUAL FACTORS**

In order to address the problem of non-disclosure of a person's HIV status as a leading barrier to patients ending up being LTFU, ways to encourage and deal with the possible need for the disclosure of HIV status should be pre-emptively discussed with patients before the lay counsellor performs an HIV test so that should the patient test positive, potential plans for disclosure have been developed. Should a person test HIV positive, these potential plans for the importance of disclosure and practical methods for a patient to disclose their HIV-positive status to key individuals who they trust should be further discussed. Patients should be aware of the benefits that disclosure of their status to selected individuals has, that is, of having someone who can provide them with emotional support. Disclosure will also assist those on ART to receive assistance, if and when necessary, with collection of the ART when difficulties arise preventing the worker from leaving work to collect medication. It can also assist in provision of adherence support. This can also be an opportunity to improve knowledge if gaps in knowledge are identified. Patients should be encouraged to be accompanied by the person to whom they have chosen to disclose their HIV status when they attend their second scheduled appointment at the health facility. This will assist the person who accompanies the patient to become a support person to the patient and allow the lay counsellor and social worker to assess the level of knowledge the supporter has on HIV and in treatment. This can also be an opportunity to improve both the patient's and the support person's knowledge of HIV and ART, if gaps in the knowledge are identified. As the national HIV/AIDS guidelines being implemented in KwaZulu Natal involve 'test and treat', many individuals are now being initiated on ART before they begin to experience signs of AIDS-related illness. This stresses the need for counsellors to provide more in depth and convincing information to patients about the importance of continuing on ART despite feeling healthy, as this will ensure that they do not experience future possibilities of opportunistic infections and ill health as a result of HIV weakening their immune system.

Knowledge gaps identified with regards to treatment literacy among the SACTWU ART patients need to be attended to by the HCW at the SACTWU clinics. Further opportunities need to be created for HCW to continue to strengthen ART treatment literacy with patients at every follow up appointment. Improved ART literacy will create improved patient knowledge on ART drugs and HIV as a whole so as to encourage greater commitment and motivation to continue taking ART so as to remain healthy.

Patients should also receive counselling on the risks of alcohol intake while on ART and encouraged to avoid excessive consumption. They should also be counselled not to stop taking ART if they have been drinking but to rather continue even if they have missed some medication doses. Support groups could be established for those who are at serious risk of being unable to stop consuming alcohol.

Frequent travelling has also contributed to patients becoming LTFU. They should be adequately informed of the different options available to receive their medication, when travelling or if travelling is extended unexpectedly. Those who travel frequently can be equipped with referral letters certifying that the patient is on ART treatment and which type of ART they are on, so they are able to seek for refills of their treatment at any nearby facility while travelling. Patients without referral letters can be informed that they should always have their clinic carrier card in their possession so they can produce the card at the nearest facility as evidence to the next facility that the patient is on ART, so they can be assisted with a refill of their treatment. These patients should also be advised not to wait till their medication is finished before seeking help.

Herbal medication use as an alternative to ART was also identified as a contributing factor to SACTW patients being LTFU. The use of herbal medication and its potential risks in causing some negative effects on organs in the body should be discussed during literacy education. It should also be emphasized that herbal medication cannot cure the HIV virus.

### **6.3.2 RECOMMENDATIONS REGARDING SOCIO ECONOMIC FACTORS**

Costs and logistical problems contributed to the SACTWU ART clients being LTFU when they became unemployed or were temporarily unemployed. Unemployment sometimes occurred when factories closed down either permanently or temporarily - when factories closed down during the slack periods leaving the patients without an income and therefore with no means to pay for transport costs to attend at the clinic situated near their work area. A strategy should be developed to assist those who are unemployed in applying for their unemployment insurance fund (UIF) benefits, to

assist the patients financially while they are unemployed and seeking new employment. Those who are unemployed should be issued with transfer letters to their local clinics, where cost of transport can be reduced or eliminated.

Food shortages have contributed to LTFU among the SACTWU ART patients. Patients on ART therapy are usually instructed to take their ART medication after a meal. This can cause frustration when there is not enough food in the household for patients to eat before taking medication. This has been a cause of some patients interrupting their ART treatment and sometimes stopping collecting their medication from the clinic altogether. Strategies that could be implemented include for the SACTWU clinic to organise and offer food parcels, a food allowance or food vouchers for those members who are ART patients, as long as they are adherent to his or her medication. This could also encourage other SACTWU union members who have never been tested for HIV to get tested and know their status because they will realise that the SACTWU ART clinic takes good care of their members on ART treatment.

Stigma and discrimination emerged as a cause of LTFU among some SACTWU ART patients. Stigma and discrimination towards PLWH result from lack of knowledge among community members about HIV/AIDS. This leads to community misconceptions and myths about HIV and AIDS. A strategy towards reducing stigma and discrimination could be to develop community-based campaigns that educate the community about HIV/AIDS to ensure that they are knowledgeable about HIV and can therefore treat those living with HIV like any others living with a chronic illness. Communities can be enlightened about different ways of contracting HIV, which could lessen the perception that this virus is contracted through promiscuous behaviour. Communities could be educated that HIV positive people are 'still normal' individuals and that the HIV virus is not transmitted in an airborne manner and cannot be contracted like influenza or by being in the same room as an HIV positive individual. Health care workers could also visit different clothing and textile factories to give educational talks on HIV/AIDS.

Overcrowding and lack of privacy in the homes also emerged as one of the contributing factors for SACTWU ART patients being LTFU. Those who had not disclosed their HIV-positive status were most affected by this, as it was difficult to take their medication religiously, as they feared that those they lived with might notice they are taking medication on a regular basis and may start asking uncomfortable questions. Patients who are initiated on ART should be encouraged to disclose their HIV status, especially to those they live with, so that it becomes easier for them to take their treatment, without having to hide that they are doing so. Offers could also be made to bring in those individuals they live with on their visits to the clinic or for the clinic health care workers to conduct

home visits so as to educate those with whom clients live on the HIV and AIDS illnesses. With a more knowledgeable and accepting community, people on ART would not feel ashamed when having to take their ART and so would be less likely to resort to becoming LTFU.

Work related pressures were also among the barriers contributing to patients becoming LTFU, with some of the participants choosing to go to work over attending the health facility to collect medication, because they felt that they could not leave work. Work related pressures led to their feeling unable to take time off work, even if this was only for a few hours because of work or because of employee shortage at their workplace. They felt pressurised in these circumstances by the employer not to take time off to attend at the clinic. The SACTWU ART clinic managers should engage with the employers and educate them and provide them with accurate information on HIV/AIDS and what it means when a client is started on ART. This could influence employers in having an improved understanding of why workers living with HIV need to take some time off work to attend clinic appointments. The employers could in addition employ a qualified health care worker at their company who could assist with collecting pre-packed medication at the ART SACTWU clinic and dispensing these to their employees living with HIV, thus eliminating the need for them to take time off to attend at the clinic, unless this was necessary in order to have their bloods taken. This strategy could increase adherence and decrease clients being LTFU. This would also mean that patients agreeing to this arrangement could be made more comfortable in indirectly disclosing their HIV status to their employer. This strategy could save the SACTWU ART patients from taking time off work only to collect their monthly medication, and could also make employers satisfied as fewer employees will be absent or late for work due to medication collections. Those patients who would prefer not to have their medication dropped off at their work place could be linked to the Central Chronic Medication Dispensing and Distribution (CMDD) programme in their area, where they are able to collect medication after hours or during weekends. Offering these kinds of convenient services could encourage patients who were not adherent to become adherent to their medication by providing easier ways of receiving their medication, either at work or at a CMDD site.

### **6.3.3 RECOMMENDATIONS REGARDING HEALTH SYSTEMS FACTORS**

Long waiting times at the SACTWU ART clinic emerged as a contributing factor to clients becoming LTFU. A number of individuals reported having to spend much of their time out and stop all their other activities to wait at the clinic to collect their ART medication. Some patients reported that having limited time available to allocate to collect their medication caused them distress.

Participants highlighted that the long waiting times at the clinic also caused them to lose payment for the hours they spent at the clinic rather than at work as this decreased their salary payments. Strategies that could be put in place include a fast tracking system at the SACTWU clinic for those patients who are clinically stable and show signs of good adherence. These patients could be fast tracked by allowing them to proceed straight to the pharmacy where their medication would be pre-packed and ready for pick up. These patients could also be given a larger medicine supply to cover more months of treatment so as to minimise the time they had to allocate in their busy schedule to visit a health facility. These patients could additionally be given the opportunity to be able to send a friend or a relative to collect their ART on their behalf, except on occasions where their annual blood tests have to be conducted or when they had to attend the clinic themselves in order to receive their blood test results. A further strategy that the SACTWU clinic could adopt is to have ART medication pre-packed for those patients who are stable on their medication and have it delivered to the work place or a collection point of their choice. SACTWU could also implement a CMDD programme and link their stable patients to community programmes, where they could collect their ART. All these strategies could have the potential to increase adherence and retention of the SACTWU members on ART.

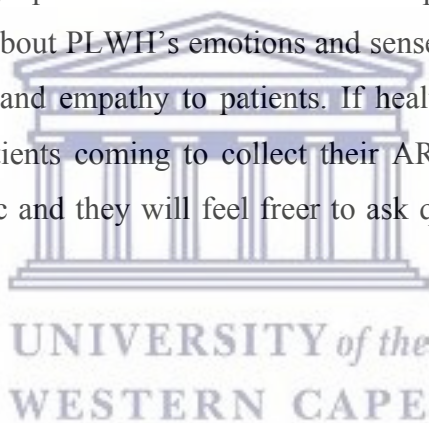
Patients will realise that if a person is adherent to his/her medication, the system of collection of ART medication can be made more convenient, without compromising their employment situation. These strategies would also assist decrease the number of patients needing to consult a HCW at the clinic and ultimately decreasing the waiting times for all patients.

Having to attend frequent monthly clinic visits to collect ART treatment emerged as a contributory factor to patients becoming LTFU. Reasons why patients are recalled to visit the clinic frequently include poor adherence to ART, having other chronic medical conditions, or shortages of drug supplies in the facility to provide clients with more than one month's medication supply. Patients who need to see the health care worker monthly should be provided with a proper explanation for why they need to return monthly. If adherence is the key reason for attending monthly, if provided with an explanation, these clients may be motivated to ensure improved adherence to avoid having to make frequent to see a HCW. The SACTWU clinic appears to be experiencing a problem of receiving insufficient supplies of ART from King Edward hospital to enable all patients to receive more than one month's supply of medication. The SACTWU clinic managers should attempt to obtain their own demander code from the department of health (DOH) so that the clinic can receive its own drug supply directly from the suppliers. A demander code is having the SACTWU health facilities registered independently so they are able to order and receive their drug supplies from the

manufacturers. This will enable stable ART patients to receive more than one month's supply of their ART drugs, and therefore decrease the clinic visits necessary.

Having a stand-alone SACTWU ART clinic was intended to create space for the growing number of patients being initiated on ART, and also to provide specialised care to the ART patients. However, this emerged as contributing to patients becoming LTFU as they feared being seen at the clinic by other fellow employees. A strategy should be employed to offer ART services at both SACTWU clinics (the stand-alone ART clinic and the general PHC clinic) so that a patient who did not wish to be seen as living with HIV has the option of obtaining their ART without having to collect this from the ART clinic. This will cause less frustration and fear of being discriminated against and exposed as a person living with HIV.

Healthcare worker attitudes towards patients on ART were found to contribute to some SACTWU clinic patients becoming LTFU. When healthcare workers are employed, they should not only be knowledgeable about the HIV disease and treatment, but should also be trained in good quality of care and adopting positive and sympathetic attitudes towards all patients including those LWHIV. They need to be better informed about PLWH's emotions and sense of vulnerability, so that they are in a position to provide support and empathy to patients. If health care workers display a caring attitude and understanding to patients coming to collect their ART, it will make it easier for the patients to come to visit the clinic and they will feel freer to ask questions or talk about any issues they might have.



#### **6.4. CONCLUSION**

In conclusion, HIV/AIDS still remains a problem in the health sector. Managing HIV/AIDS requires a public health approach, which entails holistic management around the illness. While the SACTWU union assists with offering ART health service to its members living with HIV, holistic management will assist in addressing the underlying issues that cause LTFU amongst patients on ART care. Addressing underlying issues of patient-related factors, socio-economic factors and health system factors will decrease patients becoming LTFU, which in turn reduces public health effectiveness of provision of ART care. This will assist in reaching the '90-90-90' goal of ending the HIV epidemic.

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## APPENDIX 1A: CONSENT FORM

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7535, South Africa

Tel: +27 21-959 9382

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### CONSENT FORM

**Title of Research Project: An exploration of loss to follow up from HIV care among the South African Clothing and Textile Workers Union.**

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

Participant's name.....

Participant's signature.....

Date.....

Researcher

I have read this document to the participant, in Isizulu or given this to them to read. I have tried to answer his questions to the best of my knowledge.

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

Signature of Researcher: \_\_\_\_\_

**BIOMEDICAL RESEARCH ETHICS ADMINISTRATION**  
Research Office  
New Arts Building,  
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## APPENDIX 1B: CONSENT FORM



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E-mail: snziqubu@gmail.com

#### CONSENT FORM

**Isihloko socwaningo: An exploration of loss to follow up from HIV care among the South African Clothing and Textile Workers Union.**

Lolu cwaningo liye lachazwa kimi ngolimi engilaziyo nengiliqondayo. Imibuzo yami mayelana nesifundo iye yaphenduleka. Nginyaqonda ukuthi ukuhlanganyela kami nokuzibandakanya futhi ngiyavuma ukubamba iqhaza ngokuthandayo kwami nangokuzikhethela. Nginyaqonda ukuthi imininingwane yami ngeke yaziswe omunye umuntu. Nginyaqonda ukuthi ngingahoxa kulolucwaningo noma inini ngaphandle kokunikeza isizathu futhi ngaphandle kokwesaba imiphumela engemihle noma ukulahleka izinzuzo.

Igama lobambe iqhaza.....

Isignesha yobambe iqhaza.....

Usuku.....

Umcwaningi:

Ngibafundele ngolimi lwesiZulu, ngabanika iphepha ukuze bazifundele mayelana nocwaningo laba abazozibandakanya nocwaningo. Ngizamile ukuphendula yonke imibuzo yabo ngocwaningo.

Usuku:\_\_\_\_\_

Sayina:\_\_\_\_\_

**BIOMEDICAL RESEARCH ETHICS ADMINISTRATION**  
Research Office  
New Arts Building,  
C-Block, Top Floor, Room 28  
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## APPENDIX 2A: INFORMATION SHEET-CLIENT



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*Tel: +27 21-959 382 Fax: 27 21-959 2872*

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#### INFORMATION SHEET-CLIENT

**Project Title:** An exploration of loss to follow from HIV care among the South African Clothing and Textile workers Union.

#### **What is this study about?**

This is a research project being conducted by Dr S.N Ziqubu as part of Masters in Public Health course at the University of the Western Cape. We are inviting you to participate in this research project because you stopped coming to HIV care for your ART for a while at the SACTWU Worker Health Program Clinic. The purpose of this research project is to explore the difficulties you faced in continuing coming for HIV care and how these were overcome. Exploring these reasons will assist the SACTWU Worker Health clinic in coming up with strategies to provide better services to clients to assist people such as yourself in continuing to come to the clinic. We would like to ask your permission to interview you.

#### **What will I be asked to do if I agree to participate?**

You will be asked to participate in an interview if you agree to be part of the study. The interview will be conducted with your permission and I will be interviewing you. I will be asking you some questions and discuss with you the issues that you think are contributing to clients having difficulties in returning for to HIV care or make it easier for them to come here. This session will take an about hour. I will be talking to you alone. Our conversation will be tape recorded with your permission so I can be able to listen to our interview again to make sure I can remember all that you have said.



**Would my participation in this study be kept confidential?**

The researchers promise to protect your identity and what you tell them. To ensure your anonymity that no- one knows what you have said I will give you a number codes and not use your real names in talking about what you have said to anyone. I will be the only person who will keep the informed consent forms and consent for interview sheet which you have signed. These forms will be kept separate from the information you will provide me during the interview so that what you say will not be linked to your signature. To ensure confidentiality after the interview, the information which you have given me will be kept in locked cupboard and what you have told me will only be identified by your unique number code.

If we write a report or article about this research project, your identity will be protected. I will use a number or name that cannot be linked to you.

**What are the risks of this research?**

There may be some risks from participating in this research study. For this study you may feel some emotional discomfort. Living with HIV and talking about it may bring about feelings of emotions of sadness.

Whenever people talk about themselves or others this carries some amount of risks or discomfort. We will make these risks or discomfort smaller by quickly helping you if you experience any discomfort, psychological or otherwise during the interview. If you feel you would like this, an appropriate referral to the right type of care worker will be made if you want any help or intervention.

**What are the benefits of this research?**

This research is not designed to help you personally, but the results may help me learn more about reasons why clients get lost to ART care at SACTWU Worker Health Clinic. We hope that in the future other people like you might benefit from this study through improved understanding of what made people like yourself to get lost from HIV care. This can help assist the clinic in coming up with strategies to improve services in such a way to help clients stay in care.

**Do I have to be in this research and may I stop participating at any time?**

Your taking part in the research is voluntary. You may also choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

**What if I have questions?**

This research is being conducted by Dr Sibusisiwe Ziqubu at the University of the Western Cape. If you have any questions about the research study itself, please contact:

Dr S.N Ziqubu

Tel: 0313055581

Cell:0764402134

Email:snziqubu@gmail.com

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

**Supervisor: Prof Diane Cooper**

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This research has been approved by the University of the Western Cape's Research Ethics Committee. (REFERENCE NUMBER: BM/17/1/10)

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION

Research Office

## APPENDIX 2B: ULWAZI SHEET - CLIENT



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#### ULWAZI SHEET - CLIENT

Isihloko Project : An Exploration of Loss to Follow Up from HIV care among the South African Clothing and Textile workers Union.

#### Simayelana nani isifundo ?

Lena wocwaningo olwenziwa ngo- Dr S.N Ziqubu njengengxenywe ye Masters eqeleni Public Health e-University of the Western Cape . Siyakumema ukuba ubambe iqhaza kule project ucwaningo ngoba wake walahleka ekuzinakekelweni HIV nokuza kumtholampilo wakho wakwa SACTWU Worker Program emitholampilo . Inhloso yale phrojekthi ucwaningo ukuhlola ngenxa yezizathu zokuthi kungani ubungasezi ukuqhubeka uzela ukunakekelwa HIV . Ukuhlola lezi zizathu ezizosisiza emtholampilo yethu SACTWU Worker Health ekhuphuka nge amasu ukuze sihlizweke izinhlelo ezingcono kubo amaklayenti ukusiza abantu abanjalo njengoba uzithanda wena ekuqhubekeni ukuza emtholampilo ekubeni . Sithanda ukucela imvume yakho ukuze interview kuwe

#### Yini edingeka kumina uma ngivuma ukuba kucwaningo?

Uma uvuma ukuba babe yingxenywe yokutadisha, uma kutholakale imvume yenu ngizakuphiwa ithuba lokuxoxa nawe. Mina ngibe ngibuza imibuzo futhi nixoxe izimpikiswano sandla kumakhasimende nobunzima e kokubuyela ngoba HIV ukunakekela .Lokhu kuzothatha ihora. Ngizobe ngikhuluma nawe wedwa . Ingxoxo yethu uyoba iqoshiwe ngemvume yakho ukuze ngikwazi ukuyisiza uzokwazi ukulalela interview yethu ukuze uqiniseke Nginilobele futhi zikhumbule nakho konke lokho wena uthé.

#### Ingabe ukuhlanganyela kwami kulo kulolu cwano iyogcinwa iyimfihlo?

Umcwaningi uzokwenza isiqiniseko sokuthi akekho owaziyo ukuthi ungubani futhi lokho okushilo. Ukuze uqinisekise igama lakho; ngiyakuninika okufaneleyo amakhodi hhayi ukusebenzisa amagama akho yangempela ukukhuluma ngalokho wathi ubani. I kuyoba kuphela umuntu kuyogcina wazisa amafomu emvume nolwazi ishidi ngazo ngemvume. Lawa mafomu izobe bazigcina behlukile ulwazi uyobe uhlinzeke kimi. Ngemva interview

ukuqinisekisa ubumfihlo, ulwazi onginike kimi azohlala amakhabethe lockable futhi kuyokwenziwa kuphela ekhonjwe yi ikhodi yakho ehlukele okuzokwenziwa kuphela ungazise kuphela.

Uma sibhala umbiko noma isihloko ngalokhu wocwaningo, mina ngeke niphathe igama lakho noma yini engase zembule ukuthi ungubani.

### **Ziyini izingozi zalesi ucwaningo?**

Kungase kube ezinye izingozi ngokomzwelo ukubamba iqhaza kulolu cwano ucwaningo. Being HIV positive nokukhuluma esingase silethe ngayo ngemizwa noma ukuphoxeka noma nokudabuka.

Zonke ekuxhumaneni womuntu nokukhuluma self noma abanye baphatha nenani izingozi. Sizokwenza nokho wukuzama lezi zingozi njengoba encane ngangokunokwenzeka futhi usabela ngokushesha ukukusiza uma uhlangabezana ukungakhululeki, ezingokwengqondo noma yanoma iluphi uhlobo ngesikhathi inqubo kwakho iqhaza kulolu cwano. Lapho kunesidingo khona, uma ungathanda lokhu, i yokudluliselwa ezifanele, zizokwenziwa a professional efanelekayo olunye usizo noma ukungenelela.

### **Ziyini izinzuzo zalesi ucwaningo?**

Lolu cwano ngeke eklanyelwe ukusiza wena uqobo, kodwa imiphumela ingase isize umphenyi ufunde kabanzi mayelana nezizathu eziye zenza ukuba amaklayenti ulahleke ukuba ukunakekelwa HIV ngesikhathi SACTWU Worker Umtholampilo wezempilo. Ngithemba ukuthi, esikhathini esizayo abanye abantu bangase bazuze kulolu cwano ngokusebenzisa ukuqonda kangcono ukuthi yini eyenza abantu abafana nawe bakwazi ukubuyela ukunakekelwa HIV ozokusiza kimi uzongisiza e ekhuphuka nge amasu ukuthuthukisa amasevisi e ezifana ngendlela ukuze asize uhlale ekunakekelweni.

### **Kumele yini ngibe kulolucwano, ngingayeka yini uma ngithanda?**

ingxenye Your ukungenisa cwano yokuzithandela. Ungase futhi ukhethe ukuba angathathi ingxenye nhlobo. Uma unquma ukuba iqhaza kulolucwano, ungase uyeke iqhaza nganoma yisiphi isikhathi. Uma unquma hhayi iqhaza kulolu cwano noma uma uyeka iqhaza nganoma yisiphi isikhathi, ngeke bajeziswe noma ukulahlekelwa yinoma yiliphi izinzuzo kuso ngenye ufanelekele

### **Kuthiwani uma nginemibuzo?**

Lolu cwano lwenziwa ngu Dr Sibusisiwe Ziqubu e-University of the Western Cape. Uma unanoma yimiphi imibuzo mayelana ucwano ngokwayo, sicela uthintane:

Dr S.N Ziqubu

Tel: 0313055581

Cell:0764402134

Email:snziqubu@gmail.com

Uma kufanele unemibuzo mayelana lolu cwaningo kanye namalungelo akho njengoba umhlanganyeli ucwaningo noma uma ufisa ukubika izinkinga uke wabhekana ahlobene cwaningo, sicela uthintane:

**Supervisor: Prof Diane Cooper**

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Email: [dcooper@uwc.ac.za](mailto:dcooper@uwc.ac.za)

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This research has been approved by the University of the Western Cape's Research Ethics Committee. (REFERENCE NUMBER: BM/17/1/10)

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION

Research Office

# APPENDIX 3A: FOCUS GROUP CONFIDENTIALITY BINDING FORM



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Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 382 Fax: 27 21-959 2872

E-mail: snziqubu@gmail.com

### FOCUS GROUP CONFIDENTIALITY BINDING FORM

**Title of Research Project: An Exploration of Loss to Follow Up from HIV Care Among the South African Clothing and Textile Workers Union.**

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone by the researchers. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits. I understand that confidentiality is dependent on participants' in the Focus Group maintaining confidentiality.

I hereby agree to uphold the confidentiality of the discussions in the focus group by not disclosing the identity of other participants or any aspects of their contributions to members outside of the group.

**Participant's name**.....

**Participant's signature**.....

**Date**.....

Researcher

I have read this document to the participant, in Isizulu or given this to them to read. I have tried to answer his questions to the best of my knowledge.

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

Signature of Researcher: \_\_\_\_\_

**BIOMEDICAL RESEARCH ETHICS ADMINISTRATION**

Research Office  
New Arts Building,  
C-Block, Top Floor, Room 28  
University of the Western Cape  
Private Bag X17  
Bellville 7535



UNIVERSITY *of the*  
WESTERN CAPE

## APPENDIX 3B: Isivumelwano



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Isivumelwano sokuthula ngokukhulunyiwe kwiGroup yocwaningo

Isihloko Research Project: An isihlonzi Ukulahlekelwa Yokulandela Phakamisa HIV Care Among the Clothing South African and Textile Workers Union.

Lolu cwano iye yachazwa kimi ngolimi Ngiyaqonda. imibuzo yami mayelana nesifundo Kuye waphendula. Ngiyaqonda ukuthi ukuhlanganyela kwami kuzobandakanya futhi ngiyavumelana iqhaza engiwuthandayo siqu yokuzikhethela. Ngiyaqonda ukuthi ungubani lami ngeke wachazela kunoma ubani kwenziwa yinoma abacwaningi. Ngiyaqonda ukuthi enyuke asuke cwano nganoma isiphi isikhathi ngaphandle kokunikeza isizathu futhi ngaphandle kokwesaba imiphumela engemihle noma ukulahleka izinzuzo. Ngiyaqonda ukuthi imfihlo yawo ixhomeke kwababambiqhaza in the Focus Group egcine ubumfihlo.

I uyavuma ukugcina into exoxiwe kwiFocus group imfihlo nokuthi ikhulunywe ngubani.

Igama obambe iqhaza .....

isignesha obambe iqhaza .....

Usuku .....

Umcwaningi:

Ngibafundele ngolimi lwesiZulu, ngabanika iphepha ukuze bazifundele mayelana nocwano laba abazobandakanya nocwano. Ngizamile ukuphendula yonke imibuzo yabo ngocwano.

Usuku: \_\_\_\_\_ Sayina: \_\_\_\_\_

### BIOMEDICAL RESEARCH ETHICS ADMINISTRATION

Research Office  
New Arts Building,  
C-Block, Top Floor, Room 28  
University of the Western Cape  
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Bellville 7535



## APPENDIX 4A: INFORMATION SHEET –SERVICE PROVIDER



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E-mail: [snziqubu@gmail.com](mailto:snziqubu@gmail.com)

#### INFORMATION SHEET –SERVICE PROVIDER

**Project Title:** An Exploration of Loss to Follow up from HIV Care among the South African Clothing and Textile Workers Union.

#### **What is this study about?**

This is a research project being conducted by Dr S.N Ziqubu as part of her Masters in public Health course at the University of the Western Cape. We are inviting you to participate in this research project because you work at the SACTWU worker health clinic and have engaged with clients that are lost to follow up from HIV care. The purpose of this research project is to explore why you think clients get lost to follow up and to assist come up with strategies to prevent this from happening.

#### **What will I be asked to do if I agree to participate?**

You will be asked to take part in a group interview with other service providers from your clinic if you agree to participate in the study. You will be asked questions and discuss the issues contributing to clients being lost to follow up. The group session should take about an hour. The interview will be tape recorded with your permission so I can be able to listen to it again to make sure I remember everything and have captured everything that the group has said.

#### **Would my participation in this study be kept confidential?**

The researchers undertake to protect your identity and the nature of your contribution. To ensure your anonymity you will all be given number codes and I will not use your real names in talking about what you have said in the group. I will be the only person who will keep the informed consent

forms, information sheet and focus group confidentiality binding form. These forms will be kept separate from the information the group will provide me with during the discussion. After the group interview to ensure confidentiality, the information which you have given together with the rest of the group will be kept in a lockable cabinet and will only be identified by your unique individual number code.

If we write a report or article about this research project, I will not mention your name or anything that might reveal who you are.

Since this interview will be done in a group the extent to which your identity will remain confidential is dependent on participants in the group maintaining confidentiality.

**What are the risks of this research?**

There may be minimal risk associated with participating in this research study such as emotional risk. You may experience fear or feel uncomfortable talking among the group as they are your colleagues or because I am interviewing you and also at the same time I am your manager at the clinic. All human interactions and talking about self or others carry some amount of risks. We will nevertheless minimize such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

**What are the benefits of this research?**

This research is not designed to help you personally, but the results may help the investigator learn more about reasons why clients get lost to HIV care at SACTWU Worker Health Clinic. I hope that, in the future, other people might benefit from this study through improved understanding of what makes people in the clinic get lost to follow up from HIV care which may assist in contributing to recommendation for strategies to prevent this from happening.

**Do I have to be in this research and may I stop participating at any time?**

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify or affect your work negatively in any way.

**What if I have questions?**

This research is being conducted by Dr Sibusisiwe Ziqubu at the University of the Western Cape. If you have any questions about the research study itself, please contact:

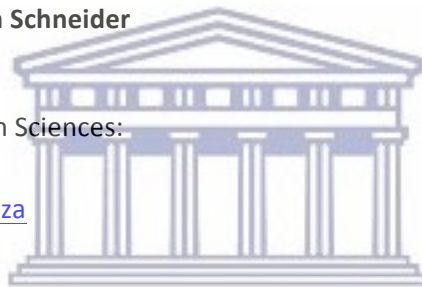
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WESTERN CAPE

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BIOMEDICAL RESEARCH ETHICS ADMINISTRATION

## APPENDIX 4B: ULWAZI SHEET (PROVIDER)



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E-mail: [snziqubu@gmail.com](mailto:snziqubu@gmail.com)

#### ULWAZI SHEET Zokusebenzela PROVIDER

Isihloko Project: An exploration of loss to follow up from HIV Care among the South African Clothing and Textile Workers Union.

#### **Lumayelana nani ucwaningo?**

Lena wocwaningo olwenziwa ngo-Dr S.N Ziqubu njengengxenywe ye Masters wakhe eqeleni Health yomphakathi e-University of the Western Cape. Thina ukumema ukuba iqhaza kule project ucwaningo ngoba ukusebenza SACTWU isisebenzi sezempilo emtholampilo futhi ne-amaklayenti kwabalahlwayo zokulandelela ekukhathazekeni HIV. Inhloso yale phrojekthi ucwaningo ukuhlola ukuthi kungani amaklayenti ulahleke ukulandela up nokusiza beveza amasu ukuvimbela lokhu kungenzeki.

#### **Ngizodingakalani kumina uma ngizibandakanya nocwaningo?**

Uma uvuma ukuba babe yingxenywe yokutadisha, uma kutholakale imvume yakho uzobe ezibandakanyekayo interview yeqembu nomunye bezempilo emtholampilo wakho. Uzocelwa imibuzo futhi nixoxe izimpikiswano sandla kumakhasimende ukuduka ukuze silandele udaba lwakhe. The selicembu kumele uzithathele ihora. I interview kuyoba tape aqoshiwe ngemvume yakho ukuze ngikwazi ukuyisiza uzokwazi ukulalela futhi ukuze uqiniseke ngiyakhumbula konke futhi wanqoba konke leli qembu ngoLwesine.

#### **Ingabe ukuhlanganyela kwami kulo kulolu cwano iyogcinwa iyimfihlo?**

Ukuze kuqinisekiswa igama lakho niyakubhubha ngokunjalo nonke uzonikezwa amakhodi ezahlukenene hhayi ukusebenzisa amagama akho yangempela ukukhuluma ngalokho kusho leli qembu. I kuyoba kuphela umuntu kuyogcina wazisa amafomu emvume, ulwazi ishidi bese sigxila iqembu ngaphandle kokugcinwa kuyimfihlo ngibopha ifomu. Lawa mafomu izobe bazigcina behlukile ulwazi qembu ngenzele. Ngemva interview iqembu ukuqinisekisa ubumfihlo, ulwazi onginike ndawonye neqembu uyogcinwa Ekhabetheni lockable futhi

kuyokwenziwa kuphela ekhonjwe yi ikhodi yakho ehluke ngamunye okuzokwenziwa kuphela ungazise kuphela.

Uma sibhala umbiko noma isihloko ngalokhu wocwaningo, mina ngeke niphathe igama lakho noma yini engase zembule ukuthi ungubani.

Njengoba le interview kuzokwenziwa iqembu ngezanga elingakanani ubuwena bakho ngeke yimfihlo luncike abahlanganyeli eqenjini egcine ubumfihlo.

### **Ziyini izingozi zalesi ucwaningo?**

Kungase kube ingozi sakugcina ezihlobene ne iqhaza kulolu cwano ucwaningo ezifana ingozi ngokomzwelo. Ungezwa ukwesaba noma wawa ungakhululekile ukukhuluma phakathi kweqembu njengoba benjalo osebenza nabo noma ngoba ngiyahamba enkhulumoluhlo lawe ngesikhathi esifanayo I am umphathi wakho emtholampilo. Zonke ekuxhumaneni womuntu nokukhuluma self noma abanye baphatha nenani izingozi. Sizokwenza nokho ezimboza ingxenywe enkulu ezingozini ezinjalo futhi senze ngokushesha ukukusiza uma uhlangabezana ukungakhululeki, ngokwengqondo noma ngenye ngesikhathi senqubo kwakho iqhaza kulolu cwano. Lapho kunesidingo khona, i yokudluliselwa ezifanele zizokwenziwa a professional efanelekayo olunye usizo noma ukungenelela.

### **Ziyini izinzuzo zalesi ucwaningo?**

Lolu cwano ngeke eklanyelwe ukusiza wena uqobo, kodwa imiphumela ingase isize umphenyi ufunde kabanzi mayelana nezizathu eziye zenza ukuba amaklayenti ulahleke ukuba ukunakekelwa HIV ngesikhathi SACTWU Worker Umtholampilo wezempilo. Ngithemba ukuthi, esikhathini esizayo, abanye abantu bangase bazuze kulolu cwano ngokusebenzisa ukuqonda kangcono ukuthi yini eyenza abantu emtholampilo ulahleke ukuze silandele udaba lwakhe ekunakekelweni HIV oluzosiza kimi enomthelela isincomo sokuba amasu ukuvimbela lokhu kungenzeki.

Ingabe Kudingeka ngibe kulolucwano futhi kwangathi ngiyeke iqhaza nganoma isiphi isikhathi?

Ukubamba kwakho iqhaza kulolucwano kuyinto yokuzithandela ngokuphelele. Ningase nikhethe ukungaxoxi ukuthatha ingxenywe nhlobo. Uma unquma ukuba iqhaza kulolucwano, ungase uyeke iqhaza nganoma yisiphi isikhathi. Uma unquma hhayi iqhaza kulolu cwano noma uma uyeka iqhaza nganoma yisiphi isikhathi, ngeke bajeziswe noma ukulahlekelwa yinoma yiliphi izinzuzo kuso ngenye ufanelekele.

### **Kuthiwani uma nginemibuzo?**

Lolu cwano lwenziwa ngu Dr Sibusisiwe Ziqubu e-University of the Western Cape. Uma unanoma yimiphi imibuzo mayelana ucwano ngokwayo, sicela uthintane:

Dr S.N Ziqubu

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Cell: 0764402134

Email: [snziqubu@gmail.com](mailto:snziqubu@gmail.com)

Uma unemibuzo mayelana kulolu cwaningo kanye namalungelo akho njengoba umhlanganyeli ucwaningo noma uma ufisa ukubika izinkinga uke wabhekana ahlobene cwaningo , sicela uthintane :

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BIOMEDICAL RESEARCH ETHICS ADMINISTRATION

Research Office

## APPENDIX 5: (PATIENTS)

### Semi-structured interview guide

#### Topic Area 1-Experiences on access to HIV services

1.1 What is your impression about availability broadly of HIV health services in ?

a) Can we speak about your experience of receiving services at the state hospitals and also at specialized clinics like this one or any other you assessed services (Probes for example: *What did you think about the general environment and atmosphere at the facility? How did you feel about the skills of those who attended to you? How did you find the attitudes of the healthcare workers who attend/ed to you? Did/do they ask you what you felt were appropriate questions about yourself? Did/do you have a chance to and want to ask them questions? How was the amount of time you spent with them and the length of time you waited to see them? Did you have time to ask them the questions you wanted to? Did they ask you questions and explained things well or not? In comparison to other centres you have assessed ART services, was the experience different. If yes or no can you tell me more about this.*

1.2 Can you think back to when you first tested for HIV and share with me your personal experience of HIV testing:

- a) What was your motivation to test for HIV and why so?
- b) What motivated you at the time to access HIV care services?
- c) Can you share with me how the test result impacted you physically, psychologically and emotionally at the time?
- d) Can you talk about whether you feel you have accepted your HIV status or not and share your journey of acceptance of your HIV status ?

(PROBES:

*Who did you confide in about your HIV status, if anyone; what were their reactions; did you get support or not, from who and what kind of support? What things helped you in accepting your status; what things hampered them; what made the biggest difference in acceptance?)*

- e) Do you think you having HIV has impacted on quality of services generally that you receive at this clinic? Why do you think it did or did not?

### **Topic Area 2- Experiences of ART therapy and access to ART**

2.1 Can you share your experience with me about how you decided to start taking ART? What were the motivating or demotivating factors to begin treatment, your inspiration, what spurred you into action? Was there anyone who persuaded you it was the right time to begin? If so, who, what did they say and what made you feel persuaded?

2.2 Can you go through step by step with me, the process that explains how you access ART at the clinic for each visit?

a) How do you come to a conclusion on the number of clinic visits you make in a year?

b) Describe the process you go through

2.3 Can you share your experiences negative or positive related to you accessing ART at this facility or anywhere else also? Compare your experiences at this clinic with the previous places you assessed ART, if any.

### **Topic Area 3- Experiences on adherence to ART**

3.1 What ART medication/s did you start on? Which ones are you on now?

3.2 What do you know or where about these medications and what were you told about them, for example , how they work in the body

3.3 When you started ART what was your experience with the drugs/medications? How did they make you feel?

3.4 How did you handle the side effects of the medications if any?

3.5 What about the ART medication now, how do you feel on them?

3.6 Can you tell me about the impact of the ART on your overall health?

3.7 Can you share with me your journey in being able to take your ART medication all the time or not consistently or not since you started the medication?

3.8 Tell me about the periods that you stopped taking the medication and events/ happenings in your life at the time that may have affected your stopping.

3.9 How was it that you came back to the clinic and started taking ART again? What things made you to do this? How have you found it taking your ART medication again? Can you



talk about anything that is making it easier or still difficult in taking your ART medication all the time now?

- 3.10 Can you talk about the major stressors in your life and how they affect adherence? Have you experienced any periods of depression or anxiety or not? What mechanisms have you put in place to cope with this? Did you get help? Or did this push you into any use of substances like alcohol or recreational drug use?
- 3.11 What are the uplifting things in your life that may help your adherence?
- 3.12 Can you speak about challenges and triumphs on your adherence journey so far? (PROBES: *What helps you in taking your medication? What hinders you in taking your medication?*)
- 3.13 What is your experience with support systems/people/ family in this adherence journey? Do they know that you are living with HIV?
- 3.14 Who are they, can you talk about their relationship with you and how this has helped you or not adhere to ART? Do they play a part in helping or hindering you to adhere?
- 3.15 Can you explain how they got involved with supporting you in this journey?
- 3.16 Can you talk about openness to your partner /s about you being a person living with HIV, and how you think this has affected how you adhere?
- 3.17 What is the role of family (parents, siblings, other family) on your adherence?
- 3.18 Can you speak about other friends – maybe some of them are in the same position as you, some not, - in this adherence journey and what role do they play in your ART adherence?

#### **Topic Area4-Societal and economic factors**

4.1. Based on your experience, do you think that there is any relationship between societal perceptions of HIV and your adherence to ART? What have you experienced? In your experience, has the way people view this in society/community, the way media representation of adherence campaigns affected your practices on ART adherence? Can you talk about the role this has played or not?

4.2 What other remedies and treatments are you currently using or have used in the past together with your ART medication? What do you use these other remedies for? What is your motivation for this? (tradition/faith/ poverty?)

4.3 What is the importance or not of financial stability on your adherence to ART?

*(Probe for shelter/ gainful employment/ access to food?)*

4.4 Can you share with us your personal living conditions and how this impacts on your adherence? *(Probe for shared living conditions (with parents/ partner/ friends) and how this affects adherence; Probe for mobility and fixed status. If he is moving around constantly, how does this affect adherence).*

*WHEN FINISHED:*

*Thank you for your time and open discussion on such sensitive issues. I really appreciate it.*

*Is there any question(s) you will like to ask me or anything you will like to discuss with me?*



## APPENDIX 6: (SERVICE PROVIDERS)

### Semi-structured interview guide

#### Topic Area 1-Experiences on access to HIV services

- 1.1. What is your impression about availability broadly of HIV health services in Durban?
  - a) Can we speak about your experience of giving services at the public sector facilities and also at specialized clinics like this one or any other you worked in previously? If this happens to be your first work experience with clients living with HIV, what do you think, from your contact with them, is their impression of services rendered here? How does it compare with public sector facilities? (Probe for example: *What do they tell you about the general environment of this clinic? Do you think they are satisfied with your skill level? Have you gotten into a conversation about healthcare worker attitudes in this clinic in comparison to other state hospitals? If yes, what is their general perception about this?*)
  - b) Do you think your clients are satisfied with the waiting times to see you? Why do you think so? Do you think you spend enough time with clients judging by their satisfaction levels after consultation? Have your clients spoken about their overall experience here in comparison to other centres they have assessed services and describe what they say? And the reason they give for it being different? How do you feel about the waiting times yourself?
- 1.2 In your experience, what motivates clients to access HIV testing services?
  - a) What issues do your clients face after a positive HIV test result? Can you share with me how you think the test result impacts them physically, psychologically and emotionally?
  - b) Can you tell me about the difficulties that your clients face in their acceptance of their HIV status? What in your experience ameliorates the difficulties and improve their journeys of acceptance (PROBES: *Who do they confide in about their HIV status, if anyone; what were their reactions; did they get support or not, from whom do they get this support*)

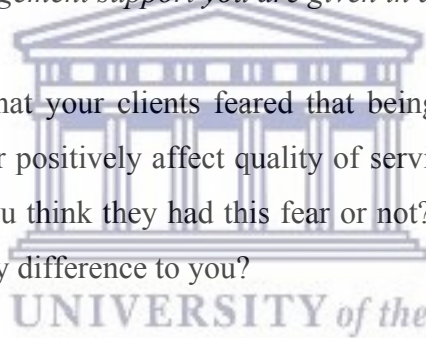
*and what kind of support? What things helped you in accepting your status; What things hampered them; what made the biggest difference in acceptance?)*

- c) Tell me about your reaction when you first diagnosed clients with HIV and now in your present position here as a health care worker.

(PROBES:

*Describe the clients' disposition in respect of their comfortability, feeling of safety and trust. Did you feel that it was a difficult process for the client? If you do, why so? Did you feel that you had enough knowledge, sensitization and competency to deal with the information on your clients' HIV status? If yes, why do you come to this conclusion? If no, why do you come to this conclusion? Can you describe your reaction after you had told them about their status, if any? How in your opinion did you think your reaction made them feel?) How do you feel about ongoing training in ART : how do you feel about the management support you are given in doing your*

- d) Do you think that your clients feared that being diagnosed with HIV would affect negatively or positively affect quality of services they would receive in the future? Why do you think they had this fear or not? What do you think – do you feel it has made any difference to you?



## **Topic Area 2- Experiences of ART therapy and access to ART**

2.1 In your experience of seeing multiple clients, what do you think persuades clients to start taking ART? Can you describe the common motivating and demotivating factors to begin treatment? What are the common reasons given as inspiration to start treatment?

2.2 Can you go through with me, step by step, the process that explains how your clients access ART at the clinic for each visit?

- a) How do you plan the number of clinic visits you designate to each client per year? What do you base this on?

2.3 What negative or positive experiences relating to clients accessing ART at this clinic, have clients shared with you? In your experience, how do they think this clinic measures in service delivery to them compared to previous places they say they have accessed ART services.

### **Topic Area 3- Experiences on adherence to ART**

3.1 When your clients start ART, what are the experiences they shared with you concerning the side effects of the drugs?

3.2 How do you describe to them their expectations around side effects before they start the drugs and how do you affirm and comfort them after they have started the drugs and are experiences side effects?

3.3 Can you tell me how clients describe the impact of the ART on their overall health? How does this make you feel when you see a client adhering and doing well on ART?

3.4 Can you share with me what your clients cite as major reasons for staying and adhering to ART and also what makes them discontinue? How do they describe their overall journey of consistently adhering or not consistently adhering to ART?

3.5 To what extent do your clients ascribe discontinuing taking their medication to happenings and events in their lives at work or at home the time?

3.6 Can you tell me what your clients describe as major stressors in their lives and how these affect their adherence? Have you had clients complain about depression or anxiety? What mechanisms have you worked out with them to cope with this? What mechanisms have they shared with you that helped them overcome it? Can you describe how you handle clients with depression or anxiety? Have you had clients share with you dependence on alcohol or other drugs as a result of their depression or anxiety?

3.7 Can you speak broadly about your personal challenges and triumphs in helping your clients adhere? Can you share an account of challenges and triumphs of some of your clients in their adherence journey? What do you know about the experiences, views and practices of other providers?

3.8 In practice, what are the experiences of your clients concerning their support systems/ people/ family/work or union colleagues in their adherence journey? How much information about their status and orientation do they share with these trusted people? What do you think about this? What role do you think health providers play in this regard?

3.9 What kind of relationship ties do they have with these people (are they close family members, partners?) How do you think this has helped them adhere or not?

3.10 Describe how your clients speak about openness to their partner/s on their HIV status and progress in treatment and how this may have affected how they adhere or not.

3.11 Do your clients cite openness to parents, siblings, other family as helpful to their adherence? If they do, what reasons do they give for how this is a positive influence on their adherence?

3.12 Do your clients speak about friends as support systems and even some friends who are also living with HIV and how they mutually support themselves? How do they describe these relationships and how this allow them adhere?

#### **Topic Area4-Societal and economic factors**

4.1 Based on your close contact to your clients, what is your perception about the portrayal of HIV status in society/ public and how this affects their adherence to ART? What is your take on media campaigns and their effect on your clients adhering or not?

4.2 Can you speak about clients using other unprescribed drugs/ concoctions along with their ART drugs. How do you deal with this and what are their motivations for using other drugs or remedies in your experience?

4.3 Amongst the clients assessing services at this Clinic, have you noticed any kind of trend around demographics in relation to adherence (race, age, socioeconomic position)? Please explain. *Probes: what role does financial stability play in your clients' adherence to ART?*

4.4 Can you describe how your clients explain the impact of their personal living conditions on their adherence? *(Probe for shared living conditions (with parents/ partner/ friends) and how this affects adherence; Probe for mobility and fixed status. Are they moving around constantly, how does this affect adherence.)*

4.5 What do you think helped your clients in returning to taking their treatment at this clinic. *(Probes: How did tracing them go? How easy or difficult was it for you or other providers to get them to come back? What were the challenges and facilitators? How do you think they are finding things now?( easy, difficult in between, why)*

*WHEN FINISHED:*

*Thank you for your time and open discussion on such sensitive issues. I really appreciate it.*

*Is there any question(s) you will like to ask me or anything you will like to discuss with me?*



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## APPENDIX 7: Ethics Approval UWC



### OFFICE OF THE DIRECTOR: RESEARCH RESEARCH AND INNOVATION DIVISION

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19 January 2017

Dr S Ziqubu  
School of Public Health  
Faculty of Community and Health Sciences

Ethics Reference Number: BM/17/1/10

Project Title: Loss to follow up from HIV care among workers in the South African Clothing and Textile Workers Union in Ethekweni district, Kwazulu-Natal.

Approval Period: 15 December 2016 – 15 December 2017

I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific methodology and ethics of the above mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval. Please remember to submit a progress report in good time for annual renewal.

The Committee must be informed of any serious adverse event and/or termination of the study.

A handwritten signature in black ink, appearing to read 'Patricia Josias'.

*Ms Patricia Josias  
Research Ethics Committee Officer  
University of the Western Cape*

**PROVISIONAL REC NUMBER -130416-050**



## APPENDIX 8: Letter of Approval SACTWU



9 September 2016

To Whom It May Concern:

Dr. Sibusisiwe Noluthando Ziqubu (ID number 841002089082, Student number 3514010) is employed by SACTWU Worker Health Programme as medical practitioner and facility manager of the Durban Clinic. The organisation is aware of her ongoing studies towards her Masters Degree in Public Health at the University of Western Cape.

The undersigned individuals have been provided with a research proposal towards a mini-thesis, titled "An Exploration of loss to follow up from HIV care among the South African Clothing and Textile workers Union."

The undersigned individuals hereby authorize Dr. SN Ziqubu to undertake the necessary research activities, in line with University of Western Cape policy, at the Durban Clinic, as we have satisfied ourselves that the initiative is appropriate from an ethical and confidentiality view point.

We trust that her mini-thesis will contribute positively to the academic institutions, health sector, SACTWU Worker Health Programme and its beneficiaries, within the clothing and textile industry.

Please do not hesitate to contact us, should you have any further queries.

Yours sincerely,

Dr. Laurene Booysens  
Clinical Director  
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