

**RETENTION IN CARE AMONGST WOMEN
INITIATED ON ANTIRETROVIRAL THERAPY
DURING PREGNANCY AT KING SOBHUZA II
PUBLIC HEALTH UNIT, SWAZILAND**

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Prevention of mother to child transmission

Default

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Care



ABSTRACT

Background: The advent of antiretroviral therapy (ART) has significantly redefined the course of the HIV pandemic making HIV, a chronic illness rather than a death sentence. To maximise the efficacy of ART in improving survival rates of HIV/AIDS patients, lowering the incidence of opportunistic infections, reducing HIV transmission and minimising the possibilities of developing drug resistance, long-term retention in care is critical. In South Africa, poor retention in care of 32% has been noted in women who were initiated on ART during pregnancy as compared to 13% in non-pregnant women initiated on ART. However, little is known in Swaziland about the retention in care in women who were initiated on ART during pregnancy and the factors that influence retention in care among this category of women.

Aim: To determine the factors associated with poor retention in care among women initiated on ART during pregnancy at King Sobhuza II Public Health Unit (PHU) in Swaziland.

Methodology: A quantitative, retrospective cohort review of 316 medical records of women who were initiated on ART during pregnancy from January 2012 to December 2013 was conducted. A data extraction sheet was used to collect data from the files of patients who were initiated on ART during pregnancy. The dataset was imported into IBM SPSS Statistic 20 Software for analysis. Bi-variate analysis was done to determine risk factors associated with retention in ART care at ART initiation and on the last ART refill visit. Kaplan-Meier analysis was used to determine retention in care at 6, 12, 24 and 36 months. Cox proportional hazards models were then used to determine factors associated with poor retention.

Results: The overall retention rate of women who were initiated on ART during pregnancy at the PHU after a median duration on ART of 25.80 months [interquartile range (IQR): 16.70 – 30.98] of follow up was 74.1% (n=316). Most women initiated on ART during pregnancy (52.4%) became lost to follow up after giving birth as compared to 47.6% who became lost to follow up before giving birth. After 6 months on ART, the lost to follow up rate was 16.5% (n=316); but increased to 20.9% (n=316), 23.5% (n=243) and 26.9% (n=52) after 12, 24 and 36 months respectively. On the ART initiation visit, the factors associated with retention in care for pregnant women included being married, having the partner on ART, disclosing one's HIV status to the partner, not drinking alcohol, being a non-smoker and reporting no financial challenges. In addition, on the last ART refill visit, the risk factors for retention in care for

women initiated on ART during pregnancy were having the ART regimen changed, having regular CD4 cell count done, rise in CD4 cell count, good adherence on ART and use of contraceptive other than the condom for family planning after delivery.

Conclusion: The retention in care for women who were initiated on ART during pregnancy was found to be lower than in the general adult population. However, the study findings on retention in care are similar to what has been found in other settings. The factors influencing poor retention also mirror those found in the other parts of sub-Saharan Africa. Whilst decentralisation of ART services improves ART coverage it should be coupled with strategies aimed at improving patient retention.



DECLARATION

I declare that **Retention in care amongst women initiated on antiretroviral therapy during pregnancy at King Sobhuza II Public Health Unit, Swaziland** is my work, it has not been submitted for any degree or examination in any other university and that all the sources I have used or quoted have been indicated and acknowledged by complete references.

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Signed...



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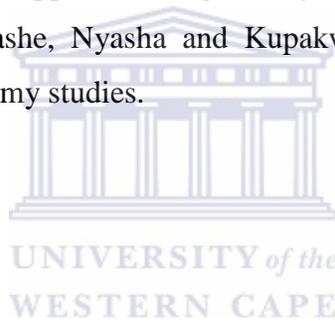


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List of abbreviations and acronyms

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral therapy
ARVs	Antiretroviral drugs
HCWs	Health Care Workers
HIV	Human immunodeficiency virus
IQR	Interquartile Range
LTFU	Lost to Follow Up
MCH	Maternal and Child Health
OIs	Opportunistic Infections
PHU	Public Health Unit
PLHIV	People Living with HIV
PMTCT	Prevention of Mother to Child Transmission of HIV
SD	Standard Deviation
UNAIDS	Joint United Nations Programme on HIV and AIDS,
WHO	World Health Organisation



Operational Definitions

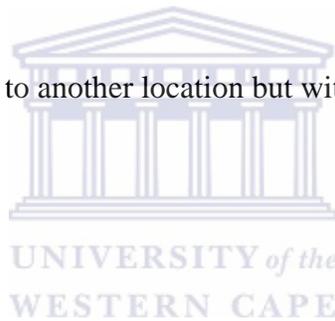
Retention in care: Refers to patients who are known to be alive and active on ART at the end of a follow up period.

Attrition: Refers to any discontinuation of ART including death, loss to follow-up, and stopping ARV medications while remaining in care.

Lost to follow-up: Refers to patients receiving ART who are more than 3 months late for a scheduled ART refill visit and are not transferred out or dead.

Transfer out: Patient transferred by healthcare workers to any other facilities.

Self-referral: Patients who moved to another location but without any official referral or transfer by health care workers.



1 INTRODUCTION

1.1 Background

The introduction of antiretroviral therapy (ART) in the 1990s brought new hope to people living with HIV/AIDS (Reynolds, 2003). In spite of the major achievements towards combating HIV/AIDS, the burden of HIV infection in sub-Saharan Africa remains very high (Colvin *et al.*, 2014). According to UNAIDS (2014), an estimated 24.7 million of people living with HIV (PLHIV) reside in sub-Saharan Africa, representing about 70% of global prevalence and 58% of them are women. Although new HIV infections have declined by 33% between 2005 and 2013, the new infections remain high at an estimated 1.5 million. With the advent of antiretroviral drugs (ARVs), the number of AIDS-related deaths in sub-Saharan Africa dropped by 39% from 1.5 million to 1.1 million people by 2013. There has been a 43% decline from just above 300,000 to 210,000 new HIV infections among children in sub-Saharan Africa from 2009 to 2013; with mother to child transmission accounting for an estimated 90% of the total HIV infections in children (UNAIDS, 2008).

ART can produce dramatic clinical improvements in people with symptomatic HIV infection (Stevens, Kaye & Corrah, 2004). According to UNAIDS (2005), the increased availability of antiretroviral drugs (ARVs) for the treatment of HIV in PLHIV including pregnant women, has dramatically improved survival rates, lowered the incidence of opportunistic infections and reduced HIV transmission to infants and HIV negative partners. Unfortunately, some sub-Saharan countries could not realise these treatment outcomes early due to delays in establishing ART programmes. Chigwedere, Seage, Gruskin, Lee and Essex (2008) highlight that delayed implementation of ART programme in South Africa resulted in a loss of at least 330,000 lives, which are equivalent to about 2.2 million person-years. In addition, 35,000 babies acquired HIV vertically, resulting in 1.6 million person-years lost by not implementing a timely and feasible PMTCT programme using single dose Nevirapine prophylaxis.

Swaziland is one of the sub-Saharan African countries severely affected by the HIV/AIDS epidemic. The country is one of the 30 low and middle-income countries that account for 89% of all new HIV infections (UNAIDS, 2014). The incidence and prevalence rates among adults aged 18-49 years old are 2.4% per year and 31% respectively (Swaziland Ministry of Health, 2012b).

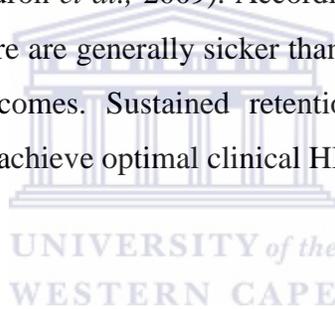
In addition, the prevalence rate of HIV in pregnant women is very high; estimated at 41.1% (Swaziland Ministry of Health, 2014), which translates to approximately 13,563 HIV exposed infants delivered annually. Nevertheless, the Swaziland government has made major strides towards achieving high ART coverage in all population with less than 10% of pregnant women living with HIV not receiving ARVs in 2013. The implementation of the prevention of mother to child transmission of HIV (PMTCT) programme as from 2003 has tremendously reduced mother to child transmission of HIV from an estimated 35% in 2007 to 12.6% in 2012 (Swaziland Ministry of Health, 2014). In an effort to achieve Millennium Development Goals by 2015 and UNAIDS 90-90-90 targets by 2020, Swaziland has redirected efforts towards virtual elimination of new paediatric HIV infections.

Many countries have embarked on the Fast-Track strategy to end the AIDS epidemic by 2030. Without scale-up, the AIDS epidemic will continue to outrun the response, increasing the long-term need for HIV treatment and increasing future costs (UNAIDS, 2014). According to the Fast Tract 2020 targets, 90% of all people living with HIV should know their HIV status, 90% of all people with diagnosed HIV infection should be linked and sustained on antiretroviral therapy, and 90% of all people receiving ART should have viral suppression. For viral suppression to occur, McMahon *et al.* (2013) underscored the need for interventions that foster optimal adherence. In circumstances of optimal adherence, ART can delay the progression of the HIV infection by inhibiting viral replication. Cohen *et al.* (2011) supplement that consistent and optimal adherence to ART significantly reduces the chances of vertical and horizontal transmission of HIV.

In addition to the provision of ART and maintenance of optimal adherence, retention in care is one of the key determinants of HIV treatment success (Thompson *et al.*, 2012). Both adherence to ART and retention in care are necessary to optimise the clinical outcomes in PLHIV. However, most of the studies conducted in resource-limited settings have focused solely on adherence to treatment and have provided limited information on effective and practical approaches to improve retention in care (Patel *et al.*, 2010; Hodgson *et al.*, 2014). World Health Organisation (2011) defines retention in ART care as continuous engagement with the health facility from the time of ART initiation to ensure lifelong ART. There is need for sustained retention in care for optimal clinical outcomes to be realised in PLHIV. So far, studies have not

shown any benefits of discontinuing therapy. Rather, the Strategies for Management of Antiretroviral Therapy (SMART) Study Group (2006) noted that ART interruption has deleterious effects leading to faster progression of HIV infection, emergence of HIV drug resistance and increased HIV vertical and horizontal transmission. Stevens, Kaye and Corrah (2004) also highlighted that stopping ART results in high viral loads, which can further increase the risk of transmission within a community, to sexual partners and to the children during pregnancy, labour, delivery and the postnatal period.

Scientific evidence shows that retention in care is a critical element of clinical success at both patient and programme level. While good patient outcomes among PLHIV on ART have been associated with attending clinical appointments (Nachega *et al.*, 2006), high mortality and morbidity for ART clients have a positive association with poor retention in both high-income and resource-limited settings (Amuron *et al.*, 2009). According to Jarret and Mwamburi (2009), patients who are not retained in care are generally sicker than those who are retained in care and experience poorer long-term outcomes. Sustained retention in care, therefore, becomes a prerequisite for any programme to achieve optimal clinical HIV treatment outcomes.



1.2 Problem Statement

Poor retention in care has a potential negative impact on outcomes of both PMTCT and ART programmes. Studies have shown that pregnant women have a lower likelihood of being retained in care than non-pregnant women (Myer *et al.*, 2012; Dourado *et al.*, 2014). In the neighbouring South Africa, studies have shown low retention rates of 68% in women who were initiated on ART during pregnancy women as compared to 87% in non-pregnant women initiated on ART (Toro *et al.*, 2010). The available ART retention data in the country for the general adult population shows the retention rate of 78% at 3 years (Swaziland Ministry of Health, 2014),

Although considerable coverage data is collected in Swaziland, there is paucity of ART retention data throughout the PMTCT interventions including retention in care for women initiated on ART during pregnancy. Geng *et al.* (2010a) highlight that the extent and the factors associated with retention vary substantially and encourage studies in different settings to inform programmatic decisions.

1.3 Aim and Objectives

Aim

The aim of this study was to determine the factors associated with poor retention in care among women initiated on ART during pregnancy at King Sobhuza II PHU in Swaziland.

Objectives

1. To describe the demographic, socioeconomic and clinical profile of pregnant women who were initiated on ART at King Sobhuza II PHU in Swaziland.
2. To describe retention in care among women who were initiated on ART during pregnancy before and after delivery.
3. To determine the retention in care for women initiated on ART during pregnancy at 6, 12, 24 and 36 months.
4. To determine clinical, socioeconomic and health system related risk factors of retention in care among women initiated on ART during pregnancy at King Sobhuza II PHU in Swaziland.



1.4 Outline of thesis

In Chapter 2, a literature review of different scientific sources on retention in care for different population groups including pregnant women and factors associated with retention among patients on ART in different settings will be outlined.

Chapter 3 will delineate the research methodology which includes an overview of the study design, description of the study setting, the process of data collection, and a synopsis of the ethical considerations used for the study.

Thereafter, in Chapter 4, the results obtained from the study will be presented with focus on both significant and non-significant factors.

Chapter 5 will focus on the discussion of the study findings.

In Chapter 6, the conclusion and recommendations from the study will be presented.

2 LITERATURE REVIEW

2.1 Introduction

Retention in ART care has been a topic of research for more than a decade (World Health Organisation, 2011). However, the introduction of the 2013 World Health Organisation (WHO) Guidelines which recommended ART for all HIV positive pregnant and lactating women has pushed retention in care for women initiated on ART during pregnancy into a high priority agenda for PMTCT and ART programmes. Swaziland chose Option B+ which entails ART initiation for all HIV positive pregnant and lactating women regardless of CD4 cell count and/ or the WHO clinical stage. The ART initiation in all HIV positive pregnant and lactating women highlights the need for accurate methods of monitoring retention in care through the continuum of antenatal care and into adult ART follow-up systems (Rollins *et al.*, 2014).

Scientific evidence identifies retention in care as a key element for improved clinical outcomes at both patient and programme level. A retrospective cohort by Rich *et al.*, (2012) reinforces published evidence by demonstrating that HIV treatment outcomes in resource-limited settings can match or exceed those in wealthy countries if long term retention rates are maintained above 90%. In addition, the study proves that excellent results can be sustained in large programmes. Therefore, sustained high long-term retention in care becomes crucial for any programme to realise optimal clinical HIV treatment outcomes.

In this chapter, the following concepts of the study are reviewed: definition of retention in care, retention in care in sub-Saharan Africa, retention in care in Southern Africa, retention in care in Swaziland and factors associated with retention in ART care.

2.2 Definition of Retention in Care

Retention is a critical component for both ART and PMTCT programmes to achieve optimal clinical HIV treatment outcomes such as improved survival rates, lowered the incidence of opportunistic infections, reduced HIV transmission and minimised possibilities of developing drug resistance. According to Patel *et al.* (2010:2), “*Retention in care is the ability to adhere to critical aspects of care such as attending regular follow-up appointments, scheduled laboratory tests, and other monitoring activities according to health system standards and as prescribed by*

a health care provider". In addition, continuous engagement with the health facility is essential for one to be retained in ART care from initiation to lifelong ART (WHO, 2011).

2.3 Retention in care and lost to follow up

A patient is considered retained in care when they visit a facility within 90 days of their last scheduled appointment for medicine collection, laboratory testing, and/ or clinical review and is not documented as having died, stopped treatment, transferred out, or as lost to follow up (LTFU). LTFU is on the other extreme on retention in care spectrum. Patients LTFU may have unknown outcomes and LTFU rates point at gaps in knowledge and information systems (WHO, 2011).

A sample of LTFU patients traced actively by Geng *et al.* (2010b) revealed that 29% were deceased but not registered as dead at the health facility. Of the remainder, 10% were alive but no longer in care, 39% were alive and of unknown care status, and 51% were self-transfers to other health facilities. After incorporating the outcomes among the sample of lost patients into the entire clinic population, this study found that the corrected estimate of retention on ART at 24 months rose to approximately 79% to 86%, as compared to 69% if all LTFU were considered as those not retained. This therefore means that the corrected LTFU is obtained by factoring out all dead and transferred out patients including self-transfers.

Studies have shown significant levels of LTFU on ART particularly during the first 1 to 2 years, largely due to death and silent, non-documented self-transfers (Yu *et al.*, 2009; Maskew *et al.*, 2007). World Health Organisation (2011) supplements that LTFU can be distorted by unregistered transfers of patients to other facilities, alternative health beliefs and practices, provision of inaccurate personal information by patients, health service delivery issues and financial issues. For any programme to actively retain clients on ART and to be sure that patients are receiving the package of services as required, there is need to monitor and actively follow up patients who miss or default their appointments before they become LTFU.

In addition, another study conducted in South Africa showed similar mortality rates for pregnant and non-pregnant women initiated on ART and a substantially higher 3-year LTFU rate in women initiated on ART during pregnancy women of 32% compared to 13% for non-pregnant

women (Toro *et al.*, 2010). Similarly, Wang *et al.* (2011) identified pregnancy as a risk factor for LTFU in a cohort of adult men and women initiated on ART at community care sites. The potentially high attrition rates in cohorts of women initiated on ART during pregnancy call for better understanding of the factors associated with poor retention in care to ensure better programme retention.

LTFU patients have been shown to have no viral suppression but have detectable, high viral loads (Krishnan *et al.*, 2011). At high viral loads, the risk of HIV transmission is also high. If pregnant or lactating women have high viral loads, they predispose their partners and children to HIV infection. De Cock *et al.* (2000) approximate the rates of HIV transmission during breastfeeding at 10 to 15%. In Swaziland, women breastfeed for longer duration of about 2 years; thereby further exposing their babies to HIV infection.

2.4 Retention in care in sub-Saharan Africa

Sub-Saharan Africa is home to just above two-thirds of PLHIV globally, and the number of people accessing antiretroviral treatment rose to about 10.7 million people in 2014 from fewer than 100,000 people in 2002 (UNAIDS, 2014). Whilst there is undisputable need to scale up provision of ART in sub-Saharan Africa, there is also need to closely monitor and ensure retention in care in the cohort of patients on ART.

Poor retention in ART care occurring among PLHIV on ART in sub-Saharan Africa has been widely documented (Maskew *et al.*, 2007; Boyles *et al.*, 2011). In West Africa, retention in care has been reported as 76% by 12 months after ART initiation whilst in Southern Africa 12 months retention rates range from 67–70% in countries like Mozambique to 82.7% in Botswana (Bussmann *et al.*, 2008; Lambdin *et al.*, 2011).

Poor long term retention in care has been identified as a major barrier to the success of ART programmes in Africa. A systematic review of ART programmes by Rosen and Fox (2010) in sub-Saharan Africa found that on average only 64% of patients are retained in care after two years of ART. LTFU is highlighted as the commonest cause of attrition, followed by death, which is often under-estimated in most sub-Saharan African countries. Another analysis in South

Africa of 44,177 patients accessing ART services in the public sector found about 71% and 59.6% retention in care at 2 and 4 years after ART initiation respectively, with the proportion of LTFU patients increasing over time (Cornell *et al.*, 2010).

Efforts to further accelerate ART service coverage in sub-Saharan Africa through decentralisation of ART services to lower level health-care facilities and task-shifting of service provision to nurses have resulted in increased ART coverage, and improved adherence and retention in care (Boyer *et al.*, 2010; Chan. *et al.*, 2010; Fatti *et al.*, 2010). However, there is limited data on retention throughout PMTCT interventions as well as longer-term retention on ART for women initiated on ART during pregnancy.

2.5 Retention in care in Southern Africa

Access to ART continues to increase in Southern Africa through decentralisation of ART services, task shifting and involvement of the community in the delivery of health care. However, long-term retention in ART care remains one of the major challenges to long-term survival with HIV infection (Rasschaert, Koole, Zachariah, Lynen, Manzi & Van Damme, 2012). The retention rates in the region are very similar to the sub-Saharan Africa rates as estimated by Fox and Rosen (2010) in a meta-analysis of published cohort data. For example, after pooling data in a random-effects meta-analysis, retention at 12 months was 80.2% compared to the 12 month retention of Zimbabwe, Zambia, Swaziland, Lesotho and Botswana that were found to be 85%, 80%, 89%, 72% and 86% respectively (World Health Organisation, 2011).

According to World Health Organisation (2011), retention in care in Southern Africa remains complicated as a result of an interplay of many factors. The identified factors influencing poor retention in ART care in Southern Africa include patient, provider, socio-cultural and health system factors. Most individuals and communities may later elect for traditional healers in preference to consulting with health care facilities (Mshana *et al.*, 2006). These patients could eventually drop out from ART programmes and thus may become LTFU.

A study conducted in South Africa found health system related factors such as financial challenges as the leading causes of LTFU in 34% of the patients on ART (Maskew *et al.*, 2007). Other health system factors come into play when patients have high frequency of appointments

difficult for patients because of high transportation costs, consequences of missing work and home responsibilities. In addition, a significant proportion of patients are lost in care because of death, especially during the first year following initiation of ART. This is due to a significant proportion of patients who come presenting with advanced HIV infection (Mutasa-Apollo *et al.*, 2014).

2.6 Retention in care in Swaziland

Swaziland has operationalised appointment attendance definitions as kept appointment, missed appointment, defaulted and LTFU (Swaziland Ministry of Health, 2012a). Kept appointment is any visit to the facility 7 days prior to the appointment date to 3 days post appointment. Patients with missed appointments are those who get in contact with the facility 3 to 7 days after their appointment dates. Any patient who misses their facility appointment by more than 7 days, but less than 90 days is categorised as having defaulted. If a patient does not have any contact with the health facility for a period of at least 90 days, they become LTFU. The tools that are available for monitoring retention in care include: ART file, ART register, electronic ART medical records, appointment register and call logbooks.

According to the Swaziland Ministry of Health (2014), the 6 months retention in care for adults on ART remains high at 96% and the 12, 24 and 36 months retention rates drop to 88%, 82% and 78% respectively. The national 12 months retention rate for the adult population is 88% implying that there is a 12% attrition rate at 12 months after initiation of ART. In order for the country to realise optimal clinical HIV treatment outcomes, studies in resource limited settings have shown the need for sustained long term retention in care (Rich *et al.*, 2012; Mutasa-Apollo *et al.*, 2014).

A considerable amount of data is routinely collected from the health facilities and serves the purpose of monitoring and evaluation. Regular reports are sent to the national level on the status of the national ART programme. Nevertheless, there is still limited data on retention in care for PMTCT interventions especially for women initiated on ART during pregnancy. Even after the adoption of lifelong ART for all HIV positive pregnant and lactating women, this aspect of care has received relatively little attention

2.7 Factors associated with retention in care

There is a large and growing literature on factors associated with retention in care. Literature has identified a wide range of key factors and addressing these factors has been emphasised as an important element for clinical success at both patient and programme levels. However, most of the research has focused on the general population without elucidating the factors contributing to poor retention amongst women initiated on ART during pregnancy. Reiter *et al.* (2000) highlight a number of factors that are associated with retention in care for patients in PMTCT and ART programmes. These factors can be divided into the following five categories: patient variables, socio-economic, treatment regimens, disease characteristics, and health system related factors (Figure 2.1). Apart from treatment regimens, all patient and community barriers to adherence to treatment are also associated with retention in care (Patel *et al.*, 2011).

Patient variables include socio-demographic factors such as age, gender, race, income, psychosocial support, education, literacy, stigma and discrimination, and *socio-economic factors*. Several studies have elicited age as a risk factor for retention in ART care, albeit in contrasting ways. A study from Tanzania found that younger women are less likely to be retained in care than older women (Kirsten *et al.*, 2011). In contrast, a multiple country study on retention on ART in Latin America found that poor retention increased by 6 percent with each one-year increase in age (Cohn *et al.*, 2008). This means that increasing age can either increase or decrease the likelihood of retention in care depending on the setting.

Some studies done in ART programmes in sub-Saharan Africa, show that male sex is associated poor retention in care (Stringer *et al.*, 2006; Wang *et al.*, 2011; Labhardt *et al.*, 2013; Mutasa-Apollo *et al.*, 2014). Compared to females, males are poorly retained in ART care mainly because male HIV patients in sub-Saharan Africa have a higher probability than females to present with advanced HIV infection at ART initiation (May *et al.*, 2010) and men have significantly higher rates of employment outside the home than women (Toro *et al.*, 2010). In addition, Toro *et al.* (2010) also show that the retention of pregnant women in care was lower than that of non-pregnant women and men at 82% compared to 87% and 86% respectively at 30 months of follow-up.

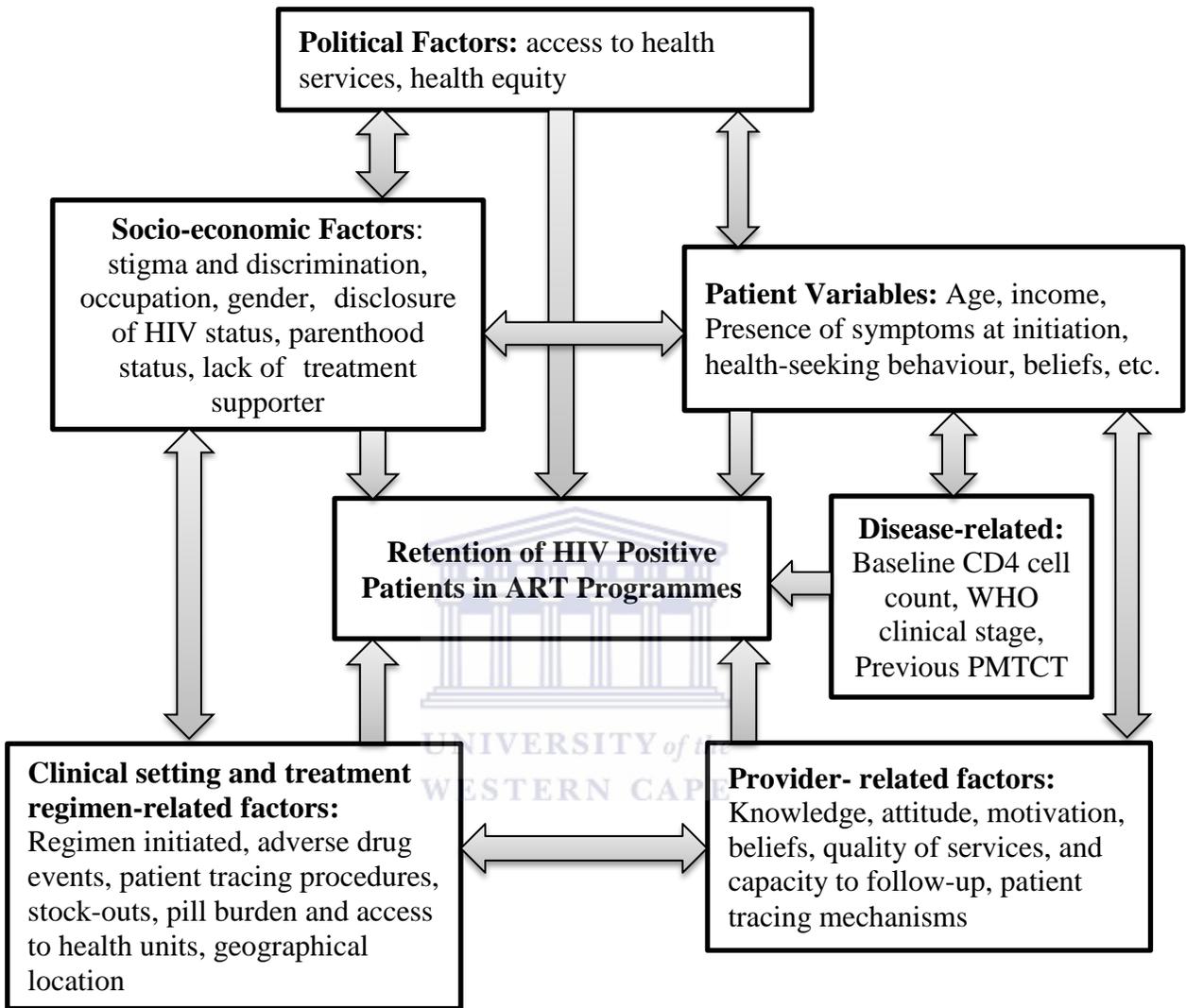


Figure 2.1: Conceptual Framework for Retention in Care

A systematic review of studies on retention in care in developing country settings reported the following socioeconomic factors: cost of transport, food insecurity and lower literacy as barriers to retention in care (Geng *et al.*, 2010a). In addition, low financial income has been reported as a barrier in some studies done in sub-Saharan Africa (Hodgson *et al.*, 2014). Income is needed for transport to the health facilities to pick the ARV supply and procure food. These indirect costs of ART and other spending while seeking care, serve as disincentives when the distances to the health facilities are long. Studies have shown that the direct and indirect costs of care affect the ability of PLHIV to remain in ART care (Siedner *et al.*, 2013; Assefa *et al.*, 2014).

Lack of knowledge and misconceptions about HIV and its treatment have also been elicited as barriers to retention in care (Smith *et al.*, 2012; Colvin *et al.*, 2014). Similarly, studies included in the systematic review by Hodgson *et al.* (2014) reported sufficient knowledge about HIV/AIDS, ART, or need to protect one's child and commitment to a child's health as enhancers of retention in ART. The authors postulate that higher levels of education contributed to better health literacy, which in turn promoted retention in care. With sufficient knowledge, patients would always want to stay healthy, have healthy children and protect their partners from reinfection. In studies in Uganda, South Africa, and Tanzania, a lack of knowledge about health services or ART was identified as a barrier to ART retention (Duff *et al.*, 2010; Watson-Jones *et al.*, 2012). Similarly, the same finding was reported in pregnant women initiated on ART during pregnancy, before and after delivery. For example, a study done in Ghana found that the majority of the study participants had a high level of essential HIV knowledge on HIV and ART basics, and women with inadequate levels of knowledge on PMTCT and ART had a high likelihood of being poorly retained in care (Boateng, Kwabong & Agyei-Baffour, 2013).

Disclosure of HIV status with associated stigma and discrimination are other patient characteristics that have been associated with poor retention in care in studies across sub-Saharan Africa (Arrive *et al.*, 2012; Hodgson *et al.*, 2014). A study in Kenya by Ujiji *et al.* (2011), reported that fear of negative consequences by partners was associated with poor retention in care. The negative consequences include domestic violence, divorce and blame for bringing HIV into the family. It is possible that women who choose to disclose to their partners already have positive and supportive relationships with their partners, and that these positive relationships in themselves promote ART retention. Furthermore, nondisclosure of HIV status in fear of

stigmatisation by family members or the community can result in lack of psychosocial support and consequently poor retention in care.

Other behavioural determinants of retention in care that have been associated with retention in care are physical impairments and substance abuse. For instance, Smith *et al.* (2012) in a mixed-methods qualitative analysis reported that drug abuse and / or alcohol consumption could mask the need for HIV care resulting in poor retention in care. The internalised stigma related to substance abuse resulting from self-shame or anticipated judgment from providers, discourages patients from continuing with their ART care attendance. In addition, individuals who smoke cigarettes were reported to have a high likelihood of becoming LTFU (Krishnan *et al.*, 2011).

The *treatment regimen* related determinants of retention in ART care include adherence, tolerability, and toxicity profiles of ART, the number of pills prescribed, the complexity of the regimen and the specific type of ARVs (World Health Organisation, 2003).

Retention in care is an important aspect of ART, but at times less recognised. To achieve high rates of retention in ART and favourable HIV treatment outcomes for patients in the PMTCT and ART programmes, adherence to therapy remains an important component (Makunde *et al.*, 2012). Adherence measures the percentage of patient behaviour to a prescribed therapy. In contrast, retention in care measures the duration during which a patient remains on a prescribed therapy. However, achieving sustained retention in care and having optimal ART adherence with ART have proven to be difficult and may have more challenges than with many non-communicable diseases (Bae, Guyer, Grimm & Altice, 2011). This could be due to HIV-related stigma – a significant barrier to retention in care, dosing schedule and the complex treatment regimens that may also have undesirable adverse effects and other drug interactions. Effective, one pill and once daily potent ARV regimens with minimal toxicities or drug interactions have significant positive impact on adherence and consequently retention in care.

Other barriers of retention in care include the ART regimen (Velen *et al.*, 2013). This could be due to the toxicity, dosing frequency or complexity of the regimen causing patients to abandon ART. Similarly, a systematic review by Gourlay *et al.* (2013) revealed that the type of ARV regimen taken during pregnancy influenced maternal adherence and that women taking twice-daily regimen were less likely to adhere than women taking once-daily regimen. On the

recommendation of WHO, many countries in sub-Saharan Africa have opted for Zidovudine or Tenofovir based triple fixed dose combinations (WHO, 2013), but poor retention remains a challenge. This shows the complexity of retention in care and the need for further research to elicit the determinants of poor retention especially amongst women initiated on ART during pregnancy.

Disease characteristics factors include WHO clinical stage, duration of HIV infection and associated opportunistic infections. Several studies have found the following barriers to retention in care; advanced HIV infection (Toro *et al.*, 2010; Thida *et al.*, 2014; Mutasa-Apollo *et al.*, 2014), low baseline CD4 cell count (Wang *et al.*, 2011; Labhardt *et al.*, 2013), low body weight at ART initiation (Mutasa-Apollo *et al.*, 2014). Most patients with advanced HIV infection may be too sick to come to the health facility and are more likely to be lost in care due to death. In addition, DiMatteo (2004) cited disease characteristic factors affecting retention in care from a different perspective by looking at HIV infected adults with other chronic diseases such as psychiatric conditions. Similarly, other studies in resource limited settings have reported comorbidities such as mental health (Sherer *et al.*, 2002; Geng *et al.*, 2010a) and diabetes (Giordano *et al.*, 2007; Patel *et al.*, 2011) to influence poor retention in care.

Studies have shown that women initiated on ART during pregnancy have a significant survival advantage although they are at greater risk of becoming LTFU (Wang *et al.*, 2011; Boyles *et al.*, 2011). This is mainly because pregnant women are twice as likely to present early compared to non-pregnant women (Dourado *et al.*, 2014). HIV positive pregnant women usually present for ART initiation when they are still stage 1 or 2 (Toro *et al.*, 2010). Although advanced HIV infection has been associated with poor retention, paradoxically pregnant with advanced infection are retained better than those in HIV clinical stage 1 and 2 because majority of pregnant women have never been sick with HIV infection and may take ART for granted. Generally, sick pregnant women come back to the health facility because they need more attention whereas those who have never been sick never come back and never realise the benefits of early ART initiation. Therefore, improved retention in care is a prerequisite for women initiating ART early during pregnancy to realise optimal clinical HIV treatment outcomes.

Other disease characteristic factor that has been associated with retention in care is CD4 cell count level. Some cohort studies have shown the association of low CD4 cell count with poor retention in ART care (Giordano, 2011). This finding reinforces the crucial importance of early HIV diagnosis and timely initiation of ART in the broader perspective of increasing survival rates. Similarly, another retrospective study by Thida *et al.* (2014) singled out baseline CD4 cell count less than 100 as a barrier to retention in care. This could be due to the high mortality in patients with advanced HIV infection.

According to Harries, Zachariah, Lawn and Rosen (2010), an ART programme can be used as an opportunity to improve holistic linkages and provide additional services such as family planning, nutritional assessment, counselling and support, which in return may encourage better retention in care.

Health system factors can be divided into patient-provider relationship related and clinical setting factors. The patient-provider relationship factors includes the patient's overall satisfaction and trust in the provider and clinic staff, the patient's opinion of the provider's competence, the provider continuity, the provider's willingness to include the patient in the decision making process and the effectiveness tone of the relationship as exemplified by warmth, openness and cooperation of the caregiver (Sihvonen, Käyhkö & Kekki, 1989).

A qualitative descriptive exploratory study by Duff *et al.* (2010) found that optimal provider-patient interactions enhance retention in care. The more the provider interacts with the patient, the more the patient trusts the provider and clinic staff in general, and the more likely the patient is retained in care. During the interaction, the provider may also include the patient in the decision making process to improve the overall satisfaction and foster patient ownership of their treatment. Patient satisfaction may also come from the provision of health services tailored to the needs of patients. A literature review by Sherer *et al.* (2002) concluded that patient satisfaction leads to better health outcomes and retention in care.

Other factors that enhance retention in care include provider continuity (Smith *et al.*, 2012; Siedner *et al.*, 2013) and use of peer support groups (Sherer *et al.*, 2002). Provider continuity nurtures patient trust to the provider and confidence in accessing the service thereby promoting persistence in care. Psychosocial support can be support from the available support structures

such as support groups that help in attending to scheduling conflicts, facilitating appointment reminders, or accompanying one to an appointment thereby encouraging retention in care. Some cross-sectional and nonrandomised studies of HIV-infected persons in care have shown that access to social services, and flexible clinic hours are associated with retention in care (Giordano *et al.*, 2007). Flexible clinic hours help in reducing waiting hours, which in turn encourage patients to continue coming to the health facilities to pick up their ARVs.

Kalogianni (2011) adds the clinical setting related factors, which influence retention in care. These factors include; distance to the clinic, general environment, system of appointment, facility staff attitude and training of staff on ART. A mixed methods study conducted in Ethiopia elicited long distance to the ART clinic as a barrier to retention in care (Assefa *et al.*, 2014). Similar results were found in rural Uganda and Malawi (Tuller *et al.*, 2010; Yu *et al.*, 2009). Distance to the clinic has a direct bearing on the cost of travel, which serve as a disincentive when the distances to the health facilities are long and consequently result in poor retention in care.

An enabling environment is required to support retention in care through stigma reduction, strengthened capacity to provide, support and promote linkages and access to prevention, care and support (WHO, 2011). Otherwise, a fragmented health care system often forces PLHIV to obtain care through multiple delivery systems, making it difficult to coordinate and attend appointments thereby leading poor retention in care.

Other clinical setting factors associated with retention in care include the system of appointment (Mwatawala *et al.*, 2012; Chalker *et al.*, 2013), facility staff attitude (Gerbert *et al.*, 1991; Smith *et al.*, 2012), and lack of proper training of staff on ART (Assefa *et al.*, 2014; Rollins *et al.*, 2015). If health care workers have a bad attitude, acting unprofessionally, patients are more likely to be discouraged from persisting in care. Studies have shown that women, especially, are less likely to participate in programmes if health care workers have negative attitudes (Gerbert *et al.*, 1991). Systems of appointment that involve the patients, allow less frequent visits and are flexible have been reported to encourage patient retention in care (Giordano *et al.*, 2007).

Summary

Retention in care remains a key element in maximising the efficacy of ART in improving survival rates of HIV/AIDS patients, lowering the incidence of opportunistic infections, reducing MTCT and minimising the possibilities of developing drug resistance. Hence, the recent global efforts through the 90-90-90 initiative to have at least 90% of the PLHIV knowing their HIV status, 90% of the HIV positive people linked and retained on ART, and 90% of the people on ART having their viral load suppressed by 2020. Poor retention in care has been noted among pregnant women and little is known about the factors that influence persistence in care among women initiated on ART during pregnancy. Identifying factors that influence retention in care is an important process in designing interventions aimed at sustaining long-term retention in care.

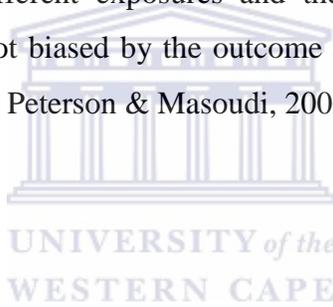
The next chapter outlines the methodology used to achieve the specific objectives.



3 METHODOLOGY

3.1 Study design

A quantitative, retrospective cohort study design was used (Ho, Peterson & Masoudi, 2008). Data was collected using a data extraction sheet (Appendix 1) from 316 clinical records of women who were initiated on ART during pregnancy within the defined period. Using this study design, records of pregnant women initiated on ART during pregnancy were abstracted for different exposures and outcome for the study that had already happened. Data on patient variables, treatment regimens, disease characteristics and health system related factors were abstracted for the study and LTFU was the endpoint. The direction of study was retrospective. Using the retrospective design the outcome of interest– retention in care – has already happened. This saves time and reduces all logistical and travelling costs. The design establishes the temporal relationship between different exposures and the outcome, thus ensuring that the measurement of the exposure is not biased by the outcome and reducing the likelihood that an association is cause and effect (Ho, Peterson & Masoudi, 2008).



3.2 Study Setting

The study was conducted at one of the busiest PHUs in Swaziland, King Sobhuza II PHU. PHUs are departments of the hospitals and health centres, which offer Maternal and Child Health services. Swaziland has integrated HIV care and treatment services in the PHUs (WHO, UNFPA, UNAIDS & IPPF, 2011).

King Sobhuza II PHU provides a range of services such as dental clinic, sexually transmitted infections clinic, skin clinic, antenatal clinic, post-natal clinic, family planning clinic, child welfare clinic, outreach services and ART services. PMTCT services started in 2003 (WHO, UNFPA, UNAIDS & IPPF, 2011). With assistance of Elizabeth Glaser Paediatric Foundation in 2007, HIV care and treatment services were integrated in the setting and the facility offers ART services to pregnant women, lactating women and their families.

The PMTCT programme follows national guidelines for ART initiation and used Zidovudine, Lamivudine and a non-nucleoside reverse transcriptase inhibitor as first-line regimen, and

protease inhibitor based regimens for second line regimen. In 2015, the national guidelines were updated in accordance to 2013 WHO recommendations and Swaziland adopted Tenofovir, Lamivudine and Efavirenz, the once daily regimen as the preferred first line regimen (Swaziland Ministry of Health, 2015). The move from a twice daily regimen to a once daily regimen was implemented to improve adherence and retention in care among women initiated on ART during pregnancy.

3.3 Study Population and Sampling

The study population was women who were initiated on ART during pregnancy at King Sobhuza II PHU from January 2012 to December 2013 and were followed up to the end March 2015. The study participants were identified using the ART registers and the electronic database. All patients meeting the inclusion criteria identified from the ART register or electronic database had their ART chronic file retrieved for data abstraction.

The exclusion criteria include the following women; women who were initiated on ART during pregnancy but were transferred out from the facility, those women who initiated treatment during pregnancy but miscarried, died or had an abortion whilst on ART. Of the 372 women who were initiated on ART during pregnancy, 2 who had miscarriages and 54 were transferred out from King Sobhuza II PHU to other health facilities and were excluded from the study as shown in Figure 3.2 below.

The inclusion criteria included all women who started ART during pregnancy and had term delivery. At the end of the recruitment process, 316 files were reviewed and analysed for the study. Caution was taken to identify all study eligible patients as listed in the ART register and were verified by the available electronic database at the study site to ensure that all eligible ART initiated pregnant women were included in the sampling frame.

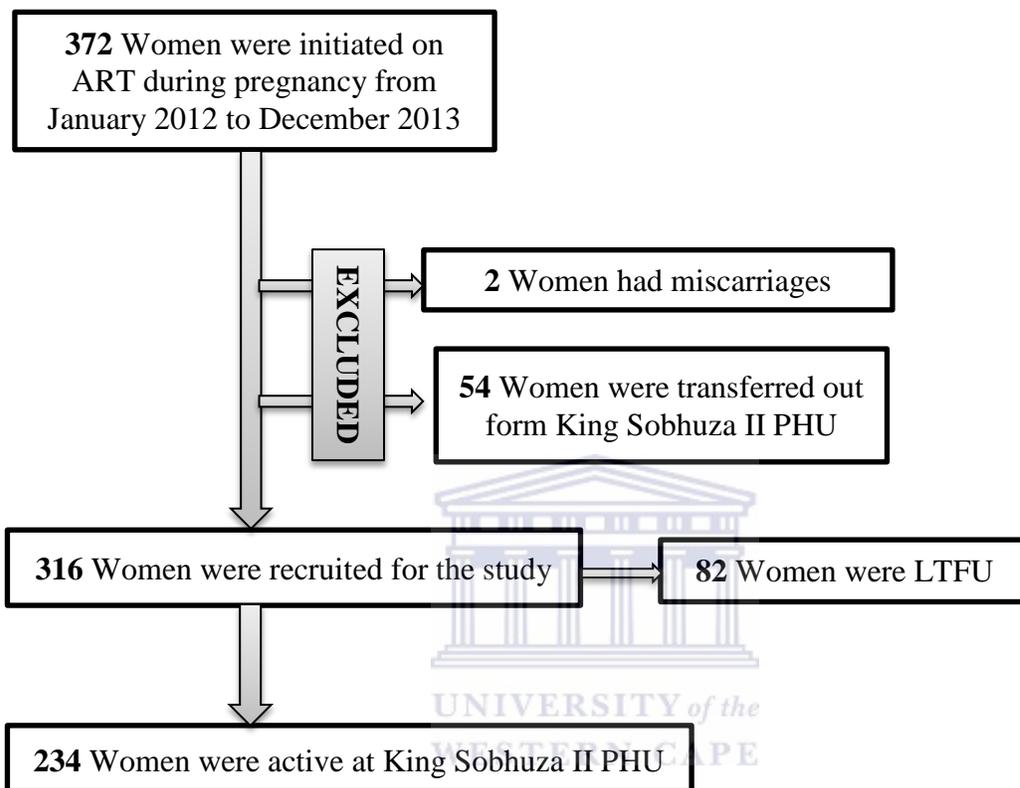


Figure 3.2: Recruitment process for the study participants

3.4 The Pre-test of Data Abstraction Tool

The data extraction tool was pretested in 15 patients at Raleigh Fitkin Hospital to ensure its validity and reliability. The pre-test was done to check for any hidden cognitive and communicative biases that the investigator was not aware of. Pretesting of the data abstraction tool allowed for the identification of any source of bias. The purpose was to identify the sources of measurement bias that could have been detrimental to the actual data abstraction. Refinement of the instrument was then done with a focus of minimising measurement error. Some questions were added to the abstraction tool. Some questions were eliminated.

3.5 Data Collection

Data was collected from the 1st of April to the 30th of April 2015 for all women who fitted in the inclusion criteria for the study period. The investigator developed a data extraction sheet which was used to abstract all the required information from the patient files (Appendix 1). The variables extracted included *patient, socio-economic, treatment regimens, disease characteristics* and *health system* related factors. Unlike prospective cohort studies, in which the investigator has control over what exposure variables and outcomes are measured, the flexibility is not possible in retrospective cohort studies because the documentation of variables has already happened. The investigator was limited to the variables documented in the patient files and / or captured in the electronic system.

Retention in the ART programme was defined as a visit to the health facility for a scheduled clinic or ART refill visit at least once in the past 3 months. For the survival analysis, the “event” of interest was LTFU leading to discontinuation from the ART programme. Patients retained in care were censored at their latest date of last clinic or ART refill visit (“last ART visit date”). Women who did not come to the clinic during the last 3 months, and were not transferred out and did not die were considered as LTFU from the ART programme (“event”). As discontinuation (“event”) time, the last date of clinic or ART refill visit was used. Variables were abstracted on the date of ART initiation for variable at ART initiation, and some variables were abstracted on the last ART visit date for both LTFU patients and those retained in care. For all patients, the last ART visit date was the latest date of ART refill visit after ART initiation.

Patient variables

The patient variables extracted included age, level of education, patient weight and body mass index (BMI) at ART initiation, patient weight and BMI on the last ART refill visit. Swaziland has a different education system after primary education, form 1 to 3 is secondary education and form 4 and 5 constitute high school. After high school, one then enrolls for tertiary education. The investigator used the patient reported and health provider calculated age from the given date of birth at ART initiation as recorded in the medical records. In the patient file, there is a field on level of education and this is the highest level of education attained by the day of ART initiation. Patient weight and height were abstracted as recorded in the records on the day of ART initiation and on the last ART refill visit. Additionally, the BMI was calculated using the weight and height as documented in the file.

Socio-economic variables

Socioeconomic variables were as follows; marital status at ART initiation, disclosure to the partner at ART initiation, reported consistent condom use at ART initiation, partner status known at ART initiation, and HIV positive partner known to be on ART by the time the woman initiates ART. The facility staff routinely documented marital statuses of patients in the records. During the psychosocial assessment of patients before ART initiation, the following variables were captured into the records; whether disclosure was done to the partner, whether the woman consistently used a condom during sexual encounters with the partner and whether the partner is on ART.

Treatment regimens variables

Treatment regimen related variables included ART regimen initiated, changes in regimen after initiation, family planning use after delivery, any reported side effects whilst on ART and any reported poor adherence after ART initiation. The file had different options of ARV regimen and the health care worker would check the applicable regimen initiated to the patient. If for any reason the regimen was changed, then the new regimen would be documented on the given date of visit. The records had a field to document the family planning option the woman was taking on every visit and of interest was family planning used after delivery. After patients were started

on ART, records were searched for any reported and documented side effects and poor adherence. Patients were encouraged to take their medication same time(s) every day and pill count was done. On every visit the extent to which the patient was taking medication as prescribed medication by the health care provider was calculated, expressed as adherence rate and documented on each visit. Poor adherence was defined as any adherence rate less than 95% including missed and defaulted appointments. The data was carefully abstracted for any history of poor adherence by checking the adherence levels on every visit as documented in the records.

Disease variables

The disease characteristic variables abstracted were duration between HIV testing and ART initiation, presence of comorbidities at ART initiation, HIV clinical stage, previous PMTCT received by the woman, baseline CD4 cell count, number of CD4 cell counts done and trend of CD4 cell counts. The dates of HIV testing and ART initiation were routinely documented in the patient records. The duration between HIV testing and ART initiation were then calculated using the two variables. On ART initiation, health care workers were expected to obtain a comprehensive history, examine all patients and document the findings. History taken includes demographic, presenting complaint, past medical history, drug history, social and family history. On examination, the following findings are elicited; weight, height and findings from different systems. It is then from such findings that a patient is staged clinically based on the WHO clinical staging. In addition, any comorbid diseases and history of previous PMTCT were required to be documented in patient records accordingly. The CD4 cell counts done before ART initiation were documented and then abstracted as baseline CD4 cell counts. The number of CD4 cell counts done included all CD4 cell count done for the duration of ART and the baseline CD4 cell count. Furthermore, the trend of CD4 cell counts was then analysed and abstracted accordingly.

Health system variables

Health system related variables included documentation of other baselines laboratory investigations and distance to the facility. Documentation and interpretation of other baselines which included at least one of the following: the haemoglobin levels, the liver function tests and renal function tests. Distance from the patient's home to the clinic was estimated using distance

from the recorded address to the clinic. The other health system related factors such as general environment, system of appointment, facility staff attitude and training of staff on ART were not documented in the patient records and were assumed to be constant since the study was conducted in one health facility. However, further studies are recommended to investigate these factors in women initiated on ART during pregnancy.

For all data collection, the investigator completed a data extraction sheet. All variables were obtained from the study patients' medical records that included the individual patient files and the electronic records. The investigator then summarised the information from the data extraction sheet electronically using an excel sheet.

3.6 Data management and analysis

The data extraction sheets were completed onsite and checked for completeness before the investigator departed from the health facility. Reasons were given for any incomplete files. Names of study participants were not recorded. Instead, unique identification numbers were used for purposes of data analysis. As discussed in the data collection section, data extraction sheets were kept in a locked place where only the investigator was able to access the files.

Every effort was made to abstract all available data. Unless explicitly stated otherwise, missing data were not be imputed. Data were analysed and presented as they were recorded in the database. In calculating dates, estimated dates were as follows; for partial start dates, if the month or year was unknown, then the date were not imputed and were assigned a missing value. If only the day was unknown, and if only the month and year match the month were available or the year only, then the day of the date were imputed; otherwise, the date was imputed as the first day of the month. In addition, missing any clinical/ immunological assessment data were not imputed.

The first step to data analysis was to prepare and organise data. Data was summarised on an Excel sheet. All responses to questions summarised on an excel sheet were coded accordingly. Data cleaning and sample duplicate data entry was used to assure data quality. The dataset was imported into IBM SPSS Statistic 20 Software for analysis.

Summary statistics were presented to give a general description of the patients studied and an overview of the patient characteristics, clinical factors, and factors associated with retention in care. All analysis tables were summarised for all patients accordingly. Categorical variables were summarised as the number and percentage of participants in each category. Continuous parameters were summarised using numbers, mean, standard deviation (SD), median, minimum (min), and maximum (max) values.

Type I error rate (α) for statistical tests was set at 0.05 and 95% confidence intervals (CI) were provided when appropriate. P-values were reported to three decimal places with a leading zero (0.001). P-values of 0.000 were reported as <0.001 and not 0.000. All percentages and means were reported to one decimal place, standard deviation reported to two decimal places and min and max values to the same decimal places as the original data are recorded.

A descriptive analysis of all pregnant women who were initiated on ART within the specified period; those who defaulted before delivery; those retained in care and those lost in care after delivery was done. Of all the women initiated on ART during pregnancy, the study is eliciting the time at which those not retained are getting lost from care. Some women would get lost before they deliver whereas some would get lost after delivery. Assessment of any significant differences characteristics were conducted using an analysis of variance (ANOVA) model or a chi-square test for continuous and categorical data, respectively, Frequency distributions and cross tabulations of all variables were generated. Bi-variate analysis was done to determine significant associations between the dependent variable – retention in ART care at ART initiation and on the last ART refill visit – and the independent variables. Chi-square test (χ^2) statistics, p -values, odds ratios (OR) and 95% confidence intervals (CI) were computed to show the statistically significant variables. Furthermore, survival analysis including Kaplan-Meier analysis was used to estimate cohort survival functions at 6 months, 12 months, 24 months and 36 months. A proportional hazards model was fitted assuming a Weibull distribution for the survival time. The following statistics were computed; hazard ratio, 95% CI and the p -value.

3.7 Validity and reliability

There were challenges in the study design that could alter the study results. The investigator designed the data abstraction tool. Variables were modified and customised in consultation with colleagues from the National ART programme, facility sister in charge and some nurses working in the PHU.

The data extraction tool was pretested in 15 patients at Raleigh Fitkin Hospital to ensure its validity and reliability. The pre-test was done to check for any hidden cognitive and communicative biases that the investigator was not aware of. Pretesting of the data abstraction tool allowed for the identification of possible source of bias. The purpose was to identify the sources of measurement bias that could have been detrimental to the actual data abstraction. Refinement of the instrument was then done with a focus of minimising measurement error. Some questions were added to the abstraction tool while some questions were eliminated. No inter-rater reliability was checked since there was one data abstracter.

Selection bias was addressed by using the list of patients as it appears in the ART register at the PHU on the data collection days as the sampling frame, and using all records of study eligible patients as the study sample. Chance was further reduced by using the maximum possible sample size.

The PHU ART register had a lot of missing data. However, triangulation of data sources such as the chronic care file and the electronic database was used. All missing data on the independent variables were documented but not imputed. There was likelihood that the data sets with missing variables could introduce a hidden bias which had a positive or negative effect on the outcomes of interest. To minimise this bias, missing values for both numeric and character variables were explicitly labelled as missing in tables and data listings.

The natural interpersonal variability was eliminated by having the investigator as the only person abstracting data. The researcher played an important role to ensure the integrity of data throughout the course of the study. Every effort was made to abstract all available data, ensured data were recorded exactly as intended and hard copies secured in a lockable cabinet where only the researcher had access. A password was created to login and gain access to data in the database.

There are unmeasured confounders that may affect the findings of this study. These included the level of competence and experience of the HCWs filling in the patient medical records. One would assume that the more experienced the HCW is, the fewer the errors that would occur. To ensure reliability and determine the quality of data abstraction, the investigator abstracted all data and reassessed 10 % of the sample of all patients initiated on ART.

3.8 Generalisability

The results of this study could apply to the study population. Nonetheless, it is anticipated that the findings will have relevance more broadly. The purpose of this study was not to extrapolate to the population at large but to provide an insight into the magnitude of poor retention in women initiated on ART during pregnancy and identify some of the factors associated with poor retention in care.

3.9 Ethics considerations

The Senate Higher Degrees and Research committees of the University of the Western Cape reviewed and approved the study protocol. In addition, the King Sobhuza II PHU authorities granted the permission to access data in the PHU. The study had no explicit risks to the study subjects and its findings were to inform processes for improving the retention of patients in ART programmes especially in HIV positive women who initiate ART during pregnancy. Unique identification numbers instead of names were abstracted using the data extraction sheet. Furthermore, careful measures were taken to treat patient records with confidentiality; ensuring that information collected was used only for that study, removing personal identifying information from data extraction sheet and computer files, and making sure that no identifiable data was published. All data records were kept in lockable box files for safety and confidentiality during data collection and analysis.

4 RESULTS

During the study period, 316 records of women who were initiated on ART whilst pregnant were recruited at King Sobhuza II PHU in Swaziland. During the analysis all records were used.

4.1 Patient characteristics

After the analysis, the independent variables were further classified into patient variables, socio-economic, treatment regimens, disease characteristics and health system related factors. The patient variable included the demographic data – age, marital status and relationship with treatment supporter.

The age of the women initiated on ART during pregnancy ranged from 16 – 45 years (Figure 4.3). The median age was 26 years (IQR: 23 – 30) and the mean age was 26.92 (SD= 4.86) years.

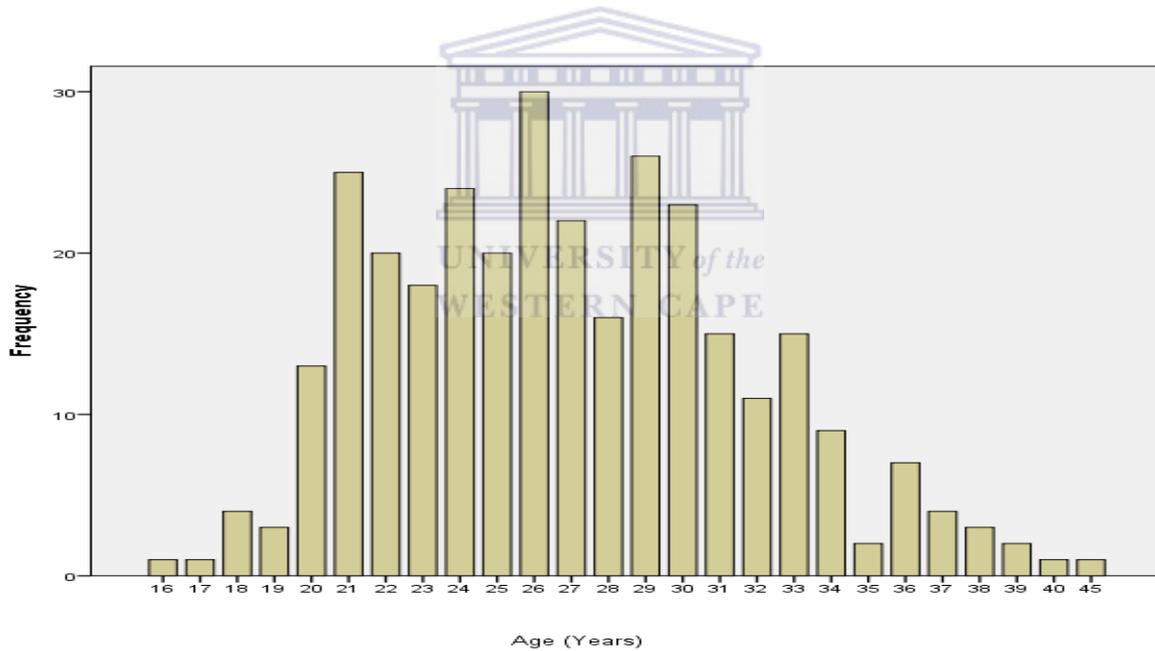


Figure 4.3: Age distribution of the study participants

At ART initiation, 61.7% of the pregnant women initiated on ART were single and the remainder, 38.3% were married. Of the 316 women who participated in the study, 81.7% of the women attained at least secondary education while 2.2% and 16.1% of the women had no education at all and attained only primary education respectively. Table 4.1 below summarises the socio-demographic characteristics of the study participants.

Table 4.1: Socio-demographic characteristics of pregnant women initiated on ART (n=316)

		Frequency	Percentage (%)
Age (in years)	15 – 24	109	34.5
	25 – 34	186	58.9
	35 – 44	20	6.3
	> 45	1	0.3
Marital Status	Married	121	38.3
	Single	195	61.7
Level of Education	None	7	2.2
	Primary	51	16.1
	Secondary	134	42.4
	High School	89	28.2
	Tertiary	35	11.1
Employment Status	Employed	129	40.8
	Unemployed	186	58.9
	Missing	1	0.3
Relationship with treatment supporter	Husband	103	32.6
	Boyfriend	21	6.6
	Mother	108	34.2
	Sister	46	14.6
	Aunt	14	4.4
	Daughter	1	0.3
	Father	7	2.2
	Other	16	5.1
Distance to the Health facility	≤5 km	174	55.1
	6 – 10 km	73	23.1
	11 – 15 km	33	10.4
	≥ 16 km	36	11.4
Reported financial challenges at ART initiation	Yes	48	15.2
	No	265	83.9
	Missing	3	0.9

More than half (186/316) of the participants were unemployed. In addition, all the study participants had treatment supporters with 32.6% and 34.2% reporting their husbands and mothers as treatment supporters, respectively.

Geographically, more than half of the patients (174/316) stayed within a 5 km radius while 11.4% reported that they had to travel over 16 km from their homes to the PHU. The median distance was 5.0 km (IQR: 4 – 9) while the maximum distance travelled by one woman was 90 km. The majority (83.9%) of participants reported no financial challenges and could afford to come to the facility for their ART refills as recommended by the facility staff and thus, retained in care.

As shown in Table 4.2 below, the majority (86.7%) of the women were eligible for ART based on CD4 cell count less than 350. Only a single patient initiated on ART had a CD4 cell count above 500. The median estimated gestational age (EGA) at ART initiation was 24 weeks (IQR: 18 – 31) with 6% and 60.8% of the patients being initiated on ART in the 1st and 2nd trimester respectively.

Of the patients coming in with a known positive status, 62.9% had taken a PMTCT regimen, short course Zidovudine, intra-partum dose and the tail (Under Option A of the 2010 WHO Guidelines). Disclosure levels remains very low with 45.6% of the women being initiated on ART without disclosing their status to their partners.

Swaziland National ART programme rolled out the 2010 Guidelines to all facilities in the country. With the 2010 Guidelines, the preferred first line for pregnant women was Zidovudine, Lamivudine and Nevirapine but with new evidence coming from WHO, Efavirenz and Tenofovir have been found to be safe in pregnant women. From June 2012, the facility started to give Tenofovir and Efavirenz to pregnant women although it had not been adopted as part of the National Guidelines. More than three quarters of the study participants were initiated on Zidovudine, Lamivudine and Nevirapine and less than 30% were initiated on Tenofovir based regimens.

Table 4.2: Clinical characteristics of pregnant women initiated on ART at King Sobhuza II PHU (N=316)

		Frequency	Percentage (%)
Baseline CD4	≤ 200	86	27.2
	201 – 350	188	59.5
	351 – 500	41	13.0
	> 500	1	0.3
Estimated Gestational Age at ART initiation	1 st Trimester	19	6.0
	2 nd Trimester	192	60.8
	3 rd Trimester	105	33.2
Previous PMTCT	Yes	56	17.7
	No	33	10.4
	N/A	227	71.8
Disclosure of HIV status to partner at ART initiation	Yes	170	58.3
	No	144	45.6
	Missing	2	0.6
Regimen	AZT + 3TC + NVP	251	79.4
	TDF + 3TC + EFV	59	18.7
	Other	6	1.9
Changes of regimen	Yes	33	10.4
	No	283	89.6
Consistent condom use at ART initiation	Yes	207	65.5
	No	109	34.5
Other family planning use on the last ART refill visit	None	127	40.2
	Oral	39	12.3
	Injectable	99	31.3
	IUCD	1	0.3
	Tubal ligation	2	0.6
	N/A	48	15.2
Weight changes on ART on the last ART refill visit	Weight gain	80	25.7
	Weight loss	184	59.2

		Frequency	Percentage (%)
Body mass index at initiation	No change	47	15.1
	Underweight	1	0.3
	Normal	103	32.6
	Overweight	125	39.6
	Obese	83	26.3
	Missing	4	1.3
Body mass index on the last ART refill visit	Underweight	8	2.5
	Normal	118	37.3
	Overweight	113	35.8
	Obese	68	21.5
	Missing	9	2.8
Timing of being LTFU	Before delivery	39	47.6
	After delivery	43	52.4

After ART initiation, 89.6% of the women maintained their ART regimen and no changes were made to the ART regimen. However, 10.4% of the women had side effects such as anaemia secondary to AZT with led to the substitution of the offending drug from the ART regimen.

At ART initiation, only 32.6% of the women had normal BMI as compared to 37.3% on the last ART visit. The occurrence of underweight in the women of childbearing age during and after delivery was found to be very low at 0.3% and 2.5% respectively. Reported condom use was low with only 65.5% reporting consistent condom use at the time of ART initiation. On the last ART visit date, 84.8% of the study participants were eligible for family planning with only 0.6% choosing permanent surgical methods and 12.3% and 31.3% opting for oral and injectable methods respectively. The majority of women (40.2%) opted not to be on any family planning after delivery.

Of the 316 women who were initiated on ART during pregnancy, 52.4% became LTFU after delivery and 47.6% before delivery. Figure 4.4 below shows the timing of becoming LTFU.

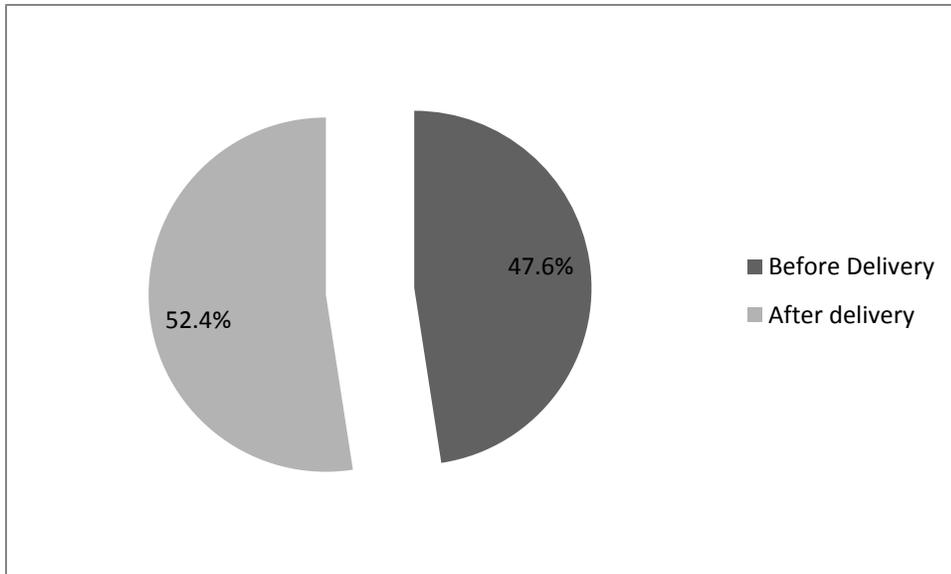


Figure 4.4: Timing of LTFU

4.2 Factors associated with retention in care

The overall retention rate at the PHU for the women initiated on ART during pregnancy after a median duration on ART of 25.80 months (IQR: 16.70 – 30.98) of follow up was found to be 74.1% (n=316). The overall retention in care was calculated for women who had been on ART for a total duration of up to 39.4 months. The mean duration that the women had been on ART was 22.84 (SD = 11.61) months. Approximately 67.7% (214/316) of the participants had been on ART for at least 20 months. However, 9% (n=316) of the women became LTFU by 2 months. At 6 months on ART, the LTFU rate was 16.5% (n=316); but rose slightly to 20.9% (n=316), 23.5% (n=243) and 26.9% (n=52) at 12, 24 and 36 months respectively.

As shown in Table 4.3, the statistically significant risk factors for retention in care at ART initiation included; the estimated gestational age ($p < 0.001$). Pregnant women initiated on ART during the early weeks of pregnancy were retained better than those initiated close to delivery. In addition, women with shorter duration between testing for HIV and ART initiation were retained better than those delaying ART initiation. However, duration between HIV testing and ART initiation was not significant ($p = 0.169$).

Retention rates were lowest in women having one child at 66.4% followed by those with 4 children at 71.4%. Pregnant women initiated on ART with more than 5 children were all retained in care. Nonetheless, parity at ART initiation was not significantly associated with retention in care ($p=0.153$). Gravidity was also not significantly associated with retention in care ($p=0.159$). Other factors at ART initiation such distance to the facility, weight, baseline CD4 cell count and BMI were found to be not significant.

On the last ART visit, the factors associated with retention in care were regular CD4 cell counts done for ART monitoring ($p<0.001$). Those who had regular CD4 cell count every 6 months were more likely to be retained in care than those who did not have CD4 cell count regularly. Other factors such as BMI on last ART refill visit, duration on ART, weight on last ART refill visit, number of CD4 cell count done were found to be not statistically significant.

Table 4.3: Predictors of retention in care for women initiated on ART during pregnancy (ANOVA)



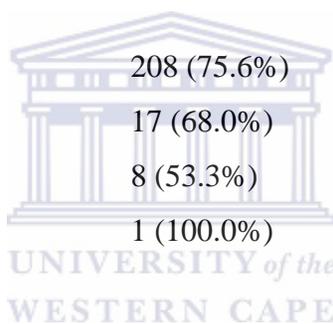
	<i>p</i> -value
On the ART initiation visit date	
Estimated Gestational Age	<0.001*
Parity	0.153
Gravida	0.159
Distance from the facility	0.886
Weight	0.709
Baseline CD4	0.193
BMI	0.236
Duration from testing to ART initiation	0.169
On the last ART visit date	
BMI on last ART refill visit	0.387
Duration on ART	<0.001*
Weight on last ART refill visit	0.261
Number of CD4 cell counts done for ART monitoring	<0.001*

* Significant at 5%

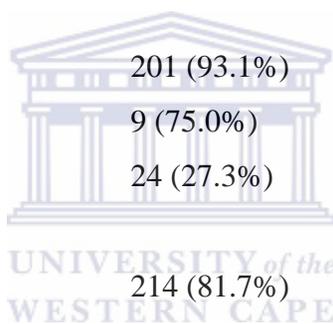
Table 4.4: Predictors of retention in care for women initiated on ART during pregnancy (Bivariate Analysis)

	Number retained in Care (%)	<i>p</i> -value
Age (in years)		0.014*
15 – 24	69 (63.3%)	
25 – 34	147 (79.0%)	
35 – 44	17 (85.0%)	
45+	1 (100.0%)	
Level of Education		0.389
None	4 (57.1%)	
Primary	39 (76.5%)	
Secondary	96 (71.6%)	
High School	65 (73.0%)	
Tertiary	30 (85.7%)	
Marital Status		0.006*
Married	100 (82.6%)	
Single	134 (68.7%)	
Employment status		0.096
Employed	101 (78.3%)	
Unemployed	133 (71.5%)	
Distance from the facility		0.448
</= 5km	125 (71.8%)	
6 - 10km	56 (76.7%)	
11 - 15 km	23 (69.7%)	
>/= 16	30 (83.3%)	
Baseline CD4		0.348
</= 200	58 (67.4%)	
201 – 350	143 (75.7%)	
351 – 500	32 (80.0%)	
> 500	1 (100.0%)	

	Number retained in Care (%)	<i>p</i> -value
Duration from testing to ART initiation		0.444
≤90	129 (72.5%)	
> 90	103 (76.3%)	
Regimen		0.002*
AZT+3TC+NVP	197 (78.5%)	
TDF+3TC+EFV	34 (57.6%)	
TDF+3TC+NVP	3 (50.0%)	
Presence of other co-morbidities		0.504
No	224 (74.4%)	
Yes	10 (66.7%)	
Clinical stage at ART initiation		0.209
I	208 (75.6%)	
II	17 (68.0%)	
III	8 (53.3%)	
IV	1 (100.0%)	
Previous OIs		0.096
No	208 (75.6%)	
Yes	26 (63.4%)	
Weight at ART initiation		0.463
≤ 55 kg	27 (69.2%)	
> 55 kg	207 (74.7%)	
EGA at ART initiation		<0.001*
1 st Trimester	18 (94.7%)	
2 nd Trimester	162 (84.4%)	
3 rd Trimester	54 (51.4%)	
BMI at ART initiation		0.104
Underweight	1 (100.0%)	
Normal	84 (81.6%)	
Overweight	85 (68.0%)	



	Number retained in Care (%)	<i>p</i> -value
Obese	64 (77.1%)	
Relationship to Rx supporter		0.062
Husband	86 (83.5%)	
Boyfriend	14 (66.7%)	
Mother	70 (64.8%)	
Sister	38 (82.6%)	
Other	26 (68.4%)	
Previous PMTCT		0.097
Yes	46 (82.1%)	
No	22 (66.7%)	
CD4 cell count trend		<0.001*
Going up	201 (93.1%)	
Dropping	9 (75.0%)	
N/A	24 (27.3%)	
Baselines (Hb, LFTs or KFTs)		<0.001*
Yes	214 (81.7%)	
No	16 (43.2%)	
Any reported side effects		0.262
No	210 (73.2%)	
Yes	24 (82.8%)	
Changes of Regimen		0.020*
No	204 (72.1%)	
Yes	30 (90.9%)	
Any reported poor adherence		<0.001*
No	214 (79.6%)	
Yes	20 (42.6%)	
Family Planning Use on Last Visit		<0.001*
None	106 (83.5%)	
Oral	33 (84.6%)	



	Number retained in Care (%)	p-value
Injectable	91 (91.9%)	
IUCD	1 (100.0%)	
Bilateral tubal ligation	2 (100.0%)	
N/A	1 (2.1%)	
Weight on the last ART refill visit		0.330
≤ 55 kg	55 (79.7%)	
> 55 kg	179 (74.0%)	
Weight changes on ART		<0.001*
Weight gain	62 (77.5%)	
Weight loss	152 (82.6%)	
No change	20 (42.6%)	
BMI on the last ART refill visit		0.040*
Underweight	7 (87.5%)	
Normal	97 (82.2%)	
Overweight	76 (67.3%)	
Obese	54 (79.4%)	
Consistent Condom Use at ART initiation		0.123
Yes	159 (76.8%)	
No	75 (68.8%)	
Partner Status Known at initiation		0.088
Positive	82 (82.0%)	
Unknown	148 (70.5%)	
Disclosure to the partner at initiation		0.015*
Yes	133 (78.2%)	
No	101 (70.1%)	
Partner on ART		0.002*
Yes	39 (86.7%)	
No	44 (80.0%)	

	Number retained in Care (%)	<i>p</i>-value
N/A	151 (70.9%)	
History of alcohol		<0.001*
Yes	6 (60.0%)	
No	228 (75.7%)	
History of smoking		<0.001*
Yes	0 (0.0%)	
No	234 (75.7%)	
Financial challenges at ART initiation		0.011*
Yes	34 (70.8%)	
No	200 (75.5%)	

* Significant at 5%*



Patient-related Factors

Age was significantly associated with probability of being retained in care at ART initiation ($p=0.014$). LTFU was highest among younger women aged 15 – 24 years at 36.7%; and decreasing with increase in age, with those between 25 – 34 years and 35 – 44 years reporting LTFU at 21% and 15% and no LTFU among women above 45 years (Table 4.4).

Level of education was not significantly associated with the chance of being retained in care at ART initiation ($p=0.389$). Retention in care was lowest in the women who had no education at ART initiation at 57.1% and increased with increasing level of education, with those who had attained primary, secondary and tertiary education being retained in care at 76.5%, 71.6%, 73% and 85.7% respectively.

The estimated gestational age at ART initiation was significantly associated with retention on ART ($p<0.001$). The majority, 94.7% of the women initiated during the first trimester were retained in care compared to 84.4% and 51.4% of the women retained in care after being initiated on ART during the second and third trimester respectively.

Retention on ART was not significantly associated with weight of the women at ART initiation ($p=0.463$) and on the last ART visit ($p=0.330$). However, weight changes after initiation of ART were significantly associated with retention in ART care ($p<0.001$). The majority, 82.6% of women losing weight after ART initiation were retained in care compared to 77.5% and 42.6% of those gaining weight and with no changes in weight being retained in care respectively.

BMI at ART initiation was not significantly associated with retention in care ($p=0.104$). Underweight pregnant women were less likely to become LTFU than women in other weight categories in which at least a 19% of the patients were LTFU. However, BMI on last ART visit had a significant association with retention in care ($p=0.040$). Women who were overweight on the last ART visit were the least likely (67.3%) to be retained in care than other underweight, normal and obese BMI categories whose retention rates were at 87.5%, 82.2% and 79.4% respectively.

Pregnant women acknowledging consistent condom use at ART initiation were retained in ART care better than those reporting inconsistency at retention rates 76.8% and 68.8% respectively.

However, the association between retention in care and reported consistent condom use at ART initiation was not statistically significant ($p=0.123$).

Disease related factors

There was no significant association between the duration between testing HIV positive and ART initiation ($p=0.444$). It took on average 35 (SD=10.13) days for a women to be initiated on ART from the time of testing HIV positive. Interestingly, women who took more than 3 months to be initiated on ART had a comparable retention on ART with to those who took less than 3 months to be initiated on ART. In addition, presence of comorbidities did not show any statistical significance ($p=0.504$). Those women with no other co-morbidities such as asthma, diabetes among others were more likely to be retained in ART care than to those having comorbidities at 74.4% and 66.7% respectively.

The WHO clinical staging at ART initiation was not significantly associated with retention in care ($p=0.209$). All women initiated on ART in HIV Stage 4 were retained in care. At least three quarters, two thirds and half of the women initiated on ART in Stages 1, 2 and 3 respectively were retained in care. Furthermore, presence of previous opportunistic infections also had no significant association with retention in care ($p=0.096$).

Having a previous exposure to ARVs for PMTCT was not significantly associated with retention in care ($p=0.097$). The majority, 82.1% of the pregnant women initiated on ART having a previous exposure to a short course of ARVs for PMTCT were retained in care better compared to 66.7% of those who were taking a PMTCT regimen for the first time.

Socio-economic Factors

There is a significant association between marital status of the woman at ART initiation with retention in care ($p=0.006$). Patients who were married were more likely to be retained in care than pregnant single women. About 82.6% of the married women initiated on ART during pregnancy were retained in care compared to 68.7% single women initiated on ART, retained in care.

Relationship to the treatment supporter was not significantly associated with retention at ART initiation ($p=0.062$). LTFU was lowest among those having their husbands as treatment

supporters at 16.5% followed by those whose treatment partners were their sisters. Those pregnant women who had their mothers as treatment supporters had the highest probability of becoming LTFU at 35.2%.

Employment status was not significantly associated with retention in care at ART initiation ($p=0.096$). However, those employed had a higher probability of being retained in care than those who were unemployed at ART initiation at 78.3% and 71.5% respectively.

There was a statistically significant association between disclosing one's HIV status to the partner and retention in care ($p=0.015$). Disclosure of HIV status to the partner before ART initiation helped women to be retained in care. Non-disclosure to the partner before ART initiation continues to be a critical barrier to retention at King Sobhuza II PHU. Stigma remains a very serious impediment to long-term retention as those women who did not disclose were more likely to become lost to follow up. However, the association between knowing the partner's status and retention care was not significant ($p=0.088$). At ART initiation, 82% of pregnant women who knew their partners to have a positive status were retained in care. Only 70.5% and 66.7% of the women who did not know the status of their partners and those with undocumented status respectively were retained in care.

The association between retention in ART care and having partners on ART by the time women are initiated on ART achieved statistical significance ($p=0.002$). Pregnant women whose partners were on ART were retained in ART care better than those whose partners were not on ART at retention rates of 86.7% and 80% respectively.

History of alcohol consumption at ART initiation was significantly associated with the probability of being retained in care ($p<0.001$). In addition, history of smoking at ART initiation was significantly associated with the probability of being retained in care ($p<0.001$). Those who neither consumed alcohol nor smoked were retained in care better than those who consumed alcohol or smoked.

Acknowledging having no financial problems on the ART initiation visit was significantly associated with the chance of being retained in care ($p=0.011$). Those who acknowledged facing financial challenges at ART initiation were less likely to be retained in care than those who said

they had no financial challenges.

Treatment Regimen-related Factors

The choice of the ART regimen at ART initiation was found to be significantly associated with retention in care ($p=0.002$). About 78.5% of pregnant women initiated on the preferred first line regimen, Zidovudine, Lamivudine and Nevirapine were retained in care better than those initiated on other alternative regimen such as Tenofovir, Lamivudine and Efavirenz and Tenofovir, Lamivudine and Nevirapine on which 57.6% and 50% of the women were retained in care respectively. In addition, history of poor adherence on the subsequent visit was found to be significantly associated with retention on ART ($p<0.001$). Women who had a history of poor adherence to ART were less likely to be retained in care at 42.6% than those never had challenges with adherence at 79.6%. However, the association between retention in care and any reported side effects was not statistically significant ($p=0.262$). Retention in care was noted to be better in women who experienced side effects than those who never experienced any side effects at rates of 82.8% and 73.2% respectively.

On the last ART visit, the change of ART combination was significantly associated with the probability of being retained on ART ($p=0.02$). Those who had changes in regimen were noted to be retained in care better than those who maintained the same regimen. About 90.9% of the women initiated on ART during pregnancy who had changes in regimen were retained in ART whilst 72.19% who maintained their regimen were retained on ART.

Starting any contraceptive other than the condom for family planning after delivery was found to be statistically associated with retention on ART for pregnant women initiated on ART during pregnancy ($p<0.001$). On the last ART visit, women who started any contraceptive other than the condom for family planning after delivery had a better retention on ART than those who never started any family planning method other than the condom. Lost to follow up was found to be further compounded by those women who could not start any contraceptive for family planning.

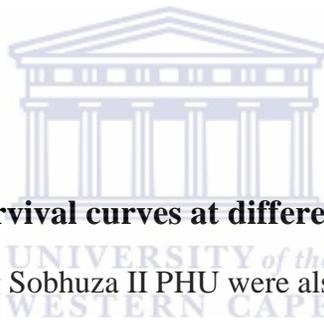
Regular CD4 cell count monitoring was noted to be associated with the probability of being retained in care on the last ART visit ($p<0.001$). Women who had regular CD4 cell count done for immunological monitoring whilst on ART had a lower risk of getting lost to follow up. In addition, those with CD4 cell count trends going up were retained better than those women with

dropping CD4 cell counts, and the association was statistically significant ($p<0.001$). Nevertheless, baseline CD4 cell count had no significant association with retention in care ($p=0.348$).

Health systems factors

Having results of at least haemoglobin, liver function tests or kidney function tests at ART initiation was significantly associated with retention in care ($p<0.001$). The highest rate of retention in care was observed among women who had documented and interpreted baselines results of liver function tests, or kidney function tests haemoglobin levels at 81.7%.

However, the association between distance to the health facility and retention in care was not significant ($p=0.448$). Women staying further than 16 km had a highest likelihood of being retained in care at 83.3% whereas those staying 11 – 15 km from the PHU had the highest risk of being LTFU at 30.3%.



4.3 Retention rates from survival curves at different time intervals

The retention rates on ART at King Sobhuza II PHU were also estimated using the Kaplan-Meier survival functions at 6, 12, 24 and 36 months.

According to the survival curves shown in Figure 4.5, the retention rates at 6, 12, 24 and 36 months is 83.5%, 79.1%, 76.5%, 73.1% respectively. Women initiated on ART during pregnancy had an 83.5% chance of being retained in care at 6 months at King Sobhuza II PHU. At 12, 24 and 36 months the probability of being retained in care decreased to 79.1%, 76.5% and 73.1% respectively. The proportion that was not retained in care was LTFU after factoring out the known deaths and transfers out, who were excluded from the study population.

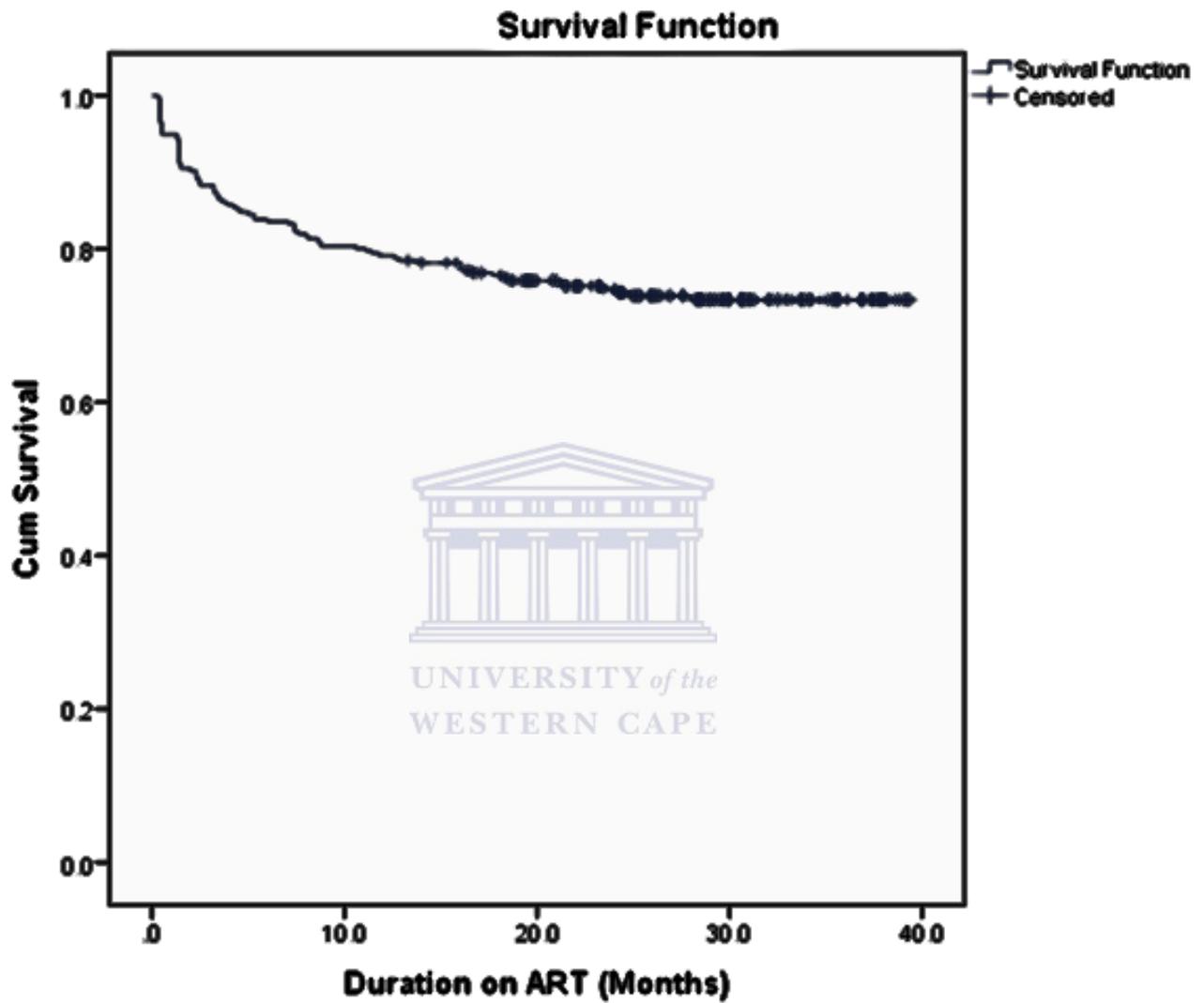


Figure 4.5: Retention rates at different time intervals

4.4 Predictors of retention in care for women initiated on ART during pregnancy

Bi-variate analysis proved the following to be statistically significant risk factors of poor retention in care for women initiated on ART during pregnancy, at ART initiation; age, marital status, ART regimen initiated, disclosure to the partner, EGA, interpretation of other laboratory investigations, partner on ART, history of smoking and alcohol consumption and reporting financial challenges. Significant factors on the last ART refill visit include; BMI, changes in regimen, CD4 cell counts trend, any reported poor adherence and family planning use.

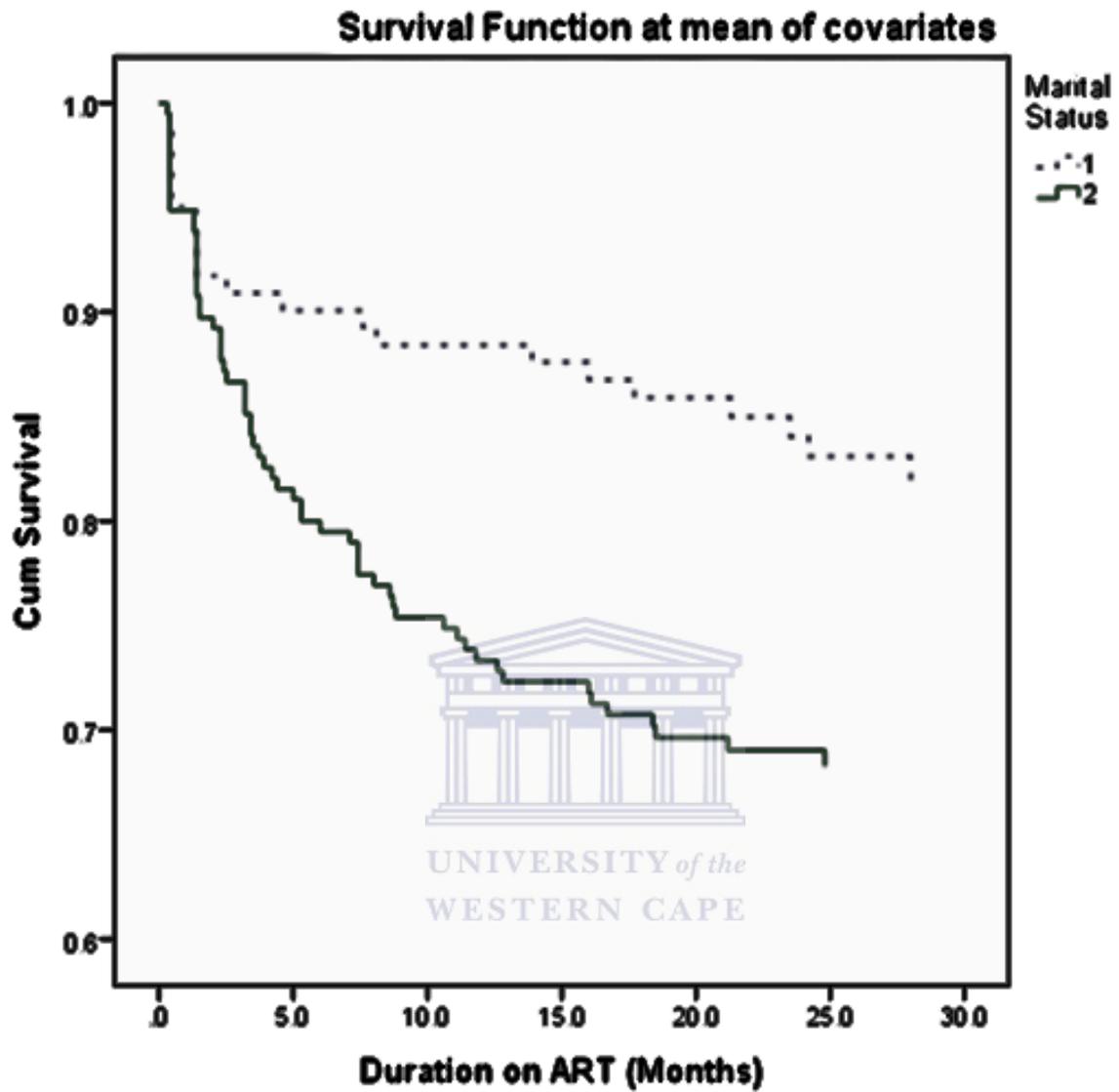
Independent variables that were significantly associated with retention of pregnant women in ART care in the bivariate analysis were further analysed by Cox regression to explore the relationship between the survival of the women and several explanatory variables.

4.4.1 Predictors of retention in care at ART initiation

The following factors were analysed to assess the relationship between variables and survival time after ART initiation; age, marital status, estimated gestational age, trimester, history of alcohol consumption, history of smoking, reported financial challenges, documented and interpreted baseline results, disclosure to the partner, partner known to be on ART and regimen initiated. Table 4.5 shows the survival analysis of predictors of retention in care at ART initiation.

The hazard of LTFU was reduced with increasing age. As shown in Table 4.5, there was a decrease of 7.5% in the hazard of being LTFU for a one year increase in age, and this achieved statistical significance ($p=0.001$).

Pregnant women who were single at the time of ART initiation were found to have a 1.999-fold increased hazard of becoming LTFU as compared to those who were married (Figure 4.6). This implies that at ART initiation, pregnant women who are married had a reduced risk of becoming LTFU as compared to single pregnant women. This could probably mean that the former had less psychosocial support compared to the latter and hence would not stay long-term ART. The difference achieved statistical significance ($p=0.006$).



Key: 1 – Married 2 – Single

Figure 4.6: Survival of women according to marital status

There was an increase of 10.3% in the hazard of becoming LTFU for every week increase in estimated gestational age. Of the women initiated on ART, those who came at lower gestational age are more likely to be retained in care than those coming late and this was statistically significant ($p<0.001$). Similarly, pregnant women initiated on ART in the third trimester (HR 12.387; $p=0.013$) had an increased risk of becoming LTFU as compared to the first trimester. However, the 3.297 increase in hazard of becoming LTFU in the second trimester as compared to the first trimester was not statistically significant ($p<0.241$).

In this study, pregnant women who did not consume alcohol had a 44.8% reduction in the hazard of being LTFU as compared to those who did consume alcohol. However, this reduction was not statistically significant (HR 0.552; $p=0.248$). Consequently, the hazard between those who a history of smoking and those with no history of smoking at ART initiation was statistically significant (HR 0.171; $p=0.792$). The hazard of becoming LTFU was reduced by 82.9% in those who had a history of smoking at ART initiation compared to those who did not smoke.



Table 4.5: Predictors of retention in care at ART initiation

	Hazard ratio	95% CI	p-value
Age	0.925	0.882 – 0.970	0.001*
Marital Status			
Married**	1.000		
Single	1.999	1.217 – 3.284	0.006*
EGA	1.103	1.070 – 1.137	<0.001*
Trimester			
1 st Trimester**	1.000		
2 nd Trimester	3.297	0.450 – 24.179	0.241
3 rd Trimester	12.378	1.710 – 89.616	0.013*
History of alcohol consumption			
Yes**	1.000		
No	0.552	0.202 – 1.512	0.248
History of smoking			
Yes**	1.000		
No	0.171	0.042 – 0.698	0.014*
Reported financial challenges			
Yes**	1.000		
No	0.808	0.454 – 1.440	0.470
Documented Baseline results			
Yes**	1.000		
No	4.600	2.742 – 7.717	<0.001*
Disclosure to the partner			
Yes**	1.000		
No	1.451	0.935 – 2.252	0.097
Partner known to be on ART			
Yes**	1.000		
No	1.569	0.580 – 4.242	0.375

Regimen			
AZT+3TC+NVP**	1.000		
TDF+3TC+EFV	2.569	1.592 – 4.145	<0.001*
TDF+3TC+NVP	3.044	0.951 – 9.745	0.061

* Significant at 5%; ** Reference category

Pregnant women who reported no financial challenges at ART initiation had a 19.2% reduction in the hazard of becoming LTFU as compared to those women who reported financial problems. The difference was statistically non-significant (*HR* 0.808; $p=0.470$). In addition, those women who had no results of baselines such as haemoglobin levels, kidney function tests or liver function tests had a 4.6 fold increase in the hazards of becoming LTFU as compared to those who had documented and interpreted baselines (*HR* 4.600; $p<0.001$).

At ART initiation, pregnant women who had not disclosed their HIV status to their partners were found to have a 1.451-fold increased hazard of becoming LTFU as compared to those who had disclosed their HIV status to the partners. However, this difference did not achieve statistical significance (*HR* 1.451; $p=0.097$). Consequently, those who knew that their partners were not on ART also had a 1.569-fold increased hazard of becoming LTFU as compared to those who knew that their partners were on ART and this did not achieve statistical significance (*HR* 1.569; $p=0.375$).

Pregnant women initiated on a twice daily regimen – Tenofovir, Lamivudine and Nevirapine – a dual fixed dose combination and a single formulation of Nevirapine, had a 2.569-fold increased hazard of becoming LTFU as compared to those on the preferred first line regimen – Zidovudine, Lamivudine and Nevirapine – a triple fixed dose combination taken twice daily. The difference was statistically significant (*HR* 2.569; $p<0.001$). Similarly, those on a once daily regimen – Tenofovir, Lamivudine and Efavirenz – a triple fixed dose combination, had a 3.044-fold increased hazard of becoming LTFU as compared to those on the preferred first line regimen but without statistical significance (*HR* 3.044; $p=0.061$).

Table 4.6: Predictors of retention in care on the last ART clinic visit

Variable	Hazard Ratio	95% CI	p-value
CD4 cell count trend			
Going up	1.000**		
Dropping	4.021	1.163 – 13.900	0.028*
Changes of ART regimen			
No	1.000**		
Yes	0.284	0.090 – 0.901	0.033*
History of poor ART adherence			
No	1.000**		
Yes	2.871	1.810 – 4.5553	<0.001*
Family planning use			
None	1.000**		
Oral	0.883	0.356 – 2.188	0.788
Injectable	0.459	0.203 – 1.037	0.061
IUCD	0.000	0.000 – 0.000	0.982
Bilateral tubal ligation	0.000	0.000 – 0.000	0.973
Weight changes on ART			
No change	1.000**		
Weight loss	0.268	0.148 – 0.488	<0.001*
Weight gain	0.200	0.119 – 0.334	<0.001*
Body Mass Index			
Underweight	1.000**		
Normal	0.563	0.074 – 4.278	0.578
Overweight	0.850	0.432 – 1.671	0.637
Obese	1.745	0.943 – 3.229	0.076

* Significant at 5%; ** Reference category

4.4.2 Predictors of retention in care on the last ART visit

The following factors were analysed to assess the relationship between variables and survival time at on the last ART refill visit; CD4 cell count trend, changes of ART regimen, history of poor ART adherence, family planning use, weight changes on ART and BMI. Table 4.6 shows the survival analysis of predictors of retention in care on the last ART clinic visit.

Women who had dropping CD4 cell count trends on the last ART clinic visit were found to have a 4.021-fold increased hazard of becoming LTFU as compared to those who had CD4 cell counts going up. This implies that on the last ART refill visit, women who had CD4 cell count going up had a reduced risk of becoming LTFU as compared to those with dropping CD4 cell counts. The difference achieved statistical significance (*HR* 4.021; *p*=0.028).

The hazard of becoming LTFU was reduced by 71.6% among women who had changes in their regimen as compared to those who never had changes in their ART regimen (Figure 4.7). This means that those who don't have changes in their ART regimen stand a higher risk of LTFU as compared to those having changes in their regimen. The difference achieved statistical significance (*HR* 0.284; *p*=0.399). This could be due to lack of counselling provided to women who never have changes in their ART regimen as compared to the counselling provided to those having or about to have changes in their regimen.

Women who had a history of poor adherence on the last ART refill visit were found to have a 2.871-fold increased hazard of becoming LTFU as compared to those who never had poor adherence before. On the last ART refill visit, women who had no history of poor adherence had a reduced risk of becoming LTFU as compared to those with a history of poor adherence, and this achieved statistical significance (*HR* 2.871; *p*<0.001).

Women who started family planning use after delivery had a reduced hazard of becoming LTFU as compared to those who never used any family planning method such as oral contraceptives (*HR* 0.883; *p*=0.788), injectable (*HR* 0.459; *p*=0.061), intrauterine contraceptive device (*HR* 0.000; *p*=0.982) and bilateral tubal ligation (*HR* 0.000; *p*=0.973). However, these differences were not statistically significant.

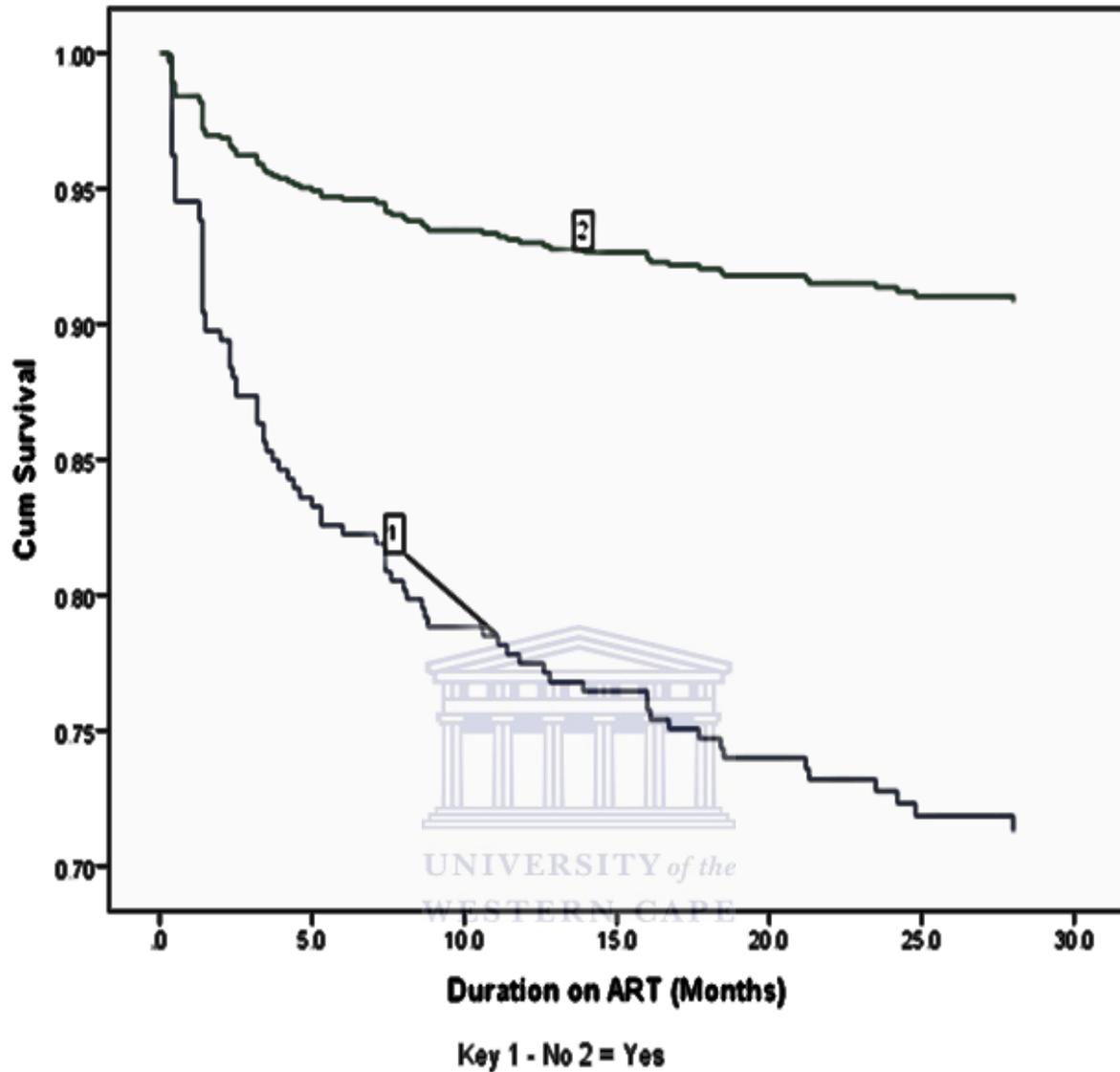


Figure 4.7: Survival of women according to changes of regimen

The hazard of becoming LTFU was reduced by 73.2% in women who had weight loss from ART initiation to the last ART refill visit as compared to those who had no change from the pregnancy weight at ART initiation to the last ART refill visit. This difference was statistically significant ($HR\ 0.268; p < 0.001$). Similarly, those with weight gain had an 80% reduction in the hazard of being LTFU as compared to those who had no change from the pregnancy weight at ART initiation to the last ART refill visit ($HR\ 0.200; p < 0.001$).

Patients who had normal BMI were found to have a 43.7% reduction in hazard of becoming LTFU relative to those underweight. Nevertheless, the difference did not achieve statistical significance (*HR* 0.563; *p*=0.578). Similarly, the hazard of becoming LTFU was reduced by 15% in women who were overweight as compared to those underweight (*HR* 0.850; *p*=0.637). Consequently, women who were overweight on the last ART refill visit were found to have a 1.745-fold increase in the hazard of becoming LTFU as compared to those who were underweight (*HR* 1.745; *p*=0.076).

4.5 Summary

Bi-variate analysis found the following to be statistically significant risk factors of poor retention in care for women initiated on ART during pregnancy, at ART initiation; age, marital status, ART regimen initiated, disclosure to the partner, EGA, interpretation of other laboratory investigations, partner on ART, history of smoking and alcohol consumption and reporting financial challenges. Significant factors on the last ART refill visit include; BMI, changes in regimen, CD4 cell counts trend, any reported poor adherence and family planning use.

After further analysis using Cox regression, statistically significant factors of poor retention in care at ART initiation include; younger women; single pregnant women, higher EGA, being initiated in third trimester, history of smoking, no other baseline results and being initiated on an ART regimen that is not the preferred regimen. In addition, the significant risk factors of poor retention in care on the last ART refill visit included; dropping CD4 count trend, no changes to the ART regimen, history of poor ART adherence and weight gain or loss.

5 DISCUSSION

This study is one of the first to investigate the factors contributing to poor retention among women who initiate ART during pregnancy in Swaziland. The significant risk factors investigated are supposed to reflect the risk factors for poor retention among women who initiate ART during pregnancy for a given environment. These findings are particularly important for the national PMTCT programmes to prioritise the identification of patients with a high likelihood of being LTFU for intensified patient education and counselling to foster sustained viral load suppression and patient retention in care.

5.1 Retention in care

Retention rates for women initiated on ART during pregnancy at King Sobhuza II PHU at 6, 12, 24 and 36 months were 83.5%, 79.1%, 76.5%, 73.1% respectively. These rates are much lower than those elicited in a study done for all ART patients in Zimbabwe (Mutasa-Apollo *et al.*, 2014) and those estimated by Fox and Rosen (2010) in a meta-analysis of published cohort data from 16 countries in sub-Saharan Africa. In the meta-analysis, the estimated retention rates of ART patients at 6, 12, 24 and 36 months were 86.1%, 80.2%, 70.0% and 64.6% respectively. Also, in the Zimbabwe Study the rates of patient retention at 6, 12, 24 and 36 months were 90.7%, 78.1%, 68.8% and 64.4%, respectively. The retention rate for women initiated on ART during pregnancy at 6 months is lower than in the general adult population on ART. In addition, the study identified that 47.6% of the women becoming LTFU are lost in ART care before delivery compared to 52.4% who are lost after delivery. Given that the median EGA at ART initiation was 24 weeks (IQR: 18 – 31), most women became LTFU by 6 months of ART initiation.

5.2 Factors associated with retention in care

The observed association of poor retention in care of the women initiated on ART during pregnancy with some patient related factors, socio-economic factors, disease related factors, treatment regimen related factors and health system related factors are consistent with other

knowledge (WHO, 2009). The statistically significant patient related factors included age, estimated gestational age at ART initiation, BMI on the last ART visit and trend of CD4 cell count done for monitoring purposes. Effectuated changes in the ART regimen, any reported side effects, family planning use after delivery, any prior poor adherence to ART and the actual regimen initiated were identified as the significant drug related factors. The socio-economic factors which were associated with retention in care were as follows: marital status, disclosure to partner at ART initiation, whether the partner is also on ART, history of smoking and alcohol consumption at ART initiation and acknowledgement of financial challenges at ART initiation. Health system related factors included the distance to the facility and documentation and interpretation of the other baseline investigations.

5.2.1 Age

Age at ART initiation was identified as a contributing factor to retention in care with older women retained better in care than the younger women. Similarly, Hodgson *et al.* (2014) also identified lower ages as a barrier to retention in ART care and higher ages as an enablers to retention in care. Of the women above 45 years, all of them were retained in care compared to 85%, 79% and 63.3% for the age groups 35 – 44, 25 – 34 and 15 – 24 years respectively.

5.2.2 Baseline CD4 cell count and regular CD4 cell count monitoring

For women who were initiated on ART during pregnancy, the mean observed CD4 cell count was 250 cells per ml at baseline. The trend of CD4 cell counts done for monitoring purposes for women already on ART showed that only 3.8% of the women had dropping CD4 cell count during the duration of the study. These findings are consistent with findings from other studies in Africa demonstrating good immunologic response to ART (Coetzee *et al.*, 2004). Contrary to the findings by Mutasa-Apollo *et al.* (2014), baseline CD4 cell count was found not to be significantly associated with retention in care. This finding is similar to what was elicited by Toro *et al.* (2010) that poor programme retention was not associated with CD4 cell count.

5.2.3 Estimated gestational age (EGA) at ART initiation

Nationally, pregnant women are having their first booking at 18 weeks (Swaziland Ministry of Health, 2014) and based on the study findings, the EGA at ART initiation was 24 weeks. In addition, 97% of the pregnant women nationally are tested on the first antenatal care (ANC)

visit. This means that on average it took 6 weeks for the women to initiate ART and is further supported by the duration between testing and ART initiation which was on average 35 (SD=10.13) days. EGA at ART initiation was found to be significantly associated with retention in care. Women who were initiated on ART in the third trimester were less likely to be retained in care compared to those initiated in the first trimester..

5.2.4 BMI on the last ART refill visit

The study elicited low BMI as an enabler of retention and high BMI as a barrier to ART retention. Contrary to this finding, Thida *et al.* (2014) alluded to low BMI contributing to poor retention in ART care. This could be due to the popular belief in Swaziland that being overweight or obese is a sign of good living resulting in poor retention in ART care. Those with low BMI receive other services such as food by prescription thereby further encouraging them to be retained in care.

5.2.5 Regimen

The recommended first line regimen for pregnant women in Swaziland according to the 2010 WHO PMTCT Guidelines Option A was Zidovudine, Lamivudine and Nevirapine. Consistent with the recommendation, 79.4% of the women initiated on ART were initiated on this regimen. This regimen was significantly associated with retention in care. Similarly, Harries, Zachariah, Lawn and Rosen (2010) highlight consideration of simple, non-toxic ART regimens as key interventions to improve retention in care. This could be further strengthened by availability of the regimen as a fixed drug combination, which is taken once a day. The other available regimens come as dual fixed dose combinations and separate third drug are taken at least twice a day.

Women who had their regimen changed for severe side effects or adverse drug reactions were retained well in care because they received additional counselling on the new regimen. This could also probably mean that those whose ART combination was not changed lost hope and stopped treatment, perhaps thinking they were on an inferior combination Also, prior ART adherence challenges had a statistically significant association with poor retention. Most of the patients who ended up being LTFU had previous episodes of poor adherence. As for the general patients on ART, Makunde *et al.* (2012) highlighted that adherence to ART is an important

aspect for ART programmes to attain retention of patients in ART care. Similarly, the study identified prior adherence challenges as a contributing factor to poor retention in care. The majority, 79.6% of the women with no reported poor adherence were retained in care compared to only 42.6% of those women who reported prior adherence challenges. This could be due to the same factors contributing to both poor adherence and poor retention in care.

5.2.6 Distance to the health facility

Despite the findings from Mozambique showing that long distance travel to healthcare facilities reduce retention on ART (WHO, 2011), distance was found to be non-significant. This could be due to the short distances in Swaziland where only 11.4% of the women were staying more than 16km away from the health facility. However, those women who acknowledged financial challenges at ART initiation had a lower retention than those who had no financial challenges. This association was also statistically significant.

5.2.7 History of smoking and alcohol consumption at ART initiation

Individuals with alcohol and other substance use disorders including cigarette smoking are at increased risk of poor retention in care, poor adherence, and virological failure (Leisegang *et al.*, 2011; Krishnan *et al.*, 2011). Similarly, pregnant women initiated on ART during pregnancy and have a history of either smoking or alcohol consumption were noted to have poor retention.

5.2.8 Documentation and interpretation of the other baseline investigations

Interpretation of documented baseline results such as haemoglobin, liver function and kidney function tests was identified as a determinant of retention in care for pregnant women initiated on ART during pregnancy. Explaining the results to the women could allay all the anxieties about the side effects of ARVs and make the women more confident to persist in care.

5.2.9 Disclosure to partner at ART initiation

Non-disclosure to the partner before ART initiation continues to be a critical barrier to retention at King Sobhuza II PHU. Stigma remains a very serious impediment to long-term retention as those women who did not disclose were more likely to become lost to follow up than those disclosing to their partners. As elicited by the study, disclosure of HIV status by pregnant women

to the partners at ART initiation was significantly associated with retention in ART care. Similarly, studies have shown that disclosure has added public health benefits that include improved uptake of PMTCT services, increased ART use (Waddell & Messeri, 2006) and retention in care (Halperin 2013). The disclosure rates among pregnant women initiated on ART at King Sobhuza II PHU were very low as only 58.3% of the women had disclosed their HIV status by the time of ART initiation. There is need to foster disclosure to partners through counselling and patient education to empower the women to make informed choices that can lead to risk behaviour reduction.

5.2.10 Family planning use after delivery

According to Harries, Zachariah, Lawn and Rosen (2010), the ART programme can be used as an opportunity to improve holistic linkages and provide additional services such as nutritional assessment, counselling and support, and family planning, which in return may encourage better retention in care. The study showed that using family planning had better retention than those not using any family planning. In addition, use of family planning was elucidated as significant factor for retention in care. This then means that family planning counselling should be the mainstay of counselling during the antenatal visits so that they start family planning methods as soon as possible after delivery.

5.2.11 Marital status

The study identified the association between marital status and retention in care. In addition, having the partner who is on ART improved retention in women initiated on ART during pregnancy. This could be due to the psychosocial support from the male partner after ART initiation. According to Hodgson *et al.* (2014), one study found lack of male involvement as a barrier to ART retention and another found it as an enabler.

5.3 Limitations of the study

The study had several limitations. These limitations were mainly related to documentation in the medical records by the facility staff. The PHU ART register had a lot of missing data. However, triangulation of data sources such as the patient's chronic care file and the electronic database

was used. All missing data on the independent variables were documented but not imputed. There was likelihood that the data sets with missing variables could introduce a hidden bias which had a positive or negative effect on the outcomes of interest. To minimise this bias, missing values for both numeric and character variables were explicitly labelled as missing in tables and data listings.

The above mentioned limitations may therefore lead to biased estimates on retention of pregnant women initiated on ART during pregnancy and factors associated with poor retention in care in the PHU cohort.



6 CONCLUSION AND RECOMMENDATIONS

6.1 Conclusions

This study is one of the first of its kind conducted in Swaziland and the findings have provided useful baseline data on the retention rates and some insights into the determinants of retention in care among women initiated on ART during pregnancy at King Sobhuza II PHU. However, further studies are required at National level to support this study.

Poor retention in care can result in negative HIV clinical outcomes such as reduced ART survival rates, increased incidence of opportunistic infections, increased HIV transmission and high possibilities of developing drug resistance. Thus, in view of the individual and public health implications of poor retention in care, these findings indicate an urgent need to improve and sustain high rates of retention in care among women initiated on ART during pregnancy at King Sobhuza II PHU. This may in part be achieved by provision of intensive education and counselling, use of support groups or treatment clubs (Bedelu *et al.*, 2007), strengthening of defaulter tracking systems (Mwatawala *et al.*, 2012; Chalker *et al.*, 2013) and availing retention data as part of routine data in PMTCT and ART programmes. In addition, the findings from this study show that there is need for efforts are to ensure that PLHIV seek ART before their HIV infection progresses to advanced stages.

The study elicited retention rates for women initiated on ART during pregnancy at King Sobhuza II PHU of 83.5%, 79.1%, 76.5%, 73.1% of 6, 12, 24 and 36 months respectively, which are lower than those of the general adult population on ART. According to the Swaziland Ministry of Health (2014), the 6 months retention in care for adults on ART remains high at 96% and the 12, 24 and 36 months retention rates drop to 88%, 82% and 78% respectively. The higher rates retention in care reported in the general population on ART or similar clinical studies in other sub-Saharan African settings point to the feasibility of achieving higher rates of retention in care among women initiated on ART during pregnancy in this setting.

Similarly, in light of the scaling up the ART programme in Swaziland, there is need to not just monitor the rates of retention in among women initiated on ART during pregnancy, but also to identify and address factors contributing to poor retention in care. Addressing the identified factors ensures that the increasing number of patients receiving ART would realise the fully

intended benefits of ART. The study found that the significant risk factors of poor retention in care for women initiated on ART during pregnancy, at ART initiation; age, marital status, ART regimen initiated, disclosure to the partner, EGA, interpretation of other laboratory investigations, partner on ART, history of smoking and alcohol consumption and reporting financial challenges. This means that for any pregnant woman initiating ART the significant factors listed above should indicate the risk of being poorly retained in care. The significant factors on the last ART refill visit include; BMI, changes in regimen, CD4 cell counts trend, any reported poor adherence and family planning use. These factors should also be considered as indicators of poor retention in care whenever the women come for their ART refills.

6.2 Recommendations

Recommendations are provided on monitoring of retention in care and interventions to improve retention in care for women initiating ART during pregnancy. In addition, the recommendations cover specific issues pertaining to pregnant women although they can be applicable to the general population. In accordance to the findings from this study, the following recommendations should be considered when there is need to improve retention in care among women initiated on ART during pregnancy at King Sobhuza II PHU.

- Since use of family planning other than just a condom had a significant association with retention in care, family planning counselling should be provided during pregnancy, in maternity and throughout the breastfeeding period. Furthermore, initiation of contraceptive method with ongoing counselling should be done as soon as recommended. This calls for integration of family planning services in all units initiating ART in pregnant women.
- Women maintaining their ART regimens should receive ongoing structured adherence counselling as they come for their ART refills. Most programmes providing ART provide more counselling to those patients changing regimen. In addition to this group of patients, counselling should be provided even to those patients maintaining their ART regimens.
- The study showed that women with dropping CD4 cell counts were less likely to be retained in care. Therefore, in any PMTCT or ART programme, women with dropping

CD4 cell count and /or unsuppressed viral load should undergo stepped up adherence to improve their retention in care.

- There is need to conduct pill count and calculate adherence percentage in all patients on ART when they come for their ART refills. Those with adherence rates less than 95% should receive remedial counselling for them to maintain optimal adherence and hence be retained in care.
- Disclosure of HIV status to the partner at ART initiation should be encouraged to all pregnant women. Disclosure should be a critical component of post-test and ongoing adherence counselling. In addition, women should be equipped with disclosure skills so that they can easily disclose to their spouses. Awareness programmes should be implemented in male dominated environments to discourage and criminalise domestic violence.
- Since pregnant women with HIV positive partners on ART were retained in care better than those whose partners were HIV positive and not on ART, there is need for intervention to ensure partner testing and initiation of HIV positive partners. Initiatives that prioritise partner testing, couple testing and family testing should be implemented in health facilities.
- Intensive health education and counselling should continue to be provided to women to avoid alcohol consumption and smoking. Centres for alcohol, smoking and drug abuse rehabilitation should be available and accessible with proper referrals and linkages for patients with such problems.
- Efforts should be directed to improve the livelihoods of those acknowledging financial challenges at ART initiation. The Ministry of Social Welfare should be engaged to avail help to such patients so that they can also be retained in care.
- Community mobilisation activities should include messages to encourage women to book their pregnancies early preferably in the first trimester, family planning use after delivery and couple testing during pregnancy. The messages should also be available on Information, Education and Communication (IEC) materials, which include brochures, pamphlets and billboards among others. The mobilisation may also involve the media, newspapers and even the social networks.
- Health care workers especially nurses initiating patients on ART should be trained on

results interpretation since those with documented and interpreted baseline results were more likely to be retained in care.

Retention in care has become an increasing public health problem in low and middle-income countries especially in women initiated on ART during pregnancy. This necessitates the implementation of appropriate public health interventions: provision of intensive education and counselling; use of support groups and treatment clubs; strengthening of defaulter tracking systems and availing retention data as part of routine data in PMTCT and ART programmes.

6.2.1 Strengthening patient tracking systems

To foster retention in care, reliable patient tracking and tracing systems are prerequisites to the identification of patients who have missed visits or are LTFU. This could involve simply putting aside the charts of patients who miss appointments, followed by tracing the patient's whereabouts and facilitating their return to care. Besides tracking patients telephonically, efforts should be made to conduct home visit through the community health workers.

6.2.2 Intensive counselling and patient education

All patients initiated on ART should receive preART counselling and ongoing adherence counselling. Adherence counselling during ART can be routine adherence assessments during ARV therapy and counselling interventions for patients with poor adherence. Information, education and communication (IEC) materials can be used to help women understand the counselling messages. These should be available in the health facilities and should be given to the patients at all visits.

6.2.3 Referral for support groups

Generally, support groups provided peer support for disclosure and members learn from each other's experience. Support groups have been shown to be effective in fostering retention in care in some countries (Bedelu *et al.*, 2007). These support groups could be based on sex, age groups, HIV status or pregnancy status.

6.2.4 Use of treatment clubs

Use of treatment clubs has been shown to improve retention in care. Treatment clubs are groups of patients from the same family or geographical area who take turns to visit the ART centre to

pick ARVs. These initiatives reduce transport costs and at the same time decongesting health facilities whilst promoting retention in care.

6.2.5 Strengthening of patient tracing systems

Tracing mechanisms are needed to ensure that all patients initiated on ART are retained in care. Different strategies have been implemented in different settings. The process involves identification of the patients who have missed appointments, defaulted or become LTFU and tracking patients to bring them back to care. The appointment register can be used as part of the appointment system to identify patients who have missed appointments, defaulted or become LTFU. Different methods can be used to track the identified patients. These include calling telephonically, conducting home visits and the use of community health workers to locate LTFU patients in their communities.

6.2.6 Further studies in Swaziland

Further studies, involving both quantitative and qualitative methods, should be conducted to further investigate the factors that influence retention in care among women initiated on ART during pregnancy in this setting. This will further strengthen retention in care after adoption of lifelong ART for pregnant and lactating women (Option B+ of PMTCT) in Swaziland.

6.2.7 Availing retention in care indicators as routine data

At programme level, there is need to have routine data on retention in care. This helps programmes to monitor different cohorts and identify patients who miss or default appointments and bring them back to care before they are LTFU.

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APPENDICES

Appendix 1: Data abstraction tool

There are three different components used in the data abstraction for this study. The first component is about the patient's demographic and socioeconomic information. The second component is on baseline clinical information. The third component is about clinical information at last ART refill visit and the outcomes in relation to retention in care

Patient ID: _____

No	Question	Response
Demographic and socio-economic status		
1.	Age of patient?	Years: _____
2.	Residence	_____
3.	Distance from KS II	_____ km
4.	What is the patient's highest level of education? (Select one)	None <input type="checkbox"/> (1) Primary <input type="checkbox"/> (2) Secondary <input type="checkbox"/> (3) High school <input type="checkbox"/> (4) Tertiary <input type="checkbox"/> (5)
5.	What is her current marital status? (Select one)	Married <input type="checkbox"/> (1) Single <input type="checkbox"/> (2)
6.	Employment Status	Employed <input type="checkbox"/> (1) Unemployed <input type="checkbox"/> (2)
7.	Parity	_____
8.	Gravida	_____
9.	LNMP	_____
10.	EGA	_____
11.	Rx supporter	Yes <input type="checkbox"/> (1) No <input type="checkbox"/> (2)
12.	Relation to Rx supporter	Husband <input type="checkbox"/> (1) Boyfriend <input type="checkbox"/> (2) Mother <input type="checkbox"/> (3) Sister <input type="checkbox"/> (4) Aunt <input type="checkbox"/> (5) Daughter <input type="checkbox"/> (6) Father <input type="checkbox"/> (7) Other <input type="checkbox"/> (8)
13.	Disclosure to the partner at initiation?	Yes <input type="checkbox"/> (1) No <input type="checkbox"/> (2) Missing <input type="checkbox"/> (3)
14.	Partner status?	Positive <input type="checkbox"/> (1) Unknown <input type="checkbox"/> (2)

No	Question	Response
		Missing <input type="checkbox"/> (3)
15.	Is the partner currently on ART?	Yes <input type="checkbox"/> (1) No <input type="checkbox"/> (2) N/A <input type="checkbox"/> (3) Missing <input type="checkbox"/> (4)
16.	History of alcohol	Yes <input type="checkbox"/> (1) No <input type="checkbox"/> (2) Missing <input type="checkbox"/> (3)
17.	History of smoking	Yes <input type="checkbox"/> (1) No <input type="checkbox"/> (2) Missing <input type="checkbox"/> (3)
18.	Consent to a home visit by RHMs	Yes <input type="checkbox"/> (1) No <input type="checkbox"/> (2)
19.	Financial challenges at initiation	Yes <input type="checkbox"/> (1) No <input type="checkbox"/> (2)
Baseline Clinical Information		
20.	Date of testing Positive	
21.	Weight	
22.	Height	
23.	Consistent Condom Use	Yes <input type="checkbox"/> (1) No <input type="checkbox"/> (2)
24.	CD4 cell count	
25.	Documented and interpreted baselines (Hb, LFTs or KFTs)	Yes <input type="checkbox"/> (1) No <input type="checkbox"/> (2)
26.	Clinical stage at initiation	I <input type="checkbox"/> (1) II <input type="checkbox"/> (2) III <input type="checkbox"/> (3) IV <input type="checkbox"/> (4)
27.	Other co-morbidities	None <input type="checkbox"/> (1) Yes <input type="checkbox"/> (2)
28.	Previous PMTCT	Yes <input type="checkbox"/> (1) No <input type="checkbox"/> (2) N/A <input type="checkbox"/> (3)
29.	ART Start Date	
30.	Regimen	AZT+3TC+NVP <input type="checkbox"/> (1) TDF+3TC+EFV <input type="checkbox"/> (2) TDF+3TC+NVP <input type="checkbox"/> (3)
Clinical Information while on ART		
31.	Number of CD4 cell counts done	
32.	Most recent CD4 cell count	
33.	Date done	
34.	CD4 cell count trend	Going up <input type="checkbox"/> (1) Dropping <input type="checkbox"/> (2) N/a <input type="checkbox"/> (3)
35.	Any reported SEs	Yes <input type="checkbox"/> (1)

No	Question	Response
		No <input type="checkbox"/> (2)
36.	Changes of Regimen	No <input type="checkbox"/> (1) Yes <input type="checkbox"/> (2)
37.	Any reported poor adherence	No <input type="checkbox"/> (1) Yes <input type="checkbox"/> (2)
38.	Problem	
Clinical Information at Last ART Refill Visit		
39.	Last Appointment Date	
40.	Weight	
41.	Nutritional Status	
42.	FP Use other than condom use	None <input type="checkbox"/> (1)
		Oral <input type="checkbox"/> (2)
		Injectable <input type="checkbox"/> (3)
		IUCD <input type="checkbox"/> (4)
		Bilateral tubal ligation <input type="checkbox"/> (5)
		N/A <input type="checkbox"/> (6)
43.	Duration of last Refill	
Outcomes		
44.	Date of delivery	
45.	Retained in Care	Yes <input type="checkbox"/> (1) No <input type="checkbox"/> (2)
46.	If LTFU, timing in relation to date of delivery	Before <input type="checkbox"/> (1) After <input type="checkbox"/> (2)

