



**Antiretroviral therapy adherence counselling practice in primary
healthcare facilities in the City of Tshwane, Gauteng, South Africa**

Johanna Theunissen

A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master of Public Health.

March 2020

Declaration

I, Johanna Theunissen, declare that this Research Report is my own, unaided work. It is being submitted for the Degree of Master of Public Health at the University of the Witwatersrand in Johannesburg, South Africa. It has not been submitted before for any degree or examination at any other university.

Signed: Johanna Theunissen

Date: 20 March 2020

Location: Sussex, Wisconsin, United States

Abstract

Introduction

South Africa's growing HIV treatment programme is integrated into primary healthcare services, thus improving access for people living with HIV. However, there are mounting concerns regarding adherence, as less than half of clients are retained on antiretroviral therapy (ART) 60 months after initiation. Adherence counselling is one of five key strategies in the *Adherence Guidelines for HIV, TB and NCDs: Policy and service delivery guidelines for linkage to care, adherence to treatment and retention in care*, which were developed in 2016 to standardise and improve adherence approaches. While client perspectives on factors affecting adherence have been well-researched, there is limited literature on practice among professional nurses implementing nurse-initiated management of antiretroviral therapy (NIMART). Moreover, little is known about the factors affecting quality service provision, particularly from the perspective of healthcare providers implementing NIMART. Consequently, this study aimed to explore ART adherence counselling practice by professional nurses in five primary healthcare clinics in the City of Tshwane. Study objectives included discussing the context of ART adherence counselling practice, describing ART adherence counselling practice from the perspective of the professional nurses, analysing the reported adherence counselling practice in relation to the national *Adherence Guidelines*, and discussing factors that influence the professional nurses' provision of ART adherence counselling.

Methods

The study employed a qualitative research approach, applying a cross-sectional exploratory design. Five primary healthcare clinics located in the City of Tshwane in Gauteng province, South Africa, were selected, with two in suburban areas, two in townships, and one in the inner city. In-depth interviews were conducted with 10 professional nurses at these facilities (two at each facility), who were purposively sampled based on experience and availability. The in-depth interviews were transcribed and a codebook developed through deductive and inductive coding of data, which was applied to facilitate thematic analysis. This data was compared to the *Adherence Guidelines'* fast-track initiation counselling using a table with section headings to assess similarities and differences.

Results

Due to perceived lay counsellor unavailability or inadequate capacity, the professional nurses reported that they provide adherence counselling themselves, consisting of education on HIV, ART and the treatment process; addressing side effects; medication scheduling; and reminders. They employ simple, appropriate language and supportive attitudes to build client rapport. In addition, they address behaviours (substance use, traditional and alternative medication use,

and diet) which can affect adherence, explaining how these behaviours may affect treatment efficacy and viral load through drug interactions and hindering absorption of the antiretrovirals (ARVs). While messaging is largely didactic, the professional nurses support clients to adopt their guidance related to these behaviours, including facilitating disclosure through re-testing with clients' partners. In the absence of official job aids, they create their own analogies using everyday examples and props to explain complex concepts such as viral suppression. The professional nurses' adherence counselling practice is comparable to that outlined in the *Adherence Guidelines*, particularly in terms of messaging, counselling methods, roles, and parameters (frequency, time, and duration). While the professional nurses are confident in their ability to provide counselling following NIMART training, supportive interventions are appreciated, including additional human resources provided by District Support Partners and collaboration with service providers such as Ward-based Primary Healthcare Outreach Teams (WBOTs). System-related improvement measures yield mixed results: integration of HIV care into clinic services and rotation of nurses through various service areas has reduced stigma, but hinders continuity of care. Similarly, the appointment system helps manage workload, but can discourage client access. On the other hand, staff shortages, unrealistic daily consultation targets, and clients' clinic preferences limit the professional nurses' time to provide adherence counselling and compromise quality of care. Health facility location affects the feasibility of adherence interventions such as support groups, as well as the extent of assistance from other government and community-based service providers. Client understanding and cooperation are important, with the professional nurses acknowledging the powerful influence of social, economic, and cultural factors, which can undermine adherence.

Discussion and recommendations

While the professional nurses reported that their adherence counselling practice does address social, economic, and cultural factors relevant to their clients' context, messaging related to the direct effect of specific behaviours on treatment efficacy and viral load go beyond findings in existing literature. This indicates a need to specify and standardise core adherence counselling messaging. Measures to improve HIV care such as system adaptations and support structures, and better use of existing resources such as lay counsellors and WBOTs, can contribute towards improving professional nurses' adherence counselling practice. However, it is important to ensure that these adaptations do not inadvertently undermine adherence behaviour. The differences identified between reported practice by the professional nurses and the *Adherence Guidelines* – in terms of messaging, counselling methods, roles, and parameters – can play a valuable role in the revision of the guidelines and preparation for national rollout.

Conclusion

As the number of people on ART in South Africa grows, nurses will likely continue to be the main providers of clinical HIV services, including adherence interventions. By exploring adherence counselling practice by professional nurses in primary healthcare settings, this study hopes to provide insight into areas of strength as well as those requiring improvement, particularly in light of the future implementation of the *Adherence Guidelines* to build on and enhance efforts to promote client adherence and retention in care.

Acknowledgements

I firstly want to extend my deep appreciation to the professional nurses who participated in this study as a proxy for all nurses across the country, who serve as the backbone of South Africa's primary healthcare system. Their passion and honesty were refreshing and inspiring. Their skill and commitment have transformed many lives. Without them we cannot achieve our health goals – including those related to HIV.

I would also like to thank my former colleagues Zuzelle, who was completing her MPH when I was starting mine and was a source of many helpful insights and enthusiastic discussions, and Sandisile, whose excellent research report was my model for everything, from structure to how to approach the discussion section.

Sincere gratitude goes to the Wits faculty for providing compassionate support while pushing us to work, think, present, and write better. They provided all the tools we needed and gave us invaluable advice – I still hear Janine White telling us, “When you don't know what to write, read!” Special thanks to my supervisor, Dr Daphney Nozizwe Conco, for helping me to “tell the story.”

Finally, I thank my husband Luke for his support throughout the entire MPH process. He gave me exactly what I needed to persevere, nagging me when I was procrastinating and giving me lots of space to work.

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List of acronyms

ART	Antiretroviral therapy
ARV	Antiretroviral drug
EDL	Essential Drug List
FPD	Foundation for Professional Development
HCT	HIV counselling and testing
HCW	Healthcare worker
HIV	Human immunodeficiency virus
HREC	Human Research Ethic Committee
IDI	In-depth interview
IEC	Information, education and communication
IMB	Information-motivation-behavioural skills (model)
MSF	Médecins Sans Frontières
NCD	Non-communicable disease
NGO	Non-governmental organisation
NIMART	Nurse-initiated management of antiretroviral therapy
PLHIV	People living with HIV
PMTCT	Prevention of mother-to-child transmission
RCT	Randomised control trial
STI	Sexually transmitted infection
TB	Tuberculosis
TCAM	Traditional, complementary and alternative medicine
UNAIDS	United Nations Joint Programme on HIV and AIDS
WBOT	Ward-based Primary Healthcare Outreach Team
WHO	World Health Organisation

CHAPTER 1: INTRODUCTION

Chapter one contains an overview of the importance of adherence to antiretroviral therapy (ART) and current adherence challenges in South Africa, including measures to address them – particularly the introduction of the *Adherence Guidelines for HIV, TB and NCDs: Policy and service delivery guidelines for linkage to care, adherence to treatment and retention in care (Adherence Guidelines)*. The chapter outlines the problem statement and study justification, and reviews the research question regarding what lessons can be learned from exploring professional nurses' reported practice of adherence counselling, as well as the study aim and objectives identified to answer this question.

1.1 Overview

More than two decades into the HIV epidemic, ART has been shown to be the most effective intervention to prevent new infections(1). ART is central to the United Nations Joint Programme on HIV and AIDS (UNAIDS) global strategy to end the HIV epidemic, based on achieving the 90-90-90 targets (90% of people living with HIV know their status, 90% of those who are HIV-positive are on ART, and 90% of those on ART are virally suppressed)(2). UNAIDS states that provision of ART to people living with HIV (PLHIV) as early as possible is the best long-term return on investment by reducing HIV incidence and saving costs resulting from HIV-related illness(2).

South Africa has the largest HIV treatment programme in the world, with 4.4 million PLHIV on ART in 2018(3). The country's ART programme has achieved important health improvements, such as higher life expectancy, which at 62.4 years in 2016 was four years more than in 2011, at 58.3 years(4). Likewise, HIV-associated mortality, maternal mortality, and mother-to-child transmission of HIV at six weeks were all lower in 2016 than they were five years before(4). South Africa's implementation of universal treatment from September 2016 has the potential to bring many more people into the programme to ensure that all of the seven million people estimated to be living with HIV in the country are on ART(4).

ART can prevent new infections and prolong and improve quality of life, transforming HIV into a chronic and manageable condition. This requires achievement of viral suppression, which in turn requires a high rate of adherence to treatment. However, adherence to ART has been found to be a challenge. A systematic review consolidating data from 39 cohorts of clients on ART in sub-Saharan Africa (14 of these cohorts in South Africa), with a total of 226,307 people on treatment, revealed client retention was at 70% at 24 months and declined to 64% at 36 months(5). In South Africa, of the 59.6% of active patients on ART in 2014 who had viral load testing done, 81% were virally suppressed(6). However, the country also reported that its retention of people on ART was 78.9% at six months after initiation and 48.3% after 60 months(6) – indicating that levels of viral suppression, a reflection of adherence, are not known among the majority of people on ART, and particularly among those who have been on treatment for longer periods of time.

The recognised importance of high levels of treatment adherence, as well as acknowledgement of poor tracking and data management systems, led South Africa's National Department of Health to develop the *Adherence Guidelines* and accompanying standard operating procedures in 2016(6). The guidelines include a stepwise approach model and evidence-based implementation guidelines for provision of an adherence minimum package. They also detail adherence strategies, approaches, messaging, and tools to be used to support fast-tracking of ART initiation and provide enhanced adherence counselling to those not stable on treatment(7). The guidelines were developed based on international and South African research and best practice, and are intended to guide the provision of services, including adherence counselling, by healthcare workers (HCWs)(7). The impact of the *Adherence Guidelines* on health outcomes is currently being assessed through a cluster randomised evaluation at 12 health facilities in four provinces, prior to national rollout(8).

1.2 Background

In South Africa, ART is provided in primary healthcare facilities, with treatment initiation and ongoing management conducted by professional nurses in order to better manage increasing client numbers and improve access to care and treatment(9). A South African study of 30,000

ART clients from 59 health facilities in four provinces demonstrated better health outcomes, including higher levels of retention in care and viral suppression and lower mortality and loss to follow up, after 12 months at primary healthcare clinics than at district or regional facilities(10). It was noted, however, that an increasing client load and client-staff ratio was likely to decrease the quality of care(10), and this concern has been echoed by other studies from South Africa(11–14).

Poor adherence compromises the cost-effectiveness of South Africa's ART programme, and is one of the core obstacles the country faces in achieving the goals of the National Strategic Plan on HIV, TB and STIs 2017-2022(4). Moreover, it results in sub-optimal health outcomes, higher rates of transmission, and higher costs related to ineffective treatment, requiring second-line regimens due to drug resistance(7).

ART adherence counselling is often assumed to be a standard and essential component of HIV care(15), and is one of the key interventions included in the *Adherence Guidelines*(7). However, there is limited literature on the practice of adherence counselling among professional nurses providing ART, particularly in South Africa, where just over half (55%) of people ever initiated on treatment are retained in care(16).

1.3 Problem statement

South Africa has introduced universal ART for PLHIV as a critical intervention for the prevention of new infections, as well as for the achievement of the UNAIDS 90-90-90 targets. However, poor adherence to treatment has been identified as a challenge to the country's HIV response(4). The levels of retention noted in South Africa's 2015 Global AIDS Response Progress Report are consistent with findings from a systematic review of client retention in ART programmes in sub-Saharan Africa, which noted retention of 79.1% after six months on ART, and 61.6% after 24 months on ART(5). The *Adherence Guidelines* and accompanying standard operating procedures are aimed at addressing this challenge by providing a standard of practice for adherence interventions, including counselling by HCWs. While implementation of the guidelines is being assessed at a limited number of health facilities, there is a need to gain insight into existing ART adherence counselling practice from the perspective of the

professional nurses providing it, including the context in which it is provided and factors affecting its practice, as well as how it relates to the *Adherence Guidelines*.

1.4 Justification for the study

The *Adherence Guidelines* acknowledge research findings on the value of adherence counselling on client behaviour, which in turn affects health outcomes such as viral suppression(7). This study applied in-depth interviews (IDIs) to investigate the current practice of ART adherence counselling from the perspective of the professional nurses delivering it, enabling exploration of the content of the adherence counselling, as well as the context of the practice and the factors perceived to affect it. The professional nurses' reported practice was appraised against the *Adherence Guidelines* to identify areas of alignment as well as areas for improvement to promote optimal treatment adherence among ART clients. Understanding current adherence counselling practice can assist in informing and refining the *Adherence Guidelines* to strengthen adherence counselling provision, and ultimately address the challenges which are preventing the country from reaching its HIV response goals.

1.5 Research question

What do we know and what lessons can be learned about ART adherence counselling practice by primary healthcare clinic professional nurses in the City of Tshwane in Gauteng province, South Africa?

1.6 Study aim and objectives

The aim of the study was to explore ART adherence counselling practice by professional nurses in five primary healthcare clinics in the City of Tshwane. The study objectives were to:

1. Explore the context in which ART adherence counselling is practiced by professional nurses working in primary healthcare clinics in the City of Tshwane.
2. Describe the professional nurses' ART adherence counselling practice, including content, approaches, and techniques.
3. Analyse the similarities and differences between the professional nurses' ART adherence counselling practice and South Africa's *Adherence Guidelines*.

4. Discuss factors that influence the professional nurses' provision of ART adherence counselling.

1.7 Chapter summary

This chapter presented the background to the research and an explanation of the value of exploring adherence counselling practice by professional nurses in South Africa. The next chapter will further place the study topic into context, presenting existing literature on adherence counselling – particularly with regard to approaches and content, service delivery guidelines (and assessment of their implementation), and factors reported to affect adherence counselling provision.

CHAPTER 2: LITERATURE REVIEW

This chapter reviews existing literature related to the study topic of ART adherence counselling practice in primary healthcare facilities. It provides an overview of the critical role that adherence counselling has in promoting treatment adherence and retention in care. The chapter also reviews the literature on adherence counselling practice in South Africa, including methods, content, and tools used. The country's service delivery guidelines as related to adherence counselling are reviewed, including the *Adherence Guidelines*, as are factors reported to affect the provision of adherence counselling.

2.1 Strategies used to improve ART adherence

The provision of ART to PLHIV as soon as possible after HIV diagnosis is recommended as the most effective approach to promote client survival and quality of life and reduce HIV incidence at population level(2). However, inadequate adherence to treatment is a challenge hindering achievement of these outcomes.

Adherence is defined by the World Health Organisation (WHO) as “the extent to which a person’s behaviour – taking medication, following a diet, and/or executing lifestyle changes – corresponds with agreed recommendations from a health care provider”(17). Counselling is defined by UNAIDS as “an interpersonal, dynamic communication process between a client and a trained counsellor, bound by a code of ethics and practice, who tries to resolve personal, social, or psychological problems and difficulties. In the context of an HIV diagnosis, counselling aims to encourage the client to explore important personal issues, identify ways of coping with anxiety and stress, and plan for the future (such as keeping healthy, adhering to treatment, and preventing transmission)”(18).

Multiple systematic reviews have been conducted to evaluate effective strategies to improve adherence, yielding mixed results(15,19–24). Only a few studies have found positive, long-term effects of interventions on both behavioural outcomes (such as adherence) and biological outcomes (such as viral load)(15,19,21,24). However, adherence interventions are often complex, making it difficult to assess the impact of individual components(21). Nevertheless,

common findings include the use of education and counselling (particularly those applying aspects of cognitive behavioural therapy), treatment supporters, and reminder and communication technology such as SMS messaging(15,19–24). Interventions specific to sub-Saharan Africa which have been found to be effective in promoting adherence include reminder devices, treatment supporters, directly-observed treatment, education and counselling, and food supplements – other studies in sub-Saharan Africa fail to demonstrate a significant effect from each of these interventions(24).

2.2 Evidence on the efficacy of adherence counselling

There are a limited number of studies assessing the effect of adherence counselling specifically, possibly due to it often being considered part of a standard package of HIV services and a benchmark against which other adherence interventions are tested(15). Yet the existing evidence does suggest that adherence counselling is an important element in the provision of HIV treatment to achieve positive health outcomes. For example, a randomised control trial (RCT) conducted in Kenya demonstrated that the provision of adherence counselling positively affected client adherence behaviour and consequently improved health outcomes(25). The study found that clients who received three sessions of adherence counselling were 29% more likely to adhere to at least 80% of their prescribed doses, and were 59% less likely to have viral failure after 18 months, compared to those who did not receive the counselling(25).

However, RCTs in Tanzania and South Africa – while assessing separate adherence interventions and outcomes – found no significant differences between adherence counselling and other adherence measures (such as a calendar and treatment assistant). In the Tanzania RCT, conducted between 2004-2007 at a large teaching hospital in Dar Es Salaam, adherence counselling was provided during 5-10 minute sessions at each visit by a nurse counsellor, and adherence levels were self-reported(26). In the South Africa RCT, conducted at a large HIV-TB clinic in eThekweni between 2007-2009, the didactic counselling was comprised of three 20-45 minute sessions provided by a non-governmental organisation (NGO), while the motivational counselling was five sessions of the same duration provided by a nurse educator, with adherence levels measured by pill count at six months after initiation(27). As participants in

each of these two RCTs achieved high levels of adherence (above 95%) regardless of study arm, the researchers concluded that quality adherence counselling on its own may be adequate to effectively promote treatment adherence(26,27).

On the other hand, Médecins Sans Frontières (MSF) developed and implemented a counselling model which achieved retention rates of 85.9% after six months of treatment among 449 clients enrolled in an observational cohort study in Khayelitsha, South Africa, from 2012-2013(13). Of those retained in care, 80.2% had a viral load test done within six months of initiating treatment, of which 95.4% were virally suppressed(13). This model forms the basis of the fast-track initiation counselling approach used in the *Adherence Guidelines*.

2.3 ART adherence counselling practice

Adherence counselling practice includes how it is provided – counselling methods and tools – as well as the content and parameters, such as frequency, duration, and timing. Despite adherence counselling being considered an important part of a standard package of HIV services(15), these adherence counselling practice elements vary and are not always well-defined in the literature.

2.3.1 Adherence counselling methods and tools

An important part of adherence counselling's overall practice is the way in which it is provided, such as by applying cognitive behavioural therapy, which has been shown to improve client adherence(15,19,21–24). In addition, counselling approaches play a crucial role in promoting client understanding of the treatment plan, as demonstrated in a study involving 22 clinics in Tshwane municipality. The study found a significant association with continuity of care (the client seeing the same clinician three or more times), the consultation being conducted in the client's first language or a similar language, the client stating that the clinician had explained his/her health problem, and the client stating that he/she had participated in the diagnosis(28).

Adherence counselling can also be supported by the use of tools, particularly those which help explain complex concepts related to HIV and its treatment. In a study with HIV-positive clients in the United States, for example, communication tools designed to support ART adherence

counselling improved adherence knowledge one year after use(29). These tools included picture-based images to reinforce concepts such as drug resistance and taking treatment at the same time daily, which the study emphasised was applicable in low-resource settings(29).

The adherence counselling in the RCTs conducted in Kenya and Tanzania primarily employed models which incorporated client-centred approaches and social and behavioural change theory. This included assessing client understanding and readiness to begin treatment, as well as discussing specific adherence barriers and challenges experienced and identifying strategies to address them. These elements involved substantial client engagement and tailored messaging based on client need – beyond a strictly didactic approach. The Tanzania RCT also used a questionnaire to assess adherence and guide the session in terms of specific causes of non-adherence.

The RCT conducted in South Africa compared the standard adherence counselling to a motivational counselling approach, which was client-centred and tailored to each client's circumstances and needs(27). This approach applied motivational interviewing by encouraging clients to be involved in their own behaviour change and employed the information-motivation-behavioural skills (IMB) model: providing information on treatment (including dosing, side effects, and the risk of drug resistance), motivation through managed disclosure (assisting clients to disclose their status to another person over six months), and skills such as building treatment into daily routines(27). The motivational counselling approach used several tools, including a flipchart in English and Zulu, posters, and a treatment plan card. In addition, clients were referred to other required services for psychosocial issues or substance abuse(27). Motivational interviewing methods were applied in the MSF counselling model as well, together with cognitive behavioural and problem-solving techniques. The model also incorporated tools to support the counselling, including a visual aid and educational pamphlet for the client(13). In contrast, the standard adherence counselling in the South Africa RCT was didactic, focusing on treatment literacy and readiness in line with the country's guidelines at the time of the study(27).

While good practice from the literature favours counselling approaches which engage clients and promote their involvement in their own care and treatment, a qualitative systematic review exploring the experience of being HIV-positive and on treatment in Africa reveals that in practice, health systems are often authoritarian, with healthcare workers setting specific lifestyle rules for clients to follow, including stopping alcohol use, reducing sex, avoiding pregnancy, eating a healthy diet, reducing stress, and accepting their HIV status(30). Healthcare workers expect compliance with these rules and ignore clients' circumstances which could affect their behaviour, and clients who do not comply are viewed and treated negatively(30).

2.3.2 Adherence counselling content

The foundation of adherence counselling practice is the content, or messaging. For example, the key adherence counselling content in the three RCTs and the MSF counselling model included two main components: 1) education on HIV and its treatment; and 2) addressing barriers to adherence, with recommendations of tools and practical solutions to mitigate these barriers(25–27).

Education on HIV and its treatment

Educational content provided during adherence counselling in the Kenya and Tanzania RCTs incorporated information on HIV and ART as well as the importance of adhering to treatment – including the risk of treatment failure due to inadequate adherence(25,26). The documentation of the South Africa RCT provided more detail in terms of the standard adherence counselling content: the first session addressed stigma and discrimination, nutrition, and client ownership of the treatment regimen; the second session covered HIV, transmission, HIV testing, and basic ART; and the third session incorporated ART, drug regimens, the importance of treatment adherence, side effects, monitoring the effect of treatment, and prevention of resistance(27).

Addressing barriers to adherence

Assessment and discussion of client adherence barriers and challenges was cited as a key element in the adherence counselling provided in the three RCTs – although these barriers are not specified. The MSF counselling model, which is based on a Life Steps intervention to

medication adherence, addresses 14 specific adherence steps addressing potential barriers which were identified by MSF based on the organisation's programmatic experience(13). These include understanding HIV, identifying a support system, planning future appointments, preparing to start treatment, creation of a medication schedule, managing missed doses, reminder strategies, storing medication and extra doses, dealing with side effects, planning trips, dealing with substance abuse, communication with the treatment team, learning from mistakes, and making treatment goals(13).

There have been a number of studies conducted on the barriers and facilitators of ART adherence in South Africa, incorporating client and HCW perspectives. Issues commonly identified as adherence barriers can be classified as social, cultural, and economic; individual; and health system factors. It is important to note that these issues are often interconnected and mutually reinforcing. For instance, social, cultural, and economic factors include stigma and lack of social support for PLHIV, poverty, and food insecurity(31–34); individual factors include depression and fear of disclosure, use of substances and alternative medication, and lack of treatment knowledge and skills(31–34); and health system factors include overcrowding and waiting time at the health facility, as well as inadequate communication capacity between clients and HCWs(31–34). These findings are echoed by two global systematic reviews and a meta-analysis on adherence, which emphasise depressive symptoms and a lack of trust/satisfaction with the care provider as particularly important factors for low- and middle-income countries(35–37).

An individual barrier like lack of treatment knowledge and skills – which can be affected by health system factors, such as inadequate communication with healthcare providers – can play a substantial role in adherence in terms of taking treatment correctly and having the skills to self-manage potential challenges. A study involving 600 PLHIV from six health facilities in Cape Town, South Africa, for example, found information, motivation, and behavioural skills to be notably associated with adherence, with more than 50% of participants reporting experiencing information-related barriers, such as inadequate knowledge regarding missed doses and the consequences of sub-optimal adherence(32).

A systematic review on the association between HIV-related stigma and discrimination, disclosure, and treatment adherence found that these factors undermine coping skills and social support, which are important in overcoming adherence barriers(38). Of the nine African studies included, five reported a statistically significant association between non-disclosure (or stigma and discrimination) and lower adherence, including three South African studies(38). Varying levels of disclosure of HIV status to sexual partners has been found in South African research – from 58% of 673 pregnant women across 12 health facilities in Mpumalanga(39), to 62% of women and 83% of men who chose to disclose to a family member in a study of 385 PLHIV initiating ART in KwaZulu-Natal(40). In the study of pregnant women in Mpumalanga, disclosure to a male partner was found to be strongly associated with ART adherence, with participants citing fear of negative reactions including rejection, violence, and discrimination as reasons for non-disclosure(39). In contrast, the study of adults in KwaZulu-Natal did not find that stigma and non-disclosure affected client adherence(40).

Many of the social, cultural, and economic factors – such as stigma and lack of social support – can contribute to depression among PLHIV, which in turn can reduce the motivation to adhere. Of the over 10,000 South African PLHIV surveyed for the *People Living with HIV Stigma Index*, 11% expressed suicidal feelings in the last 12 months(41), and half of the 673 pregnant women in Mpumalanga were found to be depressed(39). A systematic review focused on sub-Saharan Africa found that people on ART who had depressive symptoms were 55% less likely to have good adherence to their treatment(42), while lower depression scores and higher scores on indicators of social support were associated with better adherence in a South African study in KwaZulu-Natal(31).

Poverty can also affect adherence in various ways. Firstly, it can interrupt consistent treatment access. For instance, the inability to afford transportation to the health facility among those on ART has been noted as a barrier by several South African studies(12,31,32). Poverty also affects access to food. The *South African National Health and Nutrition Examination Survey* estimated that 26% of the population is food insecure, and nearly 40% of people have low dietary diversity(43). Food insecurity is cited as a barrier to adherence which can affect health outcomes, primarily related to clients not taking ART due to concerns or experiences with

increased hunger and side effects on treatment, or having to make difficult financial decisions such as either purchasing food or going to the health facility to access treatment(44).

Global and regional (sub-Saharan Africa) literature indicate that alcohol use negatively affects adherence as well(42,45). A study on alcohol use and adherence among 304 ART clients in Tshwane municipality found that approximately 40% had ever used alcohol, and of those who did, 30.1% reported missing doses of medication due to alcohol use(46). Substance use, including drinking alcohol, causes clients to forget to take their medication, or clients delay taking ART because they are using substances in a public place and do not want to be seen taking treatment(42,45).

Another factor associated with lower adherence in South Africa is the use of traditional, complementary and alternative medicine (TCAM)(31,47), as cited by HCWs in several South African studies(12,33,34). TCAM use among HIV-positive clients before ART initiation is relatively common in South Africa, at 21.9% and 36.6% of clients in two studies in KwaZulu-Natal province(47,48). However, its use tends to decrease over time on ART – proposed to be an effect of messaging received at health facilities discouraging its use(47,48). A study of 81 HCWs – half of them nurses – in KwaZulu-Natal province revealed low levels of knowledge regarding TCAM, with 79% stating that they did not know if TCAM was safe and expressing the opinion that antiretroviral drugs (ARVs) should not be mixed with other therapies, as they can cause drug reactions, affect blood test results, and reduce adherence(49).

Health system factors include overcrowding and waiting time at the health facility, which discourages client access to services, as well as inadequate ability to communicate among clients and HCWs, which can hinder clients' understanding and treatment knowledge and skills(31–34).

2.3.3 Parameters of adherence counselling

The number and duration of adherence counselling sessions, as well as when they were provided in relation to client treatment initiation, varied among the three RCTs and the MSF model. The Kenya RCT was comprised of three sessions (two sessions prior to ART initiation and one session one month after initiating treatment), and each session was 30-45 minutes in

length, as compared to a 15-minute educational session provided to the control group in the study(25). The Tanzania RCT did not specify the number of sessions, stating that they were provided during monthly client visits by nurse counsellors and were 5-10 minutes in length(26). The standard adherence counselling in the South Africa RCT was comprised of three sessions provided over two to three client visits before treatment initiation, with each session lasting 20-45 minutes, while the motivational counselling included a pre-initiation session and five sessions to clients over six months on treatment, with each session lasting 30-40 minutes(27). The MSF counselling model provides for four counselling sessions, each 12-18 minutes in length, with one conducted before initiation, one on the day of treatment initiation, and two post-initiation(13).

2.4 Service delivery guidelines and their implementation

South Africa has multiple service delivery guidelines which incorporate adherence counselling. These include the *National Consolidated Guidelines for the Prevention of Mother-to-Child Transmission of HIV (PMTCT) and the Management of HIV in Children, Adolescents and Adults (National Consolidated Guidelines)*, released in 2015, as well as *Performance Standards for Antiretroviral Therapy*, released in 2009(50,51). Nationally-accredited nurse-initiated management of antiretroviral therapy (NIMART) training also provides guidance on ART service provision, including adherence counselling, as does the Primary Health Care training for professional nurses.¹ However, the *Adherence Guidelines* are the first national guidelines focused solely on promoting adherence and retention among people taking chronic treatment – including ART(7). The three guidelines available in the public domain (*National Consolidated Guidelines*, *Performance Standards for Antiretroviral Therapy*, and *Adherence Guidelines*) all contain basic adherence counselling guidance, including explaining HIV, ART, and the importance of adherence to treatment(7,50–52). The *Performance Standards for Antiretroviral Therapy* contain more detail in terms of specific actions to take, while the *National Consolidated Guidelines* and *Adherence Guidelines* promote the development of a tailored

¹ As ongoing courses for professionals, the NIMART and Primary Health Care training materials are not available in the public domain.

treatment plan based on client-specific challenges experienced(7,50,51). The *Adherence Guidelines* go further, specifying 12 topics considered key to promote treatment adherence(7).

According to the *National Consolidated Guidelines*, adherence counselling should begin at the time of HIV diagnosis, with monthly counselling visits for the first three months – although adherence support should be ongoing(50). The guidelines stipulate that quality adherence counselling includes four key elements: spending time with the client to explain HIV, treatment goals, and the importance of adherence; discussing viral load and viral suppression; developing a treatment plan with the client; and explaining possible adverse drug-drug interactions and how to avoid them(50). Additional adherence strategies promoted by the guidelines include supporting the client with adherence tools (such as support groups and pillboxes) and modifying client behaviour by ensuring clients understand the risks of poor adherence, addressing client concerns, and providing encouragement and recognition of good adherence(50). The guidelines promote client involvement and empowerment in discussion and decision-making, involving family members/caregivers for additional support, and regular reinforcement of information(50).

Adherence counselling as per the *Performance Standards for Antiretroviral Therapy* should include education on taking treatment at the same time daily, side effects, reminders, preventing transmission (including PMTCT), how ART works, the importance of adherence to prevent resistance, not sharing or stopping ART without consultation, the need to disclose other medication, and that ART is a treatment and not a cure(51). It also requires service providers to address substance use, preventing HIV superinfection, and nutrition and exercise(51). Counselling methods include assessing client knowledge and showing examples of ARVs(51).

Four main components are included in the *Adherence Guidelines*: education and counselling; repeat prescription collection strategies; patient tracing; and an integrated model for patients co-infected with HIV, TB and/or NCDs. The education and counselling component consists of fast-track initiation counselling, enhanced adherence counselling for unstable clients (those with an unsuppressed viral load), and child and adolescent disclosure counselling for children

living with HIV. The fast-track initiation counselling is further comprised of 12 key topics (“steps”) to address over four sessions, and creating a documented adherence plan for each client which takes into account personal barriers and acceptable strategies to address them(7). The fast-track initiation counselling also recommends setting treatment objectives with the client, providing the client with his/her clinical results, and explaining the implications of the results(7). The client should be provided with information, education and communication (IEC) materials and be referred to other services as needed(7).

Table 1: Overview of fast-track initiation counselling in the Adherence Guidelines(7)

Session	Timing of session	Topic (“step”)
1: Start adherence plan	Day of eligibility for treatment	1. Education on illness and treatment
		2. Identify life goals
		3. Identify support systems
		4. Plan for future appointments
		5. Assess readiness to start treatment
2: Continue with adherence plan	Day of treatment initiation	6. Medication schedule
		7. Managing missed doses
		8. Reminders
		9. Storing medication and extra doses
		10. Dealing with side effects
3. Last steps of adherence plan	One month on treatment	11. Plan for travel
		12. Dealing with substance use
4. Education and goals	Two months on treatment	Education and goals

2.4.1 HCWs’ perspectives on the Adherence Guidelines

While the *Adherence Guidelines* are currently being assessed through a cluster randomised evaluation, a process evaluation was conducted to acquire insight from HCWs on the five adherence strategies contained in the guidelines, including IDIs with 48 HCWs from four intervention sites and four control sites(8). This information will help inform revision of the guidelines and future rollout throughout the country(8).

The HCWs viewed the fast-track initiation counselling positively, as it was reported to assist the client to understand ART and the treatment process and gives the HCWs a tool to “help patients

understand the responsibilities of taking treatment” (8). However, they did note that completing an adherence plan for each client may be time-consuming and an additional burden(8).

In addition, the HCWs cited a number of factors which facilitate implementation of the *Adherence Guidelines*, including a strong team of staff, district-level support, high staff capacity due to the rotation system, and the availability of resources, including lay health workers and community-based organisations to provide tracing support(8). Some of the barriers to implementation mentioned were staff shortages for the existing volume of clients – including inadequate numbers of lay workers – and lack of resources for communication and tracing of clients, such as funding and printed materials (like pamphlets)(8).

2.4.2 Assessing HCW implementation of service provision guidelines and quality of adherence counselling

Various studies have noted inadequate implementation of policies and guidelines, which may affect patient outcomes. A 2011 study in two clinics in Blantyre, Malawi, for example, found poor implementation of national HIV care guidelines pertaining to provider-initiated HIV counselling and testing (HCT) and WHO clinical staging to guide provision of ART: only 13% of patients were tested for HIV, and of those who tested HIV-positive, less than half (48%) were assessed for ART eligibility(53). Of those who were assessed at WHO stages three or four, 54% were referred for ART as per the country’s HIV care guidelines(53). The nurses interviewed as part of the study acknowledged these findings, stating that time limitations constricted their provision of WHO staging(53).

There have been few studies conducted on assessing adherence counselling provided by professional nurses in South Africa, although several have incorporated it as an element of overall assessment of clinical care and service quality. An assessment of nurses from eight health facilities in the Western Cape who participated in a clinical mentorship programme for those implementing NIMART from 2011-2012 found that there was inadequate provision of clinical care: half of the nurses in the study assessed and documented client adherence, 41.3% listed client adherence challenges, and 72.5% documented a treatment plan(54). A second

study at three health facilities in Limpopo affirmed the need for clinical mentorship to support nurses in implementing national policies and guidelines, citing a substantial improvement in conducting routine blood tests, including viral load, after mentorship(55).

However, several South African studies have been conducted to assess the quality of adherence counselling provided by lay counsellors, as it is often assumed that this cadre conducts the bulk of adherence counselling, particularly in the context of conducting HCT. These studies raise concerns regarding the quality of counselling services, citing a lack of standard approaches and consistent messaging(56,57). An assessment of service delivery at 16 ART clinics in Gauteng province (including Tshwane municipality) using the *Performance Standards for Antiretroviral Therapy* found HIV counselling conducted by lay counsellors to be the second-lowest performing service area, with a median of 70.7%(51). Although the range of HIV counselling scores varied widely across health facilities, from 25% to 90.9%, common gaps were identified, including inadequate or inconsistent provision of basic information on ART and adherence, prevention of transmission, and lifestyle issues(51).

2.5 Factors affecting adherence counselling provision

There have been several studies conducted in South Africa on factors affecting the provision of HIV services – including adherence support to clients – incorporating the perspective of HCWs(30,34,55,58–60). Common factors cited were staff capacity (in terms of knowledge/skills and workforce), health systems and support, and client understanding and cooperation.

2.5.1 Staff capacity: knowledge and skills

Staff capacity with regard to the knowledge and skills needed to effectively provide HIV services, including adherence counselling, is critical. A qualitative systematic review highlighting issues affecting client retention in care notes that HCWs report receiving inadequate training and skills to address the range of challenges (including social issues) that clients experience which can affect their treatment adherence(30). South African HCWs specifically have cited inadequate numbers of nursing staff trained in NIMART in several studies, contributing to a high workload among those who have been trained(55,58–60).

Based on a review of 29 South African studies, lay counsellors are able to provide behaviour change counselling with positive health outcomes(61), although six of the studies questioned the quality of services provided by lay counsellors, finding inadequate implementation based on the quality of training received and provision of counselling, which was didactic rather than client-centred(61). Challenges cited include inadequate definition of roles, a lack of standard training, and poor supervision and support(61). More recent studies in South Africa confirm the findings regarding inadequate service delivery by lay counsellors based on observations, analysis of sessions, and questionnaires with this cadre(57,62,63).

2.5.2 Staff capacity: workforce and workload

The number of clients on ART is expected to continue to increase following South Africa's implementation of universal treatment in September 2016: approximately 60% of PLHIV are currently on treatment, and the country seeks to provide treatment to all seven million people estimated to be living with HIV(4). Simultaneously, the Department of Health seeks to improve the quality of care provided. One of the quality improvement measures is national core standards for health facilities, which include a reduced waiting time and positive and caring attitudes among HCWs(64). These factors reveal a dual effort toward increasing the quality of services as well as reaching more clients with services. However, there are concerns regarding an increasing client load negatively affecting quality of care in the absence of increased human resources(10–14).

South Africa acknowledges challenges with its health workforce, including a shortage of nurses to meet the demand and inconsistent staff-client ratios(65). In addition, there is growing strain on services as urban populations grow and health facilities accommodate populations from beyond their catchment areas, including those from other countries(66). These factors are recognised to have a potentially detrimental effect on staff performance(65). The South African government is therefore in the process of applying the WHO's Workload Indicators of Staffing Need method to inform its staffing levels in facilities, although implementation has been affected by issues such as data availability, and has only been completed at district level to date(67).

The recognition by South African HCWs that high workloads and inadequate staffing negatively affect their HIV service provision is borne out in a qualitative study of ART integration in four primary healthcare clinics in Tshwane municipality, which sought the perspectives of 35 clinicians (33 of whom were professional nurses) on factors affecting integration and quality of care(60). The clinicians expressed concern regarding their workload as a result of inadequacy of staff (both clinicians and lay staff), growing client load, and increased labour related to providing ART services(60). They also stated that not many staff were trained in ART, including on the national guidelines(60). In terms of their views on ART integration into services, clinicians agreed that the revised system led to less stigma and greater confidentiality, but may contribute to increased waiting time and compromised quality of care due to the increased workload and limited staff skills(60).

These findings were echoed by engagement with 25 NIMART-trained nurses and 18 managers in two municipalities in Gauteng (City of Johannesburg and Ekurhuleni)(59). They too raised concerns regarding how their workload and shortage of lay staff (enrolled nurses and counsellors) affected their ability to provide quality care and support. However, they also shared how they creatively addressed implementation challenges related to staffing and space constraints, such as by employing a rotation system to manage time-consuming ART initiation and by capacitating all nurses in ART provision(59).

An assessment of data on professional nurses' workload affirms their concerns. In Gauteng province, for example, an average of 24.5 clients were seen by one primary healthcare professional nurse per day in 2017/18, just below the national average of 25.4 per day per nurse(67). If calculated on an eight-hour day, the average client can spend a maximum of 20 minutes with the professional nurse, encompassing activities including clinical tests and examinations required, taking medical history and discussing client concerns or questions, and documenting the consultation in the client's file and the health facility's registers. Likewise, the assessment of 16 ART clinics in Gauteng province noted that the number of clients seen at the facilities were substantially higher than those recommended by the National Department of Health, with counsellors seeing a median of 357 clients a month, compared to the recommended 100 per month(51). Additionally, adherence counselling session length was a

median of 25 minutes, compared to the recommendation of 60 minutes(51). However, the researchers also found that a lower number of clients and a longer session were not always associated with higher quality of adherence counselling, and suggested that the quality of counselling may instead be related to the attitude and motivation of the counsellor(51).

2.5.3 Health system and support

South Africa provides ART at primary healthcare facilities, with treatment initiation and ongoing management primarily conducted by professional nurses. HIV care and treatment have been integrated into the standard package of services offered at primary healthcare level(11,60). At the facility level, there are lay health workers and Ward-based Primary Healthcare Outreach Teams (WBOTs) who are involved in the provision of adherence support (including adherence counselling)(63,67).

With the decentralisation of ART provision to primary healthcare level between 2008-2013, several studies have investigated the process of integration of HIV services in health facilities. For instance, two qualitative studies found a range of service delivery models based on local context, from fully integrated services (with HIV services provided by all nurses), to specific nurses providing ART and nurses being rotated through various programme areas (including ART provision)(11,60). While participants (nurses, managers, and clients) appreciated that full integration of HIV services reduced the stigma of a separate area and/or specific nurses for clients on ART, and nurses valued rotation through various service areas to gain skills and experience, they expressed the desire to specialise in specific services and recognised the importance of good nurse-client relationships and continuity of care – aspects which are hindered in the full integration model(11,60).

Lay health workers have become an important part of South Africa's health system, providing supplementary HIV services – including adherence support – at both facility and community levels. They not only provide the bulk of HCT in primary healthcare facilities, but their services have extended to support provision of adherence counselling as well(63). As part of the country's re-engineering of primary healthcare, WBOTs were adopted in 2011, comprised of community health workers and nurse team leaders who provide community-based primary

healthcare services in collaboration with local health facilities(67). While WBOTs are considered a key part of South Africa's primary healthcare system, the intervention has experienced challenges, such as poorly-defined relationships with health facilities, inadequate management and supervision, and teams which are under-resourced(67–70). A policy framework was therefore developed in 2017 to address these implementation challenges and establish programme goals, which specifies the WBOTs' scope of work, including support for treatment adherence and tracing of clients who are lost to follow up(67,71). South Africa's 2016 Global AIDS Response Progress Report also recommends making better use of WBOTs to improve the country's ART client retention rates(72).

In addition, the South African government values collaboration and support from other service providers. Under the country's Ideal Clinic model, an initiative to promote high-quality service provision, each health facility should have a list of implementing partners containing partner name, area of focus, activities, and contact details(73). This includes community interventions and support, which have been demonstrated to improve service delivery, including health outcomes(74,75).

2.5.4 The role of clients

A number of studies have revealed that HCWs recognise the critical role that clients play in relation to service provision. For example, one qualitative study with 42 individuals (9 doctors and nurses, 10 counsellors, 10 traditional healers, and 11 caregivers of children living with HIV) in the Eastern Cape cited challenges such as poor understanding of treatment among clients, language barriers between client and HCW, denial and limited disclosure of HIV status, traditional medicine use, and food insecurity(34). Three other qualitative studies in South Africa reported many of the same challenges, along with additional ones, including stigma/fear of disclosure, denial, poor understanding (particularly among older and illiterate clients), communication/language challenges between HCW and client, food insecurity, traditional medicine use, substance use, client migration/mobility, and sharing medications with others(12,33,58).

2.6 Chapter summary

This chapter reviewed the literature on adherence counselling practice, including methods and tools, content, and parameters. It also provided an overview of South Africa's service delivery guidelines related to adherence counselling, including the national *Adherence Guidelines*, and cited findings on the implementation of service delivery guidelines. The chapter further explored factors affecting the provision of ART services, including adherence counselling, as documented in existing literature. Chapter three will cover the study's methodology.

CHAPTER 3: METHODOLOGY

This chapter describes the research methods applied to achieve the study aim of exploring ART adherence counselling practice by professional nurses in five primary healthcare clinics in the City of Tshwane. The chapter covers study design, population and setting, sample, and data collection, management and analysis, as well as ethical considerations.

3.1 Study design

The study employed a qualitative and cross-sectional approach as most appropriate for exploring the views, perceptions, and reported behaviours of primary healthcare nurses related to their provision of ART adherence counselling. The use of in-depth interviews facilitated understanding of the professional nurses' behaviour (or reported practice) as well as of the context and rationale behind the behaviour(76), in addition to providing insight into how different factors influence this practice in the context of primary healthcare facilities.

3.2 Study population and setting

The study population was made up of professional nurses delivering ART adherence counselling in five primary healthcare clinics in the City of Tshwane metropolitan municipality (Tshwane municipality), one of the five municipalities in Gauteng province, South Africa. Tshwane municipality has 3.3 million residents(16) and provides ART at 16 of its 24 fixed primary healthcare facilities(77). HIV is the leading cause of death among people aged 5-14 years and 25-64 years, and HIV prevalence is 11.6%(16). Tshwane municipality is one of the 11 pilot areas for South Africa's National Health Insurance, and 90.4% of its primary healthcare clinics have achieved Ideal Clinic status(16). Despite this, Tshwane municipality's 44.4% ART retention rate (people ever initiated remaining on treatment) in 2017 is more than 10% below South Africa's average of 55%, making it one of the three lowest performing districts in the country(16). Of those remaining on treatment in the municipality, 59.6% had a viral load test done at 12 months, and 90.2% of these clients had a suppressed viral load(16).

3.3 Study sample

The six primary healthcare facilities which were part of the study, made up of five study sites and one pilot site used to pre-test the interview guide, were proposed by the Deputy Director of Primary Health Care Region Four Clinics within the City of Tshwane, who the researcher knew through prior work experience and who agreed to assist in identifying study sites after being informed about the study aim and objectives. The five study sites varied in location, with two based in suburbs, two based in townships, and one based in the inner city.

The Deputy Director sent each primary healthcare facility manager an introductory email regarding the study and confirmed their willingness to participate in the study before the researcher contacted them to request preliminary permission – a requirement for ethics approval from the Human Research Ethic Committee at the University of the Witwatersrand.

Each of the five study sites' facility managers then identified two professional nurses delivering ART and arranged the interviews with them. The selection criteria for the nurses were that they had to have at least three months' experience in providing ART adherence counselling, consent to being involved in the study, and be available to be interviewed. Several facility managers noted that they identified nurses with the most experience in HIV services, as their facilities had more than two nurses who met the selection criteria. A total of 10 professional nurses delivering ART in five primary healthcare clinics participated in the study – two from each facility.

The researcher e-mailed each facility manager the study information sheet and consent forms, with the request that these documents be given to each professional nurse to read before meeting to invite them to participate in the study. At the meeting, the researcher provided the professional nurse with a hard copy of the information sheet and gave a verbal overview of the study, explaining that participation was voluntary. In addition, the identified professional nurses were given an opportunity to ask questions about their participation in the study. After the confirmation of agreement to participate, the researcher explained the consent forms (for the interview and for the recording) and then requested their signature.

The researcher interviewed all but one of the professional nurses identified by the facility managers. In one case, when the researcher arrived at the health facility to conduct the interviews, one of the two nurses identified declined to be interviewed.² The facility manager identified another professional nurse, who accepted the researcher's invitation to voluntarily participate in the study.

The principles of trustworthiness were considered in the sampling strategy in several ways. To ensure credibility, data triangulation was applied, as the professional nurses worked in five different health facilities located in three location types (suburb, township, and inner city), and two professional nurses were selected from each facility (78). In addition, the report provided a thorough description of the service delivery context, including information on the study participants' demographics, training on adherence counselling, and use of service delivery guidelines. This implies that the study results may be transferrable to similar contexts.

3.4 Data collection

The IDIs were conducted in English and audio-recorded with the written consent of each professional nurse. The interview guide was comprised of four sections: an introductory section on the participant's experience with HIV care and the process and roles of adherence counselling in the health facility; training received and guidelines used to provide adherence counselling; adherence counselling messaging and counselling methods and tools used; and factors influencing the practice of ART adherence counselling.

The interview guide was pre-tested with one professional nurse providing ART adherence counselling in a primary healthcare clinic in the City of Tshwane that was not one of the five study sites. The pre-test confirmed that the interview guide was clear, understandable, of acceptable length, and that it facilitated comprehensive responses. Based on this pre-test, the need to add two more questions to the interview guide became apparent in order to probe for the roles, methods, and approaches adopted by professional nurses when providing ART adherence counselling.

² The researcher was not informed as to why the professional nurse declined to participate in the study.

The IDIs were subsequently conducted with each of the 10 professional nurses from April to June 2018. Each interview was conducted in a separate, private room in the health facility – usually the participant’s examination room (and in two cases, in the health facility’s boardroom). They ranged in duration from 33 minutes to 94 minutes, with an average duration of 57 minutes. They were conducted on a day and at a time convenient for the professional nurse and selected by the facility manager to minimise disruption to each nurse’s daily activities – usually Friday afternoons.

The researcher used memoing to document field notes, observations, and reflections, including on the health facility and its context, non-verbal cues from the professional nurse (such as body language, interest and comfort level, and degree of focus on the interview), the overall quality of the interview, and key points made by each participant. The memoing also included reflection from the researcher on her own reactions and thoughts during the IDIs and during the time spent at each study site. Memoing was done within one day of each interview, primarily after conducting the two IDIs at each site, but field notes were at times captured at study sites between IDIs and, in a few cases, during times when the researcher waited for a professional nurse to become available.

3.5 Reflexivity

As a white, middle-class female from the United States, the researcher is aware of social and cultural differences between herself and the study participants, as well as the research context. However, the researcher has lived in South Africa for nearly 18 years, with over 10 years’ experience in managing an HIV and TB service delivery programme under a small community-based organisation and in close collaboration with a primary healthcare facility in the City of Tshwane, Gauteng province. The researcher is consequently familiar with the study context and was able to relate to the information shared by the study participants, such as how the health facility functioned, experiences with clients living with HIV, and adherence challenges. The researcher took detailed field notes and used memoing to document and reflect on her thoughts and perceptions during the course of the research.

3.6 Data management

Each IDI was transcribed verbatim into Microsoft Word and de-identified of health facility and individual names, replacing them with a numbering system, within one week of the IDI. The transcripts were coded deductively and inductively using a codebook developed specifically for the study. All transcripts and documentation (recordings and consent forms) have been stored in a password-protected file and will be destroyed after two years if published, or after six years if not published.

3.7 Data analysis

The researcher developed a codebook based on deductive and inductive coding of data and conducted thematic analysis on the data. The deductive coding was based on themes from existing literature on adherence counselling practice, including the national *Adherence Guidelines*, while the inductive coding was done by reading the data (transcripts) and memoing. The codebook was then applied to the transcripts, using constant comparison to ensure consistent application of codes(79). Following this process, thematic areas were identified and explored by organising the coded data and distinguishing patterns(79). The themes were then mapped to consolidate them and identify linkages, and text segments which best supported these themes were identified(79).

In analysing the reported adherence counselling practice as compared to the *Adherence Guidelines*, the researcher created a table with section headings related to key components from each source, including content, counselling methods and tools, and roles. The data from the IDIs further enriched the comparison by providing context to the reported adherence counselling, including study participants' perspectives on factors which positively or negatively affect their provision of adherence counselling.

Approaches to enhance the rigour of the study included documenting the research process through memoing and keeping an audit trail, concurrent data collection and analysis, demonstrating reflexivity, and conducting interviews until saturation was reached(80).

3.8 Ethical considerations

The study received ethical approval from the Human Research Ethic Committee (HREC) at the University of the Witwatersrand, followed by ethical approval from Tshwane Research Committee. The HREC ethical approval process included acquisition of preliminary permission from each health facility. The facility managers at the five study sites and one pilot site confirmed their willingness to participate in the study after receiving the Tshwane Research Committee clearance certificate. The professional nurses who participated in the study were fully informed about the purpose of the research before the IDI and provided written consent for the IDI itself as well as for the audio recording of the IDI. The IDI transcripts were de-identified after completion and have been stored in a password-protected file. Written notes have been stored in a locked cupboard, and all records will be destroyed after two years if published, or after six years if not published.

3.9 Chapter summary

This chapter described the study's research methodology employed to explore ART adherence counselling practice by professional nurses in five primary healthcare clinics in the City of Tshwane. The next chapter will present the study findings related to adherence counselling practice as reported by study participants, comparison of the reported practice to the *Adherence Guidelines*, and factors which affect the provision of adherence counselling.

CHAPTER 4: RESULTS

This chapter reports the findings on adherence counselling practice from the perspective of 10 professional nurses in five primary healthcare facilities. The research results are discussed under four sections: the first describes the service delivery context; the second provides an analysis of the ART adherence counselling practice reported by the professional nurses; the third provides an analysis of how the reported practice compares to the national *Adherence Guidelines*; and the fourth and final section explores factors that the study participants – hereafter referred to as the professional nurses – perceived to affect ART adherence counselling practice.

4.1 Service delivery context

The service delivery context – the environment in which the professional nurses worked – soon emerged as playing an important role as the professional nurses described their adherence counselling practice. The described context included systems such as integration of HIV into the broader health facility services, rotation of staff, and an appointment system. It also included staffing support, collaboration with other service providers, and specific adherence systems. This section describes the service delivery context as reported by the professional nurses during the course of the IDIs. The service delivery context was essentially the same across the five primary healthcare facilities where the research was conducted, with some variation related to the location of the health facility (suburb, township, or inner city).

All five health facilities involved in the study have integrated HIV care and treatment into their broader services, such as chronic conditions and antenatal care. The nursing staff followed a system of rotating through the various health facility service areas, although the rotation periods vary from facility to facility, from monthly to yearly, or even more frequently (weekly or daily) in some cases to “fill gaps” or support service areas with high client volumes. The health facilities have implemented an appointment system with clients, giving them a specific date and time to attend the health facility. The number of clients served in the health facility and their waiting time was monitored closely, and the professional nurses had specific consultation targets of clients to be seen per day.

Staffing at each health facility was supplemented by a professional nurse and lay counsellors from Right to Care, the District Support Partner for Tshwane municipality at the time of the study. The professional nurse initiated new clients on ART, while the lay counsellors primarily provided HCT, initial adherence counselling during the ART initiation process, and adherence counselling for those with a high viral load result.

The health facilities also collaborated with other service providers, including social services, WBOTs, NGOs, and rehabilitation centres. The level of collaboration varied by health facility location, with those located in suburbs having fewer service providers available locally. The service providers provided psychosocial support, client tracing and linkage back to the clinic, substance abuse rehabilitation, and resources such as social grants and food parcels. In addition, the health facilities were implementing adherence systems, such as support groups/adherence clubs, as well as the Central Chronic Medicine Dispensing and Distribution Programme, which enables stable, adherent clients to access ART at sites other than the health facility.

4.2 Study participant profiles

Before exploring the professional nurses' reported adherence counselling practice, it is useful to outline their demographic characteristics, their training, and the guidelines they use as related to ART adherence counselling.

4.2.1 Demographic characteristics of the study participants

All 10 professional nurses who participated in the study were females. The fact that there were no male participants is most likely related to the low proportion of male professional nurses in South Africa (10%) and particularly in Gauteng province (7.7%)(81). Among the study participants, there was diversity in terms of age and years of experience, as well as mother tongue. Two were under 40 years old while the remaining eight were 40 years or above. The age of participants mirrored their experience in nursing, with seven having more than 20 years of experience. All spoke more than one language, and several indicated the ability to speak multiple languages. They were also all fluent in English – the language the interviews were conducted in.

Table 2: Demographic characteristics of the professional nurses

Characteristic	Categories	Number of participants
Gender	Female	10
	Male	0
Age	Under 40 years	2
	40 years and above	8
Years of experience in nursing	Under 20 years	3
	20 years and above	7
Mother tongue	N. Sotho	3
	Tswana	1
	Sepedi	2
	Tsonga	1
	Xhosa	1
	Afrikaans	2

4.2.2 Study participant training received on ART adherence counselling

The professional nurses were all trained in NIMART, a two-week course provided by the Foundation for Professional Development (FPD), the District Support Partner which provided health-focused technical assistance in Tshwane municipality with United States Government funding until the end of 2017. Nine of them noted that they received this training between 2011 and 2016.³ Other training related to adherence counselling which was reported to be received included the one-year Primary Health Care training for nurses, HCT training, and PMTCT training, although it was noted that adherence counselling was typically integrated into these trainings rather than being a specific or separate section. However, the NIMART training in particular provided them with basic information required for adherence counselling:

³ The remaining professional nurse was trained in NIMART when she worked for FPD prior to joining the health facility where she is currently working in 2010.

They taught us almost everything. In a nutshell, comprehensive care for the patient...about teaching the patient how to take the medication, what to expect when they take the medication, the first time they take the medication, what can happen, it doesn't mean it will happen, but just alerting them. Like if this happens, you come and tell us what you are experiencing. And how they should take their tablets, time, and they should take it daily. So, they did teach us a lot.

– Professional nurse with 20-29 years of experience, township health facility (trained in 2011)

While there was a generally positive attitude toward the NIMART training, two professional nurses (from two separate suburb health facilities) indicated that adherence counselling was not well-covered during the training.

No, I think they didn't cover it properly. I wish they did go deeper into the counselling part, especially if you need to counsel clients on what medications to avoid, or diet and lifestyle things that they need to look at when taking ARVs. I think they mostly focused on the treatment and the guidelines on how to initiate on ART, things like that, and not on the counselling part.

– Professional nurse with 1-9 years of experience, suburb health facility (trained in 2016)

4.2.3 Study participant use of service provision guidelines

The professional nurses noted that the service provision guidelines they used which addressed adherence counselling included the *National Consolidated Guidelines*, NIMART training manual (*Basic HIV for Nurses*), Primary Health Care training manual, and a clinical care mobile phone app. They also reported referring to the Internet for information, including Google and *The Body*. However, the *National Consolidated Guidelines* seemed to be the most commonly used service provision guidelines, as it was noted by all professional nurses. None appeared to be

aware of the *Adherence Guidelines* – they were not mentioned by the professional nurses as guiding or informing their adherence counselling practice.⁴

With regard to the information related to adherence counselling contained in the guidelines they used – typically the *National Consolidated Guidelines* – the professional nurses noted that:

It includes, not only about medication, it also talks about the patient's dietary...it talks about family planning, it talks about...other medication, that they must not, on top of ARVs, mix it with other traditional medications or other, you know patients like buying a lot of medications. That is not necessary for them to buy over the counter when they are already on ARVs.

– Professional nurse with 20-29 years of experience, inner-city health facility

There was a perception that the guidelines which the professional nurses had did not adequately cover adherence counselling for HIV. To demonstrate this, a comparison with the detailed information provided in the family planning guidelines was shared.

You see with family planning, when you open the book, they will tell you that, "If a patient misses a pill, today, and then tell them to take the pill when they remember. When they miss it for two days, tell them to take two. If they miss for two days, they will have to start on a new..." but for now, they don't actually, there is no book that will stipulate fully about the adherence counselling exactly.

– Professional nurse with 20-29 years of experience, inner-city health facility

When asked how they used these guidelines, the professional nurses reported that they typically referred to them for clinical issues, not adherence counselling.

Ok, honestly speaking, ne? So far after coming back from NIMART, ne? I remember myself consulting the book they gave me that I am telling you about on adherence once, where they are showing me different steps of adherence counselling and what I can

⁴ This apparent lack of familiarity with the *Adherence Guidelines* may be due to the phased rollout throughout South Africa.

teach the patient. I remember going to that once; I don't often go back to it.

– Professional nurse with 1-9 years of experience, township health facility

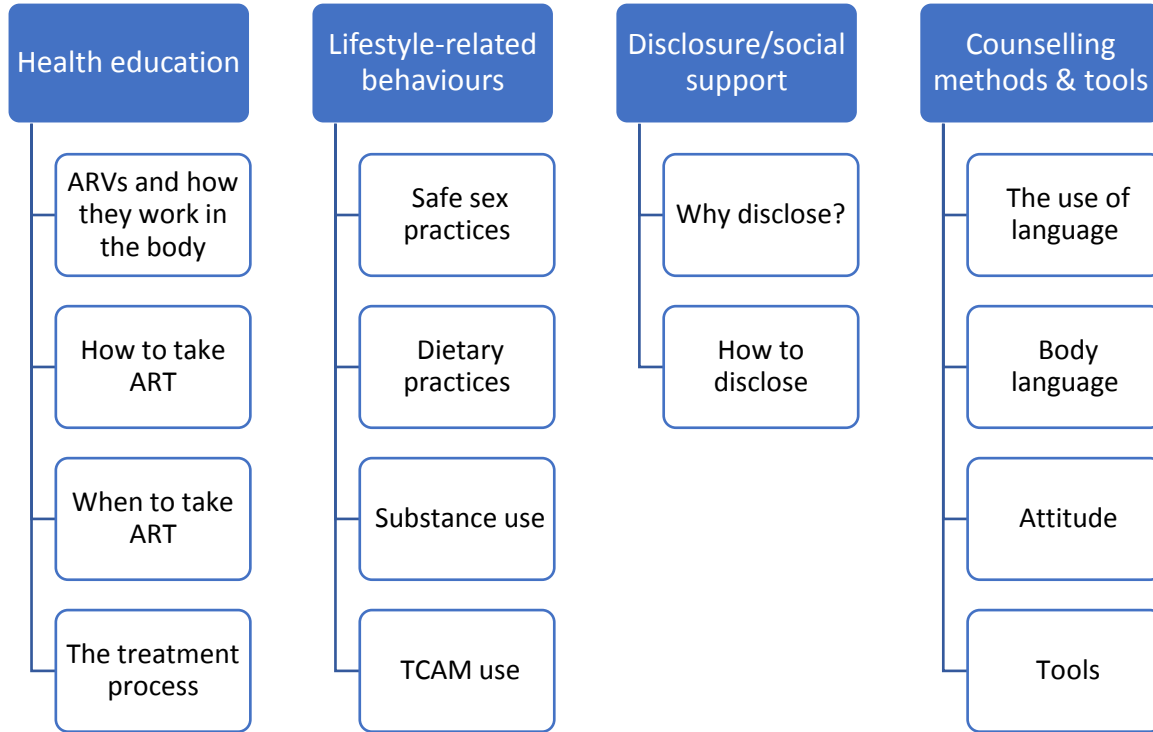
Um, most of the time with adherence, we just know...For the adherence, I didn't refer for a long time.

– Professional nurse with 20-29 years of experience, suburb health facility

4.3 ART Adherence counselling practice

Findings on adherence counselling practice are categorised according to four themes: providing health education; addressing lifestyle-related behaviours; facilitating disclosure/social support; and application of counselling methods and tools (see figure 1 below). The health education theme encompasses taking ARVs, including how the medication works in the body, how and when to take it, and the treatment process. The second theme deliberates on lifestyle-related behaviours which are believed by the professional nurses to be relevant to the clients' context and which could affect treatment adherence and efficacy. This includes behaviours that the client should or should not engage in to facilitate the ART being most effective in the body and to help keep the viral load low, such as safe sex practices (primarily condom use), dietary practices, substance use, and use of TCAM. The disclosure theme depicts how the professional nurses considered this to be prerequisite to establishing social support to reinforce adherence to both ART and the recommended behaviours. They explained to clients why disclosure is important and guided clients in how to disclose, including facilitating disclosure at the health facility. The fourth theme, counselling methods and tools applied by the professional nurses, includes simple and appropriate language and body language, a positive attitude, and tools to aid their adherence counselling provision.

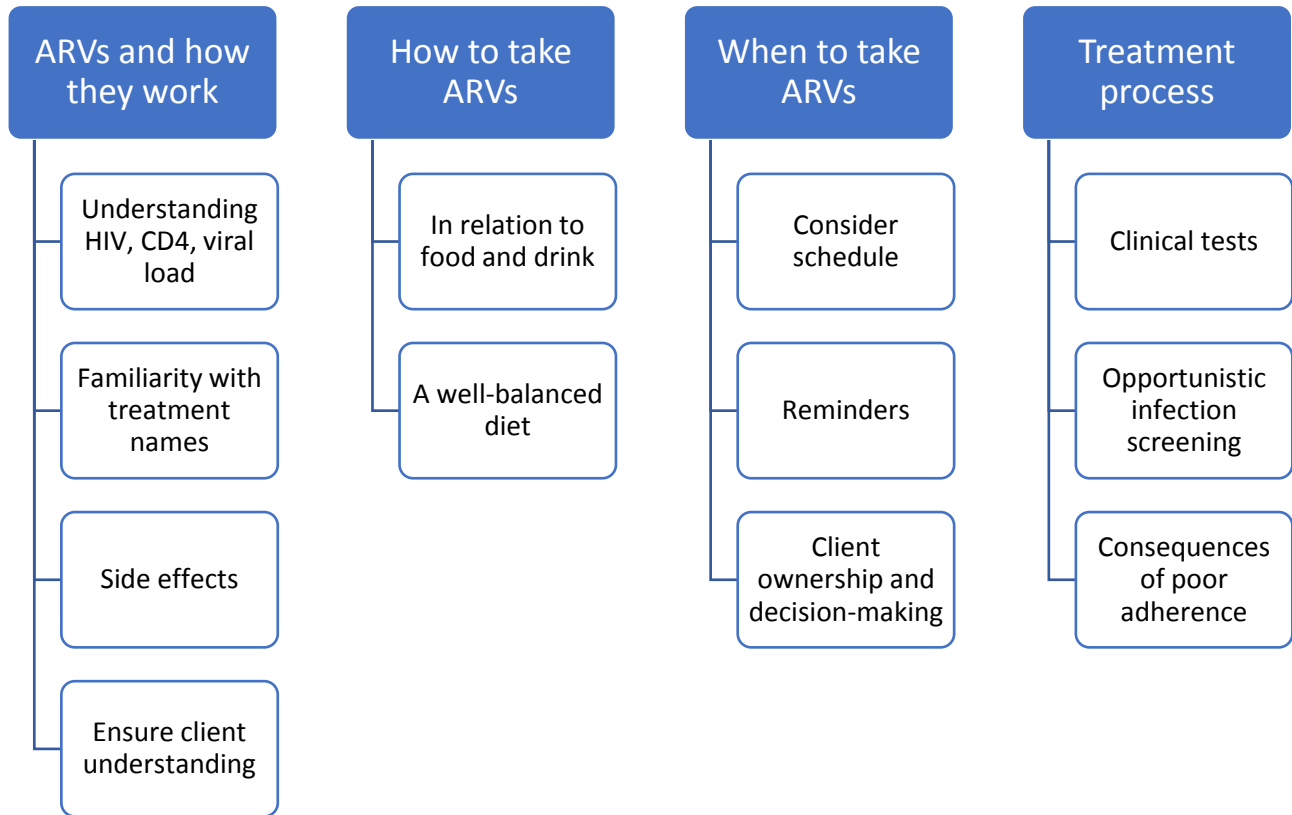
Figure 1: Reported adherence counselling practice



4.3.1 Health education on HIV and ART

The professional nurses reported providing health education as part of their adherence counselling, including introducing ARVs and explaining how they work in the body, discussing how and when to take the medication, and providing an overview of the treatment process (see figure 2 below).

Figure 2: Reported adherence counselling – Health education on HIV and ART



ARVs and how they work in the body

Health education reported by the professional nurses included information on treatment and how it works in the body. They addressed HIV as a disease, describing what it does to the body and immune system, explaining terms such as CD4 count and viral load, and sharing how treatment works to suppress HIV. They also reinforced that ART is a lifelong treatment (not a cure) and how effective it is, countering negative client perceptions about ART.

Firstly, the patient will need to understand, what is HIV. And then, understand what is HIV-negative, what is HIV-positive. And then, they also have to say, what is their HIV status. And then, what does that mean to them? It is then that you start to talk about the ARVs...you explain how does it work. Talking about the ARVs, I mean the HIV, we want to make sure that it's under control. So, you'll also be talking about the viral load and explaining in simple terms the power of the virus in your system...And I tell them,

because it doesn't die. It means the medication, you are going to take it for life.

– Professional nurse with 20-29 years of experience, inner city health facility

The importance of clients becoming familiar with the names of the specific ARVs which are part of the treatment regimen was highlighted. This was to prepare clients for changes in the brand names and appearance of the medication bottles and medication itself, which was a regular occurrence as a result of changing treatment suppliers under the Department of Health.

I've got a bottle that I use to show them, I tell them there's different types...I like to compare them to sugar: you get white sugar, you get brown sugar, but it is still sugar. You get Selati, you get Hulets, you get Pick 'n' Pay, you get Checkers, you get Spar, but it is still sugar...It's the same for this one: you get a white one, you get a pink one, but it's still your ARVs...Every time I tell them, when you take your pill for the first few months, every time you open your bottle, read those three names so you can start to recognise them...You need to know your medication that you are using.

– Professional nurse with 30+ years of experience, suburb health facility

The health education provided by the professional nurses also included advice on how to manage anticipated side effects that clients may experience due to ARVs, as well as what action to take. The potential side effects of ARVs, particularly when clients first start treatment, include coughing, headache, rash, dizziness, disturbing dreams, nausea, and vomiting. They emphasised that clients should return to the health facility as soon as they experience problems or have concerns, rather than stopping their treatment or trying to treat the side effects themselves.

And that as soon as they see side effects, they must report the side effects. They must not sit until they have complicated. Once they realise they have developed some side effects, we say it's ok for them to come. They must not be afraid to come back to report anything that they feel doesn't go well with them.

– Professional nurse with 20-29 years of experience, inner-city health facility

The professional nurses assured clients that they would help resolve the side effect by giving them medication to treat it, referring the client to the health facility's doctor or to a tertiary-level facility if needed.

How to take treatment

As part of the health education, the professional nurses explained how to take ART in terms of diet, with several providing detailed information to clients on the type of food and drinks which should be consumed, as well as when they should be consumed in relation to taking ART. They advised clients to eat a well-balanced diet in order to boost their immune systems, as well as to avoid "junk food" and eat at home to ensure hygienic preparation and maintain control of what is added to their food. Food and drink promoted by the professional nurses includes fruit and vegetables, protein, and water. Foods to be avoided include those that are fatty, spicy, or oily, and drinks to be avoided include those that have caffeine or sugar ("fizzy" and energy drinks).

Yes, it's very important that they must take care of their diet. They must know what is it that will make their stomach irritable, already because of the HIV, their immune system is still weak. So, they have to strengthen it through eating proper diet, vegetables, avoiding spicy food, avoiding oily food. Trying to eat, boil and cook at home rather than buying food at restaurants when they don't even know when was that food last cooked, because they will end up with the diarrhoea, and it's very difficult to control the diarrhoea of a person who's HIV-positive.

– Professional nurse with 20-29 years of experience, inner-city health facility

However, contradictions were noted between what different professional nurses told clients in terms of the timing of eating and taking ARVs, from advising clients to wait two hours after eating before taking their medication; to taking the treatment first and then eating after 30-60 minutes.

Um, the same with food, we prefer them to have two-hour gap between, they eat and wait for two hours and then drink the ARVs. So, that is basically on an empty stomach, to better their absorption. But we also tell them, if you feel nauseous or you feel very dizzy, then you can have something small, but don't have a big fatty meal that will prevent the

absorption of the tablet.

– Professional nurse with 30+ years of experience, suburb health facility

Another professional nurse told clients that they could take ART on an empty stomach if they did not have food.

When to take treatment

Setting the right time for taking ART was viewed as a critical part of the health education. The professional nurses guided clients to identify the best time to enable them to take ART at the same time daily, at a time which was convenient for the client and which the client could maintain long-term. This assistance included discussion of the client's schedule, exploring practical reminders and the use of verbal codes with supporters.

But we do encourage them to take their medication every day at the same time so that they can...you see with the medication, it has to be a routine thing, so it can form a chain, so that we can be able to control the virus. If you take it like haphazard, it won't be effective. We tell them how the medication is not going to be effective. Daily, same time, so they can be able to control the virus.

– Professional nurse with 20-29 years of experience, township health facility

The professional nurses highlighted that the decision as to the best time to take the medication must come from the client to promote adherence, but helped the client think through his/her schedule to identify the most convenient time, taking into consideration work and transportation requirements. One professional nurse shared that her approach changed after attending the NIMART training.

We used to tell patients to take medication at 6, at 12, 6, 12, you don't even check how is the schedule of the patient...But you find we were not giving them an opportunity. It helps me to understand that...a patient is a full package of the health system. So, without a patient, I don't have a health system...In the olden days, it was like the nurses, we are dictating to patients. But these days when the patient come, they understand that ok, I am a king here. You see? So, you are there to guide the patient. You know, it

actually makes life easier for the patient, because it makes the patient to take the ownership...Because the patient, if the patient is taking responsibility, it becomes much better.

– Professional nurse with 20-29 years of experience, inner-city health facility

Treatment reminders were also addressed by the professional nurses as useful for client adherence. They presented reminders as a series of options for clients to choose the most convenient and relevant methods for themselves. These options included the use of phone alarms, a routine activity (favourite television show or brushing one's teeth), a pillbox, or a calendar (an existing calendar or one that the client makes for him/herself).

So, the patient will decide when I am going to take at the particular time, and then what's going to help me remember, you discuss with the patient. The patient will tell you, "Ok, I have a watch, I have a friend who is a buddy" and maybe sometimes, this time of the night, that's the time I am brushing my teeth or I'm doing this, and I know that I won't be, I won't forget that I must take the medication at the same time every day.

– Professional nurse with 20-29 years of experience, inner-city health facility

A professional nurse reported encouraging clients to develop a private, verbal code with a treatment supporter and using this code via telephone as a treatment reminder.

If they have a supporter who can support them to take the drugs, that person can be able to remind them...So I said they must make a code and they know when it's time for tablets, they just send an SMS, like a code, maybe they say "shap" or anything that they can...something that if you pick up the phone, you won't know what it means. Unlike if they phone in front of the people, "Did you take your tablets?" People will want to know which tablets...It's just that, "shap" or "cousin!", something that does not really make sense. But for them it makes sense because they know what it means. On the phone, "cousins", oh no, she was reminding me I must phone my cousin. But she knows it's time to take her tablets, she goes and takes her tablets. So, they must have that kind of a

thing to remind themselves.

– Professional nurse with 20-29 years of experience, inner-city health facility

Treatment process

The treatment process was cited as an important part of health education, including information on what clinical tests – such as viral load or creatine monitoring – would be required at what stage and why they were necessary, as well as addressing the risk of opportunistic infections and the importance of regular screening for conditions such as cervical cancer and tuberculosis. The consequences of poor treatment adherence were also explained, such as drug resistance and consequent switching to a second-line treatment regimen.

When I start with them, I tell them, at three months we're going to check your kidneys, because the side effect of this medication can be a problem with your kidneys. Then at six months we check your kidneys again because we want to make sure we don't harm your kidneys. We want to make sure that the virus is sleeping, so we're going to do your viral load. And at one year, we're going to check it again, and every year in between... Once you make the patient understand his condition, his treatment, and his treatment plan, and why should he do this, then adherence is better.

– Professional nurse with 30+ years of experience, suburb health facility

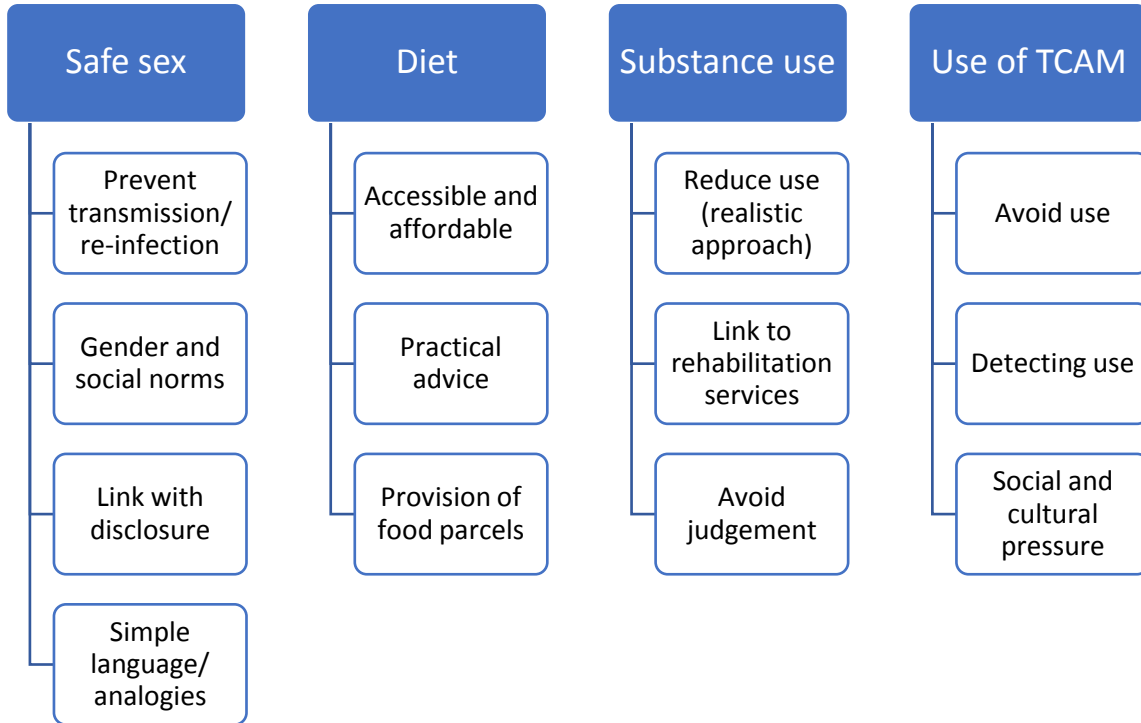
Health education was considered a crucial aspect of adherence counselling by the professional nurses, including introducing ARVs and explaining how they work in the body, addressing how and when to take the medication, and outlining the treatment process. The following section presents lifestyle-related behaviours which the professional nurses addressed as part of adherence counselling.

4.3.2 Addressing lifestyle-related behaviours

This section covers aspects of lifestyle-related behaviours that the professional nurses deemed as important because of how they could affect treatment adherence and efficacy. This included behaviours that the client should or should not engage in to facilitate the ART being most effective in the body and to help keep the viral load low, including safe sex practices (primarily

condom use), dietary practices, and avoiding the use of substances and TCAM (see figure 3 below).

Figure 3: Reported adherence counselling – Addressing lifestyle-related behaviours



Safe sex

The professional nurses considered condom use and family planning to be essential elements of addressing lifestyle-related behaviours during adherence counselling. They emphasised that consistent condom use was critical to prevent further transmission of HIV, even if both partners were HIV-positive, due to the risk of re-infection. According to the professional nurses, re-infection with a different type or strain of HIV (also known as superinfection) could negatively affect the viral load, even if the client was taking ART as prescribed.

And also, part of what they should be doing is to condomise, always. So, they cannot re-infect themselves...We explain to them, because sometimes they take it as if they are both positive, they can engage themselves in sexual intercourse without a condom. But we explain to them about being re-infected. Now and then, when they don't use a protection. They will be re-infected themselves and we won't be able to control the

virus.

– Professional nurse with 20-29 years of experience, township health facility

The professional nurses employed simple, “layman’s” language as well as analogies to help explain to clients why condom use was so important.

I normally even go furthermore to explain to them, we’ve got types of this HIV virus, maybe they’ve got this one, Type One. Then they were diagnosed and put on ARVs. Now it’s time to close the gate. Nothing else must come in. That is how I normally explain it to them. Nothing else must penetrate this gate (interlaces her fingers and holds up her hands to demonstrate a gate). What we have is enough. We don’t want anything else penetrating this gate. Because your body won’t be able to deal with all these things, so close, what you have is enough, we cannot put anything extra again.

– Professional nurse with 20-29 years of experience, suburb health facility

They also encouraged condom use as part of family planning, particularly to ensure that the client’s viral load was low before becoming pregnant to reduce the risk of mother-to-child transmission.

The professional nurses pointed out that condom use and family planning were closely related to disclosure, as partners would want to know why it was necessary to use a condom. This was noted as an ongoing challenge by several professional nurses and cited as stemming from gender and social norms.

They will tell you, “Sister, my husband.” Most of the time they can’t negotiate safe sex. So, most of them, you know, we used to say it’s because people are not working, but even the people who are working. Even the people who are financially stable. They still can’t negotiate safe sex...I think men still have power over us. So maybe women are afraid of losing a partner...I’m not really sure what they are afraid of, but maybe they are afraid. They don’t wanna lose this man and maybe like, they can’t negotiate sex. Because, especially in our culture, men are the ones to say issues about sex. You can’t really say to him, “Can we have sex?” He doesn’t really understand you are talking about...So they will be the one to tell you, “No, you can’t use family planning.” And then,

“You can’t use a condom.”

– Professional nurse with 20-29 years of experience, inner-city health facility

Dietary practices

The professional nurses emphasised the importance of good nutrition as one of the lifestyle-related behaviours to address during adherence counselling, claiming that eating too much fat interfered with the body’s absorption of ART and could consequently negatively affect the viral load.

[In counselling a client who had an unsuppressed viral load result] And I started afresh. Telling her about diet, what she is not supposed to drink, those herbals, those fizzy drinks, those caffeine drinks. And then she said, “Ok, sister, now you are talking. Because I am eating chicken, chicken skin. I like the skin. And then I fry it and eat it. I just go straight to the shops to buy it and fry it because I like it.” Then that is where you see the viral load going up, because of too much fats.

– Professional nurse with 20-29 years of experience, suburb health facility

However, the professional nurses acknowledged that access to nutritious foods – or even adequate food – could be a challenge for clients. They told clients to eat the food that was available and affordable to them, and encouraged them to plant their own vegetable gardens for better access to healthy foods.

With nutrition, we usually say, “Don’t say I’m not eating this, I’m not eating that.” You need to have your veggies almost every day. One veg every day, if you are able to. And the protein, have protein, enough protein. If you cannot, the very chicken feet that you buy every day, it’s part of food. Don’t go and get into Woolworth’s and buy the best foods. The little that you have in the house, make use of it.

– Professional nurse with 30+ years of experience, township health facility

Several professional nurses noted that they had food parcels to give to needy clients, and that local organisations were also able to assist clients in need. Both of these were used as tools to help promote adherence.

But if you see them on a month-to-month basis, then I can ask them, you know what, last month you said you were very stressed about your money situation, did something change, can I help you, is there, must I give you a food parcel? We do have a church that is providing us with food parcels. It's basic stuff, it's like mealie-meal and sugar and beans and peanut butter and powdered milk and stuff like that. Oil. So, sometimes they do have a financial problem and then they don't drink their medication, because I'm hungry when I go to bed, I haven't had anything to eat, then this medication makes me feel dizzy and nauseous, and then I skip it.

– Professional nurse with 30+ years of experience, suburb health facility

Substance use

The professional nurses advised clients to avoid substance use, including drinking alcohol, smoking, and taking illegal drugs. They encouraged clients to reduce or stop the use of substances and explained why this was important. The professional nurses believed that substance use could affect client adherence by causing them to forget to take ART, and several also stated that substance use could negatively affect critical body organs such as the lungs, which could make the client more vulnerable to lung disease and opportunistic infections. Likewise, they asserted that as the liver metabolises the ARVs, alcohol use and subsequent liver damage could cause the medication to be less effective in the body.

Alcohol, smoking drugs, interferes with the liver and you need the liver to work properly to metabolise the drugs, so, as soon as you smoke or drink, then the medication is not going to work.

– Professional nurse with 1-9 years of experience, suburb health facility

We tell them about the alcohol. To avoid alcohol and also to avoid smoking...Because if you take alcohol, I think it might affect you because you might forget to take your tablets. Sometimes you are out and you are going to have some drinks and forget to take your tablets. The other thing is the effect of alcohol on the body organs, like the liver. So, everything, most of the medication they go bypass the liver and to be...for absorption and it affects them because if the liver is damaged, those tablets that are

supposed to go bypass the liver function, they are not going to be effective. They will be just as they are in the body system, and then it will form toxins to them. So, we encourage them not to...take alcohol.

– Professional nurse with 20-29 years of experience, township health facility

However, one professional nurse was not aware of any scientific evidence that demonstrates that alcohol use negatively affects ART efficacy (Professional nurse with 20-29 years of experience, inner-city health facility).

While telling clients to avoid substance use, the professional nurses acknowledged that this lifestyle-related behaviour needed to be addressed carefully, and they advised clients to reduce their use of substances rather than stop completely, viewing this as more realistic for clients. They pointed out that it was also important to explain why substance use was harmful, or they may be perceived as judgmental by their clients.

You know, this thing of drinking is a little bit of a challenge, ne?...I normally tell them to reduce drinking. Because I wish to tell them, "Stop drinking" but I'm not realistic. Unless the patient decides on their own and they say, "I want to stop drinking." And I try first to explain what is the problem. Because if I don't explain what is the problem, it simply means I am judging them, that they are drinking alcohol. So, I try not to be seen as judgmental. It's a little bit of a tricky subject when it comes to that one. So as long as they understand that that one...alcohol and my treatment. Because it's with every treatment, not only the ARVs.

– Professional nurse with 20-29 years of experience, inner-city health facility

The professional nurses from the inner-city health facility and one of the township health facilities also made use of rehabilitation services to help clients overcome substance abuse, providing clients with an alcohol abuse self-assessment form to complete in order to help them identify if they had a substance use problem.

TCAM use

The professional nurses also told clients to avoid the use of TCAM, including traditional medicine, “holy water”, and over-the-counter medicines, due to potential drug interactions with the ARVs.

We have many clients that consult traditional medication or herbal medication when they get sick. Or some that still believe that HIV is like a demon or something bad so they need to go for traditional medication to get the HIV out of their system. So that definitely, we can see that can have a drug interaction with the ARVs, so then we easily see virological failure in these types of clients.

– Professional nurse with 1-9 years of experience, suburb health facility

While advising avoidance of TCAM use, the professional nurses noted that this issue was related to social and cultural norms and needed to be addressed in a sensitive manner. The professional nurses reported raising the issue of TCAM when the client first began ART, asking clients to tell them what other medication they were taking in order to avoid drug interactions. However, they often only learned about clients’ use of TCAM when their viral load remained high and they probed for the reason.

Most of the time, we find that the patients, even though they are taking their ARVs, they still go and consult the traditional healers and they give them the imbiza and other things, and usually they don’t interact so well with the ARVs. So, I just give the patient the information, and then – usually – they take it. But others, joh! They will just agree, but when they get home, they do what pleases them, unfortunately.

– Professional nurse with 1-9 years of experience, township health facility

The professional nurses acknowledged that clients often experienced pressure from others, such as their churches, to take alternative treatments, and consequently tried to work within rather than disregarding clients’ belief systems. This included advising clients to temporarily stop TCAM to “give the ART a chance”, telling them that taking ART fits within (rather than being opposed to) their belief systems, and offering to communicate with those exerting the pressure to take alternative medications.

Is it a side effect that is putting you off from taking it? Is there someone that is influencing you? Is there a church issue? Because many of them has got church issues... The church sometimes doesn't allow them, because I've prayed for you. And now, you must believe. And if you take your pills, it means you don't believe. And then, um, they don't want to disappoint the church or act like they don't believe in God or in their God, so they don't take the pills, because the church has prayed for them. And some even say that the church says they are not allowed to take pills.

– Professional nurse with 30+ years of experience, suburb health facility

In their effort to address the lifestyle-related behaviours, the professional nurses demonstrated understanding of the power of social norms and expectations related to these behaviours – including pressure clients could experience from family and peers – but at times expressed frustration when clients returned to their daily lives and did not adopt the recommended behaviours.

Because others, like I say, they don't know. But others just do it, like having sex without condoms. That one they won't stop. Because when you ask, they just say, "I use condoms" and then the next time she comes pregnant and that means she's not using condoms, then what do we do? They still come pregnant, unplanned pregnancy, so it means, it's not everybody who's listening. They still decide on their own what to do. There are many things, lifestyle, that people don't accept to change. The smoking, they still smoke. They still drink alcohol. They still don't use condoms. Then you just go on and on and teach.

– Professional nurse with 20-29 years of experience, suburb health facility

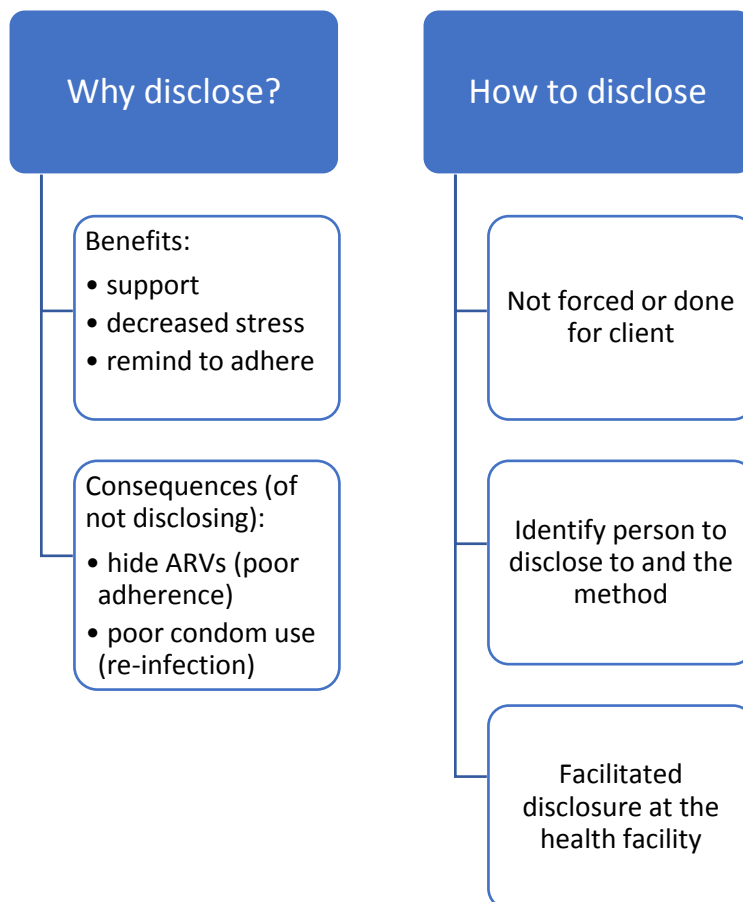
While the professional nurses addressed lifestyle-related behaviours which they perceived to affect client adherence and treatment efficacy as part of their adherence counselling, including promoting safe sex and healthy dietary practices, as well as avoiding alcohol, other substances, and TCAM, they were often inflexible regarding these behaviours and expected clients to heed their advice. Nevertheless, they did try to help clients to embrace the recommended behaviours by providing food parcels when necessary, helping identify substance abuse and

linking clients to rehabilitation services, and offering to help respond to pressures related to TCAM use. The following section presents another aspect of the professional nurses' adherence counselling: disclosure of HIV status.

4.3.3 Disclosure/social support

Client disclosure of HIV status was a key adherence counselling topic for the professional nurses and was reportedly addressed on a regular, recurring basis (see figure 4 below). The professional nurses promoted client disclosure to at least one other person, primarily for social and treatment adherence support. They explained to clients why disclosure was important and helped clients in planning how to disclose. Further, the professional nurses helped facilitate disclosure, particularly to partners, at the health facility.

Figure 4: Reported adherence counselling – Disclosure/social support



Why disclose?

The professional nurses acknowledged that clients found disclosure of their HIV status to be challenging and framed this issue in terms of benefits and consequences. Benefits for the client included reducing stress and not feeling alone, having someone to help them remember to take their ARVs, and having someone who could ensure that they had access to their medication if they became sick and were admitted to hospital. Additional benefits included that disclosure could help other people be open about their own HIV status and that the professional nurse would have someone to assist in promoting the client's well-being. Consequences which the professional nurses reported sharing with clients to promote disclosure included the client having to hide his/her medication, which could result in skipping or delaying taking the ARVs.

For better adherence, we encourage them to disclose. If the core family or whoever is close to him or her knows about his or her condition, then it's easier for him or her to take the medication freely, because hiding will make one to forget, because there will be no chance at all to say, this is the time for me to go take medicine, because this person is here. And he or she cannot say what is it for. To be honest, to disclose is better for improvement of adherence.

– Professional nurse with 20-29 years of experience, suburb health facility

The professional nurses also pointed out to their clients that another consequence of failing to disclose their HIV status was the possibility of being re-infected with different strains of HIV or infecting their partner and/or children with HIV.

If they don't disclose, firstly, they won't have support system. That's the problem. Secondly, if they don't disclose, they will have problem taking their medication. If they don't disclose, they might have a problem using a condom, because imagine if someone didn't tell the partner that, "I'm HIV-positive."

– Professional nurse with 20-29 years of experience, inner-city health facility

How to disclose

While the professional nurses reinforced disclosure during adherence counselling, they noted that they did not force clients to disclose and they did not disclose for clients. Instead, they described their role as that of encouraging clients to disclose. They assisted clients to identify who they could disclose to and provided guidance on how to disclose their HIV status, such as using a story about someone else living with HIV to gauge the person's response. Another way they helped facilitate client disclosure was by allowing clients to bring their partners to the health facility to test together for HIV. This allowed the client and his/her partner to receive information and counselling on HIV and to "discover" their HIV status together.

And then you ask them, is there anyone you are staying with that you would be comfortable telling them about your status? Sometimes they will tell you, "I am only staying with my partner and he is so violent. I'm afraid that my partner would hurt me." Sometimes I even advise them that if they are not able to do it but they want to disclose, they can even come with their partners here to the clinic and we can help them to disclose...and then when they come for testing, if they do want, they can get into the same room. That is when we get a chance to counsel both, the couple on HIV...and usually that helps most of our patients. And then from the partner getting information about HIV, the other partner can test, and if they are negative or what, they can help them with disclosure at HCT most of the time.

– Professional nurse with 1-9 years of experience, township health facility

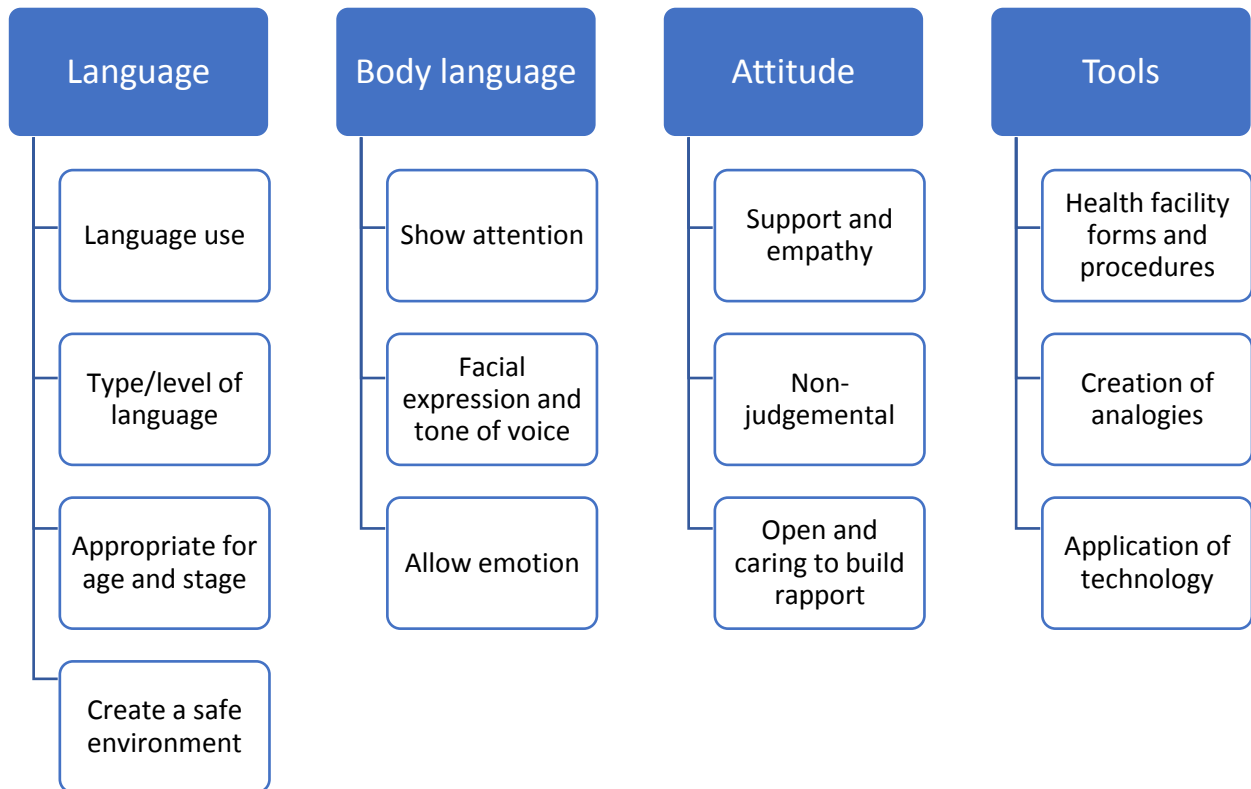
The professional nurses regularly and repeatedly emphasised client disclosure of HIV status during adherence counselling for social and adherence support. This included highlighting the benefits of disclosure and helping clients to disclose by assisting them to identify who to speak to and how to go about the process. They also facilitated disclosure at the health facility, particularly to clients' partners. The following section presents the methods and tools which the professional nurses used to support their adherence counselling.

4.3.4 Counselling methods and tools

The professional nurses used various methods and tools to support and reinforce adherence counselling so as to ensure that clients understood the content and experienced a supportive and safe environment where they felt respected and cared for (see figure 5 below). The professional nurses emphasised that these factors were vital to promote adherence.

Counselling methods were related to the use of language, body language, and attitude toward the clients. Tools and resources employed to support adherence counselling provision included those available at the health facility as well as those developed by the professional nurses themselves.

Figure 5: Reported adherence counselling – Counselling methods and tools



The use of language

The professional nurses expressed the importance of language use as one of the methods to ensure that clients understood the adherence counselling. They proposed that language should be appropriate in terms of type, level, and context, and should support in creating a safe

environment for the clients. Given that they attended to clients who spoke a wide variety of South African languages, in situations where they did not share a common language, the professional nurses requested a colleague to translate for them. They also encountered clients from other countries, where no one in the health facility was able to translate for them. In these cases, the professional nurses encouraged the client to bring someone to the health facility to assist in translation.

And sometimes you find a patient that is speaking Tsonga. I do not know Tsonga, joh, I tried different languages, but...the patient does not know English or any other language, and that will affect...So, in other instances you find yourself having to go out of the room to ask someone to come and interpret once in a while. So, it is important to give information in the language that the patient understands...I know where to go, if it is this, I am going to ask this sister. Luckily.

– Professional nurse with 1-9 years of experience, township health facility

The professional nurses also described the efforts they made to ensure that adherence counselling content was communicated at the level best suited to the client's ability to understand, taking into consideration the individual's educational background and experience. They used questions to assess client knowledge and confirm understanding of the information provided.

You don't use this jargon of ours. You go and try to be as simple as you can when you explain, like when you try and explain family planning and their menstrual cycle. You actually make a picture and show them so they understand you are talking about what. Sometimes we tell patients, we think they understand what we say, yet they don't understand anything. So, try to be at the patient's level.

– Professional nurse with 20-29 years of experience, inner-city health facility

According to the professional nurses, adherence counselling needed to be individualised and appropriate for the client's context in terms of age and stage of life. Moreover, the professional nurses pointed out that in order to be effective, adherence counselling should be adapted and tailored for each client based on their existing knowledge and needs.

You have to understand that patients, they are individuals...I can't generalise the manner in which I am giving adherence [counselling]. I can't just say, "Hey, don't take your traditional medication" to everyone. "Use a condom every day" to everyone. It is important to listen to the challenges of the patient. And then when you advise them, you are going to be checking at that specific situation of the patient...I have to listen to what they have to tell me, listen to their challenges.

– Professional nurse with 1-9 years of experience, township health facility

The professional nurses reported using language to create a supportive and safe environment for clients. This included assuring clients regarding confidentiality of their HIV status and any other information shared, as well as using friendly and respectful language; for example, complimenting clients when they had good viral load results and using culturally appropriate language as an expression of respect.

The respect that you show to them...You know, me, I'm used to checking the patient's name and then I check - Sothos, you say "ntate", it depends, "ntate" means "father", it's respectful...even if it's Joseph Molemela, I will say, "Ntate Molemela, Joseph".

– Professional nurse with 20-29 years of experience, inner-city health facility

Establishing a supportive and safe environment also meant using inclusive language that did not assume the sex of a client's partner or the number of sexual partners.

And some of the patients, they are our gay patients. They will come, you know, come for the STI, ne? Yes. And, they don't actually tell you, they will tell you that they've got piles...You have to be very tactful to go there, ok, also then to ask...you know, normally what I say, "Ok, where is your girlfriend or boyfriend?" I say girlfriend or boyfriend (emphasised)...And then sometimes I can perceive that there are other partners. When I give the contact slip, I ask them, "How many contact slips must I give you?"

– Professional nurse with 20-29 years of experience, inner-city health facility

The professional nurses felt responsible for creating an environment that encouraged clients to be open about their adherence challenges in order to address them. To facilitate this openness, they applied intentional listening and discussion with clients.

Sometimes a patient will tell you, "But you know, ah, my wife, ah, I know that you're talking about my wife." You can ask an open-ended question, "Tell me more about your wife." You see? Then they tell you what's happening with the wife, they are no more staying with the wife, maybe they tested long time ago or this and that, maybe they also blame their wife, you find out...you can get more. And then, you can find out, is it gonna go well with the medication or is it not gonna go well.

– Professional nurse with 20-29 years of experience, inner-city health facility

The professional nurses advocated using open, honest, and straightforward language, as well as humour, to help clients open up.

Yeah, so you just come up with something that will make the patient talk. Without pushing them to talk. Like without giving them questions, "Why were you not here, why..." no, no. You just come with something and make a joke. Sometimes I just say, "Ah, when you are so many, did you buy, which shop did you buy these babies?" And they will laugh. "Shoprite" "Checkers" "No, Wimpy." And in that way, you have already made them open up. When they come in for consultation, it is very easy for you to speak to them. They will even tell you something they never even tell anyone else, that they didn't even tell the mother about. They start to tell you.

– Professional nurse with 20-29 years of experience, inner-city health facility

The use of body language

The professional nurses identified body language as a method to establish a supportive and safe environment during adherence counselling. This included paying attention to the client as well as observing the client's body language. It also incorporated the professional nurses' facial expression and tone of voice. Further, the professional nurses allowed clients to express emotion and reciprocated to show their support.

While the professional nurses acknowledged that they were often busy and engaged during consultation sessions with clients, they advocated slowing down and listening to the client, using body language to demonstrate that they were paying attention to what the client was saying.

I think, part of those things, you know we are so busy, ne? And part of being busy is that, when you are seeing a patient, you just want to finish and see the next one. And most of the time you find yourself, while you are talking to the patient, you are busy with your pen, you are writing, ne? I think there is a point where sometimes you just have to put your pen down and give the patient a little bit of attention. Listen to what they are saying, and then advise them properly. Like, show the patient that you are listening to them. So, I try here and there to just put my pen down and listen to the patient. And then when they talk, obviously you will be nodding to show them that you are listening to them.

– Professional nurse with 1-9 years of experience, township health facility

The professional nurses also paid attention to the client's body language and were able to discern if there was something the client needed to talk about. For example, expressions of emotion (such as crying or anger) indicated a problem and the need for discussion and support.

You will see the patient is relaxed when she's talking. Sometimes when you are interviewing someone, you will see if she's withholding any information or not. Some will also, you will see if there is a problem, they'll easily break into tears. Then you will see that there is something that needs to be attended to.

– Professional nurse with 20-29 years of experience, township health facility

The professional nurses did not force clients to speak, but allowed them space to share when they were ready to do so.

I think firstly you must be observant, because others don't talk, but you can see the patient when she comes in, she's not well. Then that's when you ask, "Are you fine today?" If they are not ready to talk, there are those that will tell you, "Sister, I'm not well but I'm not ready to talk." Then you'll give her space, she'll talk when she's ready.

– Professional nurse with 20-29 years of experience, suburb health facility

Facial expressions and tone of voice used by professional nurses were believed to contribute to effective adherence counselling as well. They noted that a friendly and welcoming facial expression – either smiling or having a calm and neutral appearance – established a positive

atmosphere where the client felt comfortable and could be open. Likewise, they shared that they strived to maintain a calm tone of voice even if the client was emotional or upset.

Whether I'm smiling or not, from the tone that I am asking them in and the facial expression that I am approaching them in, they tell you that, "Sister, because of the way you approached me, I am able to tell you all of my complaints. But if maybe I find you sometimes not...being happy or what, I am unable to tell you my problems because I'm afraid of how you'll react to that." So, a clear facial expression, I think it's good.

– Professional nurse with 1-9 years of experience, township health facility

A safe and supportive environment was further established by the professional nurses allowing clients to express emotion and showing they cared by responding in kind. A professional nurse shared an experience with a client who returned to the health facility after being referred to the hospital and losing her baby:

She even had that strength, just to come and tell me the outcome of the pregnancy...And she said, "Sister, my child died when I went to theatre." And she was crying. I think she just wanted a shoulder to cry on. And I sat, and I let her to cry. And when she finished, she was fine, and she said, "Sister, thank you very much for giving me a hearing ear. And she hugged me and off she went.

– Professional nurse with 20-29 years of experience, inner-city health facility

Attitude toward clients

The professional nurses recognised that their attitude towards clients could foster a positive environment during adherence counselling, and therefore worked to convey an attitude which was supportive, empathetic, and non-judgmental. They sought to build rapport and establish a caring and open relationship with clients by relating to them as a mother or close family member. They explained that a respectful and non-judgmental attitude helped create an open relationship where clients could share adherence challenges and work together to address them. They demonstrated non-judgmental attitudes by explaining why certain behaviours (such as alcohol use) were harmful, using inclusive language in terms of the sex and number of a client's sexual partners, listening to the client, and providing information rather than advice.

While professional nurses acknowledged that they were strict with clients, they professed that this was due to their concern and care for the clients.

Your personal approach is almost your biggest counselling tool that you've got, is how do you approach your patient. I'm very strict with my patients. And they are really, really, some of them, are scared in a good way. Because they know that I'm strict, and if I'm strict with you and I'm talking hard to you, it's because I want the best for you. And if they understand that concept, then they do open up to me. They say, "you know what sister, you're gonna shout at me. Because I haven't been good. I've been stressed, so I keep on forgetting my pills." And the moment they're honest with me, I will never shout at them. Because now I'm connected with this person. And then you can try and work around the problem. So, I've got a really good relationship with most of the long-term patients, and we got quite good results.

– Professional nurse with 30+ years of experience, suburb health facility

The professional nurses also tried to empathise with clients and their context, listening closely in order to identify specific challenges affecting a client's adherence.

So, every time when a patient is coming to you and saying a problem, you must be human enough to listen and try put yourself to what they are going through before maybe you are just going to dismiss that and say, "The right thing to do is this one." You hear what they are dealing with first and then...even though at the end of the day you are going to give them the correct information...Listen to the patient first. Yeah. That's what I believe in.

– Professional nurse with 1-9 years of experience, township health facility

The professional nurses recognised the continuous effort necessary to maintain a positive attitude. One professional nurse attested to this, saying that she did her best with clients, sometimes disregarding the pressure of time constraints, because if she were in the client's position, she would want to receive good care and not "be rushed off."

In an effort to facilitate open conversations with clients, the professional nurses sometimes adopted a maternal role, encouraging clients to relate to them as a mother or close family

member. The professional nurses believed this made clients feel comfortable and facilitated the sharing of sensitive information that could enhance the adherence counselling, as well as encourage the clients to listen to them as a caring advisor.

But some of them appreciate it if you say, “Mntwana,” isn’t it, “My child.” You tell them that, “Now I’m not going to be a Sister anymore, I’m going to be a mother to you. Just listen to me the same way you listen to your mom.” And then the patients maybe, they feel, some of them, feel free. They start to understand that you are not that nurse...they listen when you try to be a mother to them.

– Professional nurse with 10-19 years of experience, township health facility

I act as a mother to them, most of them. Isn’t it they are young? I usually tell them, take me as your mom. I know mothers are very, very, very strict and don’t want to hear anything. I’m your mother in this department...I want you to be open to me and tell me whatever...I just don’t see them as patients. If they have problems, even if it is a social problem, I sit down and talk to them.

– Professional nurse with 30+ years of experience, township health facility

Adherence counselling tools and resources

Various tools and resources were used by professional nurses to support their adherence counselling. Some of these were provided by, or available at, the health facility, such as brochures, forms, adherence assessments (pill count and viral load), and food parcels. Other tools and resources were developed or employed independently by the professional nurses, either individually or as a strategy of that particular health facility. These included analogies, props, and mobile and digital technology.

No professional nurses reported having or using official tools specifically created to support adherence counselling, such as an education flipchart. Several – including both professional nurses at one of the township health facilities – stated that they did not have any tools or resources to support their adherence counselling, although others reported using existing resources or processes, as well as developing their own tools.

What I have is information. I do not have any specific tool, if I may be honest with you. I do not have any specific tool. Even with our counsellors, I doubt if they have anything, I really doubt they have anything.

– Professional nurse with 1-9 years of experience, township health facility

But truly speaking, it's just us talking one-on-one with the client. And, looking to, whether this patient is coming to the clinic maybe on time, or at the right date, and maybe monitoring that viral load to see if it's suppressed or not. That's all, no other supportive things that we can do.

– Professional nurse with 20-29 years of experience, suburb health facility

Some professional nurses who had educational brochures in their facilities admitted to not using them for adherence counselling, although one professional nurse used an educational brochure for diabetics to guide clients on a healthy diet during her adherence counselling sessions. Some professional nurses were not familiar with the brochures that were available in their facilities as per the observation of the researcher.

We don't have the brochures. I don't know if the counsellors, they do, but we don't have brochures. We just teach them what we've learned.

– Professional nurse with 20-29 years of experience, suburb health facility

Furthermore, the professional nurses expressed challenges with the stocking of educational brochures in the health facilities.

There are brochures for antenatal [care], there are brochures for TB, HIV... You find they have to collect them there by Department of Health, you will find there is not a lot... Yeah, so sometimes you find that they really don't have.

– Professional nurse with 20-29 years of experience, inner-city health facility

Among the resources noted to be available to the professional nurses to support adherence counselling were male and female condom demonstrators and condoms. In some health facilities, there were food parcels to distribute to clients, which they used to support treatment

adherence. The professional nurses also drew on other service providers such as social workers to assist in addressing client adherence challenges.

The patient specifically mentioned his problem in that particular case. That he does not have food. He is staying alone; he doesn't have anyone. So, when he doesn't have a meal, he is unable to take his ARVs, because after taking them, he experiences some cramping and whatnot. So, in that specific case, I, as a practitioner, I tried to talk to the social workers about it. We also arranged some food parcels from the clinic to address that specific problem for the patient, so he doesn't have to go to bed hungry. So, if the patient had a meal, I would know that he would definitely take his medication.

– Professional nurse with 1-9 years of experience, township health facility

In addition, various client forms enabled gathering of information that assisted the professional nurses with adherence counselling. For example, the admission forms documented each client's socio-economic situation, including income, type of dwelling, if they have a treatment buddy, and disclosure status. The continuation chart, where the professional nurses record the client's pill count and viral load results, prompted them to address certain topics at every visit as well, such as screening for STIs, and, as previously noted, an alcohol abuse self-assessment form was used to link clients in need to a local outpatient rehabilitation centre. The professional nurses further noted that the adherence assessments built into the health facility procedures – the pill count and viral load testing – also functioned as adherence counselling tools, helping them to detect adherence problems which required more intensive counselling.

Because we must count the medication. But actually it's not about counting, it's actually trying to check if they are actually taking the medication. If you're gonna count the tablets, she only took two tablets, she still has 26 tablets. And it's after two weeks. Then you know there's a problem. Then you start to find out, who else in the family knows about your condition. Then if nobody knows about the medication, definitely the patient's not gonna take the medication.

– Professional nurse with 20-29 years of experience, inner-city health facility

Due to the limited official methods and tools available and perceived as appropriate for supporting adherence counselling, the professional nurses developed their own analogies that clients could relate to and used everyday items as props to help illustrate these analogies. These were used particularly when explaining how ART works in the body to suppress HIV (and what happens if the client does not adhere to treatment), why it is important to use condoms, and how medication may come in various shapes, sizes, and colours, and with different brand names. Analogies used by the professional nurses included an egg, a thief, a gate, and types of sugar. Props used included the ART medication containers as well as bottles in their consultation rooms.

And then you inform them that if you drink the tablets and you stop, you actually go back and show them how HIV started, and then what is the ARVs doing to them. Like, I will give an example of an eggshell (cups her hands into an egg shape). When you are taking ARVs they are actually forming something like an eggshell around your HIV. And like an eggshell is closing like an egg, the HIV is still inside there. It multiplies, it mutates, it does all this story. But because you are taking ARVs every day, your egg will never break. So, once you stop taking your ARVs, your egg is gonna break. And it's gonna release the millions of the HIV that are there. Because we are not treating HIV, we are controlling the disease. The ARVs are not treating anything. They are just controlling the disease, so if you take it in a proper way, you'll live like any other person who is not HIV. As long as you know you are taking your treatment every time.

– Professional nurse with 20-29 years of experience, inner-city health facility

One of the professional nurses used WhatsApp groups to support adherence counselling and described various ways of employing this method, such as to collaborate with other service providers and to communicate with clients. For example, one WhatsApp group, made up of members from the WBOT and local NGOs, was found useful for tracing clients who had missed appointments. The professional nurse also used WhatsApp groups to send treatment reminders. She noted that the group dynamic further reinforced adherence, as some clients responded positively on the group, which encouraged other members to continue to adhere.

In the morning, I can just send a message to remind the patients to take their medication. Because of the SMS for the government right now is not working. So that's why we have this WhatsApp group, and there are some who don't have WhatsApp. We just send a SMS to remind them. So, it also helps, because even if somebody decides to give up hope, not to take medication, then they see the reminder every day...Some will say, "Thank you, thank you, you help me" or "I've already taken." Then you ask yourself, why didn't you take? You see, it also helps the patient to adhere.

– Professional nurse with 20-29 years of experience, inner-city health facility

The professional nurse also noted that clients who were part of the WhatsApp group sent private messages to her with their concerns, such as a rash, and she responded with the appropriate support, such as telling the client to come see her at the health facility. She monitored the group and followed up with clients who did not read the daily message to check on their well-being.

The same professional nurse further shared that she used the website [The Body](#) as a resource for herself and recommended it to clients for further information and engagement with experts and other people living with HIV.

This section outlined the four themes that adherence counselling practice is categorised into; namely, providing health education, addressing lifestyle-related behaviours, facilitating disclosure/social support, and application of counselling methods and tools. The following section compares the reported adherence counselling practice with the national *Adherence Guidelines*.

4.4 Comparison of reported adherence counselling practice to the *Adherence Guidelines*

As the *Adherence Guidelines* are the first in the country to specifically focus on the practice of adherence counselling, among other adherence and retention strategies, and represent good practice, comparison of these with the professional nurses' reported adherence counselling practice is useful to identify areas of alignment and differences in preparation for the refinement of the guidelines and national rollout.

The comparison looked at adherence counselling content, methods and tools, parameters, and roles and found that there were both similarities and differences between the reported practice and the guidelines in terms of content and counselling methods. However, reported practice differed from the *Adherence Guidelines* in terms of adherence counselling parameters and roles.

Table 3: Comparison of adherence counselling content in the *Adherence Guidelines* to nurses' reported practice

Adherence Guidelines: steps	Nurses' reported practice
Education	√√
Identify support systems	√√
Medication schedule	√√
Reminders	√√
Side effects	√√
Substance use	√√
Identify life goals	x
Plan future appointments	x
Assess readiness for treatment	√
Missed doses	x
Storing medication and extra doses	x
Plan for travel	x

*x: not addressed by nurses; √: addressed, but infrequently; √√: addressed frequently

4.4.1 Adherence counselling content

The *Adherence Guidelines* specify 12 steps to be covered during adherence counselling. They are: education on illness and treatment, identifying life goals, identifying a support system, planning for future appointments, assessing readiness to start treatment, medication scheduling, managing missed doses, selecting reminders, storing medication and extra doses, dealing with side effects, planning for travel, and dealing with substance abuse. The professional nurses' reported adherence counselling addressed six of these topics, as well as three additional topics: dietary practices, safe sex, and TCAM use.

Content similarities between the reported practice and Adherence Guidelines

The key topics covered by the professional nurses which were aligned to steps in the *Adherence Guidelines* included provision of education, identification of support systems (equivalent to the

disclosure topic mentioned by the professional nurses), medication schedule, reminders, side effects, and substance use.

The importance of education on HIV and treatment as part of adherence counselling content as highlighted by the professional nurses is similarly articulated in the *Adherence Guidelines*. This includes an explanation of what HIV is and its effect on the body, how ART works, possible side effects, and the consequences of poor adherence.

Likewise, the way in which the professional nurses approached disclosure as a means for the client to acquire support to take treatment, by discussing who the client could go to for support and why this would be beneficial, is equivalent to the step in the *Adherence Guidelines* on identifying social support. This step involves posing questions to the client on who can support medication adherence, where support can be accessed, and the importance of discussing the client's HIV status with others. However, the professional nurses went beyond the *Adherence Guidelines* by helping clients with the disclosure process itself. On the other hand, the *Adherence Guidelines* recommend that the client be consulted about his/her willingness to be supported via home visits or phone calls from the health facility. Although this consultation was not mentioned by the professional nurses, they did note that they requested other service providers (such as WBOTs) to trace clients at home and used the phone to engage clients and provide supportive messages.

Scheduling when to take ART was a key topic for the professional nurses as well as a step in the *Adherence Guidelines*, incorporating discussion with the client to identify the most suitable time to take medication. The professional nurses reinforced the need to take ART at the same time daily and encouraged clients to take work and transportation arrangements into consideration when making scheduling decisions.

Reminders were noted by both the professional nurses and the *Adherence Guidelines* as an important aspect to address in adherence counselling. Aligned to the messaging in the *Adherence Guidelines*, the professional nurses reported providing a variety of options to use as reminders and allowing the client to choose the best method for him/herself. Specific options

noted by the professional nurses included a phone alarm, treatment supporter, routine activity (such as a regular TV show or brushing one's teeth), calendar, and pillbox.

Side effects of the treatment was also noted as a key topic by the professional nurses as well as in the *Adherence Guidelines*, including telling clients that side effects are common when starting treatment but often improve over time, and discussing common side effects. Both sources emphasise encouraging clients to return to the health facility if side effects persist or are severe, or if the client is concerned about them, rather than stopping treatment or seeking alternative medication. A professional nurse noted that certain side effects (such as bad dreams) were sometimes seen as a sign of witchcraft, and it was important to address this perception to promote adherence.

Addressing substance use among clients is another key aspect of the professional nurses' adherence counselling content and the *Adherence Guidelines* alike. Both sources advocate advising clients to reduce their intake of substances such as alcohol when on treatment. The professional nurses stated that it was important to explain why clients should reduce their substance use to avoid appearing judgmental. The reasons they gave to clients included that substances such as illegal drugs and alcohol could damage body organs, cause clients to forget to take their treatment, and interfere with the efficacy of the medication. The professional nurses from the township and inner-city health facilities reported referring clients to local rehabilitation centres when they recognised that they had a substance abuse problem, aligned with the *Adherence Guidelines'* recommendation. Professional nurses from the inner-city health facility in particular reported dealing with substance use regularly and had clients complete a self-assessment to gauge whether they need to consider rehabilitation services. They also stated that they worked closely with local service providers to address substance use among clients.

Content differences between the reported practice and Adherence Guidelines

Of the 12 steps included in the *Adherence Guidelines*, six were not specifically covered by the professional nurses, although they did allude to several of them. These are identification of life goals, planning for future appointments, assessing readiness to start treatment, managing

missed doses, storing medication and extra doses, and planning for travel. However, the professional nurses spoke of three additional key topics which were not part of the *Adherence Guidelines*' 12 steps: dietary practices, safe sex, and the use of TCAM.

The step in the *Adherence Guidelines* on identifying life goals, which includes engaging the client to think of reasons to stay healthy, such as loved ones or things the client wants to achieve in life, was not a key topic raised by the majority of the professional nurses, but was mentioned as part of one professional nurse's enhanced adherence counselling.

Similarly, assessing readiness to start treatment, one of the steps in the *Adherence Guidelines*, was mentioned by the professional nurses but not highlighted as a key topic of their adherence counselling. The professional nurses did note that client readiness to start treatment was important for adherence and touched on several aspects of this step, including addressing myths related to treatment and side effects, and encouraging those who are not yet ready to start treatment to return to the health facility for initiation soon. They did not, however, bring up other aspects noted in the *Adherence Guidelines* as part of this step, such as offering a meeting with an HIV-positive peer, referring to the life goals established, or congratulating clients who decide they are ready to start treatment.

Managing missed doses – ensuring clients know what to do if they forget a dose and advising them to take the ART as soon as they remember – was also not included as a key topic in the professional nurses' adherence counselling, but is a step in the *Adherence Guidelines*. The professional nurses noted that clients did forget to take ART, usually due to substance use or stress, but did not mention providing guidance to clients on what to do in that situation. However, two key topics addressed by the professional nurses to prevent missing doses included scheduling of the time to take ART and treatment reminders.

Storing medication and extra doses, a step in the *Adherence Guidelines* which incorporates helping the client to identify a safe place to store treatment and advising the client to carry 1-2 extra doses at all times in case of unexpected situations, was not a key topic addressed by the professional nurses. However, they did refer to storing the medication in relation to disclosure;

specifically, that failure to disclose led clients to hide their medication, including using bottles for other medication (such as vitamins) to store their ART.

The professional nurses did not address planning for future appointments or planning for travel – two of the steps in the *Adherence Guidelines* – although these issues were both mentioned as a challenge in the context of client mobility and the need to ensure consistent treatment despite expected or unexpected travel or relocation. Specifically, they spoke about clients not planning for travel and future appointments due to work and personal commitments as a potential challenge and barrier to adherence, but did not mention explicitly addressing this with clients. In the *Adherence Guidelines*, planning for future appointments includes engaging the client on how he/she will ensure that he/she is able to attend the health facility for future appointments, taking into consideration transport or other potential challenges. Planning for travel involves discussion with the client on upcoming travel plans and how the client will ensure that he/she has enough treatment, including for unexpected travel. Clients should be encouraged to come to the health facility to receive a referral and/or extra treatment, but if this is not possible, should go to the local health facility at their travel destination with documentation of HIV status and current treatment.

In addition to the 12 steps, the *Adherence Guidelines* include a review of education and goals with each client. This consists of explaining viral load testing and establishing a goal for the viral load result six months after starting treatment; providing advice on healthy eating, exercise, reducing smoking, and managing stress; and conducting a mental health assessment. While not applied as a separate topic by the professional nurses, they reported addressing many of these items in their adherence counselling. For example, information on viral load was part of the health education provided to clients and smoking was addressed as part of substance use, while diet was considered a key topic on its own. Even though the professional nurses did not mention conducting mental health assessments, they did acknowledge the value of disclosure and social support to help manage stress and adhere to treatment. They also noted the availability of social work services to provide further mental and emotional support to clients – although they admitted that they rarely refer clients to these services.

The use of TCAM was a key adherence counselling topic among the professional nurses but is not included as a step in the *Adherence Guidelines*⁵. This included over-the-counter or traditional medication, or treatment from a church (such as “holy water”). The professional nurses addressed this issue when clients first started ART, as well as if a client had a high viral load result. They explained to clients that other medications may cause drug interactions and interfere with the effectiveness of the ARVs. The professional nurses encouraged clients to avoid TCAM, taking care to respect their belief systems and the external pressure they may face to take them.

The professional nurses also addressed safe sex (including condom use and family planning) as a key topic during their adherence counselling, which is not included as a step in the *Adherence Guidelines*. Messaging included consistent condom use – to be reinforced at every visit – with explanation of why it is important: to prevent re-infection with HIV as well as onward transmission. The professional nurses used analogies to help explain this concept and noted that condom use remained a challenge, particularly as women were often not able to negotiate condom use and were consequently either not willing or able to use condoms.

Dietary practice was another topic considered crucial by the professional nurses but is not a step in the *Adherence Guidelines*. This included what constitutes a well-balanced diet and what food and drink to avoid, as well as what food to eat and at what time to consume it to best support absorption of the ARVs. The professional nurses also reported providing support such as food parcels and practical advice appropriate for clients’ socio-economic context, such as encouraging clients to eat foods which are affordable and accessible to them.

Having compared the professional nurses’ adherence counselling content in terms of similarities and differences to the 12 steps in the *Adherence Guidelines* – noting areas of alignment with six of the steps in the guidelines as well as featuring a further three key topics not included as steps in the guidelines – the following section will compare the professional nurses’ adherence counselling methods to that contained in the *Adherence Guidelines*.

⁵ This topic is addressed in the Enhanced Adherence Counselling section of the *Adherence Guidelines*

4.4.2 Adherence counselling methods

Both the professional nurses and the *Adherence Guidelines* cite counselling methods – or how adherence counselling is conducted – as an important part of its provision. The professional nurses' methods were similar to that contained in the *Adherence Guidelines* in terms of language use and a positive attitude during adherence counselling, as well as the use of supportive resources, such as educational brochures and external organisations and structures. On the other hand, professional nurses spoke about body language as part of adherence counselling methods, which was not noted by the *Adherence Guidelines*. In addition, the tools used by the professional nurses to support their adherence counselling were different to those specified in the *Adherence Guidelines*.

Content similarities between the reported practice and Adherence Guidelines

The professional nurses highlighted the use of language in their adherence counselling, as did the *Adherence Guidelines*. This included starting the counselling with an introduction, asking questions of clients to assess understanding, reminding clients of the confidentiality of the session, listening to the client, engaging in discussion, and giving encouragement. The professional nurses also noted the value of using language appropriate to a client's level of understanding, education, and context. They reported using friendly, open, respectful, and inclusive language to promote adherence, and underscored the importance of being honest and straightforward themselves to create an open environment with the client.

Both the professional nurses and the *Adherence Guidelines* address the importance of a positive attitude during adherence counselling, emphasizing being supportive and non-judgmental to create a safe space for clients to be open about adherence challenges. The professional nurses stated that they expressed non-judgmental attitudes by explaining why certain behaviours (such as alcohol use) were harmful, using inclusive language, providing information rather than advice, and listening to the clients. Several professional nurses expressed empathy for clients and sought to build rapport by relating to them as a mother or family member. They reported making an effort to be seen as approachable, caring, and calm.

The professional nurses and the *Adherence Guidelines* also both cite a helpline and educational brochures as tools to support client adherence, although the brochures were reportedly not actively used by the professional nurses during their adherence counselling. Additional tools to provide adherence support noted by both sources include external organisations and structures, such as WBOTs.

Content differences between the reported practice and Adherence Guidelines

The professional nurses spoke of the use of body language during the provision of adherence counselling, which is not addressed specifically in the *Adherence Guidelines*. According to the professional nurses, this included active listening (putting down the pen and nodding), having a welcoming facial expression and calm tone of voice, and dressing professionally. It also included paying attention to a client's body language and allowing clients to express emotion (such as crying), as well as reciprocating (such as hugging) to show support.

The professional nurses did not cite the use of adherence counselling tools listed in the *Adherence Guidelines*, which include an adherence plan, adherence education flip file, and a mental health assessment tool. Instead, they noted the use of tools not covered in the *Adherence Guidelines* – most of them developed or adapted by themselves – such as analogies and props to explain concepts and the use of technology such as WhatsApp groups. Health facility resources that the professional nurses cited as tools they use to support their adherence counselling included food parcels, condoms and condom demonstrators, and adherence assessments (such as pill counting and viral load testing). A professional nurse noted the use of a substance use self-assessment and another cited the admission form as a tool prompting her to address certain issues during her adherence counselling.

The professional nurses' adherence counselling methods contained both similarities and differences to those recommended in the *Adherence Guidelines*, with similarities in terms of language use and attitude toward clients, and differences related to the use of body language and adherence counselling tools. The following section compares the professional nurses' parameters of adherence counselling to that contained in the guidelines.

4.4.3 Parameters of adherence counselling

The parameters of adherence counselling relate to the frequency, timing, and duration of sessions with clients. The professional nurses emphasised that adherence counselling was continuous and necessary at every appointment, as adherence needed ongoing reinforcement and new challenges could arise over time. Conversely, the *Adherence Guidelines* outline the 12 steps of adherence counselling as four sessions at specific times in relation to treatment initiation: the day of treatment eligibility, the day of initiation, one month after treatment, and two months after treatment. While the professional nurses highlighted the frequency of adherence counselling, this was not related to the provision of particular content at specific times, as it is in the *Adherence Guidelines*.

We initiate today, we want him in two weeks, to come and see how he's faring on those ARVs. Then he comes again on the second week, then it's monthly...Tell them the importance of taking treatment, daily without fail, at the same time. So, the counselling is ongoing, every time that the patient comes.

– Professional nurse with 30+ years of experience, township health facility

Whereas the professional nurses spoke of how they did not have adequate time to provide quality adherence counselling, the *Adherence Guidelines* do not provide guidance on the duration of an adherence counselling session. Likewise, the professional nurses emphasised ongoing provision of adherence counselling at every appointment, rather than specific content to be covered at particular stages of treatment as stipulated in the *Adherence Guidelines*. However, neither cite an ideal duration of adherence counselling. The following section compares adherence counselling roles as noted by the professional nurses with those prescribed in the *Adherence Guidelines*.

4.4.4 Adherence counselling roles

While the roles of those involved in client care (clinicians, non-clinicians, and the client) are clearly delineated in the *Adherence Guidelines*, the professional nurses' reported practice reveals that these roles and responsibilities are blurred in some cases. In the *Adherence Guidelines*, clinicians (such as professional nurses) are responsible for screening, emphasising

continued treatment, exploring side effects and client concerns, providing the next appointment, and informing the client about tracing and retention systems. Non-clinicians (such as lay counsellors), on the other hand, should provide education, create an adherence plan with the client using the steps outlined in the *Adherence Guidelines*, inform the client about next steps in the treatment journey, and help the client set goals. Although the professional nurses acknowledged that the health facilities had lay counsellors to provide HIV testing and adherence counselling, they reported doing much of the ongoing adherence counselling themselves due to a range of reasons, including doubts regarding the ability and/or availability of lay counsellors, sensitivity of the issues, client preference for the professional nurse, and convenience.

Most of the time, we are the ones counselling the patients, because at times you find it's one person, other counsellors didn't come on duty. So, it becomes a problem for patients to go and queue there. You do everything in the room...Because those ladies, the clinic becomes so full that they test almost more than counsel. So, then we are the ones, we took it upon our shoulders to counsel them in our rooms.

– Professional nurse with 30+ years of experience, township health facility

The continuity of counselling. Even us, we are doing the continuity of adherence counselling. They [the lay counsellors] are doing it, even us we are doing it. Sometimes when you find out the viral load is high, and then, when you do your counselling you realise that their partner doesn't want to use a protection, things like that. So, you'll find out that I'll call the partner. I'll be the one doing the counselling on both, both partners. Yeah, I don't even refer that side. Because maybe what I've identified, it needs me because I'm the one who identified...I have to do the counselling.

– Professional nurse with 20-29 years of experience, inner-city health facility

Nevertheless, the professional nurses did acknowledge the value – including time saved – in having a nurse from Right to Care initiating new clients and the lay counsellors providing the adherence counselling as part of treatment initiation. They also noted using the lay counsellors

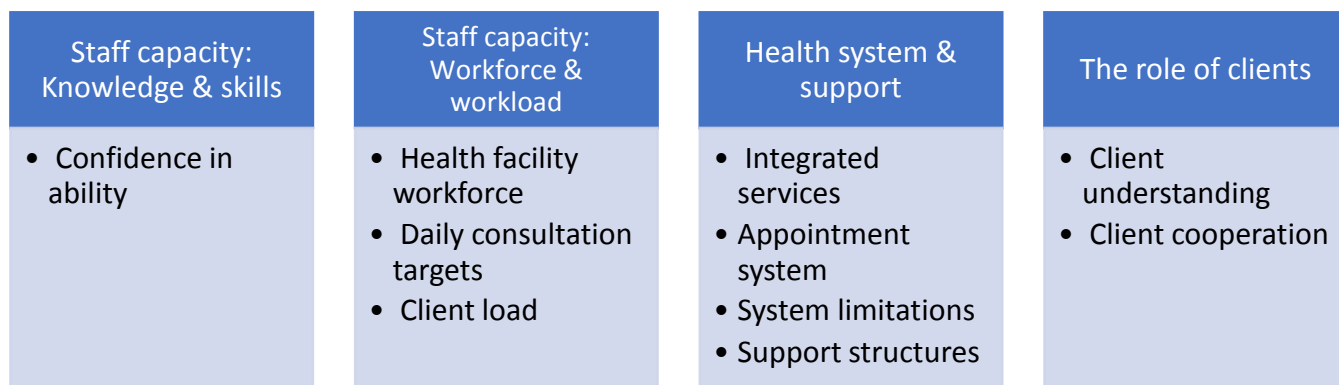
to provide counselling to clients who had ongoing adherence challenges and high viral load results.

This section presented the similarities and differences between the adherence counselling practices of the professional nurses and that contained in the *Adherence Guidelines* in terms of content, counselling methods, parameters, and roles. The following section examines the factors which affect the provision of adherence counselling from the perspective of the professional nurses.

4.5 Factors affecting the provision of adherence counselling

The professional nurses noted factors which had either a positive or negative effect on their provision of adherence counselling, including training and experience, staff capacity, health facility systems and support structures, and the clients themselves (see figure 6 below). In a few cases, the professional nurses cited the same factor (such as the appointment system) as both a positive and negative factor, or had different opinions on the same factor.

Figure 6: Factors reported to affect the provision of adherence counselling



4.5.1 Staff capacity: Knowledge and skills

The professional nurses expressed confidence in their ability to provide adherence counselling, noting that the NIMART training they received gave them the knowledge and skills needed to provide ART, including adherence counselling. They shared that along with providing them with the capacity they needed for service delivery, the training influenced their approach to incorporate more input and ownership from clients – something they considered beneficial to

both themselves and the clients for treatment adherence. They also gained confidence through the experience of attending to clients living with HIV.

I think it [NIMART training] helped me...it actually helped me to help the patients. To know what is it that I must say to the patient and to give a patient a chance to tell us how they feel they want to do it. Because at the end of the day, they are the ones to take the medication. So, it's not about us deciding for the patient. But it's about the patient participating in her own treatment.

– Professional nurse with 20-29 years of experience, inner-city health facility

4.5.2 Staff capacity: Workforce and workload

The workforce- and workload-related factors cited by the professional nurses that affected adherence counselling practice were the available staff, client load, and daily consultation targets. Specifically, these factors limited the amount of time which professional nurses had for adherence counselling, and they expressed concern about this compromising the quality of care they could provide.

Health facility workforce

All the health facilities involved in the study received human resource assistance from Right to Care, comprising a nurse for ART initiation and lay counsellors. Several professional nurses also noted support from NGOs and WBOTs.

Ok, um, the time is limited, ne? Sometimes you can, it is supposed to be 12 minutes but sometimes you find that you extend, ne? But you have counsellors...there are patients who are coming from the counsellors. The counsellors, already they have done the adherence counselling...So, when they send the patient to you, they send the patient to you so you can do the history, full history, examine the patient, and do the baseline bloods. So, the counsellors actually make life easier. And then, we also have a sister from Right to Care. She is here specifically for HIV, especially those that are starting treatment for the very, very first time. So, it also makes life easier.

– Professional nurse with 20-29 years of experience, inner-city health facility

While valuing the human resources support, the professional nurses still noted a high workload due to staff shortages – including from resignations and absenteeism.

I think I can say, only absenteeism. If Sisters are not at work you need to do everything on your own, whereby the queue is too long and then they are complaining...if there is too much patient and you are on your own, you are trying by all means to push the queue, so you must see each and every patient. And on the other hand, you need to have time to make the patient understand what you are telling them.

– Professional nurse with 10-19 years of experience, township health facility

High client load

The professional nurses noted that their health facilities experienced larger client loads than anticipated due to client preference for specific health facilities. A professional nurse at the inner-city health facility, for example, said this was due to its location – that clients perceived having a greater degree of anonymity there, while professional nurses at the suburb health facilities reported having large client volumes because clients were working in the area and it was more convenient for them to seek health services close to their place of employment. The professional nurses also reported that some clients preferred specific health facilities due to beliefs that they provided superior services.

So that's the problem that we face. Others, the families go take them from where they stay. They say [clinic name], that is the best. "I like that clinic" and they'll come from far and bring the patient here for treatment because they believe it's working here, from where they come from...Like there are those who'll come and say, "I was working here." She started treatment when she was still working here. Now she is no more working. She is staying in Mpumalanga. Then you will try to explain the disadvantages of coming here from Mpumalanga on monthly basis, or those, in that two months. Then she will tell you, "But, I like the clinic. Are you sure at home there is treatment for me?" So, they are not yet aware that in South Africa, we use the same guidelines, the same protocol, the same policies, the treatment is the same, everything that is done here is done even in the rural

areas.

– Professional nurse with 20-29 years of experience, suburb health facility

Daily consultation targets

The professional nurses cited daily consultation targets as a factor putting them under extreme pressure to deliver services to a large number of clients. Some expressed their frustrations and concerns about how this was negatively affecting the quality of service which they could provide.

Because we are pressured for stats. They shout at me, for instance yesterday, because my stats is not high enough. But why is my stats not high enough? Because I feel it is important for you to understand your disease...what is HIV, how do you get it, and what is this ARV doing? Why should you take it? How is it working in the body? And that takes time...if they understand it, then they are going to comply. And they're going to do, the adherence is going to be better...They want us to see 40 patients a day. Do you have any idea, how long should you spend on 40 patients a day?...It's like five minutes per patient.⁶ That is like a machine. And I can do it. I don't have a problem with that. But my question is, am I going to give the right care to my patient? This is what is eating at me. I cannot go to bed tonight and know, you walked out of this room, in five minutes I was done with you. How did I examine you, what did I miss?...Because there's no way you can give anyone counselling in five minutes and do all your writing that you need to do.

– Professional nurse with 30+ years of experience, suburb health facility

There was an observation that clients had experiences and concerns that could affect their adherence, and that addressing these issues required time that the professional nurses did not always have due to consultation targets.

We are supposed to see 35 patients a day. So, when you calculate it, it's like 12 minutes per patient. And then, patients they want to say what they think about the treatment.

⁶ A target of 40 clients per day gives a nurse approximately 10.5 minutes with each person, factoring in time for lunch and short breaks

Because you are supposed to encourage them to say what they think. Because some might have a very bad dream, they found themselves in bed with their daughter...They might think it is witchcraft, this medicine has some witchcraft. They stop taking the medicine.

– Professional nurse with 20-29 years of experience, inner-city health facility

Factors which affected the provision of adherence counselling – particularly the time available to provide quality services – included the health facility workforce, client load, and daily consultation targets. The following section addresses factors related to the health system and external support.

4.5.3 Health system and support

The professional nurses cited factors such as integrated service delivery, the appointment system, system-related limitations, and external organisations and structures as having an effect on their adherence counselling practice, with differing opinions on whether these factors had a positive or negative influence.

Integrated service delivery

The integration of HIV care and treatment into each health facility's broader services entailed attending to clients living with HIV in every service area rather than having a separate section or service area for them. Nursing staff rotated through the various service areas, gaining experience in each area and filling in to address staff shortages and client backlogs where necessary.

The professional nurses stated that the integration of HIV treatment and care into the general health facility services supported their provision of adherence counselling by reducing the stigma of having a separate section which could identify a client as living with HIV.

Because now we are not like isolating them. They are integrated with other people. So, there's no way that you can be identified. That was the other problem, that they used to be on the other side. And then the people will default because they are afraid that

somebody from my neighbourhood will see me, that I am attending the clinic that side.

– Professional nurse with 20-29 years of experience, township health facility

On the other hand, there was an opinion that a separate section providing HIV services was better, as it allowed HIV-positive clients to meet and speak with each other, facilitating informal peer support and reinforcing adherence.

The support groups, we've been struggling to get it off the ground, and there is need for support groups. But we're just struggling. Because it's always good if you can speak to other people. That's why they used to love it when there was a separate waiting space for them, because they would sit and talk to each other and give ideas and chat...So, it was almost like a mini support group.

– Professional nurse with 30+ years of experience, suburb health facility

At the same time, the integration of services was seen by professional nurses to hinder continuity of care to clients, as clients are served in various service areas and nurses regularly rotated through these service areas at the health facility. They noted that this lack of continuity impeded consistent client monitoring and following up on potential or existing adherence challenges with clients. They also reported that this prevented the building and sustaining of rapport with clients and could consequently negatively affect client adherence.

Because of this rotation...I'm not happy about it, because you stay sometimes for a long time without seeing the patients. When you go back to the services, you find that a lot of things have changed. You find, we work differently. A lot of things have changed. Like we are supposed to - I'm giving you an example - we are supposed to check on their treatment at every visit. They must bring their medication every visit. They don't come with their medication because you are no more there, and the other sisters don't even bother to ask for the medication. Then you find people, when you go there with the bloods, you check the bloods and see, oh, this person has deteriorated, what happened? The viral load is so high. [With the rotation system], the patient becomes out of touch with you. Then they get a new person. Then they are supposed to try and know the person, build a relationship with them, it becomes a bit of a problem...patients tend not

to be happy. Patient tends to look for that person that they have started with. That they are able to tell them their problems. Because, some of us, we are not as good as all that in dealing with these HIV patients.

– Professional nurse with 30+ years of experience, township health facility

Appointment system

The appointment system was reportedly introduced to help manage the workload, ensuring that each client was allocated an adequate period of time for the consultation.

I think the appointment system benefits clients according to waiting time. If you enter the clinic, you have an appointment, you are being consulted, you can go back to work. You know it's your date, it's your time. You're on time to take bloods, to do pap smears, to be examined. The clinic is not overloaded, the waiting time is reduced. I think that is mostly why they brought in the appointment system.

– Professional nurse with 1-9 years of experience, suburb health facility

However, the same professional nurse who noted that the appointment system was a potentially positive factor for adherence counselling provision reflected on how it could be a negative factor as well if clients did not follow the system.

We have a lot of clients that are not adherent...especially now with the appointment system, we are very strict, you have to come on your time and if you're late you have to wait in the queue. I think that's also encouraging, not encouraging, but more people are going default because they don't want to wait until the end of the appointments. We aren't turning clients away, but clients are going to be more easily without medication if they can't wait until after the appointments to be consulted.

– Professional nurse with 1-9 years of experience, suburb health facility

Managing system-related limitations

The professional nurses noted there were system-related limitations which affected their provision of adherence counselling, but that they found ways to manage these factors. Some professional nurses expressed that current guidelines, such as the Essential Drug List (EDL), as

well as procedures on the distribution of food parcels, limited their practice against their best professional judgement in terms of supporting client adherence.

They [guidelines] do help, but sometimes they do limit. Because being a nurse, as an old professional nurse there are things you know you can do to help the patient, but you can't do if it is not on the guideline or not on the protocol...There are those patients who come, maybe, having loss of appetite and whatever. Then you feel that you can help by giving Vitamin B-co and whatever, but in the EDL, it's limited, you can't just give anybody the Vitamin B-co. You must have the real reasons. You can't just decide, this patient, according to me she needs. Or let me give an example about the food packages that we have. Sometimes these clients will come saying, "I don't have money to buy food." And will tell you the problems. But you are not supposed to give the food packages if the weight is not below 40 [kilograms].

– Professional nurse with 20-29 years of experience, suburb health facility

The professional nurses described ways in which they nevertheless worked around system-related limitations for the good of the client, including refusing to be rushed during their provision of adherence counselling. They explained their actions, sharing that they were in the best interest of clients and resulted in positive outcomes.

Sometimes you just say, "You know what, God knows." I'm not sitting here with the patient doing nothing. They might say what they want to say, but this patient, I'm not gonna leave this patient. I have to do the proper job, because I know that once I did the proper job on one patient, I've saved a lot of time to see more patients. Because that patient won't come with a lot of complaints, this and that. You see, if you do things the first time right, actually, you have saved everybody. To tell the honest truth, if ever you do something haphazardly for two minutes, then you're rushing to have 40 patients, then all the 40 patients, within no time they're coming back to the clinic, you're making the clinic full.

– Professional nurse with 20-29 years of experience, inner-city health facility

The professional nurses also supported clients with facilitated HIV disclosure to partners – allowing clients who already knew their HIV status and were on treatment to test with their partners and “discover” their HIV-positive status together. While the professional nurses noted that re-testing a client who already knows his/her HIV-positive status could be considered a waste of resources, they felt it is valuable, as this disclosure was expected to enable better adherence.

I had a pregnant woman who said, “Sister, I don’t know what to do with my husband.” And I said, “No, I can talk to him over the phone if you want.” “Please, Sister, speak to my husband.” “Hello, baba, how are you? Eh, we are doing certain tests mo-klinikung just to make sure the woman, whatever tests that we do is to protect the baby. So, it will be good if you also come and do the tests together with your wife. That is how you support her.” And when he comes, you start to give them information. “If you feel you want to test, you have the right to say yes or no to test. But it would be good, because if you both test positive, you can take ARVs and protect the child.” But already the woman was tested. Already she started ARVs. But the man did not know. And now I was saying, “Because your wife is refusing to test. Maybe, I’ll leave you together and you speak about it and you tell me if you want to test.” Then I left. And then they said, “No, Sister, test us together.” But already the wife knew she was positive. And then they tested, and then I separated them...The mother delivered, and then they chose not to breastfeed because the mother was not suppressed. They are coming together for treatment and they are coming to collect medication for each other.

– Professional nurse with 20-29 years of experience, inner-city health facility

The lack of official adherence counselling tools and limited availability of other resources (such as educational brochures) which could support adherence counselling was also noted by the professional nurses as a limitation to its practice.

Ok, I think things that are affecting me from doing the adherence counselling is lack of resources, ne? Like you said, sometimes it would be nice if I can demonstrate to a patient with something, or I can have a pamphlet giving the patient more information that they

can also read on their own. We do not have enough resources, which is quite of a challenge.

– Professional nurse with 10-19 years of experience, township health facility

However, the professional nurses managed this by creating or adapting existing resources to support their adherence counselling, such as analogies which help explain how ART works in the body.

Availability of supportive organisations and structures

Some of the professional nurses noted support from external organisations and structures in reinforcing client adherence, such as food parcels and tracing assistance provided by NGOs and WBOTs, although the availability of these supportive services varied by health facility location.

The Right to Care employees, there are specific people in the clinic who deal with...usually they trace defaulters, that's what I can say. They call them to come back to the clinic. Yeah, they check up on patients who are not coming for their treatment and they contact them to come back. Otherwise, the team that is helping us at the moment, let me say it's WBOT, ne? Because the thing they are helping us with the most is those patients who are defaulting, honestly speaking. They are able to go and get them, those that are not able to come on their own and bring them to the clinic.

– Professional nurse with 1-9 years of experience, township health facility

Conversely, the professional nurses working in the suburb health facilities stated that they lacked external service providers to help support the clients and reinforce their adherence counselling due to their location. They reported having to refer clients to other health facilities or areas for social services, including for psychosocial counselling and social grants, as these were not available in the surrounding community.

We can refer them to social services. But I must say to you, I don't know, I think clinics in the rural areas are sometimes more privileged than us in the communities, like in this community...we don't even have in our area. We need to refer to [another health

facility], which is far for the patients, or [another health facility]. Which is also far. But if it comes to a push, we do refer them.

– Professional nurse with 30+ years of experience, suburb health facility

While the professional nurses considered support groups to be a valuable adherence intervention, they observed some challenges, including unclear roles related to who is responsible for conducting these groups and inadequate resources (like staffing and knowledge) to establish and maintain them.

Honestly speaking, I do wish for support groups, ne? But I just, for me personally as a nurse, I just don't know where to start...There was never any support group, you do wish that there was one, but you don't even know where to start...Honestly speaking, when we get to work, we are really focused on all of those people and making sure they go home and received help, rather than doing the groups and everything. Even though I think they are very important, they are too important.

– Professional nurse with 1-9 years of experience, township health facility

In addition, they expressed the opinion that few clients were able and/or willing to attend support groups due to other commitments, such as work.

Because we don't have, we can't get support groups off the ground. Because the patients don't necessarily stay here. They stay somewhere else, but they work here and then they come to the clinic. But they can't come to our support groups, because they can't take time off to go to the clinic and then time off to go to a support group. So, we struggle to get support groups, we've been trying, even the counsellor, the adherence counsellor who was here, tried to get a support group off the ground. He couldn't manage.

– Professional nurse with 30+ years of experience, suburb health facility

Although common factors, including integrated service delivery, the appointment system, system-related limitations, and external organisations and structures, were reported to affect adherence counselling practice, the professional nurses expressed an array of perspectives on

how these positively or negatively affected the practice. The following section presents the role of clients as a factor affecting adherence counselling practice.

4.5.4 The role of clients

The professional nurses noted that clients also played a role in the provision of adherence counselling; namely, through their understanding of the adherence counselling content and cooperation with the professional nurses, following their guidance and embracing the recommended lifestyle-related behaviours. The professional nurses' adherence counselling practice therefore incorporated measures to promote client understanding and cooperation and minimise the potentially negative influence these factors may have.

Perceptions of client understanding of adherence counselling

With regard to client understanding of the adherence counselling, the professional nurses highlighted the importance of clients understanding their treatment, citing clients who did not know the names of their medicine and stopped taking it when they were given tablets which had a different colour or shape to those they took previously.

They will come here and say, "Sister, I didn't take my medication for this whole month, because I don't know this one"...so I try to make them aware that you need to know your medication that you are using so you don't get a fright if you get a different name. Because it's the government. You are going to get different brands. But if you see the three ARVs, then you should be ok.

– Professional nurse with 30+ years of experience, suburb health facility

Consequently, the professional nurses reinforced client understanding by seeking translation services as needed and encouraging clients to become familiar with the specific ARVs they were taking to prevent misunderstandings if their appearance and brand names changed.

Perceptions of client cooperation with adherence counselling

Client cooperation, or following the professional nurses' guidance provided during adherence counselling, was deemed a critical factor affecting its provision. This included clients taking the

treatment as prescribed – following the health education aspect of the adherence counselling – as well as embracing the lifestyle-related behaviours to sustain treatment efficacy and disclosing their HIV status to at least one other person for social and adherence support. While the professional nurses reported some clients to be cooperative, others did not follow their guidance. In some cases, they attributed this to external factors, such as clients not having money to travel to the health facility for an appointment, pressure to use alternative medication by the client’s church, or gender and social norms preventing a female client from using condoms with her partner.

We do have those who are defaulting, some of them we know why, the reason is that at this clinic, we are having patients from different areas...So, when the patient, I think if the patients if ever they had money, they wouldn't be falling into non-adherence. The problem is that they don't have money to come to the clinic. But they like to come to the clinic in town.

– Professional nurse with 20-29 years of experience, inner-city health facility

However, others viewed a lack of cooperation, such as clients not planning ahead to have an adequate supply of medication when travelling or re-testing for HIV to confirm their status, as being “mischievous” or “naughty”, tending to label such clients as a “problem”.

Most of the HIV clients are a problem, if I can put it that way. And there's a lot of movement of clients. Coming from "I'm from Free State," "I'm from Lesotho, I don't have, please help, help, help." "I don't have medicine. I thought I was just going to be here for a week, but it happened that I'm here for two weeks." No transfer letter, those kinds of things, you know. It's part of adherence, because if you have, if you went back to your clinic on time and you told them "On such and such a day, I'm leaving for Pretoria," maybe from Lesotho to Pretoria, "Can you please give me transfer letter?" Or, "I won't be at the clinic for two months, can you give me two months' supply?" Other patients are responsible. Like here, they will tell you, "Sister, please, I'm leaving. I won't have enough medicine. Can you give me more?" Or, "Can you give me the follow-up date before this one, I won't be able to make it" You see, that's responsibility there. There's

responsibility, you can see this person is in charge of her programme. But others, no! And again, what I've realised, you will find that some, they've been using ARVs from other clinics or elsewhere. And they come here, pretending as if they are new. They go the other side and come in again to test for HIV...They want to make sure maybe that they are really, really positive.

– Professional nurse with 20-29 years of experience, suburb health facility

On the whole, the professional nurses employed specific methods to promote client cooperation with adherence counselling, including using open and respectful language, demonstrating support and lack of judgement, and building trust and rapport with clients.

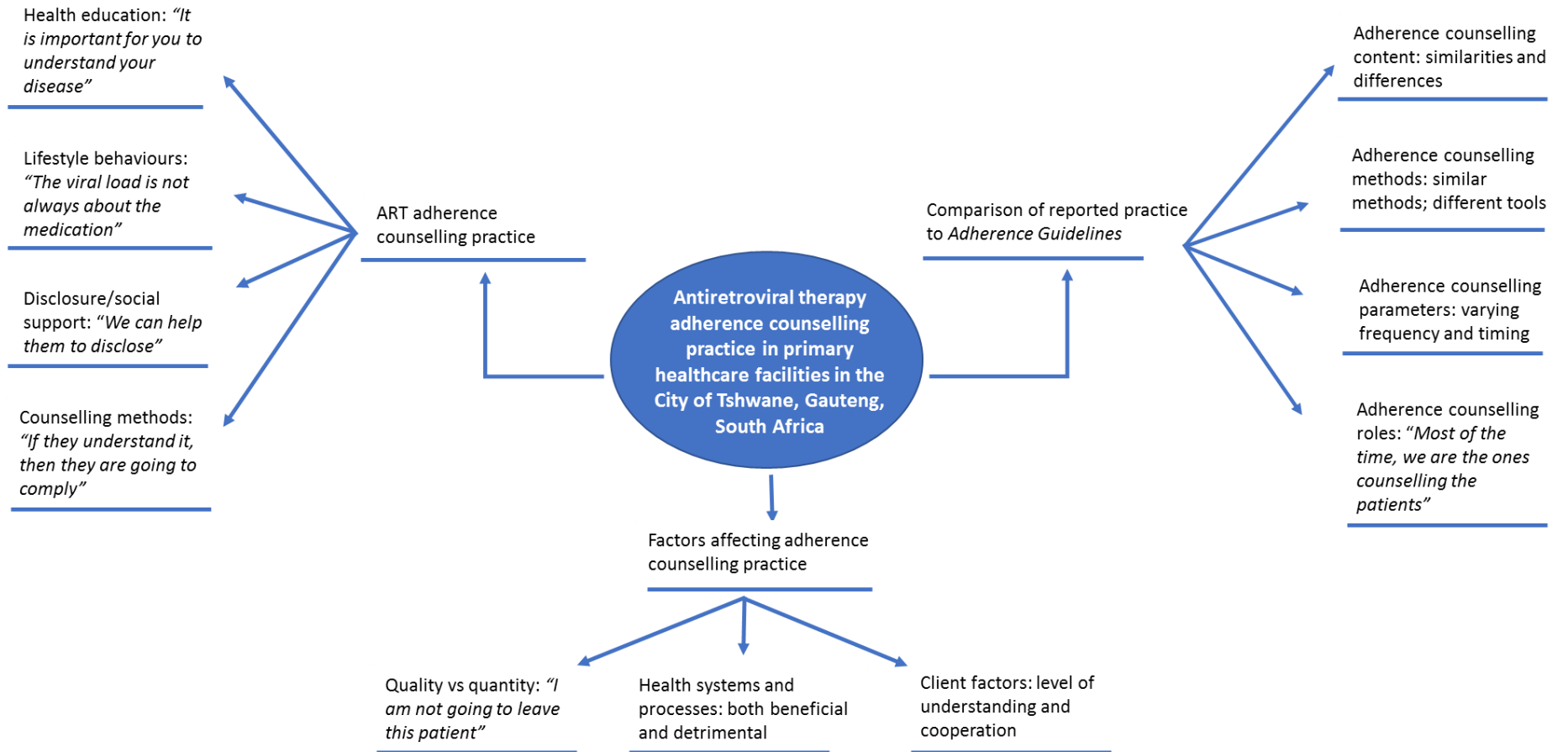
4.6 Chapter summary

This chapter documented the reported adherence counselling practice by 10 professional nurses in five primary healthcare facilities, compared this reported practice to the national *Adherence Guidelines*, and shared factors reported to positively or negatively affect the provision of adherence counselling by the professional nurses. The next chapter discusses these findings in light of existing literature.

CHAPTER 5: DISCUSSION

This chapter discusses the findings on adherence counselling practice by professional nurses in five primary healthcare clinics in the City of Tshwane in view of existing literature to explore what lessons can be learned from provider perspectives and reported practice (see figure 7 below). This includes reflection on the professional nurses' messaging on lifestyle-related behaviours as related to treatment efficacy, as well as the use of adherence counselling methods and tools to foster client understanding and cooperation. It also reflects on future implementation of the *Adherence Guidelines* considering findings from a process evaluation, including factors which have a positive or negative role in adherence counselling practice, particularly in relation to current human resource capacity, health systems and processes, and client behaviour. The chapter includes recommendations as well as study limitations.

Figure 7: Summary of study findings and themes



5.1 Adherence counselling practice in South Africa

The study findings indicate that adherence counselling practice addresses social, cultural, and economic factors relevant to clients' context which are demonstrated to affect adherence, although messaging related to the direct effect of specific lifestyle-related behaviours on treatment efficacy and viral load go beyond findings in existing literature. Counselling methods employed demonstrate behavioural theory considered as good practice in the literature as well as didactic elements.

5.1.1 *"The viral load is not always about the medication": The role of lifestyle-related behaviours*

The study found that behaviours such as consistent condom use, a healthy diet, and avoidance of TCAM and substance use were considered a critical part of adherence counselling due to their potential influence on client adherence. Findings from international and South African research confirm the views expressed by the professional nurses regarding how these behaviours affect treatment adherence(31,35–37,42,44–47). The professional nurses further displayed understanding of how social, cultural, and economic factors can affect clients' daily lives and decision-making related to adherence behaviour. They acknowledged that these factors could exert more influence on behaviour than their own adherence counselling messages when the two were contradictory; for example, clients who do not use condoms due to gender and social norms despite the professional nurses' guidance. Other studies have also observed the influence of social and cultural norms over medical advice – particularly in relation to fertility and pregnancy – in multiple sub-Saharan African countries, including South Africa(82–84). While recognised as a reality by the professional nurses, they expressed frustration that they could often do little more than continue to share information if clients did not embrace their guidance regarding these behaviours.

On the other hand, the professional nurses allowed for little flexibility in terms of clients adopting these behaviours, with some referring to clients who did not behave accordingly as "mischievous" or "naughty" – in line with multiple African studies which cite HCWs who are insensitive to client circumstances which might affect their ability to adhere to treatment and

related behaviours(30). However, the professional nurses did make an effort to assist clients in embracing the recommended behaviours, including facilitating disclosure through re-testing with the client's partner at the clinic, offering food parcels, and linking those with substance abuse problems to rehabilitation services. The professional nurses reiterated that it was important not to be perceived as judging clients for their behaviour, as this would undermine rapport and potentially further diminish client adherence.

Messaging on lifestyle-related behaviours and their effect on treatment efficacy and viral load

Study findings indicate that the professional nurses understand that lifestyle-related behaviors and underlying social, cultural, and economic factors play a role in client adherence. However, some professional nurses articulated a link between the behaviours and effects on treatment efficacy and viral load, demonstrating a view that went beyond what was found in the literature(31,42,44,45,47).

Substance use (particularly alcohol) was believed to hinder the body's ability to absorb ARVs, reducing their efficacy and consequently allowing an increase in the viral load. Although substance use has been linked to adherence behaviour due to factors such as causing a client to forget to take treatment(42,45), results from studies assessing the effect of alcohol use on health outcomes (including viral load and CD4 cell count) are inconclusive, with findings from a seven-year prospective cohort study among 5,067 HIV-positive clients showing a relationship between severe alcohol use and ART interruption, but no relationship between alcohol consumption and viral load or CD4 count(85). Therefore, while this issue is consequently important to address considering its effect on adherence behaviour, a direct effect on treatment efficacy and the viral load has not been convincingly demonstrated.

Eating too much fat was believed to hinder the body's ability to absorb ARVs, with a similar effect on medication efficacy and viral load as with substance use. Again, studies demonstrate that diet (including access to food, or food insecurity) can affect clinical outcomes primarily by impacting client adherence behaviour, such as clients not taking ARVs due to concerns or experience with increased hunger and side effects, or having to make difficult financial

decisions such as either purchasing food or going to the health facility to get the medication(44). On the other hand, studies on the link between food insecurity and viral suppression have found that adherence behaviour does not fully explain the relationship, and there is a suggestion that food is required for proper absorption of ARVs, particularly protease inhibitors(50,86).

Alternative treatments such as herbal medications are also believed to interact with the ARVs, decreasing efficacy and increasing viral load. Indeed, various studies have assessed pharmacokinetic interactions between ARVs and herbal medicine, which is widely used among South Africans, including PLHIV(46), and found that some can affect the absorption/elimination of drugs, which may contribute to treatment failure and resistance(87). However, a randomised control trial of one specific herbal medicine – *Sutherlandia frutescens* – with 107 clients on ART in KwaZulu-Natal province did not find significant differences in viral load and CD4 count among study participants(87).

Condom use – preventing transmission and re-infection/superinfection

Another lifestyle-related behaviour believed to affect viral load was unprotected sex. The professional nurses believed that HIV-positive partners who did not use condoms were re-infecting each other and this continuous introduction of more HIV could increase the viral load and overwhelm the body's ability to suppress the virus – even if the client was on treatment.

From the beginning of the HIV epidemic, the promotion of condom use has been one of the main strategies to prevent HIV transmission between sero-discordant partners. The early findings from research into HIV superinfection (transmission of a new viral strain to someone already infected with HIV) reinforce condom use messaging for people living with HIV, even if the partner is also living with HIV – although there are not yet clear results regarding the effect of HIV superinfection on viral load, immune response, and disease progression, as well as the effect of ART(88,89).

However, while condom use remains a key approach to prevent HIV transmission and superinfection among those living with HIV, there is now strong evidence demonstrating that people who are virally suppressed do not transmit HIV sexually any longer(1,90). This has led

UNAIDS to recommend the “Undetectable = Untransmittable” message for clients on ART – that is, those who are virally suppressed do not need to use condoms – to help address stigma and motivate clients to achieve viral suppression(44). Nevertheless, UNAIDS emphasises that “Undetectable = Untransmittable” is not universal and should be part of tailored messaging based on a client’s adherence and viral suppression(44).

Despite these research findings and subsequent recommendations, condom use will likely remain an important strategy, even though existing literature does not support messaging on re-infection/superinfection between HIV-positive partners having a detrimental effect on viral load, as claimed by the professional nurses. This may be an issue that needs to be addressed widely, as 37% of the 10,473 PLHIV involved in a study on stigma in South Africa across 18 districts in all nine provinces stated that access to ART was conditional on the use of contraceptives(41) – raising concerns regarding conditional provision of treatment.

5.1.2 “If they understand it, then they are going to comply”: Counselling methods and tools applied to promote adherence

The study findings suggest that adherence counselling methods – how adherence counselling is delivered – is just as important as the content provided. This is supported by the literature, with the application of behavioural theories demonstrated to affect client adherence(15,19,21–24).

The professional nurses’ counselling methods focused on two key objectives: ensuring that a client a) understands the content; and b) experiences a supportive and safe environment where he/she feels respected and cared for. These are expected to lead the client to cooperate with the adherence counselling by taking treatment as prescribed and following other recommended behaviours. In the *Being HIV positive and staying on antiretroviral therapy in Africa* qualitative systematic review, it was noted that support – including from HCWs with whom clients build “mutually respectful long-term relationships” – can be important for client adherence and retention in care(30). In particular, negative experiences with health services can be the tipping point for clients to disengage from HIV care(30).

In many aspects, the professional nurses’ adherence counselling was didactic, conveying standardised messaging on health education, lifestyle-related behaviours, and the need to

disclose HIV status to at least one other person – similar to the standard adherence counselling assessed against motivational counselling in a South African RCT(27). Clients are expected to adhere to the guidance provided, and those who do not are sometimes labelled negatively. However, the reported adherence counselling also contained elements of social and behavioural change theories and approaches in line with good practice in the literature and the *Adherence Guidelines*. For example, the professional nurses stated that it was important for clients to take ownership of their own treatment and allowed them to select the best time to take treatment, as well as what reminders would help prompt them to take it on time. The professional nurses emphasised paying attention and listening to clients to help identify specific challenges which may affect adherence, reflecting that clients may need encouragement (reminding them that the information they share is confidential or making them laugh) to be open about sensitive issues such as TCAM or condom use. In addition, the professional nurses pick up on issues which need to be addressed through cues, including a client’s body language and emotional expression (such as anger or crying). As these strategies are identified by the clients, they are more likely to be utilized by them to support their treatment adherence – in line with motivational interviewing techniques(27).

The professional nurses also sought to build behavioural skills among clients by supporting them to disclose as a means of creating social support: they helped to identify someone to disclose to and offered strategies for disclosure, including the provision of a safe environment (the health facility) for facilitated disclosure through re-testing with the client’s partner. This is reflective of the information-motivation-behavioural skills (IMB) model, as the professional nurses reported providing information on the value of disclosure, highlighting social support (social motivation) from this action, and working with the client on strategies (skills building)(27).

The existing literature – particularly from the Tanzania and South Africa RCTs and MSF model – feature the use of tools to support adherence counselling: typically including a visual aid/flipchart for using during the sessions and pamphlet for the client to review on his/her own (25–27). However, the professional nurses reported creating their own analogies using everyday concepts and props to explain complex concepts such as viral suppression in the

absence of official tools to support adherence counselling. They also apply technology such as WhatsApp to reinforce their adherence counselling messaging. These findings are aligned to those of other South African studies which have pointed out site-level implementation differences based on each health facility's resources and context(60,91). In an assessment of HCW and client experiences of changes in South Africa's PMTCT programme, the researchers recommend that innovations and ideas to facilitate and support implementation be acknowledged, affirmed, and packaged for use by others(91).

Overall, the study findings indicate that adherence counselling provided by professional nurses contains both positive elements aligned to good practice in terms of content and methods, as well as cause for concern with regard to messaging on the role of specific lifestyle-related behaviours on treatment efficacy as well as didactic approaches.

5.2 Assessing current practice against future implementation of the *Adherence Guidelines*

The comparison between study findings on the professional nurses' adherence counselling practice and the *Adherence Guidelines* can be useful in terms of informing future rollout and implementation of the guidelines – with further insight based on the findings of the process evaluation conducted with HCWs from both intervention and control sites. This includes adherence counselling parameters and roles, as well as content.

ART is lifelong, and monitoring data show that retention in care decreases the longer clients are on treatment(5,6). Therefore, adherence support should be ongoing, as cited by the professional nurses, not limited to four sessions as stated in the *Adherence Guidelines*. The professional nurses also noted that it is important to address client-specific challenges as they arise – demonstrating a flexibility which could be limited depending on how closely HCWs are expected to implement the *Adherence Guidelines'* 12 topics during the four sessions with each client.

Lay counsellors are often assumed – and reported – to do the bulk of adherence counselling in primary healthcare facilities, and in fact, the *Adherence Guidelines* specify that lay health workers should be responsible for client adherence counselling. However, the study findings suggest that professional nurses often provide adherence counselling themselves due to lay

counsellor unavailability or perceived inadequate capacity. These concerns are borne out by findings from other studies citing inadequate numbers of support staff and sub-optimal quality of counselling by lay counsellors(51,56,57). Additionally, inadequate role definition for lay counsellors has been cited as a challenge(61). A study on PMTCT implementation in KwaZulu-Natal province, for example, found frequent disagreement on roles between nurses and lay counsellors, including on who should provide group counselling and infant feeding counselling, give clients their CD4 results, and refer clients for other services(92).

The areas of similarity between the study findings and the *Adherence Guidelines* in terms of content provide a foundation for future rollout and implementation. However, the areas of difference – particularly the professional nurses’ adherence counselling messaging on lifestyle-related behaviours – may indicate that the *Adherence Guidelines* does not provide adequate information, both on the key topics that are addressed as well as those not addressed but which are relevant to clients based on South Africa’s social, cultural, and economic context. This is important in relation to the existing literature, which provides a caveat regarding clinical guidelines: they need to be tailored to the people served and to the service delivery context to be relevant and feasible, and ultimately to ensure optimal uptake and use(91,93).

Feedback from the process evaluation of the *Adherence Guidelines* indicates that the fast-track initiation counselling will likely be accepted and viewed positively(8). Factors noted to be in place which will support implementation are aligned to the professional nurses’ input on factors undergirding the provision of adherence counselling, including knowledgeable and skilled colleagues and resources such as partners (including WBOTs) to assist with tracking clients(8). Similarly, barriers to implementation of the *Adherence Guidelines* noted in the process evaluation are aligned to factors which the professional nurses reported negatively affect the provision of adherence counselling, including staff shortages and a lack of the required resources(8). In addition, the professional nurses reported that time limitations impede their ability to provide quality care to clients, which is echoed by process evaluation participants, who questioned adding an adherence plan for each client to the existing documentation burden(8).

5.3 Factors affecting adherence counselling practice

The study findings point to adherence counselling practice being affected by current human resource capacity, health systems and processes, and client behaviour. Several of these factors point to trade-offs that have to be made: the quantity of clients in need of services limits the time available and thus the quality of those services; while measures adopted to improve HIV care (such as integration of HIV into the broader health facility services) simultaneously undermine it (for example, by hindering continuity of care).

Contrary to the findings from other studies regarding a lack of trained and skilled nurses, most nurses at the health facilities involved in the study had been trained in NIMART – potentially due to these studies being conducted before or during the widescale rollout of the training from 2011. The 2016-2017 process evaluation of the *Adherence Guidelines* concurs that South Africa has made significant progress in training nurses at primary healthcare level in NIMART: HCWs cited a strong team of staff and district-level support, as well as high staff capacity due to the rotation system, as facilitators to implementation of the *Adherence Guidelines*(8).

5.3.1 Quality vs. quantity: “I’m not gonna leave this patient”

The study findings indicate that the quality of adherence counselling is affected by the quantity of clients which require services, despite support from other organisations and structures. The professional nurses expressed concerns regarding compromised quality of care due to increasing client volume and staff shortages. They reported feeling pressure regarding the time they were able to spend with clients given the need to serve all the clients in the health facility and meet daily consultation targets. These concerns are echoed and acknowledged by a wide range of stakeholders – from South Africa’s National Department of Health to the HCWs and clients(10–14,65).

Nevertheless, the professional nurses cited supportive factors mitigating the time constraints, such as human resources from Right to Care (including a nurse to initiate clients on ART and lay counsellors), as well as other service providers such as WBOTs. These factors were also noted as facilitators to implementation of the *Adherence Guidelines* by HCWs, particularly as related to provision of client tracing(8). However, this use of WBOTs to primarily support client tracing

indicates limited understanding and/or use of WBOTs to further support client adherence, something that is reflected in the literature, which has found poorly-defined relationships between WBOTs and health facilities(67–70). Similarly, the professional nurses reported providing adherence counselling themselves rather than using lay counsellors – another potential area of underutilisation of existing resources.

5.3.2 Health systems and processes can be both beneficial and detrimental

Health system adaptations, such as integration of HIV into health facility services, introduction of nurse rotation, and client appointment systems, were reported to have both positive and negative implications in terms of adherence counselling and client adherence. While the integration of HIV into overall health facility services was cited as beneficial in reducing stigma among PLHIV, the professional nurses also noted that this reduced the opportunity for clients to provide mutual support while mixing together in a separate space. This contradiction has been acknowledged in a study of health facility spatial organisation and HIV stigma, as well as qualitative studies on the integration of HIV services in South Africa(11,29).

Adherence clubs are promoted as an effective strategy in both the *National Consolidated Guidelines* and *Adherence Guidelines* for stable clients to more quickly access their treatment and receive social support from other PLHIV(7,50). However, the professional nurses reported that efforts to begin and maintain support groups in their health facilities were largely unsuccessful due to lack of clarity regarding who is responsible for the groups and lack of client availability and/or interest.

In terms of nurse rotation through various service areas, although this was reported to help in developing multi-skilled staff who are all able to provide ART, it was also cited as hindering continuity of care and building of rapport between nurses and clients, which the professional nurses considered an important factor in the provision of adherence counselling. Continuity of care has been shown to be associated with client understanding of the treatment plan(28), and ongoing support from HCWs can play an important role in client adherence behaviour(30). In addition, a meta-analysis of factors associated with client adherence found that trust and/or

satisfaction with the client's HCW was important, particularly in low- and middle-income countries(37).

Likewise, while the appointment system was reported to be beneficial in terms of spacing clients and providing for adequate time for each person, on the other hand, the system may discourage adherence behaviour among those who are unable to keep the appointments, as clients are penalised by being made to wait until all other clients have been seen or have to make a new appointment at the health facility. While this is intended to reinforce client behaviour in keeping appointments, long waiting times are often associated with poor service delivery and is considered a barrier to client adherence and retention(30–34).

The professional nurses also cited health facility systems or processes that they disagreed with, such as restrictions on the provision of food parcels and specific medications (such as Vitamin B) to clients. The professional nurses felt that they were more experienced and familiar with client context and realities and yet were sometimes limited in their efforts to provide quality care to clients due to the health facility's systems or processes. In some cases, they were able to adapt to the limitations and find other ways of supporting clients which were not necessarily endorsed by the health system, such as taking photographs of clients to assist in tracing those who were homeless and did not have formal addresses. This use of innovation by HCWs to address service delivery challenges has been noted in a study on NIMART implementation in South Africa(59).

5.3.3 Client understanding and cooperation are key factors affecting the provision of adherence counselling

The study findings suggest that clients themselves play a significant role in influencing the professional nurses' adherence counselling provision, and specific adherence counselling methods are applied to promote client understanding and cooperation, which are considered key for treatment adherence. However, challenges exist with regard to client understanding due to the use of different languages and the complexity of HIV and treatment, factors which are widely acknowledged in existing literature as potential barriers to adherence(12,33,58). To counter this, although they do not have tools such as education flipcharts or job aids to assist in

explaining relevant concepts, the professional nurses use simple language appropriate for each client's level of education and experience, and have developed their own analogies to explain issues such as treatment resistance.

The professional nurses also apply counselling methods to promote client cooperation with the guidance provided during their adherence counselling. They acknowledge the role and influence of clients' social, cultural, and economic context on their behaviour, such as stigma, food insecurity, mobility, and the use of substances and TCAM – which are also factors cited as potential barriers to adherence(12,33,58). However, the professional nurses seek to optimise their own influence by building rapport with the clients and creating a safe and supportive environment through the use of respectful language and positive body language, as well as portraying a non-judgmental attitude.

Nevertheless, negative attitudes of HCWs and poor treatment of clients is cited as an important factor affecting client adherence behaviour and retention in care, including by the National Department of Health, which has incorporated positive and caring HCW attitudes into its core standards for health facilities(64). Likewise, literature citing structural barriers to client adherence notes negative attitudes and treatment by HCWs and often links this to high workloads and staff shortages, although recent studies – including one conducted in the City of Tshwane – convey feedback from clients on receiving friendly and supportive treatment from HCWs as well, which had the potential to reinforce client adherence(29,30,60).

Ultimately, factors which affect adherence counselling practice – including current human resource capacity and health systems and processes – do not operate in isolation. Instead, they precipitate trade-offs and may have unintended, opposing effects for client adherence. The role of clients is leveraged through the use of specific counselling methods in line with existing literature.

5.4 Chapter summary

This chapter reflected on the study findings in view of existing literature on adherence counselling practice, including parameters of adherence counselling, roles, content, and methods and tools.

CHAPTER 6: CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

As the number of people on treatment in South Africa grows, nurses will likely continue to be the main providers of clinical HIV services, and adherence interventions – including adherence counselling – will remain key to the country achieving its goals toward improving quality of life and reducing new HIV infections. This study contributes to the body of literature by exploring the adherence counselling practice of 10 professional nurses across five primary healthcare clinics in the City of Tshwane, Gauteng province, South Africa. It highlights areas of alignment with good practice cited in international and South African literature (including South Africa's 2016 *Adherence Guidelines*), as well as differences. These differences include innovations and methods applied to enhance adherence counselling practice in view of South Africa's social, cultural, and economic context, as well as the health system within which the study participants operate. This study also contributes to existing literature in terms of factors which affect the provision of adherence counselling, acknowledging strengths while simultaneously identifying challenges which should be addressed to optimise efforts to promote client adherence and retention in care.

6.2 Recommendations

6.2.1 Further consideration of study participant messaging

The messaging contained in the professional nurses' adherence counselling points to the need to specify and standardise core adherence counselling messages based on scientific evidence and South Africa's social, economic, and cultural context, and adapt the *Adherence Guidelines* accordingly. HIV is a complex disease affecting nearly every area of life, and health workers often feel unprepared – with inadequate skills and support – to address the breadth of challenges affecting clients(30). Consequently, and particularly as the *Adherence Guidelines* are evaluated and revised before national rollout and implementation, it may be advisable to provide training and ongoing supervision to periodically assess adherence counselling provided by HCWs (both professional nurses and lay counsellors). HCWs should be given the skills and

tools to help clients address the complex issues they are faced with daily, such as stigma, food insecurity, and pressures to use substances and TCAM. The WHO recognises this need, recommending adherence training for HCWs, including an adherence counselling toolkit which includes information on adherence, guidance on clinical decision-making, and behavioural tools(17).

It may also be advisable to further research the source of the professional nurses' messaging on the effect of specific behaviours on treatment efficacy and viral load. Is this messaging a form of risk compensation, with the professional nurses seeking to reduce an assumed possible increase in risky behaviour among clients on ART? Or does this anecdotal evidence from the professional nurses require further research into factors which do affect treatment efficacy and the viral load? In either case, HCWs should have clear, evidence-backed messaging to provide to clients regarding treatment efficacy and achieving a suppressed viral load.

6.2.2 Make better use of existing resources

Measures to improve HIV care include system adaptations such as additional human resources support and rotation of nurses to ensure that all nurses are able to provide ART. In addition, structures such as WBOTs have been introduced to support client care, including adherence. However, based on reported practice, some of these measures may need to be re-examined for unintentional consequences and underutilisation. Workload challenges reported to negatively affect service quality could be alleviated by better using existing resources such as lay counsellors and WBOTs. This could include efforts to build stronger relationships and clearer roles and processes for collaboration to optimise client adherence support. Suburb health facilities may need to make a particular effort to identify support structures and establish cooperative relationships.

6.2.3 Prepare for implementation of the Adherence Guidelines

As noted above, initial feedback from the process evaluation of the *Adherence Guidelines* indicates that the fast-track initiation counselling will likely be accepted and viewed positively. However, the HCWs involved in the process evaluation raised concerns such as staff shortages and inadequate resources for implementation. The process evaluation report emphasised that

these concerns should be addressed, including human resource shortages, provision of supplies and materials, and training and ongoing mentorship(8). This study's findings on blurred roles for adherence counselling, differences noted between content currently provided and that included in the *Adherence Guidelines*, and a lack of specific adherence counselling tools add weight to the call for ensuring that staff and health facilities are fully prepared for implementation of the *Adherence Guidelines*.

6.3 Limitations

Factors which could affect the quality of the interview data included the potential for social desirability and recall bias, level of familiarity with English as the interview language, interruptions and distractions during the interviews, and time constraints among the professional nurses interviewed. Furthermore, conducting observations of provider-client interactions was outside the scope of the study, which limited the researcher's ability to triangulate some of the findings reported by the nurses.

Social desirability, or the professional nurses telling the researcher what they think they should do in adherence counselling rather than what they actually do, is a potential limitation. There may also be recall bias from the professional nurses regarding their provision of adherence counselling. Each of these limitations may potentially distort findings toward a more positive impression of ART adherence counselling than what is provided in practice. To address social desirability as a limitation, the researcher emphasised the confidentiality of the information at the beginning of the interview, ensured questions and probes were phrased objectively, and avoided indicating that there was a preferred or ideal answer. To address recall bias, the interview guide included probes requesting specific examples of adherence counselling provided to clients to help in prompting accurate recollection.

While the professional nurses often seemed cautious at the beginning of the interview, they appeared to become more comfortable over the course of the discussion, sharing detailed interactions with clients and specific analogies used during adherence counselling. The professional nurses shared personal frustrations related to client behaviour and consultation targets, and actions they take which may not be endorsed directly by their management, but

are taken for the greater good of the clients. This sharing of detailed information and potentially compromising information leads the researcher to believe that recall bias and social desirability may not have been significant factors.

All professional nurses were fluent in English (the language used for the interviews), but a few seemed to struggle at times to fully express themselves in English, and requested additional explanation of interview questions. This may limit the quality and richness of the interview data.

In addition, despite efforts to minimise distractions by conducting interviews at a convenient time and requesting them to be held in a quiet and private place, most interviews were interrupted more than once by other nurses or staff members. One interview was not private, with a junior staff member also in the room for the duration of the interview. The professional nurses clearly experienced time pressure with regard to the interview, with several mentioning the need to keep the duration short in order to return to work. However, the average interview time was 57 minutes, and only one interview was severely curtailed due to time constraints, with a duration of 33 minutes.

6.4 Chapter summary

This chapter presented a conclusion, detailed recommendations based on the previous chapter (Discussion) and addressed study limitations.

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Appendices

Appendix A: Interview guide

Anti-retroviral therapy adherence counselling practice in primary healthcare facilities in the City of Tshwane, Gauteng, South Africa

Johanna Theunissen

Interview guide

Introduction

My name is Johanna Theunissen and I am doing a Master's in Public Health at Wits University. For my research project, I am looking at the provision of anti-retroviral therapy adherence counselling in five primary healthcare facilities in the City of Tshwane. This research involves an approximately one-hour interview with the professional nurse who provides this counselling. The information you give me will be confidential. I would like to audio-record this interview for transcription purposes. There will be no identifying information in the transcript, and the information will be accessible only by myself and my Wits supervisor for use in my research report.

Have you had a chance to read the information sheet that I shared with you? Do you have any questions about this research or about your participation in it?

If you agree to the interview and audio-recording, please sign this consent form (provide form for signature).

Interview questions

1. Involvement in HIV care
 - 1.1 What is your role in HIV care?
 - 1.2 How long you have been working in this field?
 - 1.3 What made you choose it?
2. Providing ART adherence counselling
 - 2.1 Please describe what ART adherence counselling provision involves
 - 2.2 Tell me about your own practice:

- What works well for you when conducting ART adherence counselling?
Probe: an example of a situation you consider a success
- What does not work well for you when conducting this kind of counselling?
Probe: an example of a situation you do not consider a success

2.3 When conducting ART adherence counselling:

- What are the key messages you give to the client?
- Are there things that you use to support the counselling?
Probe: forms, brochures, tools, etc.

2.4 In your opinion, what are the most important elements of ART adherence counselling to promote adherence/retention in care?

3. Factors influencing the practice of ART adherence counselling

- What factors have a positive influence on your provision of ART adherence counselling?
Probe: training, guidelines & policies, time, infrastructure, tools, support
- What factors have a negative influence?
Probe: training, guidelines & policies, time, infrastructure, tools, support

4. ART adherence counselling practice

- Tell me about any training you have received in adherence counselling
Probe: when, duration, who provided it
Probe: How well do you think the training prepared you for doing adherence counselling?
- What policies or guidelines do you refer to in your provision of adherence counselling?
Probe: usefulness, user-friendliness, relevance

5. Would you like to add anything further?

Thank you very much for your participation.

Appendix B: Human Research Ethics Committee (Medical) clearance certificate



R14/49 Ms J Theunissen

**HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M171034**

NAME: Ms J Theunissen
(Principal Investigator)
DEPARTMENT: School of Public Health
Medical School

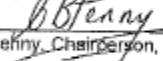
PROJECT TITLE: Anti-retroviral therapy adherence counselling
practice in primary healthcare facilities in the City of
Tshwane, Gauteng, South Africa

DATE CONSIDERED: 27/10/2017

DECISION: Approved conditionally

CONDITIONS: Formal approval to conduct the study must be
obtained from the Provincial Health Authority and a
copy sent to the office of the HREC (Med) Secretariat

SUPERVISOR: Dr D Conco

APPROVED BY: 
Professor CB Pehny, Chairperson, HREC (Medical)

DATE OF APPROVAL: 17/01/2018

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

DECLARATION OF INVESTIGATORS

To be completed in duplicate and ONE COPY returned to the Research Office Secretary on 3rd floor, Philip V Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.


I/We fully understand the conditions under which I am/we are authorised to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated from the research protocol as approved, I/we undertake to resubmit to the Committee. I agree to submit a yearly progress report. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in October and will therefore be due in the month of October each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).


Principal Investigator Signature

26 January 2018
Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix C: Tshwane Research Committee clearance certificate

 **GAUTENG PROVINCE**
HEALTH
REPUBLIC OF SOUTH AFRICA

Enquiries: Dr. Lufuno Razwiedani
Tel: +27 12 451 9036
E-mail: lufuno.razwiedani@gauteng.gov.za

TSHWANE RESEARCH COMMITTEE: CLEARANCE CERTIFICATE

MEETING: 10/2017
PROJECT NUMBER: 16/2018
NHRD REFERENCE NUMBER: GP_201801_039

TOPIC: Anti-retroviral therapy adherence counseling practice in primary healthcare facilities in the City of Tshwane, Gauteng, South Africa

Name of the Researcher: Mrs Johanna Theunissen

Supervisor: Dr. D Conco

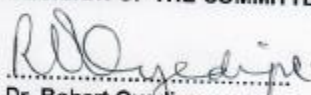
Facility: Rooihuiskraal clinic
Olievenhoutbosch clinic
Lytelton clinic
Ladiuam Clinic
FF Ribeiro clinic
Atteridgeville clinic


Name of the Department: University Witwatersrand

NB: THIS OFFICE REQUEST A FULL REPORT ON THE OUTCOME OF THE RESEARCH DONE AND

NOTE THAT RESUBMISSION OF THE PROTOCOL BY RESEARCHER(S) IS REQUIRED IF THERE IS DEPARTURE FROM THE PROTOCOL PROCEDURES AS APPROVED BY THE COMMITTEE.

DECISION OF THE COMMITTEE: APPROVED


.....
Dr. Robert Oyedipe
Acting Chairperson: Tshwane Research Committee
Date: 01/03/2018


.....
Mr. Pitsi Mothomone
Chief Director: Tshwane District Health
Date: 2018-03-07

Appendix D: Information sheet

Information document

Study title: Anti-retroviral therapy adherence counselling provided in primary healthcare facilities in the City of Tshwane, Gauteng, South Africa

Good day. My name is Johanna Theunissen and I am doing a Master's in Public Health at Wits University. For my research project, I am looking at the provision of anti-retroviral therapy adherence counselling in five primary healthcare facilities in the City of Tshwane by interviewing the professional nurses who provide this counselling. I have been granted permission to conduct this study by the Gauteng Department of Health and Tshwane Research Committee, and have received ethics approval from Wits University.

Invitation to participate: I would like to invite you to participate in this study.

What is involved in the study: This is a qualitative study using in-depth interviews with professional nurses from five primary healthcare clinics in the City of Tshwane. Participation will entail a one-hour one-on-one interview on a day and at a time convenient to the professional nurse, and as agreed with the facility manager. The interview will be audio-recorded for transcription purposes.

Participation is voluntary, and refusal to participate, or stopping participation at any time during the study, will not result in any penalty.

Confidentiality: Efforts will be made to keep personal information confidential, but absolute confidentiality cannot be guaranteed, as personal information may be disclosed if required by law. All participants will sign a consent form before being involved in the study. The information from the interviews will be private and confidential. Names and other identifying information will not be included in the transcriptions, and the information will be accessible only by the researcher and her Wits supervisor for use in her research report.

There are no specific **risks or benefits** related to participation in the study.

Participant will be given pertinent information on the study while involved in the research and after the results are available.

Contact details of researcher:

Johanna Theunissen

Wits second-year student: Master's in Public Health

Phone: 082 441 6337

Email: Johanna_mcmurry@hotmail.com

Contact details of Wits University Research Ethics Committee:

Phone: 011 717 1234

Email: HREC-Medical.ResearchOffice@wits.ac.za

Appendix E: Interview consent form

Interview consent form

Anti-retroviral therapy adherence counselling practice in primary healthcare facilities in the City of Tshwane, Gauteng, South Africa

I hereby confirm that I have been informed by the researcher, Johanna Theunissen, about the nature, conduct, benefits and risks of the study on ART adherence counselling practice in primary healthcare facilities in the City of Tshwane.

I have also received, read, and understood the Information Document regarding the study.

I am aware that the results of the study, including any personal details such as those regarding my name and place of work, will be anonymously processed into a study report.

In view of the requirements of research, I agree that the data collected during this study can be processed in a computerised system by the researcher.

At any stage, I may withdraw my consent and participation in the study without penalty or prejudice.

I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.

PARTICIPANT:

Printed Name: _____

Signature: _____

Date and Time: _____

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

RESEARCHER:

Printed Name: _____

Signature: _____

Date and Time: _____

Appendix F: Interview audio-recording consent form

Audio-recording consent form

Anti-retroviral therapy adherence counselling practice in primary healthcare facilities in the City of Tshwane, Gauteng, South Africa

I hereby confirm that I have been informed by the researcher, Johanna Theunissen, about the need to audio-record the interview for transcription purposes, and that all identifying information will be removed from the transcript.

I agree for the interview to be audio-recorded.

PARTICIPANT:

Printed Name: _____

Signature: _____

Date and Time: _____

RESEARCHER:

Printed Name: _____

Signature: _____

Date and Time: _____

Appendix G: Participant demographic information form

Demographic information

Please circle the relevant category or fill in the requested information:

Gender

Male	Female	Other
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Age

20-29 years	30-39 years	40-49 years	50-59 years	60+ years
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Mother tongue: _____

Other languages used: _____

Years of experience in nursing

Under 1 year	1-9 years	10-19 years	20-29 years	30+ years
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