Key barriers to antiretroviral (ARV) treatment adherence: Experiences of health care workers (HCW) and antiretroviral therapy (ART) clients in the uThukela district of KwaZulu-Natal

Jabulani Reginald Cele
215068698

Supervisor: Dr Mary van der Riet

Masters of Social Science (Masters by thesis)

School of Applied Human Sciences
Discipline of Psychology

University of KwaZulu-Natal

Declaration

I would like to declare that this dissertation (*Key barriers to antiretroviral (ARV) treatment adherence: Experiences of health care workers (HCW) and antiretroviral therapy (ART) clients in the uThukela district of KwaZulu-Natal*) is my own work and all sources of information have been referenced. I am not aware of any study on the same phenomenon in the same area that may have been submitted for the same purposes at any university or college.

Student Name: Jabulani Reginald Cele
Student Number: 215068698

_____

Signature

_____

Date

Supervisor: Dr Mary van der Riet

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Signature

_____

Date

Acknowledgements

I would like to send volumes of appreciation to Dr Mary van Der Riet, who, without her warm attitude, unshaken support and focus, this work would not have been this rich. Without her, I would not have gone this far. The road has been very tough, but with your support it was doable. Thank you for being available, even in times I would expect it would not be possible. To me, you have been something beyond a supervisor and a mentor. Thank you for that; you came across as an individual with an attitude that makes a scary load approachable and tolerable with joy.

A heartfelt thank you goes to Sister (Sr.) Geetha Ganes Sarjoo firstly for opening the gates of the Injisuthi clinic as the operational manager for the facility through her prompt response with a letter of permission for this study to be conducted at Injisuthi clinic, a clinic that the KZN MEC for Health liked to mention a lot when preparing abstracts for the 2016 world AIDS conference. Secondly, Sr. Ganes provided support that is beyond the words "thank you" when I was in the facility conducting interviews, providing a dedicated space for interviews, to an extent of sacrificing her office when she was out of the facility, just to ensure that I could comfortably conduct interviews without any disturbance in her absence. Sr. Ganes also offered to leave her management seat and 'went down' to be one of the research participants. The road has been tough, but through your kindness it all went well, and I thank you.

T. P. Ngobese: a big word of thank you goes to 'Tholah', a HAST (HIV AIDS STI & TB) counsellor for Injisuthi clinic. She took the enormous task of recruitment of the clients using ARVs upon her shoulders, and ran with it like she was getting paid for it, tirelessly organising the interview space, ensuring that it was confidential and promoted the dignity of the interviewees. She communicated with all the staff, ensuring that the facility personnel were aware that there was a study going on within the facility, and ensured that the next research participant to follow was alerted when to follow when the interview was finished for the previous participant.

I would also like to send a big thank you to Mr Sizwe Zondo who volunteered to provide admin support and be a messenger for this study. He ensured that, in this study, I only had to worry about core issues that related to the details of the study, and he took upon himself

work relating to making copies, and organizing and filling necessary documents while going to the field. He also ensured that there were enough money, pamphlets and leaflets for the researcher to distribute to the research participants, prior to departure to the research field.

To Dr M. T. Zulu, the district director for uThukela health district, who made it possible for this study to be conducted within the health district under her directorship. She opened wide the gates for this study to be conducted, and threw in some necessary advice where needed, as well as support that is worth recognition. She was able to respond and coordinate that a letter of support for this study reached my hands within a week's time upon her awareness of this study, while she was out of the office.

Matron T. S. Hlongwa, who within two days after hearing about my intention to conduct this study in a facility that was under her management, made sure that I got a letter of support within a period of two days. This happened within her very tight schedule, since she had her duties, plus an action position as a CEO. On top of these, here I was asking her to provide me a letter of support as per the district director's advice. Above all that, within two days, the letter of support was in my e-mail box. For that I thank you very much, since that was the last critical step for me towards going to Injisuthi clinic for data collection.

Mr Sizwe A. Coka always travelled an extra mile and assumed a role of an emergency consultant when I was desperately in need of computer technology support, even late at night, when the computer started to became a barrier. He never got tired of me, and, where necessary, he would even drive to wherever I was to provide support so that I could continue writing.

A gesture of gratitude also goes to Ms I. L. Nyembe, uThukela district ARV coordinator, who has always been willing to answer any question relating to ARVs, in support to this study. This sometimes happened even in informal consultations, in the parking in front of the shops, on social media or over the phone. Through your years of experience working on ARV programs and expertise, I went through this with confidence.

Mrs J. L. Lubanga, uThukela health district pharmacy manager, who supported me with all the necessary pharmacological information and provided me necessary references in any

need that arose. Moreover, Mrs Lubanga would answer and attend to any question with a great demonstration of burning passion when I would have stopped her on her way rushing to somewhere to ask any ARV treatment-related question. For that, I would really, from the bottom of my heart, like to thank you.

I would like to thank the three community care givers (CCGs) who participated fully in this study as research participants, while they came to the clinic for their reports. When they were asked to participate in the study, without any reservations, they participated. Their years of experience in supporting patients living with HIV at a community level brought some valuable and insightful information into this study.

I would like to thank all three Injisuthi counsellors who participated in this study, your participation and openness in sharing information from your experience brought some tremendous light into this study. Your willingness and eagerness to share information and selfless participation in this study are highly appreciated.

To the three Injisuthi professional nurses who participated in the study, you may not be aware of the level of the height and length of the value of the light in the information you shared. This contributed and made a strong pillar of the insight built around the human behaviour in relation to the use of ARVs. You have made me think the MEC for Health, Dr Dlomo, was correct in many aspects when saying: Without nurses with ARVs, we would not be where we are in the province.

To all Injisuthi clinic staff who showed an understanding and cooperated in all aspects to ensure that interview processes conducted in their clinic ran smoothly, I thank you all for your cooperation, noticed and unseen.

And last but not least I would like to send a heartfelt big thank you to the five research participants who are using ARVs. You responded positively and shared as far and as deep as you could, though you became aware of this at a very short notice. What you have shared will contribute a lot in the struggle against AIDS.

Thank you Vivien ‘Viv’ Carol O’Neill for your wonderful work in editing this.

Dedication

It would only serve as some relief for me to dedicate this to a person who gave me courage and passion to work with people living with HIV: my late sister, Khanyisile Sweetness Cele, who slipped away, through HIV/AIDS, during the national roll out of ART, on the 27th of April 2004.

It would be sober too, to dedicate this to all the people from all walks of life who are living with HIV, especially in South Africa. I hope it is not too long before an HIV-positive individual will lead a normal life without fear of death and anxiety.

Abstract

In the fight against HIV and AIDS, the world managed to put more than 17 million people on anti-retroviral treatment (ART) in 2016. More than three million of the people on ART are in South Africa, and more than one million of them are in KwaZulu-Natal. South Africa is the epicentre of HIV and AIDS and has adopted the United Nations' (UN) 90 90 90 strategy to end AIDS and the World Health Organization's (WHO) Universal Test and Treat Policy for people living with HIV. All this could be challenged by the level of adherence to treatment by the individuals put on antiretroviral (ARVs). This study sought to identify barriers to adherence for people using ARVs in a rural area in South Africa.

The main aim of this study was to identify key barriers that make HIV-positive people who are using ARVs fail on ART. In total, 14 research participants were purposefully sampled and interviewed using semi-structured questions. Of the 14 research participants, five were clients who are on ARVs (two men and three women), three facility lay counsellors, three facility community care givers (CCGs) and three Nurse Initiated and Management of Antiretroviral Therapy (NIMART) nurses.

Data from interviews were analysed using thematic analysis to identify barriers to adherence for ART. In this study, 12 barriers to adherence for Injisuthi clients who were using ARVs were identified. The barriers identified included: 1) side effects, 2) pill burden, 3) no improvement while on ART, 4) use of alternative (traditional) medicine, 5) improved health, 6) communication with health care workers, 7) practical problems/socio-economic issues (poverty), 8) mobility and migration labour, 9) gender and social organisation (masculinity), 10) stigma and discrimination leading to fear of disclosure, 11) lack of community support, and 12) service delivery.

In the rural context, it is critical for improved adherence to ART to establish interventions that tackle socio-economic, stigma and gender issues, together with providing appropriate continuous psychosocial support for clients using ARVs when they complain about side effects and pill burden.

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Chapter 1: Introduction

Three and a half decades have passed since AIDS (Acquired Immune Deficiency Syndrome) was discovered in the summer of 1981. At almost every corner, AIDS was met with fear of death, since there was no cure. According to van Dyk (2011), it was only in 1987 that the first antiretroviral drug was approved to treat the HIV (Human Immunodeficiency Virus), a virus that leads to the AIDS condition if left untreated. That breakthrough was then, however, met with resistance from the virus (HIV), as it mutated. Endeavours continued to make treatment for HIV better until a set of three drugs was developed to treat HIV; this was called Highly Active Antiretroviral Therapy (HAART). According to van Dyk (2011), HAART was introduced in 1995, but in South Africa the use of HAART only commenced in March 2004, in the Gauteng province, followed by a nationwide rollout in April of the same year.

In 2016, the whole world celebrated meeting a target of 15 million people initiated on ART. In the event, this target was exceeded by over two million, since there were more than 17 million people initiated on ART by 2016. In South Africa, there were more than 3.5 million people initiated on ART in 2016, while KwaZulu-Natal celebrated reaching a target of putting over one million people on ART, which is the highest number ever seen on ART in the country among all the provinces. This made KwaZulu-Natal the only province in the country with more than a million people on ARVs. This also shows that KwaZulu-Natal is the province with the most people living with HIV in South Africa.

Policies have been changed globally and locally to allow more and more people to be put on antiretroviral treatment and new targets are being set. The World Health Organisation (WHO) devised a policy called 90 90 90 which identified specific targets for countries to adopt. This means countries have to ensure that 90% of the people living with HIV know that they are living with HIV; put 90% of the individuals living with HIV on ARVs; and ensure that 90% of those on ARVs adhere to treatment to have their viral loads suppressed. In 2016, criteria to put individuals on ART improved to accommodate every individual living with HIV, and this is known as the Universal Test and Treat policy (UTT) policy (NDoH, 2016a). Starting all individuals who are living with HIV on ART regardless of their CD4 count is a recommendation by the WHO Guidelines on ART. According to the WHO *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection* (2015,

p. 6), “efforts should be made to reduce the time between diagnosis and ART initiation to improve health outcomes”. Starting all HIV-positive individuals on ARVs is seen as contributing to improving health outcomes, thus reducing mortality and improving life.

However, the main threat to the success of the use of ART to control HIV and to curb AIDS is how people use ARVs. Taking the lessons learned from tuberculosis (TB), which is curable, one will see that the misuse of TB treatment led to resistant types of TB and, consequently, TB is still the number one cause of death in the country (Statistics South Africa, 2017). This is the case in uThukela District (health plan) as well (UThukela District Health, 2014). Most of the resistant strains of TB have resulted from poor adherence to TB treatment.

With ARV treatment, there are also people who used ARVs but failed on them and were changed onto a second set of pills which are said to be less tolerable and more expensive (WHO, 2011). This shows that taking ARVs is not just a smooth journey for individuals using them. The taking of pills is not what people do under normal circumstances. People have to start taking pills daily because of the need to control their HIV, which means a change in their normal day-to-day behaviour. To make that change of behaviour to accommodate taking of pills is difficult, and there are a numerous barriers to taking ARV treatment.

This study explored the barriers that are hindering taking of ARVs by people who are living with HIV in the rural setting of Injisuthi clinic in the uThukela district in the province of KwaZulu-Natal. To achieve this, this study examined the experiences of clients who used ART and failed on the first-line regimen, and the experiences of the health care workers who support them (nurses, lay counsellors and community care givers).

Chapter 2: Literature review

2.1 Introduction

This chapter looks at the burden of HIV in South Africa and provides motivation for this study on adherence in the uThukela district of KwaZulu-Natal. This chapter also looks at the goals of ART in light of how far the country has travelled towards meeting these goals. The state of adherence in the country is attended to through looking at the policies and strategies that were supporting adherence previously, as well as the current strategies and policies.

Some of the frameworks on barriers to adherence are explained, interrogated and compared with each other. The Department of Health (DoH) national adherence guidelines (NDoH, 2016b) are also used since they also contain a list of barriers to adherence to TB/HIV and the treatment of non-communicable diseases. How the current theories are falling short in giving specific information about barriers to adherence at a local level will also be discussed.

2.2 Burden of HIV

More than 36 million people in the world are living with HIV (UNAIDS, 2016). While AIDS was first discovered in the United States of America, its weight has been resting on Africa, especially sub-Saharan Africa and more specifically on South Africa. In the ranking of the top ten countries in terms of HIV prevalence, South Africa is leading, contributing 18% to the world's people living with HIV, followed by Nigeria at 9% and India third, contributing 6% (Piot et al., 2015). In South Africa, the Human Sciences Research Council (HSRC) has reported the national prevalence to be at 12.2% (HSRC, 2014), and KwaZulu-Natal has been leading among the nine provinces of South Africa (UNAIDS, 2013). The KwaZulu-Natal Department of Health (KZNDoH) reported HIV prevalence at 16.9% in 2016 (KZNDoH, 2016b). According to the antenatal sentinel surveillance report (NDoH, 2013), the uThukela district within KwaZulu-Natal (KZN) had an HIV prevalence of 46% in 2009, a prevalence never seen anywhere else in the world. This report also indicates that there has been a drop from 46% to 40% in the prevalence in this district in 2013. However, the uThukela district still remains one of the districts with the highest prevalence of HIV in the province of KwaZulu-Natal.

Given the burden of HIV in the country, South Africa is at the forefront of the fight against the AIDS disease. South Africa should therefore demonstrate leadership coming from insight gained from local studies that are conducted from within the country. This might provide hope for better control and management of the epidemic.

2.3 Antiretroviral therapy

The main goal of antiretroviral therapy (ART) is to control HIV. Since its discovery, HIV has been a life-threatening virus that has been known to cause AIDS and eventually death. Until the discovery of treatment to control HIV, there was no hope for people with this infection. HIV replicates itself within the human body while destroying its key defence mechanism, thereby exposing the infected individual to other infections. With the discovery of treatment, some hope was restored for people who are both infected and affected by the virus. The Southern African HIV Clinicians Society (Maartens, Venter, Meintjes & Cohen, 2008) identified four main primary goals for antiretroviral therapy: 1) the improvement of quality of life, 2) reduction of HIV-related morbidity and mortality, 3) maximal and durable suppression of viral load, and 4) restoration and/or preservation of immunological function. However this may be threatened by inability to adhere to ART. Van Dyk comments that "only 40% of the respondents were able to reach the optimum adherence level of 90% or above" (van Dyk, 2010, p. 235).

2.3.1 Improvement of quality of life

Before the introduction of ART in South Africa, HIV and AIDS meant getting very ill, experiencing despair, fear and a sense of doom, and eventually death. A decision to make ART accessible to individuals living with HIV renewed hope and improved the quality of health care, since it meant that HIV could now be managed. There has been a dramatic improvement in the quality of life of those with HIV since the introduction of ART. Even the transmission of HIV has been reported to be in decline. According to the *Global AIDS report* (UNAIDS, 2013, p. 12), studies have provided evidence that "antiretroviral therapies can reduce the risk of HIV transmission by as much as 96%". The South African National Department of Health on its ART Universal Test and Treat (UTT) fact sheet (NDoH, 2016a) indicates that putting HIV-positive people on ART improved general life expectancy in South Africa in 2011 by three years for men (from 54 to 57.2) and by five years (from 55.5 to 62.8) years for women. The impact of ARVs on improving the duration of life is clear.

2.3.2 Reduction of HIV-related morbidity and mortality

Rolling out of ARVs in the world has changed the picture of HIV infection from that of inevitable death to a chronic and manageable disease. There has been a 43% global decline in AIDS-related deaths from 2003 to 2016. In the Southern and Eastern African regions, AIDS-related deaths have been reported to have been reduced by 36% (UNAIDS, 2016). There is hope that if ARVs are used correctly, the world will be in a position to put an end to AIDS, hence the ambitious 90 90 90 strategy as 'a call to end AIDS' (UNAIDS, 2013). Van Dyk (2011) comments that the impact of the inaccessibility of ART is seen in the estimated loss of about 330 000 lives in South Africa in about three years prior to the national public rollout of ART. In the UTT fact sheet, the South African Department of Health claims that the breadwinners and parents living with HIV are now able to lead their lives free of the fear of death and of leaving behind their children as orphans (NDoH, 2016a).

If ARVs are used correctly, countries are in a better position to reduce HIV-related illnesses (morbidity) and deaths (mortality). This is even more critical for countries that are carrying the burden of HIV such as South Africa. ARVs could help reduce AIDS and deaths, if used correctly, meaning proper adherence by those who are put on ART programmes. If the clients who are put on ARV treatment adhere, the virus could be suppressed, and the third 90 of the 90 90 90 goals could be met.

2.3.3 Maximum and long-term suppression of viral load

The third 90 of the UNAIDS '90 90 90 by 2020' goals urges countries to ensure that at least 90% of the clients who are taking ARVs should have an undetectable HIV viral load (UNAIDS, 2014). However, when one looks at what people usually do when they are put on treatment, it becomes hard to determine how the third 90% goal is going to be achieved. The majority of people fail to complete a seven-day treatment course of antibiotics despite the message written on the box encouraging them to "finish the course". What people do is critical when it comes to the use of medicine to control viruses, bacteria, and parasites (van Dyk, 2011). Van Dyk (2011) comments that when using antimicrobial drugs to control viruses, bacteria and parasites, one of two things will happen – the microbes will either die or adapt.

TB treatment has become less effective over time, and it is important for that not to happen with HIV treatment. While TB is easily curable compared to HIV, it has adapted to treatment and remains the number one killer in the country (Statistics South Africa, 2015). ARV treatment reduces HIV viral load. Viral load suppression is expected to curb HIV transmission. We have seen this in the reduction of mother-to-child transmission (MTCT) of HIV. According to Montaner (2011), sustained optimum ART could reduce HIV transmissions and thus reduce HIV incidence in a country. Putting more people on treatment is a strategy to tackle HIV transmission in communities through suppressing HIV viral loads at a community level (van Dyk, 2011). This strategy is echoed in the South African government's UTT fact sheet (2016a). When more people are put on treatment, it suppresses the community viral load. One of the major contributory factors to viral load suppression is adherence to ART. In 2016, the Department of Health added another goal of ART: the prevention of HIV transmission. The Department of Health saw the benefit in suppressing the communal viral load by ARVs as part of preventing the spread of HIV (van Dyk, 2011).

2.3.4 ARVs and the restoration of immunological function

HIV is known as a virus that damages the immune system, thus opening the gates for opportunistic infections and leading to AIDS. ARVs are known to suppress viral replication (or the self-multiplication) of HIV. If HIV is stopped from multiplying while destroying cells that are crucial to the functioning of the immune system, known as CD4 cells, this allows the immune system an opportunity to recover if it has been already damaged.

2.4 South Africa's ARV programme

Treatment of HIV by using ARVs is an important intervention that does more than controlling HIV in an infected individual. It has been pointed out that "HIV treatment is a unique tool in the AIDS response, preventing illness and death, averting new infections and saving money" (UNAIDS, 2014, p. 3). Since ARVs are one of the key interventions in the fight against AIDS, more and more individuals who are living with HIV are being put on ART. South Africa has the largest number of people living with HIV in the world and the largest ARV programme in the whole world. According the *Global AIDS update* (UNAIDS, 2016), the world is reported to have 17 million people on antiretroviral therapy and three million of these people are in South Africa. This makes South Africa number one in terms of the number of people on ART. Out of over three million people who are on ART in South

Africa, the province of KwaZulu-Natal is leading amongst other provinces. In 2016, KwaZulu-Natal had more than a million people on ARVs.

ARVs are used in South Africa, like elsewhere in the world, as a means to control HIV spread from the infected individuals. ARVs are also used in South Africa to prevent further spread of HIV in four ways. Firstly, ARVs are given to pregnant HIV-positive women to prevent HIV being transmitted from the pregnant mother to her unborn child. Secondly, they are given within 72 hours to anyone who may have had an unintended exposure to HIV, as a means to prevent HIV replication and infection after the incident, regardless of the situation (NDoH, 2016a). This is known as post-exposure prophylaxis (PEP). Thirdly, ARVs are given to the most vulnerable groups, such as sex workers, prior to exposure to HIV. This is done to prevent infection by HIV, where an HIV-negative individual is given ARVs for a certain period of time before he/she gets exposed to HIV. This is known as pre-exposure prophylaxis (PrEP) (NDoH, 2016c). Lastly, ARVs are now given to all individuals who test positive for HIV. This comes from the knowledge that, in the presence of ARVs, replication of HIV in the body of an infected individual becomes suppressed. This will lead to an infected individual having a very low HIV viral load.

However, to achieve this low level of virus in the body of an infected individual, one needs to adhere to taking ARVs as prescribed. This means taking ARVs every day, at the specific times. If the viral load is low or at a level known as an undetectable viral load, there is a very slim chance of infecting others with HIV. Now the government is putting every HIV-positive individual on ARVs regardless of their CD4 count in the hope of controlling the further spread of HIV (NDoH, 2016a). In this strategy, individuals are expected to start treatment (ART) immediately after they are discovered to be HIV positive. For this programme to be successful, it will need the individuals to adhere to the treatment given to them.

2.5 ARV adherence

Adherence is defined by van Dyk (2013, p. 493) as "tak[ing] every dose of medication strictly as prescribed". While the country is doing well in initiating HIV-positive clients on ARVs, there is a need to ensure that the individuals on ARVs are adhering to ART. This is very important to avoid the mutation and resistance of the HI virus. According to the 90 90 90 targets, the second 90 is about ensuring that 90% of the people who have discovered that

they have HIV are initiated on ART. The third 90 focuses on ensuring that the viral load of those who are put on ART is suppressed (UNAIDS, 2014).

Adherence plays a vital role in viral load suppression. According to Kgasi (2017, p. 3), "[v]irological failure is almost always related to poor adherence". It is hard to ensure that people who are using treatment are continuing to do so, in order to be certain that a desired level of viral load suppression will be attained. While there is a need to focus more on long-term adherence (WHO, 2015), the National Department of Health has been observing a decline of 'retention in care' for the clients who are using antiretroviral therapy, with low rates of adherence to ARVs, of only 35% in adults at 48 months (NDoH, 2016b). If the viral load suppression is currently at 35%, it means there is a long way to go in order to reach the goal of a 90% viral load suppression. One of the most important aspects for achieving viral load suppression is adherence to ART. This also means that, of the people who are using ARVs in South Africa, about 65% of them are *not* adhering to their treatment. If viral load is not suppressed, there are also increased chances that the HI virus will adapt and be able to continue multiplying itself in the presence of ARVs. When this happens, there is a risk of spreading that resistant strain of the virus to others in the country.

The South African Department of Health is currently changing policies around how HIV is managed in the country. These changes include the implementation of a new strategy for adherence, with improvements in HIV testing services (NDoH, 2016b) and ensuring that HIV-positive clients are initiated on ARVs without being delayed by the ARV literacy classes (NDoH, 2014b).

2.6 A need for adherence to ART

Even though ART clients are not expected to adhere 100%, there is an expected degree of adherence in order to achieve better treatment outcome. According to Nsimba, Irunde and Comoro (2007, p. 1), a "'[n]ear-perfect adherence' should be defined as 95% and above adherence". Studies have so far shown contrasting findings on the state of adherence in the sub-Saharan region. According to Mills, Nachega, Buchan et al. (2006, cited in Watt et al, 2009, p. 1794)

> Initially, findings about adherence to ART regimens in sub-Saharan Africa have been promising. A meta-analysis found that a pooled estimate of 77% of patients in African settings achieved adequate adherence (most often measured as taking 95% of prescribed pills), compared with just 55% of patients in North American settings.

On the other hand, in her study on clients on ART since the rollout of the ART programme in South Africa in 2004, van Dyk (2011, p. 121) discovered that only 40.1% of the clients "attained a 90% level of adherence, which is an ideal level of adherence required for treatment success". In the context of HIV and AIDS in South Africa, adherence remains a pillar of HIV and AIDS control. Van Dyk's findings seems to be in line with the *Global report* (UNAIDS, 2013) which demonstrates that in terms of HIV viral load suppression, which is an outcome of good adherence, sub-Saharan Africa is only at 29%, which leaves 71% of people with an HIV level that is not suppressed. Since sub-Saharan Africa is the region with the highest HIV prevalence in the world, and KwaZulu-Natal has the highest prevalence in the country, this creates a particular problem in dealing with HIV. If adherence is not addressed, the control of HIV in South Africa as a whole could be seriously affected, since poor "treatment adherence has been closely correlated with viral suppression, while non-adherence has contributed to progression to AIDS, the development of multidrug resistance, and death" (Weiser et al., 2003, p. 282).

One more problem could be the development and spread of a resistant strain of HIV as is currently the case with tuberculosis (TB). Studies have demonstrated that lack of adherence can lead to the spread of resistant strains of HIV, treatment failure, more opportunistic infections for people that are living with HIV, and ultimately an increase in the death rate in the country (Kagee, Swartz & Swartz, 2013). If there is poor adherence to ART, it means that the HI virus may get a chance to adapt and replicate itself in the presence of ARVs. Once this happens, it means that the virus will start replicating itself regardless of the presence of sufficient ARVs.

While adherence to treatment has recently been given more attention, there is still more to learn if we are to provide relevant support for people living with HIV. As a country (South Africa), we have a very limited choice when it comes to controlling HIV/AIDS. The Department of Health and other institutions that are giving ARVs to people living with HIV are enrolling individuals into ARV programmes with the hope that they will do as they are

told. Van Dyk (2010, p. 244) states that "it is of utmost importance that our 'access to all' ARV campaigns also include an 'adherence by all' component in order to avoid the serious health problems we are currently facing in Africa with extreme drug-resistant tuberculosis, for example". The reality is that, in most cases, treatment does not go according to the plan of the clinicians. ARV users try, but various barriers prevent them from sticking to the plan proposed by the clinicians.

2.6.1 The use of literacy classes to promote adherence to ART

From 2004, when ARVs were rolled out widely in South Africa, there used to be ARV literacy classes. This was done because of a belief that, if users of ARVs are educated about the medicine they are taking, adherence to treatment may be better. ARV literacy classes comprised three sessions that were attended by the clients who had tested HIV positive before embarking on their treatment. These classes used to be a prerequisite for ARV initiation for clients living with HIV. They empowered clients with, among other things, knowledge about HIV, dealing with issues of disclosure, dealing with stigma, dealing with side effects, dealing with opportunistic infections and strategies to adhere to ARV treatment.

Since 2014, there have been changes to this educational support for people who need treatment. The new guidelines stated that these classes are no longer a prerequisite before starting ARVs, but could rather run concurrently with the taking of ARVs (NDoH, 2014b). Van Dyk (2011) says that education in a group or individual form is important for treatment adherence. For now, however, clients who test HIV positive are put on ARVs without the information they would have received from these classes. It is hoped that they will get such information along the way, as they carry on with taking their treatment.

2.6.2 HIV pre-test counselling

From 1998 to 2016, there used to be an extensive pre-test counselling process in the Department of Health to establish some level of readiness prior to testing for HIV. This is no longer recommended by the Department of Health (NDoH, 2016c). This means that since 2016, clients testing for HIV could be tested without pre-test counselling, this if they have attended a group information session and seem not to have any concerns before testing. These guidelines recommend that provision of information in a group setting is sufficient for a client to be tested for HIV. Extensive counselling is only requisite as post-test counselling,

that is, after the client has tested. However, this might be affected by the emotional response to the HIV test results. In a case where a person tests positive, it may not be a good time to bombard that person with information that is important for him/her to adhere to treatment.

In pre-test counselling, a person used to get enough information that could support him/her to live with HIV. Now with the current lack of emphasis on pre-test counselling, this opportunity to prepare a person for adherence is taken away. This means that many people are currently put on ARVs, with scanty or no psychosocial preparedness. This is also worsened by taking away the three ARV literacy classes that have been referred to above. Removing both literacy classes and pre-test counselling, combined with a very short period before a person is expected to start treatment (i.e. same day after testing HIV positive), may negatively affect later adherence.

2.6.3 New adherence guidelines of 2016

The South African adherence guidelines (NDoH, 2016b) provide guidance on what is supposed to be done from when a person is discovered to be living with HIV until he/she is given treatment. When the person has been enrolled to take chronic medication, he/she is expected to take his/her treatment from the clinic and be seen by a clinician monthly for a period of six to 12 months. If a person using ARVs has taken the medication correctly, and appears to be doing well on ARVs or any other chronic medication, he/she is given an opportunity to choose one of three methods of getting their medication that are thought to be much easier.

The new South African adherence guidelines seem to be dealing with a barrier that relates to ARV clients accessing ARVs. These guidelines specify three ways in which clients may access their treatment easily. The first one is called ‘spaced fast lane’. This means that the clients can now take their ARVs straight from the clinic pharmacy, without joining any queues and without seeing a clinician for a period of about six months. The second one involves the ‘adherence clubs’. Adherence clubs are run by a community care giver (CCG) who is expected to bring medicine from the clinic to the community for all chronic illnesses for people who were registered for this programme. The CCG or adherence club facilitator would bring their pre-packed medication and provide health education. These clubs are expected to meet once in two months. This method allows the clients using ARVs to access

their ARVs in the communities where they live, without any need for them to travel to the clinic to collect their medication. They can get a two-month supply in order to limit the number of trips it takes to access their treatment. Within these adherence clubs there is health education, but the guidelines have limited details about what exactly needs to be done within the adherence clubs to enhance adherence.

The third strategy is the use of 'pick-up points'. This allows stable clients on ART and on other chronic medication to access their medication from an accredited (approved) pick-up point of their choice (NDoH, 2016ba). A pick-up point could be any place that has been assessed and seen as qualifying to store medication, taking account of the safety of the medication and that of the clients who would be accessing their medication from that particular pick-up point. In all these three methods, there is an ease of access to treatment, which addresses some of the barriers to adherence. However, there are some barriers that are minimally or not at all addressed by this national adherence strategy. A number of barriers that have been identified and may not have been addressed by the national adherence guidelines are provided in the discussion below.

2.7 Barriers to adherence

In order for one to support people who are HIV positive and using ARVs to control it and live healthily, one would need to understand the factors that prevent them from adhering to their treatment. There is a need to understand how people come to fail on their therapy. Before developing interventions to support people on therapy, one needs to gain a deeper understanding of barriers to adherence. A number of studies about barriers to adherence are summarised in Table 1 below. This information will be merged with van Dyk's (2013) framework of barriers to adherence to form an overarching framework. Although barriers to adherence have been given attention, there is still inadequate information about what makes people fail on ARVs in various contexts. For instance, there are hardly any studies conducted in the province of KwaZulu-Natal about barriers to adherence

2.7.1 Van Dyk's (2013) framework of barriers to adherence

Barriers to adherence have been proposed, categorised and ranked in various studies. In the literature, barriers vary, perhaps due to context. The framework of barriers to adherence that will be used for this study is adapted from research conducted in South Africa in 2011 by van

Dyk (van Dyk, 2013). Van Dyk (2013) identified barriers to adherence and classified them into eight main barriers: 1) psychosocial or person-centred barriers, 2) practical problems, 3) relationship between client and health care worker, 4) medication-related barriers, 5) service delivery-related barriers, 6) stigma, 7) health control, and 8) cultural aspects. In this listing, the numbering has no value for frequency of the barriers; therefore, it does not mean that the barrier labelled as number 1, is more dominant than any other.

To compensate for issues that may not have been covered by van Dyk, barriers from a cardio-vascular therapy framework are included. As much as this framework focuses on a different health issue, it provides a comprehensive framework of barriers to adherence. According to the National Heart Foundation of Australia (2011), barriers to medicine adherence and treatment strategies can be categorised into five issues: 1) condition-related, 2) therapy-related, 3) patient-related (intentional), 4) patient-related (unintentional), and 5) social or economic factor issues.

Most of the barriers identified above also appear in the South African adherence guidelines for HIV, TB and non-communicable diseases (NCD) (NDoH, 2016b) as barriers to linkage, adherence and retention in care. In these guidelines, barriers to adherence are classified into three main categories, which are: 1) patient-related, 2) provider-related, and 3) structural barriers. The three main categories also have their own sub-categories. Most of the issues mentioned under these guidelines match the issues mentioned above. A summary of the barriers is provided in Table 1, after the barriers from a variety of studies have been discussed. Frameworks from other studies will later be merged to form a single framework (see Table 2), which will be used to interpret the results from this study.

2.7.1.1 Psycho-social or person-centred barriers

Van Dyk (2013) understood *psychosocial or person-centred barriers* to relate mostly to what a person does when on ART. According to van Dyk (2013), psychosocial or person-centred barriers include forgetting (to take the medication); treatment fatigue; alcohol abuse; sharing ARVs; having no intention to adhere; poor support; and failure to disclose.

Forgetting to take treatment may be aggravated by substance abuse. Van Dyk (2011) comments that 21% of the ARV users who defaulted claimed that they forgot to take their treatment when they *used alcohol*. Under this category, van Dyk (2013) also mentioned

sharing of ARVs as a threat to adherence. ARVs are distributed such that they are enough to cover an individual patient for a month. This means that when ARVs are shared with a friend, partner, or anyone else, for any reason, they will be insufficient to cover the person who is sharing them for the whole month.

Van Dyk (2013) also mentioned that *lack of support* from significant others is one of the challenges that affects adherence for people on ART. *Treatment fatigue* could mean that some individuals may stop taking ARVs just because they are tired of doing so. Van Dyk's (2013) framework also mentions *lack of intention* to use ARVs by the client. This may be the case where a person living with HIV may have been pressured to do so either by the health care worker or a family member. *Failure to disclose* because of stigma and fear of discrimination is dealt with in more detail in the section about stigma below.

The cardiovascular framework (National Heart Foundation of Australia, 2011) on the barriers to adherence expands this concept of person-centred barriers. In this framework, this barrier is split into two sub-categories, in which the intention of the person on therapy is considered (i.e. intentional or unintentional) (National Heart Foundation of Australia, 2011). According to this framework, *patient-related intentional* barriers can be sub-categorised into lack of symptoms; perceived side effects; rejection of diagnosis; not understanding the importance of medicines; interpersonal skills; loss of faith in medicines; and costs and burden of therapeutic regimen medicines (National Heart Foundation of Australia, 2011). However, some of the sub-barriers mentioned under person-centred in the cardiovascular framework (National Heart Foundation of Australia, 2011) fit very well into other of van Dyk's (2013) barriers to adherence and they will be dealt with as complementary in those barriers.

Lack of symptoms in this framework is referring to the situation when a client feels well and therefore thinks there is no need for medicine. In this category, the patient believes that, for instance, high blood pressure is not as serious as the clinicians say, since the client sees no symptoms. As most people take treatment because they want to see symptoms disappear, if there are no more symptoms, it could be easy for them to just forget and eventually stop taking treatment. Alternately, when the symptoms have disappeared because of the medication, clients may be tempted to stop medication, for they may now be feeling well.

Perceived side effects, according to this theory, could be a barrier to adherence. This National Heart Foundation of Australia (2011) framework lists factors that may influence the client's perceptions such as media reports, belief that there will be side effects because the clinicians talked about them, experiences of side effects from other medications, misinterpretation of symptoms as side effects, patients insisting that the treatment they are taking is causing side effects, and incorrect interpretation of the consumer medicine information (CMI). With ARVs, almost all of these could be applicable. For clients, it could be easy to misinterpret the CMI because of illiteracy, and that information may be provided in a language that is not the client's home language. In addition, often the information is provided using medical and pharmacological jargon. Clients might therefore find it difficult to follow instructions and information provided in the packaging material of the medication.

The *rejection of diagnosis* is seen as a barrier to adherence in the cardiovascular barriers to medicine theory. This also relates to clients who are undergoing ART. Clients who are diagnosed with HIV, in most cases may deny the fact that they are living with the virus. According to the theory of the stages of grief by Dr. Elizabeth Kübler-Ross, denial and shock are part of the common reactions when one is experiencing loss. These are mentioned as part of the stages toward acceptance of loss or diagnosis (van Dyk, 2013). If one is in denial or is rejecting the fact that one has been diagnosed with HIV, there may be a chance that one might reject anything that is associated with the diagnosis. Therefore, this may lead to poor adherence.

Loss of faith in medicines comes when the clients start feeling that the medicine is doing too little to improve their health condition. This may work in support of the above-mentioned barrier (i.e. *not understanding the importance of medicines*). If the client is not aware of the importance of taking the medicine, it is easy to lose faith in the medicine and try other alternatives. For example, if clients continue to see symptoms while taking the medication, there are chances that their faith in the medication may be lost and they may perceive the medication as not working.

Many issues in the cardiovascular framework (National Heart Foundation of Australia, 2011) overlap with issues mentioned by van Dyk (2013). However, some of the overlapping issues are discussed under this heading for comparison purposes.

2.7.1.2 Practical problems and challenges

In the van Dyk (2013) framework, *practical problems and challenges* include such things as transport to the clinic, not having food with which to take the ARVs, robbery (e.g. losing the whole month's supply through this), working shifts, and failure to keep enough supply of ARVs when not going to be at home during time for treatment. These barriers relate to a set of barriers identified in another study conducted in South Africa. Thus, Knight, van Zyl, Sanne, Basset and van Rie (2015) also identified leaving the house without tablets, running out of tablets between visits, and lack of transport money as some of the eight reasons they identified for sub-optimal adherence to ARV medication. The mention of transport to the clinic is not specific in van Dyk (2013). However, Knight et al. (2015) indicate that lack of transport money could be a barrier to adherence for individuals on ART.

2.7.1.3 Relationship between client and health care worker

According to van Dyk (2013), problems in terms of *relationship between client and health care worker* may include lack of support and poor sharing of information with clients (e.g. viral load and CD4 count results) so that clients will know when they are doing well (or not) and relate this to their previous adherence. An issue about *sub-optimal skills of the health care professional* is emphasised as a barrier to adherence in the cardiovascular framework of barriers to adherence (National Heart Foundation of Australia, 2011). However, in their classification of barriers, this is listed under socio-economic barriers. The communication skills of the health care practitioner are very important when dealing with clients who are expected to adhere to treatment for a very long time.

Both van Dyk (2013) and the National Heart Foundation of Australia (2011) found that the relationship between client and health care worker could negatively affect adherence to treatment. However, this seems to be based more on poor communication skills from the care worker's side. Under *patient-related: intentional* barriers, the cardiovascular framework (National Heart Foundation of Australia, 2011) refers to the interpersonal skills of a patient. According to the cardiovascular framework, interpersonal skills could be a barrier in a situation where the client fails to communicate how he or she understands and experiences his/her condition to the clinician who prescribes the medication. This could be because the client does not want to offend the clinician or because of a language barrier.

These two aspects together may leave the client not wanting to go back to the health facility and they therefore become a 'loss to follow-up case' in the health care system. A loss to follow-up case, according to the National Department of Health, is a phrase used to describe clients who are no longer coming to the clinic, while all the means to trace them and bring them back to the clinic for care have failed. According to this, a person becomes a loss to follow-up case after a period of three months, over which time all strategies would have been used to find the client who is no longer coming to collect his/her medication. This could be the case where the clients experienced reprimands from the clinic. According to Campbell et al. (2015), reprimands are linked to poor adherence to ART and poor adherence to clinic times.

Another aspect in the relationship between the health care worker and the client on therapy could be a lack of trust. According to Dale, Bogart, Wagner, Galvan and Klein (2014), general medical mistrust was seen to be contributing to low adherence and thus poor health outcomes in African American males living with HIV in America. In the cardiovascular framework (National Heart Foundation of Australia, 2011), mistrust could be related to barriers such as lack of confidence by a patient in a prescriber; sub-optimal interpersonal skills for the health care professional; and when the health care worker has insufficient knowledge about the health condition he/she is managing.

2.7.1.4 Medication-related issues

For van Dyk (2013), *medication-related issues* include such things as *side effects*, for example lipodystrophy, a condition where body fats get redistributed and an individual will appear to be changing shape physically. Alternately, one may have been put on a regimen that is difficult to follow, such as a regimen that requires taking medication an hour before food. This requires planning for both food and medication on a daily basis. In the cardiovascular framework (National Heart foundation of Australia, 2011), medication-related barriers are referred to as therapy-related barriers.

The *therapy-related* barriers, according to this cardiovascular framework, include *multiple doses per day*, *side effects* and *frequent changes in medicines* (National Heart Foundation of Australia, 2011). This class of barriers relates to the pills themselves, as well as the procedure for taking them.

Multiple doses per day may mean that the client has to remember different times and different pills, and the amount of pills to take on a daily basis at different times. For example, in the patients who are using ARVs, in the first-line regimen in South Africa prior to January 2015, one had to take three types of pills. Out of these three pills, two had to be taken in the morning and in the afternoon, 12 hourly, at the same time every day, and in the afternoon, the client had to remember to take the third pill as well as in the evening. This is because the third one is effective for 24 hours, and need to be taken only once a day. Usually the first line regimen contains a drug called *efavirenz* (EFV) which is known for making ARV clients to feel drugged(NDoH, 2015). This becomes even harder if the client also had to take other pills for other conditions.

Side effects differ in their manifestations. With ARVs, there are side effects that may make the client uncomfortable, as is the case with cardiovascular illnesses. Clients on ARVs may experience mild to moderate side effect such as headaches, dizziness, an upset stomach, sharp pain, nausea, and vomiting (van Dyk, 2011). In addition, there are side effects that could have an impact on the client's lifestyle, such as severe skin rash. This may affect the way one looks. Side effects may also change the shape of an individual who is using ARVs. This may be due to a redistribution of the body fats in a condition medically termed lipodystrophy (Lekhuleni, Mothiba, Maputle & Jali, 2013). This condition was known to be caused by Stavudine, one of the three pills prescribed for new users of ARVs as first-line regimen prior to 2011 (Lekhuleni et al., 2013).

In a study conducted in Limpopo, South Africa, the clients on ARVs expressed their "concerns related to side effects of the antiretroviral drugs" (Lekhuleni et al., 2013 p. 80). One man commented: "Since I have started the ARVs, I have developed breasts and this caused embarrassment and I was reluctant to continue with ARVs" (Lekhuleni et al., 2013, p. 80). If clients are experiencing these side effects, this could be a barrier to adherence. If clients are feeling ashamed or feel discomfort caused by ARVs, the chances may increase for clients to abandon ARVs. Renal problems have been associated with use of Tenofovir for individuals who are using ARVs (Brennan et al., 2014). Tenofovir is a drug that is included in the set of pills used currently and as a first-line regimen in the country since 2010 (Brennan et al., 2014).

Frequent changes in medicines, according to the cardiovascular framework (National Heart Foundation of Australia, 2011), relates to changes of the dosage, or maybe the regimen. On ARV, changes often come with the implementation of new guidelines, or if a client is experiencing severe side effects related to the medicine.

In the adherence guidelines (NDoH, 2016b), *medication-related* barriers are mentioned as well. According to these guidelines, medication-related issues include pill burden and regimen complexity, treatment adverse effects, medicine toxicities or cross-interactions with other drugs, and medication palatability or the taste of the medication.

Burden of therapeutic regimen relates closely to how the amount of medication which needs to be taken is a barrier to taking medicine. In the theory related to treating cardiovascular conditions (National Heart Foundation of Australia, 2011), *large amount of medicines* relates to the fact that the client may be expected to adhere to lifelong therapy, and may have other infections or other conditions for which he or she is taking treatment. The amount of medicines becomes a barrier when the client is expected to take many medicines, either a combination of drugs (regimen) for one condition, or other drugs for other treatments. An example of the large number of medicines for people living with HIV would be that, prior to the fixed dose combination (FDC) era, a client was expected to take a combination of three drugs for HIV. If there was co-infection or presence of other opportunistic infections such as TB, a client would also have to take additional medication.

In a study that looked at the impact of the combination of antiretroviral therapy initiation on adherence to anti-tuberculosis treatment, results showed that clients adhered to TB treatment prior to being initiated on ART (Knight et al., 2015). However, when the clients were initiated on ART, an 8-10% drop was observed according to pill count in their adherence to TB and an 18-22% drop was observed when measured by an electronic Medication Event Monitoring System (eMEMS). This shows how a large amount of medication can become a barrier to adherence. Depending on the number of other conditions and the treatments to be taken, the client may feel overburdened and therefore adhere poorly to their treatments. According to Hodes, Vale, Thabeng, Toska and Cluver (2016, p. 12), "…heavy pill-burden *is* associated with ART non-adherence".

2.7.1.5 Service delivery issues

In van Dyk's (2013) framework, *service delivery-related* barriers would include bad-mannered staff, clinics or hospitals closing early and therefore preventing access of clients to medication, industrial strike action which means clinic employees are not available to give medication to their clients, treatment stock-outs and incarceration (e.g. when one is in prison and access to treatment may be delayed). The National Heart Foundation of Australia (2011) mentions health system or health care team-related barriers. These include such things as the patient does not know how to take her/his medication, the patient lacks confidence in the prescriber, the patient visits different facilities and the patient miss appointments (National Heart Foundation of Australia, 2011).

2.7.1.6 Stigma

In van Dyk (2013), the *stigma* barrier leads to *fear of disclosing* one's HIV status or the fact that one is taking ARVs. This might mean hiding of medication (making it easier to forget to take it) and fear of rejection by those surrounding an individual living with HIV, including significant others. This may lead to secrecy and thus poor support from others for they may not be aware that one is in need of support. The fact that HIV is often stigmatised means that people living with HIV may not like to disclose their status in order to avoid being discriminated against by others.

According to adherence guidelines, the stigma that is attached to the diagnosis and disclosure of one's status, in this case of living with HIV, is a barrier to treatment adherence (NDoH, 2016b). In the South African adherence guidelines, stigma is listed as a barrier to adherence under a sub-category of barriers called *affective barrier*s. These include depression, anxiety, lack of motivation, reduction of self-worth, fear of violence, stigma, and abandonment. Stigma has also been pointed out in the literature as one of the causes of poor adherence. According to Kehler, Mthembu, Ngubane-Zungu, & Mtambo, (2012) females in Cape Town, South Africa feared to disclose their status to their male partners due to stigma and discrimination (gender base violence against them). Studies in the United States of America have demonstrated that stigma attached to HIV is related to poor adherence to HIV treatment (Li, Murray, Suwanteerangkul & Wiwatanadate, 2014). In a study that was conducted in Thailand, it was concluded that HIV-related stigma "is a stronger predictor of treatment adherence than any type of stigma alone" (Li et al., 2014. p. 6). It is clear that HIV-related

stigma could still be a strong barrier to ART adherence despite the fact that HIV has been known for more the 30 years.

2.7.1.7 Health control

Health control barriers in van Dyk (2011) involve a poor will to live, feeling that one has less control over what is happening in one's life (external locus of control), and feeling powerless and helpless over one's health and life (e.g. a "What can I do?" attitude). There is little information on health control barriers available in the literature. This relates to the *health beliefs and attitude* barrier in the cardiovascular framework of barriers (Heart Foundation of Australia, 2011). However, this is listed under socio-economic issues in this framework. What comes out clearly is that the attitude and beliefs of the person about the health condition that he/she may be expected to take medicine or therapy for could be a barrier to adherence.

2.7.1.8 Cultural aspects

Lastly, in van Dyk's (2013) framework are the *cultural aspects* which include religious beliefs. This barrier includes use of alternative-medicines, for example, traditional medicines from unapproved sources who claim to either cure AIDS or to be able to 'boost one's CD4 count'. Research in three African countries (Tanzania, Zambia and Uganda) in 2011 indicated that consultation with traditional healers posed a threat to adherence for clients who are using ARVs (Wanyama et al., 2017). When the data were further analysed to explore the characteristics of the clients who consulted the traditional healers, it was discovered that clients who accessed their treatment from a facility that has a traditional healer nearby, and clients who had fewer symptoms and had been on ARVs for more than five years, were more prone to consult with traditional healers and were therefore at greater risk of failure to adhere to the ART (Wanyama et al., 2017).

2.7.1.9 Condition-related barriers

This set of barriers is not directly mentioned in van Dyk's (2013) framework, but many of the issues pointed out in it are valuable for adherence. According to the cardiovascular framework (National Heart Foundation of Australia, 2011), *condition-related* barriers include long *duration of therapy.* Long duration of therapy refers to the duration of time the client is expected to adhere to treatment. As is the case with many chronic disease therapies to maintain health, this applies to people who are living with HIV and are using ARVs to control it so as to stay healthy for as long as possible.

2.7.1.10 Socio-economic issues (poverty)

Social or economic factors include categories of barriers such *as high costs of treatment*, and *poor health literacy* (Heart Foundation of Australia, 2011). If people living with HIV are to succeed in adhering to their medication, something may need to be done to address poverty. In the cardiovascular framework, poverty is mentioned partially under social or economic barriers. Poverty (or socio-economic issues) also appears in other categories as lack of food and transport money to the clinic (see table 1 below)

The South African adherence guidelines (NDoH, 2016b) also refer to the issue of socio-economic status as a barrier to treatment adherence. This is mentioned under a cluster of patient-related barriers as a *socio-demographic* barrier. This refers to issues of age, sex and socio-economic status of the individual expected to take treatment. Costs of medication can also be a barrier to adherence. However, in South Africa, with the decentralisation of ART from the public hospitals to primary health care (PHC) facilities, cost of ARVs has been eliminated. All the services that are given through PHC clinics are free of charge. This includes HIV care and ARVs.

While *cost* of the medications has been eliminated as one of the barriers in medication adherence, there are costs involved in *travelling* to where the medication is available. Clients are still travelling long distances in South Africa to fetch their medications, either because of unavailability of health care services in their area or because of stigma attached to HIV. If the treatment is accessed a long distance away from where the person lives, this means that the users of ART will have to have transport money to the public health facility.

2.7.1.11 Gender and social organisation

There is no category for gender issues in the Van Dyk (2013) framework. However, there is some mention of gender issues when commenting on stigma and discrimination affecting adherence (van Dyk, 2011). Van Dyk (2011, p 14) comments that:

> Some, especially women, kept their HIV status as well as their ARV-taking behaviour a total secret from their sex partners. Of those who kept it a secret from their sex partners, only 21% could reach optimum adherence levels. Fear of blame, rejection, losing their children, violence and even being killed were some of the reasons given by participants for their silence.

Clearly in this comment by van Dyk (2011), stigma and discrimination are closely related to gender-based violence. It is also clearly shown how this stigma affects adherence by females in particular, where females have to hide the fact that they are taking ARVs based on their fear of being discriminated against by their male counterparts. In the South African context, one would expect gender to play a role in the uptake of treatment since some studies have demonstrated differences in terms of gender in health-seeking behaviour. Men seem to be less active in taking up HIV-related services compared to women (Skhosana, Struthers, Gray & McIntyre, 2006). This poor health-seeking behaviour for men, according to the CAPRISA AIDS treatment programme, leads to them accessing treatment at a very late stage of having HIV, which contributes to a high mortality rate in men when they are initiated on ART (Naidoo et al., 2017).

While it is often not clear why men seem to be reluctant to seek HIV-related services, some studies point to masculinity issues. In a study conducted in Zimbabwe, it was observed that the "notion of masculinity that required men to be and act in control, to have know-how, be strong, resilient, disease free, highly sexual and economically productive" contributes to this (Skovdal et al., 2011). In the African rural setting, it is generally accepted that men have the last word on most issues, and appear as decision-makers in the families in which they live. If men are not taking part in finding out about their HIV status, it is possible that they could also influence their partners not to access health care services. Table 1 below shows a summary of barriers to adherence discovered by other researchers from 2003 to 2017.

In van Dyk's (2011) work in the South African context, there is no indication of which barriers to adherence seem to be more common than the others. An insight into which barriers are dominating in a particular community may assist health care providers and decision-makers to direct their efforts in the right direction. It might also lead to the development of a better-tailored psychosocial support framework for people living with HIV while improving adherence to ART and consequently it would lead to better treatment outcome. The following section describes the framework of barriers from studies that attempt to identify the most dominant barriers to adherence.

Table 1: Barriers to adherence

CARDIOVASCULAR FRAMEWORK OF BARRIERS TO ADHERENCE (National Heart Foundation of Australia, 2011)	**SOUTH AFRICAN ADHERENCE GUIDELINES FRAMEWORK OF BARRIERS (NDOH, 2016b)**	**VAN DYK'S FRAMEWORK OF COMMON BARRIERS TO ADHERENCE (van Dyk, 2013)**	**BARRIERS TO ADHERENCE: SOME AFRICAN) EXAMPLES (Atibioke & Osinowo, 2015; Campbell et al., 2012; Croome et al., 2017; Weiser et al., 2003)**	**REASONS FOR SUB-OPTIMAL ADHERENCE (Knight et al., 2015)**
Social or economic factors		Practical problems	Financial constraints Lack of access to adequate food	Lack of transport money
Patient-related: intentional barriers Patient-related: unintentional barriers	Patient-related barriers	Psychosocial or person-centred barriers	Travel/migration Forgetting	Forgetfulness Distractions, Leaving house without tablets Running out of tablets in between visits
Therapy-related barriers		Medication-related barriers	Side effects	Medication side effects Dosing errors
Condition-related barriers		Stigma	Stigma and discrimination	
	Provider-related barriers	Relationship between client and health care worker		
	Structural	Service delivery-related barriers		
				Taking pills as prescribed whilst not using eMEMS lid
		Health control		
		Cultural aspects (use of alternatives) medicines)		

2.7.2 Most dominant barriers to ARV adherence

Some of the studies did not only discover barriers to adherence, but also identified which ones were found to be more dominant than the others. It is important for the health care workers who support people on ARVs to be aware of which barriers to adherence are

dominant. This helps the health care workers to be in a position to know the issues they should screen for and be talking about when seeing their clients.

In a study conducted in Botswana, findings indicated that "[p]rincipal barriers to adherence included financial constraints (44%), stigma (15%), travel/migration (10%), and side effects (9%)" (Weiser et al., 2003, p. 28). In this study, it was concluded that "if cost were removed as a barrier, adherence is predicted to increase from 54% to 74%" (Weiser et al., 2003, p. 28). Financial constraints seem to dominate in this study (Weiser et al., 2003), and stigma seems to have been number two in the barriers to adherence in Botswana. However, in a study in Nigeria that that looked closely at stigma as a barrier to adherence, the authors concluded that the effect of stigma and feelings of discrimination were not significant to HIV-positive clients who were taking ARVs (Atibioke & Osinowo, 2015). However, other studies still see stigma as an important factor influencing poor adherence in the sub-Saharan region. According to Campbell et al. (2012), in Zimbabwe, poor adherence in most cases resulted from stigma for ART users of all ages.

Most of the barriers identified and ranked in the Botswana study mentioned above were common in the Zimbabwean setting. According to Campbell et al. (2012), barriers that often appear to be obstacles to the use of ART in Zimbabwe include costs and high clinic fees. This shows that in countries where clients pay clinic fees, costs could result in being a serious barrier. This is different for South African citizens, where public clinic services are free of charge. In the South African context, however, costs (socio-economic issues) could become a barrier when clients have to use transport to the point where ARVs are to be accessed. Thus, long distances to the clinic where ARVs are to be accessed by the users in the South African context could still be a challenge and therefore a barrier to adherence. In Zimbabwe, transport and long distances to the clinics are also still a challenge for the clients who are taking ART (Campbell et al., 2012).

A recent study has also been conducted looking into the barriers and facilitators to adherence in sub-Saharan Africa (Croome, Ahluwalia, Lyndsay, Hughes & Abasa, 2017). This study looked into barriers that have been identified from 2005 to 2016 and ranked them in order of frequency. According to this study, the most frequently identified barriers (in descending order) are: 1) forgetting, 2) lack of access to adequate food, 3) stigma and discrimination, 4) side effects 4), and being outside the house or travelling (Croome et al., 2017). The main

issue in this study was clients forgetting to take their pills. In the literacy classes held in the past, clients were encouraged to choose and use reminders to overcome forgetting.

A second barrier was not having adequate food while on ART. As much as there are no clear rules that ARVs must be taken with food, ARV users mention unavailability of food as one of the challenges for not taking their medication. According to van Dyk (2011), 37% of the ARV users who were not adherent mentioned that they did not have food and therefore could not take their ARVs. Stigma and discrimination were also barriers to adherence. Experience of the side effects from the ARVs is mentioned as the second-last dominant barrier, followed by being away from the house without treatment. This set of barriers is similar to the ranking in the Botswana study (Weiser et al., 2003). However, the only difference is that the most dominant issue was forgetting to take medication, while in the Botswana setting the main issue was financial constraints.

In a study conducted in the Gauteng province in Johannesburg on barriers to ART adherence in the South African setting, several reasons for poor adherence were identified. In their study of the impact of combination ART and TB treatment on adherence, Knight et al. (2015, p 37) discovered that:

> Leaving house without tablets (n = 8) and running out of tablets between visits (n = 8) were the most frequently stated reasons for missing doses, followed by forgetfulness (n = 3), dosing errors (n = 3), taking medication as prescribed whilst not using the eMEMS lid (n = 3), distractions (n = 2), medication side effects (n = 2), and lack of transport money (n = 1).

Most of the barriers identified in Knight et al.'s (2015) study are in line with what Van Dyk (2013) refers to as person-centred barriers.

Since there are quite a number of issues that have been suggested by various sources and covering different aspects, there is a need for a merged framework for this study. A number of barriers to adherence available in the literature are provided using van Dyk's (2011) framework as a master framework, while issues identified by other frameworks to cater for the issues that may not have been mentioned in van Dyk's work have been added. This is represented in Table 2 below.

Table 2: Framework of barriers to adherence (adapted from van Dyk, 2011)

BARRIER TO ADHERENCE	EXAMPLES/SUB-BARRIERS
Psychosocial or person-centred barriers	Relationship between patient and health care worker; treatment fatigue; pill burden; forgetfulness; lack of health care support; bad planning and running out of ARVs; lack of symptoms; sharing ARVs with friends; alcohol abuse; no personal intention to adhere; non-disclosure of status; and lack of sharing information with the patient.
Practical problems/socio-economic issues (poverty)	Transport problems to get the clinic; not enough food to eat with ARVs; difficulty in planning ahead to have enough ARVs; mugging and robbery of ARVs; and working shifts.
Medication/therapy-related barriers	Side effects; difficult treatment regime to follow; pills too big to swallow; multiple medicines for one disease state or several conditions; frequent changes in medicines; no improvement; loss of faith in medicine; not understanding significance of the medicine; and long duration of therapy.
Service delivery-related barriers	Hospitals and clinics not having enough stock; health care workers on strike; poor discipline in clinics (bad service and early closure); being imprisoned (access to treatment).
Stigma and discrimination	Secrecy; fear and lies; hiding of pills; non-disclosure; no support groups due to secrecy and fear of community rejection; and rejection of the disease.
Health control	No control over own health; fatalistic attitude ("Nothing I can do will make a difference."); external locus of control; poor health literacy.
Cultural aspects	Using medicines from traditional healers with ARVs without disclosing to health care worker. Communal life style reduces privacy for stigmatised infection such as HIV.
Gender and social organisation (masculinity)	Men have need to maintain masculinity; avoiding health seeking; women have less power in relationships with men, making decisions including about health seeking.

From the above discussion of the literature review, I have indicated that South Africa is overburdened with HIV and has the largest number of people on ARVs. South Africa should be leading in finding solutions to deal with HIV. In order to reach the United Nations 90 90 90 targets, South Africa will have to ensure that barriers to adherence are addressed. In this section, a set of barriers to ART from a range of studies was presented and then merged into a framework to be used for the basis of understanding the results of this study. In the next section, the theoretical framework for this study will be presented.

2.8 Theoretical framework

Various health behaviour theories were considered for this study; however, they had limitations. Some of these theories focus on the individual and issues affecting adherence to medication. However, focus on the individual and their cognitions in relation to adherence is insufficient to explore the range of processes which impact on adherence. For example, the behavioural learning theory perspective (Munro, Lewin, Swart & Volmink, 2007) posits that the patient's behaviour depends on the consequences such as punishment or reward. Communication theory (Munro et al., 2007) puts forward the patient-practitioner relationship as a factor that influences adherence. The cognitive perspective focuses on what is in the mind of a patient (perceptions and beliefs) about the disease itself and taking medication, as a facilitator or barrier to adherence and, lastly, the self-regulation perspective, like cognitive theory, focuses on the individuals' perceptions of the disease as a threat or not (Munro et al., 2007).

However, most of these theories have not been developed for a specific context, such as a rural African context which is the focus of this study. The focus on the individual and individual cognition does not give sufficient explanation for adherence practices which might be related to the circumstances surrounding an individual. In a rural context such as that of the community in which this study was conducted, there are many other issues outside of the individual which influence expected behaviours from the people.

Barriers to adherence, especially in a deep rural setting in an African country, may include issues beyond the individual, which are group or community related. Van Dyk (2013) cautions counsellors and health care workers to consider collective existence when counselling and providing health education to Africans in a traditional African setting. In an African perspective, one's individual behaviour (and consequently adherence to treatment) may rather be influenced by the surrounding individuals. This is the basis for the Zulu saying: "*umuntu ngumuntu ngabanye abantu*" (loosely translated as a person is a person through other persons).

This collective existence in the African traditional context often contributes to the decisions to be taken by individuals, including decisions about health and treatment. Diseases like AIDS may be kept as a secret at a wider community level and only disclosed in a smaller

group like a family, sometimes not to all family members, therefore affecting taking of treatment. With HIV in the African setting, there may be family, partner and community issues which may not have been taken into consideration by the health care workers when giving medication to their clients. Although these issues may not be significant for the practitioners, they may be very important for their clients and thus affect adherence to medication. When concluding on the failure of the health behaviour theories to provide a single simple solution to medicinal adherence, Munro et al. (2007, p. 14) said: "to understand and overcome the barriers to treatment adherence, considerable research is needed".

Seeing that health behaviour theories focus mostly on individual aspects of adherence to medication, frameworks of barriers were seen as more appropriate for this study. The barriers identified in a variety of studies were merged to formulate one framework which was used in understanding the findings of this study.

2.9 ART and behaviour change

The taking of treatment is not what people normally do but is necessitated by a need for survival in the face of medical challenges. In the presence of HIV, like with many other life-threatening diseases, behaviour change is needed, which is a challenge on its own. For example, the WHO (1988) recommends condom use to prevent the transmission of HIV. However, despite the risk, people do not easily change their behaviour to use condoms in sexual interactions. In a Tenofovir gel study conducted within the uThukela district (as one of the nine sites), it was reported that only 35% of the clients (women) adhered to condom use (Qhakaza Mbokodo, 2015). This was despite adherence counselling provided on a monthly basis and condoms being given to them. Non-adherence to condom use and other sexual risky behaviours such as unprotected sex with multiple partners, of HIV-negative or unknown HIV status, has been associated with poor adherence to ART.

According to Frank and Duncan (2009, p. 2) it was found that "patients who reported a significantly greater number of sexual partners, greater rates of unprotected vaginal intercourse, including with partners who were HIV negative or of unknown status, were more likely than others to be non-adherent" to ART. This makes it clear that factors that may have led to non-adherence in condom usage could be linked to non-adherence to ART as well.

ART, too, is expected to contribute as a prevention strategy. This has been the case ever since it was discovered that, by suppressing the communal viral load by putting all who are HIV positive on ART, there are greater chances of reducing viral transmission (van Dyk, 2011). However, it is disappointing that only about 40% of the people on ART manage to achieve the desired above 90% adherence. According to van Dyk (2011), studies have shown that, like in other chronic treatments, adherence to ART is at around 40% in the sub-Saharan region and in South Africa.

Treating HIV requires that an infected individual takes ARVs and adheres to the specific way of taking them, as prescribed by the clinicians. Doing exactly as expected and following all the procedures proves to be difficult for people at times. The strict adherence to treatment that is expected from an individual taking ARVs is sometimes beyond that of other medications that are familiar to people. Before 2014, a person using ARVs in South Africa had to remember specific times to take their treatment in the morning as well as in the evening, and specific pills to take in the morning and in the evening. For example, someone on the first-line regimen (the first set of pills to start with for everyone being put on ARVs) had to take two different types of tablets (Stavudine and Lamivudine) in the morning and in the evening the same two types of pills and a third one (called Efavirenz). If one decided to take these pills at seven o'clock in the morning, it means one has to take the evening pills at the same time in the evening, at seven o'clock. This was so because if an individual is not strict with these times, there are chances for HIV to continue multiplying itself and thus creating a resistant type of itself. However, since 2014 up to today this challenge does not apply for clients on a regimen one with the availability of fixed dose combination (FDC). FDC is only available for clients on regimen on in the public health service, thus if an ART client is losing regimen one he/she would also be losing a benefit of FDC.

It is clear that taking treatment requires commitment and an extra effort since this introduces changes from what an individual normally does. Much more caution needs to be exercised for an individual to meet the strict expectations that come with taking ARVs for a person living with HIV, to ensure that the virus stays under control. This will also need psychosocial support for an individual who is committing to this change of behaviour. For this support to be targeted at the right place, there needs to be information available about what may make local people fail to maintain this new behaviour (adherence to ARVs) in their lives.

2.10 Need for more insight on barriers to ARV adherence

It is becoming clear now that even with the best treatment available, adherence remains important, if not more important than, the medicine itself. This study seeks to explore the issue of adherence and barriers to adherence in a particular rural community. There has been no such study conducted within the uThukela district since the roll out of ARVs in 2004. In most of the districts in KwaZulu-Natal, there is a need for such information to be available. Given the highest HIV prevalence and number of people on ART compared to other provinces, a focus on this geographic area is important.

Putting clients on treatment is very expensive, and this is also a lifelong therapy. Treatment requires a vigilant and easy-to-implement psychosocial support process that is informed by evidence from the local context. The results of the study may also give some insight into non-adherence to other forms of treatment and to other health care interventions such as condom use, family planning and TB treatment.

Focusing on adherence and minimising barriers to adherence may be vital in the fight against HIV, AIDS and TB, and may help sustain the impact of any other treatment or therapy since there is consensus that ART clients' high viral load is attributable to non-adherence before any other factors may come into play. Wasti, Simkhada, Randall, Freeman & van Teijlingen, (2012, p. 1) pointed out that "poor adherence can lead to the virologic failure of patients using cheaper first-line treatment regimens and the spread of drug-resistant forms of the virus, resulting in a public health calamity". Thus, a study that focuses on exploring barriers to adherence could assist in avoiding future devastating effects of HIV infections.

Identifying the most common barriers in the local community may also assist in provision of psychosocial support for individuals who are supporting ARV users. This is particularly useful within the context of fast-tracking clients and the strain on human resources in the health care sector. Knowledge of key barriers to ART adherence is necessary for the nurses when in consultation with clients already on ART, to screen for poor adherence. This could prove of value since the luxury of having lay counsellors to provide adherence counselling is falling away with the KZN policy for career-pathing lay counsellors (KZNDoH, 2013), implemented in 2013.

Identifying barriers that are most likely to lead to non-adherence for clients who are on ART may also assist health care providers in dealing with loss to follow-up (LTFU), which, according to the KZNDoH HAST quarter four report, is at 27% (per 12 months cohort) in the province of KwaZulu-Natal, while the target is no more than 10% of the clients who are on ART (KZNDoH, 2016a). This LTFU has been increasing gradually over the past four years. According to this report, in the 2011/2012 fiscal year it was at 15.1%, in 2012/2013 at 17.1%, 2013/2014 at 24.5%, and in 2014/2015 it was at 27.5% (KZNDoH, 2016a).

2.11 Value for money

The ART regimen 1 is cheaper than regimen 2, while regimen is 2 cheaper than regimen 3. This shows that the cost value escalates with the regimens that a client is re-initiated on. According to WHO, in an early warning indicator (EWI) workshop conducted by Dr Jacqueline Pienaar, it was shared that it costs $115 to put one client on the first-line regimen; $330 for the second-line regimen and $1 500 for the third-line regimen per year in South Africa. Keeping clients on the first-line ARV regimen could help save the country money which could be invested in other challenges that the country is facing. To keep ART patients on the first-line regimen, reasons for poor adherence should be identified and addressed.

Chapter 3: Aims and objectives

3.1 Aim of this study

The aim of this study was to identify key barriers to adherence for the clients who are using ARVs at Injisuthi clinic, in the uThukela district of KwaZulu-Natal province.

3.2 Objectives of this study

The objectives of this study were:

1. To explore the reasons for non-adherence for clients who use ART.
2. To discuss barriers to adherence to ART from the perspective of health care workers involved with clients who are using ARVs.
3. To identify barriers that play a major role in poor adherence in clients who are on ART.
4. To compare barriers to ART experienced by clients on ART with barriers reported by the health care workers who are involved with ART clients.

3.3 Research questions

This study attempted to answer the following research questions:

1. How do clients come to fail to adhere to ART treatment?
2. What makes it difficult for ART clients to adhere to treatment?
3. Which are the most common barriers to ART adherence experienced by local clients?
4. How do health care workers perceive barriers to adherence for their clients on ART?
5. How does the perception of barriers to adherence by clients on ART differ from that of the health care workers?
6. How do challenges of living with HIV relate to poor adherence?

Chapter 4: Methodology

4.1 Research design

The study used a qualitative approach. According to Nieuwenhuis (2008, p. 51), qualitative research involves "a research methodology that is concerned with understanding the process and the social and cultural contexts which underlie various behavioural patterns and is mostly concerned with exploring the 'why' questions of the research". This approach provides an opportunity to gain in-depth knowledge of the phenomenon since, when working with research participants, it is able to "focus on the 'emic' perspective, the views of the people involved in the research and their perceptions, meanings and interpretations" (Holloway & Wheeler, 2010, p. 3). This study seeks to develop an understanding of the reasons for poor adherence to ART for the individuals who are using ART to control HIV once they are infected by it. A qualitative approach helped in developing an understanding of the subjective experiences of research participants.

4.2 Location of the study

The study was conducted at the Injisuthi clinic in the uThukela district because the Injisuthi clinic is one of the clinics under Estcourt Hospital, which is the sub-district with the second highest number of clients on regimen 2 amongst the four sub-districts of the uThukela district. The Injisuthi clinic is a high-volume clinic within the uThukela district.

A programme manager for HCT at HAST unit advised me to contact Dr Lutge, who is the head of research within the KwaZulu-Natal Department of Health to find out the procedures for obtaining permission for this study. Dr Lutge's response is attached as Appendix one. Permission to conduct the study at the facility was received from the Injisuthi clinic's operational manager (see Appendix two).

4.3 Sampling

In criterion sampling, according to Nieuwenhuis (2008), the researcher decides the criteria to be met by the research participants to be selected for the research. The number of the participants and their characteristics are decided upon prior to the study. Criterion sampling was used for this study, since the client research participants had to meet important specific

criteria: 1) HIV-positive individuals, 2) have a history of using antiretroviral treatment (ART), 3) have failed on the first combination of ART, and 4) still continuing to come to the clinic (on a different combination set of antiretroviral treatment). The number of clients on ART interviewed was five as this is a sufficient number for an in-depth qualitative study.

The criteria for the health care workers were also set prior to data collection. Participants who met the criteria were selected and interviewed. This study included three nurses involved with HIV-positive clients on ART and three HIV lay counsellors involved with the provision of psychosocial support to clients who are on ART and living with HIV. In addition, the study include three community care givers (CCGs) linked to this clinic, as they are also involved with community support for clients who are on ART.

4.3.1 Recruitment of ARV clients

Lay counsellors from the facility, since they are already aware of their client's HIV status and whether they meet the criteria, were asked to identify and recruit potential participants. Prior to recruitment, lay counsellors who opted to participate in the recruitment process were provided with training on how to conduct briefing and recruitment of the participants on ARVs while taking care of ethical issues. In this training, the rights and autonomy of clients to participate in the study were discussed. The information sheet for participants, which was available in both English and isiZulu (see Appendix three A – *English* and Appendix three B – *isiZulu*), was given to the counsellors for use while recruiting. The rights of a client to choose not to participate and to withdraw from participating during the study without any fear of consequences were discussed. Clients' right to privacy and confidentiality was emphasised.

When recruiting participants, lay counsellors gave potential participants a copy of an advertisement (*Invitation to participate in a study*). This invitation was also available in the local language, *isiZulu* (see Appendix four A – *English* and Appendix four B – *IsiZulu*). The participants who were willing to participate were taken through the information sheet, described above. The lay counsellor helped clients with understanding the content of the information sheet and addressing any questions as they came. Participants who were still interested after going through the information sheet were then booked for a research interview time slot by the counsellor.

4.3.2 Sampling and recruitment of health care workers

When recruiting health care workers (lay counsellors, community care givers and nurses), the researcher asked the operational manager (OM) of the facility (during a briefing meeting with her) to identify two or three nurses who met the criteria for the study (i.e. nurses who are directly involved with clients who are on ART). The OM was herself willing to participate in the study, since she fulfilled the criteria. She then identified another two nurses who met the criteria. All three lay counsellors at the clinic met the criteria since they were all directly involved with the provision of psychosocial support to clients who are living with HIV and on ART. CCGs were at the clinic on the first day of data collection for their report meeting. They were approached by the lay counsellor who was involved in recruiting the ART clients and asked if they were willing to participate in the study. Three CCG's agreed to participate.

4.4 Data collection methods

Semi-structured interviews were used to interview the five participants on ART, as well as the nine health care workers. Nieuwenhuis (2008, p. 87) defines a semi-structured interview as "a two-way conversation in which an interviewer asks the participants questions to collect data and to learn about the ideas, beliefs, views, opinions and behaviours of the participant". This data collection method was suitable for this study for it allowed participants to narrate their experiences of the barriers to treatment adherence at their own pace and share information they were willing to share. Semi-structured interview schedules were used for this study with probes for clarification where necessary. Two sets of semi-structured schedules were used and translated into *isiZulu*. The first schedule was used for participants on ART (see Appendix five A – *English* and Appendix five B – *isiZulu*), and the second one was used for the health care worker participants (see Appendix six A – *English* and Appendix six B – *isiZulu*). Data were collected from participants from the 2nd to the 11th of November 2016.

The interviews were conducted in a private space; some in the operational manager's consulting room and others in the Emergency Medical Services (EMS) team room in the clinic. Prior to the interviews, the researcher first established whether the client had agreed to participate in the study and understood the contents of the information sheet. For the participants using ARVs, the researcher ascertained the ART regimen the client was on, and confirmed that the client had been on another ART regimen prior to the current one.

The researcher further explained the purpose of the study, disclosed the information about the institution he is working under and the contacts of the relevant persons in the institution (UKZN). The researcher also explained the rights of the participant in the study, emphasising voluntariness of participation and the right to stop participating without fear of negative consequences, as well as the right not to answer questions should they not wish to do so. The informed consent form was read to all the clients in the language of the client (*isiZulu*) and signed by the clients (see Appendix seven A – *English* and Appendix seven B – *isiZulu*). Permission to audio-record the interview was obtained from all participating clients (see Appendix eight A – *English* and Appendix eight B – *isiZulu*), and written informed consent was obtained prior to interviews.

ART research participants were asked to respond to open-ended questions about the discovery and disclosure of HIV status; source and kind of support (from the clinic community and other); personal reasons for needing ARVs; health status prior to ART; what happened immediately after ARV initiation; duration on ART; challenges experienced on ART; the most difficult times on ART; ensuring taking ARVs even when they were to travel; what they used/are using to remind themselves when it is time for ARVs; storage of ARVs when at home; their reasons for being switched from the first-line regimen and what they were doing to ensure that they did not run out of medication (see Appendixes Five A and B). This was accompanied with probes where necessary.

All the health care workers were interviewed using semi-structured questions with probes for clarification where necessary. Health care workers responded to questions about services they offer to HIV-positive clients; duration of time they have spent working with people living with HIV in their lives including before their current occupation; average number of HIV-positive people they offer services to and people who use ARVs they meet per day; type of services they offer to their clients; difficulties and reasons for stopping ARVs they may have been told by their clients; and their own opinion of what makes their clients stop taking ARVs (see Appendixes Six A and B).

Interviews were conducted in *isiZulu*, the mother tongue of the participants. The interview with the OM of the clinic was conducted in English. All participants were encouraged not to mention their names and identifiable features of themselves during data collection. The

clients were asked their age in terms of range rather than a specific age (e.g. between 30 and 35, or between 35 and 40).

All collected data were transcribed verbatim and translated by the researcher. To check the validity of this translation, the English version transcription was given to a fluent *isiZulu*- and English-speaker (with a post-graduate qualification) to back-translate, that is, to translate back into *isiZulu*. The researcher then checked the translated transcript for consistency of the original translation with the back-translation and made adjustments where necessary.

All 14 participants were compensated at the rate of R75 per participant (including the nurses, lay counsellors and CCGs) for transport costs and their time spent in the research. This was only disclosed to participants at the end of the interview. Participants on ART also received a variety of health information and educational material in the form of booklets and pamphlets.

4.5 Data analysis

Thematic analysis, according to Braun and Clarke (2006), is a method that is used in qualitative research to identify, analyse and report patterns (also known as themes) within data. Data for this study were analysed using this method. Braun and Clarke (2006) further state that thematic analysis involves six phases in which the researcher *familiarises him/herself with his/her data*; *generates initial codes*; *searches for themes*; *engages in theme reviewing*; *defines and name themes*; and *produces the report* out of the themes identified. These phases are not meant to follow any serial process (Braun & Clark, 2006).

In this study, the researcher started getting some sort of familiarisation with data during data collection from research participants and data transcription from audio-recordings. Further familiarisation with data occurred during data translation from isiZulu to English. This was followed by reading and re-reading data while generating codes across the data set. Issues were coded during data reading and re-reading at the time they were recognised or seen as important prior to interpretation (Fereday & Muir-Cochrane, 2006). This process was followed by identifying themes among participants who use ARVs, where patterns were identified based on the codes that were given in the previous phase. This was followed by identifying patterns for health care workers in their respective categories (i.e. lay counsellors,

community care givers, and lastly the NIMART nurses, who initiate and manage clients on antiretroviral therapy).

Identified themes were labelled and presented to a fellow student who is also doing a master's degree in psychology at another university and to the researcher's supervisor, in order to review identified themes so as to ensure objectivity in these themes. Adjustments were done where necessary as per the fellow student's and supervisor's suggestions. Identified themes were also compared across all four categories of the research participants in order to establish the perspectives of the research participants. This was followed by comparing themes that were identified in this study with the ones that were identified and discussed in the literature review. Lastly, the discussion of themes was produced from the analysed themes and presented to the supervisor as the first draft for a review, and adjustments were made as per the supervisor's recommendations and advice. This research report follows a structured framework that was formulated from a number of studies identified during literature review in which van Dyk's (2013) framework was used as an overarching framework.

4.5.1 Credibility

Credibility is defined as the degree to which the research represents the actual views of the research participants and not those of the researcher (Moon, Brewer, Januchowski-Hartley, Adams & Blackman, 2016). Credibility seeks to ensure that research claims are as objective as possible and free from the researcher's bias. In this regard, Nieuwenhuis (2008) further comments that, if qualitative researchers speak about research validity and reliability, they mean the credibility and trustworthiness of the research. These aspects were achieved in this study by ensuring that data were collected from participants who were involved in many aspects in antiretroviral therapy. This combination of participants with a variety of backgrounds included people who used ARVs and defaulted but were still on the ARV programme; nurses who initiated clients on ARVs and monitor their progress; lay counsellors who tested people for HIV, linked them to an ARV programme and supported them to adhere to their treatment; and CCGs who supported people living with HIV in the community through home visits. This variety was aimed at ensuring that this phenomenon was looked at from a variety of perspectives.

Interviews were conducted through semi-structured questions which were made available both in English and *isiZulu* (see Appendixes five and six) until saturation was reached. This was done to limit the language barrier during interviews that may have limited the quality of the data. The researcher took steps to ensure that data transcription was done verbatim from the audio-recording, and compared with notes taken during interviews. Translation and back-translation were used to confirm that the meaning was not lost during translation from English into *isiZulu*. Lastly, analysis and interpretation were done as closely as possible to the data and through going back and forth from themes to the data to confirm the analysis. Furthermore, the researcher was assisted by a post-graduate student from another university and a study supervisor to decide on some of the issues and to make conclusions from the data.

The researcher also made sure compensation for time and travelling costs (for clients who travelled to the venue of the study) was only disclosed and provided at the end of the interviews, in order to ensure that this did not influence what the participants had to say during the interviews.

The researcher possesses more than 17 years of experience working in the field of HIV, teaching, coordinating prevention programmes, counselling, supervising, as a programme manager, and working for the Department of Health. This means that the researcher had to be extra sensitive when interviewing participants who were on ARVs, allowing them enough time to respond to the questions and offering additional time should they wish it, in order to guard against leading the participants towards favourable answers or influencing either ARV clients or clinic staff.

4.5.2 Dependability

Dependability of an enquiry "refers to the consistency and reliability of the research findings and the degree to which research procedures are documented, allowing someone outside the research to follow, audit, and critique the research" (Moon et al., 2016, p. 2). This was achieved in this study through a comprehensive and thorough description of the data collection, the data analysis procedures, and steps taken to guard against any other interference that may have influenced the outcomes of this study. Furthermore, tools that were used during data collection are attached as appendices in this report.

4.5.3 Transferability

Transferability is defined by Moon et al. (2016, p. 2) as a kind of external validity that "refers to the degree to which the phenomenon or findings described in one study are applicable or useful to theory, practice, and future research". Maree (2008) points out that the aim of the interpretive study is not necessarily the generalisation of the study to other populations, but rather to gain rich descriptive perceptions of the research participants of a particular study. In this study, the accounts of the research participants in the form of transcribed and translated data are presented as extracts in support of the themes identified during data analysis. The context of the study was provided including the demographic information of the participants (see Tables 3 and 4 in the following chapter), and their backgrounds were also described to ensure that all these characteristics be considered in terms of transferability of the findings.

4.6 Ethical considerations

It is very important to consider ethics when one is conducting a study that involves human beings in order to protect research participants from any harm, ensure they are free from abuse and to ensure that as they participate in the study, their welfare is guaranteed. According to Terre Blanche, Durrheim and Painter (2006), what led to the growth of research ethics were the problems and consequences of the abuses committed by the Nazi medical researchers in the times of World War Two in Germany. Therefore, in order to make sure that there are no more abuses of research participants while researchers are conducting their studies, ethical guidelines were created, research ethics committees (RECs) were formulated, and legal acts that protect research participants from abuse were passed and incorporated into the constitutions of most countries. An example of this would be the South African Health Act (Act 61 of 2003, Chapter 9, Section 71). This act prescribes that all research that involves human participants must be approved by an independent accredited research ethic committee.

Approval of this study from the Humanities and Social Sciences Research Ethics Committee was received (see Appendix nine). This approval was followed by approval to conduct the study from the KZN Department of Health (see Appendix ten). Approval was also supported by letters from the uThukela district manager, Dr M. T. Zulu (see Appendix eleven) and Mrs T. S. Hlongwa, the acting chief executive officer (CEO) of the Estcourt Hospital as a mother hospital to Injisuthi clinic (see Appendix twelve).

According to Terre Blanche et al. (2006), ethical research is guided by four philosophical principles: beneficence, non-maleficence, justice, and autonomy (which includes respect for individuals' dignity).

4.6.1 Beneficence

Beneficence ensures that individuals, as far as possible, should be asked to participate in studies that will in one way or the other benefit them. Participants in this study were made aware of direct and indirect benefits from this study. This information is included in the information sheet and was explained in the interview.

4.6.2 Non-maleficence

Non-maleficence as a principle ensures that research participants are not going to experience any direct or indirect harm as a result of them participating in a research study. Care was taken in this study that all participants were not asked to respond to offensive or embarrassing questions during their interviews. Participants were made aware of their right not to respond to some of the questions should they wish not to do so. In addition to this, their names were not linked to the study or study findings, and their identity was kept confidential through the use of codes in the reporting of the data.

4.6.3 Justice

Justice denotes the presence of fairness during the course of the research. The rights of the clients who participated in this study were taken care of and clients were made aware of them, including the right to participate in the study or not. Interviews were conducted in a way that was as fair as possible to the participants, and participants reserved their right to stop participating in the study should they have felt that the study was no longer fair to them.

4.6.4 Autonomy and respect

Autonomy and respect for research participants' dignity is a philosophical principle that is there to ensure that individuals are neither forced nor coerced to participate in the research. They could opt to withdraw from the study at any time should they wish to do so, without negative consequences to them; they could give their consent to participate in the study; they were informed of the details of the study; their identity was protected; and their participation was voluntary.

Participants were given details of the authorities (researcher's supervisor and university research ethics committee) to contact should they have questions, or should they have felt there was a need to contact relevant people with matters arising from the study being conducted. Information about the purpose and the process of the study was given to the participants prior to their participation (see Appendices three A, B, and C for the information sheets). Written informed consent was obtained for both participation in the study and for audio-recording of the research interview. Raw research data linked to participants' names were not disclosed to any other person before it was anonymised, transcribed and translated. Participants were made aware of this procedure which protected their identity. Furthermore, interviews took place in a private room/office and nurse's consultation room as there was only an interviewer and the research participant. Participants on ART were encouraged not to use their full names during their participation. Participant's names were not included in either the research data or when the research report was written.

4.7 Storage of data

Data will be stored securely in a locked filing cabinet with my supervisor (Dr Mary van der Riet) for a period of five years. When the period of five years has lapsed, all collected data will be destroyed. Paper-based, transcribed and translated data will be shredded. Electronic audio and written data have been deleted from all electronic systems including data storage devices.

4.8 Dissemination of the results

Research participants were made aware that the results of this study would be made available in various forms, and presented to a variety of platforms without mention of their names or any identifiable features to protect their right to privacy and confidentiality. This might include conference presentations and/or possible journal publications.

Chapter 5: Results

In this chapter, the findings of this study will be presented. I will first give a brief description of the participants of this study and then the thematic analysis of the data is presented.

5.1 Research participants

Research participants for this study included people from a variety of backgrounds: people living with HIV and using ARVs; lay counsellors; community care givers (CCGs); and nurses.

5.1.1 Antiretroviral therapy (ART) clients

Five clients who were using antiretroviral treatment (ART) were interviewed. All of the five clients who were using ART had been changed from the first-line regimen to another regimen. Some had been switched once and put on the second-line regimen, while others had been changed twice. Two of the five participants on ART were men, and the remaining three were women. Four participants were married. All of the participants on ART were above the age of 18. Table 3 presents a summary of demographic information for participants on ART.

Table 3: Demographic information for participants on ART

Participant	Age	Period on ART	Gender	Race	Employment status
01	30-35	2 years	Male	African	Unemployed
02	55-60	>3 years	Male	African	Unemployed
03	40-45	8 years	Female	African	Unemployed
04	30-35	Not available	Female	African	Unemployed
05	30-35	9 years	Female	African	Unemployed

5.1.2 Health care workers (HCWs)

Nine health care workers who are involved with people living with HIV participated in this study. These health care workers were in three categories (lay counsellors, community care givers and nurses).

Lay counsellors are employed by the Department of Health. They work in the clinics to provide psychosocial support in HIV. Their work includes counselling and testing for individuals who want to know their HIV status and provision of ongoing counselling and psychosocial support for clients who test either HIV positive or negative. Ongoing counselling also includes adherence counselling for clients who are using ARVs. Three lay counsellors participated in this study (see Table 4). Their knowledge is valuable, since they talk to clients who are using ARVs from the point where they got to know their HIV status, up to where they have failed on their treatment.

CCGs are also employees of either the Department of Health or the Department of Social Development, employed to provide health care support for patients at household level. Their normal work is to go to the community to provide health education, and assess the state of health for individuals at home and refer them if necessary. Three CCGs employed by the Department of Health participated in this study. At the time of their interviews for this study, they all had more than ten years of experience in the community, supporting people who are living with HIV and the ART clients in this study.

Nurses who are helping HIV-positive individuals with ARV initiation and further support were also interviewed. Three nurses who are trained in NIMART (Nurse-Initiated Management of Antiretroviral Therapy) participated in this study (see Table 4). They are based at the clinic to provide, amongst other services, HIV-related services to HIV-positive individuals. Information from these nurses is also valuable for this study, for it is part of their work to start clients on ARVs and talk to them very often when they come to the clinic to collect their medication; when they are sick; when they experience side effects; and when they may have failed on treatment.

Table 4: Demographic information for HCWs

Part-icipant	Designation	Time worked with HIV-positive people on ART	Gender	Race	Services provided to clients living with HIV and on ART according to the health care workers (HCW)
06	CCG	+/- 16 years	Female	African	Health education; counselling on treatment adherence; education on the importance of adherence to clinic appointment dates; nutrition.
07	CCG	+/- 11 years	Female	African	Counselling on disclosure; healthy eating; and substance abuse.
08	CCG	+/- 21 years	Female	African	Family HIV education; counselling on HIV, nutrition and on healthy living; referrals to the clinic.
09	Lay counsellor	+/- 10 years	Female	African	ARV education; ongoing counselling; adherence counselling (including screening for side effects); education on blood check-ups; disclosing blood results (CD4 count and viral load).
10	Lay counsellor	+/- 13 years	Female	African	disclosing blood results (CD4 count and viral load), Ongoing counselling, Adherence counselling
11	Lay Counsellor	+/- 12 years	Female	African	Disclosing blood results (CD4 count and viral load); ongoing counselling; adherence counselling.
12	NIMART nurse	+/- 10 years	Female	Indian	Facility management; provision of treatment; counselling; address questions on HIV and treatment; education about ARVs; management of children on ARVs.
13	NIMART nurse	+/- 6 years	Female	African	Provision of treatment; counselling; initiation on ARVs; TB and STI screening; address questions on HIV and treatment; education about ARVs.
14	NIMART nurse	+/- 5 years	Female	African	Provision of treatment; counselling; initiation on ARVs; TB and STI screening; address questions on HIV and treatment; education about ARVs.

5.2 Key barriers to adherence

In the analysis of the data, it is clear that the different participants in the study highlight different issues in relation to adherence. The findings will be presented and discussed in terms of how the four groups of participants highlighted particular issues (i.e. participants who are using ARVs; lay counsellors who are supporting them from the clinic; CCGs who support them from the community; and nurses who put them on ARVs and provide ARVs to them while attending to their other clinical needs).

In the process of data analysis, a number of themes were identified. The following twelve issues were dominant in the transcripts: 1) side effects, 2) pill burden, 3) no improvement while on ART, 4) use of alternative (traditional) medicine, 5) improved health, 6) communication with health care workers, 7) practical problems/socio-economic issues (poverty), 8) mobility and migration labour, 9) gender socialisation and organisation (masculinity), 10) stigma and discrimination leading to fear of disclosure, 11) lack of community support, and 12) service delivery. These themes will be presented using extracts from the data, commencing with problems mentioned by the participants that are medicine related.

Extracts from the research participants are used in this section to illustrate the issue that is being identified. Where necessary, brackets are also used to give an interpretation of what was said by the clients if it was in *isiZulu* and was hard to translate. In this case, the extract would include what was said by the client in *isiZulu* in *italics* with an interpretation put in brackets. To illustrate parts of the transcript which were left out, an ellipsis is used. Some sounds that were made by the participants while thinking before responding to a question are written in *italics* like: *Uhhh ...; ah ...; errr; ehhh.* Exclamation marks were included when participants were talking in a raised tone of voice, implying exclamation. Pauses were indicated in brackets.

Extracts from research participants are presented without their original names but with codes, for example: ‘Participant 01 (MC 30-35)’, where M stands for male, C for client using ARVs and 30-35 is the age of the participant. In the case of a female participant, an F is used making the descriptive code look like ‘FC 35-40’. In the case of health care workers, three different codes are used: 1) ‘Participant 09 (L/C)’ is used for a lay counsellor at Injisuthi

clinic; 2) in the case of CCGs, it might be 'Participant 06 (CCG)'; and 3) in the case of the NIMART nurses at Injisuthi clinic, it would be 'Participant 14 (NN)'.

5.2.1 Side effects

All five participants who were antiretroviral therapy clients complained about side effects when they were asked about their most difficult time on ARVs. The side effects mentioned included: changing of body shape/growing and hardening of the stomach, feeling drugged by the medication, vomiting, and producing excessive urine ("they made me pass a lot of urine"), losing weight, and dizziness. Participant 01 (MC 30-35) said:

> The time that was the most difficult to continue with taking medication...? *Ehh...* I would just tell the truth, you see … the first day… *ehh...* just the first week, when they were drugging me.

Participant 02 (MC 55-60), when asked about the most difficult times on ART, said:

> I did not see it that badly ... it was just that condition I have experienced … but now it has stopped … that thing of having dizziness like that.

On the same question, the female participants also mentioned side effects. Participants 03 and 05 complained about their stomach growing. Participant 03 (FC 40-45) and Participant 04 (FC 30-35) complained about the pills making them vomit. When asked about the most difficult times on ART, Participant 04 (FC 30-35) said:

> On the first ones*? Errr ... ukuthi ayengiphalazisa-ke lawo!* [The thing is they made me vomit, those ones!] They really made me vomit *uhhu*.

When asked the same question, Participant 03 (FC 40-45) said:

> *Hha ...! Ukuphalaza! hha ...!* [Vomiting …!] I saw it as the most difficult one.

This was expressed with fear of imminent death, saying:

> ... when you vomit, you could see that you are going straight away *hhayi!* … no I could see that I was losing power, *phela ukuphela kwamandla uyahamba! Ukuphela kwamandla, uyahamba!* [If you are losing power, it means you are dying!]

In their narratives, clients talked about the side effects and how these disturbed their lives. For almost all the clients, side effects seem to have played a vital role in non-adherence. The

next sub-topic is about how side effects for ARVs interfered with the daily lives of the people who use ARVs, thus affecting adherence.

5.2.1.1 Side effects affected life routine

The side effects of taking ARVs affected different aspects of the clients' lives. When clients were not getting support and appropriate guidance in order for them to cope with side effects, they made decisions that affected adherence. This included reducing dosage, not taking the pills for some time, or even abandoning ARVs for a while. The two male clients complained about a noticeable increase in the need to urinate, interfering with work and travel. Participant 02 (MC 50-55) says:

> Now if I were to travel by car, they bother me such that I must go and stop the car, now and then for passing the urine **…** Things use to happen like this, they make me urinate a lot. If I am to travel, maybe I am supposed to go to *eGoli* [Johannesburg].

It is interesting that both male participants complained about a noticeable increase in the need to urinate; however, it was not clear what treatment regimen they used, and therefore the relevant cause could not be established. Participant 01 (MC 30-35) said:

> *Ukuchamake kade ngichama impela … hhayi mfowethu angifuni ukuqamba amanga* [passing of urine, no, my brother, I don't want to lie] *cishe u two litre kade ugcwala* [approximately, I would make two litre full]. Approximately two litres would be full of urine! Every day in the morning, two litre, every day in the morning two litre [repeating and indicating by his hands to emphasise this one]! *Engichamisa!* [… making me to pass a lot of urine!] – [with a high tone of voice now]. *Engichamisa* [making me to pass urine].

Participant 01 (MC 30-35) did not mention how a noticeable increase in urine affects his taking of ARVs; however, Participant 02 (MC 55-60) did comment on this, mentioning that he does not take them at all when he is to travel, in order to avoid disrupting the journey for the need to urinate.

Participant 01 (MC 30-35) also complained about feeling drugged, and this interfered with his university studies. He mentioned that the pills would keep him feeling drugged for a long period of time, preventing him from studying at night.

> But those ones [the previous regimen], I was no longer studying because, *kade ongathi ngingalidla lingidakwe mpelampela* [the time I took it, it would really – really drug me] as from 10:00, I would look at time, after two hours it would start becoming a drug to me,

> drugging me … it would be until morning until maybe it is about 3:00 … 4:00. *Engidakiwe nje* [just drugged] … while I want to study.

He continued mentioning how the side effect of feeling drugged impacted on his academic performance, saying:

> … *Manje nje* [right now] you see now … 2015 *eyi*! You can see my results [academic ones] they are not really, really, really not good *angithi manje nje ayikho into ekade ngizoyenza uma kuthiwa "dlana"! Dlana!* [The thing is now, there is nothing I could do; if they say "eat!" You must eat!]

Clearly, these side effects affected the participants emotionally. This is considered in the following section.

5.2.1.2 Emotional dimension of the side effects

Some of the participants associated the side effects with death, saying that, with the dizziness, and the vomiting, they felt that they were dying. Participant 01 (MC 30-35) said:

> ... they would drug me such that I would see that no ... I am really going to fall now here, I would fall hitting the ground with my face, now that is what was making me scared, *ehhe*, I used to have dizziness [and] hold onto the house to maintain balance ... These pills are strong; I could see that, no I am going to go [meaning I am going to die].

Participant 03 (FC 40-45) commented that she had reported the vomiting and feeling of dying to the health care worker:

> I said *hhayi bo! Wentombazane* [Hey, young lady], I am dying I can see, if I am not even able to raise the head! I am dying! *Ngiyafa nje qoboqobo!* [I am really dying] and you are still pushing me to it!

Here it becomes clear how the lives of the individuals taking ARVs appeared to be interrupted and in some cases threatened by the experience of side effects. There were various responses to participants reporting these side effects to family and health care workers**.**

5.2.1.3 Response to complaints about experiences of the side effects

Three of the clients reported that when they complained about these side effects to family members and health care workers, they were told that they will eventually get used to them. Participant 01 (MC 30-35) said:

> ... because now, I am looking at life, I have been hearing them saying *"uzowajwayela, uzowajwayela"* [you will get used to them, you will get used to them]. And as am saying that at home, I made them aware, and my sister, my sister is already eating them, now she kept on saying *"hhayi uzowajwayela, uzowajwayela uzowajwayela* [no, you will get used to them, you will get used to them, you will get used to them].

He commented that he tried to get used to them, but found it very difficult:

> *Eyi!* While I am trying, at school, hoping that I will get used to them, I will get used to them, *Hhayi, ayijwayeleki into ekudakiwe* [No! It is not doable to get used to something that has drugged you].

A health care worker responded similarly to Participant 03 (FC 40-45):

> When I came here to the clinic, no I was still fetching them from *Emtshezi* [Estcourt hospital]; the lady there said *uzowajwayela* [you will get used to them].

What has been mentioned by Participants 01 (MC 30-35) and 03 (FC 40-45) "*uzowajwayela*" (you will get used to them) is a rather encouraging response. However, when the clients realised that these side effects were persisting, they made their own decisions about ARVs.

Some of the responses to these complaints were not very supportive or encouraging. When Participant 5 (FC 30-35) complained about painful feet and her growing stomach, she said that the health care worker's response was:

> *"Ngesikhathi uqala amaphilisi sakutshela nje ukuthi amaphilisi anama* side effects, *manje uthi senzeni-ke thina*?" ["We have told you when you started to take pills that the pills have got side effects! Now, what do you want us to do?"]

This shows that there is a lack of empathic support from some health care workers. The users of ARVs continued experiencing side effects despite the responses from their supporters, professional and non-professional, and in most cases this affected their adherence to ARVs. Clients then responded to side effects in various ways.

5.1.2.4 Clients' responses to side effects

In response to their experience of the ARVs, all of the clients interviewed made their own decisions about their ARV treatment. These included abandoning ARVs for a while, not taking them at certain times, reducing the dosage, seeking alternative treatment, or continuing them. Participant 2 (MC 55-60), who complained about increased urination, said:

> ... the urine ... it happens frequently such that if I am to travel by car *ngivele ngingawathinti, ehhe, ngize ngiwathinte ntambama* [I just don't even touch them until afternoon] … *ngize ngiwathinte kusasa,… mhlambe ngeqise usuku nje lonke ... ngoba kufanele ngiwathathe ekuseni ngiphinde ngiwathathe ntambama* [Or until tomorrow … maybe I skip the whole day ... because I am supposed to take them in the morning and in the afternoon as well]. But then ... it means maybe it happens when maybe I am to take a long journey … it is just that, maybe it could be one day maybe two days … *yebo*.

When asked about the most difficult times on ARVs, Participant 03 (FC 40-45) mentioned a loss of power. Rather than continuing to complain about this side effect, she decided to reduce her dose:

> If you are losing power, you are dying, yes I would lose power! They said you are going to get used to it *ngathi woh ukukhuluma ukuhlupha angivele ngithule*, [I then said, oh ... if I talk it's like I am nagging them ... let me just keep quiet], I will put aside the big ones and just take the only other one.

When Participant 01 (MC 30-35) saw that the ARVs were interfering with his studies, he decided to stop them:

> The thing is now I was seeing that ... *ehh! Ngiwamise* [I would stop them] *ehhe*! You see if I stopped them today, I would be able to study at night [with a faster pace and higher tone of voice now] ... it would be possible to study at that time**.**

When she was talking about the difficulties experienced by her clients taking ARVs Participant 09 lay counsellor (L/C) said:

> Sometimes I can see that it is ... maybe not easy for them to take their treatment because others would say, the treatment makes him/her vomit … That is what they would say.

It is interesting that some of the clients were still complaining of the side effects even on the regimen they were using currently. Some had already made adherence-related decisions. For example, one of the participants who is already on the second-line regimen, and still

complains about side effects, has decided to take only the evening dose to avoid vomiting. She mentioned that since she is only taking the evening dose, she is no longer vomiting during the day. This differs from the expected treatment dose of pills which is twice a day, in the morning and in the evening.

In addition to the side effects, pill burden and treatment fatigue were issues which affected adherence.

5.2.2 Pill burden and treatment fatigue

Two of the clients used expressions that show that they feel overburdened by the number of pills they have to take and prefer a single dose treatment in the form of a fixed dose combination (FDC), which are three pills in one tablet. Participant 02 (MC 55-60) said:

> ... *ngashintshelwa kuyo le nqumbi esengiyiphuza manje* [I was changed to this heap I am drinking now] … *ehhe*.

Participant 03 (FC 40-45), after an unsuccessful attempt to be switched on to the single dose (FDC), said:

> … *ngiyeke kuso lesi siwakla*. [Let's leave it alone, I will have to take this bundle.]

Both of these participants expressed their dissatisfaction with taking a number of pills rather than a single dose. *Isiwakla* and *inqumbi* (heap) are both labels that exaggerate the amount of pills. To express his unhappiness about the number of pills and preference for the FDC, Participant 02 (MC 55-60) said:

> **...** because they are too much, these pills I am eating … they are not like those ones … [pause] that one I was taking, it was just one pill … now they are two.

Participant 05 (FC 30-35) commented:

> I don't know if I had no appetite because I was consuming a lot of pills or the other doctor's pills or the *Procydin* [an antioxidant] itself, but I was drinking or consuming lots of pills.

While the clients using ARVs expressed their dissatisfaction with the number of pills they were taking, there was also an experience of being tired of taking treatment for a very long time. This is referred to as treatment fatigue. The following extracts demonstrate how taking treatment for a long time becomes tiring and thus a barrier to adherence. Participant 09 (L/C),

when she was still talking about the difficulties her clients expressed about taking ARVs, said:

> Someone would report that he/she cannot drink the pills every day … yes it would be better if they would have a break on their treatment.

Participant 10 (L/C) referred to clients stopping treatment for a similar reason. She commented:

> People always have their own reasons … but when you talk to him/her nicely, someone may tell you that ... someone said that "it is just painful to know that at 20:00 you must take the pills"; others are complaining about fatigue, that it is just tiring.

The same issue was also highlighted by Participant 12, a NIMART Nurse (NN):

> It is because it's a long time treatment; it's not like treatment of six months like TB, you know. HIV is not curable, they have to take this treatment lifelong and sometimes, ah.

Another medicine-related barrier involved a lack of improvement on the ART. This potentially led to loss of faith in ARVs, likewise affecting continuing with the medication.

5.2.3 No improvement while on ART

Some clients took the ARVs for a number of years but did not see an improvement. Some believed that after taking ARVs for a while, there should be a difference and they should no longer be bothered by symptoms like severe loss of weight or serious diarrhoea.

Participant 03 (FC 40-45) said:

> Years had gone by just about three … four years, there was supposed to be a difference there but there was no difference, the only thing I was getting thinner, *nakhu ngizofa ngihamba* [I could see that I was dying while I was walking] *Hhayii* [laughing]... I could see that I was going now [dying]. They kept on saying "Don't you see that you are going?".

Participant 02 (MC 55-60) said:

> *Ayi*, what started was *Ngivele ngikhishwe yisisuke mfowethu* [I started now having running stomach, my brother], I had a running stomach! [ending with a high tone of voice and pause] It was March! *Ngakhishwa yisisu ukubhubha* [I had a severely running stomach - like it was an end of the world]. I had a running stomach, running stomach! Running stomach! Running stomach! [repeating four times emphasising with hands and a fist] while I was there in Free

> State, I went to their clinic there, *errr* the, Phuthaditjhaba clinic. Even there they tried to help me, *kodwa nje kwashaya eceleni* [it didn't work]. The running stomach never stopped, it never let me alone … the stomach never let me alone, until I came to this clinic. I told them that the stomach is really giving me a problem. They said to me let us check the CD4 count and check the viral load as well. *Eyi!* They checked me [they did my check-ups]; they said to me "Hey man, your CD4 count has dropped here. It is not going well. And your viral load is high, it is at about 23 000". Yah! They said to me, no, it is not going well. And then from there I rushed to doctor Mzinyane [snapping a finger].

These extracts illustrate the difficulties the participants had in taking ARVs. Although they did not directly link this to poor adherence, these experiences may lead to doubts about effectiveness of ARVs.

All the medicine-related issues discussed above may also have played a role in one way or another in the search for and use of alternative-medicines.

5.2.4 Traditional medicines

Some of the clients talked about resorting to traditional medicine when they did not experience any improvement while on ART. They seemed to be doing this to deal with some of the symptoms such as loss of appetite or when they did not feel well. However, only two participants mentioned use of alternative medication while on ART. These two participants mentioned use of Procydin and *okwesintu* (traditional medicine). Participant 02 (MC 55-60) said:

> I would not know how it is going because *ngibuye nami ngiphuze iziphuzo lezi zesintu, ehhe ... angimile nakuzo.* [I sometimes drink these drinks traditional medicines … ehhe … I have not stopped using them either.] *Ngiyapeyta, ngiyaphalaza ngenze zonke izinto lezi* [I take enema, induce vomiting, and do all the other things].

Participant 05 (FC 30-35) mentioned the use of Procydin, which according to Lekhooa (2015) is a herbal traditional immune booster. Participant 05 (FC 30-35) said **"**I once used Procydins" and the participant went on describing why she used Procydin and that it, at some stage, proved to be too expensive for her:

> I once used Procydins in the mornings but since Procydins were over my budget, I stopped using them because I had no money anymore. I heard that Procydins help a lot ... Yes, Procydins help because I had no appetite, but after using Procydins, I had appetite once again

> I don't know if I had no appetite because I was consuming lot of pills or the other doctor's pills or the Procydin itself.

The use of alternative treatment together with ARVs was also mentioned by a counsellor and a community care giver; these health care workers linked this use of alternative medication with ART interruption. Participant 07 (CCG) mentioned the use of traditional medicines as one of the barriers that leads to defaulting. They commented that the clients' use of traditional medicine seems to be motivated by looking for a cure:

> ... while believing that the pills are working, but something on the other hand you would see that *hhayi* … they have that faith that something else on the other side can help and end up stopping the pills *ehhe.* You would find that after that they default *errr* … you would find that most of the people *basebenzisa izimbiza lezi abakholelwa kuzo ukuthi yizo ezisebenzayo noma ngabe ... ayingasali ngiyawadla amaphilisi kodwa imbiza ethile angiyithole nayo*… [are using traditional medicine which they believe that it is working even if they do eat/take the pills, but a certain traditional medicine should not be left behind, I should also get it] *errr* … most of the times it is … *izimbiza* [traditional medicine].

And Participant 09 (L/C) commented:

> … Others, more especially in the past year, they were reporting mostly the story of going to a person whom they were saying is helpful. When they have gone to that person they come back saying he said he is going to help them … the healer … a traditional healer.

When this was followed up, exploring whether her clients were really getting 'helped' when consulting the traditional healer, she said:

> I would say they were not getting helped because they would quickly come back here … and sometimes a person would come back … you find that a person has some illness … when he/she comes back, he/she would say … when being asked why he/she was no longer coming to collect treatment, then he/she would say, no I was there.

The traditional healer's advice was in contrast to medical advice from the clinic:

> … They were … saying … they said … he said to them, they must stop taking pills and drink his medicine because his medicine will eradicate the virus.

The inclination to stop ARVs seemed to be coming from the healer him/herself, with claims that her/his medicines will cure the HI virus. A nurse emphasised how the use of traditional

medicines affects adherence and how this relates to clients' search for a cure. Participant 13 (NN) comments about this usage and how it affects adherence:

> *Okunye kukhona lokhu ababuye bathembisane kona ezindaweni zokuhlala izigubhu lezi ababuye baziphuze zesintu* [The other thing is that there is that thing which they promise each other, where they stay, these traditional medicine, these bottles which they also drink] ... by the time they are taking that, so often that they would stop taking the pills ... by the time they are taking that, so often that they would stop taking the pills, because when you ask others what happened exactly, they would say that, no there is something that they have tried which it was believed that it finishes/cure the virus [HIV].

She comments that clients seemed to go to traditional medicines, and when they are not effective, they come back to the clinic, leading to poor adherence and interruptions in the treatment regimen:

> You would find that they have stopped on the other side [referring to pills/ART] and focus on the other side *amabhodlela omuthi wesintu* [traditional medicine], and after they have realised that it doesn't work for them, they come back to us … others would miss the due date.

Some clients used alternative treatment in combination with ARVs and did not abandon ARVs. However, the nurse's account illustrates how use of alternative treatments can lead to the client abandoning ARVs.

If seeing no improvement while using ARVs led to poor adherence and even to the search for alternative-medicines, one may expect that if there is improved health, adherence would also improve. Sadly, the data highlighted the opposite. When the medicine was taken and health conditions improved, some users of ART stopped taking their treatment.

5.2.5 Improved health

The results highlighted that some of the clients seem to have had a poor understanding of the need for ongoing treatment when they have recovered from the opportunistic diseases they may have had because of HIV infection. This reason for failure to adhere was pointed out mostly by the health care workers.

Participant 09 (L/C) mentioned that some of the clients may not come up with serious reasons as to why they have stopped taking ARVs. She said:

> A person would just say no, he/she just saw that he/she was better now and then he/she stopped taking them … and then he/she abandons them … when he/she feels better and say I am now coming back because *errr* … I am now suspecting something … and he/she comes back then.

When Participant 13 (NN) was responding to a question about clients' reasons for non-adherence, she said:

> Others would say "I saw that I was better", but then when he/she started the treatment, he/she was told that he/she's going to take the pills for rest of his/her life … "I saw that I was better, then I stopped" ... *Umhh* … the others *ehhee* … the other thing which make them to stop is this thing where a person would say that "I saw that I was better" and stops.

For Participant 14 (NN), this was one of the main reasons for lack of adherence:

> ... others stop them due to that he/she no longer likes to drink/take them anymore. Yes, there are those who say so … they say they did not like to … because he/she was well.

She also mentioned that clients may have wanted the ARVs to treat a specific condition and when that condition is gone, the client may stop taking them:

> Others would start because they are facing a certain problem … for now maybe he/she's having a non-stop diarrhoea and start ARVs and become well, he/she will see that he/she's well … well ….well [drawn out].

She commented that clients were influenced by others in the community who may have stopped taking ARVs themselves:

> When he/she's having a conversation with others, they would mislead him/her, telling him/her that "I also stopped them [ARVs]; nothing will happen, after two years you will be fine, you won't have anything". Eventually, he/she stops them for real and come back again.

In these accounts, improved health and the influence of peers become barriers to adherence.

Communication between the health care workers and their clients is critical because health care workers are the ones who are expected to communicate all the critical information about taking medication, support clients on ART, and counsel them on the challenges that may be experienced by the users of ARVs. The success of ARVs may be hampered if there is a poor relationship and communication between the health care worker and the client using ART.

5.2.6 Communication with health care workers

Some of the lay counsellors commented on the relationship between the clients and the health care workers. They said that some clients avoided coming to the health care service because of the way they would be treated, for example, being shouted at for missing appointments or for defaulting their treatment. A lay counsellor (Participant 09 (L/C) commented:

> … and then he/she decided not to come at all because he/she thinks that he/she would be shouted at, and then he/she ends up not coming at all … and come back when he/she is seriously ill … when he/she is avoiding being shouted at … If he/she does not get shouted at, you would see that she/he gets better.

Nurses also mentioned that problems with communication affected treatment adherence. Participant 13 (NN) mentioned that clients may not come for treatment after defaulting because they thought the nurses would shout at them:

> Others would miss the due date; they would say "No I was afraid that you would have shout at me!" Why would we shout at them [raising voice]? Because these people are old, isn't it? We are not shouting, *siyabonisana* [we are just having a conversation with each other]… Sometimes you are trying to dig out the answers from the person, wanting to know what happened; you want to look for the reason that made the person not able to come for collection.

In this account, the nurse positions the client as not understanding the nurse's probing questions. However, another nurse, Participant 12 (NN), referred to the clients as lying to them and providing incorrect cell phone numbers:

> ... but sometimes they give us the wrong numbers, they give us the wrong numbers. Patients are ... are … I don't know whether *ehh*. Whether, what they think we are gonna do with their cell numbers, because they sometimes even give us the wrong cell numbers themselves, because sometimes when you try like *emhhhmm* … for example, we trying to do the loss to follow babies, the phone numbers are not going through. It's the wrong numbers that they have written on the files, so we don't know how to trace these patients, we don't.

This participant showed her distress and frustration with clients:

> We don't know whether they are really living at those areas or they lied to us. So we believe what the patients tells us, but it difficult for these transfer-ins because mostly they come from Johannesburg, far in those Soweto clinics there … [dragging the word]. They say, no they were on treatment.

Another nurse also commented on clients 'lying' to them. Participant 14 (NN) expressed her exasperation with this behaviour:

> There are, those mothers who stop the pills while they are HIV positive and continue breastfeeding the baby; others would even lie when they come here at the clinic … "Is the child being breastfed?" They would say "no". I don't know what should be done … [laughing].

She added saying:

> … she would say no, while you are busy writing that a baby is being formula fed, formula fed, whereas she knows that she is breastfeeding the baby, *ehhe* ... You would be surprised when the child is HIV positive, when you follow her story thoroughly and accordingly, you would find that she was not only breastfeeding the baby, but she was mix feeding the baby.

And she added that:

> ... they say one thing and do the other. It seems as if they don't actually see the danger [giggling].

This introduces the question of trust between the health care worker and the patient. In an earlier extract, a nurse commented that clients feared that they could be "shouted at". From the above narratives, one could see that there is an issue about communication, as well as issues of trust between the nurses and the clients. Clients seem to fear the nursing staff, and nursing staff are frustrated at the client not telling them the 'truth' about their health practices.

The next section presents the issues that are not medicine or person related but rather relate to access. The clinic in this study serves a relatively remote rural community. Access to treatment affects the economy of households in the area. The next section will discuss socio-economic issues and how poverty affects access to treatment and adherence to medication.

5.2.7 Socio-economic issues (poverty)

Poverty appeared to be affecting adherence negatively through lack of funding for transport to the clinic to collect ARVs, thus making ARVs inaccessible. Poverty also affected the availability of food in the household, affecting adherence. Some of the participants spoke at

length about how lack of money for transport affects access to ARVs, while some participants felt that it is not easy to take ARVs without food.

5.2.7.1 Difficulties relating to taking ARVs on an empty stomach

Two of the participants using ARVs talked about the challenge of taking pills on an empty stomach. Participant 02 (MC 55-60) said:

> I have to eat early [pause] because now if I take them without food ... *ayangigqilaza* [they enslave me/they give me problems]. *Ayangikhweba nje impela* [it becomes a real problem] … [pause] … *ehhe angiqeda amandla* [they make me feel tired].

Participant 03 (FC 40-45) commented how lack of food made her skip doses:

> Yes, there are difficulties because you would not just take them without eating and just take them like that, just saying that because now they are available, you are taking them ... I would not take them, I would leave them alone ... I would tell myself that I would not die in just one day by missing one dose.

5.2.7.2 Money for transport to the clinic

When responding to the question about reasons for non-adherence, a nurse (Participant 12 NN) commented that the clients said that they could not pay for transport to the clinic:

> Also, it's like ehh ... ehh ... they would say they don't have transport, they don't have money for transport come to the clinic.

She also believed that this was the reason for defaulting on ART:

> All the time, I think it's more about the transport *mhh* ... and the clinic is ... is like far for them, because we only ... its one clinic here in Loskop for them, and the areas are far wide out, you know?

She also commented on the nature of the rural context and the distances clients had to travel to the clinic:

> And the very deep rural …so they can't access the clinic; they have to pay like I don't know ... 30 something like 30 Rands or something to come. Single trip is 20 *aahh* ... or 30 Rands between 30 or 20 Rands to come to clinic, *yah*.

She elaborated that the limited transport options also affected their clinic attendance:

> ... and then the transport come early in the morning and then it goes early, so if they come early and they not even seen at the clinic, they need to catch the taxi back, so sometimes it's you know! It's difficult for them because the, the ... the far-out areas, they leave early from Bolton to go to that maybe *ehh* ... *ehh* ... that place *Sinikamehlo* you know far … it's very far *mmhh* … It's very far out.

Another nurse, Participant 13 (NN), also highlighted the challenges of rural clients getting to the clinic:

> ... they usually say maybe a person haven't come for collection, or he/she does not adhere to the treatment accordingly, when you look at his/her viral load and ask where the problem is, others would tell you that they had no money for transport, then I couldn't come on due date.

The lay counsellors and the CCGs also pointed out the challenges relating to transport money to go to the clinic. Participant 09 (L/C) commented:

> Others would complain about the transport … you would find that one did not get the money to come on that day and then he/she decided not to come at all.

Poverty thus affects access to treatment and adherence to treatment due to lack of food. In the next section, mobility and migrant labour as disruptions to adherence to ART will be discussed.

5.2.8 Mobility and migrant labour

Since the communities around the Injisuthi clinic are rural and poverty stricken, many of them travel far from their homes in search of work. This is also the case for the clients who are taking ARVs. Most of the health care workers highlighted that adherence is affected by the fact that people move around in relation to job opportunities, which affects their access to treatment and therefore adherence.

Participant 12 (NN) said:

> Ok, some people would say that they went to ... to find jobs like probably in Durban and Johannesburg.

Participant 13 (NN) commented:

> ... others would say I got the job maybe in Bloemfontein, *ay* ... then [drawn out], you see …?

The third nurse, Participant 14 (NN), also commented on this:

> *Ohhhhh* ... o …… others they stop because they went to work - a person would say I got a job in Johannesburg … *ehhe,* then he/she didn't take a transfer letter, he/she didn't have time … saying that he/she didn't get time because he/she had already gone to work ... sometimes they are working like far as domestic workers, so they don't get off all the time to come back home, to come and collect treatment, *uhhumm.*

Working far away from the clinic meant that they would need to take time off from work to visit the clinic. Participant 13 (NN) said:

> Others would complain that they are at work on that side, so they don't want to be absent.

These people would not attend the clinic near their work. A nurse argued that they preferred the familiarity of their own clinic. Participant 13 (NN) said:

> And that a person is not familiar with the place; he/she would be scared to even go to the clinic, a person would want something that he/she is familiar with … that he/she knows that I will do this and that ... until they get their treatment in that way.

Some clients would have their treatment collected on their behalf, and have it sent by taxis to Johannesburg or Durban. Participant 13 (NN) referred to a mother who opted to collect the treatment for her child and send it in this fashion, after her child defaulted and became ill. She said:

> ... because their pills are collected by their mothers most of the times, I would ask why doesn't she collect near where she is working from? Her mother would say she had once done that but she ended up not taking her pills and my child came back home severely sick … Now I am making sure she gets her pills; now I am actually the one who sent them as a parcel to her; those are the appearing reasons.

The lay counsellors also commented on how migrating for work reasons affected adherence. Participant 10 (L/C) said:

> Someone will tell you that *eyi*! "Me I have found a job at *eGoli* [Johannesburg]", the way … the the … the place, *eyi!* "I was not able to take the transfer letter" … *errr* … someone would say *eyi!* "It is the kind of a job that I am doing; I travel as a trucker, as I travel with a truck sometimes I send someone, and you would find that when I send someone, the person that I would have sent would come back saying 'A*yi!* They now need you to come personally, it has been a long time being a sent … sent … sent …' … but I can tell the reason … that it is the

> working conditions I am working under, of which *Ngigxamalazile* [I have one leg in the other situation and the other on another]. I cannot abandon the job, while I do want to continue taking my treatment … *yebo*, and the job is here waiting for me".

Three work-related issues that seem to be coming up here are: 1) finding a new job as far as 400 km away in Johannesburg; 2) the type of job that one is doing (e.g. being a trucker); and lastly 3) not being able to go to the clinic for treatment, because of working hours.

Apart from work-related travelling, health care workers highlighted travelling and being away from home as one of the reasons mentioned by their clients for stopping ARVs. Participant 13 (NN) commented

> *Ehhee* ... actually it is the visiting thing. A person would say I was not here; I was in Johannesburg.

She said that someone might disappear for three to five months and come back later on. When the nurse asked why this was, the client might say:

> That is the thing … I had visited somewhere then I wasn't able to collect ... It is just those things they use to say, my brother.

When users of ARVs were away from home, because of work or social reasons, their adherence was affected.

The data also show that there are issues of gender in various forms that appeared to have affected taking of ARVs.

5.2.9 Gender and social organisation (masculinity)

Certain forms of masculinity played a role in ARV adherence for both men and women. Participant 10 (L/C) highlighted that the difficulties with ART adherence are different for men and women said:

> It differs with gender … the challenges for males and females are not the same … *ehheee*.

She went on to deal with challenges for men on ART saying:

> Males … usually it is the behaviour change that the problem they are having … the change is that there are things which they have to stop when they start the treatment … things which are

habits like alcohol and cigarettes and that they have to use condoms when they engage in a sexual intercourse.

She also went on to talk about how a man is perceived in the community, and how he might avoid being seen as 'sick':

> Something else, it depends on areas. As for these places where we are, which are rural areas, they look at it as if the man is not a real man if they drink pills; they believe that a male should just have live naturally.

This need to be seen as 'well' rather than 'sick' might relate to maintaining a particular image of being a man and not being associated with HIV which is stigmatised. She said:

> ... others see themselves as not normal when they must drink the pills ... They would want to be normal just like everyone else because he/she sees him/herself better.

Another aspect of the social organisation of gender in rural contexts is how female clients on ART were affected by being under the control and supervision of other people. If they were married, they might find it difficult to continue taking ARVs for they feared being stigmatised and discriminated against by their husbands and in-laws.

Participant 13 (NN) mentioned that a client may default because the husband is in denial, which could lead to conflict that may prevent the female partner from fetching ARVs from the clinic, thus defaulting:

> Others will tell you about the arguments/problems between them and their husbands, that they don't want them to take the pills, so as he was home, maybe he works in Johannesburg: "As he was present at home. I then couldn't come for collection."

The denial of HIV as well as the stigmatisation of the illness was evident in men's exertion of control over their wives' movements Participant 13 (NN) said:

> … because they say that he says that he doesn't want any HIV news in this home, and the mother/women will end up not collecting her pills and you will find out that she is breastfeeding at the moment.

Participant 14 (NN) also commented on these tensions within the family which affected ARV adherence:

> ... the husbands do not want them to take ARVs. They [husbands] still have that belief, that they themselves don't have HIV. Even if the female/mother does have it, they believe that they don't have it [HIV].

Participant 13 (NN), also comments on a 'problematic' husband affecting a mother's practices. Continuing with breastfeeding might put the child at risk of HIV infection. With sadness, she said:

> We find out that others are breastfeeding the children. They've tested and given FDC [fixed dose combination – a combination of three ARVs in one pill] and as time goes on, she stopped collecting but she still continues with breastfeeding the child and tell you about her problematic husband … It is just those things just [drawn out], which we usually come across.

Another nurse, Participant 14 (NN), also commented on the 'problematic husband':

> *Ehhee* ... yes it is at times really difficult, especially here in rural areas because the women are married and their husbands are problematic, usually others will verbalise it … mostly the females, the problem is the husbands, the husbands do not want them to take ARVs. A person would default, defaulting because her husband doesn't want her to come and collect ARVs, *ehhee*.

Stigma related to HIV was also a factor in ARV adherence. It affected disclosure of one's status and the taking of ARVs.

5.2.10 Stigma, discrimination, non-disclosure affecting adherence

It has been highlighted that taking of ARVs is affected by stigma, discrimination, and non-disclosure. Most of the participants highlighted that there is still a lot of stigma around living with HIV in the communities where they live. Because of fear of being stigmatised and discriminated against, most of the people opt not to disclose that they are living with HIV and therefore taking ARVs. This means that, very often, people who are taking ARVs do so alone and without support, which affects their adherence to treatment. Participants on ART highlighted their preference to disclose to their families. However, they were afraid to disclose to the community and even to the CCGs. This fear seems to be coming from stigma and therefore fear of being discriminated against.

Only one participant on ART mentioned the non-disclosure of her HIV status and two participants on ART referred to issues relating to stigma and fear of being discriminated

against. Participant 04 (FC 30-35) mentioned that she was taking her treatment (ARVs) in secret and feared to take her ARVs openly because of the fear of being stigmatised. She mentioned that during that time, taking ARVs was still seen as a shame, saying:

> *Eyi* I was hiding them [referring to ARVs] … [giggling and pause] I was hiding them, maybe, maybe I would hide them in the bag, I would not be able to put them maybe in the wardrobe you see *ehhe* ... for them to just stay in the hidden place ... *errr*... it is just that, it [living with HIV and therefore taking ARVs] was not that widespread, I don't know how, there were still very few people using them [ARVs], and that I would see it [using ARVs] as a shame, something like that [pause] *uhhu*.

This participant commented that, nine years ago, it was difficult to take ARVs when one had not disclosed, due to fear of being discriminated against. She refers to the shame of taking her medication:

> You would be scared even to drink them … it was 2008. You would be scared … You see then ... [giggling] … you would fear the people. You see, maybe you were just sitting in the house; then you would fear to stand up take them and drink them, now, *hhayi*.

Participant 05 (FC 30-35) also commented on how people would stigmatise those on treatment:

> *Uhh* … nothing. Besides that people like talking badly … you will find that in your presence, while you are on these pills, they would be talking about someone else, saying so and so has HIV and *udla amaphilisi* [is taking ARVs], things just like that.

Participant 14 (NN) also mentioned the presence of stigma when she was responding to the question about the challenges she often heard from her clients, saying:

> ... because no! Coming daily to the clinic *hhayi-i* ... they say it turns out that people watch them … stigma is still there.

This stigmatisation affected her emotionally and made her keep her status a secret:

> ... they would talk badly about other people who are taking pills, while you yourself, you know that you are also taking them … That would make one feel pain, but it is just that there is nothing one can do, you would just keep quiet while they are saying what they are saying … The ones who know that they are still negative, they would talk badly about the ones who are already positive.

Her fear of disclosing was reinforced when she observed how people with HIV were stigmatised:

> … *hhayi*, there is still stigma … it is still there because it is just not easy to tell a person about your status, because you would not know if he is stigmatising others or not. Sometimes you would find that, when you are just going, you would hear them stigmatising others.

One of the CCGs also commented on how stigma and fear of discrimination led to non-disclosure which affects adherence to ARVs. Participant 06 (CCG) said:

> Let me just say, the youngsters, the thing what makes some of them not to take the pills, *ukusaba ukuphumela obala nakubangani bakhe axoxe ngesimo ayisona* [it is being afraid of coming out and disclose to friends his/her [HIV] status].

Another Participant 07 (CCG) commented that it was mostly men who did not disclose. This affected their adherence:

> The males, most of the times, what they usually do is that they hide it, they do not disclose. They hide it too much; that's what makes them to default, they are secretive … That is what I usually come across with mostly, they hide it.

Secrecy around one's HIV status prevented clients from getting appropriate information related to HIV and adherence to ARVs. Participant 08 (CCG) commented that she could not provide health education when she went to the household:

> You may find that someone else is still keeping it as a secret... but he/she needs information, … while having it, but still keeps his/her status as a secret… *ihhi.*

Participant 08 (CCG) also mentioned that some of the clients do not like others to know that they are living with HIV. This affected their participation in support group meetings:

> When you say that they should meet you, you will find that the other is afraid of being seen by the other, that he/she is living with this illness, you see?

This CCG also commented that this fear of being stigmatized and discriminated against affected married women and indicated how this affects adherence to ART, saying:

> It was very difficult for people to come and collect their treatment, and they were looking at it as serous disgrace to have that illness and to follow the treatment routine … they were afraid in a way you can never imagine.

Participant 09 (L/C) also commented on this stigmatisation:

> What I would say is … to some, the stigma is not really gone yet … of the fact that they are taking ARVs.

She went on, elaborating that a female client would miss an appointment while hiding her HIV status. When she asked the client why she had not come:

> ... and a person tells you that no, *ngasuke ngifica u…mnakwethu ngase ngiyajika* [when I came here, I bumped into the lady whom I share my husband/boyfriend with] and then I went back. When the person has come to the clinic to collect the treatment.

Participant 10 (L/C) referred to the stigma and people's "negative attitude" to HIV as affecting treatment adherence She said:

> I think it is their own attitude towards HIV ... they still have a negative attitude to HIV. There is still that thing that a person who get it [HIV], is someone who is misbehaving.

She explained how HIV is associated with sexual immorality, saying:

> ... *uke ubone mhlambe uma uthesta abantu abadala athi hhayi ngizotester nje phela mina angisagijimi* [you would see/notice that, maybe, when you are testing adults, he/she would say, no I am here just to test because I am no longer running [sexually active]], *ehhee*.

While still commenting on the difficulties for the clients on ART, a nurse, Participant 12 (NN), referred to the gender issues in these communities. A married woman (a *makoti*) is under the supervision of her husband and her mother-in-law. Married women would not reveal their status to their in-laws:

> ... most of them, I would say majority of them, haven't disclosed at home because they are *makotis* at home; they don't want their in-laws to know that they are positive, you know.

Participant 14 (NN) also commented on how non-disclosure made it difficult for married women to attend the clinic. They would be questioned by their in-laws about their frequent clinic visits:

> *Ehhee* ... and that they are scared of their mothers-in-law because they live with them, and the sisters-in-law, since we have extended families here in rural areas, now if you go repeatedly to the clinic, they end up suspecting that [saying] "What is it that you are actually doing at the clinic?".

Lack of disclosure to family might mean that clients lacked support in taking treatment. Participant 09 (L/C) commented:

> I usually talk to them; maybe you find that someone has a problem when he/she has to start treatment, he/she doesn't know how to take his/her treatment because they haven't told anyone where they live about their HIV treatment.

Married women were not free to attend the clinic or take medication if they had not disclosed to their husbands. Participant 09 (L/C) commented:

> You may find that a person would tell me that her husband has arrived, so she hasn't disclosed to him, and then she will be unable to take her pills.

This lack of adherence to ARV treatment by married women was also commented on by Participant 10 (L/C):

> For females, in most of the times it is disclosure; it's the disclosure with their partners, you will find out that she didn't tell her partner then; now there is problem that she has to hide the pills when she has to drink them … *nakuma*-in-laws *kulaba abasuke beganile* [and to the in-laws to those who are married, or to the family to those who are not married].

Non-disclosure by female clients was related to fear of losing the relationship: Participant 11 (L/C) said:

> … if I and Cele (the researcher's name), we are in the relationship, but it is difficult to tell him … disclosing to Cele that you know Cele as we are meeting for the first time, me I am already on ARVs.

Disclosure by female clients to their husbands was very difficult. Participant 07 (CCG) commented that:

> Others state that it becomes difficult especially those that are married, who are daughters-in-law; they used to say that it becomes difficult to tell their husbands because the husband *usho kuqala ukuthi* [is the first one to say] "If I could find out that you have this disease/virus, I would kill you" *ehhee* … *angithi* [isn't it?].

Participant 07 (CCG) commented that from her support groups she has learnt about how mothers in-law pose a challenge for married women in terms of disclosing, as well as clinic attendance. She said:

> It then becomes difficult, sometimes mother-in-law/the husband's mother would be a problem *ehhe* ... then the wife wouldn't be able to say that "I am like this" [referring to HIV] because it would be said that she is the one who came with this thing and my child was very clean/had nothing [no HIV], *ehhhe*.

There seems to be a stigma-related issue around carrying ARVs in their containers as they make a noise and clients feel it could be noticed that they are carrying ARVs. One of the participants on ARVs mentioned this aspect, which was interesting and hardly, if ever, appearing in the literature. This creates a need for further research on the issue. When audio-recording was stopped, Participant 01 (MC 30-35) said:

> But *eish*! The pills are making noise when travelling with them, even when they are inside the bag [and laughed].

From the extracts above, it is clear that in the communities surrounding the Injisuthi clinic, there is still stigma around HIV. Thus, people who are using ARVs fear that they could be discriminated against by others and therefore they will choose not to disclose that they are HIV positive. This means that they will also have to hide the fact that they are taking ARVs. If their status is not public, and they are not alone in the household when they need to take their medication, this will affect their treatment adherence. Another issue which affected the use of ARVs was the lack of support for people living with HIV.

5.2.11 Lack of support (community, clinic or home)

This issue is closely related to the issue of stigma that is still dominant in the community. All of the clients reported receiving support from their families and people in the clinic setting, but not from the community. Participant 05 (FC 30-35) said:

> From the community, I don't get any support because, I don't know if they know or what, I never disclosed to the community that I am taking the pills [dragging the word].

Support from the community seems to be blocked by the issues of stigma and fear of discrimination, and therefore, clients opt not to disclose that they are living with HIV. Some participants pointed out that 'talking' (leading to fear of being stigmatised and discriminated against) was a barrier to sourcing support from the CCGs, while stigma seemed also to be a barrier when asked about support from the general community.

When responding to a question about community support and CCGs, Participant 04 (FC 30-35) commented on their lack of confidentiality:

> *Hhayi bayasekana nabo*, they are supportive, they are supporting too [giggling] *uhh* … [pause]. It is just that they are then not the same; some then do talk [meaning disclosing/gossiping]… *uhhu***.**

Participant 03 (FC 40-45) commented on why she would not disclose her status to the CCGs. She described how she avoids them in order to keep her HIV status a secret, saying:

> Now you cannot tell him/her something because sometimes we will have conflict with each other. If they come to enquire, I would say "No, I am not sick at all; just go and look for the ones that are sick, me I am fine" [laughing].

This lack of disclosure (because of the fear of stigmatisation) might prevent access to community-level support provided by the government through the CCGs.

On the other hand, one of the CCGs, Participant 07 (CCG), commented about challenges relating to non-disclosure (due to stigma and fear of being discriminated against) at home, especially the married females, and said that the clients on ARVs are getting pressure (instead of support) from their in-laws:

> The home … where she is married to *ehhee* … where she is married to, most of them here are married, *unenkinga yokuthi uzo...manje njalo aye-eclinic njalo aye-eclinic usuyokwenzani* [she will be having a problem of always going to the clinic, going to the clinic … the question now would be, what are going to do [at the clinic]?] They are under that pressure, you would find that she … they end up defaulting, that pressure of "What are you now going to do at the clinic; each and every month, you are going to the clinic"!! Until they default, to the others the problem will be … that as she has hidden her status, at home....

The lack of support in the communities where the clients using ARVs live was also highlighted by a nurse. Participant 12 (NN) said:

> I feel that with the community ... they have a very poor support system because most of them, if you look at it, they don't have their parents living. Some of them, their parents are living out of town because of work purposes, so they don't have [dragging the word] a good support system for them to lean on.

In addition to this lack of community support, the delivery of health services also affected access to treatment and, consequently, adherence to treatment.

5.2.12 Service delivery

Health systems for service delivery at public health facilities affected adherence for clients who are using ARVs. The long waiting times, non-availability of ARVs for clients who are serviced by a mobile clinic, and the need for clients to come monthly for treatment all contribute to poor adherence. Incarceration also appeared to be playing a role in accessing ARVs.

The length of time it took to get the ARVs had an effect on the clients' adherence. Before 2010, clients were only getting their ARVs from the hospitals. In 2010, the government changed ARV policies for managing patients on ARVs. Nurses were trained to initiate and manage patients on ARVs, and this made it possible for the hospitals to send their clients on ARVs to their nearby clinics. Over time, more clients were initiated on ARVs by the clinics, adding to the number of people who were already using the clinics. This increased pressure on the clinic services affected the time it took the clients to get their ARVs. In 2016, the government implemented a policy which made it easy for the clients to access their treatment from the community and places other than the primary health care (PHC) clinics. The rationale for this policy was to help reduce waiting times for clients at clinics and to improve adherence. However, the process to implement this policy has been going very slowly.

Two of the participants on ARVs mentioned long waiting times as a challenge for them. Participant 03 (FC 40-45) on ART said:

> While I was still fetching them from here [in this clinic], I would come at about 06:00am; 12:00 pm would come and pass without getting them and we would have just done nothing at all. While we were still fetching them from here, it was really difficult, to a point that I hated myself, saying why had they brought me back from *Emtshezi* [Estcourt hospital] because there it was better than here!

Participant 04 (FC 30-35) commented that sticking to her clinic appointments was easy but the waiting time was very long:

> It is easier, but it is just that you will have to know that you will come back late … [giggling]. You will come back at night; you get here in the morning and go back at night [laughing] …

> Maybe I leave home at about 7 [am], and from here I would be going back at about 4 [pm]…*uhhu.*

Participant 13 (NN) mentioned that the clinic is too often full. Some of the clients would come and wait but give up and go back without consulting the staff. She said:

> ... and also our overcrowded clinic, others would go back ... when [drawn out] … what would I say? They … [pause] a person would say "I came and went back, because the clinic was full", not because he/she couldn't come inside because he/she saw that people were many and decided that he/she should just go back home.

She also added that they try to serve all the clients that have been to the clinic despite the clinic being full:

> ... it is, yes it is that at the end of the day who is inside we make sure that we leave the clinic while he/she have been given his/her pills. There is no single person whom we send back home and say come back the next day. No! … We do not do that.

Some of the nurses felt that the rules related to medication distribution are also a barrier to adherence. During the time of this study, nurses were only allowed to supply medication for one to two months. However, the nurses who initiate and manage clients on ARVs suggest that, if their clients should be given a three-to-four-month supply of medication, the situation would be better. Participant 14 (NN) commented that:

> At a time even when a person is stable … a person should at least come in two months, or one month; that causes a person to come to the clinic repeatedly. *Kanti ukube abantu banikezwa amathathu noma awu* - four *ngabe bayezake abadoji* [while if the people were being given three or four [supplies], they would be coming without dodging], if they were receiving a bulk, *ehhee.*

Although there is also a policy on the provision of health services through mobile clinics, ARVs were not yet accessed from the mobile clinics during the time of the study. Participant 08 (L/C) mentioned that clients have requested ARVs be available through the mobile clinics:

> ... yes they really do have that request … the mobile [mobile clinic] does not come with ARVs … yes it does come with other pills but not with ARVs …. Now, we did ask from the nurse requesting … but he/she said no, it is still not authorised. *Umhhh.*

Participant 12 (NN) commented that, if a client was imprisoned, their treatment might not be continued, and this affected adherence:

> Some I would say that they were arrested [and] in prison so when they tell the sisters there in prison, they don't believe them that they are on ARVs, so that's how they default … They come out of prison, you know like they are awaiting trial whatever prisoners and then they come to the clinic afterwards when they already have defaulted, so those are some of the reasons.

From the above, it is clear that service delivery could also be a contributing factor to poor ARV adherence. From the above issues it is clear that the health systems, although developed to serve the communities, can be a factor contributing to poor adherence.

This section has reported the many issues that impact on adherence to ART. These barriers were mentioned by some or all of the participants, and the barriers also clearly relate to each other in various ways. Figure 1 is a diagram representing the interplay of the barriers to adherence and their relationship, as observed from the analysis of the data. The barriers as identified by the participants are mapped out, and each barrier is linked to the participants who mentioned it. Most of these issues do not occur in a vacuum but inter-relate with and influence one another.

In the diagram (Figure 1) below, issues that were identified in the data are presented in boxes (in different colours to represent different themes) with an indication of who mentioned such an issue (the participants are listed in a box below the main box). This is done for comparison of the perceptions of the barriers among types of participants. In the diagram (Figure 1), pointed arrows represent the relationship observed among the issues. A double-pointed arrow indicates that the issues affect or influence each other, while a single-pointed arrow indicates that a particular issue leads to the one that is pointed to. In the discussion chapter, the significance of some barriers being mentioned by certain participants and not others will be discussed.

Following diagram figure 1 below, the themes identified in the data are presented.

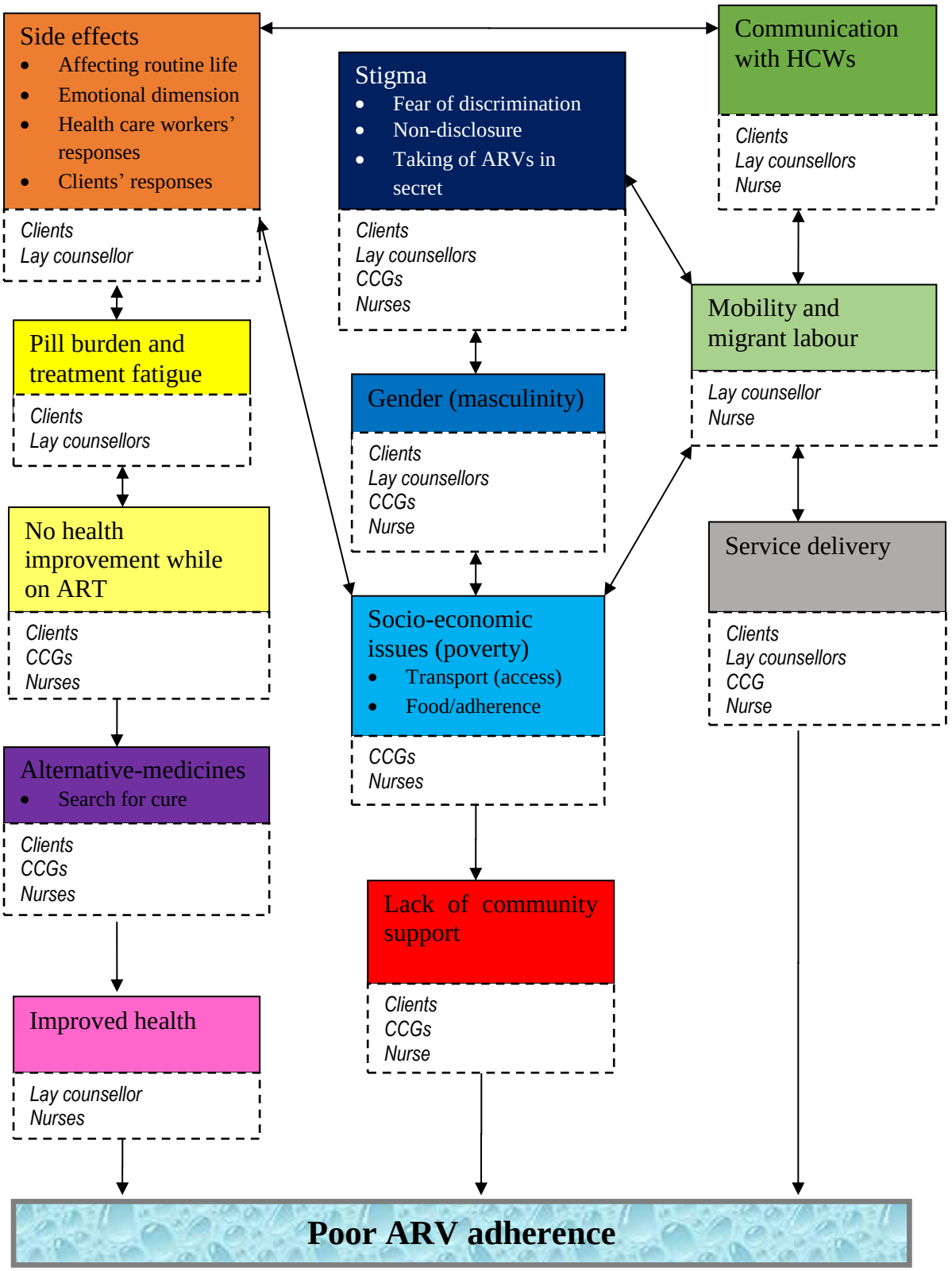

Figure 1: Representation of barriers to adherence and their inter-relationships (issues that are affecting adherence for clients taking ARVs at Injisuthi clinic)

In this diagram, it is clear that in terms of barriers to adherence, for example, when *side effects* (mentioned by all clients, plus one lay counsellor) are experienced by a client on ART, *communication with health care workers* (mentioned by clients, lay counsellors, and nurses) will influence how these side effects will be managed. Poor management of side effects may lead to clients feeling overburdened by treatment and experiencing *treatment fatigue* (mentioned by clients and lay counsellors, especially when they see *little or no improvement* (mentioned by clients, CCGs, and nurses) while taking ARVs.

A combination of *side effects* (mentioned by all clients and by one lay counsellor) combined with *feeling overburdened* by the treatment (mentioned by clients and lay counsellors) could lead to clients *seeking alternative treatments* such as traditional medicines (mentioned by clients, CCGs, and nurses). Some of the clients seek *alternative-medicines* in order to see symptoms disappearing quickly or to cure HIV. This could be also motivated by seeing *no health improvement* while using ARVs (mentioned by clients, CCGs, and nurses). The use of *alternative-medicines* or traditional medicines also affects the clients *economically* because it is paid for and most of these medicines may be very expensive. The use of *traditional medicines* in many cases includes abandoning ARVs.

On the other hand, it is not only seeing *no health improvement* that leads to abandoning ARVs and seeking alternative-medicines. While some of the clients on ART take traditional medicines because they *do not see improvement* on their health when using ART (as discussed above), *improved health* (mentioned by lay counsellors and nurses) can also lead directly to poor adherence.

Another link between the barriers is the fact that HIV is still *stigmatised* (mentioned by clients, lay counsellors, CCGs, and nurses). Stigma leads ART clients to fear that they may be discriminated against should others find out that they are using ARVs; therefore, they hide this fact. Experience of stigma seems to be more severe depending on *gender* (mentioned by clients, lay counsellors, CCGs, and nurses). Married women are most stigmatised and often fear that they may be discriminated against by their in-laws as well as their husbands who want to maintain their *masculinity* and therefore do not come to the clinic to learn about their HIV status. Should a woman find out first that she is HIV positive, HIV would be blamed on her by either her husband or in-laws, which may justify the discrimination against her. Young

married women are under surveillance from their in-laws and might take their medication in secret, miss clinic treatment dates and default on treatment.

On the other hand, the husbands and men who *travel for work opportunities* (mentioned by lay counsellors and nurses), fail to go to their nearest clinics due to *stigma* (mentioned by clients, lay counsellors, CCGs and nurses), and inability to *communicate with health care workers* (mentioned by clients, lay counsellors, and nurses).

It also appeared that some of the clients fail to access treatment when travelling due to challenges related to *service delivery* (mentioned by clients, lay counsellors, CCGs, and nurses), where there are long queues and waiting times while they have limited time to wait. This led to clients not collecting treatment from the nearby clinic when away for work, nor from the clinic back home because they are far away from the clinic they used to go to. Thus, these clients on ART will stay without medication and therefore default on their treatment. Most people from the area go far away for work opportunities because the area is rural and there are few economic opportunities.

Socio-economic issues (referred to by the CCGs and nurses) also impacted negatively on adherence to ART due to lack of funds for transport to attend clinic appointments and due to lack of food to eat while on ARVs. Participants on ART mentioned that *side effects* are more severe if ARVs are taken without food. In the community, there is also very *limited support* (as was pointed out by clients, CCGs, and nurses). As most of these issues happen in the community, without adequate support, individuals using ARVs fail to adhere to treatment.

5.3 Summary

From the above analysis of data, it becomes clear that effectiveness of ARVs or ART depends not only on the efficacy of the pills, but also on many personal and social issues that may facilitate or hinder adherence. ARVs are made, tested and tried in a laboratory, a controlled and easy-to-manipulate environment. It is clear that the end-users of the ARVs themselves, when using the treatment, are confronted with a number of challenges which become barriers to them but which may not have been considered on the scientific-, production- and health-system levels. These barriers influence one another to produce an environment which is not conducive for individuals to adhere to ART.

In this chapter, I discussed the themes that were identified through data analysis and demonstrated how they seem to be influencing each other. I used a diagram to present these themes while demonstrating their relationships with one another. I linked the category of research participants to identified themes to demonstrate the source of the perspectives. In the next chapter, I will discuss these findings while comparing them to the barriers to adherence identified from the literature review. I will also discuss the perception of barriers to adherence across the different research participants.

Chapter 6: Discussion

This study investigated the reasons for failure to take treatment for HIV by people who are living with HIV. Understanding this is crucial for the improvement of support for people living with HIV and using ARVs. Support for people using ARVs is necessary to improve adherence, thus contributing to the United Nations 90 90 90 targets to combat AIDS.

This study investigated how clients fail to adhere to ART treatment, what makes it difficult for ART clients to adhere to treatment, the most common barriers to ART adherence for local clients, and the perceptions of barriers to adherence by clients on ART compared to those of the health care workers. In this chapter, the findings of the study will also be compared to issues that were identified in the literature reporting similar studies.

To do this, a framework that resulted from the merged frameworks of barriers to adherence will be utilised. The merged framework of barriers to adherence (see Table 5) consists of the following headings identified as barriers to adherence to antiretroviral therapy (ART): psychosocial/person-centred barriers, practical problems/socio-economic issues, medication/ therapy-related issues, service delivery-related issues, stigma and discrimination, health control, cultural aspects (traditional medicines), and gender and social organisation (masculinity). This table also includes examples or sub-themes. In this table, an extra column has been added to indicate the category of participants who commented on the issues in the first or second column. This table (Table 5) plays a significant role in the discussion hereafter, for it represents barriers to adherence from the literature integrated with the research participants' views.

Table 5: Merged framework of barriers linked to research participants

BARRIER TO ADHERENCE	EXAMPLES/SUB-BARRIERS	CATEGORY OF PARTICIPANT WHO COMMENTED ON THE ISSUE
Psychosocial/person-centred barriers	Relationship between patient and health care worker; treatment fatigue; pill burden; forgetfulness; lack of health care support; bad planning and running out of ARVs; lack of symptom; sharing ARVs with friends and alcohol abuse; no personal intention to adhere; non-disclosure of status; and lack of sharing information with the patient.	CCGs Lay counsellor Nurse
Practical problems/socio-economic issues (poverty)	Transport problems to get to the clinic; not enough food to eat with ARVs; difficulty in planning ahead to have enough ARVs; and mugging and robbery of ARVs while working shifts.	ART clients CCGs Nurses
Medication/therapy-related issues	Side effects; difficult treatment regime to follow; pills too big to swallow; multiple medicines for one disease state or several conditions; frequent changes in medicines; no improvement; loss of faith in medicine; not understanding significance of medicine; and long duration of therapy.	*All* ART clients Lay counsellor
Service delivery-related issues	Hospitals and clinics not having enough stock; health care workers on strike, poor discipline in clinics (bad service and early closure); being imprisoned (access to treatment).	ART clients Nurses
Stigma and discrimination	Secrecy; fear and lies; hiding of pills; non-disclosure; no support groups due to secrecy and fear of community rejection; and rejection of the disease.	ART clients Lay counsellors CCGs Nurses
Health control	No control over own health; fatalistic attitude ("Nothing I can do will make a difference") and external locus of control; poor health literacy.	*None*
Cultural aspects	Using medicines from traditional healers with ARVs without disclosing to health care worker.	ART clients Lay counsellors CCGs Nurses
Gender and social organisation (masculinity)	Men's need to maintain masculinity and avoid health seeking; women have less power in relationships with men making decisions including about health seeking.	Lay Counsellors CCGs Nurses

What follows is a discussion of the findings of this study. To do this, barriers identified in the merged framework (Table 5) will be used as sub-headings for this discussion. In this discussion, barriers identified in the literature, and part of the merged framework, are compared to the findings of this study. Throughout the discussions, each barrier is also discussed in terms of the perspectives of the research participants in their respective categories.

6.1 Psychosocial/person-centred barriers

Person-centred barriers, according to van Dyk (2013), include treatment fatigue; forgetfulness; lack of health care support; bad planning and running out of ARVs; sharing ARVs with friends and alcohol abuse; no support from significant others; no personal intention to adhere; non-disclosure of status; and lack of sharing information with the patient. In the cardiovascular framework (National Heart Foundation of Australia, 2011), patient-related barriers to adherence include lack of symptoms and burden of therapeutic regimen; these aspects also overlap with other barriers mentioned in van Dyk (2013).

In this study, participants commented that the pills were 'too strong' and 'too much'. Participants seemed to be overwhelmed with the strength and quantity of medication. This seemed to indicate that users of ARVs felt overburdened by the pills they have been using. Although clients on ARVs did not talk about pill burden directly, they indicated their dissatisfaction with taking ARVs as three separate tablets and showed a preference for a fixed dose combination (FDC) of pills. It seems that the client's experiences of taking ARVs are similar to that in other studies.

Pill burden has been pointed out as one of the reasons for poor adherence. Hodes et al. (2016) highlight the link between pill burden and ART non-adherence. Pill burden has also been mentioned in the South African guidelines for adherence (NDoH, 2016b), and in Van Dyk's (2013) theory, it possibly falls under psychosocial barriers as treatment fatigue. In the cardiovascular framework (National Heart Foundation of Australia, 2011), burden of the therapeutic regimen is clearly listed as one of the barriers to adherence. Health care workers in this study indicated that the long duration of ART affects their clients' adherence. This means that for clients to continue taking pills as expected for the rest of their lives, there should be continuous scheduled psychosocial support for people using ARV.

In this study, HCW mentioned pill burden and treatment fatigue as the reasons their clients gave for poor adherence in ARVs. This was mentioned by two lay counsellors and one nurse, empathising with their clients that it would be better if there was a break at some point, as opposed to taking pills every day and forever. Health care workers see this as a tiring and daunting exercise for their clients. The Australian cardiovascular framework of barriers highlighted that long duration of therapy is a barrier to adherence (National Heart Foundation of Australia, 2011). However, this is mentioned under condition-related barriers in this framework.

In contrast to the above, it seemed that if there was improvement in the client's health condition, adherence was also affected. According to the cardiovascular framework (National Heart Foundation of Australia, 2011), lack of symptoms is a barrier to adherence. In this study, one lay counsellor and two nurses mentioned this as a reason for their clients defaulting on treatment. All three health care workers mentioned that some of their clients said they saw that they were better and decided to stop taking ARVs. This factor does not seem to have been identified in other studies. In both the sub-Saharan Africa study (Croome et al., 2017) and the Botswana study (Weiser et al., 2003), there is no mention of improved health as a barrier to adherence. Even the South African adherence guidelines (NDoH, 2016b) have no comment on improved health as a barrier to adherence. In addition, in the eight barriers identified by van Dyk (2013), there is no clear articulation of health improvement as a barrier to adherence. This means that it is also important to support clients who have recovered and are now feeling well, in order to maintain their adherence.

In van Dyk's (2013) framework, health improvement barriers to adherence relate to such things as lack of health care worker support; lack of information sharing with a patient; and poor understanding of need to adhere to treatment. In this study, all clients on ARVs mentioned that they felt supported by the health care workers, especially the lay counsellors and nurses. However, some of the clients indicated that they intentionally rejected support from the CCGs because of stigma and fear of being discriminated against. This indicates a seriously strained relationship between CCGs as health care workers in the community and clients. Interventions to reduce stigma in the community and to improve the upholding of confidentiality by the CCGs side should be considered.

The relationship between the client and the health care worker seems to play a critical role in adherence. If the relationship is negative, it may affect the client's adherence. According to Dale et al. (2014), general medical mistrust was seen to be contributing to low adherence and thus poor health outcomes in African American males living with HIV in America.

According to Campbell et al. (2015), reprimands (by health care workers of clients) are linked to poor adherence to ART and poor adherence to clinic times. In this study, only one participant on ART commented on being reprimanded by a health care worker when complaining about side effects. However, health care workers (nurses, in particular) highlighted how clients seemed fearful of them and fearful of being reprimanded. Both lay counsellors and nurses said that clients said they missed clinic appointments because they were afraid of being reprimanded for not adhering to treatment, or for missing other appointments.

Van Dyk (2013) mentioned poor information sharing with a patient as a contributing factor to poor adherence. The same ART client, who said she had been reprimanded, highlighted a concern about her blood results not being shared with her. From the HCW's perspectives, clients were not always honest (e.g. they gave them the incorrect contact information). Whether the clients were deliberately deceiving the HCWs is not clear, but this relationship of suspicion, and the fact that the HCWs seem to feel frustrated at not being able to maintain continuous contact with the clients, have consequences for adherence. Poor communication skills and lack of information sharing by the health care workers lead to patients adhering poorly. When the clients feel that they may have not adhered to treatment as prescribed, they fear coming to the clinic, thus they miss appointments. This means they will not have sufficient medication. When tracing clients, this attempt could be unsuccessful due to wrong contact information given by the clients at the facilities. Another system for tracing clients is the use of CCGs. This too could be unsuccessful because of the wrong directions given by the clients and due to the fact that most of the clients do all they can to avoid contact with CCGs.

Previous literature has commented that nurses are aware of the hardships faced by the clients and therefore empathise with their clients on ARVs (Campbell et al., 2015). In this study, it is the nurses who mentioned the issue of patients fearing that they would be reprimanded and thus defaulting. According to the South African guidelines for HIV, TB and NCD (NDoH, 2016b), the patient and health care provider relationship is mentioned as a barrier to

adherence from the cognitive perspective under patient-related barriers to adherence and retention in care. It is mentioned that the perception of the health care provider could be a barrier to adherence. Therefore, improvement of the relationship between the client and the health care worker should be considered.

6.2 Practical problems and socio-economic issues

In van Dyk's (2013) framework, practical problems include transport problems to the clinic; shortage of food to take with ARVs; challenges related to planning ahead to have enough ARVs when going away or travelling for work; restrictions in getting time off from work; working shifts; and getting mugged and robbed of ARVs. In this study, problems related to transport to go the clinic were found to be most dominant amongst the practical problems and socio-economic issues experienced by clients. This is due to the fact that Injisuthi health clients are all from a rural setting; therefore, to access the clinic means travelling fairly long distances. This relates to the challenge of not having money to pay transport fees to go the clinic to collect ARVs. This barrier to adherence is also recognised by the Department of Health. The adherence guidelines (NDoH, 2016b) mention lack of transport money to the clinic as presenting behavioural and socio-demographic challenges under patient-related barriers. Some of the clients in my study miss their appointments due to unavailability of funds for transport; sometimes they had to wait until the pension (government social grant) date before they could go to the clinic. This was mentioned by two nurses and a CCG, but not by the ARV clients.

While van Dyk (2013) referred to losing ARVs through robbery, in this study, a CCG referred to a client losing ARVs because a family member had stolen them, because s/he could not go to the clinic because of lack of transport money. In this case, adherence is affected because of insufficient medication and lack of transport funds. Lack of transport money as a barrier to adherence has been found in other studies as well (Knight et al., 2015; Lekhuleni et al., 2013). However, the challenge of having ARVs stolen by a family member who also needed them but was constrained by lack of transport funds seems to be unheard of and may need further exploration. The government is currently trying to intervene on this barrier through the implementation of the Central Chronic Medicine Dispensing and Distribution (CCMDD) programme. In this programme, the government is trying to bring medicine closer for clients who are on chronic medicine.

Van Dyk (2013) also speaks about shortage of food to take with ARVs for those that need to be taken with food. In this study, there was no indication that clients were on ARVs that were required to be taken with food. However, there is a general belief that if one is using the pills, there should also be sufficient food. Shortage of food was repeatedly mentioned by all the CCGs and two ARV clients. Both ARV clients mentioned that they would rather skip their ARV doses when there is no food. All the CCGs mentioned lack of food in the area and reiterated how this becomes a challenge for clients on ART. Issues of poverty, where there is a lack of food and transport money, were emphasised by the CCGs as a challenge that affects adherence for clients on ARVs. This is emphasised mostly by the CCGs, perhaps because of the fact that they work in the community and witness this at the household level.

Van Dyk (2013) spoke about work-related challenges that affect adherence; these included being away for work, as well as working shifts and being unable to ask for time off in order to go to the clinic. In this study, none of the clients on ART spoke about this, perhaps because they were all unemployed. However, this could relate to what was said by one client on ART who could not attend the clinic in Bloemfontein because its times were in conflict with university lecture times. This affected his adherence, for he ran out of his medication until he came back to the Injisuthi clinic to ask for a three-month supply of medicine, which was the option that worked best for him.

From the health care workers' perspective, it appears that the work-related barrier is multifaceted. Working too far from home (e.g. as a truck driver or domestic worker), the type of work the person is doing, and restrictions in getting time off from work to collect treatment, were all challenges. This is similar to what was proposed by van Dyk (2013). From what the health care workers said, it appears that most of their clients who are defaulting are the ones who had found work as far away as in Johannesburg, Durban or even in Bloemfontein. Many of these clients did not take a transfer letter for them to be transferred to the health care facilities near their work, and did not adhere to their clinic appointments.

Lastly, the individuals on ART seem to be placed in a situation where they have to choose between ARVs and work. Under practical problems, Van Dyk (2013) also referred to being away from home for holidays. In this community, being away is often due to education, visiting relatives or looking for work. However, travelling and being away has been reported

by the health care workers, especially the nurses, as one of the biggest challenges for ARV adherence. This is similar to what was found in other studies conducted in sub-Saharan Africa. Croome et al. (2017) found that being outside the house or travelling is a barrier to adherence to ARV treatment in the sub-Saharan region. To demonstrate its importance, Weiser et al. (2003) ranked travel/migration as number three and commented that it was responsible for 10% of poor adherence in Botswana. This demonstrates that there is a need for extra support for clients who indicate that they are travelling or might travel in the near future.

6.3 Medication/therapy-related barriers

On medication-related barriers, van Dyk (2013) mentioned a difficult treatment regime, side effects and problems where a pill may be too big to be swallowed by a client. In this study clients on ARVs reported a lot of issues in relation to medication as a barrier.

Treatment side effects are known to form part of the barriers to adherence resulting from medicine. Side effects are mentioned as a treatment adverse effect and as a patient-related barrier to adherence in the South African guidelines for HIV, TB and NCD (NDoH, 2016b). This is also supported by a study that was conducted in Johannesburg by Knight et al. (2015), which also identified medication side effects as one of the reasons for sub-optimal adherence. Treatment side effects have been listed as one of the top barrier to adherence. In a sub-Saharan study that identified 40 barriers to ARV adherence, side effects are listed as number three out of the first four (Croome et al., 2017). All clients using ARVs in this study experienced side effects and these were severe, according to them. Their subjective experience of side effects was very significant to them. Furthermore, this experience of side effects has affected their adherence to ART.

However, the health care workers did not consider side effects as an issue affecting their clients' adherence to ART. Apart from one lay counsellor, no other health care worker referred to side effects as an issue affecting adherence for their clients. The unempathic and ineffectual responses the clients received when complaining about side effects to the health care workers indicates a lack of skill in managing clients' frustrations and dissatisfaction with ARV treatment. Lekhuleni et al. (2013) commented that side effects play a role in poor adherence and recommended that health care workers should employ a patient-centred

approach in order to teach their clients about side effects. In the cardiovascular framework (National of Heart Foundation of Australia, 2011, p. 99), adherence is reported to suffer if "health professionals have sub-optimal interpersonal skills" to support their clients on therapy.

Regardless of how the clients on ART were managed, the experiences of side effects had an impact on ARV adherence. Though some of the clients continued taking ARVs, four of them changed their way of taking ARVs following their experiences of side effects. This included skipping doses and seeking alternative treatment.

There might be different side effects for men and women, and depending on the type of ARV medication taken. In this study, two male clients identified increased urination as a severe side effect. This was not mentioned by women. Tenofovir is one of the drugs that are known to affect individuals' renal systems (Brennan et al., 2014); however, there is no evidence that these two male clients were on the medication that contained Tenofovir.

In the literature, side effects are frequently mentioned as a barrier to adherence and ranked as one of the highest barriers. However, the findings of this study also show how these side effects are handled by clients, how threatening they are for individuals on ART, and how ART clients may default in the process because of these side effects.

A particular concern for participants using ARVs, but not mentioned by the health care workers, was not seeing any improvement whilst on ART and well adherent to the treatment. This may discourage someone who is taking treatment hoping to see some benefits, which would act as a 'reward' for good adherence. It becomes a challenge for one to continue taking treatment while one is noticing health problems. These may also be mistaken by the clients as side effects of the medication. This may relate to what the National Heart Foundation of Australia (2011) says about medicine-induced side effects and perceived side effects. Two of the participants using ARVs mentioned problems related to continuing to experience illnesses even while being on ART for some time. In this situation, adherence to HIV treatment may be affected, and the user of ARVs may be confused as to whether they are working or not. Perhaps this could be a reason why some clients try to look for alternative treatments. According to the cardiovascular framework of barriers to adherence, patients may lose faith

in medicines if they believe that there is too little or no improvement in their health conditions (National Heart Foundation of Australia, 2011).

6.4 Service delivery-related barriers

Van Dyk (2013) mentioned service delivery-related barriers such as medication stock-outs, health care workers being on strike, poor discipline in clinics leading to early closure and bad service, and the fact that prisoners find it difficult to access their treatment. In this study, no participant mentioned challenges relating to drug stock-out or inability to access treatment due to strike actions. Bad service and early closure were not mentioned as a problem either. However, inability to access ARVs due to imprisonment seems to be a reality for some clients on ART at the Injisuthi clinic. This was highlighted by one nurse. It seems that some of the clients on ARVs would miss appointments because they got arrested. According to this nurse, clients stop taking their medicines when arrested because it seemed the clinician in prison may sometimes not trust the inmate when he/she says they are on ART. Therefore, this means that ARVs will be discontinued until they are released from custody.

This barrier could be improved by strengthening communication between the Department of Health, the police and Department of Justice. Defaulting due to incarceration did not appear in other frameworks of barriers. There is still a need to explore this further as this could assist in understanding adherence among prisoners. What makes this important is the fact that prisons are listed in South Africa as one of the high-transmission areas (HTAs) for HIV (NDoH, 2014a).

Another issue relating to service delivery that appeared in this study but was not covered by the framework from a variety of studies including van Dyk (2011; 2013) and the cardiovascular framework (National Heart Foundation of Australia, 2011) is clinic overcrowding, resulting in long queues and long waiting times. This is similar to what was observed in Zimbabwe by Campbell et al. (2015). Campbell et al. (2015) commented that, in Zimbabwe, patients would wait in a queue of over 30 patients, moving at a rate of one patient an hour. In the South African adherence guidelines for HIV, TB and NCD (NDoH, 2016b), long clinic waiting times are considered under structural barriers as a provider-related barrier to adherence and retention to care for people using ARVs and other chronic medications.

Injisuthi is one of the high-volume clinics in the uThukela district. This results in a high number of clients in a context of limited human resources. This results in bottlenecks, overcrowding and longer waiting times. Two of the participants on ARVs mentioned long waiting times as one of the difficulties experienced when coming to the clinic. One of the participants mentioned that, at some times, she would have to leave home as early as five o'clock in the morning to wait in the clinic until midday without getting her medication. This was confirmed by the nurses who, however, emphasised that they do all they can to make sure that all the clients do get their medication, no matter how crowded the clinic is. The nurses mentioned that some of the clients get discouraged by the long queues and decide to leave without medication, which has implications for adherence.

It seems some of the country's health systems and policies are not supporting adherence to the treatment. Some of the health care workers felt that clients would adhere better if they were to be given at least a three-month supply of medicine and also have ARVs available from the mobile clinics. This could prevent ART clients having to come to collect their treatment on a month-to-month basis, which often costs them time and money. During the time of this study, ARVs were not yet made available for patients through the public mobile clinics. Making ARVs available through mobile clinics may help clients who are on ART and reduce the long queues at clinics.

6.5 Stigma and discrimination

In van Dyk's framework (2013), stigma leads to secrecy, fear and lies, hiding of pills, non-disclosure, lack of support groups due to secrecy and fear of community rejection, and rejection of the disease. In this study, only one participant using ARVs talked about hiding her status and her medication. However, all participants using ARVs mentioned that they had disclosed their status at least to either a family member or to the entire family. They reported receiving support from their families and the clinic but not from the community, since they felt a need to keep their status a secret from the community due to fear of discrimination. This is in line with what is mentioned in van Dyk (2013) as a fear of community rejection.

Four of the ARV clients highlighted that they would prefer not to disclose their status to the community because people from the community gossip, and some mentioned that they have heard people from the community talking badly about the people living with HIV. Two of the

participants described how they would lie and hide their status from the CCGs. Most of participants mentioned stigma as a reason for their non-disclosure to the community and to the CCGs. The CCGs in this study also mentioned that they often come across people who do not want to disclose their status. This blocks access to support they should be receiving from the CCGs.

Non-disclosure was mentioned by all of the health care workers. From the care workers' perspective, clients hide their HIV status from their husbands, and do not come for treatment collection when their husband is back from work. This non-disclosure in one case was because the husband threatened to kill his wife if he found out that she is living with HIV. All of the health care workers mentioned that married women did not disclose to their mothers-in-law. This led to married women not being able to come for their treatment collection appointment, thus defaulting on ARVs.

One of the lay counsellors mentioned that some of the clients may even opt to go back home, when they may have seen someone at the clinic. Specifically, she mentioned an instance where a person said she come for her appointment but left when she saw a woman she was sharing a partner with. This is supported by what was mentioned by a nurse, that clients at the clinic may feel that they are 'watched' by others. In addition to this, a nurse and a lay counsellor participant mentioned that "stigma is still there".

HIV-related stigma has been listed as one of the important barriers to ART adherence in sub-Saharan countries in Africa. In Botswana ten years ago, stigma was shown to be number three, accounting for 15% of poor adherence to ARVs (Weiser et al., 2003). This raises a concern that, after all the effort put into education and awareness campaigns on HIV-related stigma, it is still appearing as one of the high-ranking barriers to ARV adherence. In a study conducted in sub-Saharan Africa, it was also found to be the third most significant barrier to adherence (Croome et al., 2017). This shows that stigma has been, and still is, a barrier to adherence. Interventions to reduce HIV-related stigma through dialogues and various platforms should be continued and strengthened.

6.6 Health control

In van Dyk's (2013) framework, health control relates to such issues as having no control over one's own health, having a fatalistic attitude ("Nothing I can do will make a difference."), an external locus of control and poor health literacy. In this study, there was no indication that patients struggled with control over their own health, or had a fatalistic attitude or external locus of control. However, married women did experience disempowerment, as discussed in the section about stigma. This study also did not find poor health literacy to be a challenge for clients who are using ARVs, and thus a cause for poor adherence.

6.7 Cultural aspects

According to van Dyk (2013), cultural factors are seen as a barrier to adherence; this refers to the fact that some of the clients on ARVs take and use medicines from traditional healers without disclosing this behaviour to their health care workers. This use of traditional medicines while on ART was observed as a threat to ARV adherence in a sub-Saharan setting (Wanyama et al., 2017). In this study, two of the clients on ARVs, as well as CCGs and nurses spoke about the use of traditional medicines. Sometimes this happened in conjunction with taking ARVs and sometimes ARVs were suspended. One client mentioned stopping using ARVs while using traditional medicines and the other one suspected that her use of traditional medicines in the form of immune boosters was responsible for her high HIV viral load. On the health care workers' side, lay counsellors, CCGs and nurses referred to the use of traditional medicines as one of the reasons for poor adherence or clients stopping ARVs. Both clients using ART and health care workers indicated that, usually, use of ARVs is suspended when traditional medication is used. This creates a problem for viruses like HIV, since it may lead to the HIV viral load not being suppressed and later resistance to ARVs.

It is not known how widely traditional medicines are used with ARVs in South Africa. However, in a study that was conducted in sub-Saharan Africa (Tanzania, Zambia and Uganda), Wanyama et al. (2017) comment that 5.8% of the participants on ART in their study had consulted a traditional healer 'in the past three months'. In that same study, participants said that traditional healers claimed to be able to cure HIV, something also mentioned by a nurse in this study. Use of traditional medicine is also mentioned as a barrier to adherence in the South African adherence guidelines for HIV, TB and NCDs (NDoH,

2016b). If use of traditional medicines goes unnoticed and users of ARVs are not supported accordingly in their use of alternative-medicines, this will directly affect adherence, which will affect health outcomes and health budgets. This is because these clients will have to be switched onto a new regimen when the first (and the less expensive) one is no longer working.

The communal lifestyle in the rural and traditional setting as a context also becomes a challenge for an individual who is taking ARV medication. Having HIV is still stigmatised, therefore there is always a need for taking treatment in private. This privacy is often limited by this communal life, since every move is being watched by everyone in this setting.

6.8 Gender and social organisation (masculinity)

Van Dyk's (2013) framework does not specifically mention gender or social organisation as barriers to adherence. However, Van Dyk (2011) found that women would hide the fact that they are taking ARVs from their male counterparts, for fear of rejection, losing children and even getting killed. This affects adherence to ARV medication. According to van Dyk (2011), this made 79% of her participants fail to adhere optimally. In terms of masculinity, according to van Dyk (2011), men seemed unwilling to seek medical help even if they were living with HIV. This could be based on a need to maintain a masculine identity in which a 'real man' is not sick. This was mentioned by health care workers in this study. This is similar to what was found by other studies. According to Skhosana et al. (2006), men delay seeking medical help in order to maintain their masculine image. This makes them come to health facilities very late and some even die of HIV because of coming so late for health services (Naidoo, 2017). These gender-based aspects and late health-seeking behaviour do not only affect males, but their female counterparts as well.

Married women seem to be more at risk of defaulting on ART. Household social barriers seem to mostly affect women, particularly in the rural communities of Injisuthi clinic. This seems to be an issue particular to this context as it is not identified in the literature. Married women appeared to be mostly stigmatised, and often feel they must take their treatment in secret since they live with their in-laws and fear being discriminated against by them. Thus, they do not disclose their HIV status. All categories of participants pointed out household conflict as a barrier to adherence. In this study, it was discovered that married females often

fail to adhere to clinic appointments because they are either prevented by their partners from coming or they have not disclosed to their in-laws that they are taking ARVs. This could be due to the denial of HIV status by their partners and the fear of being stigmatised and discriminated against by their in-laws.

A lay counsellor mentioned that most of her clients are married females and they often miss their clinic appointments because they have not disclosed to their in-laws or their husbands. All three nurses spoke at length about how the clients' relationship with either their husbands or mothers-in-law was a barrier to adherence for young married women in the area. The nurses commented that the husband might be in denial and therefore prevent his wife from going to the clinic to collect treatment, claiming they 'don't want any issues relating to HIV in their house'. The nurses also mentioned that the husbands of the married women do not want them to take ARVs. Interestingly, none of the five participants on ART mentioned gender-related issues as a reason for non-adherence.

6.9 Summary

Ever since the discovery of AIDS in 1981, international communities and governments have been trying all they can to curb the scourge of the disease and promote life through research, education, change of policies, and prevention and treatment interventions. However, the success of these interventions depends among other things on the behaviours of individuals and the factors that influence those behaviours.

In this study, 12 barriers to adherence for people using ARVs at Injisuthi clinic were identified through data collected from 14 research participants. The identified barriers varied across the different research participants (clients and health care workers). The participants who use ARVs mentioned ARV side effects and difficulties relating to fetching medication, since they are the ones who are directly involved with taking pills and therefore have direct experience of what it feels like taking ARVs and going to the clinic to collect them. Their perspective focuses on how it feels to be a user of ARVs and living with HIV. The challenges they indicated included side effects; clinic waiting times; use of alternative (traditional) treatment; taking ARVs on an empty stomach; non-disclosure and stigma; lack of support at a community level; pill burden; and poor treatment outcomes.

On the other hand the health care workers, depending on their area of intervention, gave a different (though sometimes overlapping perspective) on what was mentioned by the clients who are using ARVs. Their perspective also varied with their level of involvement with the clients, and with their role in helping people living with HIV and ARV users. Their duty is to focus on making sure that their clients take ARVs, through preparing them for ARVs, giving ARVs, monitoring that ARVs are taken as prescribed, as well as tracing them in the community and bringing them back to the facility for care should they default and lose their contact with the clinic.

1. The lay counsellors, whose focus is to ensure that clients who test positive for HIV are linked to an ARV programme, and also to provide them with adherence counselling to ensure that they stay on ARVs, indicated non-disclosure and stigma; resistance to behaviour change; use of traditional medicine; health care worker/patient relationship; transport money; work-related challenges; side effects; treatment fatigue; and improved health as the main barriers to adherence for their clients at Injisuthi clinic. Only one lay counsellor mentioned the side effects as an issue, which is a major concern for the clients who are using ARVs. This shows how the priority issue amongst the clients who use ARVs is missed. This impacts on adherence to treatment since it might mean that clients are not fully supported in issues around side effects.

2. The community care givers (CCGs) who work in the community to provide basic health care services through door-to-door household visits indicated that poverty (taking ARVs on an empty stomach and lack of transport money to go to the clinic); social issues (household conflicts with husbands); stigma and non-disclosure; substance abuse; use of traditional medicines and challenges relating to access to ARVs in mobile clinics are barriers to adherence for clients on ART at Injisuthi clinic. Their perspective is valuable for its focus on the issues affecting adherence at the level of the community, having worked there for years supporting individuals living with HIV. All of the CCGs pointed out poverty, stigma, non-disclosure and discrimination as the main challenges affecting adherence for their clients in the community.

3. It is interesting here that the main reasons being mentioned by CCGs and lay counsellors are not the side effect issues, which is what the focus was with the clients.

CCGs may have been overwhelmed by the poverty that they witness when doing their work. Some of the CCGs donated their own food to the families that they visited.

4. The nurses' duty is to enrol clients on ARVs and monitor their bloods to see if the treatment is working. The nurses indicated that long duration on treatment/treatment fatigue; poor community support system; non-disclosure and stigma; poverty (no transport money to the clinic); work-related issues; incarceration; social issues (family conflicts with husbands and in-laws); clinic overcrowding (clinic waiting times); travelling (being away); improved health; use of traditional medicines; health care worker/patient relationship; and authorities (the health system) appeared to be the barriers experienced by their clients on ART.

5. The narratives of the nurses focussed mostly on barriers relating to accessing treatment and person-related issues, rather than how it feels for their clients to be on ARVs. This may result from the fact that their duty is to issue medication and order their clients to take their treatment as prescribed. This approach overlooks the experience of what it is like to be on this prescribed treatment and might mean insufficient support is provided to the client about the emotional experiences of being on ARVs. This potentially creates the conditions for poor adherence since there is poor insight into, and little management of, the most important needs of the client. Empowering clinicians to explore the experiences of the client on ARVs is recommended. This should be combined with equipping clinicians with skills to respond adequately and efficiently to clients' needs. This could help shift the focus from a health system-centred approach to one that is centred on clients' needs.

In this study, it appears that the different foci of the participants resulted in different perspectives of the barriers to adherence. This may also result from different experiences of needs. In this study, all the clients who had used ARVs and defaulted highlighted side effects as their main concern, while on the other hand, out of nine health care workers, only one referred to this as one of the barriers to adherence. Nurses and CCGs are mute on side effects. Only one lay counsellor referred to this. This could be because lay counsellors are trained to be empathic when dealing with their clients. However, the other two lay counsellors, like the nurses and CCGs, did not refer to side effects.

From the responses of the participants who use ARVs, one could clearly see how the issue of side effects is brushed off when they complain about them. This suggests that most of the services are more health system centred and less client's need centred. Therefore, adherence to treatment suffers when the demands of the treatment are not adequately noticed and dealt with appropriately. A psychosocial support system that is more client need centred and empathetic would be recommended, given the rush to enrol all HIV positive patients on ARVs, as per the World Health Organisation's (WHO) recommendations for 2030. Taking care of the needs of the users of the services, in this regard ART, may assist in reducing the number of defaulters and avoid challenges like the formation of resistant strains and the further spread of the HI virus.

Chapter 7: Conclusion

Non-adherence to ARVs is one of the major contributing factors to treatment failure because of viral resistance that may occur. This study was an attempt to answer such questions as: Why do clients fail to adhere to ART treatment? What makes it hard for ART clients to adhere to treatment? What are the most common barriers to adherence for local clients? This study showed that taking ARVs is not always easy. There are a variety of issues involved in the process which contribute to ultimate failure to remain on ARVs. When the findings of this study are compared to findings from the previous researchers it becomes clear that most of the barriers that were identified in 2010/2011 were still affecting adherence in 2016. This study also found that there is still a big gap in the health care services when it comes to counselling and provision of adherence support for clients on ART.

Different perspectives used in this study made it possible to gain sound insight into barriers to adherence. This is due to the fact that the different backgrounds that participants were coming from allowed for a comparison of the different perceptions of barriers. The use of multiple perspectives in this study was also useful to illustrate how the ART programme is more health system centered rather than person centered, despite the fact that the ultimate success of the ART programme rests largely on the behaviour of the person (i.e. adherence) who is taking the treatment as prescribed.

This study showed that Injisuthi clinic clients on ART experience similar barriers to adherence as those that have been found by other researchers in other contexts. However, in some instances, the manifestation of the experience of these barriers differed with the context. For instance, male research participants reported an additional side effect of increased urination when using ARVs. The experience of stigma and discrimination was also found to be more severe for women, and especially for married women.

This study also demonstrated that people do not only fail on ARVs because of the side effects, but also because of the responses they get from health care workers and others who should support them. Some of the responses from health care workers appeared to be of no use at all for clients on ARVs, especially when they complained about side effects. This leads

to clients abandoning or the prescribed way of taking pills, for an example, skipping the morning dosage because of side effects and taking only the afternoon one.

This study confirmed most of the barriers found in other studies and also added more insight into some of the issues that were reported in other studies. On issues such as side effects, more insight is still needed in order to explore their manifestations across gender. A stronger psychosocial support system that integrates the experiential needs of the client on ART should also be considered, in order to manage other barriers that are influenced or linked to this, such as looking for alternative treatments and the experience of pill burden.

The framework used in this study included gender and social organisation as a barrier for people on ARVs. This study confirmed the existence of gender issues as a barrier to adherence mostly affecting women through stigma, discrimination and gender-based violence, whilst for men, the need to maintain masculinity had a negative impact on their health-seeking behaviour and thus adherence. Gender and social issues were fairly dominant findings in this study but have not been referred to significantly in other studies. There is a need to explore these further, especially these dynamics in African rural communities.

7.1 Strengths and limitations of the study

There were many aspects that contributed as strengths in this study. These will be considered in this section.

1. There were 14 people interviewed, from a variety of backgrounds, providing access to information from different world views. Five clients using ARVs, with an experience of failing on the first-line regimen, shared their experiences of how they had come to fail. This information was compared to information shared by the nine health care workers who supported people on ARVs at various levels (i.e. psychosocial, clinical and community levels). This means that the barriers to ARV adherence were examined from different perspectives. However, the number of participants per category was limited due to the qualitative design of the study.

2. Themes from the data were identified objectively from the data and later compared to barriers already available from the literature, as opposed to being guided by the pre-existing information. The analysis was thus initially data driven.

3. The researcher has had experience of more than 17 years working in the field of HIV, as an HIV youth coordinator, trainer, counsellor (including adherence counselling), and counsellor mentor, at a private or public institutional and community level. This means that, over the years, I have gained adequate awareness around how sensitive living with HIV is and the need for confidentiality for clients. As a former HIV lay counsellor and research assistant, I could draw from previous experiences the skills to ensure that the interviews ran smoothly, with appropriate probes where necessary.

4. Clients were interviewed in their own language. This serves as strength for it allowed them to express themselves as deeply and as far as they could during their interviews. The collected data were then translated by the researcher into English. This means that the researcher was able to incorporate non-verbal cues into the transcribed data, and translated it with an understanding of what was said and how it was said. This therefore was able to include the implied messages apparent in what was said by the participants.

5. This study only investigated barriers to adherence in the context of one clinic (i.e. Injisuthi clinic), a high-volume clinic serving the population from a rural area with areas far apart from each other This means that the findings of this study cannot be generalised to other facilities with a different setting from Injisuthi clinic. However, the detailed description of the data collection process, and the details provided in the presentation of results, mean that the findings could be transferable to similar participants in similar settings.

6. Inclusion of men and women in this study assisted in obtaining the experiences of both genders of being on ART. This allowed for findings to emerge that were different across genders, for example, increased urination on the part of men in relation to ARVs. This study did not, however, explore the extent of this phenomenon and could not give the reasons for this phenomenon.

7. The analysis showed that, for some of the barriers, the perception of the barriers was the same for the health care workers and the individuals using ARVs, for example, in relation to side effects, stigma/non-disclosure, pill burden and use of traditional medicines. However, perceptions differed in relation to poverty, travelling, work-related issues, social issues (conflicts at a household level) and improved health.

8. As for the last research question about how challenges of living with HIV relate to poor adherence, the data show that stigma that is attached to HIV is still active and that it leads to non-disclosure and thus poor adherence. Stigma meant that clients left the clinic if they saw someone they knew. Non-disclosure and stigma were evident when participants on ART rejected support at a community level, fearing that the CCGs would gossip about them. As a result, the individuals on ART seemed to prefer to keep their HIV status to themselves.

7.2 Recommendations

There are a number of recommendations related to ARV medication adherence. Given the seriousness of the side effects, one would recommend the use of drugs with fewer or tolerable side effects. The currently used first-line regimen has fewer side effects than earlier ARVs. This study recommends stronger psychosocial support for people who are using ARVs in order to keep them on a regimen that is tolerable. This should be combined with continuous screening for side effects and ongoing counselling for patients using ARVs. In addition, packaging of the medication such that is makes less or no noise may reduce shame in carrying the ARVs by the clients on ART.

Recommendations related to managing and reducing stigma include that there is an urgent need to address stigma. This could be addressed at the individual and community level. HIV-positive individuals need to be protected and assisted to overcome stigma, while interventions that reduce stigma at a community level should also be conducted.

There is also a need to implement strategies to alleviate poverty, so as to increase access to food for clients on ART, as well as strategies to minimise travelling costs for clients who are using ARVs.

In terms of gender, there is a need to implement interventions that would address gender-based violence affecting married women on ART. Such interventions should target men in the communities with dialogues that would see them empowered to access HIV services themselves. These interventions should help men in the community know and accept their HIV status and take leadership in HIV prevention and treatment.

In terms of access to treatment, a workplace-based distribution of ARVs programme for clients who are working would be recommended. This may reduce time requested to attend the clinic. It might also address some of the fear clients expressed about dealing with attitudes of health care workers at clinics. However, this should be combined with distribution of other medications, in order to avoid or reduce stigma.

In addition, availability of ARVs in various forms at a community level is recommended for ease of access to ARVs. This is currently being implemented by the Department of Health. This is done through a model that allows all people who are using chronic medicine to collect their treatment in the community, in the form of clubs known as adherence clubs. However, the establishment of these clubs is slow and has been met with many challenges. If this is fast tracked, this could make a significant difference in terms of access.

An intervention that shortens waiting times for clients on ARVs at the facilities is also recommended. Since 2016, the government has started implementing this. The Department of Health implemented a model in which clients who go to the public clinic for their chronic medicine (including ARVs) can now choose to just go straight to the clinic dispensary to collect their medicine and leave without sitting in the queue.

A training and mentorship process to empower health care workers about on how to deal with and counsel their clients on ART (or any other chronic medication) about side effects is recommended. This study has shown that if their clients are simply ignored when complaining about side effects it impacts on adherence to their treatment.

In terms of further research, the increase in male urination whilst on ARVs needs to be followed up as it interferes with adherence, and was a significant problem for two of the clients in the study.

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Appendix One: Enquiry about research project permission

Enquiry about research permission.

Jabulani cele <jabulani.cele@kznhealth.gov.za> Wed, Feb 3, 2016 at 1:54 PM
To: Elizabeth.lutge@kznhealth.gov.za
Cc: ndosimagaye7@gmail.com

Dear Dr. Lutge,
I work for the department of health and I am intending to do a study for my Master's Degree in Psychology with UKZN. My area of interest is HAST. I would like to conduct a study on ART (ARV) Adherence barriers to patients that are on regimen 2, due to non-adherence on regimen one. I am looking at conducting a qualitative study that will recruit and interview 5 (adult) clients, 3 Lay counsellors and two ART Nurses.

For a permission to conduct such a study I have asked for an advice from a provincial head office. Part of the response I got was that, I have to ask for permission from the DM, and also have been referred to you for further advice. On the kznhealth website it appears as if non clinical studies may not need a form that needs approval from the ethics committee.
Please help with an advice.

Kind regards

Jabulani Cele

Lutge Elizabeth <Elizabeth.Lutge@kznhealth.gov.za> Wed, Feb 3, 2016 at 2:14 PM
To: Cele Jabulani <Jabulani.Cele@kznhealth.gov.za>
Cc: "ndosimagaye7@gmail.com" <ndosimagaye7@gmail.com>, Khumalo Gugu <gugu.khumalo@kznhealth.gov.za>, Xaba Xolani <Xolani.Xaba@kznhealth.gov.za>

Dear Mr Cele
You will need to get letters of support from the institutions that you wish to conduct your research in. If you are hoping to work in 4 or more facilities in the same district, then you should get permission from the district manager, but if in three or fewer facilities then you should get permission from each facility manager. You need to submit these letters, plus your letter of ethics approval and your full protocol, onto the website of the National Health Research Database (nhrd.hst.org.za/), from which it will be forwarded to us. If you have any difficulties with this process please contact Mrs Gugu Khumalo or Mr Xolani Xaba (copied above).

Best wishes

Elizabeth.

Appendix Two: Permission letter from the facility

Injisuthi clinic

Private bag x 7013

Estcourt

3310

23 February 2016

To: Mr Jabulani Cele

Hiv/Aids Co-Ordinator

District Office

Ladysmith

RE: PERMISSION TO DO RESEARCH SURVEY

I, **Mrs G. Ganes** Operational Manager at **Injisuthi Clinic** grant permission for **Mr Jabulani Cele** to do a research project at **Injisuthi Clinic.**

Thank you

Yours faithfully

Signature..... .....**(Mrs G. Ganes)**

Appendix Three (A): Information sheet (for the participants on ART)

The Study
The purpose of this study is to establish an understanding of key barriers to adherence to antiretroviral treatment (ART) for clients that are living with HIV.

This is a study about the experiences of the clients that are living with HIV and are using (ART) to control HIV. The main focus is to find out the challenges that people experience when taking ARVs.

You may directly benefit from the fact that you will get an opportunity to talk to someone about the problems you came across when taking ARVs, and living with HIV. This may be therapeutic. The results (not exactly your words) will be shared with the decision makers. This may influence decisions that they take to support HIV positive and on ART people. This may be a benefit more people that are living with HIV and are using ART.

The interview process (for individual participants on ART)
In this interview you will be talking to a researcher for about an hour. The interview will take place in one of the clinic rooms. The researcher will ask you questions about living with HIV. He will also ask questions about what happens when you are taking ARVs, and challenges you had about taking.

The aim of this study is to get to understand better the challenges that are met by the people living with HIV and are using ARVs. You are invited to share as much as you can and as free as possible. Whatever you say during the interviews will be kept confidential. When the results of the study are shared with other people, your name will not be mentioned.

All that you talk about is not going to be looked at as not going to be judged in terms of wrong or right, good or bad. It is important in this study that you just share whatever happened as it is. If you do not want to answer some of the questions please feel free to do so.

You will be talking to a researcher (Jabulani Cele) who is a male. He is a student at the University of KwaZulu Natal. He is a doing this research as part of his studies for Master's Degree in Psychology. He is also experienced in HIV counselling and in conducting research interviews.

Interviews will be conducted in either English or *isiZulu* (or a combination of both). It will depend on the language you feel more comfortable with)

Recording
In order to capture all you say, we ask for your permission to record the interviews which will be later be written on paper word for word on what you have said. The researcher will then analyse it so as to understand better what you have talked about.

Participation in the study
Your participation in this study is absolutely voluntary. Please be aware that you have the right to stop your participation in the study at any given stage and that is not going to have any bad results in the services you receive in this clinic.

During the study if I feel that you are getting upset, I will ask you if you still want to continue participating.
Should your participation in this study lead to a situation where you are feeling distressed and that you need to talk to someone an arrangement has been made for you to see a counsellor here at this clinic, who can be contacted as follows:

Name of a counsellor: Ms Tholakele Ngobese

Contact: 036 431 8133 (Injisuthi clinic)
And you can also call the AIDS helpline at: 0800 012 322

HIV/AIDS information will also be provided by the researcher after the interviews.

If you decide to leave the study and have already participated, the researcher is going to ask for your permission as if you would like the data that has already been collected to be used in the study or not. If you happen to be asked whether you want data to be used or not, you still have a right to agree or disagree. And that will again, not have bad consequences on the way you are treated in this clinic in future.

After the interviews
After the interviews discussions all recorded data will be transcribed word for word and translated in to English. Transcribed and translated data will be analysed and the research report is going to be written out of it. The same researcher who conducted the interviews will do the transcription and translation, the second person will only come into contact with the data when checking if the translations from isiZulu to English are correct This person will not know the names of the people who participated in the study because she will only be working with what is written on papers.

Throughout all the stages of working with data, from transcription, translation, verification of translation analysis and reporting of research findings research participants will not be referred to by names. Instead I will use codes. For an example I will be saying participant "A" or participant "B".

The findings of this study will appear in a thesis for examination for the researcher's degree of Masters in Psychology. It will be publically available in the UKZN library. Since information from this study is of a high value, findings from this study may be shared with other researchers, in AIDS seminars, AIDS conferences, HAST (HIV, AIDS, STI and TB), Meetings and with the provincial department of health. When information from this study is shared in any form or platform, there is going to be no mention of names, but rather pseudonyms and labels such as "research participant A or B" as I have mentioned before.

A summary of the results of this study may be made available to you should you wish to get them.

Storage and dispersal of research data
All data (audio, transcribed and translated) and information from this study will be stored for five years for future reference. It will be stored with researcher's supervisor, kept in lockable device (a filling cabinet). When the period of 5 years is finished it will be destroyed and incinerated. Electronic data will be protected with a password to ensure that no one else get to it except the researcher (me) and my supervisor. All electronic data will be deleted from the systems and storage devices including backups, when the period of 5 years has lapsed.

HIV/AIDS information
It may be possible that during your participation in this study you need further information and support. If you need any information on HIV and AIDS and other health matters relating to HIV, you could refer to the pamphlets provided by the researcher, go to any nearest government clinic, and speak to an HIV counsellor in this clinic.

And you can also call the AIDS helpline at: 0800 012 322
.
For counselling and advice you can call the helpline, go to any government clinic that is accessible to you, or come to this clinic to see any HIV/AIDS counsellor, or ask for Ms Tholakele Ngobese.

Name of a counsellor: Ms Tholakele Ngobese
Contact: 036 431 8133 (Injisuthi clinic)

If you have any concerns about this study you can also contact Ms Phume Ximba of the Humanities and Social Science Research Ethics Committee (031 260 3587, email ximbap@ukzn.ac.za)

If you have any questions about this study, then please talk to:
The researcher - Mr. Jabulani Cele (cell: email: ndosimagaye7@gmail.com),
The Operational Manager of Injisuthi clinic - Mrs. G Ganes (Tel: 036 431 8133) or
Talk to the researcher's supervisor - Dr Mary van der Riet (Tel: 033 260 6163 email: vanderriet@ukzn.ac.za).

Appendix Three (B): Information sheet (for the participants on ART)

Ucwaningo

Inhloso yalolucwaningo ukuthola ukuqonda kabanzi ngezithiyo nezinselelo ngqangi ekusebenziseni imishanguzo ngendlela kubantu abaphila nesandulela ngculaza abasebenzisa imishanguzo elwisana nesandulela ngculaza.

Lolu ucwaningo olumayelana nempilo yabantu abaphila negciwane eliyisandulela ngculaza (HIV) asebenzisa imishanguzo (amaphilisi ama ARV) ukulawula igciwane lengculaza. Lolucwaningo lugxile kakhuluekutholeni izinselelo abantu ababhekana nazo uma besebenzisa amaphilisi okunqanda ukudlondlobala kwesandulela ngculaza egazini.

Ongakuzuza mathupha kulolucwaningo ukuthi uzothola ithuba loxoxela umuntu ngezinkinga oye wahlangabezana nazo ngenkathi uthatha imishanguzo (ARVs), nangokuphila nesandulela ngculaza. Lokhu kungase kwelaphe umphefumulo. Imiphumela (hhayi amazwi akho enjengoba enjalo) izofinyelela kubathathi zinqumo. Lokhu kungaba nomthelela ezinqumeni abazithathayo ukweseka abantu abaphila nesandulela ngculaza nabasebenzisa imishanguzo elwisana nesandulela ngculaza.

Inqubo yengxoxo yocwaningo (kwababamba iqhaza abasebenzisa imishanguzo)

Kulengxoxo uzebe uxoxa nomcwaningi isikhathi esingangehora. Ingxoxo izokwenzelwa kwelinye lamagumbi asemtholampilo. Umcwaningi uzokubuza imibuzo emayelana nokuphila nesandulela ngculaza. Uzokubuza emayelana nokuthi kwenzakalani uma uthatha amaphilisi nezinselelo obe nazo ekuthatheni kwakho amaphilisi.

Njengoba inhloso yalolucwaningo ukuthola ukuqonda kabanzi ngezithiyo nezinselelo ngqangi ekusebenziseni imishanguzo ngendlela kubantu abaphila nesandulela ngculaza abasebenzisa imishanguzo elwisana nesandulela ngculaza. Kanjalo siyakucela ukuba uxoxe nje ukhululeke wenabe ngakho konke okusemandleni usho konke ofisa ukukusho. Konke ozokusho kulengxoxo kuzogcinwa kuyimfihlo, akuyikutshelwa muntu. Uma kwethulwa imiphumela yalolucwaningo kwabanye abantu, aliyukuvezwa igama lakho.

Konke ozokusho kulengxoxo akuzukwahlulelwa ngokuthi kuhle noma kubi, kulungile noma akulungile. Kubalulekile kulolucwaningo ukuthi ukhulume nje ngokwenzeka njengoba kunjalo. Uma ungathandi ukuphendula eminye yemibuzo sicela ukhululeke ukuba ungayiphenduli.

Uzobe ukhuluma nomcwaningi (uJabulani Cele) ongowesilisa. Ungumfundi eNyuvesi yaKwaZulu Natali. Wenza ucwaningo njengenxenye yeziqu zakhe zemfundo ephakeme (Masters) ezifundweni ngempilo yabantu (Psychology). Unesipiliyoni sokwaluleka abaphila nesandulela ngculaza nasekwenzeni ucwaningo.

Ingxoxo yocwaningo ingaba ngesiNgisi noma ngesiZulu noma kuxutshwe. Kuzoya ngokuthi yiluphi ulimi wena ozizwa ukhululekile kulona.

Ukuqopha

Ukuze bambeke kahle konke ozobe ukushilo kungasali lutho, singathanda ukucela imvumo yakho ukuba lengxoxo yocwaningo iqoshwe ngesiqophamazwi, okuzothi ngemuva kwalokho kubhalwe ephepheni igama negama lozobe ukushilo. Umcwaningi uyobe esekuhlaziyake lokhu ukuze aqonde kabanzi obukhuluma ngakho.

Ukubamba iqhaza ocwaningweni

Ukubamba iqhaza kwakho kulolucwaningo kuya ngokuzikhethela kwakho. Sicela ukukwazisa ngokuthi unelungelo lokuhoxa nomanini kulolucwaningo kantu ukuhoxa kwakho akuyikuba namthelela omubi empathweni ozoyithola kulomtholampilo ngomuso.

Ngesikhathi ucwaningo luqhubeka uma uzizwa uphatheka kabi, ngizokubuza ukuthi uyafisa yini ukuqhubeka nokubamba iqhaza ocwaningweni.

Uma ukubamba kwakho iqhaza ocwaningweni kuholela esimweni lapho uzizwa uphatheka kabi ufisa sengathi kungakhona oxoxa naye kuhleliwe ukuba ungakhuluma nomaluleki kuwo wona lo mtholampilo ongaxhumana naye kanjena:

Igama lomaluleki: Ms Tholakele Ngobese
Inombolo yocingo: 036 431 8133 (Injisuthi clinic)
Ungashayela nalenombolo yosizo olumayelana nengculaza: 0800 012 322 (imahhala uma uyishayela ocingweni lakwa *telkom*)

Ulwazi mayelana nesandulela ngculaza nengculaza luzotholakala emapheshananeni azonikezelwa ngumcwaningi ngemuva kwengxoxo yakho naye.

Uma unquma ukuhoxa ocwaningweni kanti usuke wathi ukubamba iqhaza kukhona nobese kucoshelelwe oke wakusho umcwaningi uyocela imvumo kuwena ukuba uyafisa yini ukuba obese kucoshiwe okumayelana nocwaningo kusetshenziswe ocwaningweni noma cha. Nalapho unelungelo lokuba uvume noma wenqabe. Nalokho akuyikuba namthelela empathweni oyoyithola ngomuso kulomtholampilo.

Ngemuva kwezingxoxo zocwaningo

Ngemuva kwezingxoxo zocwaningo konke okuqoshiwe kuzobhalwa phansi ephepheni igama negama bese kuguqulelwa esiNgisini. Osekubhalwe ephepheni kwase kuguqulelwa esiNgisini kuzobe sekuhlaziywa bese kubhalwa umbiko wocwaningo ususelwa kukho. Umcwaningo obuxoxa naye nguyena ozobhala phansi ozobe ukushilo bese ekuguqulela esingisini, umuntu wesibili uyongena nje kuphela lapho esezoqinisekisa ukuthi kuguqulelwe ngakho yini esiNgisini obekushiwo ngesiZulu ephepheni. Lo muntu wesibili akazukuwazi amagama

abantu ababambe iqhaza kulolucwaningo ngoba yena uzosebenza nje kuphela ngalokhu okuzobe kubhalwe emaphepheni.

Kuzona zonke izigaba zokusebenza ngolwazi olucoshwe kwenziwa ucwaningo, kusukela ekubhalweni kwalo phansi kuya ekutolikweni naseku bhekweni kwamaphutha kuhlaziywa nasekubhalweni kombiko wocwaningo, abebebambe iqhaza ocwaningweni abezukuhlonzwa ngamagama abo. Esikhundleni samagama kuyosetshenziswa *amakhodi*. Okwesibonelo ngizothi umbambiqhaza “A” noma “B”

Okutholakele kulolucwaningo kuyovela embhalweni wezivivinyo lapho umcwaningi eyobe ehlolelwa khona iziqu zakhe zemfundo ephakeme (Masters) will appear in a thesis for examination for the researcher’s degree of Masters in Psychology. Lolulwazi luzotholakala kunoma bani oludingayo emtapweni wolwazi weyunivesi yaKwaZulu Natali. Ngokuthi lolulwazi lubaluleke kakhulu, imiphumela yalolucwaningo iyonikezwa kwabanye abacwaningi ezingqungutheleni zengculazi, nasemihlanganweni emayelana nengculaza, nasemihlanganweni yezikhulu ezibhekelele isandulela ngculaza nengculaza nezifo zofuba (TB) nezocansi, bese lwedluliselwa nakubaphathi bomnyango wezempilo wezifunda saKwaZulu Natal. Uma ulwazi oluvele kulolucwaningo lunikezelwa noma kubani nangasiphi isikhathi, akuyikudalulwa gama lamuntu, Kodwa kuyomane kusetshenziswe amakhodi noma amagamambumbulu njengokuthi umbambiqhaza “A” noma “B” njengoba bese ngike ngachaza ngaphambilini.
Imiphumela yalolucwaningo efingqiwe ungase uyithole uma kwenzeka uyidinga.

.

Ukubekwa nokulahlwa kolwazi oluqoqelwe ucwaningo

Lonke ulwazi (oluqoqwe ngesiqopha mazwi, olubhalwe phansi noluguqulelwe eSingisini) nolwazi olutholakale kulolu cwaningo luzobekwa iminyaka emihlanu ukuze lisetshenziswe makuvela isidingo ngenkathi ezayo. Konke lokhu kuzobekwa kuMphathi kaMcwaningi, eNyuvesi lugcinwe entweni ekhiywayo, (ekhabetheni lokubeka amafayela). Uma sesiphelile isiskhathi esiyinyaka emihlanu, luyobe selucinwa, okungamaphepha kushiswe ngomlilo. Ulwazi olugcinwe ngamaKhompuyutha nolungekho emaphepheni luyovikelwa ngenombolo eyimfihlo ukuqinisekisa ukuthi akekho omunye umuntu okwazi ukufinyelelela kulo, ngaphandle koMcwaningi noMphathi wakhe kuphela. Lonke ulwazi olubekwe emaKhompuyutheni nolugcine kwezinye izinto zokugcina ulwazi luyocinwa uma isikhathi esingangegeminyaka emihlanu sesidlulile.

Ulwazi mayelana nengculazi nesandulela sayo

Kungenzeka ukuthi ngokubamba kwakho iqhaza kulolu cwaningo uzizwe udinga olunye ulwazi nokwesekwa. Uma noma luphi ulwazi mayelana nesandulela ngculazi nengculazi nokunye okumayelana nempilo ungabheka kulamapheshana olwazi ozowanikezelwa uMcwaningi, ungaya kunoma muphi uMtholampilo kaHulumeni, ukhulume nomaluleki oluleka ngesandulela ngculazi nengculazi.

Ungashayela kule lenombolo yosizo olumayelana nengculaza: 0800 012 322 (imahhala uma uyishayela ocingweni lakwa *telkom*)

Uma udinga izaluleko nokwalulekwa ungashayela lenombolo engenhla, ungaya kunoma muphi umtholampilo oseduze nawe, noma ubonane nanoma yimuphi umaluleki wasemtholampilo kahulumeni, noma uze kulo mtholampilo ucele umaluleki ongu Tholakele Ngobese.

Igama likameluleki : uTholakele Ngobese
Inombolo yomtholampilo : 036 431 8133 (Injisuthi clinic)

Uma unakuphi onganasiqinisekiso kukona mayelana nalolu cwaningo ungaxhumana Ms Phume Ximba wekomidi elibhekele ubulungiswa uma kwenziwa ucwaningo ngezimpilo zabantu (Humanities and Social Science Research Ethics Committee) (ucingo: 031 260 3587, email/umbikonyazi: ximbap@ukzn.ac.za)

Uma unanoma yimuphi umbuzo mayelana nalolucwaningo ungathintana no:
Mcwaningi - Mnu. Jabulani Cele (cell:XXXXXXXXXX),
Umphathi waseMtholampilo Injisuthi - Mrs. G Ganes (Tel: 036 431 8133) noma
Ukhulume nomphathi womcwaningi uDr Mary van der Riet (Tel: 033 260 6163 email: vanderriet@ukzn.ac.za).

Appendix Three (C): Information sheet for Health Care Workers (clinic nurses, counsellors and CCGs)

The Study

The purpose of this study is to establish an understanding of key barriers to adherence to antiretroviral treatment (ART) for clients that are living with HIV.

This is a study about the experiences of the clients that are living with HIV and are using (ART) to control HIV. The main focus is to find out the challenges that were met during the first line regimen, which might have contributed to poor adherence to ART and change of ART regimen.

Direct benefits of participating in this study may be that you would get an opportunity to share your experiences on helping clients that are living with HIV and their experiences of taking *antiretroviral drugs* (ARVs) and the challenges you met, which may be therapeutic to you as a health care worker.
Moreover, because the results (and not exactly your words) will be shared with the decision makers, the results of the study may influence decisions taken around supporting HIV positive and on ART individuals, thus benefiting more people that are living with HIV and are using ART.
(Brennan, 2014)

The Health Care Worker's interviews

This Interview is expected to take about 30 to 45 minutes. It will take place in one of the counselling consulting rooms in the afternoon when the clinic workload is a bit lower. It will be in a private and confidential space. Interviews will be conducted by the researcher (Jabulani Cele) who is a male and familiar with health care facility setting and has experience working with HIV positive clients.

You are going to be asked to share your experiences about clients that are taking ARVs. Challenges that are met by clients are going to be explored. Reasons for clients to stop ARVs are going to be discussed. There will be no personal questions about your own HIV status. You are encouraged to share as much as you can; your answers are not going to be judged in terms of right and wrong good or bad. During the discussions you are encouraged not to mention names (yours and that of the clients you work with) but rather refer to clients as "a client" or "another client" and then share the experience around the client. .

Please take off your name tag and not put it on during the interviews, and you are also encouraged not to mention your name during the interview so that when data is transcribed and analysed it is not possible to link what is said to your name. All information and experiences shared during the interview will be kept confidential

Recording

I would ask for your permission to record the interview. This will help me to capture all you have said during the interview. This data will then be transcribed and analysed by the researcher so as to understand better your experiences as shared during the interview. (There is a separate consent form for audio recording)

Participation in the study

Your participation in this study is absolutely voluntary. Please be aware that you have a right to stop your participation in the study at any given stage. If that happens it is not going to have any bad consequences in the future of your career. During the study if the researcher feels that you are getting upset, will indicate that to you and ask you if you are still willing to continue participating in the interview.

After the interview

After the interviews all recorded data will be transcribed word for word and translated from *isiZulu* to English. Transcribed and translated data will be analysed and the research report is going to be written out of it. The same researcher who interviewed you will do the transcription and translation. The second person will only come into contact with the data when verifying the quality of translated data in a form of a written document.

No name of participants will be mentioned when working with data. For an example during transcription (writing it down word for word), translation, verification of translation analysis and reporting of research findings research participants will not be referred to by names or any identifiable features. Coding will be used. For example Participant “A” or participant “B”

Findings of this study will appear in a thesis for examination for the researcher’s degree of Masters in Psychology. It will be publically available in the UKZN library. Since information from this study is of a high value, findings from this study may be shared with other researchers, in AIDS seminars, AIDS conferences, HAST (HIV, AIDS, STI and TB) Meetings and with the provincial department of health. When information from this study is shared in any form or platform, there is going to be no mention of names, but rather pseudonyms and labels such as “research participant A”.

A summary of the results of this study may be made available to you should you wish to get them.

Storage of Information

All data (audio, transcribed and translated) and information from this study will be stored for five years for future references. It will be stored with researcher’s supervisor, kept in lockable device (a filling cabinet). When the period of 5 years has lapsed it will be destroyed and incinerated. Electronic data will be protected with a password to ensure that access is limited to only the researcher (me) and my supervisor. All electronic data will be deleted from the systems and storage devices including backups, when the period of 5 years has lapsed.

HIV/AIDS information

It may be possible that your participation in this study triggers some of the issues and resulting in you needing further information. If you need any information on HIV and AIDS and other health matters relating to HIV, you could refer to the pamphlets provided by the researcher, go to any nearest government clinic, call a toll free number for HIV/AIDS line provided above, or speak to an HIV counsellor in this clinic. For counselling and advices you can call the helpline, go to any government clinic that is accessible to you, or talk to any HIV/AIDS counsellor.

AIDS help line: 0800 012 322

If you have any concerns about this study you can also contact Ms Phume Ximba of the Humanities and Social Science Research Ethics Committee (031 260 3587, email ximbap@ukzn.ac.za)

If you have any questions about this study, then please talk to:

The researcher - Mr. Jabulani Cele (cell: XXXXXXXXXXXX),

The Operational Manager of Injisuthi clinic - Mrs. G Ganes (Tel: 036 431 8133) or Talk to the researcher's supervisor - Dr Mary van der Riet (Tel: 033 260 6163 email: vanderriet@ukzn.ac.za).

Appendix Four (A): Invitation

Inviting ART clients to participate on ART adherence study

You are cordially invited to participate in a study that investigates barriers to adherence that lead to client to be switched from the first line ART regimen to another set of pills.

1. Have you been diagnosed with HIV, and used ARVs to control HIV, and at some stage have found ARVs to be no longer working/effective to control HIV anymore? And you had to be switched onto another set of ARVs?

If so, we would like you to volunteer to participate in a study that is investigating challenges you may have met while you were still using first combination of pills, which may have led to being changed onto another combination of pills through listening to your story.
If you would like to volunteer to participate, please read through the information regarding your participation below and let your counsellor know. She will pass on the information to me as the researcher (Jabulani Cele Who can be contacted on XXXXXXXX (for any information regarding this study.

Appendix Four (B): Invitation (*isimemo)* - *IsiZulu*

Kumenywa abasebenzisa imishanguzo yesandulela ngculaza ukuba babambe iqhaza ocwaningweni olumayelana nokusetshenziswa ngendlela kwemishanguzo

Uyamenywa ukuba uzobamba iqhaza ocwaningweni oluhlola izinselelo ezikhona ekuthatheni imishanguzo ngendlela neziholela ekutheni umuntu aze ayekiswe imishanguzo abeyisebenzisa afakwe kweminye. 2. Ngabe usuwathola ukuthi uphila nesandulela ngculaza (HIV)? Uyayisebenzisa imishanguzo ukulawula/ukuthothobalisa isandulela ngculaza? Wake waba nesikhathi lapho amaphilisi (imishanguzo) engasakusebenzeli khona? Wase ushintshelwa kwamanye amaphilisi (imishanguzo/ARVs)?

Uma kunjalo, singathanda ukuba ubambe iqhaza ocwaningweni olubheka kabanzi izinselelo okungase kube wahlangana nazo ngenkathi usebenzisa imishanguzo okokuqala, okwaye kwaholela ekutheni uze ushintshelwe kolunye uhlobo lwamaphilisi, ngokulalela udaba lwakho.

Uma ungathanda ukubamba iqhaza kulolucwaningo uyacelwa ukuba ufunde ipheshana elinolwazi mayelana nokubamba kwakho iqhaza kulolucwaningo bese wazisa umeluleki/ikhansela lakho. Yena uyobe esedlulisela lolu lwazi kimina njengomcwaningi [uJabulani Cele, otholakala kulenombolo yocingo: XXXXXXXXX (mayelana nalo lonke ulwazi ongase ube nalo mayelana nocwaningo)]

Appendix Five (A)

Interview schedule: For participants using ARVs

Semi structured questions for research participants:

1. How did you discover that you are living with HIV?
2. How did you go about disclosing your HIV status, if you did so?
3. Who would you say has been supporting you since you learned about your HIV status?
4. Would you like to share what your health condition was like before you took ARVs?
5. Would you like to share what your CD4 count was like by that time?
6. What has been your reason for using ARVs? What did you want them to do for you?
7. How did you did you start using ARVs? Or what happened when you were starting on ARVs?
8. How long have you taken ARVs before you were switched on to another type of ARVs?
9. Tell me about your experience on ART?
10. Where were you storing your ARVs?
11. What did you use to remind yourself when it was time for taking your treatment?
12. Who was supporting you at home and in the community during on ART during that period?
13. What support did you get from the clinic?
14. When you are to travel to somewhere, how did you ensure that taking your medication continues?
15. When you travel, what happens to your ARV treatment?
16. What would you say made it difficult for you to adhere to taking ARVs?
17. What would you say was the most difficult time for you to take your treatment?
18. What lead you to be switched onto the treatment you are on right now?
19. When was the easiest time for you to take you medication?
20. How have ARVs improved your life thus far?
21. When do you get your treatment?
22. When do you know that your treatment is running out?
23. How do you get prepared not to run out of treatment?
24. When do you take your treatment?
25. What are some of the challenges to taking the treatment?
26. Is there anything you would like to say about taking your treatment?

Appendix five (B)

Interview schedule: For participants using ARVs

Semi structured questions for research participants:

1. Wathola kanjani ukuthi usuphila nesandulela ngculaza (I HIV)?
2. Uma kukhona osuwamazisa ngesimo sakho sokuphila negciwane, wakwenza kanjani lokhu?
3. Ungathi ngubani oyaye akweseke selokhu wathola ukuthi usuphila nesandulela ngculazi?
4. Ungachaza hleze ukuthi isimo sakho sezempilo sasinjani ngaphambi kokuqala ukusebenzisa Imishanguzo (ARVs)?
5. Ungathanda ukuchaza ngesimo sakho samasosha omzimba ukuthi sasimi kanjani ngaleso sikhathi?
6. Kwabe kuyisiphi isizathu owabe uyidingela sona imishanguzo? Imishanguzo wawufisa ikwenzeleni?
7. Wayiqala kanjani imshanguzo? Noma, kwenzakalani ngenkathi uqala ukuyisebenzisa?
8. Wabe usuyisebenzise isikhathi esingakanani imishanguzo ngaphambi kokuba ushintshelwe kolunye uhlobo lwamaphilisi (ama - ARVs)?
9. Ngicela ungixoxele ngobekwenzeka ngenkathi usuthatha imishanguzo?
10. Ubuyaye uwabeke kuphi amaphilisi akho?
11. Yini ebiyaye ikusize ukuzikhumbuza uma sekuyisikhathi sokuthatha amaphilisi akho?
12. Ubani ongathi ubekweseka ekhaya nasemphakathini ngaleso sikhathi?
13. Hlobo luni lokwesekwa obuluthola emtholampilo?
14. Uma unohambo oluya ndawana thize, ubuwenzenjani ukuqinisekisa ukuthi kuyaqhubeka ukudla amaphilisi ngendlela?
15. Yini ongase uthi ibikwenza kube lukhuni ukuthatha amaphilisi ngendlela?
16. Yisiphi isikhathi ongathi yisona okwaba nzima kakhulu kusona ukuqhubeka nokuthatha amaphilisi?
17. Yikuphi ongathi kwaba yisizathu ngqangi sokuba ushintshelwe emaphilisini owasebenzisa manje?
18. Kunini lapho bekuba lula khona kuwe ukuthatha/ukuphuza amaphilisi akho?
19. Ungathi imishanguzo ilithuthukise kanjani izinga lempilo yakho kuze kube namuhla?
20. Okwamanje uma unohambo uyaye wenze njani ngamaphilisi?

21. Uvame ukuwathola nini amaphilisi akho avela emtholampilo?
22. Ubona nini ngokuvamaile ukuthi aseyaphela amaphilisi?
23. Uyaye wenze njani ukuqinisekisa ukuthi awakupheleli amaphilisi?
24. Uyaye uwathathe ngasikhathi sini okwamanje?
25. Yiziphi ezinye zezingqinamba obhekana nazo ekuthatheni amaphilisi wona qobo lwawo?
26. Kukhona hleze okunye othanda ukukusho nje, mayelana nokuthatha amaphilisi?

Appendix Six (A): Questions for Health Care Workers (Lay Counsellors, nurses and CCGs)

1. Would you please share with me the services you offer to HIV positive clients?
2. How long have you been working with people that are living with HIV?
3. On average how many HIV positive clients do you offer services to per day?
4. Of the HIV positive clients you see per day how many would you say are on ART?
5. Please take me through what you normally do from when the client gets in through your door until when she/he leaves?
6. Would you say that your clients sometimes find it difficult to take their treatment?
7. What do they normally mention as their reasons for difficulties for taking their treatment?
8. What are the reasons for stopping medication you have heard more frequently from your clients?
9. What do you think makes your clients stop taking their medication, apart from what they themselves say?
10. Do you have any other additional information you would like to share about your clients on ART?

Appendix Six (B): Questions for Health Care Workers (Lay Counsellors, nurses and CCGs)

1. Ngicela ungixoxele ngezinsiza oyaye nizinikezele kubantu abaphila negciwane lengculaza (HIV)?
2. Sesisingakanani isikhathi usebenza nabantu abaphila negciwane lengculazi?
3. Ngokuvamile ungathi bangakhi abantu abaphila nesandulela ngculazi oyaye ubasize ngosuku?
4. Koyaye ubabone abaphila negciwane ngosuku ungathi bangakhi abasebenzisa imishanguzo?
5. Ngicela ungixoxele ngovame ukwenze kusukela umuntu engena kuze kube uyophuma ngomnyango?
6. Ungasho yini ukuthi kwesinye isikhathi abantu abasebenzisa imishanguzo obasizayo babuye bakuthole kunzima ukuthatha amaphilisi abo?
7. Bayeye babike kuphi njengezizathu ngqangi ngobunzima bokuthatha amaphilisi abo?
8. Yiziphi izizathu zokuyeka amaphilisi ovame ukuzizwa kaningi kubantu abathatha amaphilisi obasizayo?
9. Ucabanga ukuthi yini eyenza abasebenzisa imishanguzo obasizayo bayiyeke, ngaphadle kwalokhu abakushoyo bona qobo lwabo?
10. Kukhona olunye ulwazi onalo ongase uthande uklwedlulisa mayelana nosebenza ngabo abaphila nesandulela ngculazi abasebenzisa imishanguzo?

Appendix Seven (A): Informed consent

Informed consent for research participants

I _____hereby give consent to participate in the ARV Adherence study voluntarily.

1. All the information about the study I am participating in has been given to me.
2. The nature and the purpose of the study I am involved in have been disclosed to me.
3. I have been informed that responses will be treated in a confidential manner, even though the findings of the whole study would be disclosed, but this would be done without disclosing that it is I who responded as such.
4. I have been informed about my choice remain anonymous, and I have been encouraged to do so.
5. I understand that I can quit at any time during this study should I wish to do so without fear of being punished or excluded from the clinic services and care.
6. The name and the surname of a researcher as well as the institution he is associated with and the name of his supervisor and the contacts of both the supervisor and the researcher have been shared with me.

Signed:_____ Date:_____

Appendix Seven (B) Informed consent (translated version).

Informed consent: isiZulu

Mina _____Nginika imvumo yokuba yingxenye yocwaningo olumayelana nokusetshenziswa kwemishanguzo yegciwane lengculaza ngendlela ngokuzikhethela ngingaphoqwanga.

1. Lonke ulwazi mayelana nocwaning engizibandakanya nalo ngilunikeziwe.
2. Ngichazeliwe ngenhloso ocwaningo nohlobo nobunjalo balo.
3. Ngichazeliwe ngokuthi engikushilo ocwaningweni kuzogcinwa kuyimfihlo.
4. Ngazisiwe ukuthi imiphumela iyodalulwa ngaphandle kokuveza umnikazi wezimpendulo.
5. Ngazisiwe ngelungelo lami lokukhetha ukungazisho igama lami, ngakhuthazwa ukuba ngilifihle.
6. Ngiyaqonda ukuthi ngingazikhethela noma nini ukuyeka ukuba yingxenye yalolucwaningo uma ngifisa ngaphandle kokwesabela ukujeziswa noma ngilahlekelwe yilungelo lami lokuthola usizo olutholakala emtholampilo nokunakekelwa.
7. Igama nesi bongo sowenza ucwaningo, nomphathi wakhe nesikhungo asebenzisana naso kunye nezindlela zokuxhumana nabo bobabili owenza ucwaningo nomphathi wakhe nginikeziwe kona.

Ukusayinda_____ Usuku:_____

Appendix Eight (A): Consent form for audio recording of interview

Consent to audio record interview

UNIVERSITY OF KWAZULU-NATAL ™

INYUVESI YAKWAZULU-NATALI

In order to capture all you would have said, I would ask for your permission to record interviews which will be later on transcribed analysed by the researcher so as to understand better you shared experiences during interviews. Recorded will be transcribed and translated into English by the researcher.

After translation and transcription, a second person will verify the written and translated data. All recorded data will be deleted from all recording devices once it has been written.

Recorded data is not going to have your name. Instead it will be given a code such as Participant "A" or "B"

I hereby provide consent to:

Please tick in the box below to indicate your choice

Audio-record my interview discussion

☐ **I AGREE** ☐ **I DO NOT AGREE**

SIGNATURE OF PARTICIPANT: **DATE:**

Appendix Eight (B): Consent form for audio recording of an interview *(isiZulu)*

Ukunika imvume yokuba ingxoxo iqoshwe.

UNIVERSITY OF KWAZULU-NATAL
INYUVESI YAKWAZULU-NATALI

Ukuze kubanjwe konke ozobe ukushilo, ngicela imvumo yakho ukuqopha inkulumo ngxoxo yethu. Kuzothi emva kwesikhathi umcwaningi ayibhale phansi igama negama, ayihlaziye ukuze aqondisise kangcono ukuthi oye wakhuluma ngakho mayelana noye wabhekana nakho yakho. Lokho okuzobe sekubhalwe phansi kuyobe sekuguqulelwa esingisini kusaguqulwa nguyena umcwaningi.

Ngemuva kokuba sekubhalwe phansi kwayiswa esingisini okubhaliwe, umuntu wesibili uyobe esengenelela ukuqinisekisa-ke ukuthi kuguqulelwe ngokho yini esingisini kusuka esizulwini. Okuqoshiwe kuyobe sekuyacinywa konke uma sekubhalwe phansi.

Aliyukufakwa igama lakho kokuqoshiwe. Kuyomane kusetshenziswe izinkomba (code) ezingadaluli muntu, njengokuthi nje, obebambe iqhaza wokuqala “A”, noma obebambe iqhaza wesibili “B”.

I hereby provide consent to:

Sicela ukhethe ngokukhombisa ebhokisini elingezansi, okuhambisana nawe

Lapha nginikeza imvume yokuqopha inkulumo ngxoxo yami ☐ ☐

NGIYAVUMA **ANGIVUMI**

UKUSAYINDA KOMBAMBIQHAZA:_____

USUKU:_____

Appendix Nine: Ethics approval

UNIVERSITY OF KWAZULU-NATAL
INYUVESI YAKWAZULU-NATALI

6 September 2016

Mr Jabulani Reginald Cele 215068698
School of Applied Human Sciences
Pietermaritzburg Campus

Dear Mr Cele

Protocol reference number: HSS/1099/016M
Project Title: Key barriers to Antiretroviral (ARV) treatment adherence: Experiences of Health Care workers (HCW) and Antiretroviral Therapy (ART) clients in KwaZulu-Natal in the Uthukela District

Full Approval – Expedited Application

In response to your application received 19 July 2016, the Humanities & Social Sciences Research Ethics Committee has considered the abovementioned application and the protocol has been granted **FULL APPROVAL.**

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment /modification prior to its implementation. In case you have further queries, please quote the above reference number.

PLEASE NOTE: Research data should be securely stored in the discipline/department for a period of 5 years.

The ethical clearance certificate is only valid for a period of 3 years from the date of issue. Thereafter Recertification must be applied for on an annual basis.

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully

.....

Dr Shenuka Singh (Chair)
Humanities & Social Sciences Research Ethics Committee

/pm

Cc Supervisor: Dr Mary van Der Riet
Cc Academic Leader Research: Professor D Wassenaar
Cc School Administrator: Ms Nondumiso Khanyile

Humanities & Social Sciences Research Ethics Committee
Dr Shenuka Singh (Chair)
Westville Campus, Govan Mbeki Building
Postal Address: Private Bag X54001, Durban 4000
phone: +27 (0) 31 260 3587/8350/4557 **Facsimile:** +27 (0) 31 260 4609 **Email:** ximbap@ukzn.ac.za / snymaonm@ukzn.ac.za / mohunp@ukzn.ac.za
Website: www.ukzn.ac.za

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Appendix Ten: Department of Health (DoH) Approval

health
Department:
Health
PROVINCE OF KWAZULU-NATAL

Physical Address: 330 Langalibalele Street, Pietermaritzburg
Postal Address: Private Bag X9051
Tel: 033 395 2805/ 3189/ 3123 Fax: 033 394 3782
Email:
www.kznhealth.gov.za

DIRECTORATE:
Health Research & Knowledge Management

HRKM Ref: 306/16
NHRD Ref: KZ_2016RP11_561

Date: 23 September 2016
Dear Mr J. Cele
UKZN

Approval of research

1. The research proposal titled '**Key barriers to antiretroviral (ARV) treatment adherence: Experiences of Health Care workers (HCW) and Antiretroviral Therapy (ART) clients in KwaZulu-Natal in the UThukela District**' was reviewed by the KwaZulu-Natal Department of Health.

   The proposal is hereby **approved** for research to be undertaken at Injisuthi Clinic.

2. You are requested to take note of the following:
   a. Make the necessary arrangement with the identified facility before commencing with your research project.
   b. Provide an interim progress report and final report (electronic and hard copies) when your research is complete.

3. Your final report must be posted to **HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200** and e-mail an electronic copy to hrkm@kznhealth.gov.za

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

Yours Sincerely

Dr E Lutge
Chairperson, Health Research Committee
Date: 26/09/16

Fighting Disease, Fighting Poverty, Giving Hope

Appendix Eleven: District Director's letter of support

health
Department:
Health
PROVINCE OF KWAZULU-NATAL

DIRECTORATE:
Uthukela District Office

32 Lyell Street, Ladysmith, 3370
Private Bag x9958, Ladysmith, 3370
Tel: 036 631 2202 Fax: 036 631 0530 Email: Thandeka.zulu@kznhealth.gov.za
www.kznhealth.gov.za

11 October 2016

Mr J Cele

RE: APPLICATION FOR SUPPORT TO CONDUCT A STUDY ON "KEY BARRIERS TO ANTIRETROVIRAL (ARV) TREATMENT ADHERENCE: EXPERIENCES OF HEALTH CARE WORKERS (HCW) AND CLIENTS IN KWAZULU-NATAL IN THE UTHUKELA DISTRICT" IN UTHUKELA HEALTH FACILITIES.

1. Your request letter received on 04 October 2016 refers.
2. Uthukela District must ensure adherence to all the policies, produces, protocols and guidelines of the Department of Health with regards to this research.
3. Your research will only commence once this office has received confirmation of the approval by HOD from the provincial Health Research Committee in the KZN Department of Health.
4. However your research is hereby supported.
5. I trust that you will find all to be in order.

Yours faithfully

DR M T ZULU
DISTRICT DIRECTOR
UTHUKELA HEALTH DISTRICT

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Appendix Twelve: Sub-District (Estcourt Hospital) Acting CEO Letter of support

health
Department:
Health
PROVINCE OF KWAZULU-NATAL
Physical Address: No.1 Old Main Road , Estcourt 3310
Postal Address : Private Bag X7058, Estcourt 3310
Tel: 036 3427000 Fax: 036 3427116 Email:Hlongwa.Thembile@kznhealth.gov.za
www.kznhealth.gov.za
Office of the CEO

Enquiries: Mrs Hlongwa / PRO
Date: 2016 10. 14
Tel: 0363427038 /7089

HAST MANAGEMENT & COORDINATION
Uthukela District Office
Private Bag x 9958
Ladysmith
3370

Attention: Mr J. Cele

RE – REQUEST FOR PERMISSION TO CONDUCT A STUDY ON ANTRETROVIRAL THERAPY ADHERENCE AT INJISUTHI CLINIC
The above matter refers:

Kindly be advised that you're Email dated 2016.10.14 enfolding your request on the abovementioned study has been received and has reference:

- We appreciate that you have carefully chosen Injisuthi Facility as one of our 24 hour high volume clinics within the Sub- District.as your research site on the abovementioned Study Proposal.
- Hopefully your study and will benefit the community of Loskop as the adherence reinforcement will help us achieve the third 90% of viral load reduction then the life expectancy of the entire Su-District people living with HIV will be prolonged.
- Your request to conduct a study has been approved. On behalf of the hospital Ethical Committee, and Institutional HRD Committee, PHC Management and the Hospital Management.
- You are also reminded to observe the critical ethical principles as you conduct your study such as :
  - Tighten up on adherence to maintaining confidentiality, anonymity, informed consent and freedom of choice, publishing any report relevant to your study without prior authority being granted by the Hospital Management. etc.
- Your study results and recommendations at the end will need to be formally communicated to Estcourt Hospital Management and other Stakeholders or at District level..
- The Hospital Management will need to be provided with the realistic time for the research stating the anticipating commencement and completion dates.
- You must also take note that the Hospital Management will intermittently pay site visits to monitor the progress of research activities and give you support where it is necessary as they regularly pay support visits to all the PHC Facilities within the Sub-District.

Thank you

Mrs T.S. Hlongwa: DMN
ACTING CEO