AN INTEGRATED SUPPORT MODEL FOR LAY HEALTH CARE WORKERS TO IMPROVE PATIENTS' RETENTION TO HIV CARE

by

SARAH BONOLO PITSE

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SUPERVISOR: Professor P. R. Risenga

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DEDICATION

I dedicate this work to:

- My remarkable family:
    - Mom Ruth; sister Tumi; brother Thato; the trio- Oabile, Bokao, Letlotlo: in your unique ways, you kept me sane when nothing else did. I am forever indebted to you.
    - My soulmate, Sam: Your calmness, understanding and unwavering support are out of this world. Thank you very much for being available and altruistic.

DECLARATION

Name: SARAH BONOLO PITSE

Student number: 44434960

Degree: PHD PUBLIC HEALTH

Exact wording of the title of the thesis as appearing on the electronic copy submitted for examination:

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I declare that the above thesis is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

I further declare that I submitted the thesis to originality checking software and that it falls within the accepted requirements for originality.

I further declare that I have not previously submitted this work, or part of it, for examination at Unisa for another qualification or at any other higher education institution.

19 October 2022

SIGNATURE DATE

STUDENT NUMBER: 44434960

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- The University of South Africa and the College of Human Sciences Research Ethics Committee: You saw the potential and provided an opportunity for me to soar to greater heights by accepting me as a student and providing the ethics clearance that allowed me to commence with the study.

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- My Creator: Against all odds, You, made it possible.

ABSTRACT

The Purpose of the study

The purpose of the study was to develop an integrated support model for lay health care workers (LHWs) to improve retention to HIV care. The study followed a qualitative approach and an exploratory, descriptive, and contextual design.

Study population and sample

The study population was formed by three groups that were then sampled purposively to facilitate the achievement of objectives: 22 LHWs; 10 supervisors and nurses; and 15 clients on ART; but data saturation guided the sample size.

Data collection and data analysis methods

Data collection was done through in-depth individual interviews and focus group discussions. Face-to-face and telephonic interviews were conducted with the efforts to observe COVID-19 precautionary measures. Field notes made by the researcher to indicate non-verbal cues from participants, as well as audio recordings were transcribed verbatim into Word documents, followed by conducting thematic data analysis.

Results

Common findings related to the retention experiences across the 3 groups of participants highlighted the commendable work done by the LHWs in HIV counselling, information provision, household visits and tracing of clients who missed their clinic appointments. However, the retention efforts are challenged by the limited support experienced by LHWs, as characterised by the *lack of patient-centric care in health care facilities*; *limited provision of updated HIV information, collaboration, and communication from other health care workers*; *limited work resources*; *low stipends* and *lack of debriefing*.

The support model was then developed using literature and findings from the participants, with LHWs as the recipients, and their supervisors, nurses, and Department of health as agents of support. Dynamics that positively drive support were identified as communication, positive relationships, emotional stability, and willingness; challenged by power imbalance, lack of trust and respect, as well as low self-esteem.

Contribution

Different LHWs assume various key roles along the HIV care continuum, but their support is minimal. The model has the potential to improve the LHWs’ HIV care skills; contribute to the retention of clients to HIV care, United Nations’ goal of 95% viral load suppression, thereby improving the quality of life and reducing new HIV infections.

KEY TERMS: Lay health care workers; Health care workers; Retention to HIV care; Instrumental support; Emotional support; Supervision; Patient centric care; Mutual dependence; Communication; and Positive relationships.

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LIST OF ACRONYMS AND ABBREVIATIONS

ART	Antiretroviral therapy
ARVs	Antiretrovirals
CBOs	Community-based organizations
CCMDD	Central Chronic Medicines Dispensing and Distribution
CESS	Comprehensive Evaluation of Social Support
CHWs	Community health care workers
COVID	Coronavirus Disease
CREC	College of Human Sciences Research Ethics Committee
EAC	Enhanced Adherence Counselling
HIV	Human Immunodeficiency Virus
IMB	Information-Motivation-Behaviour
KTA	Knowledge-To-Action process
LHWs	Lay health care workers
NGOs	Non-governmental organizations
NPT	Normalisation Process Theory
OTLs	Outreach team leaders
PLWHIV	People living with HIV
IPV	Intimate Partner Violence
IMCI	Integrated Management of Childhood Illnesses
PrEP	Pre-Exposure prophylaxis
SANDoH	South African National Department of health
SDI	Same Day (ART) Initiation
SSA	Sub-Saharan Africa
TB	Tuberculosis
UNAIDS	United Nations programme on HIV and AIDS
UNISA	University of South Africa
USAID	United States Agency for International Development
UTT	Universal Test and Treat
WHO	World Health Organization

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CHAPTER 1

INTRODUCTION AND BACKGROUND OF THE STUDY

1.1 INTRODUCTION AND BACKGROUND

South Africa still experiences challenges in terms of new HIV infections as well as retaining people living with HIV (PLWHIV) in care (the joint United Nations programme on HIV and AIDS: UNAIDS, 2019:21; Johnson *et al*., 2017:4). It accounted for 20% of the global HIV prevalence, which made it a hyperendemic country requiring urgent response (Allinder, 2020:1). Also, the retention to HIV care challenge in South Africa is evidenced by 20% of clients who had defaulted within six months and 30% at 12 months of starting ART (Gopal, 2019:1), as well as 22,6% who had defaulted ART at least once (Kaplan *et al*., 2017:1).

Osler *et al*., (2018:122) recommended that the focus be placed on adherence and retention strategies, and Johnson *et al*., (2017:5) similarly emphasized the scale-up interventions that focus on retention and sustained drug availability to facilitate ART coverage and viral suppression, thereby reducing new infections. The UNAIDS (2019:20) demonstrated how PLWHIV are lost to follow up as they move along the HIV care continuum, with the initial loss starting between diagnosis and ART initiation and continuing throughout to chronic care.

For South Africa (SA) to reach the goal of 95% viral load suppression, it is important that PLWHIV are retained in care and are knowledgeable about ART (UNAIDS, 2017:31). Therefore, it is recommended that client counselling and education be strengthened at every client-provider interaction so that chances of good ART adherence and retention can be increased. The World Health Organisation, WHO (2016:13), further cautioned that rapid expansion of the HIV programmes without ensuring quality may lead to other challenges such as drug resistance.

Improved access to ART in SA did not only enhance the quality of life for PLWHIV but resulted in the increased workload on the primary health care professionals. Consequently, the increased workload on the health care professionals led to task-shifting towards the lay health care workers (Moosa *et al*., 2019:10; Aithal & Aithal, 2017:35). Task shifting is one of the strategies that has been adopted and implemented in several ways to reduce the workload in most countries including South Africa (Aithal *et al.*, 2017:35; Crowley & Mayers, 2015:3). Crowley *et al*., (2015:3) further indicated that task shifting from nurses towards the LHWs became more evident in South Africa during the expansion of HIV services and re-engineering of primary health care services to increase the communities' access to health care services and reduce the number of lost to follow up clients. Different lay health care workers (LHWs) assume various key roles along the HIV care continuum: lay counsellors provide testing and counselling on HIV and antiretroviral therapy (ART) either at the hospitals, clinics, or community; community health care workers (CHWs) provide household support to PLWHIV and tuberculosis (TB) through health education and tracing those who missed their clinic appointments (Naidoo *et al*., 2018:2; Mwisongo *et al*., 2015:2).

The researcher noted that there are also health promoters and mother-mentors who provide continuous health education to the general population and maternity clients, as well as telephone tracers from the developmental partners that are placed in the public health care facilities to trace PLWHIV and TB who missed the clinic appointments. Even though the study obtained some data from patients, the interest of the study was mainly around the support provided to LHWs amidst task shifting, with the effort to improve retention to HIV care which is reflected above as needing attention.

1.2 PROBLEM STATEMENT

There are still clients with advanced HIV disease due to not being initiated on ART, presenting late at the clinics or defaulting treatment in South Africa (Gopal, 2019:1; Osler *et al*., 2018:121). Kaplan *et al*., (2017:1) found that 22,6% of clients had disengaged from care at least once since the start of ART, while Gopal (2019:1) discovered that 20% of clients disengaged from HIV care within 6 months of ART, and 30% within 12 months. Retaining patients in care is crucial because as they continue with ART, the virus becomes suppressed, consequently reducing new HIV infections, morbidity, and mortality rates (Hall *et al*., 2017:2).

Following task shifting, HIV services depend largely on different lay health care workers such as lay counsellors, tracers, health promoters and CHWs (Aithal *et al*., 2017:35). The researcher observed that previous studies focused largely on the experiences and roles of lay counsellors and CHWs as well as the HIV testing procedures, excluding other categories of LHWs. Moreover, the telephone tracers, who are mainly from the developmental partners that support the health department, do not have tools to guide them as they interact with PLWHIV and TB who defaulted treatment. The UNAIDS (2019:20) stated that HIV care occurs along a continuum, so, if key role players work in silos and do not have guidance, HIV management and outcomes will be negatively affected. Mundeva *et al*., (2018:1) further stated that the integration of CHWs' tasks into the health care system is poorly done and because they play a crucial role in HIV care and other services, the quality may be negatively affected.

The researcher observed that the CHWs would conduct the household registration duties in the community, listing family members and capturing their health challenges, but they do not have the necessary skills to communicate with patients who may have defaulted ART. This is a missed opportunity which could have been used to counsel these patients with the purpose of promoting linkage and retention to HIV care. Moreover, despite these continuous household registrations, 20% of patients who were newly initiated on ART were estimated to have defaulted within six months in a South African study (Gopal, 2019:1).

The problem is that the researcher did not find any integrated support model for lay health care workers to improve patients' retention to HIV care and that is also aligned to the changing needs of the population. Literature therefore, indicates that there is limited support for LHWs in clinical practice. The study is supported by Hodgins *et al*., (2016:5) who emphasized that the LHWs needed support that is individually tailored to enable them to offer effective health programmes, and this was crucial because they had little formal training as compared to health care professionals. Additionally, Sam-Agudu *et al*., (2018:9) emphasized the importance of support by stating that the integration and recognition of LHWs were vital to optimise the impact of their roles in health care, while Engelbrecht *et al*., (2017:6) also recommended continuous training, support, collaboration, and linkage of home-based carers to health care facilities.

1.3 RESEARCH OBJECTIVES AND QUESTIONS

The purpose of the study was to develop an integrated support model for lay health care workers to improve patients' retention to HIV care. The **objectives** of the study were to:

- Describe how the lay health care workers interact with PLWHIV.
- Describe the views of health care professionals on the support provided to lay health

care workers in carrying out their duties relating to PLWHIV.
- Explore and describe how PLWHIV experience their interaction with lay health care workers.
- Develop the integrated support model for lay health care workers to improve patients' retention to HIV care.

The study sought to answer the following **questions**:

- How do lay health care workers interact with PLWHIV?
- How do health care professionals view the support provided to lay health care workers in carrying out their duties in relation to PLWHIV?
- How do PLWHIV experience their interaction with lay health care workers?
- How can the integrated support model for lay health care workers to improve patients' retention to HIV care be developed?

1.4 RESEARCH PARADIGM

Both the structure and processes of the study are guided by the philosophical assumptions or world view known as the research paradigm (Kivunja & Kuyini, 2017:26). The study adopted the constructivist paradigm. The constructivist, also known as the interpretivist paradigm, emphasizes that individuals deconstruct and construct meaning through their lived experiences, interaction with the environment and reflection (Leavy, 2022:13; Kivunja *et al*., 2017:33).

Again, individuals are motivated through knowing the importance and impact of their learning. This study was conducted in a natural setting, and explored the reciprocal lived experiences in relation to the interaction between the LHWs and PLWHIV, as well as the support given to LHWs by supervisors and other health care professionals. The study's philosophical view is further explained by the meta-theoretical, theoretical, and methodological assumptions.

1.4.1 Meta-theoretical assumptions

The meta-theoretical assumptions relate to the philosophies of a specific discipline (Deliktas *et al*., 2019:2). The study adopted the nursing metaparadigm which has four concepts of person, health, nursing, and environment. The *person* at the centre refers to PLWHIV, their families and communities; *health* refers to their holistic well-being, that is, physical, emotional, and psychological; *nursing* refers to the care, provider-patient interrelationships, and skills, such as the quality of counselling provided to patients; and the *environment* refers to the patients' surroundings, as well as the setting in which patients' care takes place. Increased workload for nurses resulted in task-shifting towards lay health care workers in terms of HIV counselling and other tasks, leading to a need to strengthen their support (Bender & Feldman, 2015:98).

1.4.2 Theoretical assumptions

The theoretical assumptions relate to the views that serve as a support structure of the study, either in the form of models, concepts, or theories (Jackson, 2015:3). The study adopted the Knowledge-To- Action process (KTA) as shown in figure 1.1 below (Graham *et al*., 2006:18). The KTA process has two concepts: the knowledge creation which was used by the researcher to gather information from the participants, and the action cycle which the Department of Health can use to implement knowledge created during the knowledge creation process.

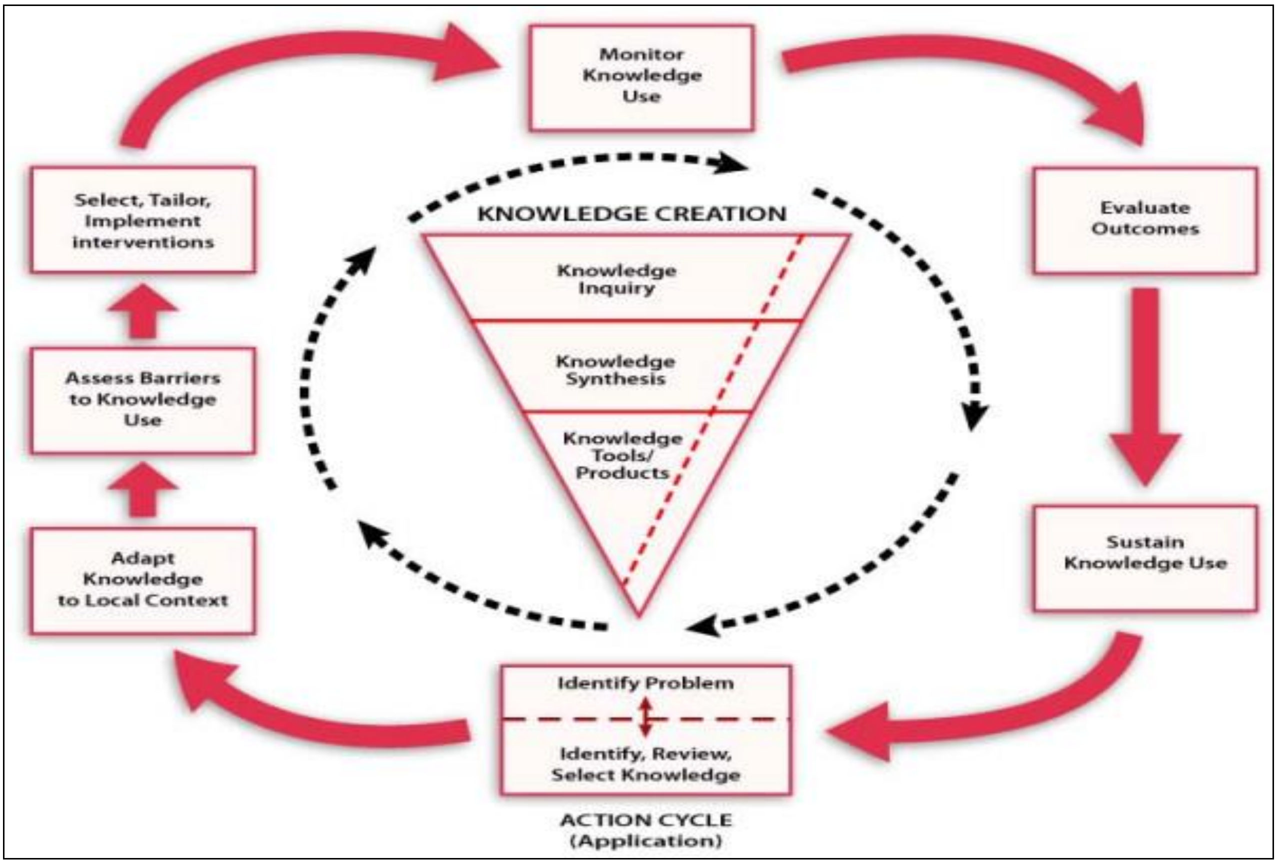


Figure 1.1: Knowledge-To-Action process

(Graham et al., 2006).

The knowledge creation process found at the centre of the model has three phases:

- Knowledge inquiry: This relates to the knowledge obtained from LHWs, health care professionals and PLWHIV through interviews. It was used in conjunction with Rolfe's framework of reflexive practice that is comprehensive as it incorporates inputs from multiple reflexive models, and directed the knowledge inquiry by asking the 'what', 'so what' and 'now what' questions (Jasper & Rosser, 2013: 61; Bishop & Blake, 2007:11).
- Knowledge synthesis: This relates to obtaining information through the existing knowledge such as in previous studies concerning the LHWs' role in HIV care and retention, as well as the available guidelines and tools used in HIV care (Graham *et al*., 2006:19; Sudsawad, 2007:9).
- Knowledge tools or products: New knowledge was then made known in a form of an integrated support model that will strengthen the LHWs' ability to improve the retention of PLWHIV (Graham *et al*., 2006:19; Sudsawad, 2007:9).

The second process of the action cycle consists of seven phases which can guide the Department of Health's managers and supervisors to implement the LHWs' support model generated during the knowledge creation process (Graham *et al*., 2006:19; Sudsawad, 2007:9). These phases are as follows:

- Identify a problem, review, and select knowledge: Low retention to HIV care has been identified as the problem and the developed model provided knowledge that can be selected to address the problem.
- Adapt knowledge to local context: The contents of the model must be adapted accordingly to suit the health care facilities.
- Assess barriers to knowledge use: The implementation challenges would be identified and mitigating factors discussed.
- Select, tailor and implement the interventions: The adapted knowledge would then be implemented accordingly.
- Monitor the use of new knowledge: Programme managers or supervisors need to engage with the lay health care workers to measure the support experiences of LHWs, guided by the model. Facility managers could also conduct the experience of care surveys with PLWHIV.

- Evaluate outcomes: The data elements that measure the retention of PLWHIV to care such as the number of clients who missed their appointments and lost to follow up could be analysed from the official source documents.
- Sustain knowledge: The knowledge would be sustained or adapted based on the processes carried out and the outcomes. This is the last phase, but because the phases are cyclical in nature, it means they are continuous.

1.4.3 Methodological assumptions

The methodological assumptions refer to the researcher's beliefs of what forms the basis of good research (Kaushik & Walsh, 2019:5). The humans' lived experiences and the context in which they occur are important in creating meaning, and therefore understanding phenomena and proposing congruent activities. This study adopted the assumptions of phenomenology, which emphasize studying the lived experiences of individuals and interpreting them through language, considering both verbal and non-verbal cues which are sometimes overlooked (Laforest *et al*., 2017:48). The researcher interviewed the LHWs, health care professionals and supervisors, as well as patients on ART, thereafter, internalised the findings to develop an integrated support model for LHWs to improve patients' retention to HIV care.

1.5 RESEARCH METHODOLOGY

The study followed a qualitative approach and the exploratory, descriptive and contextual phenomenology design. The aspects related to the methodology, which will be discussed fully in chapter 3, include the study setting, population, sampling, sample size and data collection methods and analysis. The study took place in a natural setting, at a health centre in Rustenburg sub-district, in Bojanala district, North West province. Three groups, namely, the LHWs, their supervisors and nurses, as well as clients on ART, formed the study population. Purposive sampling was done to select the most appropriate participants to assist in achieving the study objectives. The sample size was determined through data saturation across the three groups of participants and resulted in: 22 lay health care workers had data collected through focus group discussions; 10 supervisors and nurses, as well as 15 clients on ART who both had in-depth interviews.

Thematic data analysis was conducted, thereafter, the support model was developed. The ethical principles and rigour were promoted throughout the study and will also be discussed in chapter 3.

1.6 SIGNIFICANCE OF THE STUDY

The study obtained experiences of LHWs, their supervisors and health care professionals, as well as clients on ART, then used the information to develop an integrated support model for LHWs to improve retention to HIV care. The model has the potential to address the support gaps identified by LHWs in a responsive way because the study involved the LHWs. If the developed model is utilised, the support for LHWs will improve, thereby improving their knowledge, skills, motivation and job satisfaction, which in turn would potentially facilitate the retention of clients to HIV care. When clients are retained in HIV care, they are more likely to continue with ART, thereby achieving viral suppression which will reduce HIV-related morbidity, mortality, and new infections (Hall *et al.*, 2017:2).

The study was also supported by Kok *et al*., (2017:5) who revealed that CHWs did not feel supported and respected by their superiors, therefore, strategies that reduce social distance between LHWs and their supervisors could improve relationships and performance. Moreover, Caesens and Stinglhamber (2020:1) indicated that the support must be appropriate to the recipients' needs otherwise it may be meaningless or viewed negatively. Additionally, Hodgins *et al*., (2016:5) emphasized that the LHWs' support was crucial because they had little formal training as compared to health care professionals.

1.7 RESEARCH REPORT OUTLINE

This research report will be presented in nine chapters as follows:

- Chapter 1: Introduction and background
- Chapter 2: Literature review
- Chapter 3: Research design and methodology
- Chapter 4: Data analysis and discussion of findings from LHWs
- Chapter 5: Data analysis and discussion of findings from health care professionals
- Chapter 6: Data analysis and discussion of findings from clients on ART
- Chapter 7: Concept analysis
- Chapter 8: Model development
- Chapter 9: Summary of findings, recommendations, and conclusions

1.8 CONCLUSION

This chapter introduced the study by outlining the introduction and background, problem statement, objectives, assumptions, methodology, significance and how the research report will be presented. The importance of retention to HIV care and the support for LHWs who carry out different retention activities along the HIV care continuum was outlined as the focus of this study. The study aimed to develop an integrated support model for LHWs to improve patients’ retention to HIV care.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

Literature review is an in-depth search for information about the study problem, from various electronic or printed sources such as books, journals, internet, and others (McCombes, 2019a:1). It helps the researcher to build knowledge on the topic of interest, consequently avoiding duplication, then identifying similarities, controversies or gaps and justifying the study (McCombes, 2019a:1; Garrard, 2020:3). As a result, literature review can be regarded as the foundation of the study. This literature review will include global, regional, and national strides on retention to HIV care, lay health care workers' roles and experiences in HIV care, experiences of PLWHIV regarding HIV care and the support provided to LHWs in carrying out HIV care related duties.

2.2 RETENTION IN HIV CARE

Retention in HIV care relates to continued care, that is, from diagnosis, linkage to a healthcare facility, antiretroviral therapy (ART) initiation and lifelong monitoring of the health status of PLWHIV (Umeokonkwo *et al*., 2019:2; Hall *et al*, 2017:2). Care can be continued at the same health facility, or the patient can be transferred correctly to another health facility upon request. However, there have been multiple opinions on how to measure retention in HIV care.

According to Roscoe & Hachey (2020:3); Umeokonkwo *et al*., (2019:3) and Kay *et al*., (2016:3), one measure is when a patient keeps up to at least two clinic appointments scheduled three months apart and within a year. On the other hand, retention in HIV care is measured by the number of missed clinic appointments where no communication of cancellation has been received from the patient. The number of missed appointments was found to significantly predict HIV clinical outcomes; however, it needs to be used in conjunction with a second complementary measure such as the number of kept appointments (Kay *et al*., 2016:3). Roscoe *et al*., (2020:5) further recommended that the context and purpose be carefully considered before deciding on the appropriate retention measures. For the current study, the patients who missed one or more clinic appointments and those keeping up with their scheduled appointments were sampled.

2.2.1 The importance of retention on the HIV programme

Retention in care forms an important part of the HIV care continuum, which shows the care pathway of PLWHIV, from the testing entry point throughout to chronic care (WHO, 2016:20; Kay *et al*., 2016:1). Although it is appearing only once along the HIV care continuum depicted in figure 2.1 below, it is important throughout the multiple stages, such as between HIV diagnosis and linkage to care at a health facility, as well as between ART and viral load monitoring. If PLWHIV are not retained in care at any stage, they cannot move smoothly along the continuum of care, thereby impacting negatively on programme monitoring done through the HIV care cascade (UNAIDS, 2020a:70).

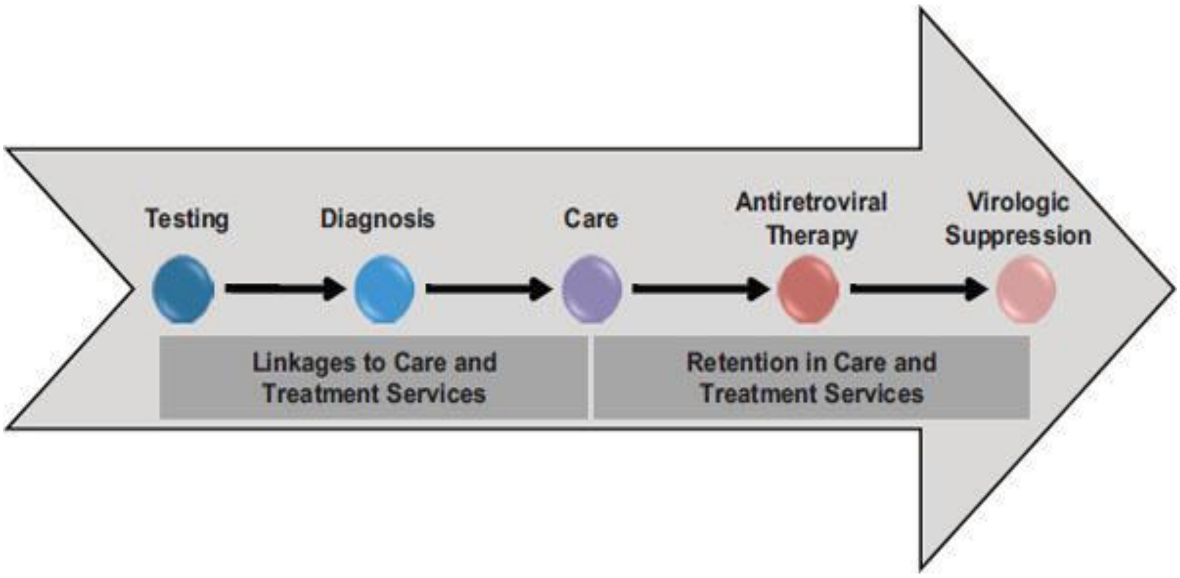


Figure 2.1: HIV care continuum

(*Institute of Medicine, 2013*).

The 2019 HIV care cascade showed that PLWHIV were lost or not retained in care at each stage. Globally, on average, 81% of PLWHIV were diagnosed, 67% were put on treatment and 59% were virally suppressed (UNAIDS, 2020a:71). In the Eastern and Southern African region, 87% of PLWHIV were diagnosed, 72% were put on treatment and 65% were virally suppressed, with Eswatini surpassing the 90% mark across all areas of the cascade (UNAIDS, 2020b:41). The same report indicated that in South Africa, as shown in figure 2.2 below, 92% of PLWHIV were diagnosed, 75% of those diagnosed were put on treatment (70% of all PLWHIV estimated) and 92% of those on treatment were virally suppressed (64% of all PLWHIV estimated).

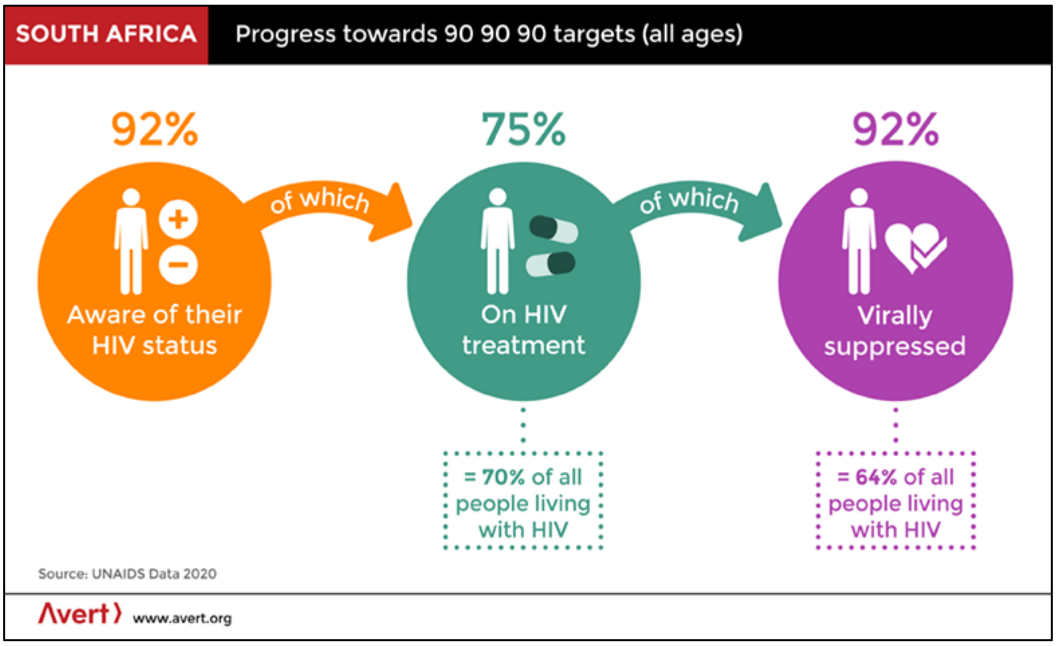


Figure 2.2: HIV care Cascade of SA, 2019

(*Avert, 2020; UNAIDS, 2020b*).

Globally, the progress shows country disparities in the achievement of HIV care outcomes. Despite different countries' projections indicating challenges in reaching the 90% targets of the 2020 HIV cascade, countries still need to accelerate their efforts towards the 2030 targets set at 95%. Retaining PLWHIV is the means to realising these 2030 targets. One of the vital outcomes for the HIV programme and individual's health, is the viral load suppression, which if optimally achieved, will prevent new HIV infections, and reduce HIV-related morbidity and mortality (Roscoe *et al*., 2020:1; Umeokonkwo *et al*., 2019:2; Hall *et al*, 2017:2). Moreover, continued care will avert high ART costs related to the treatment of resistant HIV mutations caused by poor retention and inconsistent or cessation of first line ART.

2.2.2 The challenges of retention in HIV care

Shah *et al.,* (2016:220) conducted a study to determine the economic and epidemiologic impact of poor retention to HIV care in the United States of America (USA). In the same study, it was projected that the USA may experience 1.39 million new HIV infections in twenty years due to suboptimal retention in HIV care, but improved retention could reduce new HIV infection and mortality rates by 54% and 64% respectively and consequently minimise costs. A systematic review of sub-Saharan African (SSA) studies was conducted to determine the outcomes of patients who started ART but were lost to follow up. The review found that four years after the last visit date, retention of clients on ART was as low as 9%; however, 22% had passed away, 23% stopped taking ART, 32% were not found and 15% transferred themselves to other health facilities (Chammartin *et al*., 2018:1645). In contrast, another similar study conducted in the SSA countries estimated the retention in care to be at 67%, mortality rate at 15%, ART cessation at 19% at five years (Haas *et al*., 2018:1).

The wide retention and mortality rate differences between the two studies may be because the former study did not use the standardised methods in line with the framework of the International Epidemiology Database to Evaluate AIDS, as well as to link with the countries' civil registries to account for lost clients, while the latter study did. Nevertheless, both studies recommended that tracing efforts must be intensified soon after the patients miss their appointments (Chammartin *et al*., 2018:1645; Haas *et al*., 2018:1). The findings also highlighted the movement of patients on ART between different health facilities without communication, leading to duplication and skewed data of the HIV outcomes.

A qualitative study was conducted with patients on ART and health care workers in Zambia, with the aim of conceptualizing factors that affect retention in HIV care (Mukumbang *et al*., 2017:3). The same study found that on average, 65% of clients who started ART were retained in care, while 35% were lost. Multiple factors affecting retention included the patients' attitude towards medication side effects, work issues, stigma, long distance to the health facility and long waiting time. Furthermore, the study identified a need to strengthen patient education and disease management interventions by both patients and health care departments (Mukumbang *et al*., 2017:3).

Another qualitative study was done in Swaziland (Eswatini) to explore the reasons for patients to discontinue ART (Shabalala *et al*., 2018:57). The same study found that discontinuing ART was preceded by a chain of events, not only one. Furthermore, mobility was the main factor that led to discontinuation of ART but was influenced by some crucial life events such as work, family disintegration and caring for sick family members. Again, the study recommended that the health care facilities improve patient-health care provider relationships, train health care providers to timeously identify the series of events that may lead to disengagement from care and incorporate strategies that accommodate mobile clients (Shabalala *et al*., 2018:57).

Swaziland is one of the countries that surpassed the 90% target across the HIV care cascade, and when this study was done in 2017, it highlighted that the retention on ART rate was already estimated at 85%; however, it was necessary to obtain the views of PLWHIV in efforts to improve retention of the disengaged 15% (Shabalala *et al*., 2018:54). The current study was further supported by the above-mentioned recommendations because the integrated support model has the potential to capacitate lay health care workers and strengthen their relationships with PLWHIV.

A household survey was conducted in South Africa to identify gaps that existed along the HIV care continuum, from diagnosis to viral suppression. This study found that among participants who were aware of the HIV diagnosis and had been linked to care, 33% of men and 58% of women were retained in care, while 22% of men and 50% of women were virally suppressed (Lippman *et al*., 2016:91). These findings highlight retention challenges but went further to disaggregate according to gender so that the health care providers are aware of the need to intensify support to men. Another study was conducted in South Africa to assess the national retention in HIV care using the linked laboratory system. The study found that the retention rate after 6 years of ART initiation at the health care facility was 29% in contrast to 63% at national level (Fox *et al*., 2018:2). Furthermore, mobility, especially silent or self- transfer of PLWHIV, was found to account for skewed retention rate data.

Universal test and treat (UTT) requires that PLWHIV be put on ART irrespective of their immune status and no longer places them on the pre-ART period; however, there are identified challenges with retention to care (Chauke *et al*., 2020:2). The same authors conducted a study in SA to determine the impact of UTT on retention to care at 12 months post ART initiation. Retention was around 60% and lost to follow up was associated with the UTT strategy, with patients initiated through the UTT strategy being twice more likely to be lost to follow up within six months of ART. The same study recommended intense counsellor-driven interventions to improve retention to HIV care (Chauke *et al*., 2020:2). These findings and recommendations support the current study because they highlight the changing nature of HIV policies, which require adaptations of the existing health care interventions carried out throughout the HIV care continuum.

2.2.3 Theories, models or frameworks applied to retention in HIV care

Roy *et al*., (2016:178) presented a framework for sustained retention in HIV care from the patients' perspectives and within the context of SSA countries. The framework highlights that retention is a product of both the patient (patient clinical needs) and health system aspects (ART delivery system), but focused more on the three patient principles (figure 2.3 below):

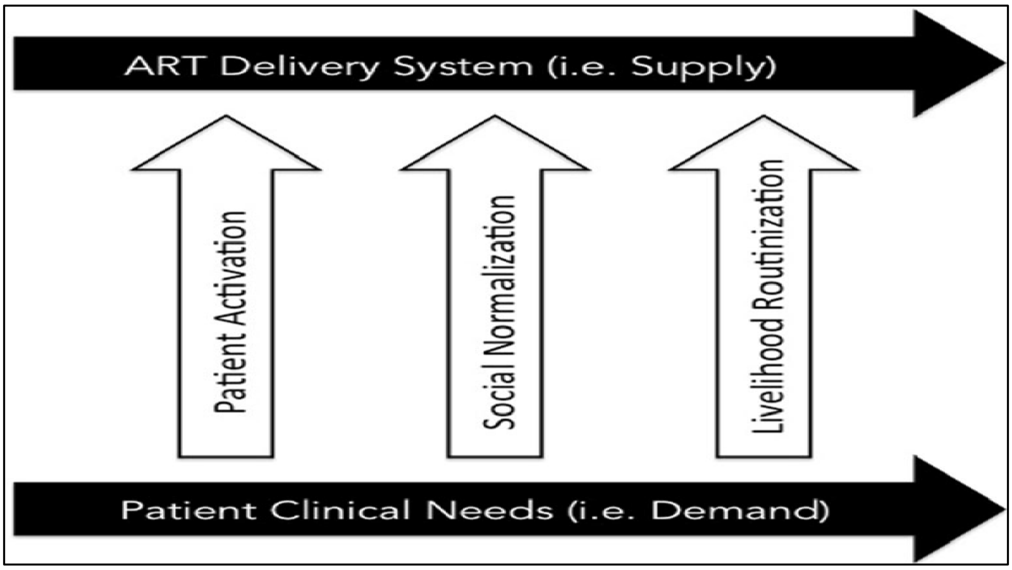


Figure 2.3: Framework for sustained retention in HIV/AIDS

(Roy et al. 2016).

- Patient activation

This refers to patients being knowledgeable about HIV, being involved in decision-making that affects their health, and ultimately taking ownership thereof. The authors identified that patients were still not actively participating in decision making, but health care providers instructed them on what to do, resulting in poor retention in care.

- Social normalisation

This relates to the relationship between the patients and their social networks or contacts. The patient must be able to disclose the HIV status to someone who will in turn provide the necessary support. However, fear of stigma was identified as a barrier to disclosure, and several mitigating factors such as being part of a support group were recommended.

- Livelihood routinisation

The patients need to balance social needs such as work, and clinical needs such as clinic visits. This balance can be difficult at times, such as for patients who are highly mobile due to their employment, and it needs to be discussed thoroughly. Some implemented strategies include differentiated care for stable patients, where they can receive ART at a convenient time from community groups or other identified pick-up points, though the challenge may be when the patient is due for viral load monitoring.

The framework outlines primary drivers that promote retention to HIV care from the patients' perspectives and are valuable for the current study. The authors further recommended that more work be undertaken to determine the role of peer health care workers in terms of their contribution to cost effectiveness of the healthcare system or their ability to leverage social support, thereby promoting retention to HIV care (Roy *et al*., 2016:178).

Skovdal *et al*., (2017:1) interviewed the health care workers, PLWHIV and family members of PLWHIV who passed away, then used the theory of practice which has four interconnected constructs depicted in figure 2.4 below, to understand the engagement or disengagement to HIV care in SSA countries.

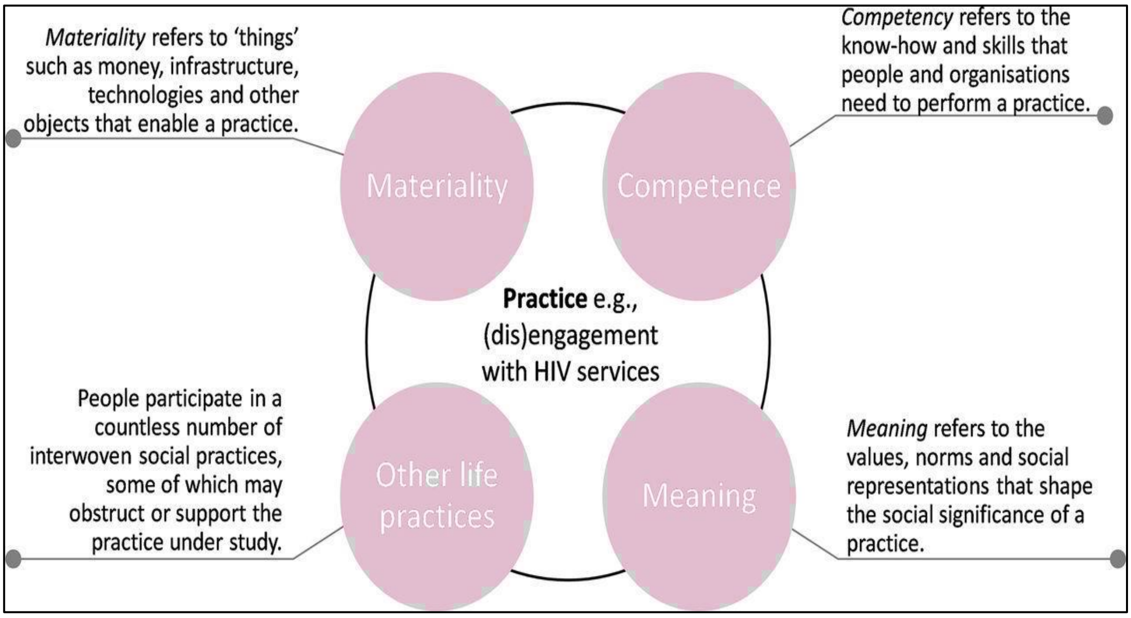


Figure 2.4: Theory of practice

(Skovdal et al., 2017).

Within the HIV care context, the theory was interpreted as follows:

- Materiality

  Participants stated that accessibility of the health facility, how ART service is provided, e.g., waiting time as well as the sustained supply of ART, promoted retention to care.

- Competence

  If patients have clear information on how HIV works, how to live with it and which untoward effects of ART to anticipate, they are more likely to be engaged in care.

- Meaning

  Participants believed that trusting the HIV services, as well as the ability to overlook the societal stigma and focusing on the advantages of continued HIV care, such as being healthy and taking care of family, facilitate retention to care.

- Other life practices

  Other social practices such as working, may interfere with the consistent keeping up of clinic appointments for ART refills or monitoring, which is why they need to be discussed beforehand to identify possible solutions.

The definitions of the practice theory constructs are in par with the sustained retention framework. The authors recommended more practically oriented retention activities which suit the local contexts. Another similar model that has been applied commonly in retention to HIV care is the Information-Motivation-Behaviour (IMB). The IMB model states that people are more likely to adhere to particular behaviour provided they are adequately informed and motivated (Graham *et al*., 2018:102; Torija *et al*., 2015:336). Although this model is used commonly for patients, the study referred to it for lay health care workers as well. Smith (2013:198) applied the IMB model to retention in HIV care in the United States and adapted it as in figure 2.5 below.

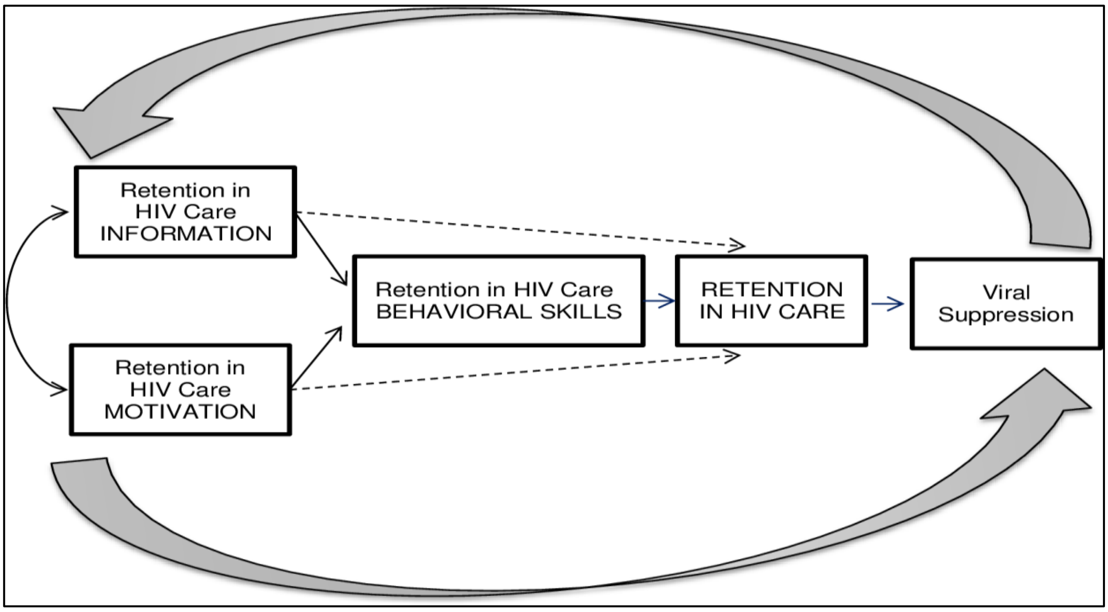


Figure 2.5: IMB Skills Model of Retention in HIV Care

(Smith, 2013).

The above IMB skills model explains that adequate **information** on HIV care: benefits, procedures, treatment, and challenges, as well as **personal and social motivation** to remain in care: - perceived individual benefits and positive reinforcement from social networks or health care providers result in retention of behavioural skills, which lead to **retention in care** and better HIV care outcomes such as **viral suppression**. Viral suppression outcome acts as a positive feedback loop to the patients' retention in care information and motivation, further strengthening retention in HIV care (Smith, 2013:198). In addition to the IMB model, another theory that guided the study is the Normalisation Process Theory (NPT) in figure 2.6 below, which is used in health care practice and highlights that both individual and collective actions are important when implementing interventions (Umeokonkwo *et al*., 2019:2; May *et al*., 2018:2).

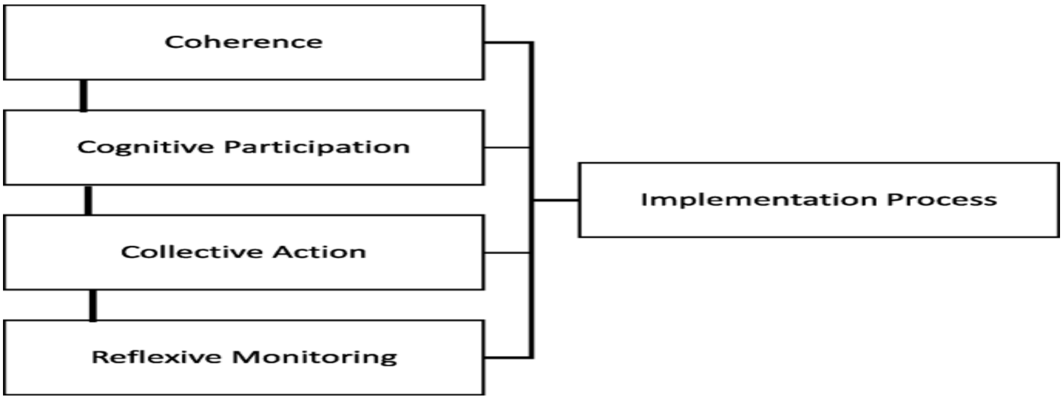


Figure 2.6: NPT

(May et al., 2018).

- **Coherence** is when meaning is attached to the intervention. Lay health care workers assume different roles throughout the HIV care continuum: lay counsellors provide counselling at diagnosis and ART, including when the viral load is unsuppressed, while CHWs and telephonic tracers trace PLWHIV who are disengaged from care. The essence of all these activities is retention in HIV care, which is crucial for viral suppression as well as reduced HIV-related morbidities and new HIV infections.

- **Cognitive participation** refers to how individuals engage and endorse the intervention. This relates to the relationship between the lay health care workers and PLWHIV and ways in which the information pertaining to continued HIV care is shared by lay health care workers throughout the HIV care continuum.

- **Collective action** refers to actions performed by individuals. Lay health care workers need to synergise their efforts and understand how their individual roles combine to form the whole, leading to comprehensive HIV care. Once one member is not performing the task optimally, it affects the whole HIV care continuum, most importantly, retention in care.

- **Reflexive monitoring** refers to the evaluation of the intervention carried out by the implementers. This relates to the time taken by lay health care workers to review the impact of their work: lay counsellors may make a follow up call to patients newly diagnosed with HIV within a week to explore their experience and provide support so as to promote retention.

Retention in HIV care requires a multi-faceted approach, so the IMB model and NPT were used to complement each other and guide the interview questions that led to the development of an integrated support model for lay health care workers to improve patients' retention to HIV care. Moreover, the theories, models or frameworks discussed above are not exhaustive; however, they shed valuable information on previously conducted research which forms the basis for future retention to HIV care studies.

2.3 THE ROLE OF LAY HEALTH CARE WORKERS IN RETENTION TO HIV CARE

LHWs play various key roles along the HIV care continuum: lay counsellors provide testing and counselling on HIV and ART either at the hospitals, clinics, or community; community health care workers provide household support to PLWHIV and tuberculosis through health education and tracing those who missed their clinic appointments (Naidoo *et al*., 2018:2; Mwisongo *et al*., 2015:2). Moreover, Schmitz *et al.,* (2019:6) stated that LHWs reminded clients of their next appointment dates, obtained a list of those who missed their appointments and tracked them. Also, they formed adherence support groups with clients and conducted home visits to support clients who had challenges with collecting their treatment.

A study done in the USA examined the impact of community health care workers (CHWs) on patients' attendance of clinic appointments, active ART prescription and viral suppression at six months after enrolling at health care facilities (Drainoni *et al*., 2020:212). The findings of the same study associated CHWs' interventions with improvements across the three elements of interest: attendance of clinic appointments improved from 49.9% to 84.7%; patients with active ART prescription moved from 66.9% to 91.3% and viral suppression improved from 22.4% to 43.7%. Furthermore, the study recommended that efforts that investigate the impact of organisational and environmental factors on CHWs' work, relationship with patients and other team members be considered in order to improve HIV care outcomes (Drainoni *et al*., 2020:212).

Similarly, Knettel *et al*., (2021:12) conducted a study in Tanzania to determine the value of CHWs in HIV care and found that patients regarded them as valuable sources of information and encouragement. Again, a scoping review that included articles from eight SSA countries: SA, Zimbabwe, Malawi, Nigeria, Uganda, Tanzania, Kenya, and Ethiopia, aimed at assessing the impact of lay counsellors in women living with HIV and exposed infants' programmes (Schmitz *et al*., 2019:19). The same review found that adequate remuneration, integration of lay health workers' activities into public health systems and supportive supervision can motivate lay health workers, then lead to quality and successful interventions.

Another study conducted in Malawi found that LHWs were able to address access barriers, thereby improving ART uptake and retention to care for clients enrolled in the prevention of mother to child transmission programme (Topp *et al*., 2020:10). Skovdal *et al.,* (2017:7) conducted a joint qualitative study in six SSA countries: Malawi, Uganda, Tanzania, Kenya, Zimbabwe, and SA to understand the patients' engagement and disengagement into HIV care and treatment. The same study found that well-managed health services, practical knowledge which is facilitated by counselling, as well as improved health outcomes, impact positively on patient engagement. Furthermore, the authors recommended that to improve HIV care and treatment, practice- and patient-oriented initiatives must be undertaken.

2.4 EXPERIENCES OF LAY HEALTH CARE WORKERS IN HIV CARE.

A study done in SA to explore the lay counsellors' experiences in HIV care revealed that lay counsellors felt that they were doing most of the work in terms of counselling, diagnosing, linking PLWHIV to care and providing adherence information, but felt demotivated due to unsatisfactory remuneration, lack of recognition as part of the health care workers and limited support (Mkhabele & Peu, 2016:322). Furthermore, lay health care workers felt that HIV care and support in health facilities were compromised during their absence and due to low morale resulting from dissatisfaction with their working conditions.

There were mixed experiences and feelings from a South African study aimed at exploring the lay counsellors' experiences with their work, where some counsellors felt happy with their work and training but needed continuous in-service training or refresher courses and support groups to relieve burnout (Pretorius, 2019:83). In the same breadth, other lay counsellors felt unappreciated; mentioned that they needed to be updated and debriefed regularly, and also regarded counselling provided during the initial stages when the client is newly diagnosed with HIV as one of the most difficult sessions.

Additionally, Geldsetzer *et al*., (2017:5) indicated that the LHWs felt frustrated when they were unable to respond to the community's questions due to lack of knowledge and therefore wished to be provided with continuous information. Also, Fleischer and Avery (2020:8) indicated that the motivation of clients who were consistent with taking ART came from them, while clients who were inconsistent were motivated by the HIV care staff. As a result, it is important to encourage the staff providing HIV care in order to improve retention.

2.5 EXPERIENCES OF CLIENTS ENGAGING WITH LAY HEALTH CARE WORKERS.

In two different studies conducted in Malaysia and SA, clients were generally satisfied with the counselling services and HIV information received, and regarded the lay counsellors and other health care professionals as their support system: counsellors were willing to listen to their stories, which in turn gave them the courage and motivation to face their daily struggles (Min & Abdullah, 2017:9; Matseke *et al.,* 2016:5). The same studies indicated that clients regarded emotional support as an integral part of counselling that helped them to live positively and meaningfully.

A mixed method study was conducted in Ukraine to evaluate the perceived quality of HIV services provided in health care institutions (The United States Agency for International Development (USAID) HIV Reform in Action Project, 2017:8). The same study found that user-friendliness had a strong influence on patients' satisfaction, which in turn was associated with improved retention in HIV care. User-friendliness, which was around 75%, was measured in terms of the health care providers' attentiveness to patients, provision of explanations, showing respect, allowing patients the comfort to ask questions and involving them in decision making regarding HIV care.

However, in terms of HIV care services: 1) *Testing:* 74.6% of patients received information before testing, 69.8% received risk reduction information and 61.3% received post-test counselling, with the hospitals being the lowest performing; 2). ART service: on average, more than 80% of clients received information on taking treatment at a scheduled time, side effects and adherence, but patients at primary health care institutions experienced challenges in the receipt of information on adherence, diet, and emotional issues (The USAID HIV Reform in Action Project, 2017:41). In contrast, Chinyandura *et al.,* (2022:6) conducted a study in SA and found that the clients were satisfied with the education and support received from the retention officers, which made them to participate in their care.

A joint qualitative study was conducted in five countries located in Southern and Eastern Africa to explore the counselling and testing experiences of PLWHIV and various health care workers. In the same study, PLWHIV felt that HIV testing helped them to know their status, but at times they were not given the option to opt-out from HIV testing and counsellors provided limited and general risk reduction options which were not aligned to their specific situation. Moreover, the manner in which the counselling messages were phrased by counsellors was sometimes inappropriate for clients, discouraging them to seek continued HIV care (Wringe *et al*., 2017:3). The same study recommended that confidentiality, informed consent, and messages aligned to the needs of PLWHIV be considered in efforts to improve retention to care.

Wolpaw *et al*., (2014:4) conducted a qualitative study in SA to determine the counselling experiences of clients with acute HIV infection. The same study found that some clients that were interviewed a week post HIV diagnosis could not recall most of the information discussed during counselling; instead, they mentioned the importance of a healthy diet and exercise without saying much about minimising HIV transmission. The same findings may reflect limited understanding in terms of the new HIV infections and the increased risk of transmission; therefore, it is important for clients to have the initial and follow-up counselling sessions that emphasise behaviour modification.

2.6 SUPPORT PROVIDED TO LAY HEALTH CARE WORKERS

In a South African systematic review that investigated the lay counsellors' services, inconsistency in terms of their training and supervision such as the difference in the duration, methods of the training provision and activities post-training were found (Petersen *et al*., 2014:201). The same review indicated that although some lay counsellors had some form of mentorship, supportive supervision was weak.

Shahmalak *et al*., (2019:11) conducted a systematic review to assess the experiences of LHWs in delivering psychological interventions. The same study found that there was limited focus on mental health issues but LHWs were capable of delivering low-intensity psychological interventions if trained. However, supervision needed to be strengthened as it would increase the confidence and help to improve the community's trust for LHWs.

Likewise, Chibanda (2017:77) assessed the role of LHWs in reducing the depression treatment gap in low- and middle-income countries, and indicated that PLWHIV were twice likely to suffer from depression than those who were HIV negative. Again, LHWs were able to deliver mental health care interventions in the absence of mental health professionals, thereby contributing positively to HIV outcomes but they needed thorough training. Visser and Mabota (2015:3) assessed the emotional well-being of lay counsellors in SA and found that they experienced high emotional exhaustion and depression, which affected the quality of counselling. As a result, the study recommended that the training and support of lay counsellors in terms of the emotional aspects be considered.

Letsoalo and Ntuli (2017:47) investigated the counsellors' experiences in SA and found that some counsellors had some kind of support from their mentors and developmental partners, but others experienced poor communication and support from their supervisors who were sometimes not reachable, and clinic staff who at times refused to assist them with patients. However, lay counsellors stated strong support for each other. Again, lay counsellors were not exposed to updated HIV care information and consistent debriefing, which they felt were necessary to improve HIV care services. Increased workload due to many clients requiring HIV services, and other tasks given to LHWs led to ineffectiveness of their work. The same study recommended that in the absence of managers, supportive supervision may be carried out by experienced lay counsellors through mentoring, constructive reflection, critical thinking, and problem solving using practical challenges (Letsoalo *et al.,* 2017:47).

Similarly, in a South African study that assessed psycho-social challenges faced by HIV counsellors, four areas of support emerged: continued in-service training with updated HIV information, emotional support through debriefing or identification of positive coping mechanisms, supervision where HIV service gaps are identified and addressed and management support where counsellors raise their concerns and provide inputs on improvements (Isaacs, 2014:30).

2.7 CONCLUSION

The reviewed articles provided the global, regional, and local information on the importance, challenges and theories of retention in HIV care; the role of lay health care workers in retention to HIV care; the experiences of both the lay health care workers and patients in interacting with each other; and the support provided to lay health care workers. In a nutshell, there is a need to continuously seek locally adapted retention to HIV care interventions and also intensify the LHWs' support in efforts to maximise their different functions along the HIV care continuum, that is, from diagnosis to chronic care; and all these aspects further support the current study.

CHAPTER 3

RESEARCH APPROACH, DESIGN AND METHODS

3.1 INTRODUCTION

The research approach refers to the tools or procedures applied to collect, analyse and interpret data (Farghaly, 2018:5). These procedures are informed by the philosophical assumptions, designs and methods. The philosophical assumptions are the researchers' world views, beliefs or orientation about the world, which then guide their actions (Leavy, 2022:12; Kivunja *et al*., 2017:33). The study adopted a constructivist worldview which emphasizes that individuals deconstruct and construct meaning through their lived experiences, interaction with the environment and reflection (Leavy, 2022:13; Kivunja *et al*., 2017:33).

Furthermore, constructivists hold the view that individuals have multiple realities and meanings of the same phenomenon, which can be helpful in generating theories (Farghaly, 2018: 6). This study explored the experiences of LHWs, their supervisors, nurses and PLWHIV in terms of HIV care and retention, then developed a support model for the LHWs. The assumptions were discussed in detail in chapter 1; therefore, this chapter discusses the study approach, design, and methods.

The study was conducted in two phases. Phase 1 entailed the research approach, design, and methods of data collection and analysis from the LHWs, their supervisors and nurses, as well as clients who are on ART, while promoting rigour and ethical aspects throughout. Phase 2 included the conceptual framework, and model development, as outlined in figure 3.1 below. Thereafter, the research report was written.

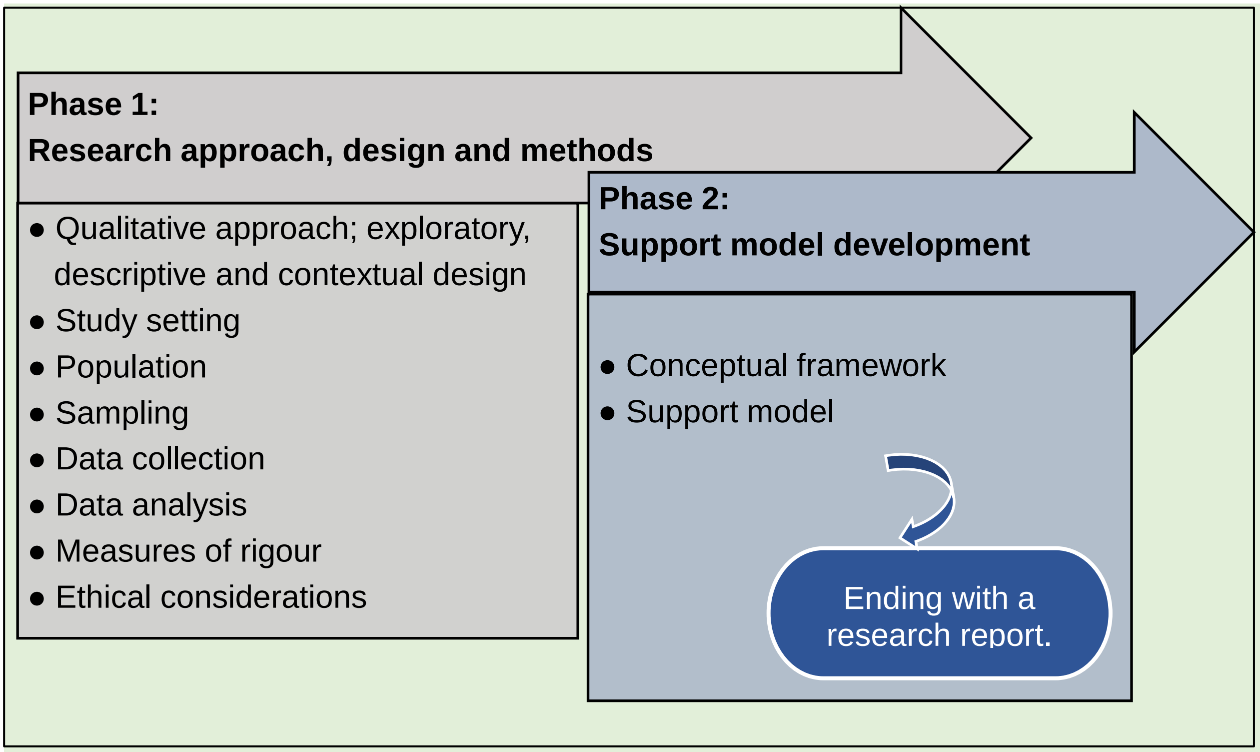


Figure 3.1: The phases of research

3.2 PHASE 1: RESEARCH APPROACH, DESIGN AND METHODS

3.2.1 RESEARCH APPROACH

The research approach refers to the tools or procedures applied to collect, analyse and interpret data (Farghaly, 2018:5). The study followed a qualitative approach which involves the exploration and interpretation of actual experiences regarding a particular phenomenon occurring in a natural setting (Leavy, 2022:9). Additionally, the research approach can be described in terms of data analysis, namely, deductive and inductive (Tomaszewski *et al*., 2020:4). The study used an inductive approach of data analysis, where the researcher did not test a theory or have assumptions from the beginning but used empirical data from the participants to understand and develop a model of support for LHWs to improve patients' retention to HIV care (Tomaszewski *et al*., 2020:4; Farghaly, 2018:7).

3.2.2 RESEARCH DESIGN

The research design is a planned structure or strategy that guides the study (Leavy, 2022:9). Furthermore, the design forms the basis for decision-making and interpretation of results. The study followed an exploratory, descriptive and contextual phenomenology design. Phenomenology emphasizes studying the lived experiences of individuals and interpreting them through language, considering both verbal and non-verbal cues (Laforest *et al*., 2017:48).

3.2.2.1 Exploratory

An **exploratory** study is a flexible design that deeply examines the phenomenon to get a better understanding (Pratap, 2019:1; Boru, 2018:3). The researcher used it to gain new perspectives and discover ideas on retention to HIV care, thereby increasing the knowledge about the study topic. The interview guide was used to explore the roles and experiences of lay health care workers and health care professionals in the retention of PLWHIV and how PLWHIV experienced their journey with lay health care workers.

3.2.2.2 Descriptive

A **descriptive** study is a subjective design that provides direct descriptions of the experiences and perceptions of participants regarding a particular phenomenon, occurring in a natural setting (Doyle *et al*., 2020:444). As a result, it encourages optimal spontaneity from the participants. A descriptive study is appropriate when little is known about a problem and accurate characteristics and categories need to be identified (McCombes, 2019b:1). In depth individual interviews and focus group discussions were conducted to collect narrative data on retention practices and experiences of LHWs, their supervisors, nurses and PLWHIV; then recorded; transcribed verbatim and described.

3.2.2.3 Contextual

Contextual design is a user-centred design that aims to understand the users within natural settings, through collecting and analysing field data to reveal hidden information and identify their actual needs (Augstein *et al*., 2018:429). The study followed a contextual design because it was conducted in a natural setting in a health centre and sub-district office in Bojanala district in South Africa, with PLWHIV being the users while the lay health care workers and other health care professionals were the implementers of HIV retention services. However, the LHWs are also the users since the study developed a support model for them.

3.2.3 RESEARCH METHODS

The research methods pertain to how the study was conducted to answer the research questions and build systematic knowledge (Patten & Newhart, 2017:3). The information on the research methods includes: the study setting, population, sampling, sample size as well as data collection methods, procedures and analysis.

3.2.3.1 Study setting

The study setting refers to a controlled or uncontrolled environment in which the study is conducted (Majid, 2018:3). In a controlled setting, the environment is manipulated by the researcher, whereas in an uncontrolled setting, the environment is natural. Description of the setting is important because it helps other people to determine the transferability of the findings to their contexts (Korstjens & Moser, 2018:121). The study was conducted in a natural setting, in Bojanala health district in the North-West Province, South Africa, at a community health centre in Rustenburg sub-district. The map of Bojanala district with its five sub-districts is shown in figure 3.2 below. Bojanala district was chosen because of the health centre with the largest ART programme in the province, with ± 7000 clients remaining on ART at the end of January 2021 as reflected by the electronic register version of the Three Interlinked Electronic Registers (TIER. net).

Figure 3.2: Map of Bojanala district

(Mphahlele, M. & Zandamela, 2021)

3.2.3.2 Research population

The population refers to all elements of interest that meet certain criteria and have a chance of being included in the study (Majid, 2018:3). The LHWs, their supervisors and nurses, as well as clients on ART in Bojanala formed the population of this study. Those who met the inclusion criteria were included in the study.

3.2.3.3 Sampling

Sampling is a process of selecting a subset of the population for inclusion in the study because the whole population cannot be included (Majid, 2018:3). Probability sampling attempts to give the participants an equal chance of being selected, while non-probability sampling does not and may be labelled as biased (Rahi, 2017:3). The researcher used purposive non-probability sampling because of its appropriateness in judging and purposefully selecting the participants that were interviewed to achieve the study objectives. The purposive non-probability method that was used is known as the maximum variation, which describes the key dimensions of variation, selects suitable participants to reflect these unique variations and similarities, thereby producing quality descriptions (Ames *et al*., 2019:3). Different categories of LHWs, supervisors interacting with them, and clients on ART who have missed or kept scheduled clinic appointments, represented this variation.

- Lay health care workers

Recruitment occurred in the facility manager’s office. An appointment was secured with the facility manager and LHWs to explain what the study entailed and then distribute the participant information sheet in annexure H, then use the eligibility checklist to identify those that are eligible for inclusion. The eligibility checklist included the demographic details, namely, age, gender, job title, the inclusion criteria questions to be answered as ‘yes or no’, and the option to provide the contact numbers if willing to participate. This eligibility checklist was important to ensure that the relevant participants were recruited and sampled to provide rich data. The consent forms were also given to the LHWs and collected after two days, for them to have a chance to decide on participation or non-participation. The LHWs who signed the consent forms then discussed a convenient date and time to conduct the FDGs.

- Supervisors and nurses

Nurses were recruited at the facility manager’s office, and the recruitment procedures followed the same pattern as the LHWs’, except that they individually chose suitable dates for the telephonic in-depth interviews. Also, supervisors who are office-based where recruited at their offices, using the procedure as the nurses’ and LHWs’.

- Clients

Clients who have been on ART for a year or more, keeping all or had missed some clinic appointments were sampled because they have undergone the different stages along the HIV care continuum and were therefore in a better position to describe their experiences with the LHWs. They were recruited in the consulting room as follows: The nurse explained to them that there was a study about their experiences of care and were requested to see the researcher in the room next to the exit door, if interested. The entrance and exit doors of the facility are different and distanced from the waiting area, so there was no fear of other clients seeing what was happening. The researcher then explained fully what the study entailed, used the eligibility checklist, and obtained written consent since the interviews were done telephonically. However, the researcher would make a follow up call to check if the client still wanted to participate, then schedule an appointment for the telephonic interview. The clients’ eligibility checklist also included their inclusion criteria and demographics such as age, gender and years on treatment.

The criteria below were followed:

Inclusion criteria

- **LHWs:** Lay health care workers involved in HIV care.
- **Health care professionals:** Nurses and supervisors that work with or supervise LHWs.
- **Clients:** Clients on ART for more than a year and keeping up with the clinic appointments; and those on ART for more than a year and have missed one or more clinic appointments.

Exclusion criteria

- **LHWs:** Lay health care workers who do not provide HIV care.

- **Health care professionals:** Nurses and supervisors who do not work with or supervise LHWs.
- **Clients:** Clients on ART for less than a year.

3.2.3.4 Sample size

The sample size refers to the acceptable number of elements selected from the target population, to participate in the study (Riley *et al*., 2020:1). Sim *et al*., (2018:3) found that the sample sizes for different qualitative methods ranged from two to 60, with three to 10 specifically for phenomenological studies. However, Hennink and Kaiser (2021:7) found that studies which determined sample sizes through data saturation, where there were no further codes emerging during the empirical data collection, stopped after nine to 17 interviews.

The sample size in the current study was determined per group of participants in order to adequately achieve the study objectives, and the data saturation concept was adopted. While there are ongoing debates on how saturation is determined, the current study used the stopping criterion, where interviews were stopped after: 1) conducting and reviewing six in-depth interviews, and then not identifying any new codes with the next three to five interviews; 2) two focus group discussions (FGDs) were conducted and reviewed, then not identifying new codes after two more FGDs (Hennink *et al.*, 2021:6). The sample size ended up as follows:

- Twenty-two (22) lay health care workers described how they interact with PLWHIV.
- Ten (10) health care professionals described their views on the support provided to LHWs in carrying out their duties relating to PLWHIV.
- Fifteen (15) clients on ART explored and described how PLWHIV experience their interaction with LHWs.

3.2.3.5 Data collection method

Data collection method refers to ways in which data was generated or collected from the participants (Hennink *et al*., 2020:17). An interview guide was used to collect data from the participants. The guide had open-ended questions which allowed flexibility and adequate expression of subjective views, but at the same time ensured that the interview focused on the same areas of interest. The following data collection methods were used per group of participants:

- Focus group discussion

Focus group discussion is a qualitative data collection method where a group of participants with the same background or experience meets at the same time to interactively discuss a specific subject that is initiated by the researcher (Nyumba *et al.*, 2017:22; Gammie *et al*., 2017:2).

The researcher chose this method for the LHWs because it was ideal to facilitate shared experiences and views on interacting with PLWHIV and provide insight on the influence they may have on each other as lay health care workers. Four focus group discussions were held with LHWs to describe their interaction with PLWHIV. Two FGDs had 6 LHWs each and the other two had 5 LHWs each. The teleconference was initially chosen to observe the COVID-19 precautions; however, due to network challenges experienced by most participants, a well-ventilated area in the health centre was then used for the interviews. All participants wore masks and were provided with individual sanitisers. The main questions that the LHWs were interviewed on include their role and contribution in HIV care and retention; the support provided to them by co-workers and supervisors; as well as the retention barriers and improvement strategies, as reflected in annexure E.

- In-depth individual interviews

In-depth individual interview is another qualitative data collection method where a participant is encouraged to provide detailed and deep experiences or views regarding a particular phenomenon (Showkat & Parveen, 2017:5). The in-depth telephonic individual interviews were conducted with ten (10) LHWs' supervisors and nurses, where they described their views on the support provided to LHWs in carrying out their duties relating to PLWHIV. This method was chosen because it would have been difficult to schedule a same-time appointment with the different health care professionals because they worked at different locations and had differing priority tasks. The interviews were done telephonically to observe the COVID-19 precautions. The main questions that the supervisors and nurses were interviewed on include their working relationship and support for LHWs, views on the role and contribution of LHWs to HIV care and retention, retention barriers experienced by LHWs and possible improvement strategies, as reflected in annexure F.

Again, the in-depth individual telephonic interviews were conducted with 15 clients on ART, where they explored and described how PLWHIV experience their interaction with

LHWs. The researcher chose this method for this group due to the sensitive nature of the topic, considering that some participants would possibly not have been comfortable to describe their experiences in a group setting. The main questions that the clients were interviewed on include their journey in relation to HIV care, their relationship with LHWs, factors that result in them honouring or skipping clinic appointments and possible suggestions to improve retention, as reflected in annexure G.

3.2.3.6 Data collection procedures

Some researchers conduct pilot studies before commencing with the main studies, however, this practice is more common in quantitative than qualitative studies, since there is no consensus yet on whether it is vital and compulsory in qualitative studies or not (Williams-McBean, 2019:1055). The same author further explained a pilot study as a small-scale study that is conducted with few participants to determine the feasibility, thus allowing for timeous improvements, such as, refining the interview questions, before moving to a larger scale.

Additionally, although the pilot study may improve the confidence of novice qualitative researchers, qualitative studies are progressive and flexible in nature, therefore, adaptations can still be made as the main study progresses (Williams-McBean, 2019:1055; Ismail *et al*., 2018:4). As a result, the pilot study can be omitted. Similarly, the current study commenced on a full scale and the researcher refined the interview guide where necessary during the interviews, through follow up questions. Also, transcription was done daily after the interviews.

The entire data collection process lasted for three months, from the 5th of September to the 7th of December 2021. Data collection procedures are discussed under three groups of participants:

- Lay health care workers

On the day of the focus group discussion, the researcher connected the participants to a teleconference and requested the participants to grant permission to record the discussion. However, due to repeated network problems, the participants and researcher agreed to rather conduct physical discussions, which were successfully conducted and recorded at the health centre, while observing the COVD-19 precautions.

- LHWs’ supervisors and nurses

On the dates chosen for the in-depth interview by individual participants, telephonic interviews were conducted, and the costs thereof were incurred by the researcher. Audio tapes, with the permission from the participants, were used to record the interviews.

- Clients on ART

On the day of the interview, the researcher checked if the phone was answered by the participant and if the time was convenient before commencing with the interview. The researcher also obtained permission to record the interview. Telephone costs were incurred by the researcher.

3.2.4 Data analysis

Data analysis is a process of describing and interpreting data in a way that provides meaning (Maguire & Delahunt, 2017:1). Thematic analysis, which was used for this study, is one of the flexible methods used in qualitative research that goes beyond just summarising data; it also creates important themes to understand or interpret a particular issue. Caulfield (2020:1) and Maguire *et al*., (2017:5) further provided guidance through the six steps described below:

- **Becoming familiar with the data**: This is the initial step where the researcher becomes conversant with the data. Audio recordings were listened to, and notes read repeatedly for familiarisation, then transcribed verbatim into Word documents.
- **Generating initial codes:** This refers to reducing data to sizable chunks of information by highlighting some text and generating labels to describe it. It may be done inductively where there are no pre-set codes, or deductively where the researcher has some anticipated codes. This study used inductive coding.
- **Searching for themes:** The code patterns were identified, and similar ones were grouped into single unifying ideas.
- **Reviewing themes**: The themes were re-examined to determine if they make sense, are useful and accurate. Where necessary, some themes were modified either through expanding, collapsing or even creating new ones.
- **Defining themes:** The themes were refined into simple, understandable names, and then interpreted through determining the relationship between them. The relationship

between the themes were then organized in a form of a thematic map and this is when the researcher developed the integrated support model.

- **Write-up** is the final step where the study proceedings are documented in different platforms such as the thesis and journals, which is the case with the current study. It mainly includes the introduction, literature reviewed, methodology, findings, and conclusion.

3.3 ENSURING RIGOUR

Rigour refers to the critical reflection and justification of the procedures followed throughout the study to promote quality (Stenfors *et al*., 2020:597). In qualitative research, rigour is assessed through measuring trustworthiness.

3.3.1 Measures of trustworthiness.

Trustworthiness refers to the extent to which the study findings can be trusted and is characterised by credibility, transferability, dependability, and confirmability (Korstjens *et al*., 2018:121). In addition, Amin *et al*., (2020:8) mentioned a fifth criteria known as authenticity. Moreover, Nowell *et al*., (2017:3) highlighted that these measures are interrelated, and strategies to promote them may overlap, as presented in table 3.1 below.

Table 3.1: Summary of measures of trustworthiness

Measure	**Strategy**	**Application to the study**
Credibility	Triangulation	-The use of audio tapes, observations and field notes during the interviews.
	Member checking	-Asking similar questions across the 3 groups of participants: LHWs, their supervisors and clients on ART.
	Representation of participants	-Verbatim transcription of participants’ responses.
Transferability	Nominated sample	- Purposive sampling done to achieve the study objectives.
	Rich description	-Clear and rich description of contexts, findings and steps used throughout the study.
	Presentation of the report	-Themes and codes presented together with the quotations from participants

Confirmability	Triangulation	-The use of in-depth individual interviews, focus group discussions, audio recordings, field notes and literature control.
	Audit trail	-Researcher referred to the audio recordings and field notes repeatedly.
	Presentation of the report	-Including raw data, e.g., quotations under the themes and the analytical narratives.
Dependability	Coding and re-coding	-Coding and recoding were done by the researcher, supervisor and independent coder.
	Triangulation	-Comparing themes identified by the researcher, supervisor and independent coder.
	Rich description	-Presentation of findings from participants together with literature control and appropriate referencing.
	Peer review	-Internal scrutiny from the supervisor. -External scrutiny anticipated before publication in peer-reviewed journals.
Authenticity	Data presentation	-Obtaining the first-hand information from the participants. -Including quotations and conducting literature control when presenting the findings.
	Transparency	-Upholding the ethical considerations such as obtaining the informed consent without coercion, and promoting fairness and confidentiality for all participants.

3.3.1.1 Credibility

Credibility refers to the truth value of the research findings and whether they accurately represent the participants' responses (Korstjens *et al*., 2018: 121). Credibility was enhanced through triangulation, where there was use of audio tape as well as field notes and observations when face to face interviews were conducted. However, to align with the COVID-19 precautions, the audio tape was used to record telephonic interviews.

Focus group discussions were changed to physical interviews due to network problems. Responses of the participants were transcribed verbatim, including non-verbal cues, and results presented in a way that described the participants' experiences and views as accurately as possible through quotations. Additionally, to promote member checking, the researcher asked some similar questions across the 3 groups of participants and compared their responses (Amin *et al*., 2020:3). In addition to the principal researcher and supervisor, there was a third coder, and the themes were compared.

3.3.1.2 Transferability

Transferability refers to the possibility of the research findings to be applied by others in their contexts (Korstjens *et al*., 2018:121). Furthermore, non-probability sampling may limit transferability; however, the researcher needs to sample participants that will effectively assist in the achievement of the study objectives and provide a logical and concise report of the study. Purposive sampling was used for this study, but the researcher provided clear and rich descriptions of the participants' contexts, experiences and behaviours during the research report writing to assist the readers to judge the applicability of findings to their settings (Korstjens *et al*., 2018:121). The themes and codes were presented together with both short and extensive quotations from the participants. Also, data coding and analysis processes, as well as the reasons for theoretical, methodological, and analytical choices undertaken throughout the study were detailed in the research write up (Nowell *et al*., 2017:4).

3.3.1.3 Dependability

Dependability refers to the extent to which the study findings can be trusted or relied upon (Stahl & King, 2020:27). In addition, trust is built as the researcher clearly explains how the study processes unfolded, but there are other research practices that feel trustworthy, such as peer or professional scrutiny internally before dissemination of the findings, and externally when publishing the research in peer-reviewed journals, and being able to separate personal opinions from facts (Stahl *et al*., 2020:27; Nowell *et al*., 2017:3). The researcher explained the research details clearly; all proceedings were reviewed by the supervisor; and an independent coder was involved in data coding and editing of the thesis. Furthermore, the researcher will submit the manuscripts to peer reviewed journals for publication. Lastly, the researcher’s personal views were clearly indicated, and factual information was appropriately referenced both in-text and in the reference list, also including findings that are in contrast with those of the current study and not only the concurring ones.

3.3.1.4 Confirmability

Confirmability is when other researchers are able to come up with similar findings if they were to repeat or analyse the study data (Korstjens *et al*., 2018:122). Nowell *et al*., (2017:3) further stated that the researcher must be able to demonstrate that the findings and interpretations are based on the data from the participants and then explain how the conclusions were reached. Moreover, when the above measures of credibility, transferability and dependability are reached, confirmability would be established. The researcher was neutral and objective by clearly outlining all the steps undertaken and the reasons for decisions made from the beginning until the end of the study. Again, the audio recorder was used to capture participants’ views so that the researcher could also refer easily, then quotations from participants were included under the themes and also embedded during the analytical narrative (Nowell *et al*., 2017:11). Thereafter, the researcher explained how the support model was developed using data from the participants and literature.

3.3.1.5 Authenticity

Authenticity is when the context and values that influence the study are taken into consideration, thereby assisting in ethical decision making and promoting reality of the findings (Amin *et al*., 2020:8; Alsharari & Al-Shboul, 2019:10). Alsharari *et al*., (2019:10) explains that authenticity may be promoted through: the presence of the researcher at the field to collect first-hand information; clear description of the context; the use of audio tapes to record the interviews; verbatim transcription and presentation of rich-text through participants’ quotations; and evidence of logic and connections with previously conducted research, e.g., literature control. For the current study, the researcher implemented the afore-mentioned strategies, as already explained under the other four measures of trustworthiness discussed above.

Amin *et al*. (2020: 8) highlighted that fairness is the most important criterion of authenticity since it is concerned with treating participants equally throughout the study, without any form of oppression. The procedures to be followed must be explained to all the participants to empower them into making informed decisions. The study participants were given both verbal and written information regarding the study, then written informed consent was obtained from those who willingly chose to participate, with the option to withdraw at any time. The permission to record the interviews was obtained from the participants; and data was not shared with anyone who was not involved in the study to promote confidentiality.

3.4 ETHICAL CONSIDERATIONS

Ethical considerations refer to the principles and procedures that were followed to promote the safety of participants and prevent the violation of human rights (Arifin, 2018:30).

3.4.1 Advocacy and safety

Advocacy relates to acting on behalf of the potential participants to support and protect their rights and safety throughout the research (Nsiah *et al*., 2019:1125). There is a need to advocate for the rights and safety of the participants through the review of the study proposal (Arifin, 2018:31). The permission to conduct the study was sought from the UNISA College of Human Sciences Research Ethics Committee (CREC) which reviewed, made appropriate recommendations, and granted the ethical clearance certificate with reference number 44434960_CREC_CHS_2021, in annexure A (WHO, 2019:14). Permission was further sought and obtained from the gatekeepers: North-West Health Research, Monitoring and Evaluation Directorate (annexure B), Bojanala health district (annexure C), Rustenburg sub-district (verbal) and the operational manager (verbal) of the concerned health care facility (WHO, 2019:21; Arifin, 2018:31).

3.4.2 Informed consent

Informed consent in research is when the study information is clearly provided to empower potential participants to either voluntarily confirm or refuse participation (Manti & Licari, 2018:146). Potential participants were informed about the study through distribution of the information sheets (see annexure H) and answering any questions or concerns. An eligibility checklist was used to recruit participants and they were given ample time to decide whether to participate or not. Informed consent was then obtained without coercion from those agreeing to participate, while at the same time given the autonomy to withdraw from participating at any time and without providing reasons or being penalised (WHO, 2019:21; Arifin, 2018:31). The participants provided a written consent by signing the printouts of the consent forms (annexure D). Furthermore, the researcher offered copies of the signed consent forms but some participants opted out as they felt that the participant information sheets in annexure H, were adequate. Nevertheless, the researcher informed the participants that the copies would still be available should they need them at a later stage.

3.4.3 Confidentiality and privacy

Confidentiality is the mutual understanding and the promise to protect and refrain from divulging the information shared between two or more parties (Pezaro *et al*., 2018: 484). The information of participants was not divulged to other people except those who were directly involved in the study, such as the study supervisor, and this was clearly stated before the participants signed the consent forms. The researcher personally transcribed the audio recording and obtained assistance with coding. The researcher and those assisting in the study signed a confidentiality clause.

Privacy relates to the protection of people or their information from unwarranted interference (Kokolakis, 2017:123). It was promoted during the in-depth individual interviews with PLWHIV as they were interviewed privately and at a time convenient for them. During telephonic conversations, the researcher first asked if the time was convenient, and also checked if the phone was indeed answered by the participant and not the third party before continuing with the interview. The information about participants was locked by the researcher and will remain as such for five years; thereafter, audio tapes will be destroyed, hard copies will be shredded, and an appropriate computer software will be used to destroy soft copies.

3.4.4 Anonymity

Anonymity means that the identity of the participants must not be revealed (Pezaro *et al*., 2018:485). The researcher facilitated anonymity by allowing the participants to use temporary names or codes and not revealing their identity when discussing and disseminating the study findings in the form of a research report, journal articles or conference presentations. The participants' names were not mentioned anywhere in the eligibility checklist or interview guide to break any possibility of linking the participants to the responses. Any documents with participants’ information were locked away so that unauthorised people were not even aware that they participated in the study. However, situations that required the involvement of other people to mitigate negative consequences, such as when the participant could get emotionally distressed and need referral to the professional nurse or social worker for counselling were clearly explained to the participants. For this study, no untoward effects were observed or reported by the participants.

3.4.5 Non-maleficence

Non-maleficence is when the study purpose is achieved without harm to the participants (Motloba, 2019:40). In this study, the researcher refrained from asking the participants uncomfortable or embarrassing questions. A prior arrangement was made by the researcher so that the facility manager was prepared to provide the necessary support to emotionally distressed participants. The interview would have been stopped immediately and the participant experiencing emotional distress referred to the facility manager, professional nurse, or social worker for counselling. However, there was no participant who experienced emotional distress.

3.5 PHASE 2: MODEL DEVELOPMENT

The model development phase started with the presentation and interpretation of findings from the study participants, followed by concept analysis of ‘support’ in order to obtain an in-depth understanding, and then the actual model development.

3.5.1 Findings from the participants and literature control

The findings, together with literature control, are presented in detail in chapters 4, 5 and 6 for LHWs, their supervisors and nurses as well as clients on ART respectively.

3.5.2 Conceptual framework

During the concept analysis, the uses, meaning, attributes and measures of support were explained, thereafter, support was conceptually defined. The eight Walker and Avant steps of concept analysis were used, and include: selecting a concept; determining the aim of analysis; identifying all possible uses of the concept; determining concept defining attributes; constructing a model case; constructing additional case; identifying antecedents and consequences of the concept; and defining empirical referents of the concept (Abdolrahimi *et al*., 2017:4969). Concept analysis is fully explained in chapter 7.

3.5.3 Support model

Thereafter, the model was developed using the survey list of Dickoff (Dickoff *et al*., 1968:423) which has six elements of developing a theoretical framework, i.e., the context, agent, recipient, dynamics, procedure and outcome. The developed model is described fully in chapter 8.

3.6 CONCLUSION

This chapter provided insights on the research design and methodology. The study followed the exploratory, descriptive and contextual phenomenology design. The aspects related to the methodology include the study setting, population, sampling, sample size and data collection methods and analysis. LHWs, their supervisors and nurses, as well as clients on ART, formed the study population. Procedures that promoted rigour and ethical aspects before and throughout the study were also explained.

CHAPTER 4: DATA ANALYSIS AND DISCUSSION OF FINDINGS

LAY HEALTH CARE WORKERS

4.1 INTRODUCTION

This chapter discusses data analysis and findings from 47 participants who were grouped into three categories of 22 lay health care workers, 10 health care professionals as well as 15 clients who have been on ART for at least a year at a community health centre in Bojanala District, North-West Province. The findings are presented as three separate sections named chapter 4 for lay health care workers, chapter 5 for health care professionals and chapter 6 for clients who are on ART. The purpose of this study was to develop an integrated support model for lay health care workers to improve retention to HIV care.

The objectives of the study were to:

- Describe how the lay health care workers interact with PLWHIV.
- Describe the views of health care professionals on the support provided to lay health care workers in carrying out their duties relating to PLWHIV.
- Explore and describe how PLWHIV experience their interaction with lay health care workers.
- Develop the integrated support model for lay health care workers to improve patients' retention to HIV care.

4.2 DATA MANAGEMENT AND ANALYSIS

Ravindran (2019:41) explains qualitative data analysis as an iterative process that attempts to describe and find meaning that participants attach to their actions, and occurs through data transcription, reading and reflecting, coding, categorisation, and development of themes. Furthermore, it allows the researchers to inductively conceptualise and generate general ideas without losing the originality of the participants' narrated experiences.

The researcher commenced with data analysis using a personal cellular phone and a digital voice recorder to ensure that all information is stored and retrieved accurately. The researcher's field notes, and the recordings were analysed together to search for words, phrases, descriptions, and terms that are aligned with the title of the study. All data obtained during interviews were transcribed verbatim and later translated into English since the interviews were conducted in Setswana. The verbatim transcriptions were sent to the independent coder to analyse data separately. After analysing the data, the researcher and the independent coder came together to discuss the coded data and reached consensus about it.

4.3 PRESENTATION OF FINDINGS

Lay Health Care Workers

The first section, chapter 4, presents the demographic details and findings obtained through 4 focus group discussions with 22 lay health care workers. FGD 1 and 2 had six participants each while FGD 3 and 4 had five participants each.

4.3.1 Demographic details of lay health care workers

The participants were selected from different categories of lay health care workers and included tracers (T), lay counsellors (LC), adherence and retention counsellors (ARC), community health care workers (CHW) and health promoters (HP). There were 18 females and four males within the age range of 22 to 59 years of age and the working experience of one to 30 years, as per table 4.1 below.

TABLE 4.1: DEMOGRAPHIC DETAILS OF LAY HEALTH CARE WORKERS

Characteristics	**Lay health care workers**					
FGD 1						
	A	**B**	**C**	**D**	**E**	**F**
Age	41	34	34	37	35	59
Gender	Female	Male	Female	Female	Female	Female
Job title	T	LC	LC	LC	LC	HP
Years of experience	2	7	3	10	9	30
FGD 2						
Age	33	25	44	28	50	22
Gender	Female	Female	Female	Female	Female	Female
Job title	CHW	CHW	CHW	CHW	CHW	CHW
Years of experience	4	1	13	1	13	1
FGD 3						
Age	37	48	36	37	41	
Gender	Female	Male	Female	Female	Female	

Job title	LC	LC	LC	LC	ARC
Years of experience	12	4	12	12	10
FGD 4					
Age	30	31	33	28	42
Gender	Male	Female	Female	Male	Female
Job title	T	T	T	LC	CHW
Years of experience	7	6	6	3	4

4.3.2 Themes and subtheme

After data analysis, four themes and 25 subthemes emerged from the data collected from the LHWs. Table 4.2 represents all the themes and subthemes. Each theme has been presented with its own subthemes and quotations supporting them, followed by literature control.

TABLE 4.2: THEMES AND SUBTHEMES OF LAY HEALTH CARE WORKERS

THEMES	**SUBTHEMES**
THEME 1	**SUBTHEMES**
4.3.2.1 THEME 1: **LAY HEALTH CARE WORKERS' EXPERIENCES IN HIV CARE AND CONTRIBUTION TO RETENTION**	*4.3.2.1.1 HIV testing, counselling and health education*
	4.3.2.1.2 Index testing services and disclosure
	4.3.2.1.3 Tracing of patients, household visits and medication delivery
	4.3.2.1.4 Tools used for HIV care by lay health care workers
	4.3.2.1.5 Lay health care workers' perceptions of HIV testing and same day treatment
THEME 2	**SUBTHEMES**
4.3.2.2 THEME 2: **SUPPORT FROM HEALTH CARE PROFESSIONALS, COLLEAGUES AND SUPERVISORS**	*4.3.2.2.1 Interactions among lay health care workers and health care professionals*
	4.3.2.2.2 Support in terms of direct patient care, provision of work material and training
	4.3.2.2.3 Discussion of performance and challenges
THEME 3	**SUBTHEMES**
	4.3.2.3.1 Limited counselling and information
	4.3.2.3.2 Clients not free to communicate

4.3.2.3 THEME 3: BARRIERS IN PROMOTING RETENTION TO HIV CARE	*4.3.2.3.3 Clients' lack of acceptance, ownership and independence*
	4.3.2.3.4 Stigma and non-disclosure
	4.3.2.3.5 Side effects of HIV treatment, clients' previous negative experiences at the facility, financial and work constraints
	4.3.2.3.6 Clients' provision of wrong information and administrative issues in the health facility
	4.3.2.3.7 Moving adherence clubs to Community-Based Organizations (CBOs)
	4.3.2.3.8 Lack of supervision, feedback and training on updated HIV information
	4.3.2.3.9 Emotional burden and lack of debriefing for lay health care workers
	4.3.2.3.10 Salary and other benefits
THEME 4	**SUBTHEMES**
4.3.2.4 THEME 4: RECOMMENDATIONS TO STRENGHTEN RETENTION TO HIV CARE	*4.3.2.4.1 Focus more on improving client information, ownership and independence*
	4.2 Active involvement of lay health care workers and prominent community members
	4.3.2.4.3 Update the information and counselling skills of lay health care workers
	4.3.2.4.4 Improve communication, teamwork and integration of activities of all role players
	4.3.2.4.5 Balance of activities
	4.3.2.4.6 Reinstatement of facility adherence clubs
	4.3.2.4.7 Filing system improvement

4.3.2.1 THEME 1: LAY HEALTH CARE WORKERS' EXPERIENCES IN HIV CARE AND CONTRIBUTION TO RETENTION

This theme has five subthemes. Each subtheme will be presented and supported by different quotations and literature control. The first subtheme highlighted was associated with their role and contribution in HIV testing, counselling and health education as discussed underneath.

4.3.2.1.1 SUBTHEME 1.1 HIV testing, counselling and health education

Many participants indicated that the role of LHWs is HIV testing, counselling and health education in HIV management. HIV counseling is essential to assist clients in understanding the distinction between test results that are positive and those that are negative. The participants mentioned that this also involves adherence counselling for clients who test positive for HIV, and it helps to prepare them to take medication utilized in HIV management. Clients are provided with health education that covers both the blood samples to be drawn and the pertinent care provided by other healthcare professionals as part of HIV management.

The participants also highlighted that the clients are taught about healthy eating. Furthermore, the participants indicated that counselling for HIV must integrate pretest, posttest and adherence information. However, some participants viewed adherence counselling as different and separate from the general HIV counselling. In general, the participants viewed their work as important and even wished to be called professional counsellors. The quotations supporting this subtheme are presented below:

“I am a lay counsellor, providing HIV testing services. I also provide adherence counselling to clients who test positive for HIV in preparation for treatment initiation. I also offer index counselling where I encourage clients to list their contacts so that they can also be tested for HIV and then started on treatment if positive” T3F3D

“Yes, me too, I am a lay counsellor” T3F3B

“I am a lay counsellor. I test clients for HIV, provide counselling and encourage HIV positive clients to start treatment” T4F4D

“Yes, in addition, I also inform the client that the nurse will collect blood, CD4 and viral load. The client is then referred to a case facilitator to continue with the support and follow up” T1F1D

“I am a lay counsellor, conducting HIV testing but I am also an adherence counsellor” T3F3C

“Same here, we provide HTS (HIV testing services) and make sure that patients are linked to treatment and adhere to it” T1F1C

"My role is to ensure that all people who want to test feel comfortable. I explain what testing is about before they can test. Some people want to test but they do not understand how it works or what they are getting themselves into. The test results may come out negative or positive, so we need to prepare the client for the outcome. I also ensure that I explain what will happen after testing, depending on the results" T1F1B

"Yes, what is also important is to make sure that the patient understands why he/she must take treatment and keep up with the next appointment dates. If I realise that the patient is unable to adhere to the scheduled appointment dates, then I provide enhanced adherence counselling which aims to explore the reasons, provide health education, and discuss possible solutions. There is a form that we fill afterwards that documents what we discussed, and it is called the adherence plan" T1F1E

"During pre-test counselling, I provide information on the testing procedure and how to interpret results. Further counselling is determined by the results. If negative, I encourage the client to remain negative by providing information on HIV transmission and prevention, e.g., the use of condoms. If positive, I explain HIV transmission and prevention, the importance of lifelong treatment and adherence. I do not necessarily use specific tools when I provide the information". T1F1C

"My role is to promote health through emphasising adherence education. I teach them to respect the return dates and take their treatment as prescribed. If they experience problems, they must go to the clinic so that the nurses can change their treatment or put them on another regimen. They must also ask how they are supposed to take their medication upon receipt and must be sure that the medication will last up to the return date provided. So, I mainly emphasise adherence, teach them the importance of a healthy diet and drinking water as well as behaviour change, e.g., the use of condoms. Even if partners are both on treatment, they need to continue using condoms to avoid the multiplication of the virus or re-infection" T1F1F

"There are others who are afraid of coming to the clinic, but we advise them that if they continue to take treatment correctly for 6 months and become virally suppressed, they will qualify to collect treatment at other pharmacies or post office. It then becomes easier for them to continue taking treatment without being afraid of being seen by others at the

clinic or waiting in long queues. I see that this form of motivation has helped clients a lot" T1F1E

"I provide group and one-on-one health talks. I used to accompany the CHWs to different households to trace, especially when I was still working at this other clinic (provided the clinic name); when I found a person on chronic medication, I taught him/her about his/her illness and treatment. Since I started working in this facility, I have been focusing on COVID-19 screening, vaccine registration and health education in the facility only, also emphasising test and treat so that clients can know that they will be put on treatment on the same day of testing positive and emphasising adherence. I also teach antenatal and postnatal women" T1F1F

"Yes, I agree with the issue of healthy eating, but I want to point out that it does not mean that the patient must eat expensive food. He/she can grow a vegetable or fruit garden at home. So, people must not be stressed about being sick, not working and not affording food, the client must continue with anything that he/she can improvise with" T2F2A

"I am an adherence and retention counsellor. My role is to give HIV positive clients support through health education. I teach them about the viral load, CD4 count and the importance of taking treatment correctly because it is important that they understand so that they can continue with treatment" T3F3E

"Yes, they have said it well, we counsel, test and ensure that the client is started and remains on treatment" T1F1D

"They (roles)do not differ. We integrate these two, we counsel for HIV, test and offer adherence counselling to HIV positive clients" T3F3B

"I agree, they do not differ. We combine everything, from HIV counselling, testing and adherence counselling" T3F3C

"No, they differ. The difference is that the adherence counsellor specialises in adherence counselling, for example, he or she provides adherence counselling to clients including those who defaulted treatment or have unsuppressed viral load. In terms of the lay counsellors, our work is just to prick, get the results and inform the client, only. However,

if the adherence counsellor is not available, it comes back to us again because we have also been trained on adherence counselling, so we then offer adherence counselling. But like I said, the adherence counsellor specialises in viral loads and teaching the client about treatment" T3F3A

"My case is different. My job title is adherence and retention counsellor, but I am under the developmental partner supporting the facility. But as the colleagues said in terms of the roles, I do not conduct HIV testing, I just offer adherence counselling to clients with high viral loads and sometimes to those who return to the clinic after defaulting" T3F3E

"Yes, for the developmental partners it is a bit different because they specifically have the adherence counsellor title. So, for me, I test and offer adherence counselling because my job title is lay counsellor" T3F3C

"We are doing a good job and have been working for a long time, I just wish our title can be changed from lay to professional counsellors (laughter from participants)" T3F3A

When asked about their contribution to retention in HIV care, some participants were not aware of their contribution, but managed to identify it as other participants explained. Some of the quotations are presented below:

"I am not directly working with retention. I just provide HIV testing, pre-ART counselling for HIV positive clients and refer them for ART initiation. Tracers and CHWs deal with retention by tracing clients who defaulted treatment" T4F4D

"Ok, no, that is not our work. That is where the adherence counsellor comes in. But long time ago when there was no adherence counsellor, we knew that we were supposed to teach the client about keeping up with the scheduled appointment dates and making sure that he/she does not default treatment" T3F3A

"Yes, I agree that we are not that much into retention. In fact, the tracers are the ones who work with retention. As lay counsellors we just assist the tracers by counselling the defaulted clients after returning to the clinic, that is it" T3F3C

"I hear my colleague saying that as a counsellor he does not contribute to retention. I think counsellors contribute a lot because they are the first people who communicate with clients after testing positive. So, as they provide information and adherence counselling, they promote retention" T4F4C

"Oh yes, if you put it that way, I now understand my contribution as a counsellor. So, after a client has tested positive, I offer post-test counselling and encourage the client to start treatment" T4F4D

"After interpreting the positive results to the client, we provide health education on prevention of HIV transmission, the importance of treatment and adherence thereof. So, I think this is our contribution to retention, yes, we contribute" T3F3D

"Oh yeah, I see, you are right. We do provide education, and when the adherence counsellor is not available, we provide adherence counselling. So yes, we are contributing to retention through information giving" T3F3B

"Most of the time we contribute by informing the clients that the treatment is lifelong. I remind them about this and encourage them to continue with treatment. Clients can also come back to discuss any treatment challenges or any other emotional burdens that they may experience, then we both discuss possible solutions and still emphasise the importance of remaining on treatment" T1F1A

"During follow up counselling, we discuss issues from the first session and that is when I see if the client retained the information or not. It is just unfortunate because sometimes the clients do not return to us for follow up counselling. We have a case facilitator who starts to support them immediately after testing positive up until the client is stable to be decanted" T1F1E

"When the client responds as I communicate with her/him during counselling, it is a sign that he/she understands. Some clients ask questions, and this shows that they heard what was discussed and are trying to interpret" T1F1B

"Adherence is very important. For treatment to work effectively, the patient has to take the correct dose as prescribed and keep up with the scheduled appointments" T1F1C

“We also encourage the client to disclose the status to a trusted family member or friend, etc., so that they can provide support. Some clients may experience medication fatigue after some time, so a treatment buddy or a family member is important to provide support” T1F1D

“But yet again, as much as family support is important, the client must learn to be independent because sometimes their support system may abandon them. So, the client may become demotivated to continue with treatment” T1F1C

“Yes, I agree that we have to find other ways of helping the client to disclose. If it is difficult for us as counsellors, we can refer the couple to the nurse or case facilitator because they are more skilled” T1F1E

“Sometimes as patients continue with treatment, they tend to forget it or even not incorporate HIV into their life. Other clients work, raise children, and do other life activities but put HIV aside, that is why I say they do not regard HIV as part of their life. So, clients need to accept HIV as part of their life and get used to living with it. So, I contribute to retention by discussing these issues and showing them the importance of taking treatment consistently” T3F3E

The findings concur with that of a study conducted by Mwisongo *et al*., (2015:5) regarding evaluation of the HIV lay counselling and testing profession in South Africa, which indicated that lay counsellors played a crucial role in HIV testing and counselling. Furthermore, lay counsellors also provided other services such as adherence counselling, health education and promotion, home based care and also facilitated patients’ support groups. A review study conducted in Sub-Saharan Africa to assess the sustainability of counselling found that the work of the lay counsellors was not regulated by any professional body, except in Zambia, where the counsellors’ council has been established and psychosocial counsellors are recognized as formal health workers (Bemelmans *et al*., 2016:3). Although the current study participants did not say anything about belonging to a professional body, one participant wished that their title could be changed from lay to professional counsellors.

Igumbor *et al*., (2019:8) conducted a study in Uganda to assess the effect of the mentor mother programme in retaining mother-baby pairs to HIV care. The same study found that the women who received psychosocial support from the mentor mothers had higher retention rates throughout the different time periods, compared to those who attended routine care. Participants also indicated that HIV testing helps in identifying clients for index testing services which further facilitate disclosure as alluded in the subsequent subtheme.

4.3.2.1.2 SUBTHEME 1.2: Index testing services and disclosure

Participants revealed that index testing is a programme available to clients who have tested positive for HIV. The participants demonstrated the significance of this service by explaining how it enables clients who are HIV positive to come with their partners for testing, while also helping them with disclosure. Others, however, discussed the dangers of retesting a client who is already receiving ART, warning that if the client tests HIV negative due to the effects of antiretrovirals (ARVs), it could be confusing; instead, other methods of disclosure should be considered. Although all participants felt that the index program was important, they also pointed out that diverse approaches were used, with some assessing the danger of intimate partner violence (IPV) and others not, as well as not using the proper guidelines. Quotations below support this subtheme:

"There is an index programme now in the facility, so I encourage clients to bring their partners for counselling and testing. When they come, it will be as if they all do not know about their status. They are then all tested as if it is for the first time, then when the results are positive, it becomes as if they are being diagnosed at that time and post-test counselling commences. This is done so that the partner of the index client does not find out that the client tested long time ago and has been on treatment" T1F1A

"We also have the index programme now where HIV positive clients are encouraged to bring their partners for testing. When the index client and partner come, sometimes the index client acts as if he/she does not know the status and we do not know how to address that. Sometimes you agree to test them, and they test positive, now the challenge comes in when you have to open files as one is unable to open the file for the known client because he/she already has one" T3F3D

“Yes, and now the partner wants to know why you are opening only one file. That is when he/she becomes suspicious that something is not right. I also remember another incident when the partner found medication in the client’s handbag, and they came to me. They were fighting and I had to calm them down” T3F3B

“Indeed, the partner becomes aware that there is something odd. Even if you can try to take one of them outside, it does not help, it becomes even worse. The partner wants to know why the other one has to go out but was available all along throughout the counselling and testing” T3F3A

“Even when the Oraquick test kit which swabs the gums for HIV self-screening was introduced, we were informed to refrain from retesting clients who are already on ART. I think re-testing is a risk and may cause confusion to the client who is already on ART if the results can be negative. So, the aim of disclosure in this situation will be unsuccessful. We need to find other ways of helping the clients to disclose” T1F1D

“But I think we were advised not to retest clients who are already on treatment. Is it not for the same reason of avoiding the possibility of getting false negative results?” T1F1C

“It has never happened. There is no way that the test results can be negative, it is only the viral load that can be lower than detectable limit” T1F1B

“Yes, that is true. Index is helping us, and the client is given options from the modalities offered. Like he/she may opt to disclose to the partner, bring the partner to be assisted with disclosure or consent that a follow up be made to his/her contacts through counselling and testing but without disclosing the status” T1F1B

“Index programme is very useful. It is just that no one takes time to take us through it. Once you counsel the index client correctly, partners come back for testing as well” T3F3C

“I also agree that the index programme is useful. Although I do not necessarily complete the stationery used for the programme, when I provide adherence counselling to clients with unsuppressed viral loads, I inform them about the negative effects of high viral load and the importance of testing their partners and children. Sometimes clients say that they

do not have partners, or that they have side partners and cannot bring them to the clinic. But those that have partners and consent to listing them, I write their details down and give them to the lay counsellors to continue with the relevant procedure. I do not force clients to accept index testing, I just explain its importance and they have a choice to agree or refuse" T3F3E

"After what the colleague said in terms of offering index testing to clients with unsuppressed viral loads, I am beginning to see that the programme is important and if done correctly can reduce HIV transmission. The only challenge is that when these programmes are introduced, we are left behind and are expected to implement at a later stage when we are already demoralized" T3F3B

"Yes, the index programme is useful. I offer it to all clients who tested positive, then document and provide follow up to clients who accepted it" T3F3D

"I have been doing index superficially so, I don't remember talking about Intimate Partner Violence (IPV). We were just trained recently so we are not yet good with index" T3F3A

"Same here, I just ask simple questions from my head, like where her partner is and how she thinks her partner will receive the news. I do not talk anything about violence (IPV)" T3F3C

"I don't remember doing that (screening for IPV)" T3F3B

"I ask the index client about the partner and whether she is comfortable with disclosing to him or not. Then I go through the IPV screening questions and tick the appropriate boxes. If the index client does not want the partner to be listed, I respect that. If you write the partner, the tracer my trace him only to find that the index client has not disclosed yet and it will be a problem which may lead to IPV as well" T3F3D

"This is not applicable to me because I just inform clients about the programme and then refer them to the lay counsellors to continue with the necessary activities" T3F3E

Jubilee *et al*., (2019:9) conducted a study in Lesotho which showed that HIV index testing promoted accessibility to HIV services, provided an opportunity for assisted disclosure in a family setting, closer rapport between providers and clients, and identified a higher HIV positivity yield than other community testing models. This is in line with the findings of this study where index testing services were also linked to HIV disclosure and linkage to care.

Similarly, another study conducted in South Africa to determine the feasibility of the index programme in partner and children testing found it to be an inexpensive way of improving HIV case-finding and awareness of one's status (Davey *et al*., 2019:7). The same study found couple counselling and testing to be a popular strategy for most participants but posed a challenge when one partner already knew the HIV positive status and had not yet disclosed. The complexity of handling couple counselling and testing sometimes led to re-testing the already known HIV positive client, which concurs with what the current study participants stated. As a result, implementers need guidance on how to effectively manage couples during index testing.

A study conducted in Kenya to determine if assisted partner testing increased HIV testing, diagnosis and treatment among partners revealed that although the programme improved HIV case finding, caution must be exercised when planning to scale up to HIV low burden sites as it may not be as effective as in high-burden areas (Cherutich *et al.,* 2017:10). The same study further highlighted the importance of screening for intimate partner violence before enrolling clients for assisted partner testing. The index testing services can also be integrated with household visits or tracing of HIV treatment defaulters as presented in the subsequent subtheme.

4.3.2.1.3 SUBTHEME 1.3: Tracing of patients, household visits and medication delivery

Another crucial responsibility of LHWs includes telephonic or physical tracing of patients on HIV and TB treatment who missed their clinic appointments. Besides those who missed their clinic appointments, community health care workers are allocated households which they visit regularly and sometimes deliver medication to clients who are unable to attend the clinic. The study findings showed that patients are visited or traced at home, then educated and encouraged to take medication as prescribed. During these visits, clients' concerns or inquiries about their health condition are also addressed, thereby improving adherence to treatment. In order to prevent mother-to-child HIV transmission, mothers and their babies are also examined to see if they are taking the prescribed medication and prophylaxis, and they are also educated on self-care. The subtheme has been supported by the following quotations:

"I provide support through providing information to the clients when tracing them telephonically. I have realized that most of the clients do not understand despite being on treatment. It looks like our counsellors do not give enough information about HIV that is why I need to provide enough information to the clients. I am saying this because the patients still use traditional medicines and do not use condoms, so I try to show them the danger of these behaviors while on HIV treatment" T1F1A

"I work as a CHW. My role is to register the households, determine if there are any family members on chronic medication and encourage adherence" T4F4E

"I do not want to repeat what they said. What I can add is that we register households and are able to identify clients on HIV and other medication. In that way we are then able to provide health education in line with their needs or questions" T2F2B

"My role is to go out in the field to check HIV positive patients, including clients with other chronic conditions. I check their well-being and provide health talk on the importance of taking treatment correctly at the same time and the dangers of defaulting. I also encourage them to reduce alcohol intake but rather drink more water because alcohol is not good for the immune system" T2F2C

"Yes, when treatment is taken at the same time it suppresses the virus and when the virus is low the immune system functions properly and the client can live a healthy life. Again, we check if mothers and their babies have attended the clinic correctly and have the necessary medication. It is also important to check if the HIV exposed baby has the necessary prophylaxis and is taking the correct dose" T2F2A

"In addition, we advise them to eat healthily, and we also emphasise good hygiene, with emphasis on the clean environment. If the environment is not clean it harbours germs which are not good for the patients. They must wash their hands regularly to prevent illnesses such as diarrhoea which may weaken the immune system" T2F2D

"We have seen people who default, they become sick and weak because now the virus is replicating and overpowering the immune system. It is bad, sometimes treatment no longer works for them and are in need of stronger medication than before. These are the

patients who are requested to list their contacts so that they can be counselled and tested as well because their risk of HIV transmission is high" T1F1E

In terms of retention, participants mentioned telephonic and physical tracing of clients who missed their appointments as a way of promoting the Welcome Back Campaign (WBC). Household visits done include the delivery of medication, reminding clients to take their medication as prescribed and motivating clients through informing them about other treatment collection options such as the treatment buddy or external pick-up points if eligible. Quotations are presented below:

"Yes, we do similar activities, and we visit the households in pairs of two or more. So, our main contribution to retention is through health education, tracing and delivering medication to some clients" T2F2B

"Sometimes we collect medication and deliver for clients, especially the elderly or those that are unable to go to the clinic due to work constraints" T2F2C

"Sometimes I offer to help clients who are working and stay in my area. I ask them to come to the clinic in the morning, check the vital signs, collect blood, give me their appointment cards, and leave for work. I then collect their medication and deliver to them on my way home from work" T4F4C

"I work as a tracer. I telephonically trace clients on ART or TB treatment who miss their scheduled clinic appointments so that they can return to care. Although I spend more time calling the clients, I also do physical tracing in the community" T4T4B

"I contribute to retention a lot because as I trace the clients telephonically, most of them return to the clinic to continue with their medication. As clients return to the facility, I sit down with them to discuss their challenges and help them to come up with solutions that will prevent future defaulting" T4F4C

"I trace and remind clients about the importance of continuous treatment collection. Stopping treatment has a negative impact on both individuals and their families because when a client becomes too sick, he or she must be cared for, and this disrupts the family's routine activities. I also acknowledge that a client may forget to take treatment on a

particular day, but it should not happen often. Reminder systems like phone alarm or putting medication where you can easily see it, are encouraged. It is also important to listen to what the client is saying without interrupting him or her because this shows respect and interest; you'll also be able to understand any concerns" T4F4A

"And now we have been encouraged to implement the Welcome back campaign where clients who missed their appointments are encouraged to return to their clinics and be fast queued. This is a good initiative but if clients start to take advantage of this and default deliberately, I do not think that they must be fast queued. It is not fair for other clients who consistently go to the clinic to get their medication" T4F4D

"We also trace patients and sometimes they complain about long queues. So, I normally advise them to be patient and continue with treatment because they will qualify for Dablapmeds. Dablapmeds is like decanting, the patient collects treatment at the external pharmacy, Pele box or post office at their convenient time and only go back to the clinic after 6 to 12 months to collect blood or renew the prescription. This encourages them because they can opt for a suitable treatment collection point" T2F2A

"To add on continuous health education and advice, I encourage clients to stick to their appointment dates; however, if they are not available on that particular date, treatment buddies can collect treatment for them using ID copies or appointment cards. And yes, I find that some clients become motivated when they hear that there is an opportunity to collect treatment at external pick-up points, provided they collect their medication correctly and achieve viral suppression" T4F4B

"Yes, clients can send the treatment buddy to collect treatment, but we need to clarify that if it is time for the client to collect viral load, he or she cannot send the buddy. Again, if the client has unsuppressed viral load, he or she needs to be seen more often, i.e., monthly, to receive enhanced counselling and monitoring. So, if a client is free and has disclosed to trusted people, they can help with treatment collection and improve adherence and retention" T4F4C

DiCarlo *et al.,* (2018:6) conducted a study in Kenya to evaluate the impact of lay health care workers' interventions in retention of HIV positive mothers and their babies, which showed an improvement. Home visits allowed for continued counselling and health education on aspects such as nutrition, adherence, and infant care, as well as the understanding of the clients' home environment and family as a whole. Schmitz *et al*., (2019:6) conducted a scoping review of studies conducted in Sub-Saharan Africa to determine the role and impact of LHWs' programme on mother-baby pairs. The study revealed that LHWs reminded clients of their next clinic appointment dates and the importance of taking medication regularly; obtained a list of clients who defaulted treatment and traced them, and also carried out follow-up visits within the community.

Another study conducted in South Africa to determine the experiences of clients who discontinued treatment and later returned to care found that the WBC encouraged clients to return to the clinics, and 5% of those who returned were traced through the WBC (Bisnauth *et al*., 2021:5). Bogart *et al*., (2022:4) found that clients and health care providers were satisfied with differentiated treatment delivery models because they promoted convenience, flexibility, reduced queues, and limited disruption of the clients' work schedule. The above results concur with the study findings.

The next subtheme reflects the importance of tools used in HIV care by lay health care workers.

4.3.2.1.4 SUBTHEME 1.4: Tools used for HIV care by lay health care workers

The participants in the study mentioned different practices in terms of the tools that guide them to perform their duties. Some participants indicated that they use household registration as well as pregnancy, STI and TB screening tools. They also use phones to capture outcomes after tracing. However, participants indicated that they do not have specific tools that guide them on what to say during telephonic or physical tracing. Some lay counsellors indicated that they use information from their heads because they have memorized the testing procedure; however, others mentioned that they use an adherence plan, stopwatches and the testing algorithm visual aids. Quotations below are from the participants:

"I do not have a specific tool that I use, I just use the knowledge that I have" T2F2E

"There are some tools that we complete during household registrations, sometimes we have the pregnancy, STI and TB screening tools and refer to the clinic where necessary" T2F2A

“Yes, we use household registration forms, but we do not have a guiding tool that we use when interacting with HIV positive clients” T2F2C

“Other than that, we have gadgets which we use to capture clients traced and provide feedback to the facility. But like other colleagues have said, there is no tool that we use as a guide when visiting HIV positive clients” T2F1D

“At the counselling room, I use the testing algorithms and the information that I have to provide both pre and post-test counselling” T4F4D

“We use a stopwatch and job aids that guide us on the testing algorithm” T3F3C

“Okay, we used to have something like that (counselling guideline) long time ago, I don’t know what happened to it” T3F3C

“Now we use the information from our heads, in fact we have memorised the procedure. We know the steps to follow, we first ask the date of the last HIV test and the results. I don’t remember referring from any document” T3F3D

“When the client tests positive, you know what to say, thereafter you refer him/her for blood collection and adherence counselling” T3F3A

“I have the adherence plan book” T3F3E

“I do not have a tool that I refer from when tracing. I just use my experience and the information that I received previously during training” T4F4C

“I also do not use any tool. When I trace telephonically, I introduce myself and check if I am talking to the right client before I proceed with the reason for my call. I then ask the client when he or she will be able to return to the clinic as well the reasons for defaulting” T4F4A

"I also do not have a specific tool for tracing clients. I just register the household provided if no registration was done previously, then use the phone to capture the tracing outcome. I screen for TB and ask about other challenges" T4F4E

"I think the situation is the same for tracers. I also do not have any specific tool to guide me when tracing clients. I rely on my experience, but I think this is challenging for new tracers or CHWs who have not developed the skills yet" T4F4B

"I do not have a specific tool that I use when tracing or providing information to clients. When a client answers the phone, I confirm his/her name, introduce myself and ask him/her to go to the clinic. I also ask the reasons for skipping the clinic appointment. The reasons include client being at work, visiting other areas, no longer interested in treatment and others refuse to give reasons" T1F1A

"I do not have a specific tool to use. However, during health promotion talks, I emphasise adherence to medication and clinic appointments. I also teach clients about viral load and explain that it checks if the client is taking treatment well to suppress the virus. I motivate them to be patient because once the viral load suppresses after 6 months, the client will be given an option to continue taking treatment at government approved pharmacies, post office or Pele box. I find that most of them become motivated by this decanting option" T1F1F

A review study aimed at assessing the sustainability of counselling in eight Sub-Saharan countries found that South Africa has guidelines that facilitate the quality of counselling, such as the HIV Testing Services (HTS), integrated adherence of HIV, TB and non-communicable diseases, paediatric disclosure, and patient education (Bemelmans *et al*., 2016:3). However, Mwisongo *et al*., (2015:4) found that the majority of lay counsellors in a study conducted to evaluate lay counselling and testing profession in South Africa had not incorporated HTS guidelines into their work and this is in line with the study findings.

Scott *et al*., (2018:10) conducted a systematic review of community health care workers' (CHWs) programmes and found educational materials and job aids such as standardised checklists and records to be contributing to effective work of the CHWs. However, training and provision of educational material need to be followed by supportive supervision to facilitate the effectiveness of CHWs. The use of tools is followed by the lay health care workers' perceptions of HIV testing and same day treatment.

4.3.2.1.5 SUBTHEME 1.5: Lay health care workers' perceptions of HIV testing and same day treatment

The study findings showed that the LHWs had varying perceptions and experiences of HIV testing and same day treatment. The participants' prediction versus the reality of what clients feel or go through are different and there is a need for thorough preparation of clients so that they can accept the HIV positive status. Some participants felt that the national HIV policy introduced the same day treatment where HIV positive clients start ART on the same day of the diagnosis; however, it did not consider the practices related to client preparation and acceptance.

The participants indicated that it is not easy at times for clients to accept taking ART immediately after diagnosis without undergoing thorough counselling. Some clients even abscond after testing positive for HIV and being informed about starting ART on the same day because they are not ready. Furthermore, the participants highlighted the difficulty of spreading and completing the adherence sessions over a number of days; instead, they complete them in one day, which is overwhelming for clients and also breaks the counsellor-client bond. The quotations below support this subtheme:

"Some people take HIV testing simple, they think you can just test and that there are no emotional aspects attached to it. Once the results become positive, they become shocked and do not accept these results. So, HIV testing is not as easy as people think. We must try as much as possible to prepare the client for the results through discussing the procedure and expectations" T1F1B

"Others state that they feel like they were forced to start treatment when they were not ready. I think this test and treat has brought problems because the patient is put on treatment before he/she can think thoroughly about it. I feel that patients must be given some time to go and think about treatment. I remember during the holidays, I used to assist with testing and counselling. I had patients who tested positive, and I informed them that I was going to call another counsellor to offer index, then take them for treatment. When I came back, clients had absconded, I think they were not ready for treatment" T1F1F

"Yes, that is why we sometimes have clients who test positive for HIV but refuse to start treatment because they do not feel ready. They need intensive counselling and preparation" T1F1D

"Yes, there was a time when I assisted with HTS. After the client tested positive, I provided post-test counselling and while I was still busy, the client insisted that she wanted to go to the toilet. She absconded and never came back. I tried calling the client back, but she did not respond. So, I think preparation is really important" T1F1F

"It is not possible. We cannot see the patient for 3 days because of test and treat. You counsel on that day and the patient starts treatment and that's it" T3F3B

"Yes, you have to complete all the sessions on the adherence plan on the same day and you cannot continue with the sessions beyond that day. We are no longer bonding with our patients; it is one session, and they are out of our hands" T3F3C

"For me it is easier because I mainly see clients with unsuppressed viral load, so I am able to schedule follow up appointments accordingly" T3F3E

In line with the findings, is a study of the health providers' perspectives on same day ART initiation in South Africa, which showed that health care workers, including lay counsellors, were worried about the clients' readiness and the possibility of disengaging from care if hurried into starting ART. Moreover, health providers felt that clients needed time to think through the HIV diagnosis, disclosure and treatment and also supported the patients' rights of agreeing or refusing treatment initiation (Onoya *et al.,* 2021:8). In addition, another South African study that was conducted to assess the implementation of same day ART initiation (SDI) found an improvement in terms of health care providers following these guidelines; however, there was a major concern of poor retention of clients offered SDI (Lilian *et al*., 2020:7). Moreover, the study highlighted the importance of preparation, readiness and continued counselling of clients who were provided with SDI.

In contrast, a study conducted in South Africa to compare the timing of ART and impact on longitudinal outcomes found no difference in retention to HIV care among clients whose ART initiation was deferred and those who received SDI (Mshweshwe-Pakela *et* *al*., 2020:5). The contrasting findings may be attributed to the methods of data collection- the latter study used retrospective chart reviews while the current and concurring studies used interviews.

4.3.2.2 THEME 2: SUPPORT FROM HEALTH CARE PROFESSIONALS, COLLEAGUES AND SUPERVISORS

The study findings under this theme elaborated on the support given to LHWs in terms of the interactions, patient care and provision of work material, as well as the discussion of performance and challenges. Three subthemes emerged from this theme, and each has been presented underneath with its quotations and literature control.

4.3.2.2.1 SUBTHEME 2.1: Interactions among lay health care workers and health care professionals

The study included several categories of LHWs such as lay and adherence counsellors, tracers, community health workers and health promoters. These participants revealed that they sometimes assist each other in doing specific responsibilities such as HIV testing, but they never really meet to discuss their work even though it is interrelated. Again, the participants expressed fears of being viewed as incompetent if they are unable to counsel certain clients; therefore, they rather call other lay counsellors for help, not the professional nurses, except when clients refuse to start ART. Again, some nurses do not offer immediate assistance to clients who need to return to work, which has a negative impact on the retention of patients. The LHWs also felt that they were not supported with the correct completion of contact details which would help them to trace clients when they default treatment. Some quotations are listed below:

"Sometimes we support each other, that is, me (health promoter) and the lay counsellors only, like I help them with testing and counselling when there is a need. At times when I need assistance with clients' return dates or those who need to be helped quickly and return to work, there is this one nurse who is always willing to help. She does not give me any problems and attend to my requests with immediate effect. Other nurses do not assist immediately, they'll let the client wait for a long time just to correct the return dates, despite knowing that the client needs to return to work. We are really failing these clients at times. It is really not right; we are tossing the clients around and this is affecting retention as

well. So, in most cases, I encourage clients to join adherence clubs or collect medication from external pharmacies, some still prefer to go to the clinic and see nurses" T1F1F

"No, we cannot call a nurse. We have to make sure that the couple leaves the counselling room with the understanding" T3F3A

"Yes, I rather call another lay counsellor whom I feel can do a better job than me. I have to make sure that the couple understands. We encourage them as much as we can, we say all sorts of things, sometimes we even lie that our close relatives had the same experiences, just to make them feel encouraged" T3F3C

"Yes, you cannot call a nurse because it will seem as if you are incompetent. So, the clients will undermine you because you do the job, yet again you call the nurse to assist you, no" T3F3D

"The only time we call a nurse is when a client refuses to start treatment, that is where manpower is needed. But for counselling, no, we do not call nurses. We are the ones who communicate better with clients, and they trust us more" T3F3B

"Clients sometimes leave the nurses at the consulting rooms and come to us if they did not understand something. I don't know why, but I think it is because they trust us" T3F3C

"Yes, it is because we have good hearts. Do you see how important a lay counsellor is? Clients trust us" T3F3A

"Yes, we communicate with them nicely. And they also tell us that they are scared of nurses because they are rude to them. So, they ask me to accompany them to the nurses" T3F3C

"Yes, we do not meet to discuss our work. And truly speaking we need each other because our work is interrelated, for example, if clients are not informed about the importance of contact numbers, I am going to struggle during tracing if numbers are wrong. You see, I am not the one who initially meets with clients to update their contact numbers, but at the end I am the one who is going to use these contact numbers to trace a client if he or she defaults treatment. Last time there was a picture sent to our work

group, it was a file with no phone numbers but just the residential area without a house number or next of kin. How am I going to trace such a client?" T4F4A

"It is true that (as a tracer) when I am not available the client may struggle to be helped; however, when I am not available, I inform other staff members that I am expecting certain clients, so they assist and give me feedback accordingly. Sometimes I retrieve the files, put them in a secured area so that it becomes easier for other staff members to take the client to the consulting room" T4F4B

The findings of this study have been supported by the results of a systematic review which revealed that LHWs needed support that is individually tailored to enable them to offer effective health programmes. This is crucial because they had little formal training as compared to health professionals (Hodgins *et al.,* 2016:5). Again, a study conducted in South Africa to determine the lay counsellors' experiences at primary health care facilities highlighted varying levels of support, from inadequate to adequate, as well as some lay counsellors feeling undermined by other health professionals (Letsoalo *et al*., 2017:35).

Similar findings were highlighted in a study conducted in several low- and middle-income African countries to assess retention roles of CHWs, where incorrect contact information of clients was identified as a major barrier to tracing those who missed their clinic appointments, therefore facility staff offered support by calling clients immediately after providing phone numbers to confirm them (Besada *et al*., 2018:9). Bemelmans *et al*., (2016:3) found that the lay counsellors were able to refer difficult cases to health professionals, in contrast to the study findings which revealed that lay counsellors tried by all means to deal with difficult cases among themselves, referring only clients refusing treatment initiation to professional nurses.

4.3.2.2.1 SUBTHEME 2.2: Support in terms of direct patient care, provision of work material and training

Participants mentioned several issues related to support from health care professionals. Other LHWs showed that they were motivated by the good support from health care professionals, while others did not and felt overburdened by patients' problems. Those who felt supported stated that the health care professionals assisted by seeing traced clients quickly, initiating clients on ARVs and explaining difficult concepts in simple terms. Same thing with working materials- other LHWs highlighted that there was enough support while others indicated that there was no support at all. The differences in support were also caused by the provision of job aids to lay counsellors of the developmental partner only, leading to feelings of discrimination among the Department of health’s lay counsellors. The other support gap was related to orientation, in-service training and refresher courses for LHWs. Quotations below are from the participants:

“There is none (support) from my side. Anyway, it depends on which side you are referring to” T1F1B

“No, there is no support. I am stressed and overburdened by the patients’ problems alone. They must just stop to pile the burden on us” T1F1C

“No, but they support us. Isn’t it that at times when a patient refuses treatment you call a clinical mentor to reach out to the client using her advanced skills? Maybe the client can understand better. I think that is how they support us” T1F1D

“To be honest, I receive good support from the clinical nurse mentor. She is helpful and explains things that I do not understand. Even though I am not clinical, she is able to go to my level and explain in a way that I understand. I am really happy with her support and when I go to work in the morning, I am motivated and looking forward to it. So, I am capable of doing my work, through her consistent support. As for my colleagues, I send details of clients to be offered index to some lay counsellors; however, we never really meet to discuss our work” T3F3E

“I get support from the manager in terms of dealing with the non-disclosure cases that I referred to earlier on. She assists me in counselling these clients. That is where we both provide the information to the partner who is not disclosing that if he/she continues with unprotected intercourse with the negative partner, it is the same as intended murder. There is also pre-exposure prophylaxis which can be given to a negative partner to prevent HIV transmission” T1F1A

“The nurses try to see the defaulted clients as soon as they can, but sometimes they have other responsibilities to attend to” T4F4B

“Nurses initiate clients (on ARVs) that have tested positive” T4F4D

“The nurses sometimes assist me by seeing clients that I have traced, but at times it is not possible due to shortage and workload. Earlier on my colleague mentioned the Welcome back campaign which not all staff members support because they feel that clients default intentionally. What I normally do is to check how many times the client has defaulted, if it is only once and the client has tangible reasons, I plead with the nurses to fast queue them” T4F4C

“The support that I am identifying is not necessarily from the supervisors. There is a case facilitator who follows up clients who tested positive. The tele-tracers and CHWs are also assisting with telephonic and physical tracing and also check reasons for defaulting. This helps because clients are returning to care” T1F1E

“On the other hand, supervisors are good at providing working material, yes, they are trying their best in this regard” T1F1B

“In terms of the other support, my supervisor provides support through provision of working material and stationery” T4F4D

“Lay counsellors from the developmental partner were given these small bags with bottles inside and these bottles will help them to teach clients about the viral load. Their supervisor came to orientate them on these bottles, but he stated that the bags are for their lay counsellors only not us” T3F3B

“How are we going to educate clients if we do not have the resources?” T3F3B

Other participants revealed that there was lack of support related to orientation, in-service training and refresher courses, which end up affecting patient care negatively, sometimes leading to failure to meet the community’s need for correct information, as in the quotations below:

“Yes, there is no support. Some of us have not been properly orientated on our roles ever since we were appointed in 2020. We just go with the flow, whether it is right or wrong, we do not know” T2F2F

“Yes, there is no orientation. Ever since I started working, the focus has been on COVID-19 but still I am expected to trace or register the households. So, I have been pairing with those who have been here before me to learn from them” T2F2B

“I have been trained on counselling and adherence, but it was long time ago. I need a refresher course” T2F2D

“I have also been trained, but I am not confident that I can provide this service to clients. It was long time ago and I think the information is outdated now” T2F2C

“I have been trained, but not here. I come from another district. I feel capable to provide these services (counselling) though I do not use these skills more often” T2F2A

“No, I have not been trained” T2F2B

“No, I am not trained” T2F2E

“Yes, I was trained at school and did the practical there. I have not really practiced in the field so I am also not confident that I can counsel optimally” T2F2F

“I think we need training on this so that we know which skills to use to encourage clients to disclose to their partners when they get home. We are only trained on pre- and post-test counselling, but we do not know how to advise the clients on disclosure strategies” T3F3D

“I don’t see the support because I have been asking for a mere in-service training since February, almost 8 months now, but it has not happened. Some of our colleagues are new in the facility and we don’t even know how to deal with hypertensive clients or rather which treatment they take. Again, it is important for me to be able to explain the pill containers, like if an elderly client needs help with taking the medication, I must be in a position to assist. Like Ridaq, it is not a medication, it is a supplier, so if the elderly client wants Ridaq and I do not have a container written Ridaq, it is a problem because Ridaq is a supplier. So, I have requested this in-service training to be done at least once a month so that we can understand the medication that our clients are taking. I should not find myself not knowing how to assist the elderly clients” T2F2A

“I would like to second this issue. There is no support, no refresher courses, no mentoring. We are just working, there is no time for reflections” T2F2D

These findings have been supported by the study conducted in South Africa to explore the perceptions of facility managers on outreach teams’ support and supervision, which indicated that there are some gaps in the supervisory and managerial relationships between ward-based outreach teams and primary health care (PHC) facility managers (Mhlongo & Lutge, 2021:9). The study highlighted that the challenge might be related to the high workload at clinics, which may undermine the capacity of PHC facility managers to support and supervise the teams, and further went on to illustrate that field supervision seemed to take place rarely, and for those teams living far away from the clinic, communication with the clinic manager may be difficult (Mhlongo *et al*., 2021:9). The other concurring findings pertain to the lack of training and preparation of the teams.

Another concurring study which was conducted in Swaziland to determine how the performance of CHWs can be improved, revealed the frustration experienced by CHWs when they were unable to answer community’s questions, and also expressed the need to undergo additional training (Geldsetzer *et al*., 2017:6). Similarly, Letsoalo *et al*., (2017:33) found that some lay counsellors started working without training while those that received training still required refresher courses to remind them of some aspects of their work that they may have forgotten. Bemelmans *et al*., (2016:7) further stated that training on adapted and disclosure counselling, as well as on the job coaching, is needed to improve lay counsellors’ ability to effectively deal with emerging responsibilities.

4.3.2.2.3 SUBTHEME 2.3: Discussion of performance and challenges

The findings reflected differences in terms of discussing work performance and challenges with nurses, clinical mentors or facility manager. Some participants explained that they often had performance meetings with the clinical mentors and facility managers. However, the meetings neither included all key staff categories nor produced positive outcomes because there was nothing done by managers afterwards. Other LHWs indicated that they had never met or been called by the facility manager to discuss the work performance or challenges. Most participants regarded feedback and communication as key elements to effective working relationships. Quotations below represent the lay health workers’ experiences:

“In terms of other support, the clinical mentor and facility manager sometimes call a performance review meeting, but it is only few counsellors, one nurse and telephone tracers who attend. Some staff categories like CHWs, OTL, and clerks are excluded, and I think it is important that we include them as well” T4F4A

“There is a performance meeting that we attend on Fridays. They also ask about the challenges, but my problem is that it ends there, nothing happens afterwards. We just talk and that’s it” T3F3A

“Okay, I am aware of the meeting, but I did not know that challenges are also discussed” T3F3B

“All categories attend, but only 1 employee per job title” T3F3D

“We all used to attend the meeting but rotating. Then it was changed and from our side only lay counsellor-mentors were asked to attend” T3F3B

“It is true, we never meet to review our work. We are pushing our individual tasks without bringing our efforts together. Now it is even worse because most of us are re-directed to focus on COVID-19 activities and are no longer performing some of our duties. Supervision and mentoring are not done consistently so I am not sure if I am doing the correct things at the field” T4F4B

“We need to discuss challenges with the clinic staff and if they are the ones at fault, they must acknowledge and address the problem accordingly so that there can be a positive change. Like the issue of non-capturing, if files can be captured correctly, I will no longer trace clients who have not defaulted. So, feedback and communication are key elements of the support that I am referring to” T2F2A

“Support, no. The managers never call us to ask about our challenges. Instead, we support each other when we meet difficult cases. But we never meet as lay health care workers to discuss our work” T3F3B

"In terms of us the tracers and CHWs, we do not really meet to discuss. I think if we meet, we'll be able to discuss our work and challenges, therefore our work will be integrated and flow smoothly. If I have a challenge, I'll know who to talk to. Sometimes I refer a client to a CHW for tracing and after some days when I ask for feedback, the CHW will just inform me that she has not yet managed to go for tracing. So, the collaboration is minimal, we really need to come up with a strategy that will enable us to work as a team and simplify our work" T4F4B

"Earlier we talked about the viral load teaching aids that we do not have; it shows that we are not supported. That is why patients have a problem, it is because they do not experience the same counselling or education due to this segregation of lay counsellors. And by the time the lay counsellors from the developmental partner struggle to continue with this viral load thing or any service that they started, then we will be expected to carry on with it. It cannot work like that" T3F3B

"If we are to care for the same patients, let us be treated the same way and be given the same tools. They must not make us feel like volunteers, yes, we can say that we are volunteering because we just receive a stipend, but we are doing the same work" T3F3C

"To be honest, we have not reported all these challenges. But I remember there was a time when the counsellor from the developmental partner was taken for kids' disclosure training and when she came back, she was the only who was supposed to implement. This created a problem because when she was not available, no one was continuing with the work. So, the manager resolved it and we were in-serviced on kids' disclosure" T3F3A

"Yes, we have not really discussed most of these challenges, but we will do that" T3F3C

Kok *et al.,* (2017:1) conducted a study in Asia and Africa related to the performance of CHWs and discovered factors influencing CHWs' performance such as the context; the health system and intervention hardware; and the health system and intervention software. The study further indicated that hardware elements included supervision systems, training, accountability, communication structures, incentives, supplies and logistics. Software elements included ideas, interests, relationships, power, values, and norms of the health system factors which influence CHWs' feelings of connectedness, familiarity, self-fulfilment and CHWs' perceptions of support, respect, competence, honesty, fairness and recognition-all which will improve CHWs’ performance if focused on.

Again, Ludwick *et al*., (2018:7) found that supervision and relationships with other health care workers were associated with CHWs’ motivation and performance. As a result, it is imperative for the supervisors and health care workers to find ways that support constructive engagements and relationships, such as referral systems and respect, thereby contributing to improved CHWs’ programme outcomes. Furthermore, Assegaai and Schneider (2022:36) found that senior managers had limited accountability towards the ward-based outreach programme and there was poor coordination which impacted negatively on the confidence and trust relationships between front-line health care workers and CHWs. It is important to pay attention to the working relationships and not only focus on set performance standards and targets.

These results concur with the findings of this study where participants indicated the importance of feedback, communication, discussion, and resolution of challenges through action-driven meetings.

4.3.2.3 THEME 3: BARRIERS IN PROMOTING RETENTION TO HIV CARE

The findings under this theme reflected that there are barriers in the promotion of clients’ retention to HIV care. These included multiple factors discussed as ten subthemes underneath. Each subtheme as a barrier has been presented with its own quotations followed by literature control. The first subtheme is limited counselling and information to clients.

4.3.2.3.1 SUBTHEME 3.1: Limited counselling and information to clients

The study findings identified that clients did not receive adequate counselling and information to enable them to remain in HIV care. Information that is lacking include the importance of viral load collection and interpretation of results, correct contact details of clients, next of kin and treatment buddies. One participant further highlighted the accidental disclosure case which was caused by the CHW not verifying if the next of kin was the same person as the treatment buddy or not. In this case, they were different, and the client had disclosed to the treatment buddy only, but the CHW called the next of kin when she could not reach the client.

Other participants questioned the time spent by lay counsellors in counselling clients and showed that a single session was not enough, as a result, ongoing counselling should be offered to ensure success of counselling sessions. Some participants indicated that limited counselling led to limited information given to clients, but other LHWs revealed that some clients have enough information related to HIV management. Also, some lay counsellors did not offer adherence counselling, but referred clients to the case facilitator to offer psychosocial support. Quotations supporting the subtheme are outlined below:

"I think clients are not well-informed from the counselling room. That is where the challenge lies. I am not sure if the counsellors take enough time to educate clients or not. You know when I was still a counsellor at another organisation (name specified), I liked the fact that we were providing ongoing counselling. You cannot just talk to a client once and stop; after a week, you need to call the client to check how he or she is coping and also emphasise the importance of adherence to treatment. This was a good and effective practice, but I do not see it happening anymore" T4F4A

"Yes, you are right about limited counselling. As counsellors, we refer to a case facilitator to continue with adherence. We only do adherence counselling when the case facilitator is not available. We have a target of at least 12 HIV tests that we need to meet daily and now with the introduction of HIV self-screening kits, our target has moved to 16" T4F4D

"Indeed, counselling seems to be a challenge. And there is only 1 case facilitator who has to follow up on all clients who test positive. I am not sure if this is effective" T4F4B

"Most of the clients have the information, but there are others who do not understand why they collect blood. They would state that they were advised to collect blood but do not know what for. I try to explain to them in a simpler way: for us to see that you are taking treatment correctly and that the virus is being suppressed, we collect blood. The results should not have a number reading, it must be undetectable; if they have a number reading, it may be due to not taking treatment as advised or there is something that is not done correctly" T1F1F

"Most clients that I trace have limited information. Yes, they do not understand viral load well, but they understand the CD4 count. And because some of them still provide wrong contact details, I think they do not have adequate information" T1F1D

"It is a mixture. Some clients are knowledgeable about their treatment, viral load and also understand their progress, then some just comply with the instructions given at the clinic even if they don't understand what the viral load means while others have limited knowledge and may not even see a reason to keep up with clinic appointments or provide correct personal details. So, our clients are different" T1F1E

"I think sometimes the clinic staff contribute to clients not sticking to the appointment dates by just issuing medication without doing the pill count or checking how many tablets the client still has. You'll find that the client still has many tablets on the appointment date and do not see the need to go to the clinic. It is difficult to convince such clients to return to the clinic" T4F4E

"We do not really discuss the contact details, once the client tests positive, I just complete these details on the file and focus on preparing him/her for treatment initiation" T1F1B

"Yes, these details (contact) are not discussed, but just collected from the client. Our main role is to open a file and counsel the client as per information we discussed earlier" T1F1D

"We also ask who the treatment buddy is and write at the back of the clinical stationery. I then explain that the treatment buddy can go to the clinic if the client is unable to" T1F1C

"The contact details aspect is a challenge. Before I trace, I have to go through the client's file to get the phone numbers. Sometimes the phone number is incomplete, wrong or on voice mail. The next step is to check the phone number for the next of kin. At times this phone number is the same as the client's, meaning that I cannot reach both; or there is no number altogether; or if I find the next of kin the client has not disclosed which makes it difficult to explain the reason for my call. Some clients have treatment buddies who are different from the next of kin, so I think this must be clearly discussed with the client" T1F1A

"What I have realized is that sometimes the lay counsellors do not ask the patient about the treatment buddy, they just assume that the next of kin is the same as the treatment buddy and write on the treatment buddy section. Again, they do not explain what the next of kin and treatment buddy means" T3F3A

"That is dangerous because during tracing, the tracer may call the next of kin and tell her the purpose of the call without knowing if the client disclosed or not. It means the tracers are not well-orientated on this. And I don't think the tracer always checks the treatment buddy when the client's phone is not going through. They just look at the next of kin" T3F3D

"Sometimes the next of kin and treatment buddy are not the same. Yes, this is important, and we once had a case. One CHW called the client and did not find her. She decided to call the next of kin and did not check if the client had a treatment buddy. Unfortunately, the client had not disclosed to the next of kin who was her mother and the CHW went ahead to tell the mother the reason for calling" T2F2C

"Yes, the contact details are important. As I also interact with the CHWs who assist with physical tracing, they sometimes struggle with wrong or untraceable addresses. It means that the client will be lost without us knowing what happened" T1F1F

"The admin clerks open files and are responsible for completing the personal details of clients, e.g., name, phone numbers, physical address, next of kin, etc. Some even ask for the ID to complete the name and date of birth" T2F2F

"I think the lay counsellors are the ones who open a new file for a newly diagnosed client. After the client tests positive, the lay counsellor completes the clinical stationery. This is when they complete the patient's details (other participants said "yes"). If the client had a case history sheet issued at the reception initially, there will be contact numbers written by the admin clerks, but I think the lay counsellors must verify those phone numbers when opening the clinical stationery" T2F2C

"Oh yes, you are right. So, the admin clerks must update the contact details during subsequent visit. It means we must emphasize the issue of obtaining correct details to the counsellors, admin clerks and anyone who sees the client. The lay counsellors must

also discuss the importance of correct contact details with clients, they must not just write them" T2F2D

"We (counsellors) are the ones who open clinical stationery after the patient tests positive for HIV. Then we complete the patient details like the contact numbers, address and next of kin" T3F3B

"We also complete the counselling session and the name and contact numbers of the treatment buddy at the back of the clinical stationery" T3F3C

"When I offer adherence support to clients with unsuppressed viral loads, I explain the importance of providing correct contact details, including the next of kin. So, clients give me the information knowing its purpose fully and I then update the clinical stationery" T3F3E

In line with the study findings, Wringe *et al*., (2017:3) conducted a study in several African countries to assess how testing experiences influenced retention to HIV care and found that counselling messages offered were disconnected with the clients' information needs and would contribute to clients not seeking further care. Similarly, Sineke *et al*., (2021:3) conducted a study in South Africa to assess HIV and ART knowledge among the newly diagnosed clients and found that some clients did not remember information immediately post-counselling. Furthermore, adherence support is necessary for continued ART, therefore it is important to address clients' concerns and misconceptions.

Another study conducted to assess clients' experiences of the ART initiation process revealed that some clients experienced delays due to being referred from one lay counsellor to another and did not receive information or explanations on the procedures to be conducted. Consequently, clients would leave the clinic feeling anxious and unsure of the next steps (Maughan-Brown *et al*., 2018:7). Lack of information and feelings of uncertainty may demotivate clients and contribute to discontinuation of seeking care.

4.3.2.3.2 SUBTHEME 3.2: Clients not free to communicate

The participants explained that clients do not communicate their challenges freely with health care professionals, seemingly because they fear that they may not be assisted after speaking up, or they trust LHWs more. Clients are not free to even discuss suitable next appointment dates. This was identified as a barrier in HIV management and retention because when LHWs were not available in the facility, other clients opted to keep quiet or stay at home until those LHWs were back on duty. On the other hand, some clients did not open up to LHWs during household visits, and only presented to the clinic when too sick. Participants' quotations are presented below:

"I agree and other clients do not even know who to go to when they experience challenges at the clinic. This may make them to lose hope and stop treatment" T1F1F

"Also, when they experience side effects, they still come to us. A client called me last week while I was on leave. She said she has been experiencing weight loss since she started with treatment, and I advised her to go to the clinic. She refused, telling me that she is scared and does not even know who to report to when she gets to the clinic. I told the client that my leave ends yesterday, and she attended the clinic today and I accompanied her to the nurse" T3F3B

"And when you accompany the client, the nurses are not rude, they just help her/him calmly" T3F3A

"Yes, and some clients cannot stand up for themselves or report the ill-treatment at the facility because they think that they may not be assisted accordingly, so they end up staying at home" T1F1C

"Yes, and I heard them advising the client to be patient because she only started treatment recently, as long as the medication is not causing diarrhea or rashes, it is okay" T3F3B

"Sometimes when you get to the household, you get a client who does not open up to you. He or she does not want to voice his/her challenges out. In that way it becomes difficult to assist and surprisingly next time you see the very same person in the clinic being sick. You cannot ask this client why she did not open up because it might seem as if you are angry or interrogating the client. If the client could have opened up, I could have assisted where possible such as delivering medication or given him/her the necessary information" T2F2D

"I have never experienced such a challenge. When the patient trusts you, you will not have a problem. I just communicate politely with patients, and we get along well. And when I arrive at the household, I do not just indicate the name of the person I am looking for. I have to establish rapport first and also make some jokes so that the environment is calm" T2F2C

"I also think that the appointment date must be discussed with clients to check if it is suitable. I do not think that this is happening, I normally see staff counting from the calendar and writing return dates. And from what my colleague said, some clients want to come at their own time, so negotiation is important. I think this can improve retention because we will be listening to individual clients and addressing their needs in a way" T4F4C

Vermeir *et al*., (2015:1265) conducted a systematic review to assess the impact of communication in the health sector. The same study identified that poor communication could lead to various negative outcomes such as discontinuity of care, compromise of patient safety, patient dissatisfaction and inefficient use of valuable resources. Similarly, Leon *et al*., (2019:8) found effective communication to be contributing to patients' satisfaction and retention to care in a study aimed at assessing the influence of patients' quality perception on retention to HIV care in Brazil.

Additionally, Kwame and Petrucka (2020:17) conducted a scoping review of studies done in Sub Saharan Africa to explore communication strategies in nurse-patient relationships. The same study found that in HIV care, health care providers who are less dominant when interacting with clients facilitated open and therapeutic communication while dominance resulted in lack of open discussions, thereby compromising care, and neglecting patients' needs. These results concur with the findings of this study because if clients fail to communicate effectively, health care and outcomes can be compromised.

4.3.2.3.3 SUBTHEME 3.3: Clients' lack of acceptance, ownership and independence

The findings of the study alluded that the clients have difficulty in terms of acceptance, ownership and independence in relation to HIV management. Clients do not prioritize HIV treatment and do not incorporate it into their lives. Participants emphasized that clients wait to be called before they go to the health facility to collect their medication, while others want their treatment to be delivered at their homes. The participants explained that these behaviors promote full dependence of clients on the LHWs for their medication and other follow up services such collection of blood for CD4 count or viral load. Some participants highlighted the difficulty of encouraging acceptance when the client is already defaulting, which suggested that acceptance should be encouraged earlier. The quotations below represent the voices of participants:

"Yes, I agree that the clients must take responsibility for their health. I have realised that some clients that I trace repeat the same behaviour because they know that they will be called, and either be fast tracked when they return to the clinic, or their medication delivered to them. So, they are dependent on the CHWs even if they have no specific challenge that hinders them from collecting their medication from the clinic" T1F1A

"I want to go back to the issue of assisting through medication delivery, other clients feel that it is our work as CHWs to deliver medication at their homes. They say it is a must for us to assist them and they do not make any effort to go to the clinic" T2F2F

"Yes, we haven't reported. Rightfully we are not supposed to deliver medication to the youth or young adults, we must assist the elderly only. These days all age groups want us to deliver their medication, it is like they are now dependent on us" T2F2C

"In fact, this adherence support was done for the elderly only, but we see this dependency from other age groups a lot now and it is a problem" T2F2A

"And what we are realising is that when we get to the households there are youth who can collect medication on behalf of the elderly clients, but they are not willing to do that. They feel that we must deliver the medication. And once you help them, they inform all their neighbours who in turn expect the same treatment. They are relaxed now, no effort to go to the clinic" T2F2D

"Isn't it that the client is always right? We inform them that we are supposed to deliver medication to the elderly, but it is not working. When these client's default, it comes back to me again, so it is a problem. I am the one allocated for that household, I have registered the family members so he/she is my patient, and I must ensure that he/she does not

default. And also, I cannot give the elderly treatment and let the youth or young adult in the same household to default" T2F2C

"I realise that we, as the community at large, only talk about HIV, when necessary, not always. Our clients do not see HIV as part of their life. They lack self-determination and do not put effort. I am not sure if this is due to us not providing enough information or they just do not want to take HIV as seriously as they take their life. As a result, some clients do not honour their appointments or even take treatment on time, that is why we have many clients with unsuppressed viral loads. So, our clients do not take responsibility for their health, they are dependent only on what is said at the clinic and do not check their cards when they are at home. I am saying this because I also assist at the decanting room and the appointment card has the return dates as well as the numbers to call to check availability of your medication in case you did not receive the message on your phone, but clients do not do that. They do not look at their appointment cards, they depend on us, they do not care about these things" T3F3E

"I agree that some clients do not take ownership of their health. Others do not even accept their status" T3F3A

"What I am observing as well is dependence from clients who do not take ownership and want to always come to me even if they are not going to work. Other clients wait for me to trace them at their households, so they default without any tangible reason" T4F4B

"I agree, clients are becoming dependent even on us, the CHWs. Sometimes I collect medication in the facility and deliver to their homes, thereafter they want me to continue even if they do not have a valid reason. So sometimes I feel like clients think that they are taking treatment for us and do not incorporate treatment collection in their routine activities" T4F4E

"Dependence is becoming a serious problem. Most clients that I have traced defaulted more than twice and some of them do not even state reasons. So, I realised that they default intentionally knowing that I am going to come and fetch them, skip the queue at the facility and get treatment faster. So tracing is very important yes, but one of the challenges is that some clients do not take ownership of their health and treatment collection anymore" T4F4A

"I agree that it is difficult to encourage ownership when the client is already defaulting, but we need to keep on providing health education on adherence. I am also informing clients who keep on defaulting without tangible reasons that I will only deliver medication to the elderly, children, and sick clients. It is discouraging for us to trace the same people every time without seeing progress, even after counselling" T4F4A

"There is this client that I traced several times and she ended up telling me that she does not want treatment anymore and that I should stop disturbing her with my calls. I tried talking to her and explained the dangers of stopping treatment, but she hung up. I saw her recently at the clinic and she was very sick. When she saw me, she apologised and said that she has learnt her lesson and will never stop treatment again. I told her that it is important for her to accept herself so that she can take responsibility for her health. Self-acceptance is key to continued adherence" T4F4E

"People here default treatment a lot, like they really default, and they are not honest. When you trace them, they promise to come to the clinic on a particular day but do not. They then come after some days, citing multiple reasons that they were busy with. So, they do not value their treatment and they prioritise anything else except treatment. This is happening even if the client is not held up at work. What I have realised is that clients do not want to queue at all, they want to just get into the consulting room, collect and leave. But this is not always possible and that is why I talked about lack of ownership earlier. When there is a nurse allocated to see defaulted clients, it becomes easier, but like I said, it is not always possible due to shortage of staff" T4F4B

A study conducted in Sub-Saharan Africa to understand the engagement with HIV services revealed that clients' commitment and acceptance of the HIV status are some aspects that influenced continued retention to care (Skovdal *et al*., 2017:5). Again, in a study conducted in Swaziland to examine factors influencing linkage to HIV care, non-acceptance was found to negatively affect both the mental and physical health, subsequently leading to limited access to health care (Horter *et al*., 2017:55).

Furthermore, non-acceptance was linked with denial in clients who did not regard themselves as being at risk for HIV or those who felt healthy. Some of these clients had a belief that HIV infection was associated with multiple partners, so clients who associated themselves with Christianity had difficulty accepting a positive HIV test result. Counselling and information were regarded as vital in improving clients' preparation, giving them hope and facilitating acceptance of the HIV status (Horter *et al*., 2017:55). In addition, a systematic review of American, European, and African studies conducted to explore the experiences and attitudes of PLWHIV found that acceptance and lifestyle adaptation was difficult as some clients felt that they had to change their lifestyles a lot, which in turn made them feel like prisoners (Arias-Colmenero *et al*., 2020:8).

These results are in support of the study findings where it was noted that clients who are HIV positive had difficulties in taking ownership of their health, accepting their HIV status and being independent from the LHWs or other social support structures.

4.3.2.3.4 SUBTHEME 3.4: Stigma and non-disclosure

Participants mentioned that one of the barriers to HIV management and retention is stigma and non-disclosure. The participants emphasized that HIV is still a highly stigmatized condition in communities; hence, clients who are HIV positive might have challenges disclosing the HIV positive status to their old or new partners and even family due to fear of rejection. These barriers contributed to some clients collecting and then disposing ARVs in toilets before leaving the clinic due to fear of disclosing their HIV status at home. Other clients go to an extent of collecting the HIV treatment at distant facilities despite having clinics nearby.

Another participant indicated that one CHW accidentally disclosed the HIV status to the client's family, not realizing that the client had not disclosed yet and the operational manager was angry with this CHW, instead of sensitizing other LHWs. One participant stated that while non-disclosure differs from client to client, most clients who have difficulty in disclosing their HIV status are those within the age group of 24 to 35 years and this may be due to them not yet having stable partners. Lastly, participants verbalized their limited skills in dealing with non-disclosure among couples. Quotations below are from the participants:

"To add, non-disclosure is another barrier. You find that a person meets a new partner with a negative status, so it becomes difficult or takes a long time to disclose. This is

because they fear rejection from this new partner and the client ends up stopping treatment" T1F1A

"Yes, the stigma is still there, and it leads to non-disclosure. Clients are afraid of what other people might say and they also do not disclose the status to their partners, hide the treatment and end up defaulting. Some clients just close up even during counselling and it becomes difficult to reach out to them" T1F1A

"Yes, they do not disclose. But it is not only in the case of new partners, even those who have been together with their partners for some time. You find that they are all taking treatment at different places, maybe the husband takes it at work and the wife at the local clinic, but they are afraid to disclose to each other. They are all hiding their tablets from each other, so it becomes a secret. They end up stopping this treatment and when one of them becomes sick, it is when the whole story comes to light. So, this is what the clients normally explain to us. Again, when I trace the client telephonically and cannot find her/him, I call the next of kin. Sometimes I realise that the next of kin does not know that the client is on treatment, and I then come up with a story, maybe that we have a project in the clinic and are recruiting people to assist us. So, non-disclosure is indeed a challenge" T1F1A

"It is not only non-disclosure to partners, even to the other family members. Clients are afraid that the family may judge them. Families are not the same, some have never supported each other from way back, even before the illness. So, when the person thinks of disclosing within that unsupportive environment, he/she decides to keep quiet to avoid problems" T1F1C

"This stigma sometimes affects clients to an extent that they leave their local clinics and go to distant clinics which costs them transport. At times they struggle with transport money, and they end up defaulting" T1F1E

"We advise them to collect treatment at their local clinics so that it becomes easier for them, and the chances of defaulting can be minimised" T1F1C

"But then again, the clients must be comfortable with their treatment collection facility, if not they will default" T1F1D

"We do not have challenges as such, it is only that most people are not open and free about their status. Even if I can provide health education, if a person is not open, he/she is not open and there is not much you can do about it. And these are the people who do not disclose to their partners or families, now we have to play hide and seek when these partners visit the facility. We also find a lot of ARVs disposed in the clinic toilets which means that some clients visit the clinic just to complete the visit history and then throw away the medication right at the clinic. This is a problem that we experience, I am not sure if these clients are keeping a secret or what, but these incidents are way too many. At times clients complain that the tablets come in hard plastic containers, and they make noise upon movement, so I have been advising them to request nurses to pack their medication in such a way that the noise is reduced, but we still find medication in the toilet cisterns, more than 10 containers" T1F1F

"Yes, and there is still the issue of non-disclosure in the families. So, when I find a client sitting with the family, I find a reason to talk to her/him privately because if the client is not ready to disclose, I cannot force him/her. Although I still advise the client to disclose but he/she must be ready" T2F2C

"Yes, I remember this difficult case. The patient called the OPM to report this accidental disclosure. And the sad part is that the supervisor did not protect this CHW, instead she blamed her for negligence and breaking confidentiality. We thought they would call all CHWs to sensitise us about this issue, but they did not. We continued to work, and I fear that those who are not aware of this incident might do the same mistake, especially considering that there are new CHWs. I think they need to be mentored on how to communicate with patients. This mistake will still be repeated" T2F2E

"Another barrier is around the disclosure issue: Some clients do not disclose their HIV status to their partners, and it is a challenge. These clients are afraid to disclose because they fear that partners may abandon them or even kill them, though we have not had such cases of extreme violence" T3F3A

"Others fear that their partners will blame or accuse them of bringing this disease into their home. But I think this happens because clients are too dependent on other people and do not accept their status and develop healthy coping mechanisms" T3F3B

“Yes, non-disclosure is a real challenge for us, and this is why some clients stop or refuse treatment. They fear the possibility of being labelled by their partners. So, clients are dependent on their relationships, they value them more than their health; and they rather stop treatment than lose their partners. Women were previously depending on men in terms of finances; however, these days even if they are working, they still do not disclose because they do not want their partners to leave them. So, women need to be empowered to be independent and develop coping mechanisms if their partners or other close relations abandon them” T3F3D

“I would say that maybe 60% of clients that I have interacted with have disclosed their status to partners. Non-disclosure differs from client to client, and I have also realised that the 40% that had not disclosed were related to a particular age range. Clients that I discussed adherence with and had not disclosed were in the age range of 24-35 years. They were still on that lifestyle of changing partners or having unstable relationships so they felt that they could not disclose their status to their partners until they get stable ones. The other age groups, specifically the elderly, do not have disclosure challenges, they inform me that they have disclosed to their partners and children. This is what I have learned from my interaction, but non-disclosure really differs from one client to the other” T3F3E

“I can’t handle these cases (non-disclosure among couples). They are difficult and require more effort. How can I put more effort if I just get a stipend, not a reasonable salary? I can’t, if the salary was better, I would be motivated to try my best” T3F3A

“The salary is demotivating, yes. But going back to the non-disclosure issue, it is a challenge, and it is difficult for me as well. We are trying to help clients to disclose but the partner ends up being aware that the client knew the status before their visit as a couple. It is not safe for us because sometimes the couple starts to argue. We just don’t know how to deal with non-disclosure among couples” T3F3C

According to a study conducted in Ghana by Gyamfi *et al.,* (2017:5) people were scared to disclose their HIV status due to fear of the aftermath of disclosure. Generally, the possibility of some undesired consequences arising from disclosure served as an important barrier to disclosure. Some of these possible undesirable consequences included the effect of disclosure on mother-child relationship, child's emotional and psychological wellbeing and the perception of mothers that their children may see them as having led irresponsible lives to have contracted HIV. This also may include the effect on the relationship between partners and family members which concurs with the findings of this study.

Non-disclosure seems to be a debatable issue. A study conducted in the United Kingdom assessed whether non-disclosure was associated with psychological symptoms, non-adherence to ART, and viral load non-suppression, or not (Daskalopoulou *et al*., 2017:190). The same study revealed that people older than 60 years had not disclosed, which is in contrast with the current study findings that identified non-disclosure to be common among clients aged 24 to 35 years. Daskalopoulou *et al*., (2017:190) further mentioned that other studies found that older clients disclosed, while others did not find any association between age and non-disclosure. Lastly, the same study concluded that non-disclosure was not associated with low social support, psychological effects, non-adherence to ART or viral non-suppression, probably because clients felt capable of coping on their own.

In a quantitative study conducted in Cameroon to determine the association between disclosure and retention to HIV care, an association between disclosure before ART initiation and retention was found, though weak (Breger *et al*., 2017:843). The same study further found that irrespective of the client's disclosure status, referral for disclosure counselling moderately increased the likelihood of retention. The contrasting results above may be due to differing contexts, cultural or societal beliefs and norms since contrasting studies are from the UK and US while those in agreement are from the African countries.

4.3.2.3.5 SUBTHEME 3.5: Side effects of HIV treatment, clients' previous negative experiences at the facility, financial and work constraints

Findings of the study also revealed that barriers such as side effects of HIV treatment, client's previous negative experiences at the clinic as well as financial and work constraints may result in clients defaulting their treatment. Some clients did not report these challenges to the health institution, they just decided to stop and not return to the facility for continued treatment despite being traced, only to return at a later stage when sick. One participant stated that the clients were not given adequate information regarding side effects, which is why they probably defaulted. Supporting quotations are presented underneath:

"They feel that the changed tablets result in dizziness and instead of going to the facility to explain this, they decide to stop it. It means that we have to trace these clients and sometimes they do not return to the clinic and only come back at a later stage when they are sick" T1F1A

"Some clients stop treatment because they were given the similar tablets but from a different supplier and containers" T1F1A

"The other barrier that we have is that we used to know the medication like we know ourselves and would teach clients thoroughly about the names and side effects of these medication, but not anymore. No one teaches us about medication anymore, we don't know anything. So, we just send clients for initiation and the nurses give them medication to take once a day without providing more information. So, when the patient experiences side effects, he/she may stop medication because nothing was explained, and the patient will come back being very sick due to defaulting" T3F3A

Other participants indicated that other retention barriers are clients' previous negative experiences at the facility such as rude staff, being treated badly and long queues. One participant justified that the nurses become rude because they want clients to do the right things by adhering to the scheduled appointments. Furthermore, the participant stated that clients need to understand that there are queues everywhere and they must be patient and own up to their health. Other barriers included lack of transport money as well as work schedules or travels that led to failure to attend the clinic as per quotations below:

"Like I said earlier, not knowing who to talk to when you get to the clinic, long queues and being treated rudely are some of the reasons why clients become frustrated and stop treatment" T1F1B

"Some clients default because they are working, and their companies do not accept sick notes from the clinic. Others are contract workers who are highly mobile and sometimes travel unexpectedly. Again, like my colleague said, other clients complain about queueing or being treated badly at the facility, such as staff members who talk to them rudely. I

acknowledge that work is important, but if the client stops taking treatment, he or she will get sick and not work anymore. So, I advise working clients to arrange with their managers to either come early to the clinic and go to work afterwards or go to work first and attend the clinic later in the afternoon and I then ask a nurse to help them quickly. For those who complain about the queue, I remind them that queues are everywhere, they must just own up to their health and be patient just for that day to get helped. And those who say nurses are rude, it is because they skip their appointments, so they need to do the correct things by sticking to their appointments" T4F4C

"Other barriers include lost patients' files, long waiting times and being talked to rudely; they are treated bad by the staff" T1F1A

"Clients complain about long queues which discourage them from collecting their medication" T2F2E

"Some clients do not have money to go to the clinic despite this being their nearest clinic" T4F4A

These findings are supported by the study conducted in Malawi relating to factors influencing adherence. The study identified several factors such as inadequate counselling on the benefits of ART, long waiting times, long distances, lack of transport money and dissatisfaction with care received. Drug related factors that influenced defaulting of the HIV treatment included complexities and side effects of ARV regimen (Chirambo *et al*., 2019:7).

Again, a study conducted in Zambia to determine how health system factors influenced retention found that long waiting time and clinic operating hours, either opening late or closing early, were not conducive as they coincided with clients' working hours (Mwamba *et al*., 2018: 5). The same study found that the conduct of health care workers such as shouting, humiliating clients in public or being disrespectful also contributed to discontinuation of clinic visits. Some clients who returned to the clinic after missing their appointments felt as if they were being punished when given frequent return dates for intensive counselling.

Moreover, a study conducted in Swaziland to understand the reasons for discontinued ART found that disengagement resulted from a chain of events preceded by clients' mobility such as changing work, then followed by negative experiences such as long waiting time at the health facility (Shabalala *et al*., 2018:55). The above results concur with the current study findings in terms of identifying side effects of HIV treatment, clients' previous negative experiences at the facility, as well as financial and work constraints, as barriers contributing to disengagement from care.

4.3.2.3.6 SUBTHEME 3.6: Clients' provision of wrong information and administrative issues in the health facility.

The participants highlighted that another barrier stems from clients providing wrong personal details such as wrong residential information and contact numbers which makes them untraceable. They further stated that even if they updated the contact details during subsequent visits, clients would change them again and it looked like clients did not wish to be contacted. The quotations below represent the participants' voices:

"I think they provide wrong contact details because they were not ready for treatment and felt that they did not have a choice. Some may provide the correct phone numbers initially and then change them afterwards so that they can be untraceable" T1F1D

"I report to the nurse or case facilitator to make a follow up (of clients refusing treatment), but unfortunately, in most cases the client does not answer the phone anymore and becomes unreachable. Sometimes clients provide wrong contact details, like the phone numbers and residential address, making it difficult to trace them when they skip scheduled appointments" T1F1A

"I agree with that. You'll find that the client has multiple contact numbers which have been changed and documented on the file. Every time when the client is traced and returned to the clinic, he/she would change the phone numbers again" T1F1C

"We also have a huge challenge of clients providing wrong addresses and contact numbers. If it is like that, there is no way that you will find that client during tracing" T2F2A

"Oh, I almost forgot, the other challenge is the wrong contact details provided by clients, which makes it difficult to trace" T3F3E

"The other challenge is that clients provide wrong contact numbers and addresses, and this makes it difficult to trace. Unfortunately, not all staff members understand the addresses around here, so they are unable to identify wrong addresses" T4F4E

"Yes, the contact numbers are a challenge. Clients change contact numbers more often, to an extent that there is no more space on the file to write the new ones. I usually update phone numbers and cancel those that are not working. And clients sometimes do not provide traceable addresses, but some CHWs are able to identify them through surnames. I do not know the areas and households well, but when I collaborate with CHWs, it becomes easier to trace" T4F4B

"I have also experienced a challenge with wrong contact details. But what I also picked up is that some clients are not from this area so they just pick random stand numbers of nearby houses because they fear that they will not be assisted if they provide correct addresses. Unfortunately, I do not document on the client's file during the initial visit but if I trace and find that the contact numbers are wrong, I immediately cancel them and put a note for the clerk to update if the client returns. If the client returns, I explain the importance of correct contact details, e.g., sometimes the viral load is high, and we want to call the client back" T4F4C

"And yes, I agree with my colleagues that a big challenge is the provision of wrong contact details by clients. If it happens that I find some of these clients, they just say they lost their phones, then I update the file with the new numbers. But to my surprise the client will default again, and the new phone numbers will not be going through again. I think these clients do not want to be contacted, they just want to go to the clinic at their own time and then miss their appointment dates" T4F4A

"Some clients are from other areas and are living here temporarily, so they just go back home without informing us" T4F4A

Participants further stated that some administrative issues in the health facility such as capturing of incomplete phone numbers, non-capturing of clinic visits and lost clients' medical records which frustrates clients, also contributed to poor retention to HIV care. Quotations are presented below:

"Yes, on this issue of wrong addresses and phone numbers, I do not understand how the admin clerks can write 9 phone numbers without questioning the client. Does it look right to them? At a later stage the problem goes to the CHW who must now trace while the phone numbers are incomplete. The first person who opened and completed the information is wrong" T2F2D

"The other challenge that frustrates us and patients is that we go out to trace them only to find that they did not default. They collected treatment at the clinic or Pele box, but the file was not updated accordingly, and they show us their appointment cards. This is not right at all; clients are unhappy about it. It's two things: is either the file was not updated or is missing, and they write on a continuation sheet" T2F2C

"Yes, you are right, 90% of the clients that we traced last week Thursday were not defaulters, they attended the clinic accordingly, but the files were not updated. The information office staff did not capture the information, but sometimes it is because the file was not found and there was no proper documentation" T2F2A

A concurring study conducted in Nigeria to investigate the challenges in the implementation of prevention of mother to child transmission found that a woman was lost to follow up and unreachable because she had provided fake contact numbers and residential address during clinic registration (Kram *et al*., 2021:4) Furthermore, the health workers believed that provision of wrong contact details may be caused by fear of stigma.

Mwamba *et al*., (2018:6) found that medical records went missing and clinic staff would search for them, which resulted in longer waiting time. Sometimes these medical records were not found, and the clients had to repeat some procedures or tests, hence additional clinic visits which demotivated clients and negatively affected retention to HIV care. The same study participants highlighted that poor file management was due to the increasing number of clients, high workload, limited space, and diminished support from non-governmental organizations.

Additionally, another study conducted in South Africa to assess tracing of ART defaulting clients found that while clients on differentiated care models were incorrectly captured which then erroneously classified them as missed appointments, some tracers also did not have tracing records (Etoori *et al*. 2020:6). Also, the importance of correct contact numbers was highlighted; however, it was found that some clients' phone numbers worked initially but clients would then ignore subsequent calls when recognising the clinic's phone numbers. These results also concur with the study findings.

4.3.2.3.7 SUBTHEME 3.7: Moving adherence clubs to Community-Based Organizations

Participants indicated that the use of adherence clubs is one of the best strategies that improved retention to HIV care; however, the movement of these adherence clubs from the clinic to community-based organizations (CBOs) resulted in clients' dissatisfaction which may lead to discontinued treatment. At times clients did not find their medication at the CBO and were referred back to the clinic where they found long queues. Some clients felt that the CBO is next to a busy road where taxis pass, so other people saw them, and this hindered privacy.

There was also lack of understanding from one LHW who thought that adherence clubs were cancelled and replaced by the Pele box (in contrast, the Pele box works like the bank Automated Teller Machine, has medication loaded already, is situated in the clinic yard and clients can get treatment at a time convenient for them). Quotations below are from participants:

"Another strategy that significantly reduced the number of clients who default was the adherence clubs, but these clubs were cancelled, and they were very useful. The developmental partner cancelled the adherence clubs and took them to Pele box" T3F3A

"No, the adherence clubs still exist, they were just removed from the clinic and taken to a community pick up point (name mentioned). But clients are not happy at that community pick up point, they are struggling. Sometimes they are told that their medication is not available. And again, they complain that that place is next to the main road used by taxis and are seen by most people while waiting to be helped" T3F3C

"Yes, and when their medication is not available there they are sent back to the clinic. And when they get to the clinic, they find a long queue and do not even know who to talk to, it is not fair. So, this will contribute to the high defaulter rate" T3F3B

“It is not fair indeed. The service went from being good to poor. In the clinic we are the ones who taught them that they do not wait in the queue, now since they went to this community point how many times were they sent back to the clinic and found long queues? They are not used to long queues, and they will default. The other one called me out of frustration after experiencing this problem. But I heard that this community point is no longer functional, and all clients will be returning to the clinic” T3F3D

“The other client called me because she was due for blood collection, and I advised her to come. The security personnel did not agree to let her in the clinic. So, if she did not have my contact details she would have gone back home, but I explained to the security that her matter was urgent. It is not right; people are being tossed around” T3F3C

“Mudavanhu *et al.*, (2020) conducted a clients’ preferences study in South Africa and found that while adherence clubs were highly acceptable to clients and may promote retention to care, most clients preferred facility-based than community-based clubs due to fear of stigma.” Another study conducted in South Africa to assess acceptability of community-based adherence clubs among health care workers found mixed perceptions. Some participants agreed that community-based adherence clubs were good for clients while others felt that they would lead to stigma and poor retention, unless these clubs included clients on other chronic medication and not just ART (Tshuma *et al.*, 2017:1529).

Similarly, Mantell *et al*., (2019: 4) conducted a study to identify facilitators and barriers of participation of HIV positive men in community-based ART refill groups in Zimbabwe. The same study found that participants viewed these community clubs as convenient and effective in providing peer psychosocial support, but they wished to initiate these groups themselves as opposed to being allocated by the clinic staff. However, the stigma from the community was a concern, and again some health care workers felt that community-based clubs needed to be dissolved because of the inability of health facilities to monitor clients frequently in terms of irregular attendance; group conflicts and lack of facilitation skills from some leaders.

The above studies concur with the current study findings in terms of perceiving adherence clubs to be good in improving retention; however, the possibility of stigma needs to be considered and mitigated when moving them to the community.

4.3.2.3.8 SUBTHEME 3.8: Lack of supervision, feedback, and training on updated HIV information

The participants highlighted that they do not receive adequate supervision, feedback and training on updated HIV information. They expressed frustration caused by lack of updated information such as changes in HIV or other chronic medication which makes them to look uninformed when interacting with clients. Participants further stated that even if they are trained, they wish to receive refresher training, and the training duration must be adequate to enable them to process the information effectively.

Again, tracers are sometimes asked to trace HIV index clients, but they have not been trained on the index programme, only lay counsellors were trained. The participants also agreed that their work is interrelated, and it is important for them to work collaboratively. Another issue is lack of feedback meetings to discuss performance, gaps and remedial actions. Instead, the LHWs felt that the facility staff blamed them for the high HIV missed appointments, and this made them feel angry, discouraged and unappreciated.

In addition, supervision became negatively affected after the contracts of the outreach team leaders (OTLs) who supervised the CHWs ended. Although there are new OTLs appointed, they have been allocated to COVID-19 activities and have not yet built relationships with the CHWs. As a result, CHWs do not get assistance when they meet challenges within the community, like a case mentioned by one participant who stated that they were allocated to assist a client with a colostomy bag but could not because they did not know what it was. This subtheme has other information presented in the subsequent paragraphs. Quotations are presented underneath:

"We do not get support in the sense that when treatment changes, no one informs us, like when Dolly (Dolutegravir) came in, we were not informed. We have to gather the information ourselves. Sometimes you become exposed in front of a patient that you do not know the new treatment. I think they forget that we are the first face of the clients who must be put on treatment, and even when on treatment, these clients still come back to us for more information because we explain things better. At times the nurses issue treatment without explaining thoroughly to the patient and this patient turns to me for explanation, that time I do not have a clue of this new tablet. So, I think as new things are being introduced, they forget that we are also part of it and do not empower us" T1F1B

"Yes, I also feel that they take time to take us for training or refresher courses. Sometimes you just work for 2-3 years without attending any training. We need a little break because we also face challenges (all agreed), sometimes the patient is free with me, at times with the nurses, or vice versa" T1F1E

"And when it happens that we attend a workshop like the index one that we attended recently, it needs more time, but they delivered it within a short period of time" T1F1D

"Indeed, 3 days information is provided within 2 days, how are we expected to process all this information?" T1F1E

"This is where the problem is. There is no time for meetings in our facility. I believe that we must have monthly meetings with the managers to discuss our challenges, but this is not happening because they are always busy. And I believe that they must make time for us because we have challenges, we are burdened. And how will I do my work effectively when I feel burdened? No, I will not be effective. It is clear that if I am not happy, there will not be production" T2F2C

"Yes, she said it all. There is no time for feedback, and this is really affecting our work negatively. We are just working, not knowing if we do the right or wrong things (others agreed: "yes")" T2F2F

"We used to have these meetings, but since 2020, everything changed. Every month we were given a chance to voice our challenges and the clinic staff would do the same. We were not oppressed, like now we are told that we are not tracing properly and the missed appointments are high. They blame us for these high missed appointments whereas they are the ones who do wrong things by not updating files after the clients' visit to the clinic or obtaining traceable contact details. They point fingers at us, but the other fingers are pointing at them for not updating the files correctly" T2F2D

"Last week there was a meeting with the facility staff, maybe it will happen consistently I do not know. It was the first time I heard that we are not working, according to the facility staff. They said that we are not tracing. We were given phones to capture the tracing feedback which is supposed to reflect on the clinic's phone as well. So, the information

was not reflecting because these phones were linked to the OTLs who were supposed to allocate the work to CHWs to trace and then capture feedback. So, because there was a time when there were no OTLs due to contracts ending, it means there was a break in this cycle, the facility user would upload the client list, but we were not able to get a list on our phones. So, it appeared as if we were not working. We have been collecting the missed appointment lists manually, tracing and updating our tracing books. So, we have the information in our manual tracing registers, but no one asked for these registers" T2F2A

"Yes, we have been working but not submitting the manual registers. We did not know that we were supposed to submit them, no one informed us. And now the clinic staff state that they also did not understand how the tracing information flows through to the tracing phones" T2F2B

"This goes back to the issue of lack of meetings and reflection on our work. It is a problem" T2F2E

"It angers me because they expect miracles from us. And no matter how hard we work, no one appreciates or commends us for our hard work (Other participants agreed: yes). Instead, they keep on putting pressure on us, they complain and complain. And when they do this, we end up being demotivated and discouraged to work, what is the use of trying to do your best when no one notices or appreciates? A 'thank you' once in a while will do" T2F2A

"Yes, we never discuss with lay counsellors or health promoters. And now we realise that our work is interconnected in a way. If we do not reflect and give each other feedback, we will not be effective in our work" T2F2C

"It would be better if we had a day, say Tuesday maybe, where we remain in the clinic and not going to the field. We would then reflect, discuss and assist each other and improve our work" T2F2B

"Yes, we can start by meeting as CHWs, but when we meet it becomes chaotic. There is nothing good that comes out of it, we just argue a lot and have no direction. So, we were

hoping that the ratio of 1:6 of OTL and CHWs would work because it is a manageable number so each OTL will meet with his/her CHWs and provide guidance" T2F2C

"Like I said, we requested in-service training and it has not been done to date. I also asked them for a day of reflections, then invited them to guide us and it has also not happened. I remember that we were once sent to assist a patient and when we got there, she had a colostomy bag. By then we did not know what it was and how to assist. No one came to assist us, and we went back to the clinic to report because we are not experienced. It is draining to try and explain something that you do not know yourself. It is really exhausting because I did not know what I was saying in front of the patient and we were just looking at each other, puzzled" T2F2A

"Laughing- (in case we do not understand something at the field) we see to finish. There is no one that we could call because we have been having only 1 OTL while we were 30 or so. So, like the colleagues have said, maybe the additional OTLs will assist, though they are allocated to vaccinate" T2F2A

"You know with the previous OTLs, they would accompany us to the households, or we would call them when we have challenges. They would teach us and even show us how to check infants. So, it means these activities stopped when they left, then we remained with just 1 OTL and there was no way that she could supervise all of us" T2F2D

"Yes, supervision has been a problem, but I heard that there are 5 more OTLs appointed so I am hoping that things will get better" T2F2C

"We just heard that there are new OTLs, but we have not seen them, so we are not sure if they are ours or not. Since they came, they have been allocated to vaccination sites" T2F2E

"Yes, we just heard about the newly appointed OTLs but have not met with them. Sometimes the OTL sends a message via our WhatsApp group, but I never respond because I cannot communicate with someone that I do not know" T2F2A

"But I still have hope that when everything settles, the supervision will improve and there will be time for us to be mentored at the households or at the clinic" T2F2F

“I don’t think the tracers were trained on index, but they know that we offer index counselling and testing” T3F3D
“Yes, I also do not think they have been trained (on index)” T3F3A

“Yes, in most cases you are trained for what you work with, so tracers mainly trace the clients who missed their scheduled clinic appointment. I think tracing for index is a new thing, unless if I am wrong” T3F3C

“No, you are right, tracing for index started recently. Lay counsellors were supposed to follow clients up, but we asked the tracer to assist so that we can continue to provide HIV testing services to other clients. I am not sure how the tracer does it or what they say when they call clients, we just give her the index book to get the list” T3F3D

Participants were not aware of the impact that mental health challenges can have on clients continuing with HIV treatment. They further identified other barriers as their limited scope in identifying mental health challenges, as well as addressing other issues like counselling couples and clients not willing to communicate, and also expressed their wish to be capacitated accordingly. Quotations below support these statements:

“Mental health? How is it involved here? No, that has never crossed my mind. I just trace and educate clients about adherence at the households” T4F4E

“Yes, I am also not capable of identifying mental health challenges. But with me it is not a problem because I work in the clinic and after diagnosing a client, I take her or him to a professional nurse who is better equipped to examine further” T4F4D

“I also never thought of mental health issues. But now that you mention it, I think it is important for tracers to at least have a checklist that helps them to screen for mental health issues especially at the households. This will help us to get the necessary and relevant help for the client and in turn contribute positively to retention” T4F4C

“I am not trained to pick up warning signs of mental health issues. And like my colleague said, I never thought it is important. And yes, we see challenging situations at the households, but I normally inform the clinical mentor if I see a client who cannot walk or

has social problems. Nothing around mental health issues but I would really love to be trained if there is such a training as this will improve my skills. I am very happy about this interview, sometimes we just wish to have someone who can just listen to us narrating our field work. Otherwise, we just bottle our feelings inside which is not right" T4F4A

"I wouldn't say I know how to communicate effectively with a client who does not open up, so I just leave him/her" T2F2D

"Some clients just close up even during counselling and it becomes difficult to reach out to them" T1F1A

"Some clients are difficult to interact with. They are quiet throughout the session, and it becomes difficult to understand them. But I just refer them to a case facilitator or professional nurse for intensive counselling" T1F1C

"I can't handle these cases (non-disclosure among couples). They are difficult and require more effort" T3F3A

"But going back to the non-disclosure issue, it is a challenge, and it is difficult for me as well. It is not safe for us because sometimes the couple starts to argue. We just don't know how to deal with non-disclosure among couples" T3F3C

Lack of communication, collaboration and work balance were also mentioned as barriers affecting LHWs' performance and participants said:

"Yes, like I said earlier on, communication is a problem. And imagine having to walk far to the household only to find that the client did not default. It is not fair for us, and they (facility staff) are sitting on comfortable chairs and under the shade, but not collecting correct contact details or not capturing the clients' information. Now we trace clients who never defaulted, it is not fair" T2F2A

"I have also realized that sometimes nurses do not document on the file that remains in the clinic, especially at maternity or child welfare sections and it appears as if a client defaulted. As a result, some clients become angry when I trace them because they did

not actually default, one client threatened to even sue me. But then again if the contact numbers are wrong, I won't be able to call the client and correct this error" T4F4C

"Indeed, communication is a problem. Sometimes as a CHW I refer a client to the facility and when the client gets to the facility, the staff informs her/him that they do not know me (other participants concurred). So how is the community going to trust us, CHWs, if the clinic staff deny knowing us? We tell the community that we work for the department of Health and indicate the name of the clinic, but the clinic staff say they do not know us. Do you think that when I go back to the same patient, he/she will believe me when I say I work at the particular clinic? No! We refer clients expecting to get a back-referral (feedback) so that I can get a copy and have evidence that I did my job, but this is not happening" T2F2D

"When she mentioned communication, she has wrapped it up. Communication is the main one" T2F2C

"There is no collaboration. I am the one who is supposed to trace, but I do not collect the initial patient information. So, I suffer because of someone else's mistake of not checking the correct contact details" T2F2E

"I do not think that we can collaborate with them (facility staff) because we are not even meeting as CHWs to discuss among ourselves. We do not have time to be together. When we arrive at the facility we are allocated to different tasks and we disperse, only 3 remain in the clinic" T2F2D

"So, we really need to think of a way to encourage clients to provide correct contact details. This is where we really need to synergize our efforts from counsellors, clerks, tracers, CHWs and nurses. We must all be involved" T4F4E

"The other challenge is our daily HIV testing target. It used to be 8 but now it is 12 and we work for 6 hours due to our contract (other counsellors concurred). So, we end up striving to reach the target before we knock off, at the same time losing focus on other tasks. We also refer clients to a case facilitator to continue with information and support, and when he is not there it is a struggle" T1F1C

“This is true. The index programme also requires that we follow up clients who tested positive so that we encourage them to bring their contacts for HIV testing. So, it is more work, and we end up not managing to do other tasks” T1F1D
“It is true, I support what the colleagues are saying. And to add, from time to time we are allocated other tasks in the clinic and our tracing work is left behind. Then when they are being flagged by the higher authorities for high numbers of missed appointments or defaulters, they blame us for not tracing accordingly whereas they are the ones who gave us other tasks” T2F2F

“Yes, now the focus is on COVID-19 activities. It’s either we are allocated to screen for COVID-19 or register for vaccination. We are no longer able to do our work properly. I wonder when this screening is going to stop. Imagine going to the facility at 7 just for screening. Other clients just pass us without screening, and we cannot run after them” T2F2C

“There is transport taking staff to vaccination sites daily, then only 2 or 3 CHWs remain in the clinic. Even if those remaining can try their best, it is not possible to do everything, they will be saying deworming is low, tracing is low, etc. So, the remaining 3 cannot go to creches for deworming and trace at the same time, it is not possible” T2F2D

“I work for the developmental partner, and it is difficult to do my work effectively if the health department staff is not doing their part actively so. And sometimes they just work for the sake of working, not thinking about the impact of their actions on client care and other colleagues; for example, there is poor filing which results in lost files and creation of duplicates” T4F4A

Discrimination and lack of involvement experienced by LHWs were presented as other barriers, as shown by quotations below:

“We are not being involved when these new programmes start, and they want us to implement later. Yes, that is what we said. Even the viral load education, we’ll just do it, what else can we say?” T3F3A

“So, medication has changed, and we do not know it anymore. Even the guidelines have changed, and we do not have the updated information. We just hear bits and pieces from

our colleagues from the developmental partner. We hear everything from them, even when there are new programmes or tools" T3F3C

"Yes, it is true. For example, lay counsellors from the developmental partner were given these small bags with bottles inside and these bottles will help them to teach clients about the viral load. Their supervisor came to orientate them on these bottles, but he stated that the bags are for their lay counsellors only not us. It just happened that I got into the room that they were in, otherwise I wouldn't have known about this" T3F3B

"Exactly, so do you expect us to be involved? It means when I get an HIV positive client, I must send her/him to the lay counsellors from the developmental partner for viral load education, it is their work. It means we do not have any important role to play there but next time we will be told to take over. How do we take over when we were initially discriminated? The index and HIV self-screening programmes started just like that, they were for the lay counsellors from the developmental partner and now we are told to implement them. We are just doing a favor when we conduct HIV self-screening. Everything is about the developmental partner. They were also taught about the new medication" T3F3A

"It is affecting performance negatively. For example, we were told to strengthen viral load education, but since only certain lay counsellors were given demonstration bottles, then it means we must refer all clients to them. How are we going to educate clients if we do not have the resources?" T3F3B

"It is the same as index, it is only now that they want us to do it. Sometimes I refuse and let the lay counsellors from the developmental partner continue with it, isn't it that they started it without involving us? But again, the salary issue is adding to it, I would also like to earn a better salary and be like them, maybe I will be motivated" T3F3A

"I am used to the low salary; my main issue now is this discrimination. Why are we not treated the same? Why must I refer a client to another lay counsellor when I am also one?" T3F3C

"We really want to work and do the correct things, but we are sad. How can we work effectively when we are sad? It is not possible. Our supervisor also does not support us.

The one from the developmental partner visits the clinic but mainly communicates with their lay counsellors. We feel lost, the problem is that when we started to work as lay counsellors we were volunteering. Even now we are still treated as volunteers and volunteers do not have any form of support" T3F3A

Shahmalak *et al*., (2019:11) conducted a systematic review to assess the experiences of LHWs in delivering psychological interventions. The same study highlighted limited focus on mental health issues but indicated that LHWs were capable of delivering low-intensity psychological interventions if trained. However, supervision must be strengthened to increase the confidence and help to improve the community's trust for LHWs. Moreover, LHWs expressed the need to be connected, share experiences and work with other health care workers in delivering health care. Similarly, Chibanda (2017:77) stated that PLWHIV were twice likely to suffer from depression than those who are HIV negative. Again, trained LHWs were able to deliver mental health care interventions in the absence of mental health care professionals, thereby contributing positively to HIV outcomes.

Geldsetzer *et al*., (2017:5) found that LHWs wished to receive refresher courses as well as training on new information related to their work and other tasks aside from the routine ones, such as being able to identify children's cases that need urgent referral. Furthermore, LHWs experienced frustration when unable to meet community's needs like responding to questions; therefore, they expressed an interest in broadening their roles. Mwisongo *et al*., (2015:4) stated that most lay counsellors experienced difficulties in counselling some cases such as discordant couples, the elderly or young children.

A study that was conducted in Nigeria to explore the working relationships between the mentor mothers who are part of the LHWs, and health care professionals, found mixed experiences (Sam-Agudu *et al*., 2018:5). The study found that some mentor mothers experienced support from the health care professionals while others felt unappreciated, belittled, left out, not included in facility meetings and were given extra work outside their scope, concurring with the study findings.

Although studies that highlighted the discrimination resulting from differences in support or provision of educational materials experienced by government and developmental partner's LHWs were not found, continued training was associated with increased motivation, while supervision and provision of educational material improved performance, which is similar to what the participants in the current study said (Kok *et al*., 2015:1220). Furthermore, role clarification, balancing of tasks, recognition and trust from the community were found to be motivating the CHWs as well. Limited supervision and training may further lead to emotional burden which is discussed below.

4.3.2.3.9 SUBTHEME 3.9: Emotional burden and lack of debriefing for lay health care workers

The participants indicated that the nature of the services that they provide lead to emotional burden; therefore, routine debriefing sessions would be helpful for them to feel at ease. Again, when debriefing sessions occur, only lay counsellors were considered, excluding other categories of LHWs such as CHWs. Quotations underneath support the subtheme:

"We are not debriefed regularly. The last time I was debriefed was in 2020 after demanding it. In most cases, tracers are not included in debriefing activities, only counsellors are" T4F4A

"True, even the CHWs are not debriefed routinely. And actually, we do not require a big thing, if we can just meet as colleagues, have a professional person and then talk about our work and how to cope, it will be good" T4F4E

"Yes, I also agree. Last time we were informed about the employee assistance programme and that if we feel burdened, we can call them individually for assistance. But sometimes I need to debrief with my colleagues because it shows me that I am not alone, and we are able to support each other" T4F4C

"Yes, the colleagues are telling the truth. Fortunately, I had a debriefing session together with some of the counsellors and a psychosocial trainer sometime this year and it was good. We talked about our experiences, shared ideas and motivated each other away from our work environment" T4F4D

Multiple studies support the findings of this study in terms of the emotional burden experienced by LHWs, limited debriefing sessions as well as the need to debrief the LHWs to improve performance and the quality of counselling (Jacobs *et al*., 2021:1087; Letsoalo *et al*., 2017: 38; Visser & Mabota 2015:3). Seelandt *et al*., (2021:6) further stated that debriefing benefits include, among others, fewer mistakes, higher work satisfaction, and more open communication. Jacobs *et al*., (2021:1987) also indicated that lay counsellors were happy with debriefing-on-the-go as well, where they would meet with their peers and supervisors weekly to share their experiences, discuss difficult cases, conduct role plays and come up with better ways of tackling problems. However, a study conducted in South Africa to describe the lay counsellors' HIV care experiences found that they expressed the need to go for debriefing where they would engage in relaxation activities and not talk about HIV or work-related matters (Mkhabele *et al*., 2016:323).

4.3.2.3.10 Subtheme 3.10: Salary and other benefits

The study findings revealed that participants are earning a low salary which does not match the work that they do or even meet their personal needs. Again, despite having worked for a longer period, they still do not have other benefits such as funeral assistance from the employer. One participant further indicated that they do not have benefits, yet their social support grants that were helping them to take their kids to school were terminated as they are regarded as government employees.

Though other participants indicated that these poor working conditions made them to release their anger on clients and hence contributing to treatment failure, others stated that they still maintained a good attitude towards the clients. Participants have also lost hope that the salary issue will be resolved as the people who had promised to help in resolving the matter have abandoned them. Quotations are presented below:

"Please do not say that name of a counsellor-mentor because we are not paid for it. This issue of the low salary is sad. Sometimes we contribute to the patient's failing treatment because we help them with heavy hearts, we have anger due to being ill-treatment and we take it out on them, we are just tired. I just wish this salary issue could be resolved" T3F3A

"The salary issue is a sad one, but I still treat my patients well. We have been working for a long time but there is nothing to show for it. If I happen to die, my family is the one that will make arrangements for me to get home (mentioned the place ± 100km away). There won't be any cent from my workplace, my kids will not get anything. Yes, I continue to help patients, but I am sad" T3F3B

“Yes, and to add, they have stopped the child support grants that helped me to pay school transport. So how can I be here working and assisting patients when my child is at home and not at school?” T3F3A

“I remember that we were on go-slow the last time and we were hopeful that our issue will be resolved. Now the people who were helping us are driving nice cars, have forgotten about us, and are no longer saying anything on the media. Who will ever help us? Since January, now we are heading to December, it is the same story throughout, our matter is forever being postponed” T3F3C

Jensen *et al*., (2022:8) presented findings of the study conducted in South Africa in relation to health care workers’ perceptions of the effort–reward-imbalance and professional quality of life. The study revealed that LHWs’ salary was between R4 000 and R4 500, which did not match their high workload and also did not meet the standard of living. Furthermore, LHWs were employed on a part-time contract basis, so they worked for half day only; therefore, allocating more work to them would be unfair. Ngangue *et al*., (2017:5) conducted a study in Cameroon to identify challenges in the delivery of public HIV testing. The same study found that lay counsellors were not happy with their salaries and working conditions but continued to work due to the passion they have for clients; however, those from non-governmental organisations were paid better.

Two other studies conducted in South Africa found that community health care workers perceived themselves as major role players in HIV care to an extent that counselling was not done when they were not on duty, yet they were merely treated as nurses’ extensions and their stipend was not enough to cater for their personal needs. They even indicated that not much was being done to address their challenges, as a result, they sometimes went on strike which led to compromised patient care (Ramukumba 2020: 58; Mkhabele *et al*., 2016:324). These results concur with the findings of this study.

4.3.2.4 THEME 4: RECOMMENDATIONS TO STRENGHTEN RETENTION TO HIV CARE

Participants were also requested to suggest recommendations that have the potential to improve retention to HIV care. Seven subthemes emerged from this theme.

4.3.2.4.1 SUBTHEME 4.1: Focus more on improving client information, ownership and independence

The participants explained that in order to improve retention, more efforts must be directed at preparing the clients for lifelong HIV treatment and not only striving to reach the HIV testing targets. Clients' preparation needs to start right from counselling to promote acceptance and must include expectations, responsibilities and advantages of independence, or disadvantages of dependence on other people for motivation. Participants also stated that once clients accept their HIV status, they will be able to take ownership of their health and adhere to treatment. Moreover, it is difficult to promote acceptance when the client is already defaulting treatment.

Again, providing HIV-related information as well informing clients about the reward of qualifying to collect treatment at external pick-up points if adherent and virally suppressed, leads to motivation, ownership and retention to care. Participants' voices are expressed in quotations below:

"I think it is important for counsellors to have a positive attitude and take time to build a good relationship with clients through unhurried and intensive counselling. Otherwise, if counsellors focus more on testing than trying to improve the chances of retaining clients to care, then we will not win" T4F4B

"I think we must prepare the clients right from counselling and health promotion sessions, highlight expectations, responsibilities as well as advantages of independence and disadvantages of dependence. The support from family, friends, clinic staff etc., is important, but the client must find ways to take responsibility for their health even if the support can be halted" T1F1F

"It is difficult to do that when the client is already defaulting. I think it can be easier to promote ownership and independence during the initial counselling, right after diagnosis. Counsellors must emphasize the importance of self-acceptance, which will probably promote ownership" T4F4C

"I agree that it is difficult to encourage ownership when the client is already defaulting, but we need to keep on providing health education on adherence" T4F4A

“Yes, and now clients who take their medication correctly and become virally suppressed after at least 6 months of treatment have the opportunity to choose from the listed external treatment pick up points and collect treatment there. This is convenient for most clients and if this information can be incorporated during the initial counselling, clients may own up to their actions” T4F4E

The participants also indicated that one of the responsibilities of lay counsellors is client follow up; therefore, they proposed that they should be given phones to communicate with clients. Provision of phones would allow the lay counsellors to even complete the adherence plan; however, HIV testing targets need to be reduced to promote these follow ups. The quotations below are from the participants:

“We need to be given phones so that we can trace our patients. We can even help to trace the defaulters” T3F3C

“The CHWs were given phones to trace, why can’t we be given phones as well? It is important for us to call the clients as a follow up, they still remember us, and it will help us to strengthen retention. We will be able to complete the adherence plan correctly through these follow up calls” T3F3A

“And if I trace, I can even form a support group with these traced clients. For example, I can choose to focus on people that were initiated during the month, form a support group and make sure that I follow them up accordingly” T3F3B

“If our targets can be reduced and more lay counsellors appointed, we can focus on quality not quantity. I really would not mind to physically follow up my clients if I cannot find them telephonically” T1F1B

Horter *et al*., (2017:56) found that client preparation was important in HIV status acceptance and if clients were allowed to opt out from testing, they would return for testing when they felt ready and prepared. However, the provision of incentives to encourage testing led to clients testing not to know their status, but to receive the incentives. Similarly, Kutnick *et al.,* (2017:12) investigated the reactions of HIV diagnosis and engagement in HIV care in New York and found acceptance to be a prerequisite for ART uptake and retention to care. Also, discussions around the impact of the HIV diagnosis on clients' relationships must be intensified to facilitate client preparation and acceptance. These results are in line with the study findings in terms of the importance of preparation and self-acceptance in retention to HIV care.

According to a study conducted by Gouse *et al*., (2018:12), there is a need to support LHWs with technological gadgets, which is in support of the findings of this study. In addition, the utilization of computer-based technology by counsellors working with patients and their treatment support partners enabled lay counsellors with minimal training and supervision to teach complex medical information and culturally relevant problem-solving skills. Although the current study findings did not specifically mention computer-based technology, participants identified an innovative strategy of continued remote counselling through technological gadgets like phones. In terms of the workload, Hall *et al*., (2017:6) stated that although counselling and encouragement by LHWs promoted retention of clients to care, high workload may hinder LHWs from conducting and maintaining follow ups of HIV positive clients.

4.3.2.4.2 SUBTHEME 4.2: Active involvement of lay health care workers and prominent community members

The study findings showed that participants want to be involved in issues related to their work because they are the ones who see the patients, not the supervisors. Again, if there is information that needs to reach clients, participants felt that they must be engaged adequately since they can cascade the information better using the language that clients understand. Furthermore, clients who return back to care after defaulting HIV treatment need to be referred to the LHWs for counselling and to build a good relationship. Another participant highlighted the value of information sharing by community leaders who are also on chronic treatment, to motivate clients. Participants' quotations are posted underneath:

"From my side, I think that if there are suggestions or opinions required, we must be involved and be asked directly. Most of the time they ask the supervisors who do not even see patients. We are the people on the ground working with clients every day and we know the challenges better than the supervisors" T1F1B

"And again, when they have campaigns and return lost clients back to care, they must ensure that these clients come back to us as well so that we can make the follow up. If the clients do not come to us, we lose the relationship that we built initially. I also think that we must be given an opportunity to go out and follow these patients up and check how they are because this strategy might help with retaining clients into care" T1F1B

"Yes, I agree. Clients who were lost and then returned to care need to also come to us after being re-initiated on treatment. This will help to re-build the relationship and I will also explore the reasons for defaulting and note the next appointment date so that I can remind him/her prior the visit. This can make things easier for the clients as well and minimise their frustration" T1F1B

"Again, there was someone last time who was informing clients on chronic medication about the survey. I did not know what she was talking about and if I was involved, I could have helped her to better explain to the clients in a way that they would understand. I am just saying that we should be part of anything that patients need to be empowered on from the beginning so that we are well-informed and can help to cascade the information" T1F1F

"There is also one client who was once a clinic committee member and is also on treatment. Sometimes when he comes for treatment collection at the clinic, he encourages other clients to stick to their scheduled appointments. Thereafter, counsellors or health promoter also provide health talk. I think when other clients see that even other known community members are on some chronic medications, they can be encouraged to own up to their acts" T4F4E

The study findings have been supported by the systematic review conducted by Hill *et al*., (2017:23) to determine the roles, characteristics, and responsibilities of CHWs in prevention programmes, which indicated that CHWs can be an important link between the community and health care facilities, an intervention programme or service delivery by providing context-specific support leading to better long-term outcomes for clients. Therefore, the need for their involvement is beneficial to the health programmes.

Likewise, Boyce and Katz (2019:3) reported that CHWs were able to communicate and cascade culturally appropriate information at community level, filling the health gaps. Ramukumba (2020:60) further stated that the CHWs suggested to be involved in policy processes regarding their work contracts and performance standards as they could provide valuable and appropriate inputs to resolve the programme challenges and address community's needs.

In terms of other stakeholders' engagement, Naidoo *et al*., (2018:8) conducted a study in South Africa to determine the facilitators and barriers of successful community-based HIV programme implementation, wherein participants stated that community leaders supported them and were involved in community awareness campaigns. The involvement of community leaders was cited as a facilitator of successful work of the CHWs; however, since the programme requires extensive networking of multiple stakeholders, the engagement of social workers was found to be lacking. The current study also found that community leaders could be effective in encouraging clients to continue with their medication.

4.3.2.4.3 SUBTHEME 4.3: Update the information and counselling skills of lay health care workers

Participants alluded that LHWs need to be provided with updated information relating to their work, such as the introduction of new drugs in HIV management. If there are new protocols or guidelines, they need to know and not just see clients coming with new drugs without their knowledge. Lack of knowledge will negatively affect information and counselling provided by LHWs as they would not even know the side effects.

Refresher courses are also necessary to improve communication and counselling skills as well as the quality of services provided by LHWs. Participants also suggested that LHWs need to be familiar with each other's work thus highlighting the importance of training them. They further provided an example of tracers who are not trained on enhanced adherence counselling. Quotations presented below are from the voices of participants:

"We, in fact, feel that if there is something new, they must engage us. Like you see the new drug, Dolly-Dolly and the previous one - FDC (Fixed Dose Combination), I for one do not know which patients receive what. So, it is difficult to explain the 2 options to patients because I do not understand this new one. If there is something new, they must tell us whether a particular treatment is for pregnant women only and so forth. They are not sharing information enough" T1F1D

“Yes, you’ll find that we are sitting with outdated information only to find that things have changed. Like now, I was allocated to work at the antenatal side and found that some things have changed, and I was implementing old things. This is challenging because I do not have the updated information, but I am expected to work at the antenatal side. For example, regarding blood collection for pregnant women, I knew that viral load was collected at the first visit provided the women has been on ART all along, but now I learned that only CD4 count, and creatinine are collected, no more viral load, then viral load will be collected again on the cohort month (month of treatment initiation)” T1F1E

“I agree that we need updated information. My role requires me to continuously provide information to clients; therefore, I need updated information as much as possible. We just receive communication about what is expected, but you do not get the information on how things are done. I remember that I struggled so much to get the information about the COVID-19 vaccine, especially for pregnant and breastfeeding women” T1F1F

“I also feel that there is not much focus directed to tracers, we just trace and there are no specific tools that guide us. I have not been trained on enhanced counselling or effective communication skills” T1F1A

“Again, our counselling and communication skills need to be refreshed every year because it will enable us to communicate with clients who do not open up, identify challenges and report to health professionals to probe and assist further” T1F1E

“I was trained a long time ago and I know HIV care changes a lot. In most cases only counsellors are trained but we as CHWs and tracers also need training so that we can communicate with clients effectively” T4F4E

“I was also trained on adherence counselling but would like a refresher course” T4F4D

“I need a refresher training on adherence counselling because I was trained long time ago when I was a counsellor at another province, that is why I do not even know the adherence tools used. In service training must be a continuous thing and not done once. Other HIV-related topics must also be discussed so that we can gain the necessary skills and have the updated information. I also agree with my colleague that counsellors are

the only ones trained on the updated adherence counselling, but we also interact with clients during tracing; therefore, adherence counselling skills are much needed" T4F4C

"Also, in most cases when there are workshops, counsellors attend, and I am left behind. I only receive brief feedback, so how am I going to provide information to clients if I am not trained? This is not nice at all. Like index programme, I do not understand it, no one trained me. If I assist with testing and get an HIV positive client, I have to run around to look for a counsellor to assist me because I do not have a clue of what they say or how they offer index testing" T1F1

"We need consistent in-service training. Our information becomes outdated, and we also do not practise some skills like adherence counselling, so we forget. So, refresher training is important" T2F2C

A South African study aimed at assessing HIV and TB knowledge among home-based carers identified limited knowledge, and recommended continuous training and support as well as linkage of the home-based carers to health facilities (Engelbrecht *et al*., 2017:6). Another study that evaluated a training intervention for CHWs in South Africa highlighted that the CHWs described their training as insufficient, inflexible, irrelevant and of poor quality and further expressed their need for additional training on aspects such as communication and counselling (Plowright *et al*., 2018:10).

Shahmalak *et al*., (2019:11) assessed the experiences of trained LHWs in psychological interventions in a systematic review and found that there is a need to improve the quality of training programmes for LHWs, including mental health issues, and that the duration and skill development should include sufficient time for learning. These results are in line with the findings of this study, where participants emphasised the need for and importance of continuous training so that they can possess updated information to effectively perform their work.

4.3.2.4.4 SUBTHEME 4.4: Improve communication, teamwork and integration of activities of all role players

The findings also indicated that there is need to improve teamwork, integration of activities and communication amongst all staff members involved in direct and indirect patient care, in order to improve the quality of care. Clear communication and feedback will help to smoothly continue with patient care and avoid duplication of services. It is important for facility teams to regularly meet to discuss performance and challenges, then come up with ways to improve. Clients can be linked to CHWs who in turn will provide feedback accordingly. One aspect that needs to be communicated as emphasized by the participants, is the updating of correct contact details of clients to promote tracing. Quotations below support the subtheme:

“We request OPMs, counsellors, admin clerks and all other staff members to improve communication. The communication must be on point and there must not be communication breakdown. Counsellors must also help us by explaining to clients that the CHWs assist the elderly client with treatment collection and not everyone. Youth must be aware that the CHWs are not responsible for delivery of medication to everyone. This information must also be spread in the adherence clubs. The files must be checked and updated before the CHWs can be sent for tracing” T2F2F

“I suggested to the facility manager to help tracers and CHWs to meet and also guide us in terms of how we can work harmoniously together. I also work for the developmental partner, and it is difficult for me to give suggestions directly to my colleagues. So, the facility manager drafted a weekly schedule of physical tracing and we have been following it. The only challenge is the CHWs who are working at the vaccination sites, but we are currently working with those available. Now I know that when I have challenges, I report to the facility manager who in turn communicates with the outreach team leader. So far there is good progress” T4F4B

“Yes, and we can also involve the CHWs. I don’t think we must duplicate efforts. We already have CHWs who work in the community, we just have to improve communication and link newly diagnosed clients to them without trying to physically trace them ourselves.” T1F1E

“Yes, this is a good idea. As we have our meetings, CHWs can provide feedback, raise their challenges and we all discuss possible solutions. This can work for us because our activities are interrelated, and we depend on each other to be successful in improving retention” T1F1F

“I also support the issue of different categories of lay health care workers and managers meeting regularly to discuss progress, identify gaps and suggest possible solutions” T4F4D

“Yes, communication is really important. Without communication, nothing will improve. Communication in this facility is really worrisome and needs attention” T2F2A

“That is true, sometimes we struggle with the hand over when our allocation changes. Patients refuse to be handed over to another CHW and I do not know what to do in such cases. It is a real struggle” T2F2C

“I think you have to ask the OTL to accompany you to the household and discuss with the clients. What I have realised is that the patients want to be informed beforehand. Change in allocation must not be done abruptly, clients must be informed and prepared accordingly. I introduced my clients to another CHW, and it went smoothly” T2F2D

“To add on the contact details issue, I normally request the clerks to ask for the contact details of the client’s next of kin and explain that the next of kin must be someone that the client trusts and can disclose to. I have realised that sometimes clients provide details of neighbours whom they have not disclosed to, and this becomes a problem during tracing as it may lead to accidental disclosure from an inexperienced tracer or even stigma. This is what the counsellors must emphasise from the beginning and also negotiate with the newly diagnosed clients to attach them to CHWs for continued support” T4F4C

“We have a serious issue of wrong contact numbers. I do not specifically trace clients but like I said, I also assist with the decanting programme. At times when I want to contact decanted clients who have not come to collect their parcels, I find that their numbers are no longer working. Sometimes clients qualify to be decanted and I want to call and explain to them so that they can come for decanting, then I cannot reach them due to wrong phone numbers. Maybe if we can have people who assist us to update contact details next to the gate, it can help. I do not know how this can be done to make sure that the files are updated with the correct contact details” T3F3E

“The individuals at the reception collect appointment cards from clients in bulk and go to the filing area to retrieve the files. They then take these files to the vital signs area, so

they do not meet with the clients. The first people who see clients are the ones working at the vital signs area, maybe that is where the updating of contact details can happen. Maybe someone like a CHW can be placed there daily to request for the updated contact details after the client's vital signs have been measured. I think it can work that way. The wrong contact details are a serious challenge, that is why even the tracer struggles to find clients who missed their clinic appointments" T3F3E

"I think you are raising an important issue. If we can find a way to update the contact details, it will be easier to trace clients" T3F3D

"I agree, but I think it still goes back to us to discuss the importance of correct contact details with clients and also encourage them to inform the facility staff when they have changed their details" T3F3C

"I am 100% confident about my skills and I am doing a lot for the facility. When I am not available there is a gap and missed appointments increase. But in general, right from the reception up to the consulting rooms, we need to improve how we communicate with clients, we need to smile and show clients love so that they feel satisfied when they leave the facility. Our clients lack self-esteem, they think that everyone knows that they are HIV positive, but if we show them a positive attitude it will boost their morale and help them with acceptance. If you listen to a client, he or she will also listen and understand what you are saying. So, the manner of approach is key" T4F4A

In terms of teamwork among facility staff and the integration of activities, participants expressed their importance as quoted below:

"Teamwork from colleagues. If someone is good or knowledgeable, he/she must assist those that are struggling so that we can improve. We must be aware of each other's activities as lay health care workers so that we can understand how our work is interrelated and work effectively" T2F2A

"I think so far, the collaboration is assisting a lot. However, I still feel that I need skills on adherence counselling" T4F4E

“Tracers, CHWs and counsellors need to understand each other’s work so that we can integrate efforts and improve retention” T4F4C

“We should be integrating our work as lay health care workers so that we can assist each other, but we cannot do that without the necessary training” T1F1F

“The integration is minimal yes, but we can still find a way to start collaborating as lay health care workers. We can approach the managers and suggest that we have our weekly or fortnightly feedback sessions so that we can improve our working relationship” T1F1A

“The integration is minimal currently that is why I think that I can follow my clients up” T1F1B

“It is not only the tracers and CHWs who need to come together and integrate their activities, even the counsellors must be included. I am saying this because adherence counselling starts with the counsellors and continues throughout” T4F4D

“In terms of skills, I feel confident about them. I can communicate well with clients because I was once a counsellor. However, for my skills to be effective, we need to come up with a strategy to reduce defaulter rate. A client must be given an appointment date and immediately be attached to the relevant CHW either physically or by being provided with phone numbers so that he or she can report any challenges. The CHW will then inform me and together we can come up with a way to assist the client to get treatment” T4F4B

Several studies supported the need for integration and collaboration among LHWs and other health care professionals: Shahmalak *et al*., (2019:9) mentioned that LHWs expressed the need to collaborate with other healthcare professionals who could offer guidance and support through their own experiences. Sam-Agudu *et al*., (2018:9) stated that the integration and recognition of LHWs were vital to optimise the impact of their roles in health care.

Likewise, Scott *et al*., (2018:11) who conducted a systematic review to understand how CHWs’ programmes can be best operated in health systems alluded that the integration that promoted respectful collaboration and communication between CHWs and other health care professionals encouraged and motivated the CHWs to share their unique, practical knowledge; therefore, contributing positively to patient care. Lastly, a study that was conducted in South Africa to evaluate the LHWs' interventions revealed that some factors that motivated clients to keep up with the scheduled clinic appointments were proactive management and better teamwork which may lead to creativity and improved performance (Limbani *et al*., 2019:10).

4.3.2.4.5 SUBTHEME 4.5: Balance of activities

The participants indicated that there is a need to balance the activities because since the start of the COVID-19 pandemic, all the resources and services have been shifted to the pandemic and the other conditions neglected. The LHWs highlighted that there are disadvantages of focusing on COVID-19 only because they might end up forgetting what is expected of them in the management of other programmes such as HIV. Furthermore, some participants have not been trained since employment because they came during the COVID-19 era, and everyone was focusing on it. Another participant suggested that if lay counsellors' testing targets could be reduced, they would be able to focus on other activities that contribute to retention. Participants' voices have been included below:

"These days all we do is COVID-19 work. You screen a person at the gate and casualty again, what is the importance of that? The clinic has many thermometers, why can't the nurses screen these people during consultation while we only screen them once at the gate? I really do not see the importance of screening more than once. That is why the clinic staff say that we are not working, we are no longer doing the CHWs' work, we go to the clinic early to screen at the gate, clinic entrances and casualty. When are we going to the field to check the nutritional status of children and do other activities?" T2F2D

"Yes, we are no longer doing our CHWs' activities. We will end up forgetting how the activities are done. So, after COVID-19 becomes controlled, all other activities will be far behind, and it will be a struggle to catch up" T2F2E

"They need to balance the activities; the other half can focus on COVID-19 while others continue with the CHWs' activities, and we can rotate monthly. Sometimes I promise the client that I'll bring his/her medication, then I am allocated to do something else. It means I am failing the client because now he/she will be on the missed appointments list. We

cannot all focus on COVID-19 activities and abandon other duties, otherwise we will have problems of other areas not performing well" T2F2A

"Yes, because we spend more time on COVID-19 activities, it looks like we have abandoned our patients. Sometimes you have to ask your colleague to deliver the medication to your patient because you have been allocated another task and this makes some patients to lose confidence in you. They feel that they confided in you and do not expect to see someone else visiting them" T2F2F

"To be honest, I am struggling to give inputs on other issues because I came in 2020. So, I have not been exposed to other activities because I have been working mostly on COVID-19 activities. I do household registrations, but I really do not have knowledge of other things. So, I am in the dark and do not know the expectations. And for tracing, I go with other colleagues" T2F2B

"If our targets can be reduced and more lay counsellors appointed, we can focus on quality not quantity. I really would not mind to physically follow up my clients if I cannot find them telephonically" T1F1B

The findings have been supported by the report presented by WHO (2020a:39) which stated that while health systems around the world are being challenged by the increasing demand for care of COVID-19 patients, it is critical to maintain preventive and curative services, especially for the most vulnerable populations, such as children, older persons, people living with chronic conditions, minorities and people living with disabilities to avoid health system collapse. The focus on COVID-19 may reverse the progress made in HIV care; therefore, HIV support needs to continue despite COVID-19 (Uwishema *et al*., 2022:30; Venkatesan, 2020: 64).

Krubiner *et al*., (2020:10) further supported the use of CHWs to continue with service provision such as the delivery of medication. Mwisongo *et al*., (2015:5) found that the lay counsellors' daily HIV testing target was 12, but they tested from nine to 25 clients per day and were also allocated other tasks. Again, balancing the lay health care workers' tasks is important because if their workload is high, they may experience burnout, and counselling will be rushed without achieving the desirable results. This finding concurs with what the study participant explained regarding the need to improve the quality of counselling and not just strive to test more clients for HIV.

4.3.2.4.6 SUBTHEME 4.6: Reinstatement of facility adherence clubs

Findings of the study alluded that adherence clubs were moved to the CBO pick-up point but there is a need to return them to the clinic because the service at the CBO has deteriorated. Participants stated that the facility-based adherence clubs were doing very well when it comes to promotion of adherence because clients did not wait in long queues, and they were helped quickly. The quotations below are the participants' voices:

"Another strategy that significantly reduced the number of clients who default was the adherence clubs" T3F3A

"They (adherence clubs) were just removed from the clinic and taken to a community pick up point" T3F3C
"The service went from being good to poor" T3F3D

"It is better for these clients to come back to the clinic; they will collect their medication at the Pele box or at external pharmacies. They have been tossed around a lot" T3F3C
"When the adherence clubs were held in the clinic, clients did not wait on the queue. They went straight to the club's meeting point, and they would find us there and they would be out of the facility by 09:00" T3F3B

A study conducted in Kenya to determine the clients' and health care workers' perceptions of adherence clubs revealed that this mode of ART provision was acceptable because it reduced the waiting time and the number of clinic visits (Venables *et al*., 2016: 9). In a South African study conducted to compare lost to follow up rates between clients in the adherence clubs and those in the clinic's mainstream, it was found that although some clients in the adherence clubs still missed their appointments, their lost to follow up rates were lower than those of clients in the mainstream (Bock *et al*., 2019:7). These results concur with the study findings in terms of the potential of the adherence clubs to promote retention to HIV care.

Multiple studies concur that adherence clubs are effective in motivating and retaining clients to HIV and other chronic care; however, there were mixed findings when comparing the community- and facility-based adherence clubs. The differences may be due to some studies using statistical analysis while others gathered participants' personal experiences. Grimsrud *et al*., (2016:19) conducted a quantitative study in South Africa and found that community-based adherence clubs were associated with a reduced risk of lost to follow up in adults than those facility-based.

On the other hand, Mantell *et al*., (2019:4) found that participants in a Zimbabwean study perceived the attendance and monitoring of community-based clubs to be poor; therefore, wished the clubs to be disbanded and returned to the clinic, which is similar to the current study findings. Cassidy *et al*., (2020:4) conducted a study in South Africa to compare the standard two-monthly and six-monthly adherence clubs' ART refills and found no significant differences in the retention and viral suppression of clients, irrespective of being in the facility- or community-based adherence clubs.

4.3.2.4.7 SUBTHEME 4.7: Filing system improvement

Most participants agreed that medical records management is a challenge in the facility; however, only one participant had a suggestion for improvement. The participant mentioned that the current filling system is very poor and thus makes the clients to wait for a long time without assistance. Furthermore, the participant proposed that once the client's file is lost, a register with the client's particulars such as name, file number and return date must be developed and the client helped; thereafter, the clinic staff can continue to search for the file. The quotation below represents the voice of the participant:

"File flow is indeed a challenge. Filing needs to be improved so that file loss can be minimised. Sometimes clients wait for a long time because the files are not found, and this leads to frustration. Duplicates are then created and sometimes the information is not captured on the system or nurses do not document on the files accordingly. I think that when a file is lost, there must a register of some kind to document the clients' names, file number and return dates and then we can continue to look for a file after helping the client. We agreed on this previously, but it never materialised" T4F4E

Marutha and Ngoepe (2017:4) conducted a study in South Africa to investigate the role of medical records in the provision of public health care. The same study revealed that most participants agreed that poor medical records management and missing records negatively affected timeous and effective health care service provision, which resulted in patients waiting longer to be treated and, in some instances, patients being treated without the medical history. This is in support of the findings of this study where the filing system was said to be very poor and thus clients had to wait for a long time before receiving the health services.

Sometimes highly motivated clients go to the clinics to seek care but become demotivated by some aspects such as administrative errors. The clinic staff must find a way to reduce errors such as lost blood results, which leads to frustration and unnecessary additional time spent by clients at clinics (Maughan-Brown *et al*., (2018:10). Bisnauth *et al*., (2021:13) further mentioned that while there are multiple factors that challenge retention, and health facilities do not necessarily have full control over them, patient-centred and responsive services such as improved administration can have a positive impact.

4.4 CONCLUSION

This chapter presented the findings from the LHWs in terms of their experiences and contribution to HIV care and retention; the support received from supervisors, nurses, and co-workers; retention barriers and recommendations to improve retention. The LHWs play a crucial role in retaining clients to HIV care but their experiences of support vary from none to adequate. Some areas of support that need improvement are around the provision of updated information, working material, transport, incentives, debriefing and collaboration with other health care workers. The next chapter is a continuation of findings as it presents the findings from the LHWs' supervisors and nurses.

CHAPTER 5: DATA ANALYSIS AND DISCUSSION OF FINDINGS

HEALTH CARE PROFESSIONALS

5.1 INTRODUCTION

This chapter discusses the second section of data analysis which presents findings from 10 supervisors and nurses who interact or supervise the LHWs. In-depth individual interviews were conducted telephonically to observe the COVID-19 precautions.

5.2 PRESENTATION OF FINDINGS

5.2.1 Demographic details of health care professionals

The participants comprised of different categories of health care workers and supervisors of the LHWs, that is, two primary health care nurses, one outreach team leader, one programme coordinator, two nurse mentors and two operational managers, all classified as professional nurses (PNs), as well as two counsellor supervisors (CS). There were seven females and three males within the age range of 31 to 58 years and the working experience of three to 33 years, as per table 5.1 below.

TABLE 5.1: DEMOGRAPHIC DETAILS OF THE HEALTH CARE PROFESSIONALS

Characteristics	1	2	3	4	5	6	7	8	9	10
Age	58	39	46	50	33	35	31	44	57	46
Gender	F	M	F	F	F	M	M	F	F	F
Job title	PN	PN	PN	PN	CS	PN	CS	PN	PN	PN
Years of experience	20	12	18	20	3	12	4	15	33	20

5.2.2 Themes and subthemes

After the analysis of data from the health care professionals, four themes and 12 subthemes emerged as outlined in table 5.2 below. The themes and subthemes are presented and supported by quotations from the participants and literature control.

TABLE 5.2: THEMES AND SUBTHEMES OF HEALTH CARE PROFESSIONALS

THEME 1	**SUBTHEMES**
5.2.2.1 THE ROLE AND CONTRIBUTION OF LAY HEALTH CARE WORKERS IN HIV MANAGEMENT AND RETENTION TO CARE	*5.2.2.1.1 Lay health care workers as the point of entry to HIV management services*
	5.2.2.1.2 Tracing and outreach health care services by lay health care workers
	5.2.2.1.3 Lay health care workers complementing health care professionals in HIV management
THEME 2	**SUBTHEMES**
5.2.2.2 LAY HEALTH CARE WORKERS' SUPPORT AND WORKING RELATIONSHIP WITH HEALTH CARE PROFESSIONALS	*5.2.2.2.1 Interactions between health care professionals and lay health care workers*
	5.2.2.2.2 Addressing gaps through supervision, training and mentoring
THEME 3	**SUBTHEMES**
5.2.2.3 BARRIERS THAT LAY HEALTH CARE WORKERS EXPERIENCE IN PROMOTING RETENTION TO HIV CARE	*5.2.2.3.1 Client- and community-related factors*
	5.2.2.3.2 Health system issues affecting clients
	5.2.2.3.3 Health system issues affecting the functioning of lay health care workers
	5.2.2.3.4 Limited communication and collaboration between health care and lay health care workers
THEME 4	**SUBTHEME**
5.2.2.4 RECOMMENDATIONS FOR EFFECTIVE RETENTION TO HIV CARE	*5.2.4.4.1 Promoting client-centric culture and ownership*
	5.2.2.4.2 Improve clients' experiences of care at health facilities
	5.2.2.4.3 Improve the LHWs' knowledge and working conditions

5.2.2.1 THEME 1: THE ROLE AND CONTRIBUTION OF LAY HEALTH CARE WORKERS IN HIV MANAGEMENT AND RETENTION TO CARE

The theme represents the views of health care professionals on the role and contribution of LHWs in HIV management and retention to care. Three subthemes emerged from this theme, and they are explained underneath, with the quotations and literature control.

5.2.2.1.1 SUBTHEME 1.1: Lay health care workers as the point of entry to HIV management services

Participants explained the role of lay counsellors during HIV diagnosis, and stated that they play an important role of testing and counselling clients for HIV. Testing for HIV is a pre-requisite for other steps in the HIV care continuum because after clients test positive, it is only then that the health care professionals can start them on ART, monitor and retain them in care. It is also at this point of diagnosis where lay counsellors offer adherence and index counselling, HIV-related health education such as medication side effects and blood collection, as well motivating clients through informing them about the possibility of collecting medication at external pick-up points if adherent and virally suppressed.

Therefore, LHWs also function as the support system for clients who tested positive, but also provide health education on preventive measures for HIV negative clients. They support the clients through counselling them to accept the HIV status which still carries stigma in communities. The mother mentors also support antenatal and post-natal women with health promotion messages and encourage them to test for HIV. Quotations below represent the views of the participants:

"Their role is very important, remember for us to get patients into our ART programme, we must start with HTS. So, the lay counsellors are the entry point into our programme, they work in terms of looking for clients in the facility, testing them, offering adherence counselling, and linking them to care. They also offer enhanced adherence counselling (EAC) to clients who are not suppressing and those that are not keeping up with their clinic appointments" T10HP10

*"With HIV, since it still has stigma, lay health care workers support clients to accept themselves and to know that HIV, like any other chronic illness has treatment. If they take treatment regularly and correctly, in no time, the side effects will subside. Some clients experience side effects initially because their bodies are not used to HIV treatment yet. Those who are working are enrolled on CCMDD and are encouraged to go to the clinic to collect blood at the stipulated intervals. They **MUST** (emphasis) go for blood collection because sometimes they are worried that they collect blood more often" T1HP1*

"The lay counsellors counsel and test the majority of patients and in most cases have the first contact with clients. This is the point where patients discover their status and begin to seek information and comfort. It is important for lay health care workers to transfer the correct information to clients and assist them in planning their journey after HIV diagnosis. I think that when they are with the lay health care workers, it is a safe space because the nurse is not there. They are now able to communicate freely" T3HP3

"The role of lay counsellors is to assist with HIV testing, linking those who tested positive to treatment and those negative to preventive services. They have HIV testing SOPs (Standard operating procedures), including index and HIVSS (HIV self-screening). The lay counsellors must test 12 daily as per DoH mandate. But from the developmental partners we encourage them to test at least 16 because other testing modalities like the HIV Self-Screening (HIVSS) allows them to facilitate more than 1 self-test at a time" T7HP7

"Their role is to support HIV positive clients and to encourage people to test and know their status. It is more of support, support for HIV testing, adherence and tracing" T8HP8

"The mother mentors encourage pregnant women, especially those coming for the first antenatal visit, to know their HIV status through testing. They inform pregnant women about the importance of testing which is to promote early HIV diagnosis, linkage to treatment and prevention of mother-to-child transmission. They further register them on Mom-connect so that when they have problems, they know who to talk to" T9HP9

"When the patient tests positive for HIV, he/she is counselled and requested to list partners and children so that they can come for testing as well. This needs to be done so that if they are also positive, they can be put on treatment without delay and thereby contributing to the goal of reducing new HIV infections" T4HP4

"The counsellors know their clients very well; they are also able to identify even those who tested positive in the past and want to re-test as new. So, if this happens, they check on the system at the data room and they are right 99% of the time. This helps us to get lost clients back to care and minimise duplication where the same client might be counted twice. It is unlike me, when the patient leaves my room, I forget him/her. I am referring

specifically to the counsellors; they have a good relationship with their clients and are able to follow them up” T4HP4

“They help, they help at the point of entry. They also help in explaining to the patients in a manner they can understand” T3HP3

“The lay counsellors promote health education” T5HP5

“The lay counsellors also teach clients about adherence and the importance of treatment” T5HP5

“Lay counsellors contribute to retention through health education so that clients do not end up defaulting treatment” T7HP7

“They provide health education on healthy living, compliance or adherence to medication and any aspects related to mother and childcare, like the importance of exclusive breast feeding, care of the baby and minor ailments. We have in-serviced them on basic aspects of IMCI (Integrated Management of Childhood Illnesses) so that they can teach women about the danger signs and when to seek help. Furthermore, during subsequent antenatal visits, mother mentors encourage women who tested HIV negative during their first visit to re-test accordingly” T9HP9

“They also educate patients on the importance of knowing their status, test them and encourage them to bring their partners and children to the clinic to test for HIV. They also encourage them to accept the HIV positive status by explaining that being diagnosed with HIV is not a death sentence, there is treatment that makes clients to live a healthy life just like anyone else. That is when they encourage HIV positive clients to bring their family members for HIV testing. Counsellors also educate clients about PrEP (Pre-exposure Prophylaxis) and infant prophylaxis so that new HIV infections can be minimised or prevented. They conduct pre- and post-test counselling and they do not only counsel for HIV, but they also discuss other issues that the client may be struggling with such as family problems. And if lay counsellors feel that the client’s problems are outside their scope, they refer them to the social worker for further counselling and appropriate assistance” T9HP9

"The lay counsellors teach clients about the importance of continued treatment and viral load during post-test and pre-ART counselling. They explain that if clients do not take treatment accordingly or mixes treatment with other traditional herbs, their CD4 cells will die, and HIV will increase. The lay counsellors do not trace, but the way they provide education on HIV and treatment, should be adequate to contribute to retention. So, there must be that kind of collaboration between the lay counsellors, tele-tracers and CHWs" T9HP9

"The counsellors do not have specific tools that they use when counselling clients. But there are new Be okay bottles that are not yet implemented. There are 3 bottles: the 1st bottle has red beads which shows that the viral load is high in a newly diagnosed person, the 2nd bottle has black and red beads which shows that the person is on treatment and the virus is being reduced, the 3rd bottle has black beads and 1 red bead which shows that if you continue to take treatment correctly, the virus will be suppressed. These bottles will be used to teach adherence" T5HP5

Participants further mentioned that although the LHWs provide health education at diagnosis, it must be an ongoing activity to promote retention. Quotations are presented below:

"Yes, continuous health education on adhering to medication and answering questions from clients" T1HP1

"They explain that we need to check if medication is working through the improved CD4 and low viral load counts. And they do not just end there, they become available for them. I mean that the client needs to call if he/she needs clarity so that we can explain and support" T1HP1

"Some of the lay healthcare workers are health promoters, if they are going to give health education on the importance of taking medication and adhering to clinic appointments, it will mean that the patients will be reminded every time when they attend the clinic" T2HP2

"In the clinic, we must provide continuous health education on adherence on the scheduled appointment dates because sometimes the queues are too long due to clients

who did not honour their scheduled appointment dates. We would know that we are expecting maybe 60 people but end up with more" T9HP9

"I think the information that they are giving to clients is key, so it is critical that we continuously empower them in terms of how they relay information to clients so that they are retained in care. The lay counsellors are not just supposed to do counselling, they must follow the appropriate guidelines and tools when advising clients in terms of what is expected from them, e.g., adhering to treatment" T10HP10

Mshweshwe-Pakela *et al.,* (2022:4) conducted a study in South Africa to determine the key constraints affecting the implementation of Provider Initiated HIV Counselling and Testing (PICT) and discovered that the level of PICT commitment differed between clinicians and counsellors. This is because the clinicians did not regard HIV testing as their duty, with others further citing lack of counselling skills, while on the other hand, lay counsellors described full participation in the delivery of HIV testing. Again, Mwisongo *et al*., (2015:5) evaluated HIV lay counselling and testing in South Africa and found that the majority of clients were counselled and tested by lay counsellors, who also performed other roles such as adherence counselling, coordinating support groups and providing health education and promotion.

Schmitz *et al*., (2019:6) conducted a scoping review to determine the roles and impact of LHWs' programme on women living with HIV and their infants and found that mother mentors provided support and health education on multiple topics such as HIV testing, disclosure, partner testing, ART initiation and adherence, as well as self- and infant care. The findings from the three studies concur with those of the current study in terms of the HIV counselling, testing and educative roles played by LHWs to promote retention to care. The next theme discusses the tracing and outreach roles contributing to retention to HIV care.

5.2.2.1.2 SUBTHEME 1.2: Tracing and outreach health care services by lay health care workers

The participants indicated that the facility tracers are responsible for telephonically tracing clients who missed their clinic appointments and if not found, communicate with CHWs to conduct physical tracing at households. CHWs are also responsible for outreach programmes such as performing household registrations and follow ups, where they check pregnant and post-natal women, clients with chronic diseases or TB and offer continuous health education on adherence and other topics.

The other outreach activities mentioned by participants include collecting and delivering medicines for clients who are unable to go to the clinic, as well as assisting clients with social problems by referring them to the social worker or other appropriate health care professionals. The above-mentioned roles contribute to retention to HIV care. Quotations are posted underneath:

“Again, if clients missed clinic appointments, tracers trace them telephonically and if not found, the CHWs trace physically” T2HP2

“Telephonic tracers trace clients who missed their clinic appointments and encourage them to return to the clinic to continue with their treatment if not, the CHWs will conduct physical tracing” T5HP5

“Tracers conduct telephone tracing and work closely with CHWs because they share a list of clients not found during telephonic tracing, so that the CHWs can trace at the community” T5HP5

“Tracers assist with finding clients who defaulted treatment, conduct EAC (Enhanced Adherence Counselling) and refer them to professional nurses for treatment re-initiation” T6HP6

“The tracers and CHWs trace clients who missed their clinic appointments. CHWs are also able to deliver medication to clients who are unable to attend the clinic, for example, clients who are working” T8HP8

“Before issuing medication refill, they count how many pills the client has so as to check if the client has been taking treatment correctly” T1HP1

“It depends on what the client’s challenge is. For example, if the client is unable to go to the clinic due to work but is stable, the CHWs deliver medication at home. If it is a client who is unable to walk, the CHW reports to the OTL to see the client and issue medication. That is how they support clients” T1HP1

“I have an experience of working with tracers and community health care workers. I saw that when they trace the patients at home, they talk to them in a relaxed mood, that is why I said that patients feel more comfortable with them” T3HP3

“The tracers are also very important because if we really need to retain patients in care, we need to have staff who can frequently remind them to come for their visits if they have missed their appointments. This will increase our TROA (Total clients remaining on ART) because the patients will be retained in care. So, the tracers are very important in the programme. And if we retain clients in care, we are able to monitor their viral load, encourage them to continue with treatment so that they can remain virally suppressed and reduce new HIV infections” T10HP10

“As CHWs visit the households, they know which clients are on treatment and they check the last and next appointment dates. They then encourage the clients to adhere to medication and clinic appointments and emphasise the importance of adherence. If it happens that the client defaults treatment, the tele-tracer calls the client and if the client is not found or does not return to the clinic, we compile a list and allocate CHWs according to their addresses so that they can conduct physical tracing. If the CHW finds the client, he/she must ensure that the client returns to the clinic” T9HP9

“I think they are important in interacting with patients, e.g., the tracers are the ones who call clients back to care. Again, they are the ones to whom patients explain reasons for not attending the clinic on scheduled dates. I also think they are very important because patients feel freer with them, they feel free like they are their peers compared to when they are with nurses” T3HP3

“So, the CHWs follow up the pregnant woman until she delivers, also check her HIV status, if positive they check if the baby has prophylaxis and if the mother has been attending the clinic correctly for the necessary examination and monitoring. They also encourage the mother to attend the 6 days post-natal visit so that the mother and baby can be examined properly and complications such as septic umbilicus can be ruled out. Because the mother has already been educated about breast feeding, the CHWs check if the mother still remembers, and emphasise issues like attaching the baby to the breast and personal hygiene; they also check the immunisation card so that if the baby is behind schedule, they can refer her/him to the clinic for catch-up” T9HP9

"If the client is unable to visit the clinic, maybe due to work reasons, the CHW checks if he/she is stable, not due for bloods and has no problems, then reports to the nurse who will pack medication for the CHW to deliver. However, the CHW must emphasise that the client must visit the clinic on the blood collection date. The CHW is also requested to inform the client about decanting either to Pele box or external pharmacies so that it becomes convenient for clients, especially those working, to continue taking treatment" T9HP9

"They are mostly allocated to outreach services; they visit the households in the community. Let me start with the pregnant women: Pregnant women are linked to the CHWs for continuous support. In fact, it starts with the household registrations by the CHWs, so the CHWs know the family composition in terms of the number of adults, youth, and children as well if there are any members on chronic medication. For those on chronic medication, the CHWs check which medication the client is on, adherence to medication and clinic appointments, and whether blood was monitored accordingly" T9HP9

"If the client is stable, then the facility staff refers her/him to outreach treatment collection, meaning that the CHW collects and delivers medication at the client's place; however, when the client is due for blood collection or review by the doctor or nurse, the CHW encourages the client to visit the clinic. So as the CHWs visit households to check the well-being of the families, they find social issues like clients with no IDs or food, and they refer these clients to a social worker to assist with ID or social grants application. If there is a pregnant woman in the household, the CHWs check her well-being by asking how she feels, if she attends the clinic in line with the scheduled appointments" T9HP9

Schmitz *et al*., (2019:6) stated that LHWs reminded clients of their next appointment dates, obtained a list of those who missed their appointments and tracked them. Also, they formed adherence support groups with clients and conducted home visits to support clients who had challenges with collecting their treatment. Also in agreement, is the study conducted by Jensen *et al*., (2022:7) who stated that there were LHWs who worked as adherence counsellors to offer community support, including health promotion and prevention, to clients with TB, HIV, as well as mother-baby pairs.

In addition to supporting tracing activities by LHWs, Etoori *et al*., (2020:2) mentioned that active tracing promoted return to care for most clients who had defaulted treatment, therefore potentially mitigating the effects of defaulting such as developing resistance. Again, effective tracing programmes are essential in the advent of universal test and treat strategy which results in more asymptomatic patients being put on ART, potentially leading to higher lost to follow up rates. The findings of this study also mentioned the importance and contribution of tracing and outreach support in retention to HIV care.

As LHWs continue to carry out their tasks, the health care professionals recognise the complementing nature of these tasks, which are discussed in the next subtheme.

5.2.2.1.3 SUBTHEME 1.3: Lay health care workers complementing health care professionals in HIV management

The findings from the health care professionals showed that the LHWs are crucial in offering HIV management services which complement the health care professionals' work. Participants mentioned that the LHWs screen and test clients for HIV, deliver pre-packed medication, identify clients who missed clinic appointments and refer those who need continued care to them such as, those who need ART or those at home who experience complications. As a result, LHWs alleviate the workload from the health care professionals, allowing them to focus on other clinical tasks and improve service delivery. Quotations are presented below:

"I think their role is VERY important (emphasis) because in HIV care, it is a very, uh-it's a very large scale of work. Because HIV is the leading condition with a lot of patients, so we need healthcare professionals, and we need lay healthcare workers so that they can be able to assist us where we are unable to reach. If we are going to do everything ourselves, then we are going to delay the service time for the people" T2HP2

"Like for example, if we (health care professionals) are going to follow up on clients that do not attend their scheduled visits at the clinic, whereas we are busy assisting clients who are currently in the clinic, then we'll need someone to assist with these follow ups. Because now we are focused on helping clients in the clinic already" T2HP2

"In most cases when the CHWs bring patients back to the clinic, I avail myself to assist so that these patients do not wait for a long period of time or are moved up and down. Also, when CHWs are out in the field, they are able to call and discuss matters with me where necessary. I then assist them where I can, that is how I support them. When I

identify that they lack knowledge, I train them or arrange with the relevant personnel to train them" T3HP3

"Lay counsellors go to all entry points such as dental, general, antenatal areas, etc., to recruit clients for HIV testing, test, and counsel them on adherence if positive. They also link HIV positive clients to treatment by referring them to professional nurses" T6HP6

"Lay counsellors test and refer HIV positive clients to professional nurses. Now we also have a case facilitator who follows the client up and have enough time to discuss the importance of treatment and adherence with the client. I think this makes it easier for clients to be retained in care" T6HP6

"We as nurses initiate clients on treatment and advise them to return after 2 weeks for the results. However, we do not wait for the client to return, we check the results upfront so that action can be taken for abnormal results" T6HP6

"For retention, the counsellors link patients to treatment. But patients are different, there will be one who is not accepting his/her status so the counsellor will refer accordingly to the psychologist or professional nurse or the case facilitator" T8HP8

Laurenzi *et al.,* (2021:2) indicated that deploying CHWs may be a solution to poor health system coverage as CHWs assist health care providers to fulfil essential tasks. Again, in resource-limited countries, CHWs may provide successful ways to reach set health goals such as the Sustainable Development Goal 3 which aims to ensure healthy lives and promote the well-being for all, therefore improving the health outcomes at population level.

A study conducted by Mhlongo *et al*., (2019:2) emphasised the importance of LHWs, stating that CHWs have been widely used to scale up HIV care and have also bridged gaps in access to care which arose from lack of communication in terms of patient follow-up and long distances travelled by patients to address health problems. Similarly, Hartzler *et al*., (2018:241) consulted several studies to analyze the roles of CHWs in primary health care and found that household visits extended the clinic's reach and CHWs were able to provide services such as vital signs screening, health education and help the health care teams to understand the clients' social background, while communicating with the clinicians remotely.

The above-outlined findings concur with the findings of this study which pointed out the crucial role played by LHWs in complementing the HIV patient care services provided by health care professionals.

5.2.2.2 THEME 2: LAY HEALTH CARE WORKERS' SUPPORT AND WORKING RELATIONSHIP WITH HEALTH CARE PROFESSIONALS

The theme has two subthemes namely interactions between health care professionals and LHWs as well as addressing gaps through supervision, training and mentoring. The subthemes are explained underneath, followed by quotations and literature control.

5.2.2.2.1 SUBTHEME: 2.1 Interactions between health care professionals and lay health care workers

The participants explained their involvement with different categories of LHWs and most of them stated that they have good working relationships. They further mentioned that continuous interactions occur between the health care professionals and LHWs to monitor the performance, discuss patient care and challenges encountered in the facility and community, as well as to brainstorm improvement ideas. One participant went on to cite an example where lay counsellors were counselling and testing clients without including consent forms in the files, then a meeting was held to discuss it, subsequently leading to cessation of this malpractice.

In terms of the working relationships and engagement of the LHWs, the quotations below represent the voices of participants, followed by literature control.

"Ok, I interact with CHWs. We had meetings every Tuesday regarding challenges that we face at the community. Every CHW has clients that he/she checks daily or monthly" T1HP1

"I work as a professional nurse and interact with lay counsellors, CHWs and sometimes the health promoter. The relationship is good because if there are gaps, I call them, we discuss, and they rectify. We used to conduct the performance reviews with them to monitor their impact, come up with improvement plans and encourage them. And I also

monitor if they are implementing what we discussed and yes, I find that they are really improving, more especially the lay counsellors, we have regular meetings” T4HP4

“There is also a performance review meeting held with staff fortnightly and we also identify gaps and discuss possible solutions. For example, some counsellors would test clients and not insert consent forms in the files, this was discussed and rectified. They were advised to count the consent forms stock every Monday and request copies when necessary. Since these meetings, the work flows smoothly” T6HP6

“I oversee the work of lay counsellors, identify the need for training and arrange accordingly. I also review their performance in line with the set targets and provide the necessary working material. I conduct performance monitoring, so when a lay counsellor does not perform well, I communicate with him/her to understand the challenges. I also observe her work closely then after understanding the gaps, I recommend in-service training or refresher course. I also provide mentoring while the counselling is in progress” T7HP7

"I communicate with lay counsellors, tracers, and CHWs as part of my role as a professional nurse and clinical mentor. Our working relationship is good, and when we encounter issues, we talk about them and find solutions. When a patient is unhappy with the manner they were served, we sit down and come to a resolution. Perhaps the patient inquiries about the dates on the appointment card, particularly for decanting, in which patients pick up their medications at the pharmacy, post office, etc. You discover that the CHWs are confused as well, so they call me to clarify. The patient might also require specialized care at Ga-Rankuwa hospital and be unable to return to the clinic in that medical condition and in that case, the CHW would call me to speak with the patient. After hearing what the patient is stating, I would ask them to bring a hospital report so we could attach it to the clinic file and update the records. Those are some of the challenges that the CHWs face” T3HP3

“I currently supervise the lay counsellors, but I previously supervised telephone tracers as well. We have a good relationship and I visit the facility every week to interact with them and check their needs” T5HP5

“I interact with lay counsellors, mother mentors and CHWs. The mother mentors and lay counsellors report directly to me and the other OPM; CHWs report to the OTL who then reports to me” T9HP9

“I have a relationship with lay counsellors mostly as they work closely with HIV. They provide HIV testing service (HTS) which is the entry point of our HIV programme. So, I am working closely with lay counsellors, though they are based at different facilities. I also interact with tracers when I visit the facilities to check how they are tracing the clients who missed their appointments, and the records that they keep as evidence of what was done in terms of tracing. We empower them in terms of giving them the updates because we all have to follow the updated adherence guidelines, consolidated HIV guidelines and other available standard procedures. So, the lay health care workers must continuously be updated on the latest developments, they don’t have to work with old information” T10HP10

“Our relationship is good, the lay health care workers report to us, that is me and the other operational manager and we know what is expected from them. The health promoter, lay counsellors and mother-mentors all report to us, but the CHWs first report to the OTL (outreach team leader) who in turn reports to us and still send their leave requests to us. We also manage their leave, and they report anything that they need to us. We also check their working material and provide if depleted. So far so good” T8HP8

“I also support them to do independent quality control (IQC) checks, these are done at least weekly on Mondays to check the quality of the test kits. I order IQC supplies from the laboratory. We also do proficiency testing twice a year to check if our counsellors are competent and able to interpret results on their own. The PT samples are also from the laboratory; counsellors are supposed to test and interpret the results. So, I interact with them frequently and check if they have enough test kits then communicate with the facility manager to order where necessary. That is how I provide support” T10HP10

In terms of direct patient care, the participants provide ART to clients tested by lay counsellors and also help to identify clients who defaulted treatment so that tracing can be done accordingly. The CHWs, with the support of their supervisor, also assist in decanting stable clients to collect treatment either at external pharmacies or community pick-up points. The other form of support is the provision of working materials to the LHWs. Quotations are posted below:

"On patient care, like if we need to trace people who missed appointments, we'll get their files and give them to the lay healthcare workers; actually, we get a list and lay healthcare workers retrieve clients' files to get the information and trace. In terms of the lay counsellors, they send HIV positive clients to me to initiate treatment" T2HP2

"I am a professional nurse and work well with lay health care workers, specifically lay counsellors and tracers. Counsellors bring clients who have to start ARV treatment while tracers bring clients that defaulted, and I assist them accordingly. The relationship is good, even when they are not sure about something, they come to me, and we discuss" T6HP6

"The OTL accompanied the CHWs after 2 months to assist or provide medication to stable clients who are unable to attend the clinic due to work reasons, the elderly or those unable to walk and have no guardians/relatives to assist. The elderly clients are enrolled on decanting or CCMDD (Central Chronic Medicines Dispensing and Distribution), where they receive pre-packed medication for a certain period. The OTL checked vital signs: blood pressure, blood sugar, weight, and their treatment before enrolling them for CCMDD. Now we are focusing mainly on COVID-19 activities" T1HP1

"It's important for the client to be stable because if stable, there won't be a need for the client to visit the clinic frequently. We can plan on how best the patient can get medication without frequent clinic visits. So that is where the issue of decanting to other places comes in. So, the viral load must be suppressed to below 50 copies, in this way the risk of HIV transmission is reduced and now CDC (Centre for Disease Control and Prevention) is promoting U=U messages which means that if the virus is undetectable, it is not transmittable" T2HP2

Ndambo *et al*., (2022:9) mentioned that CHWs in the study conducted in Malawi to explore their perspectives on motivators reported an excellent working relationship with formal health care providers and positive recognition of their work by both the facility staff and clients. Also, the CHWs stated that their work improved the community's health, decreased the number of clients requiring to visit the health facility, and hence the facility staff's workload, which in turn made the CHWs to feel proud, confident, and motivated.

Hodgins *et al*., (2016:5) conducted a systematic review to assess how LHWs tailored their interventions and found that they effectively executed interventions that aimed to serve 'hard-to-reach' individuals and communities since they potentially have a shared background with the targeted groups or communities. Moreover, while LHWs are linked to health care facilities and are supported by health care professionals to deliver health promotion activities, they are different from other health care workers in terms of their lack of formal professional training. The findings support the current study which puts emphasis on the support to be given to LHWs to be able to render their services effectively.

Similarly, Limbani *et al*., (2019:12) assessed task shifting interventions for LHWs to support the clinic staff in South Africa and alluded that amidst the shortage of health care professionals and an increasing demand for chronic health care services, LHWs assisted effectively. However, it is imperative for managers to involve them in meetings, respond to the changing situations, improve the working relationships between lay and professional health care workers, minimise conflicts and not overwhelm the LHWs with more tasks.

These interactions further enable the health care professionals to assess knowledge gaps and conduct the relevant training and mentoring to empower LHWs and improve the quality of their work. The subtheme underneath relates to supervision, training and mentoring of LHWs.

5.2.2.2.2 SUBTHEME 2.2: Addressing gaps through supervision, training and mentoring

Participants highlighted that health care professionals and supervisors must visit the LHWs' workstations in order to identify gaps and provide mentoring, training, and supportive supervision. Another participant also explained that supervision of CHWs has been a challenge due the focus on COVID-19 prevention activities. Quality activities such as checking the LHWs' HIV testing, index, and tracing programme registers; observing the counselling and testing procedures; and assessing the skills of CHWs at the households were mentioned by participants.

Some of the critical gaps identified by the health care professionals include non-usage of timers when conducting the HIV test, superficial counselling of clients, non-compliance to adherence and index guidelines as well as limited information on kids' disclosure and adolescent counselling. Furthermore, the participants emphasized the importance of using timers when testing for HIV, stating that failure to do so may lead to patients going home with false negative results, thus exposing their close contacts to infection. Again, the danger of intimate partner violence and the importance of screening thereof before listing partners for HIV testing were highlighted. On the spot training or mentoring are done to address the identified gaps. Quotations below support this subtheme:

"As I visit the lay counsellors at their facilities, I discuss with them, identify gaps and address these gaps through mentoring" T7HP7

"However, they had not been using it (adherence plan) for some time because it was not available and there was no one who reported" T7HP7

"I visit the facilities monthly as per schedule. Upon arrival at the facility, I immediately check the HTS registers because HTS is the entry point. I make sure the records are accurately filled out, then I identify and talk about any gaps before closing them. I also observe counsellors when conducting HTS to check if they are following the correct procedure, so I check the quality of testing. Despite being given timers, the majority of our lay counselors merely test without using timers. So, it is a very serious issue in terms of the quality because if you are not using the timer, you will sometimes read the results before the incubation time lapses and have false negative results, for example. The patient will then go undiagnosed, and he/she would then be a high risk for HIV transmission. I normally teach them about the importance of using timers and waiting for the incubation period as stipulated by the supplier before interpreting the results. I also check whether they are recording the room temperature in their counselling rooms because the storage of the test kit is very important especially in hot weather when the room temperature is prone to change" T10HP10

"In addition to accompanying them to clients for treatment, I also go to clients who have questions that CHWs are unable to answer. I then explain in a way that clients will understand and also touch on the importance of taking treatment correctly. Like questions from women of child-bearing age who want to conceive" T1HP1

“Thereafter, the OTLs were conducting one-on-one mentoring. The OTLs also accompanied them to the households to assess the skills against the standard checklist, identified the gaps and used the teachable moments, meaning that they addressed the gaps immediately. Fridays were put aside for meetings where CHWs and OTLs would reflect, discuss, and teach each other. The CHWs had phones which they used to call the OTL in case they struggle at the households. And they informed the clients beforehand that they have been sent by the clinic and that should there be a need, they would call a senior staff. The OTLs were also able to go where the CHW is and provide guidance. Every month, we would have a meeting with the OTLs, project managers, re-engineering focal person and any relevant cadres to discuss the outreach progress and challenges. So, most activities were accomplished effectively until COVID-19 started” T9HP9

“Like index counselling, I wanted to understand how they identify contacts when they come for testing because they are seen by different counsellors who may not be able to identify them. If these contacts cannot be identified, it will appear as if we are not doing well on the index programme. So, they told me that they list these contacts in a book so that other counsellors can identify them easily” T4HP4

“Unfortunately, I did not ask to see this book. But I doubt that if a person comes for testing, the counsellor will go to look for that book. It sounds impractical and this is a gap from my side that I did not get clarity on, but it is something that I need to follow up. However, the counsellors informed me that there will be an improvement in the index programme because now all lay counsellors are offering it, not only developmental partners’ counsellors like it used to happen before. The Department of Health’s (DoH) counsellors do not have a choice but to implement the programme because they have been trained and given official registers to document on” T4HP4

“I do go back to the lay counsellor to enquire about what happened. For others it is a language barrier issue, while with others the counselling was indeed superficial because the lay counsellor wanted to push the queue and did not explain thoroughly. However, the lay counsellors deny that they sometimes provide superficial counselling. But I also saw this gap in antenatal women. I expect the women to at least know that the baby must receive prophylaxis after birth, but we had a case of a woman who delivered at the hospital and the baby was not given prophylaxis. The woman stated that she did not worry

about this because she thought that the guidelines have changed. She also mentioned that she googled to get the prophylaxis information, so I wondered if the lay counsellors and nurses did not provide this information during counselling. So, there is still a gap, I think sometimes the lay counsellors just work in order to get through with the queue. But these days I check the name of the counsellor who provided the service and go directly to her/him to address the gaps" T8HP8

"It is difficult to answer this because I do not know when COVID-19 will be under control. Meanwhile the new CHWs pair with the experienced ones when they visit the community for household registrations and tracing. And after the previous OTLs' contracts were not renewed; we were left with 1 OTL and it was difficult for her to meet all the expectations. However, we have new OTLs appointed now, but things are not yet in place because since they started, they have been focusing on vaccination. So, it is not easy to give a clear answer on how to close the identified gaps" T9HP9

"I mentor them on index, provide supportive supervision on HTS and supply them with working material. We also review performance together, identify gaps, come up with interventions and compile an improvement plan. If there is a need for training, I train them. I do task observation when the client is there sometimes, as well as oral questioning. I also mentor when the client is not there" T5HP5

"The lay counsellors are supposed to assess the intimate partner violence (IPV) risk during counselling, follow up on clients to check if there were any adverse events and refer the client where necessary. So, I realized that most lay counsellors do not know about this, and hence are not making the necessary follow-ups or following the correct procedure" T7HP7

"I only realised this gap recently (this month) during the index programme assessments, so I plan to conduct in-service training on IPV (Intimate partner violence) and adverse events in general. I also think that it is important to strengthen the skills of lay counsellors and other providers to identify non-verbal cues from clients because most lay counsellors focus on verbal communication only" T7HP7

"I never really understood the negative effects of not assessing IPV until recently when I heard what happened in another facility. I think some counsellors also do not pay much

attention to IPV because they have never seen such cases. The client was offered index testing by a lay counsellor, then referred to a case facilitator, but there was no record of listed contacts and IPV screening. After continuing with counselling, the case facilitators gave a contact slip to the index client to give to the partner. So, there was no proper communication between the lay counsellor and case facilitator. The partner visited the clinic being very angry and threatening to harm the staff who provided testing to the index client. Anyway, the case was resolved, but it was an eye opener for most of us" T7HP7

"Sometimes I mentor counsellors at the facilities, but we also have counsellor supervisors from developmental partners who also visit facilities to support the counsellors. So, if I alert the counsellor supervisors about the identified gaps, I think they will be able to assist faster. So far, I have communicated with one counsellor supervisor to assist with the kids' disclosure and adherence plan gaps as she visits the facilities. She promised to provide information on the adherence plan and emphasise that it must be used for all clients that are starting ART, unsuppressed or returning after defaulting" T10HP10

"I haven't really managed to observe the counsellors from the beginning until the end of the testing session with clients, but I think it is important for this to be done. The little time that I spent in the counselling room, I discovered that some lay counsellors do not wait for the stipulated time before interpreting the results. They also use one approach when interacting with clients, like there is no difference between adolescents and their guardians, they just communicate with them the same way and at the same time. And we know that adolescents are vulnerable and need to be counselled properly in line with their language and needs, they may not be free when their guardians or parents are in the room with them" T10HP10

Akintola and Chikoko (2016:7) conducted a study in South Africa to determine factors that motivate CHWs' supervisors and found that supervisors accompanied the CHWs to households to mentor and guide them on practical ways to handle difficult cases, thereby improving their skills. Similarly, the WHO (2020b:17) developed an evidence guide to maximise CHW programmes for HIV, TB and Malaria and highlighted that supervisory checklists and visual job aids must be utilised for supportive supervision and mentoring to reinforce the CHWs' skills through consistent and timely performance feedback.

Mundeva *et al*., (2018:8) further mentioned that CHWs working in HIV care and other areas must be supported through ongoing training and supervision to prevent burnout. Assegaai *et al*., (2022:35) concurred that CHWs received basic training and on the spot guidance which are key to improving performance and quality; however, these activities were neither prioritised nor thoroughly planned by the supervisors. Additionally, in a study conducted to explore the experiences of facility-based lay counsellors in South Africa, lay counsellors reported that the counsellor supervisor was always available to assist with difficult cases, either telephonically or physically, even outside her working hours (Jacobs *et al*., 2021:1087).

Again, the lay counsellors felt that group supervision and the use of counsellor-client role plays improved their skills and confidence. In contrast, the current study findings reported limited CHWs' supervision which was aggravated by the focus on COVID-19 pandemic. These differences may be due to the nature of the CHWs' work which is mainly in the community while lay counsellors are facility-based and interact with multiple health care professionals.

5.2.2.3 THEME 3: BARRIERS THAT LAY HEALTH CARE WORKERS EXPERIENCE IN PROMOTING RETENTION TO HIV CARE

This theme addresses barriers that LHWs experience in promoting retention to HIV care. Multiple barriers that are related to clients and the community, LHWs, health system and collaboration with other health care workers were mentioned. There are four subthemes identified under the theme which are presented underneath, with quotations supporting them as well as literature review.

5.2.2.3.1 SUBTHEME 3.1: Client- and community-related factors

Client- and community-related barriers include non-disclosure of the HIV status, missing clinic appointments, congested housing arrangements, safety issues, client dishonesty and negative attitude.

The participants identified a barrier of HIV status non-disclosure by clients who have tested positive, emphasizing that continuous counselling is needed to promote acceptance of the HIV status. Lack of disclosure was seen as a critical barrier because once the clients fail to disclose the HIV status, it makes it difficult to test the partner or take the medication freely. However, participants indicated that the reason for lack of disclosure by clients who have tested positive for HIV is fear of abandonment by their partners. Participants said:

“Some patients still have a problem of non-disclosure to partners or family. So, it is important to keep on giving information until the client accepts him/herself and is ready to disclose” T1HP1

“Lack of disclosure is a big problem to the client and us as healthcare workers. When the client tests positive, we must encourage him or her to inform her contacts so that they can also be tested. Therefore, if disclosure does not happen, we cannot test contacts. Sometimes clients only bring children for testing, not partners. Again, if clients do not disclose, they are not free to take their treatment, they hide it and may end up defaulting” T1HP1

“They fear that their partners may abandon them (these men), thinking that they came with the illness. There is so much dishonesty among partners because at times you find that the client agrees to disclose, only to find that his/her partner is already on HIV treatment, especially those working at the mines as they are able to collect their medication there” T1HP1

Some participants cited that while some clients miss clinic appointments due to work constraints as well as lack of knowledge and social support, others do not take responsibility for their health, forget their dates and/or travel without informing the facility, as per quotations below:

Issues related to work, maybe the patient can only go to the clinic around 17:00 when some clinics are closed, you understand?” T2HP2

“In most cases they talk about the elderly clients who stay alone and cannot take medication on an empty stomach, The CHWs have to assist with food first before the client can take medication. Other clients are confused and do not understand how to take medication; therefore, the CHW has to go there or call the client daily to check if he/she took the medication correctly. At times, the CHW arranges the medication per days so

that it is easier for the client to take, then visit the client at a later stage to check if the client took the medication correctly. Those are the challenges that they face" T1HP1
"I do not think that the patients do not know, they do not take responsibility for their health" T3HP3

"By relaxing I mean that if for example the client is enrolled to receive medication at the post office, he/she forgets that he/she must go for blood collection, especially when the blood collection date is not aligned with the prescription renewal date" T1HP1

"Their reasons are not really something that can make a person to skip appointments, for example, the patient would cite that he/she visited relatives at another area. The patient knew that he/she was going away, why didn't he/she come to the clinic? You see, these are some of the reasons that nurses do not understand" T3HP3

The study findings also indicated barriers around congested housing arrangements and safety issues that CHWs face in the community. Some clients missed their appointments and when traced, they exhibited negative attitudes towards the LHWs. The participants provided examples of one CHW who was bitten by dogs, and criminals who sometimes rob CHWs of the work phones. CHWs currently work in pairs to promote their safety. Quotations are posted below:

"The other issue that the CHWs are complaining mostly about is the informal settlements around us, there are no house numbers, so it is difficult to do physical tracing in those areas. It is just congested; the area is too informal so the tracers cannot penetrate and know exactly where the client is staying" T10HP10

"Another challenge is the negative attitude from the clients in the households, like there is a CHW who was bitten by a dog. When she arrived at the household, the client peeped through the window and released the dog to bite her, so it is not safe for the CHWs, honestly. So, we group CHWs in pairs of two, but it is not safe still. Even when they walk on the streets, they meet criminals who are aware that CHWs have work phones, so they snatch the phones or rob them of their belongings. Yes, those are the challenges" T9HP9
"Sometimes the clients refuse to open the door completely, but others state fair reasons like the CHWs only visit their households and not the other neighbouring households, so it becomes obvious that the client is on a particular medication such as HIV or has a

certain problem. So, we advised the CHWs to conduct door-to-door visits and where there is an issue, then they can then spend more time. This will avoid discrimination or stigma" T9HP9

Another client-related barrier is dishonesty in terms of provision of wrong information. Sometimes clients provide wrong contact details which makes it difficult to trace and follow them up. The quotations below represent the participants' voices:

***"**They do collect this information; however, some clients would say that they left their phones at home, making it impossible for the counsellor to confirm the phone numbers. The lay counsellors sometimes confirm the phone numbers by dialling them. So, if the phone numbers are not confirmed, the chances are that the client will not be found when called in future. The lay counsellors also collect the addresses, and again some clients provide wrong ones. But I do not think that the importance of the contact numbers is emphasised" T6HP6*

"Provision of wrong contact information by clients is the main barrier. You'll find CHWs tracing at the household as per address on the file, only to discover that the household members do not know the client and they do not even have back rooms for tenants" T6HP6

***"**After testing for HIV, the lay counsellors open the clinical stationery and document the name, contact details and the counselling session information. They do not necessarily discuss with the client the importance of providing accurate details" T7HP7*

"Normally the challenges that they face in terms of retention is that sometimes when the tracers call the clients, they cannot reach them due to phones being on voice mail. And even when they are doing physical tracing, sometimes they don't find clients at the addresses provided. They'll find that the client is no longer staying there or is unknown" T10HP10

***"**Our community is mobile, so the CHWs do not find them during tracing. And some clients provide wrong details, like wrong names, addresses and phone numbers. Otherwise, I have not received reports about negative attitude of clients towards the CHWs" T8HP8*

“The other issue that they complain about is that some clients are not honest sometimes. When lay health care workers provide information to them, like advising them to visit the clinic as per scheduled appointments, they do not come back. They just come once, and off they go, then after 6 months these clients will return and state that they have been collecting medication somewhere else. So, we know that we cannot deny patients to move, but at least they should be able to report their whereabouts so that we know how to assist them” T10HP10

Ayuttacorn *et al.,* (2019:10) conducted a study in Thailand to investigate the health behaviours of migrant workers living with HIV and found that half of them had not disclosed to their partners due to fear of rejection and stigma as HIV was still associated with promiscuous lifestyle. Similar findings were cited by Gyamfi *et al.,* (2017:5) in Ghana where people were scared to disclose their HIV status due to fear of undesirable consequences of disclosure such as strained relationships among family members. Samuel (2020:1) mentioned that HIV still has a great deal of stigma and negative perceptions which may be revealed verbally or through hurtful actions the moment someone discloses the HIV status. As a result, people are still scared to disclose their HIV status which concurs with the findings of this study.

Mukumbang *et al*., (2017:5) found some of the barriers to adherence and retention to be work travels which make clients to miss clinic appointments, and social problems such as not having food to eat before taking medication. Additionally, Kok *et al*., (2015:7) conducted a systematic review and found that CHWs in Kenya perceived the community to be ignorant and uncooperative while some had low levels of education and health knowledge. These findings concur with the current study where clients travelled due to work; some elderly clients waited for CHWs to prepare food so that they could take their medication; and other clients lacked information, while others were not taking responsibility for their health.

Similar to the study findings, Jensen *et al*., (2022:8) found that some CHWs had been exposed to violence in the community and as a result, were working in pairs to promote safety even though this contributed to them not meeting the set performance targets. On the other hand, Austin-Evelyn *et al*., (2017:6) found that community members regarded primary health care re-engineering as a good programme and even informed CHWs if they could not keep up with their clinic appointments for certain reasons.

Dapaah and Senah (2016:7) stated that many clients and potential users of health services were uncomfortable with the quality of care given by some health workers, especially in breaching confidentiality about the HIV status. This has compelled many clients and potential users of the services to provide health care workers with wrong information that provided access to some services while still protecting their identity. The findings from the study above concur with what the current study found in terms of clients proving wrong contact details which makes it difficult for the LHWs to trace them after defaulting ART.

5.2.2.3.2 SUBTHEME 3.2: Health system issues affecting clients

Participants stated multiple health system issues that affect clients, leading to poor retention to HIV care. These issues include clients' negative experiences at the health facility and language barrier between clients and health care providers.

In terms of the negative experiences at the health facility, one participant cited that the clients were yelled at, not addressed properly or not given information on certain procedures such as blood collection. The participant further justified these negative actions, stating that scolding is preferred over discussing the missed appointment issue as clients will remember the experience and not miss clinic appointments again. Other participants mentioned that clients complain about long queues as well as clinic operating hours that clash with their work schedules. As a result, accessibility to HIV services in health facilities becomes difficult. Quotations below represent the participant's voice:

"They would complain that they were not given information on why blood is collected, or they were yelled at or maybe their questions were not addressed properly during counselling" T3HP3

"The clients traced by CHWs mention different challenges such as negative staff attitude of healthcare workers" T1HP1
"Patients like to say that they are afraid of nurses" T3HP3

"Nurses scold, yes, they scold patients because they want things to be done correctly. They want patients to take responsibility for their health. And in most cases when you do something repeatedly, for example, if a patient does not keep up with scheduled

appointments, as a nurse you end up scolding him/her. This is because you do not understand why the patient is skipping the appointments, you feel like the patient does not care about him/herself" T3HP3

"Scolding helps because when a patient remembers it, he/she may not skip appointments again. Discussing will not emphasize the seriousness of the matter" T3HP3

"The clients traced by CHWs mention different challenges such as long queues at the clinic" T1HP1

"The main issue is that some patients have return dates on which they are unable to visit the facility, which makes it difficult for lay healthcare workers to emphasise that the clients return to the clinic and influence the patients to do so. Issues related to work, maybe the patient can only go to the clinic around 17:00 when some clinics are closed, you understand?" T2HP2

The findings of this study also revealed that another barrier is different languages between the LHWs and clients, which makes it difficult for them to understand each other. One participant suggested that facilities must have a list of interpreters to assist in language barrier cases, as per quotation below:

"Most of them experience language barriers when interacting with clients from the neighbouring countries. I had that experience previously, luckily the case facilitator could speak that language and assisted accordingly. When we were conducting index program assessments in another subdistrict, I also observed that this facility had a list of healthcare workers who are interpreters according to the primary languages that clients speak. Therefore, this is an excellent practice that other facilities can imitate so that these interpreters can be called when there is a language barrier, either telephonically or physically, depending on their availability at that moment. I've been wanting to go to the operational managers or sub-district HIV coordinator about this since I think they may know something or have plans for it" T7HP7

A study conducted in South Africa by Lowane and Lebese (2022:5) regarding missing appointments by clients revealed that they missed their appointments because of several reasons. Some of the reasons mentioned included long waiting time due to the increased workload at health facilities which affects the quality of services provided, as well as health care workers providing unsuitable next appointment dates by not considering the clients' concerns, consequently discouraging clients from continuing with their care. Similarly, Xie and Or (2017:7) showed that the clients who were less satisfied in health care institutions perceived the amount of time they spent waiting and receiving care as less acceptable.

In addition to long queues, Chinyandura *et al*., (2022:6) found that communicating with clients in a disrespectful or belittling manner contributed to disengagement from care. Mwamba *et al*., (2018:5) found that health care providers admitted to some discretionary practices of opening the clinic late or closing early which led to limited access and frustration of clients. Furthermore, Al Shamsi *et al*., (2020:122) discovered that language barriers in healthcare led to miscommunication between the health care professionals and clients, thus negatively affecting the quality of health care delivery and patient safety. In addition, the review found that although the interpreter service was used by some health care institutions, it resulted in increased costs and patients' length of treatment visits. The multiple barriers discussed above concur with the findings of this study.

5.2.2.3.3 SUBTHEME 3.3: Health system issues affecting the functioning of LHWs

Participants cited multiple issues that impact negatively on the functioning of LHWs. They mentioned that LHWs walk long distances even through extreme weather conditions due to lack of transport, and this makes it difficult for them to conduct outreach activities in some areas. Also, some participants raised concerns over the increased workload of the LHWs versus the quality of their work. Other concerns were around the support of LHWs in terms of provision of working materials such as phones for tracers, as well as training and supervision which impact negatively on their skills, knowledge and compliance with the national HIV management guidelines. In terms of resources, participants mentioned lack of transport for outreach services and the limited number of tracing phones. Quotations are posted below:

"The first challenge is transport for CHWs. Sometimes they travel for a long distance, or it is raining or extremely hot, so they need transport" T9HP9

"The other issue that tele-tracers face is the limited number of phones to trace defaulted clients, but they normally get assistance from the facility managers who ensure that they

avail phones since this needs to be a daily activity. If we do not trace daily, we'll have more missed appointments so it is critical to avail phones so that the tracers can be able to do their work" T10HP10

Some participants indicated that there is an increased workload on the side of the lay counsellors because they are allocated multiple tasks, such as HIV counselling and testing, tracing index clients, and facilitating adherence clubs. The lay counsellors have a testing target of 12 clients per day, with those from the developmental partner expected to test 16. So, they work very fast and ignore other things, thus compromising the quality of testing and counselling. Quotations below represent the participants' voices:

"We give them multiple tasks at the same time because you'll find that the counsellor is expected to test for HIV, then trace index clients, some also facilitate adherence clubs, so there is over-allocation of work. That is why they tend to ignore other tasks and focus on consent forms only" T5HP5

"I think the lay counsellors want to reach their daily targets of 12 each and those from the implementing partners are sometimes requested to test 16. So, a client who tests positive for HIV needs more time because the lay counsellors have to offer post-test-, pre-ART- and index counselling. So, they are under pressure to reach their targets. It is even worse because DoH counsellors work for 6 hours due to their contract, so they try to push so that by the time they knock off the target is reached. I may be wrong, but I think the quality of counselling for HIV positive clients is somehow compromised" T6HP6

"The incubation time for traditional test kits may be up to 30 minutes, depending on the supplier. So, I think the lay counsellors want to finish and go to the next client so that they can reach their targets. The focus is more on quantity than quality, maybe it is because there is no clear measurement of quality so usually their contribution is measured in numbers tested. I also think that some do not believe that interpreting the results prematurely can result in false negative. This may be the reason why we sometimes have cases of clients who test negative and positive respectively a day apart at different clinics. Yes, I do understand that the client may have been in the window period where the virus is not yet detected by the body, but I believe that the quality of testing affects the results as well" T10HP10

The lack of training and supervision for LHWs emerged as a barrier that led to limited knowledge and guidance. However, the participants cited that the skills levels differ, even among LHWs within the same category, but the lay counsellors were regarded as more knowledgeable than other LHWs even though they worked superficially without complying to the guidelines. Some areas in which LHWs lacked skills are around identifying mental health issues and gaps in clients' clinic cards, conducting index and adherence counselling, and using outdated guidelines. Quotations supporting this subtheme have been presented underneath:

"The CHWs' skills levels are different. Those that started working before 2020 are adequately skilled because they attended a 5-days training" T9HP9

"The CHWs are not adequately skilled. If I can divert a little, they were trained on how to read the children's road to health cards, then refer those who missed the immunisation to the clinic. Even to date they have not done that, so I am not sure if they understand. I am not sure if the gap is mentoring, supervision or what. And remember earlier on I said that they are not able to locate clients that were previously decanted and are now on the dormant list. I needed them to bring these clients for re-scripting so that they can return to care and be removed from this list of inactive clients. So, I think they are struggling to comprehend these elements" T4HP4

"When you have trained someone, you have to provide updates and support regularly and also check implementation. Although implementation is not assessed regularly, I do not think they lack skills, they are just working to reach the daily targets. What I also like about them is that they are open to learning new things, they are not resistant to change" T6HP6

"The lay counsellors are knowledgeable, but they like working superficially, to be honest. Sometimes you see that the counselling was done yes, but not intensely so. You will be with an antenatal client and realise that she lacks knowledge due to probably the counsellor not going deep when counselling or providing information. Sometimes they would counsel and test a client with no written consent form, but this issue has since improved. So, they need to be monitored and told to work properly" T8HP8

"No, they are not trained on the updated guidelines. They were trained on the old adherence syllabus, but not on the updated guidelines" T7HP7

"Yes, it is a challenge. We expect them to provide the initial adherence counselling, but they were not trained on the updated adherence guidelines. And we have been requesting training for them, even for us as counsellor-supervisors, but haven't really had a positive response. Maybe that is why the lay counsellors refer to the case facilitator more often" T7HP7

"I wouldn't want to appear as if I am prejudging the lay health care workers, but we need to intensify the information provided because sometimes counsellors work for a long time without receiving updates or sessions, debriefing or follow ups, so I think we need to engage with them frequently if we really want to win this battle of poor adherence and retention. We really need to be in frequent contact and guide them because they really need guidance, sometimes they may provide superficial counselling if they are not guided properly" T10HP10

"I cannot think of any other barrier, but during the index programme assessments, I also realised that some lay counsellors do not know how to deal with adverse events, like identifying, tracking, and reporting them. Adverse events that I am referring to are from the index programme. Isn't it that this programme has risks; for example, a client may accept index testing and list her contacts, then when she arrives at home, the partner may become violent after being informed" T7HP7

"CHWs are not trained on mental health issues, it is beyond their scope of practise" T1HP1

"I don't think the CHWs are trained on this, but I agree that mental health problems may contribute to clients not returning to the clinic despite being traced and found at home. Maybe we need a simple tool for lay health care workers that can assist them to screen for mental health issues" T4HP4

"I do not think the lay counsellors are knowledgeable up to that level, but the case facilitator can be able to pick that up because they have higher qualifications, like a social worker or a psychologist" T5HP5

“I never thought about that, but it is a gap because it means no one discusses the importance of correct contact details when the case facilitator is unavailable” T5HP5

“Yes, this is indeed a challenge. Because you’ll find that when the client is traced telephonically and not found, the tracer calls the next of kin without necessarily checking the treatment buddy or the person that the client disclosed to. This is a serious risk because we do not know if the client disclosed to the next of kin or not. The lay counsellors do not discuss these, they just collect the information. Yes, this is important” T7HP7

“Viral load? No, lay counsellors call it viral load, but this is not understandable for clients, they become lost. The lay counsellors would then explain that the treatment would suppress the virus, but still I feel that the explanation was not at the level of the clients, so I am really happy about these new bottles, and I wish they could be implemented soon” T7HP7

“We have an in-service training plan, but our counsellors come to work late around or after 07:30 when we are already done with the discussions. So, this is a gap, and we really have to find a way to reach out to them” T8HP8

Participants expressed concern over the availability of tools that guide LHWs, especially tracers, as well as compliance to HIV testing and adherence guidelines. It was further highlighted that guideline compliance is a challenge even to other health care professionals who sometimes forget to use guidelines when there are long queues. Participants said:

“The tracers do not have specific tools also” T5HP5

“They just trace and ask the client to return to the clinic if found” T4HP4

The tracers do not necessarily have a tool, they just call the clients” T8HP8

“For counselling, they use their heads (meaning they do not use anything). But when it comes to testing, they use the algorithms that guide them on which test to use and when. Index testing also has tools that they complete” T7HP7

“They use the adherence plan while providing adherence counselling in preparation for treatment initiation. They are also able to review, change or update this adherence plan during subsequent visits” T8HP8

“They (adherence plans) guide the counsellors on which issues to discuss with clients, such as the aim of treatment, plans to collect treatment consistently, side effects and identifying a treatment buddy, etc” T5HP5

“I don’t think they see the importance of using this plan because they are able to give the information even when they do not use these adherence plans. The plan is however important because it reminds them of critical issues that may negatively affect adherence and retention to care” T5HP5

“The adherence plan is mostly not implemented in the facilities, there is no adherence plan in the patients’ records. When I was auditing for kids’ disclosure, there is a part where I have to check if there was an adherence plan when the child was initiated on ART. So, most of the time, above 90%, there is no adherence plan in the patients’ records in the facilities that I have visited already. So, I have noted that it is a gap that must be addressed because if there is no adherence plan it means that you did not plan with the guardian or the care giver of the child about the treatment that you are about to give. That is why we have issues- these children are not suppressing, they are not coming properly for appointments, it is because there was no foundation from the beginning, so we need to focus more on the adherence plan. So, the lay counsellors need to know the importance of discussing and compiling this adherence plan before any client can be initiated on treatment or linked to care and complete follow up sessions. This adherence plan gap is also identified for adult clients, it is also not done” T10HP10

“If it (adherence counselling) was happening correctly and consistently, we would not be having many clients who miss their appointments. So, I do not think that it is done accordingly” T10HP10

“Yes, this part is also appearing on the adherence plan, that is why I said that if the lay counsellors were completing the plan properly these problems would be reduced. So

sometimes the counsellors do not even know that there is an adherence plan that must be completed and miss to discuss these important issues” T10HP10

“Lay counsellors do not state any reasons for not using the adherence plan, I think they do not understand its value and think that the information in their memory is adequate. It is a challenge; it is a challenge because we are having standard tools that should be used nationally. So, we expect that even if a patient is coming from different provinces, they must get the same information because the tools are standardised. So, we need to emphasise it and change the mindset that a counsellor can just counsel without the adherence plan” T10HP10

“We are having tools that guide us on what should happen, so it is important that we use them accordingly. And they need to know, we must teach them to use adherence education tools as well, they are there. These tools have information that you need to offer for HIV, TB, etc., so they should use that book because it specifically outlines the information and illustrates it with pictures for clients to understand. So, I think if we can intensify the use of these tools and emphasise their importance we will go somewhere. And again, where you find this adherence plan in the patient’s file, you see that all the tick boxes are marked, and the ink looks the same from the first to the last session. And you wonder if the plan was done effectively or was it ticked just for the sake of complying. Ideally the sessions should be done on different days while the patient continues with treatment, so I do not know if all the information is provided in one day or what” T10HP10

Participants highlighted that even the health care professionals sometimes forget to use guidelines when there are long queues, the only thing they do is to quickly renew treatment scripts. Participants said:

“When you get in the consulting room, you become overwhelmed, the queue is long, clients are impatient and as a PN, you just want to push the queue, so using the guideline skips your mind. To be honest, assessing mental health is not a routine. There is APC guidelines available, but I use it mostly when I have a condition which I am not sure of, such as skin conditions” T2HP2

“I am not sure, but I think some are not aware of what the guideline consists of or are just pushing the queue. Like in the consulting room that I work at, I focus on script renewals

for decanted clients so there is no time to refer to the guideline because the queue is long" T4HP4

"Mental health conditions are now included in the adult primary care (APC) guideline which must be used when treating adult clients. I have observed that nurses do not use it accordingly, so I think they are also missing clients who may be depressed or having other issues, and this may negatively affect retention" T4HP4

"During consultation, I ask the client how he/she feels and also check for any physical problems. It is rare that I assess clients for mental health, it is not a routine, but when there is a need, I do. I just focus on the queue because clients become impatient when they wait for too long" T6HP6

"I screen for mental health when the signs are prominent, not as a routine" T3HP3

In terms of supervision, some participants said it was inadequate. They attributed limited supervision to the shift in focus towards COVID-19 prevention activities. One participant was also concerned about the LHWs' tracing outcomes as they would report not finding the clients but when accompanied by the supervisor, clients were found. It raised doubts in terms of the CHWs' understanding of their impact on retention.

"I don't think there is adequate supervision" T4HP4

"The challenge is that the 2020 CHWs have not had training, and because of COVID-19, I believe there hasn't been enough time to properly orient them to the program, tasks, and expectations accordingly" T9HP9.

"You know COVID-19 has tied our hands. The CHWs are now focusing more on COVID-19 activities than anything else. However, before COVID-19, I used to get the schedule of CHWs and follow them to see how they conduct their activities. This is because sometimes their output was low and unsatisfactory and they will be having only 1 or 2 OTLS while they are 30 or so, which was difficult for all to be monitored. For example, they would receive a list of clients to trace, and they would always come back with no positive feedback for all clients, either they say the client, or the address was not found, and I realised that they were not always telling the truth. So, I would go with them to

identify their challenges and support them, not to spy on them. I would also use my car to go with those who cited long distance as a challenge. And in most cases, we found clients, so I am not sure why they kept on saying they did not find the clients or the addresses, maybe they do not understand the impact of tracing on retention" T9HP9

"Now that they are focusing on COVID-19, it is difficult to reinforce and monitor tracing activities. In terms of equipment, they usually start at the clinic so whatever material they need are provided. So, they collect gloves, linen savers, etc., and we sign for them to ensure accountability. If there are challenges, for example, clients refusing CHWs access to their homes, the previous OTLs would go there because we realised that the community values nurses more than the CHWs. When they saw epaulettes, they opened up and the OTL communicated with the concerned member and ultimately the CHWs gained access accordingly" T9HP9

"I think it (lay counsellors' update sessions) should be monthly because we have many lay counsellors and we cannot take all of them at once, they can rotate so that we can be able to address them all. The only challenge now is that there are a lot of competing mandates that we are having, and this has hindered these monthly meetings. From their clinics, counsellors were able to attend scheduled trainings at the sub-district venue, unless if they did not have transport fares. But the implementing partner would assist with transport to and from the training venue. So, transport is a challenge and also, I am alone and cannot visit all of them at their facilities that is why they used to come to a central place at the sub-district" T10HP10

CHW programmes have been described as valuable in improving HIV services and adherence to treatment, but effectiveness of these programmes relies on providing enabling work environments for CHWs, including reasonable workload, supportive supervision and adequate training and supplies (Busza *et al*., 2018:1). This concurs with the findings of this study. Similarly, Austin-Evelyn *et al*., (2017:9) revealed that CHWs cited their barriers as lack of equipment, supplies and transportation which hindered them from addressing the community's health needs and providing effective referrals. In addition, Naidoo *et al*., (2018:11) found that CHWs had limited stationery and access to telephones which stopped them from carrying on with their work.

Westgate *et al*., (2021:13) identified that fifteen out of 29 large-scale programme case studies included in their exploratory research indicated weak supervision; and supervision was the fourth most commonly cited challenge after lack of supplies, financing, and compensation. Furthermore, high workload of facility-based supervisors and outreach team leaders (OTLs), as well as non-renewal of OTLs' work contracts led to difficulties in optimizing supervision. This supports the findings of the study which stated that supervision of CHWs is lacking due to few OTLs and focusing on COVID-19 related activities.

Moreover, LHWs were as overworked as other health care professionals and were allocated multiple tasks which do not even match their low stipend (Jensen *et al*., 2022:7). Geldsetzer *et al*., (2017:5) stated that LHWs did not mind for their roles to be expanded but the concern was that they were not adequately trained on aspects such as the psychosocial support, and as a result, could not identify and refer clients who were abused. Similarly, LHWs felt that they were not adequately trained on mental health issues and were unable to meet the needs of the community (Shahmalak *et al*., 2019:5). Schmitz *et al., (*2019:15) revealed that LHWs had difficulties in recording patients' outcomes on clinical forms because they were not trained. Again, although LHWs offered adherence counselling and education, patients' adherence was suboptimal. The above findings concur with the current study.

5.2.2.3.4 SUBTHEME 3.4: Limited communication and collaboration

The participants indicated that LHWs felt that there was limited communication between them and the health care professionals such as not being informed about changes in ARV regimens. One participant further raised concerns of role conflict resulting from conflicting treatment messages provided by LHWs which sometimes made it difficult for clinicians to correct with clients. According to another participant, some LHWs do not have a good relationship with their supervisor, and there are also some trust issues from the health care professionals towards LHWs. Quotations below are in support of this subtheme:

"In most cases, some lay health care workers felt that they were not informed when the new ARVs were introduced. Like Dolutegravir based regimen, I think we need to just inform the lay counsellors that there is a new pill but not get into deeper details. The reason for saying this is that I am not sure how the lay counsellors relay the message regarding the type of medication to clients, somehow the clients come to nurses

channelled already and because they met the counsellors first, they tend to believe them more than the other person. For example, when Dolutegravir was introduced, it was not given to women who wanted to conceive for fear of possible neural tube defects (but it is no longer contraindicated now) and you'd find that the counsellor informed the client that there is a pill which leads to drowsiness and is taken at night, and the one that can be taken in the morning. So, the client would come to me requesting the pill that is taken in the morning, which is Dolutegravir that was contraindicated by then. So even if I explained deeper, it was difficult for this client to understand, and she felt that I did not want to provide what she opted for" T6HP6

"So, we really need to ask lay counsellors to just inform clients that there is a new pill and refrain from going into further details, but just emphasise that the nurse is the one who assesses suitability. I remember another incident where the client came to me and said she did not want the pill that sterilises (makes people not to conceive). I asked her where she got the information from and she said she was informed by the counsellor, so I had to spend a lot of time trying to explain. I am not really sure how the message was relayed by the counsellor and how the client interpreted it. It is very important that we communicate with our lay health care workers and advise them on how to package the messages for clients" T6HP6

"I never really understood the negative effects of not assessing IPV until recently when I heard what happened in another facility. I think some counsellors also do not pay much attention to IPV because they have never seen such cases. The client was offered index testing by a lay counsellor, then referred to a case facilitator, but there was no record of listed contacts and IPV screening. After continuing with counselling, the case facilitators gave a contact slip to the index client to give to the partner. So, there was no proper communication between the lay counsellor and case facilitator. The partner visited the clinic being very angry and threatening to harm the staff who provided testing to the index client. Anyway, the case was resolved, but it was an eye opener for most of us" T7HP7

"I picked up that the CHWs do not even have a good relationship with their immediate supervisors. I am saying this because some of them come to me when they have a problem, but I expect them to go to their immediate supervisor. If I can give you an example, there is a new resolution that the CHWs must sign the duty register daily. Some of them still forget because it is a new thing, and I am not saying that it is right for them

not to sign, all I am saying is that they need to be helped to come up with a reminder system until they get used to it. One of them came to me crying because her supervisor made them (all CHWs) sign leave without pay. I feel that this is harsh and could have been handled differently. Again, it may negatively affect the working relationship" T4HP4

"It will affect their work negatively because if the CHWs are struggling with something related to work, they may not ask for assistance from their supervisor because they are afraid of her. It means they'll continue either doing the wrong thing or not doing that task at all. They are not comfortable, so it means they'll just work without a positive impact. Even if they come to me for help, I am not their line manager and do not understand their workplan and schedule in detail, so I can only answer some questions related to their field work. I am talking about things that I have witnessed these past few months. There was this other team leader who retired, I do not remember seeing these kinds of problems with her. I think the CHWs were comfortable with her and could open up and solve their challenges effectively without bringing them to the facility staff" T4HP4

Some participants doubted the work of LHWs, indicating lack of trust on the CHWs because they provide inadequate feedback and do not know their patients, as opposed to the lay counsellors who know their clients well. The other participant doubted the counsellors' consistency in complying with the testing procedures, saying that they may do the correct procedures only when supervisors are observing them, as per quotations below:

"For the CHWs, I do not trust them that much because I sometimes ask them to give me the names of the clients that they see at the households so that I can check if they qualify for decanting and they'll be reluctant, not even knowing their clients too well. I learned this when I wanted to re-script clients that have been collecting their treatment at the community pick up point and the CHWs did not know what was happening. I remember asking about this particular client and the CHW did not know his whereabouts. She only informed me that the client passed away after waiting for her response for a long time, I had even forgotten that I asked. This means that the CHWs are not good at knowing their clients as compared to the lay counsellors. And I expect them to bond more with clients because they work with the same households" T4HP4

“Sometimes the CHW gives me feedback that he/she went to trace a patient and the patient returned to the clinic. When I ask her how he/she proved this, he/she will just say the patient verbalised this. You see, the community health care worker did not check the patient’s card and even the next appointment date. This means that the feedback or report about this patient is incomplete. It is a challenge, so we have to assist them to understand things like this and be able to identify the correct documentation on the card. If the CHW calls a patient, the patient must be able to say when he/she visited the clinic and the next appointment date. Sometimes the patient did not visit the clinic altogether and the CHW will report that the patient visited the clinic” T3HP3

“When I am there, I see the lay counsellors doing everything properly, even completing the adherence plan. But I am not sure if they do that due to my presence or not and maybe stop when I leave. I really do not know how to measure this” T7HP7

Sam-Agudu *et al*., (2018:5) stated that LHWs felt side-lined by some health care professionals who also doubted their ability to execute their work effectively. LHWs stated that some health care professionals did not consider their client referrals to an extent that they would throw them away, which defeated the purpose of collaboration and communication (Ludwick *et al*., 2018:6). Kok *et al*., (2017:5) also stated that CHWs did not feel supported and respected by their superiors, and strategies that reduce social distance between LHWs and their supervisors could improve relationships and performance. In addition, lack of trust and support towards LHWs negatively affected their motivation and performance, and resulted in lack of credibility of LHWs.

Assegaai *et al*., (2022:35) alluded that the CHWs were not regarded by health care professionals as part of the primary health care teams; therefore, they were excluded from meetings. Again, some health care professionals did not understand the CHWs’ roles and would pass unpleasant remarks, stating that the CHWs think that they are nurses. The above findings are in line with those of the current study in showing unsatisfactory interactions characterized by lack of trust and communication between the LHWs and health care professionals.

5.2.2.4 THEME 4: RECOMMENDATIONS FOR EFFECTIVE RETENTION TO HIV CARE

The participants were also requested to reflect on the recommendations to improve retention and they mentioned multiple issues that were categorised under three subthemes. Each subtheme is presented underneath with the relevant quotations as well as literature control.

5.2.2.4.1 SUBTHEME 4.1: Promoting client-centric culture and ownership

Participants suggested that providing health care services that consider the needs of individual clients can help to improve retention to HIV care. Client-oriented care includes multiple activities such as discussing clinic appointments, extending clinic operating hours, offering continuous health education, the use of different treatment collection modalities suitable to individual clients and client profiling.

Participants stated that the best approach is for health care workers to plan together with clients and allow them to choose suitable appointment days such as weekends. The participants' voices are presented underneath:

"I think one of the things is giving appointment dates that are patient centred. For example, clients can be allowed to visit the clinic on weekends" T2HP2

"I think the best thing for retention is that it should be patient centred if we are going to make a decision regarding the return dates" T2HP2

"If the client was given an option to visit the clinic on Saturday, he/she would be helped accordingly on a suitable and agreed upon date" T2HP2

"I think giving out proper information as well as planning together with the client. Remember that this will be lifelong treatment for the client, so planning from the beginning is very important. So, if there is no planning and listening to what the client is saying, then we will have problems because during adherence planning, there are issues that we are addressing. You talk to the client about their goals of taking this treatment, the mode of transport to visit the facility, etc., so if these issues are addressed from the beginning,

then you can know which future challenges to anticipate because you have planned properly with your client. But if you are not planning with them, you will not be able to predict the issues that may be experienced in future" T10HP10

"Ok, in my own view, they can do health promotion like at the waiting area, inform patients that they are able to choose their next appointment dates, like Wed or Fri or Sat etc., when they are in the consulting rooms with the sisters (professional nurses). They can advise patients to negotiate return dates with the sisters because now you find that sometimes patients are just being given dates and then they feel that they do not have a word in adjusting these dates; and then a patient decides to keep quiet and not say anything about the date, then come back to the clinic when he/she is available, which causes a strain in providing care" T2HP2

One participant said there is a need to extend operating hours in order to give clients the lee way of visiting the health institutions at a time suitable to them. Again, some facilities are supposed to operate for 24 hours but after 16:00 they stop offering other services. The quotation is posted underneath:

"From our side, we need to increase our operating times for clients, especially for the 24-hour facilities. And we need to give clients the appointment dates that suit them, and not force them to accept what is suitable for us like during the week, whereas there are weekends with which clients can visit the clinic. We should give patients options, if they want to visit the facility on a public holiday or weekend or after hours, they must be allowed because the facility is open, and the medication is there. I feel that we still lack there because we just want clients to visit on weekdays and then there are facilities that operate for 24 hours, but then after 16:00 they are no longer offering certain services and only wait for emergencies. So, if we can be flexible and listen to the clients and not ourselves, I think it can be better" T10HP10

Some participants mentioned that CHWs should remind clients about crucial dates such as blood collection, either through messages or phone calls. Clients must be linked to CHWs so that they know who to call if they are unable to go to the clinic. Alternative and suitable treatment options such as decanting stable clients to external pharmacies instead of waiting on long queues at the clinic, or sending a buddy to collect treatment must be discussed with clients. The quotations below belong to the participants:

“The only challenge is when the client forgets to go for blood collection at the correct interval; because the client has treatment on hand, he/she may relax. I think the CHWs can jot these clients down, even though they are too many, so that they can remind them to go for blood collection at the correct interval” T1HP1

“I think that we can have messages that remind clients of their appointment dates” T3HP3

“Most clients have phones; I think they can be encouraged to note the blood collection date on the calendar and be educated about the importance of this blood” T1HP1

“They have good communication skills and are able to interact with clients, including those who are not open” T7HP7

“There should be open communication with clients so immediately when you test the client and he/she tests positive, we have to compile the adherence plan and be open to clients. We must give clients the contact numbers of the facility, like we can write them on the appointment cards and encourage the clients to call the facility if they are unable to attend the clinic. The client must alert the facility and reschedule the appointment so that he/she does not appear on the missed appointment list. And I think it is very important to link our clients to CHWs so that these clients can know their wards and CHWs. If the clients are unable to come for appointments, they can report to CHWs and ask if treatment can be delivered to avoid defaulting” T10HP10

“Attaching patients to the CHWs can also assist because they are allocated to the wards within the community. So, when the patient starts treatment, then we attach him/her to the CHW already so that when the patient experiences a challenge in future, he/she can inform the CHW. The CHW will know the patient and address in advance and even if there are no problems, the CHW can pass by to check the patient’s well-being. I think that would help; we must not look for patients only when they are lost on our clinic system” T3HP3

“Or the other thing will be treatment buddies in case the client is unable to attend the clinic, then he/she can send someone to collect medication and the file will be updated without the patient being there as a result of work commitments” T2HP2

“Decanting clients to external pharmacies is the best in promoting retention. Clients do not wait in long queues in the clinic. The concern however is if the client is staying next to the clinic and has to go to town for treatment due to decanting” T5HP5

“I teach them about decanting, like who qualifies and how it works. In that way they can also provide the information to clients. I initiate HIV positive clients on ART and assist clients who defaulted treatment and were brought back to care by the CHWs” T6HP6

“Most of clients attending the clinic are working, so we need to intensify decanting them to external pharmacies. If viral load is collected accordingly and is suppressed, then the client can be decanted for 12 months. The only challenge is that some clients still do not go to the clinic when they are due for viral load collection, so I am not sure whether they do not understand or what. Again, the way screening is done, delays other processes” T6HP6

“I encourage clients that they will be decanted for 12 months if they take treatment correctly and their viral load is suppressed” T6HP6

Continuous empowerment of clients regarding HIV in order to promote self-acceptance and ownership was suggested by participants. Below are the quotations from the participants:

“They also walk for long distances and are unable to reach other areas which need transport. So, we need to strengthen health education to clients before they default. It is a lot of work to keep on tracing clients especially because the clinic has a huge catchment population. Clients must be educated about their blood results because I realised that they give you more attention if you talk about that” T4HP4

“They do not have the freedom, they don’t. But if the clients are taught about the blood collection importance and intervals and we build their confidence, they will be able to confidently show the PN why they are right. If the PN sees the confidence, the PN will withdraw. This is not right; patients are encouraged to collect viral load but there are still nurses who discourage them” T4HP4

"With HIV, since it still has stigma, lay health care workers support clients to accept themselves and to know that HIV, like any other chronic illness has treatment" T1HP1

"We also have to listen to the patients' problems, like those who do not have money or stay far from the clinic need to be helped before they skip their appointments. We should not wait for them to skip their appointments first" T3HP3

In terms of clients' profiling, one participant explained that it will help to understand different groups of clients, then ensure that appropriate care is provided, and clients are not missed but receive their treatment and have blood monitored at the correct intervals. The participant's voice is represented below:

"I wish we can conduct profiling of patients, though it is a lot of work. We can allocate ourselves, maybe group a counsellor and a professional nurse, to identify clients who started ART during the month, then check if they are still on treatment or not and follow them up accordingly. I saw this strategy working for mothers. We started postnatal clubs for HIV positive women and women who are enrolled come on the same date and are attended as a group within an hour. So, when women and their infants are due for blood monitoring, all these are collected accordingly, and no one is missed. I find that the women are free to talk in a group and support each other. The mother-mentors are responsible for these support groups, but lay counsellors assist them where necessary. The nurses also attend these support groups" T8HP8

Health care workers need to value and acknowledge clients' experiences and contribution to their care through planning and discussing together with them (Dawson-Rose *et al*., 2016:579). Furthermore, as discussions continue, clients must be allowed to take time to think things through and not be rushed in order to promote self-acceptance and provider-client trust. Similarly, Chen *et al*., (2016:5) proposed a patient-centred approach, and explained that health care can only be optimised if patients are empowered and participate actively in shared decision-making. Again, clients' participation informs the development of tailored plans that will help them to take responsibility for their own health and keep them engaged in care. The study supports the findings of this study which indicated the importance of discussing next clinic appointment dates and suitable treatment collection options with clients as well as continuous client empowerment to encourage self-acceptance.

Additionally, extended clinic operating hours as well as services that extend beyond clinic visits through reminder voice calls or messages to clients promoted retention especially to mobile clients (Bisnauth *et al*., 2021:8). Bogart *et al*., (2022:4) further indicated that clients must be well-educated on alternative treatment collection options such as decanting to external pick-up points, then be allowed to choose suitable points to avoid situations where health care workers unknowingly select pick up points that are too far for clients therefore adding extra costs. Kibaara *et al*., (2016:5) also found better clinic attendance among women with treatment buddies than those without treatment buddies. However, there was no difference in men and this contrast suggests the importance of tailor-made interventions to address individual clients' preferences which is concurring with the current study findings.

In Zimbabwe, Mody *et al.,* (2021:62) identified that profiling in terms of HIV care disruption is one of the most effective patient-centric strategies that can deepen the understanding of disengagement from care; thereafter, interventions targeting these unique profiles can be implemented to improve retention and other HIV outcomes. The same study sought reasons for disengagement from HIV care from clients who defaulted treatment, then came up with 5 distinct profiles: livelihood and mobility; clinic accessibility; family and mobility; doubting the need for HIV care; and multidimensional barriers to care. These findings concur with the current study which also proposed profiling of HIV clients to understand and provide client-appropriate interventions and counselling.

5.2.2.4.2 SUBTHEME 4.2: Improve clients' experiences of care at health facilities

The participants indicated that clients' experiences can be improved through administrative processes such as minimizing the loss of medical records, reducing waiting time, improving staff attitudes and warmly welcoming clients, including those who defaulted ART.

Quotations regarding the improvement of administrative processes are posted below:

"That is the result of being irresponsible, nothing else. I have advised the clerks to pre-retrieve files because if they retrieve files in the morning when the patients are already at the clinic they work under pressure. They are not doing this, that is why they cannot find patients' files. There is this employee, he is not a clerk but was used as a queue marshal.

He is very good at filing, and he can find even files that the clerks could not find. Unfortunately, he is not an admin clerk, but he is capable. I just wish we were able to use people according to their capabilities and passion. It is pure laziness; the clerks even tell patients to go from one room to another to look for files. Maybe they need to be re-shuffled and be taken to other clinics, they are no longer effective" T4HP4

"We also need to retrieve the files and improve our filing system so that we do not have clients who become aggrieved and discouraged to attend the clinic due to having the experience of missing files. We must also improve our attitude and treat people well; you know, even if people can wait for a long time in the clinic, but being communicated with nicely and receiving progress feedback becomes better and encouraging" T9HP9

"I think it is better now, though not yet satisfactory, since our developmental partner helped us to install new filing cabinets. The other thing is shortage of blue files. You'll find that a client is initiated on ART, the clinical stationery is completed and captured on the system, then grouped with others and placed inside one envelope written the date. When the client comes for follow up, we expect the client to tell us the date of the first visit so that we can look for the specific envelope created on that date and locate his/her clinical stationery. If the client forgot the date, it is a challenge to get his/her clinical stationery. I was thinking about this recently, if we can ensure that all clients have appointment cards (though they also lose them sometimes), even if they cannot remember their last visit date, the appointment cards will show. Then the clinical stationery can be retrieved, and the client will not have to struggle with memorising the dates. So, we will continuously place orders for blue folders and appointment cards; previously we were either told that the department has no budget, or the cards are out of stock" T9HP9

One participant highlighted that another way to reduce the waiting time is to improve the screening process. Currently, the elderly clients are the first to be screened for COVID-19 and vital signs while other age groups wait. Instead, there must be at least two queues, one for the elderly and the other one for the general population. The quotation is presented below:

"Like now, they screen the senior citizens first, for both COVID-19 and vital signs, leaving out the middle aged irrespective of them coming early to the clinic. As a result, the middle aged only start to arrive at the nurses' consulting rooms late, around lunch time and this

discourages them. I suggested that the screeners should have 2 queues at least, 1 for senior citizens and the other for the general population so that all clients can be helped on time. The manager promised to look into this issue. Also, if possible, before the night staff knock off, they can assist by screening and preparing at least 10 clients per department so that the day shift can start with them immediately upon arrival. Some clients have challenges at work, if you keep on requesting day off, even if you produce proof that you attended the clinic, they do not pay for those days" T6HP6

In terms of improving staff attitudes, participants highlighted the need for health care workers to be approachable so that clients can communicate freely with them. Quotations are posted below:

"The professional nurses also need to be approachable so that clients can be able to ask them questions or voice their challenges. I have seen clients with high viral loads taken yearly and when I asked if they know about it, they deny. They say that nothing was explained to them. Clients must be taught at every visit. Our attitudes as professional nurses sometimes disempower the patients, for example, today there were clients who told me that they went to request for their files from the professional nurse so that they can go for blood collection because they realised that they were far behind on the queue, and it was getting late. Sadly, the PN returned them, asking how certain they are that it is their blood collection day. Do you think that these patients will come back again for blood collection if they go home, certainly not" T4HP4

"Also, our behaviour and attitude towards what we are doing: If we can know the importance of our work, change our attitude to be a positive one, treat our people well and welcome them nicely when they visit the facility, retention can be improved. Sometimes the experience that one had at the facility may prevent him/her from keeping up with future appointments" T10HP10

Participants also explained that the welcome back campaign (WBC), where clients who defaulted treatment are warmly welcome and fast-queued, must be strengthened. However, other participants said that WBC might lead to clients' dependence on LHWs. Quotations are presented below:

“Ok, welcome back is a system where we welcome clients that we have missed in the healthcare, meaning they left the health care and are now coming back, and we are welcoming them with warm hands so that we try to prevent them from missing again on the system” T2HP2

“If clients return to the clinic, there has to be someone dedicated to welcome them and clients can be given a particular name to look for upon return and this name is known to the facility. The dedicated lay healthcare worker will help the client to retrieve the clinic file and navigate her/him to the relevant service points without being on a long queue. They also must decide on the best appointment date that the patient will be able to keep, avoiding clients missing appointments again due to social issues like work commitments” T2HP2

“It has both advantages and disadvantages. It is a good initiative that will encourage clients who stopped treatment or are not yet linked to care to return to the clinic and take treatment. However, it may create dependence and conflict. We are beginning to see clients who miss appointments frequently and come back after tracing, so I think they do it deliberately because they know that they will skip the queue. Other clients are also not happy to queue for a long time and then those traced just get to the clinic and are assisted immediately. I am afraid that we might have more clients defaulting so that they can be traced and helped quickly when they return to the clinic” T2HP2

“I got a call from one facility manager who complained that some clients default deliberately knowing that they will be called and upon their return to the facility, they will not wait on the queue, but their files will be retrieved, and a dedicated person will ensure that they receive the appropriate care. So, in a way, other staff feel that we are creating dependency and condoning the negative behaviour of missing the appointments- these clients have defaulted, now they come back at the clinic and find other clients on the queue, but they just pass to be assisted, it is not fair. And then the other clients on the queue are starting to complain also. However, I still feel that this strategy can work for us. Again, people are different, but I feel that if clients can be informed right at the beginning of their journey before they get to the stage of the welcome back strategy, we can minimise the defaulter rates and promote independence” T10HP10

Clients identified their relationship with health care providers as one of the factors that determined decisions regarding retention (Mwamba *et al*., 2018:8). Therefore, health care workers need to provide an empathetic support that facilitates clients' comprehension, effective communication and expression of experiences, thereby positively influencing clients' decision to continue with HIV care. Similarly, Chinyandura *et al*., (2022:6) revealed that clients who felt respected and well-received at heath care facilities expressed feelings of worth, and were more willing to cooperate and actively participate in their care. Also, clients valued the retention officers who were polite, sensitive, and warm towards them, as opposed to being yelled at or belittled, and this statement concurs with the findings of the study that mentioned the importance of the welcome back campaign.

Additionally, Maughan-Brown *et al*., (2018:10) cited that apart from long waiting time due to many clients requiring HIV care services, administrative errors such as loss of medical records equally played a role. It is for this reason that health care facilities need to strive to reduce these administrative errors and promote retention to HIV care. The SANDoH (2017:1) has provided guidelines for filing of patients' records which must be done systematically, using a standard record registration system, and stored in a room that adheres to requirements for records storage areas. Moreover, the guidelines mandate that the records must be checked against the patients' registration list daily to ascertain their return to the filing room. Full implementation of these guidelines would avoid unnecessary delays of patients which concurs with the findings of this study.

5.2.2.4.3 SUBTHEME 4.3: Improve the LHWs' knowledge and working conditions

Good working conditions are essential to improve LHWs' motivation and possibly performance as well. The participants cited the importance of debriefing, training, supervision, reduced workload, increased stipend, and improved interdependence among health care workers, including functional clinic committees.

Participants mentioned the importance of the debriefing sessions for LHWs as a way of promoting their emotional well-being. This is what the participants said:

"And then emotionally, we need to check their well-being. As much as we health professionals can communicate that we are emotionally drained, we need to include the LHW in our debriefing activities" T3HP3

“Debriefing is important for all people who work with health issues because it is not easy for us to separate our problems from those of clients. We end up being burdened by patients’ problems, so it is important for us to be reminded about the boundaries and that we need to ventilate if we feel burdened. I think this can make our work a lot easier” T3HP3

“We have the employee assistance practitioner who runs the EAP (employee assistance programme). I refer all staff, including the lay health care workers for debriefing, though the lay health care workers will be saying that they want to be debriefed at a hotel. Unfortunately, hotel debriefing is above me. So, I encourage them to speak up when they have challenges so that I can arrange for individual counselling sessions. So far there is no lay health care worker that has come forward, but there are other staff categories undergoing EAP and we also had a group debriefing recently. We also have a psychologist, but I have not referred any lay health care worker. All staff, including the lay health care workers know about the availability of the psychologist and EAP” T8HP8

Participants recommended that the LHWs should be trained according to the needs, followed by mentoring and supervision. Some examples of skills development are around HIV, index, and adherence counselling as well as communication, mental health, and new guidelines. Participants said:

“Maybe there can be a checklist with statements of what to check when visiting clients, then they can report to their supervisor or professional nurse. Besides that, I think training on mental health issues is beyond their scope of practise, but I agree that retention may be negatively affected if a client is depressed, for example” T1HP1

“I think they need to be provided with the updated information. Things change now and then, and it seems like we forget about the lay health care workers. We as health professionals attend trainings more often, like now we know that this new treatment can be taken during the day as well, not only at night like the previous ones. You’ll find that LHW does not have this information and hears it for the first time from the patient. This makes it look like the LHW does not understand the new developments in HIV and it becomes a barrier in a way that the patient might question the counselling capability and lose confidence in them” T3HP3

“So, if guidelines change, the LHW must be included; it’s like we are leaving them far behind” T3HP3

“They need health education. It looks like they are working for the sake of working. If I focus on a certain aspect only, I must be good at it. So, I don’t understand if they lack interest or knowledge. Others can look at the address and immediately know who the responsible CHW is, while others can be given a client to trace, then comeback with no feedback because they forgot. I really do not know what to call this, lack of interest in their work or what. They work with the same clients, so I expect them to know them better than us, but this is not the case. Maybe if they can be interviewed, they’ll be in a better position to explain this” T4HP4

“I also think that their communication and counselling skills need to be updated to enable them to be able to identify and report (to professional nurses) communication barriers that may be signs of mental health problems “T3HP3

“The index programme was started and implemented by the developmental partners’ counsellors while DoH counsellors did not take part. This was happening despite index testing being mandated by the national HIV testing services guidelines. There is this problem that some DoH staff think that programmes are from the developmental partners, but they do not understand that the developmental partners do not have programmes, they are just supporting what is mandated by the national guidelines. The index programme was not doing well because if the counsellors from the developmental partners are not available, no one was implementing. So recently, the DoH availed the index stationery and all counsellors were trained and mandated to report on index testing. So, I think mentoring and monitoring is needed because some counsellors are only starting with implementation now and may struggle to counsel clients in a way that encourages them to list and bring their contacts for testing” T4HP4

“Their counselling skills need to be developed because sometimes they do not bring any positive feedback from tracing. So, I think they are unable to reach out to the defaulting clients to return to the clinic even if they found them at home. I also think that they are struggling with integration because since the COVID-19 pandemic, their focus has been shifted to it” T4HP4

“They need monitoring. They need to be trained and then mentored. Their performance needs to be reviewed in line with the target” T4HP4

“I think if lay counsellors can be trained on EAC, it can help” T7HP7

“But there are other updates that I personally managed to in-service them on, such as PrEP (pre-exposure prophylaxis). Immediately when I returned from training, I grouped the lay counsellors, in-serviced them and showed them the stationery to use. Yes, they really do not attend the planned in-service training” T8HP8

“The mother mentors are the ones who profile these women, following them up from antenatal throughout to the post-natal period. When the women attend the 3 days post-natal clinic, the mother mentors’ group them accordingly, give them 6 weeks return date, inform them about the support group and start a group chat to communicate and remind them of the next appointment dates. On the visit day, mother mentors group these mothers and call the allocated nurse so that he/she can assist” T8HP8

“They are trained on basic antenatal care, so they check all these components according to the checklist to see if women received the required care. They also register women on Mom-connect, assess nutritional measures like the MUAC (mid-upper arm circumference) and alert the nurse to refer to the dietician where necessary. They do everything, also check if women have not defaulted, especially those who are HIV positive, whether correct tests have been done; in fact, they follow up women and their infants for 2 years. We have 2 mother mentors who were identified from the CHWs and sent for training. They are also trained for counselling, so they conduct group counselling sessions in the morning and also one-on-one counselling especially for HIV positive women” T8HP8

One participant further proposed the delegation of tasks among LHWs as per quotation below:

“I think if there can be delegation, e.g., if there are several counsellors, they can take turns to complete other tasks. But it’s also a human resource issue, they need to increase staff, there is no other way” T5HP5

One participant indicated that the stipend given to LHWs should be increased because they are doing a good job and said:

"I think their stipend must be increased; they are doing a good job. And occasionally, let them be transported, especially those who visit hard-to-reach areas, those working locally are okay. And then I wish that in their contract, they can have overtime allowance; for example, if a patient can only be found on Saturday, the CHW can go there on that day and be paid for overtime. Like our TB clients, we must from time-to-time check and support them. So even if the CHWs work on Saturday, they do not receive any incentive, and this demotivates them. If they are motivated, they will do their work whole heartedly and be flexible" T9HP9

The last recommendation is strengthening of health care workers' interdependence and collaboration. The participants alluded that improving staff awareness on the importance of discussing tracing, obtaining consent to home visits, and documenting on the relevant part of the HIV clinical stationery, is necessary. Other participants mentioned that having functional committees can also help in retention of clients to HIV care. See quotations underneath:

"That part of the clinical stationery is being completed and it is part of the training of the CHWs. They know that the clients are supposed to be asked if they consent to telephonic or home visits, so it depends on what the client's response is. So yes, that part is completed" T9HP9

"Yes, this is true. Indeed, you are right. I do not think that the CHWs look at this part before tracing and I also don't think that the staff gives appropriate attention to this part when completing the clinical stationery. Maybe this is the reason why some clients have a negative attitude towards the CHWs. We really need to strengthen this by improving staff awareness on the importance of discussing tracing, obtaining consent to home visits, and documenting on the relevant part on the clinical stationery. This will make it easier for CHWs to trace. Yes, our activities must be collaborated because we depend on each other to function effectively" T9HP9

This is what the participant said about functional clinic committees:

“The other thing is active participation of the governance structure, that is the clinic committee. If the clinic committee was available, after holding meetings in the clinic, the clinic committee would give feedback to the community. They would inform the community about the waiting time and that when the clinic calls the defaulted client and asks her/him to look for a staff member without queuing upon return to the clinic, we are encouraging dependency. Dependency is not good because the client will repeat the same behaviour of defaulting, knowing that he/she will go straight to a staff member for assistance. Even right from counselling, the counsellors need to teach clients to be independent and responsible for their health and not blame certain issues, e.g., long queues for non-adherence. Yes, the clinic will try to improve the waiting time, but the clients are too many and the community needs to know this. The clients must be encouraged to be patient just for that particular day when they attend the clinic so that they can receive the necessary treatment. If this information could be relayed by the ward councillors, I think the clients would listen to them” T9HP9

“Specifically, for this facility, the committee is not active. The members who were active stopped to work completely because they were no longer receiving payment, which was R150, so they became demotivated. So, from those that were active, we are left with only 1 community member who helps us to open the suggestion box, so she comes sometimes, just for this purpose only. The new committee members are inactive. It was escalated to the relevant authorities and payment was made to the remaining committee members for April to June, somewhere there and it is continuing. However, our active committee members had already abandoned us and did not return” T9HP9

“I don’t know if I should say fortunately or unfortunately their contract will end in December and the new committee will be elected. The province advised us not to sit back because the committee is inactive. We can take the one who is active, then choose maybe 3 professional nurses and operational managers and discuss clinic challenges that were supposed to be referred to the clinic committee. Thereafter, we can call the ward councillor and inform him about these issues, maybe one day when there is a community meeting the ward councillor can discuss the clinic issues” T9HP9

While the health care system is still struggling to regulate and absorb the LHWs, interventions such as debriefing, training, supervision and follow up can help the LHWs to feel recognised as part of the health care team; thereby boosting their morale and improving the quality of counselling (Mkhabele *et al*., 2016:326). In a similar way, Kok *et al*., (2015:8) mentioned that the CHWs' motivation is improved by addressing their expectations which in most cases, includes monetary incentives and career development. Again, to improve the effectiveness of CHWs, there must be clear operating procedures and guidelines as well as clearly defined roles and relationships with other health care workers.

Ormel *et al*., (2019:10) investigated how incentives and expectation gaps influenced motivation and discovered that across all six study settings, incentives were found to be an important factor influencing motivation of CHWs. Although monetary incentives were highly valued by CHWs as important motivators, they need to be combined with other job enablers like working materials and training. The findings of the current study revealed that incentives for LHWs should be increased with the hope that they will be motivated to work harder, which has been supported by the aforementioned studies.

Assegaai *et al*., (2022:37) indicated that relationships of trust among CHWs and health care workers are a key outcome of effective supervision and performance in CHW programmes. As a result, managers need to discuss and implement supervision systems in ways that promote relationships, and generate trust such as role clarification, as opposed to only focusing on monitoring performance and targets. According to Tseng *et al*., (2019:1) effective supervisors supported CHWs through household visits, on-the-job training, debriefing, reviewing CHWs' daily logs and assistance with compiling the reports. In addition, supervision of CHWs by senior nurses led to better execution of tasks, while collaboration with clinic teams reduced CHWs' marginalization, hence increasing their motivation.

Amidst the emerging suggestions to train lay counsellors on mental health counselling, South Africa needs to consider revising their job description, workload, and daily targets beforehand (Jacobs *et al*., 2021:1090). On the other hand, Mwisongo *et al*., (2015:6) alluded that counselling and testing duties are strenuous; therefore, lay counsellors must not be given additional tasks that will overwhelm them, instead, there must be improved coordination to create a balance between the allocated tasks. In agreement with the study findings regarding functional clinic committees, is the study by Mulumba *et al*., (2018:17) who found that collective discussions with key stakeholders are vital in health care, and active health committees bridge the gap between communities and health care facilities, leading to community-oriented services. Additionally, Rosen *et al*., (2018:4) highlighted the need to understand and improve teamwork and coordination throughout the health care continuum to foster interdependence among health care workers.

5.3 CONCLUSION

This chapter presented the findings from ten LHWs' supervisors and nurses who work with LHWs. The themes identified are the LHWs' role and contribution to HIV management and retention; LHWs' support and working relationships with other health care workers; barriers and recommendations to improved retention. The participants indicated their willingness to support the LHWs but also attributed low support to other priorities such as COVID-19 activities. They further indicated support areas needing improvement such as incentives, transport, training, mentoring and collaboration. The next section, chapter 6, focuses on the findings from the clients on ART.

CHAPTER 6: DATA ANALYSIS AND DISCUSSION OF FINDINGS

CLIENTS

6.1 INTRODUCTION

This chapter discusses the third and last section of data analysis which presents the demographic details and findings from 15 clients who are PLWHIV and have been on ART for at least a year. In-depth individual interviews were conducted telephonically to observe the COVID-19 precautions.

6.2 PRESENTATION OF FINDINGS

6.2.1 Demographic details

A total of 15 clients who have been on ART for at least a year participated in the study. There were 10 females and five males within the age range of 20 to 55 years, all residing in the township. In terms of employment, seven were employed and eight were unemployed, including a matriculant. Only one client reported to be mobile, in search of a stable job. Out of six clients that had previously skipped clinic appointments at least once, three were employed and the other three including a scholar were unemployed, as per table 6.1 below.

TABLE 6.1: DEMOGRAPHIC DETAILS OF CLIENTS

Client	Age	Gender	Employment status	Geographical area	Mobility	Skipped appointments
C1	35	M	Employed	Township	Permanent	No
C2	45	F	Unemployed	Township	Mobile, job hunting	Yes
C3	53	M	Unemployed	Township	Permanent	No
C4	25	F	Employed	Township	Permanent	Yes
C5	52	F	Unemployed	Township	Permanent	Yes
C6	45	F	Unemployed	Township	Permanent	No
C7	37	M	Employed	Township	Permanent	Yes
C8	25	F	Employed	Township	Permanent	No
C9	55	M	Employed	Township	Permanent	Yes
C10	47	F	Unemployed	Township	Permanent	No
C11	46	M	Employed	Township	Permanent	No
C12	20	F	Matriculant	Township	Permanent	Yes
C13	49	F	Employed	Township	Permanent	No
C14	52	F	Unemployed	Township	Permanent	No
C15	51	F	Unemployed	Township	Permanent	No

6.2.2 Themes and subthemes

After data analysis from clients’ transcripts, five themes and 13 subthemes emerged. Table 6.2 below represent these themes and subthemes. Each theme with its subthemes were presented, followed by the quotations and literature control.

TABLE 6.2: THEMES AND SUBTHEMES OF CLIENTS

THEME 1	**SUBTHEMES**
6.2.2.1 EXPERIENCES OF HIV POSITIVE CLIENTS POSTDIAGNOSIS	*6.2.2.1.1 Emotions associated with HIV diagnosis*
	6.2.2.1.2 Experiences of HIV positive clients at the health care facility
	6.2.2.1.3 Support provided to HIV positive clients by health care workers
THEME 2	**SUBTHEMES**
6.2.2.2 KNOWLEDGE OF CLIENTS REGARDING HIV MANAGEMENT	*6.2.2.2.1 HIV transmission, prevention and treatment*
	6.2.2.2.2 Consequences of HIV treatment non-adherence
THEME 3	**SUBTHEMES**
6.2.2.3 MOTIVATION TO KEEP UP WITH CLINIC APPOINTMENTS	*6.2.2.3.1 Bodily changes and past experiences of clients*
	6.2.2.3.2 Value of life, social support and self-determination
	6.2.2.3.3 Health care processes at the facility
THEME 4	**SUBTHEMES**
6.2.2.4 BARRIERS AFFECTING TREATMENT COLLECTION AND KEEPING UP WITH CLINIC APPOINTMENTS	*6.2.2.4.1 Barriers associated with the health care facility*
	6.2.2.4.2 Client-related barriers
	6.2.2.4.3 Fear of HIV positive status disclosure and its consequences
THEME 5	**SUBTHEMES**

6.2.2.5 RECOMMENDATIONS TO STRENGTHEN RETENTION TO HIV CARE	*6.2.2.5.1 Improving health care facility processes and clients' experiences*
	6.2.2.5.2 Promoting clients' acceptance, responsibility and disclosure

6.2.2.1 THEME 1: EXPERIENCES OF HIV POSITIVE CLIENTS POSTDIAGNOSIS

Clients presented their experiences after testing positive for HIV. Three interrelated subthemes emerged from this theme as reflected underneath. Each subtheme has been described with the quotations supporting it, as well as literature control.

6.2.2.1.1 SUBTHEME 1.1: Emotions associated with HIV diagnosis

Clients indicated that they experienced multiple emotions after learning about their HIV positive results. Emotions included confusion, sadness, shock, guilt, being scared, non-acceptance and worry over the kind of life one would have after HIV diagnosis. However, some participants emphasized the importance and role of accepting the HIV status in continued treatment. Quotations below represent the clients' voices:

"It was not good because you do not understand what is happening and after receiving the results there, (sigh) eish, you ask yourself how people will treat you and what kind of life you will live. But generally, at the clinic, they treated me well from when I started until now. I did not experience anything negative. Not my family members, I am referring to other people outside the family in case they know about this. People gossip, you know" T2C2

"To be honest, I was very scared when I started with counselling, I'll not lie about it. But as time went by and I got used to collecting treatment, I got over it" T5C5

"HIV status, being infected at this age; how did it happen, where did I get it, will I tolerate treatment, all those things. I couldn't understand, I was confused" T5C5

"They counselled me and yes, it was difficult to accept at first, but I am okay now" T15C15

“No, I never had a problem at all. I had a smooth journey, though it feels sad after receiving the positive test results, but you get comforted after some time, if you are determined to move on” T6C6

“It was difficult at first. It was difficult for me, in terms of my illness” T10C10

“It was difficult to accept, you try to trace what happened and where you got it from. But I ended up accepting, I became okay and got used to it” T8C8

“When you are in this situation some people neglect you, but I have never experienced discrimination in any way” T7C7

“At times you’ll find that you have also not accepted yourself, questioning why things had to happen that way, why you” T15C15

“Accepting yourself helps a lot. You cannot blame yourself or question where you got this illness from. Again, if you do not accept yourself, it leads to overthinking and always being preoccupied with this illness; you lose hope and may end up not taking treatment anymore. This may result in changes in appearance like weight loss, that is why I decided to accept myself” T13C13

“I mean everything, check-ups, medication, my body in general, I am fine, I have never had a problem. The counsellors educated me about HIV, and I was okay with it, I received it well. Being stressed by the results will not change anything so the best thing to do is to accept” T3C3

“I was scared and asking myself why this had to happen to me. I felt as if people knew about my illness and were gossiping about me when I walk on the streets” T12C12

“When you find out about your status, you become shocked and scared. You fear that people will judge you. I felt satisfied and ready to start with the medication” T13C13

“I was scared, yes (emphasis). I felt like I was going to die because I tested positive for HIV” T1C1

“But you know, when you start you feel scared and sad, yes, but as time goes by you get used to treatment and accept it” T14C14

“But you know how it is, it was difficult for me to accept my situation, but I ended up accepting with repeated counselling. I was treated well even when I started treatment, so generally, I am good” T7C7

“My sister, isn’t it that they say you need to help yourself so that others can help you? This is my life and I need to take care of it by making sure that I do not forget this date and do as I have been advised” T1C1

“Some people are ashamed of the treatment, and you see how full the clinic gets at times so you can meet someone unexpectedly. And people talk, once they see you on this side where we queue, they conclude that you take this treatment, so that is how they know. Some are shy to take treatment, but they do not know the status of the very same people that they are hiding from. At times you may see a person fainting and dying due to illness as he/she did not know his/her status. That is why I say that I have accepted my condition” T7C7

Similar to the study findings, Thapa and Yang (2018:1219) showed that participants had mixed emotions when they were informed about their HIV positive status, which included having no interest in living, wanting to give up, feeling like their lives were over and experiencing guilt due to their actions that had led to HIV infection. However, three participants accepted and did not indicate problems with being HIV positive.

A systematic review conducted by Arias-Colmenero *et al*., (2020:6) indicated similar emotions, also adding feelings of disappointment and pain, and that some clients experienced intense emotions that led to depression. Furthermore, acceptance was difficult but through continuous advice and treatment collection, clients reported feeling better and responsible for their health. In addition, Wringe *et al.*, (2017:3) found that some clients, especially those who felt healthy, struggled to accept the HIV positive status to an extent of testing for HIV repeatedly even after starting ART, citing that it was part of the acceptance process.

The above-mentioned results are in line with the study findings where most participants experienced negative emotions and struggled with acceptance after testing positive for HIV.

6.2.2.1.2 SUBTHEME 1.2: Experiences of HIV positive clients at the health care facility

The participants stated that they were counselled and educated before commencement of treatment. One client indicated that she was so encouraged that she even counselled her friends who had stopped taking ARVs. The majority of clients reported that they experienced very good counselling, and others mentioned that they had good connection with the lay counsellors. However, some participants expressed their concern with long queues which made them want to skip clinic appointments. One participant further explained that she came to this clinic as a transfer and was uncomfortable as she did not know what to expect, but care continued smoothly except for the long queues. Quotations below support the subtheme:

"They counselled and educated me before I started treatment. I was not well but could understand what they were saying because they were supportive and knew their job" T4C4

"I even started counselling my friends after I adjusted and most of them had stopped taking treatment, but I told them that as old as I am, I am taking treatment consistently and I do not joke about it. Even when I go to funerals, I go with my treatment because I do not know how long I'll be there" T5C5

"At the counselling room, that brother was sharp, yes. We clicked very well" T6C6"

I had a good experience, counselling was okay, the way they were explaining was good" T7C7

"The counsellors helped me very well" T8C8

"At the counselling room: they counselled me. I went there to test because I was not feeling well. They collected blood from my finger and found that, I am positive. That is when they counselled and informed me that this thing heals, and I do not have to be afraid

of anything. They also indicated how it can occur to anyone, then I started treatment" T9C9

"I received good counselling and treatment until I recovered. They counselled me and told me that I do not have to give up as I still have a long way to live and that everything will fall into place. I am what I am because of them" T10C10

"I had a good journey with the counsellor who counselled and tested me and handed me to the nurses who also treated me well" T14C14

"The counselling that I received was okay, I was counselled before starting with the treatment. I started at another clinic but got transferred to this facility after the initial clinic was permanently closed. Care continued accordingly. It is just that it is long time ago and I forgot other details, but it was okay" T15C15

"The way the counsellors counselled me was good" T1C1

"It was not easy on the first day, but I listened to them as they were counselling and teaching me about HIV" T2C2

"The counsellors counselled me immediately after testing" T3C3

"She counselled us, she counselled me. I wish the nurses can be like these counsellors and not be rude to patients" T5C5

"No, they have been treating me well, even the medication is good. I am okay. I cannot remember everything, but I did not experience any problem, except that when you learn that you are HIV positive you become sad because it does not heal" T13C13

"You know when I have to visit the clinic, I cannot sleep the night before, I can't sleep totally; I keep on thinking about how the situation will be like at the clinic, things like those. You may end up deciding to skip the appointment because you feel like it is of no use since the queue is too long, you see things like those, yes" T1C1

“I was uncomfortable initially when I was told because I did not know what to expect and how things are done at the new clinic. And I was also thinking about the queue because we had a queue at the first facility and if now, we move to another facility which already has its own clients, it would be worse. There is not much of a difference in terms of the distance. So, I was not affected in that regard, but the queue is too long. I have adjusted now, and I am good” T15C15

Other participants appreciated the good relationship they had with the counsellors and other health care workers, as per quotations below:

“They were sharp, truly they are good. They talk nicely with us, and you even feel better afterwards. So, I am happy with the way they interacted with me” T4C4

“They talked to me nicely and did not judge me” T2C2

“I have a good experience with them. The tracers also care for us, they used to visit and check on me, but now because of COVID-19, they have stopped and are now concentrating too much on COVID-19. They no longer check us like before” T3C3

“They used to come almost every 2 weeks to check how I am doing, document then leave. However, I do not know what they were writing, they never really said much” T3C3

“I loved that sister so much; she was so good and not discriminating people” T5C5

“They treated me good” T7C7

“It was okay, they treated me well. So, we had a good relationship” T8C8

“The relationship was good, even the nurses were good. Everyone was good, truly speaking they treated me well, no one was nasty or treated me otherwise because of my illness or even made me feel discouraged, they were alright” T10C10

“It was good. I really feel comfortable and open when I am with them as compared to my family. No one has ever scolded me at the clinic, I am satisfied with how they treat me” T12C12

“When I started, it was good. They showed me love, yes, they did. I just cannot remember all the details exactly as they occurred, but they explained nicely to me” T13C13

The study findings are supported by Ndou *et al*., (2016:4) who indicated that clients felt valued when their difficulties were acknowledged and understood by others. Also, participants in the same study felt satisfied with the positive attitudes and care received from the competent health care workers at the ART clinic, who were willing to listen and treat clients as individuals. Similarly, Min and Abdullah (2017:93) found that clients’ interactions with the counsellors provided satisfactory and meaningful experiences where they could share their stories and get the strength to move on.

On the other hand, Arias-Colmenero *et al*., (2020:7) found that while some clients misunderstood the safety precautions taken by health care workers during clinical procedures as stigma towards them, other clients experienced good care and support that improved their adherence to medication. Another study conducted to assess clients’ satisfaction with HIV testing and counselling in South Africa revealed that there were high levels of satisfaction with the counselling services, the provider, the privacy, and the treatment of staff in general (Matseke *et al*., 2016:5). This concurs with the findings of the study.

6.2.2.1.3 SUBTHEME 1.3: Support provided to HIV positive clients by health care workers

Most clients explained that the health care workers and counsellors supported and encouraged them through counselling and health education. One client revealed that she had to start with TB medication before the ARVs and said it was not easy but through the support of health care workers, she managed to pull through until she started the ARVs without any complications. Another client alluded that a particular health care professional had a very good attitude and clearly explained what HIV is, while others mentioned that even lay counsellors’ attitudes were extremely good. Quotations underneath represent clients’ voices:

“Let me say, from the beginning, according to me, it was not easy because I started treatment at the time when I had TB also. So, before I could start with this treatment, I had to take the TB one first, so it was difficult but there was this man (called by name) who worked in the clinic and was very helpful to me. I stopped TB treatment because I

felt that it was making me too weak and did not want it anymore. He is the one who explained thoroughly to me that within 2 weeks my body will get used to treatment and feel better. He encouraged me and I ended up taking treatment again. I took TB treatment, and I became well, then I started this other treatment, the ARVs as well. I completed TB treatment and continued with the ARVs until today" T1C1

"I think he was a professional nurse, but I am not sure. It really didn't matter to me, just the good attitude and time to explain were enough to give me hope" T1C1

"I mean, very nice. After getting my results and knowing my status, he explained that it was not the end of the world, and that life does not end there" T6C6

"This brother used to also call to check my well-being. He would also ask me how my session at the clinic went, but I do not know what his role is, he is not a nurse and I no longer see him these days" T7C7

"They approached me nicely and explained well. I could feel their support and it made me realise that it is possible to recover and live a healthy life. I really appreciated their assistance" T9C9

"But the counsellors were good, they shared information and encouraged me to take treatment. When I realised that they did not judge me I felt comforted and accepted the results" T13C13

"Wow, wow, (repeated many times); they were flowing, they explain everything very well. They taught me about HIV, treatment and the importance of adhering to medication and the scheduled clinic appointments" T6C6

"I am motivated by the love I received from the clinic. And again, in life, you need to accept yourself. Yes, you do not have to listen to or follow the negative comments from other people but take a positive stance. That is what helps me" T13C13

"It was difficult when they talked to me, but the way they communicated with me, I understood and realised that these are women like me. They were discussing life issues

with me, and they knew what they were talking about. They encouraged me to take treatment" T10C10

"I was free to communicate with them" T1C1

"It was good because sometimes you need clarity on something, then you can ask them. If you have to go and ask at the clinic, it is a long procedure and also requires you to queue just to ask a question. So, when they are here, I am able to ask them. They answer me, but if they cannot, they call a nurse at the clinic" T3C3

"The counsellors talk to me nicely and I am able to understand. Even the PNs who assist me guide and communicate with me in a satisfactory manner. As a result, I am comfortable and free to communicate" T12C12

Many clients indicated that the care received was very good and it made them feel accepted and encouraged. The words received made them to take their treatment and they felt the need to be responsible for their own health. Most participants alluded that the explanation of HIV received made them understand that the best way is to accept HIV and learn to live with it. See quotations below:

"To be honest, I was very proud and courageous (emphasis) about the words of encouragement that I received from him, let me say, had it not been for him, I couldn't have taken treatment, maybe I wouldn't even be alive today. I was very proud (emphasis), I mean I felt capable of taking responsibility of my own health" T1C1

"I felt better and relieved. When she showed support and understanding, I got motivated and encouraged to accept my status and move on. I was scared before I told her because I did not know how her reaction will be, I thought she would be angry or blame me. But yet again the decision to tell her felt right" T2C2

"He explained well, and I was satisfied even by the way he encouraged me" T6C6

"They told me that it is not the end of the world and that I am going to live for a very long time. So even their encouragement had a positive impact on me" T1C1

“I never thought I will accept and even be here today, still healthy. It was a difficult situation. So, I suppose it is their way of showing us that a person with HIV is able to live long just like anyone because now there is treatment, unlike in the olden days” T1C1

“It was okay because they were trying to make me understand, accept the situation as it is and encourage me” T2C2

“At the clinic there was this brother (mentioned name), doctor (name mentioned) and sister that encouraged me a lot” T7C7

“I felt good that at least even if you are in this situation, there are still people who do not necessarily feel sorry for you, but they genuinely encourage you without discriminating you. When you are in this situation some people neglect you, but I have never experienced discrimination anyway” T7C7

“The counsellors encouraged me and explained the procedure of treatment collection. Hence, I am keeping up with my treatment and because I saw its importance. They helped me, yes” T11C11

“I felt encouraged to live as healthy as possible despite being diagnosed with HIV” T13C13

“They counselled me to accept the results and continue living my life as normal as possible, making sure that I take treatment as advised. They were good to me” T14C14

“To be honest, what helped me also is that the mother of my kids was already on this treatment, you understand me? And she was ‘finished’ when she started treatment. She reminded me of how ‘finished’ she was when she started treatment and how well she is currently, and that I should not give up. So, she also encouraged me a lot and that is how I accepted myself” T1C1

“I think maybe my mind was focused on my child because I was pregnant when I tested. So, I wanted to do the right thing for my child” T8C8

“I have not had any challenges in the clinic, only at home and school. But this was before I came back to the clinic. The way people at the clinic treated and explained to me gave me courage and I started feeling free to communicate. I am also having sessions with the social worker, and I feel much better now” T12C12

Participants stated that LHWs shared HIV information extremely well with them. One client stated that they explained on how to take the ARVs as well as the side effects to be expected. Others indicated that they were told about positive living. The quotations below support this subtheme:

“So, he was good in calming me down and teaching me about HIV” T6C6

“I got the information on each treatment that I received, even when they change it. They also told me about the possible side effects, what will happen and what to do when I feel dissatisfied because I had many problems, but they did not get impatient” T10C10

“I have never had a problem. Everything went smoothly from the day I started and important information was shared with me. I didn’t really have much of a problem, I continued until to date” T11C11

“I have to take my treatment at the same time every day and visit the clinic as instructed. The information helped me to understand my treatment” T11C11

“They provided information on how to live normally and how to behave” T8C8

“The counsellors educated me about HIV immediately after testing” T3C3

“Like the last time, I was given different tablets and told to take them in the morning. I was surprised because I used to take my treatment at night, so I asked them and that is when they called a nurse to explain that the tablets may result in insomnia that is why they are taken preferably in the morning. So, it is good to have them around, now I feel left out when they do not visit” T3C3

“The counsellors explained how testing works. Then when I tested positive, they continued to provide information about HIV and the treatment” T14C14

“It was good. They were able to explain the procedures and expectations, like how to care for myself, also making me aware that the family or friends may reject a person after finding out about the HIV status” T15C15

In agreement with the findings, is the study conducted by Chinyandura *et al*., (2022:6) which revealed that the health care system focuses mainly on the clinical than the non-clinical aspects that also influence their health; however, the clients in their study reported being satisfied with the education and support received from the retention officers which made them to participate in their care.

Similarly, Mwamba *et al*., (2018:7) stated that clients regarded health care workers as their trusted source of information and were able to help them understand and cope with HIV by providing health education even though there were incidents of being disrespected and shouted at by some health care workers. Again, Arias-Colmenero *et al*., (2020:7) stated that clients felt that the health care workers supported and encouraged them, which alleviated their emotions and improved adherence to treatment, while Thapa *et al*., (2018:1221) mentioned that clients were warmly received and educated about self-care and medication.

On the other hand, vulnerable populations such as mobile clients who needed a transfer letter before accessing treatment at a new facility, as well as those who were previously incarcerated and experienced labelling, felt unsupported by the health care staff to an extent that they were afraid to speak out about their HIV positive status or ask for treatment (Bisnauth *et al*., 2021:10). Moreover, this indicated the unresponsive nature of the health care system towards the clients’ changing situations and suggested client support interventions such as the reminder messages or voice calls, continued counselling, and provision of ART even without transfer letters to facilitate retention.

6.2.2.2 THEME 2: KNOWLEDGE OF CLIENTS REGARDING HIV MANAGEMENT

This theme discusses the knowledge of clients regarding HIV management, which includes two subthemes namely, HIV transmission, prevention, and treatment as well as the consequences of HIV treatment non-adherence.

6.2.2.2.1 SUBTHEME 2.1: HIV transmission, prevention, and treatment

Most clients stated that they understand how HIV can be transmitted, prevented, and treated. They also emphasised the importance of healthy habits and honouring blood monitoring dates. However, clients indicated their lack of knowledge on the blood monitoring purpose, indicating that the health care workers do not explain it clearly, but clients just follow the instructions.

In terms of HIV transmission and behavioral aspects, clients mentioned few aspects on how HIV can be transmitted and prevented, as well as healthy habits that can boost the immune system. Quotations are as follows:

"HIV is transmitted through unprotected sex" T14C14

"Yes, a mother can transmit to the baby. That is what I know" T14C14

"I understand what to do and not to do. Like there is a certain time to take your medication and you must do it. I also must collect blood on the date scheduled. There is a lot, I am just mentioning a few that I can quickly remember. Eating healthy food, avoiding alcohol and smoking helps the body to build the immune system" T9C9

"I do not know. I was told that I must take treatment every day so that I can be healthy. If I do not adhere, I may get sick. I also have to use protection with my partner" T12C12

Most clients knew about blood monitoring, but they did not understand the purpose of the blood tests. Some clients only knew about the CD4 count which checks the immune system, but not the viral load which is the goal of ART and is vital in minimizing HIV transmission if suppressed. They alluded that despite them honoring blood collection dates, nothing was explained to them regarding the blood collected. One participant even indicated a misconception, saying that blood is collected to transfuse on other people who have no blood. Quotations below are from the participants:

"This is a date that I observe and honour so much. They just inform me of the month and day of blood collection, then I go to the clinic" T1C1

“Ok, I did not understand initially, but at work they would also request for the results. At the clinic they say that I must collect blood to check if I am taking treatment properly or rule other abnormalities out. They check the immune system, the CD4, so if it is okay then I can continue to collect treatment at the external pharmacy. They do not really explain the blood results in detail, they just inform me that my results are okay” T1C1

“It is to check the immune system, whether you take treatment correctly and if it is working well. It monitors if your CD4 is okay” T3C3

“It is only now at this last visit that I understand well. The sister told me that she does not want a person who does not comply with the instructions and that it makes her angry. I did not take these statements negatively; she was good to me. If my date is July, I have to collect blood in July. They need to know how much the CD4 count is so that they can change my treatment when necessary, so they check if the treatment is working for me, or it needs to be changed” T7C7

“This blood checks if treatment is working properly and at the clinic, they advised me to always come when the date is due. So, if you are advised on something at the clinic, you have to do it because these people help us a lot and they know what is good for us. My blood results are good, and I take treatment at the external pharmacy now” T9C9

“My challenge was blood collection. They did not explain what was happening, they just kept on collecting blood. It amazed me, I did not understand why they were collecting blood or what was happening” T11C11

“I still do not understand and that is the only thing I do not really understand, but in terms of other things I am okay” T11C11

“I just go for blood collection even now. I just do as they say, I have to” T11C11

“The only challenge is the blood collection. I do not understand the results, like the CD4 count, I cannot interpret in terms of normal or abnormal. That is what I really do not understand” T13C13

“Even the viral load, there is a problem because they never show you or explain. They should explain to me what it means if the viral load is, say 10 for example. Is it low or high? That is what I really do not understand” T13C13

“They have to check your blood every year. I am going to collect next year July and go back to the chemist again. They say that there are people who have no blood, and they transfuse blood on them. That is why they collect blood” T14C14

“Initially they monitored blood every 6 months now it is yearly, I don’t know if there is a period, but I think it is important. In most cases you’ll find that you unknowingly have a kidney problem but only find out when you become sick. So, this blood collection helps to identify that on time. Sometimes it is the liver that is not working properly. These 2 conditions (kidney and liver) are dangerous and can lead to death. So, when you are checked regularly, you are benefiting. Many people have kidney and liver problems but do not know until they get very sick. I regard myself as lucky because these things are monitored at the clinic” T15C15

“They do not explain how the viral load is, this is another issue that we have; they do not explain, and the information is not enough. We do not understand, we are in darkness, they just say your blood is sharp” T4C4

“Okay, I do not understand what the viral load is, but they collected blood” T12C12

A study conducted in Malaysia to assess HIV-related knowledge found that participants lacked general HIV knowledge such as transmission; however, condom use was correctly indicated as a way of preventing sexual transmission, concurring with what the current study participants said about HIV being transmitted through unprotected sex (Saddki *et al*., 2016:225). Ilesanmi & Afolabi, (2021:138) interviewed HIV treatment defaulters and non-defaulters and found that while both knew that ART is necessary, those who had defaulted believed that ART should be stopped when there is another non-HIV medication to be taken and non-defaulters believed in daily ART for optimal benefits.

In addition, Raberahona *et al*., (2019:5) found that participants had an overall good knowledge of HIV treatment; however, most of them could not name their ART and used colours to describe them. Again, some participants did not know that ART is lifelong, should be taken at a fixed time and how it works on the CD4 count and viral load. The current study did not aim to assess knowledge in depth but managed to identify that the participants lacked knowledge on viral load significance, concurring with the latter study, but they knew that ART preserves lives and is lifelong, which is in contrast with the latter study findings where some participants thought ART could be stopped.

6.2.2.2.2 SUBTHEME 2.2: Consequences of HIV treatment non-adherence

Participants explained that non-adherence to HIV treatment has negative consequences on both the individual and family. Individuals may die or experience physical changes such as loss of weight and weakness of the body which may lead to involuntary disclosure as other people will suspect that the person is HIV positive. Again, as the defaulting person becomes sick, he or she may not be able to work and provide for his or her family. Participants' quotations are presented below:

"Skipping the appointments, eish (followed by a sigh), I don't know how to phrase it. But it is dangerous because the body will become weak again and you may lose weight just like before you started treatment" T1C1

"Let me say when you default, you are exposing yourself, you are stigmatising yourself because everyone will now see that you have a problem. Your body changes, you lose weight, have skin problems, like you just experience many problems. I never had any change. I have always been like this, and it is one of the things that encourages me to continue with treatment. I have never experienced any ups and downs where I feel this way today and that way the next day, no, it is just one way. So, I have always felt healthy with no visible changes on my body" T6C6

"I hear that people who default experience problems. I normally see people being sick, but I wouldn't really understand what their problem is or what medication they were on because you cannot ask a person that, it is their business. But you can see that a person has really changed and some even pass away. So defaulting treatment is not a good thing" T11C11

"People stop treatment for 4 months or more. Some people flush the medication down the toilet. I once saw another lady doing that and it was painful for me, and I asked her to

give them to me. It was painful because you'll never know, maybe next time when I get to the clinic the medication will not be available, but some people are throwing it away. That lady indeed gave me those tablets and I used them. If you can see her now, her feet are discoloured and swollen. I advised her to vaccinate against COVID-19 and she refused saying that the vaccine kills. This lady is not serious with her life, I think she does not want to live. They say they are tired of this treatment, maybe they want to die" T14C14

"Yes, I have interacted with those that I started the journey with. I realised that they had changed, not looking good anymore and could not understand why. Like my younger sister, she also found herself in a similar situation as mine. She stopped taking treatment and I encouraged her by reminding her how I and my husband recovered after taking treatment. I would take those pictures of when I was very sick and show other people so that they can see my journey up to now. I was sick, my whole body was swollen, had sores and I relied on Allergex tablets, but I was advised to take this treatment as it would help me. If there was a tablet that made me feel sick, I informed them at the clinic, and they changed it. Indeed, I got better and recovered, though I still have some scars from those sores" T10C10

One client highlighted the importance of taking ARVs and said if a person takes the treatment, he or she remains healthy and will be able to work and support the family. The client said:

"Now I am working, so it means I will not be able to go to work and provide for my family if I stop treatment and become sick" T1C1

Among different factors related to defaulting ART, poverty, especially resulting from unemployment was identified as one of the major factors affecting respondents' compliance with clinic visits (Ilesanmi *et al*., 2021:139). Moreover, difficulty in securing employment due to poor health was linked to failure to attend clinic visits as the client will not have enough money for food and transport. This supports the findings of the current study where a client indicated the value of having a job to be able to support family, whereas defaulting will lead to poor health.

Bisnauth *et al.,* (2021:4) explored the reasons for defaulting and then returning to care and found that feeling sick or experiencing weight loss or weakness was among the top three reasons that clients indicated. Ilesanmi *et al*., (2021:139) further identified that most respondents described good physical health as an important reason for not defaulting from care and one client who had defaulted treatment acknowledged that although ART sometimes has side effects, they are far better than the effects of defaulting. These findings concur with those of the current study where participants alluded that the changes in physical health such as being weak and losing weight experienced by clients who default HIV treatment is one of their reasons for not defaulting.

6.2.2.3 THEME 3: MOTIVATION TO KEEP UP WITH CLINIC APPOINTMENTS

Clients stated that the are some aspects which motivate them to keep up with clinic appointments and are grouped into three subthemes. Each subtheme is presented together with its quotations, followed by literature control underneath.

6.2.2.3.1 SUBTHEME 3.1: Bodily changes and past experiences of clients

Clients mentioned that what keeps them motivated to honor clinic appointments is the bodily improvements they experienced after taking ARVs, as compared to how sick they looked previously, as well the experience they gained through interactions with others. Other participants explained that they would be dead if it was not for the ARVs. The quotations below support the subtheme:

"What encourages me to keep the appointments is that I realise where I come from, you see? I realised that the treatment that I am taking is good when I look back to where I was before, where the treatment took me, I realised that if it was not for it, maybe I would no longer be alive today. You see, that is why I am still encouraged to take treatment" T1C1

"Even one counsellor told me that she doubted the results and asked me how I felt physically. I felt very good, I had no challenges" T3C3

"Number 1, I had lost weight, a lot, then I gained and became well. Previously I was forever sick and did not know that I am HIV infected. I went for testing, discovered that I am positive then started treatment and felt better in no time. So, this treatment is 100% and I can even work now. Previously I experienced headache and weight loss, but now I have gained weight in a satisfactory manner" T4C4

“I see that I have recovered and am continuing to be strong. I achieved all this because of treatment, so I have decided to take treatment consistently. So being in good health and being able to do all activities on my own motivates me” T9C9

“The positive changes that I am noticing on my body. I was sick, about to die. I was weak, lost weight had many sores and had lost hope. Even my family had lost hope and thought that I was going to die, but they kept on supporting and encouraging me. *I then realised that if I can regain the courage and take treatment as per instructions, I still have a chance to recover. I started with TB treatment, and it had side effects. I took it for 6 months and saw some changes, then I collected blood and took ARVs. The ARVs also had side effects, but the clinic staff encouraged and informed me about what to expect. I started improving and then took my husband to the clinic. He was also very sick, and I thought he was not going to survive. But we both survived, we are who we are because of this clinic” T10C10*

“I become encouraged when I collect my yearly blood and get good results. Even though sometimes I doubt that the tests are done correctly because the results are okay this year and not okay the next” T3C3

“I cannot remember well, but last year March they were okay, I just forgot how the ones for this year were. I’ll check next time when I visit the clinic which will be in November” T3C3

Some clients mentioned that what keeps them on ARVs is their past experiences and exposure to those who have defaulted treatment. Again, they said that they have seen most clients who defaulted treatment complicating, and it took them long to recuperate. Some commented that restarting treatment is painful. The quotations presented underneath support this subtheme:

“Again, when I see people who defaulted, I really do not want to see myself in that state.” T3C3

“If you default, you deteriorate a lot, and it is very difficult to pick up again. You can never be the same as before and it’s like you need to be given something stronger. Currently I

feel good since taking medication, you won't even notice that I am sick. So defaulting is dangerous" T3C3

"My father passed away due to cancer, and he also felt that he was suffering a lot and it could have been better if he had HIV instead because he would not suffer. I also see that HIV, yes at first there was stigma and there were fears that you wouldn't live, but now it is better than other illnesses. I am not saying it is okay to have HIV, but I am saying that I did not acquire it purposefully and I need to accept it and move on with my life" T4C4

"It is the way they explained to me; the counsellors made examples about their friends that are also in the same situation as mine. This showed me that I am not the only one in this situation and gave me the courage. I realised that in order to save my life, I need to accept my situation, take treatment and be free without fearing anything. Again, as I continued to attend the clinic, I realised that other people are taking this treatment as well, but it does not mean that I gossip or bad-mouth them when we meet in taxis because we are all in the same situation" T7C7

"I'll never skip or stop treatment, why would I? If I stop, it means I am defaulting and have to be re-started. How does it feel to re-start? It is very painful to re-start, do you know? He-e-e-e (sounding very concerned), I have seen many people who defaulted. Their minds regress so-so-so much. Long ago I skipped my appointment, but I still had medication. I visited my relatives but could not come back and did not know what to do. But I know now and will never skip the appointment without communicating with the facility" T5C5

"Just think about it, your body becomes wasted, you lose weight, people are looking at you and maybe you are now being pushed by a wheelchair. Yes, you see, you are only pulling yourself back. You start attracting people and they start asking what your problem is. Everyone will now want to know what is happening, you see, it is like you are a magnet, attracting people to know about you now. So, if you just collect your treatment nicely, you will not experience any pain or be labelled in any way. Accepting yourself is key" T6C6

"It is very important because it is already in my blood system. It is just like any other pill. When you stop it, you regress, and it means you go back to the beginning. And the counsellor told me that re-starting is a serious problem. You lose weight, experience

diarrhoea and all sorts of things, who will then take care of you when you stopped treatment deliberately? So never mind or be afraid of what people say because they did not create and bring you into this world, only God did. People will talk but you must continue taking the treatment as you'll be the only one to suffer the consequences of defaulting. Treatment helped me to get where I am today, I used to weigh 35,3 kg now I weigh 59,9 kg, I have really recovered. I am even keeping myself busy by assisting people with domestic chores and get paid" T14C14

"I know people who have defaulted, they relapse, get admitted to the hospital and one of them even passed away. I always encourage them to re-start treatment, but I do not disclose my status. I will never allow myself to get weak so I will not skip the clinic appointment or treatment. I went for testing before getting sick, I was just experiencing repeated yeast infections and my CD4 count was still high. After starting treatment, the yeast infection disappeared completely, and I do not have any problem. I have never skipped my treatment and will not stop it unless I am no longer fit to take the pill on my own or am dead or have an illness that negatively affects awareness of my environment. I regard treatment as my life, in fact it is indeed my life. Once I can stop it for 2 weeks or so, I am going to regress and go back to zero. So, I do not want to find myself in that situation" T15C15

The study is supported by Thapa *et al*., (2018:1221) who stated that clients reported being dedicated to treatment because they felt normal and healthy just like HIV uninfected people, after taking ART and receiving health care support from the facilities. Similarly, clients were motivated to adhere to treatment because they wanted to remain healthy, while some feared becoming emaciated due to HIV and non-adherence to medication, and others had seen people they know dying due to not taking medication (Buregyeya *et al*., 2017:3). The same was found in a study conducted by Gugsa *et al*., (2017:7) where clients had seen many people in the community living long and healthy lives with ART and those not taking it becoming sick or dying; therefore, some participants wanted to remain healthy and asymptomatic so that they could hide their HIV status from other people.

However, this study finding is opposed by studies which found that clients stopped taking treatment when they gained weight, had an increased CD4 count, suppressed viral load and generally felt well, hence not seeing the need to continue with treatment (Chirambo *et al*., 2019:5; Mukumbang *et al.*, 2017:4). This contrast may be due to non-acceptance of the HIV status or not being exposed to people who defaulted treatment and experiencing negative consequences.

6.2.2.3.2 SUBTHEME 3.2: Value of life, social support, and self-determination

Most clients alluded that what keeps them honoring clinic appointments is the value of life, support from multiple structures and being self-determined. They explained that their life is important, and they will never stop ARVs because they know the negative consequences thereof. Other clients indicated that they keep on taking treatment for the sake of their children and family, and do not want to become a burden to anyone by becoming sick after defaulting treatment. See quotations below:

"My life comes first, yes. I must not listen to other people, but I have to be responsible for my health" T2C2

"I have never missed a clinic appointment. I put my life first" T3C3

"I have told myself that this is my life. It is my way of living, if I stop treatment, I'll be killing myself" T3C3

"Treatment must be taken for life. You just take one tablet daily, as opposed to the previous one which was taken twice or thrice. You do not have to listen to people who discourage you from taking treatment. These people mislead you while on the side they go to collect their own treatment. You will be left suffering and losing weight. Other people are wasteful because they hide treatment under the beds or mattresses, nurses encounter challenges in this regard" T5C5

"I do not know how to put it. But I see life and my kids, I want to live and raise my children. If I default, I'll be failing my kids because I am supposed to be there and care for them" T6C6

"I mean that living is important because I also live for my children, you see? Imagine if I give up and get very sick, who will take care of me and my children? Will I not be a burden to my family? I think it is selfish if you allow yourself to get sick by skipping appointments

and not taking treatment correctly without thinking about the struggle that your family will go through" T2C2

"My child also motivates me because she is negative. I was able to get pregnant while on treatment, carried the baby to term and delivered normally. I realised that even if you are HIV positive, it is possible to give birth to a HIV negative child. I tested her several times and she is negative, I could not believe it, but there she is, all grown up and healthy" T4C4

"It is this girl (daughter) of mine, she motivates me. I want to live and raise her. So, I tested her, and she is negative. This made me so happy and motivated" T8C8

"And again, it is nice if your partner understands your condition and he/she supports you. As I speak, I have 2 kids and my wife supports me. She also takes treatment, and we always remind each other to take treatment daily" T7C7

"No, there was no stigma. The family was supportive, especially my mother and aunt. When I was at the clinic, I would call my aunt and she would come to see me, then communicate and thank the staff for helping us. We were like the kids of this clinic, even today" T10C10

"I realised that I am not supposed to default because I think I can have a problem. So, it is important to attend to everything that I am advised to do because these people are important, and they help us. So being healthy and being able to work is important to me. So, I have to take treatment so that I can continue to be fit to work" T11C11

"I want to be healthy. I also want to be a social worker because the situation that I find myself in pushes me to wish to help other people. Again, knowing that there are people who can help me at the clinic encouraged me. So, whenever I feel down and angry, I can go to non-judgemental staff at the clinic, and I know they will talk to me nicely' T12C12

"When I started with treatment, I called my family, informed and showed them the medication. They pointed out that the treatment holds my life, and they cannot discourage me from taking it because what really matters is life" T13C13

"Treatment is my life; without it I would not be alive today. I started treatment before people could realise that I had a problem. I was experiencing minor problems on my body, and I decided to test and that is when I got diagnosed. I decided to take treatment before getting sick and people noticing it. So, I have never been flat on a sick bed due to this virus, I started treatment when I was still strong. My children were still very young so the thought of dying and leaving them behind encouraged me to take treatment seriously. I wondered how they would leave without me, so I realised that treatment was the best option for me" T15C15

Participants emphasised their self-determination to keep up with clinic appointments and continue with their lives, irrespective of other people's opinions. They stated that it does not help to force people to take treatment, it has to come from the client accepting the HIV status and being determined to remain on treatment. Moreover, participants acknowledged that challenges are inevitable; for example, long queues, but one must be self-motivated and take responsibility for their own health. Quotations are posted below:

"I really don't know why people would skip appointments or stop their treatment because these days it is easier because they give us 6 months prescription to collect at the chemist. So, I really do not understand what the challenge is. I have never discussed with anyone who defaulted, but I wonder why people would be afraid to take just one tablet at night or before you sleep. I mean even if you go somewhere and plan to come back late, you can just take one tablet, put it in your pocket for later consumption. Like myself, when I go out during the weekends, I put one tablet in my pocket because I do not know when I would return home. When it is time to take my medication, the cell phone reminder beeps, I go out and take my medication and everything is alright. So, I do not know what makes the people to default" T3C3

"No, it's all the same. There is no way that you can encourage a person to remain in care. Isn't it that the life is his/hers? Information is shared each and every day for people to take their treatment, not that when they say the virus is undetected then you think you are healed and stop treatment. This is a lifetime thing, you live with it throughout your life, so if a person does not want to take treatment, you cannot force him/her. It depends on a person, if he is not willing to take treatment, he/she will not take it despite all the efforts. We are being advised on treatment regularly, if a person does not want to listen, you

cannot do anything to him/her. So, determination and taking responsibility of one's health is what matters the most" T2C2

"I am okay now, I have accepted. After testing positive, I called the hotline number found on the condom pack and they explained the whole process to me. I became okay, I have accepted 100%, I have moved on 100%, I am sharp. I have also decided to go to school and study counselling course for healthcare workers, I want to counsel and help people through this journey" T4C4

"I read a lot about HIV so that I know how to deal with this thing that I have been diagnosed with. I also hear how some people talk about HIV and I realise that they do not understand. They still have that mentality that you can identify an HIV-infected client by looking at him/her and that there are certain features associated with it. So, I want to help people the way I was helped, informed and encouraged" T4C4

"I have not skipped treatment to date, and I do not see any challenge that can make me to stop taking treatment. My life comes first, and I am determined to take ownership of my health so that I can live healthily" T8C8

"I don't think there is anything that can make me to stop treatment. Even my family keeps on reminding me of how sick I was; I also kept some photos of that time and when I see them now, I do not like myself. As a result, I do not want to miss even a single tablet. If I have only 2 left, I go to the clinic to refill. I and my husband remind each other take treatment. Even when he visits his home, I call his mother to remind him, and he also calls back to remind me. That is how we do it" T10C10

"I go, I do not miss any appointment date. I am determined to do the correct things so that I can be well" T11C11

"I have started. Like I said I did not know that there are people who I can talk to at the clinic, but now I know, and they are helping me to understand my life. Also, I am going to ignore what people say, focus on my studies so that I can increase my chances of becoming a social worker and take my treatment regularly" T12C12

“No, no, I cannot stop treatment or skip clinic appointments. One has to be self-motivated and determined to live and I have taken a decision to take treatment consistently. This treatment is my life, if I am going to be fearful of gossip from people, I will not gain anything. People will always have something to say no matter what. So, I have taken a stance that this is my life and am responsible for it. As long as I have accepted myself and informed those close to me, that is enough encouragement, I do not need the approval or opinions of other people. And the encouragement that I received from the clinic after testing also assisted me to accept myself” T13C13

“Challenges will always be there but like I said earlier, one has to be self-motivated and determined to take responsibility of their own health. I have never had a challenge of a lost file ever since I started treatment. And we communicate with each other when we wait on the queue, but I have not come across anyone who experienced such challenges. Long queues are everywhere, but we need to be patient and receive our medication accordingly” T13C13

“What holds some clients back is that they are concerned about other people’s comments or thoughts, but I do not do that. This is my life, I started taking treatment since that day I tested positive until today and I am going to continue accordingly.” T14C14

“No, no, I won’t find myself in that situation, I won’t skip clinic appointments or treatment, why would I do that? I’ll only stop when I am no more. I really do not see myself stopping the treatment. The problem that some people face is being ashamed of what others may say if thy hear about one’s HIV status or realise that one is taking HIV treatment. I do not fear anything or really care about what other people say, I go boldly to the clinic to collect my medication” T14C14

“I tell them that I will never be scared to go to the clinic because someone will gossip about me, there is a possibility that the very same person who gossips about you is taking treatment somewhere, so there is no use torturing yourself because of someone, you are the one who is going to die for not taking treatment. I think taking treatment is important and there is no one who will stop me from taking it because this is my life; I am the one who will die and leave my child behind. So, it is better to collect treatment and be well. I see improvements since I took treatment. HIV is a normal disease these days, I don’t feel ashamed of it, and I feel that it is better than other diseases” T4C4

“Like when I get a message regarding my treatment, I become worried and go immediately to the clinic to find out what is happening. I got a message about my medication script renewal, I got worried and rushed to the clinic because I know that I never miss my appointments, but the matter was rectified accordingly” T3C3

Öktem (2015:7) highlighted that some participants isolated themselves from their families due to fear of rejection but were surprised by the family’s positive reaction and support after disclosing the HIV positive status. Also, most participants indicated that their parents were more supportive, understanding and less authoritative than before the HIV diagnosis due to fear that they may lose them. According to Gugsa *et al*., (2017:9) some participants were motivated by a strong support system from their families and health care workers, having HIV negative babies as well the fear of consequences related to defaulting treatment.

Similarly, Thapa *et al*., (2018:1220) indicated that clients were scared to die and leave their young children behind, while others felt determined and highlighted the need to be prepared to face any challenges. Additionally, Ahmed *et al*., (2019:36) revealed that some participants felt that the source of motivation lies with the individual. Again, as the family, health care workers or others provide support and motivation to clients to remain in HIV care, the clients need to reciprocate through taking the responsibility for their health. The above statements support the study findings where participants alluded that the support from family, the desire to be in good health and take care of their children, as well as self-determination kept them motivated to continue with treatment.

6.2.2.3.3 SUBTHEME 3.3: Health care processes at the facility

Participants mentioned that the arrangements made with external pharmacies for them to collect medication has made getting treatment very easy because they can go there at a convenient time. Apart from external pharmacies, another client alluded that he was able to attend the clinic appointment and then get proof of attendance to submit at work. Others indicated that the use of reminders such as appointment cards and calendars, as well as taking just one pill a day motivates them to take their medication and attend the clinic regularly as scheduled. Quotations below support the subtheme:

"I have never skipped treatment or clinic appointment. Treatment is an important part of my life, so I have incorporated it in my daily routine. Since I am now referred to the external pharmacy to collect treatment, it reduces overcrowding at the clinics. It is a better option for me. I have seen the importance of treatment, so I continue to collect at the pharmacy. I do not foresee anything stopping me from continuing with my treatment" T11C11

"Yes, they have offered me the option to collect at the pharmacy. So, when I was at the clinic the last time, I came for renewal after the first script expired. This option is also very good because you choose where you want to go for treatment collection, you see, where it is convenient for you. And again, this option is much better because my partner is able to collect for me even if I am not there, I do not have to ask from work. I am happy with this and the visits to the clinic are reduced" T1C1

"Now it is better because I collect treatment at a certain pharmacy, so I can go anytime when I am free" T4C4

"I no longer have problems at work when I have to leave, I just request and explain, then they understand and give me permission. I then bring proof that I attended the clinic. So, things are much better now. And I also collect treatment at the external pharmacy now, so I collect on weekends when I am off from work. So, I only go to the clinic to renew the prescription and collect blood" T1C1

Participants also viewed reminders as important to keep them in care, as per quotations below:

"*Isn't it that there is an appointment card with me, I look at it, you see. So, I check on the appointment card and make sure that I come for treatment collection" T1C1*

"I put the appointment date on the calendar of my phone, and it reminds me the day before. In this way I am able to remember. But again, I placed my appointment card next to my medication, so I check it from time to time so that even if something can go wrong with my phone, I can still remember my return date" T9C9

“No (emphasised), never, I won’t forget. I set a phone reminder, even when I go to functions. When the phone alerts me, I take the tablets, sit down, and resume any tasks that I was busy with after 21:30. The medication cannot be taken after 21:00, that is what I was advised on” T14C14

One participant mentioned the ease of taking treatment once a day, as compared to previously when it was taken thrice. The quotation is presented underneath:

“I keep my appointments and treatment because the treatment has been made easy. Previously, people used to take treatment 3 times a day, but now you take it only once either at 19:00 or 20:00 depending on what time you prefer, but from 21:00 onwards you are not supposed to take it because it will not work and flow nicely with your blood at that time. Chances of getting tired of the medication are slim, just one tablet daily, this is really good” T14C14

These findings are supported by Dorward *et al*., (2020:6) who indicated that clients viewed differentiated models of care such as collecting treatment at external pharmacies or community pick up points as convenient, flexible and not disruptive to their work schedules, hence normalising ART collection. Mukumbang (2021:138) further found that although men demonstrated poor retention to ART care, differentiated models of care have the potential to attract and retain them in care. In addition, Holtzman *et al*., (2015:6) indicated that among evidence-based strategies that help clients to remember appointments and remain in care, is the use of reminders such as phone calendars, as well as optimised treatment supply which supports the study findings.

Although phone reminders are among the strategies to improve adherence, Omonaiye *et al*., (2018:79) revealed that they are not independently effective; therefore, there is a need to complement them with combined social, structural, and educational interventions such as the involvement of community leaders and lay counsellors, conducting follow up visits and providing continuous health education. Similarly, Madhvani *et al*., (2015:516) indicated that clinic appointment cards were passive reminders as clients still needed to remember to check them; therefore, clients need to use other reminders such as phone alarms to be reminded of taking the medication on time and attending their clinic appointments.

6.2.2.4 THEME 4: BARRIERS AFFECTING TREATMENT COLLECTION AND KEEPING UP WITH CLINIC APPOINTMENTS

Clients identified multiple barriers that affect treatment collection and keeping up with clinic appointments. These barriers have been grouped into three subthemes and are presented and supported with quotations and literature control below.

6.2.2.4.1 SUBTHEME 4.1: Barriers associated with the health care facility

The participants cited several barriers experienced at the health care facility which include lost medical records, long waiting time and queue, rules that did not allow buddies to collect treatment on behalf of clients, and negative staff attitudes. The lost files would sometimes not be found, resulting in clients going home without the medication irrespective of the long time that the client waited for. See quotations below:

"The first months when I started, it was a bit difficult because there was an issue with files. You would be on a queue like for a long time and they will tell you that they cannot find your clinic file. After a while they will tell you that the nurses have knocked off and you need to go home without getting your tablets and come back the next day, like it was difficult. You would attend the clinic for 3 days and not receiving your medication because of a file. But after some time, it changed. The main issue is the file, sometimes they cannot find it, like for me I have almost 6 files, at times they retrieve this one, next time they can't find it and they retrieve another, it's just chaos there. Other than that, I was treated well during counselling and treatment collection" T4C4

"I have heard people on the queue complaining that they were told that their files are lost and cannot be helped, despite having been on the queue for a long time. They are then told to go back home and visit the clinic again the next day. This is one of the things that frustrates them, sometimes they verbalise that they'll stop treatment, out of anger. But anger does not help because this is your health and not the nurses'. But according to me, they are slow in providing the service and files are lost. In fact, during the last visit, we had to go to the clinic manager to ask for the service and that is when we got helped. Had we not complained, we could have returned home without being helped" T9C9

"Mostly it is the file retrieval and queuing for medication. We are too many and the nurses are few, but sometimes I feel like they are too slow to help us. At times it is only one nurse

who assists us, or it takes long for the admin clerks to find your file, sometimes they cannot even find it" T1C1

"It is difficult, because you wake up at 4 knowing that it is your appointment date, but you remain there in the clinic without getting your file" T4C4

"Yes, I wanted to mention this. We are struggling with files; they cannot be found on the shelves. I already have 4 files and there is one lady at the reception (gave a description) who is very rude. When you ask for a file, she becomes rude. Sometimes you get your file from the antenatal section, which is very far from the filing room, how did it get there? At times it is found in a consulting room where you have never been to. When you look for your file in the rooms you are also wrong, they label you as rude or aggressive. I experience headache when I think of the queue, I feel that it is better to just go to the chemist and buy Panado. The nurses also take their time to assist us, sometimes we go to the clinic at 5 am and leave at 16:00; or at times they knock off, leaving us there with the message that the night staff will assist us when they report for duty" T14C14

"But you find that sometimes skipping an appointment may occur, like the last time when I was at the clinic, we men hate queuing so much (emphasis). You find that when I think of waking up and going to the clinic, I remember that I will come back home at night, so I become discouraged and decide to stay back and not attend, you see things like those?" T1C1

"My only problem is the long queue, sometimes you wait there for a long time without being helped; they take you from pillar to post. This is what discourages us, you get to the clinic at 6 in the morning and go home late around 4, their service is very slow. And sometimes you sit there for the whole day without eating anything. Because of these things when I sleep the night before my appointment I get discouraged. However, I am not at that stage of being completely discouraged because I know that this thing, if you dodge treatment, you are also dodging your life, yes, yes" T9C9

"One needs to be patient until he/she receives help. Yes, we are many on the queue, but we really need to be patient, not just stop attending the clinic. Health comes first and we really have to take responsibility for taking treatment correctly. Yes, challenges are there, but it does not mean that you must stop treatment completely" T11C11

One participant experienced a barrier of a treatment buddy not being allowed to collect treatment on his behalf, as per quotation below:

“But previously when the rules permitted, my partner collected treatment on my behalf. She used to collect treatment for me until they told me that the rules do not permit anymore and that I have to collect personally” T1C1

“Yes, before, yes, it was possible but now they said it is no longer allowed for my partner to collect. They say that the rules have changed but did not state any specific reason for such change” T1C1

Other barriers specified by the participants are negative attitudes and lack of clear explanations from health care workers. One participant stated that there was a date written on his appointment card, but nothing was explained and at the same time he was referred to collect treatment at the external pharmacy, so he ended up missing the blood monitoring. The quotations are posted below:

“These people, I do not want to use this word, but I’ll use it: They are rude and impatient towards us. When you ask, they shout at you and tell you that there is a queue outside, meaning that they feel that you are wasting time” T4C4

“Health workers that we come across. I like to be helped by male health workers because I see that like, they are sharp because they can explain nicely to you. They also ask how you feel; have you come across a person who asks about your well-being? It is nice, it feels good. You rarely get that from female health workers. Like today, the male health worker that helped me asked me how I feel, any illness experienced and how I have been before helping me, you see; I then responded that I was sharp. Also, I have never met a rude counsellor since I attended the clinic, only the nurses are rude, rude” T4C4

“But it is not like people do not want to go to the clinic, they want to but are afraid of the rude staff. It is very painful to be scolded by a human being like you. I do not even know who the manager is. Imagine a pregnant or post-natal woman arriving at the clinic at 5 am and only go home around 13:00 and we are supposed to keep quiet. This is a problem and some people who attend the clinic are not from the catchment areas which worsens

the queue. The management of the facility is poor, the previous manager was good and also ensured that the queue is well managed" T14C14

"Again, there are nurses who mistreat people, this is the reason why some people do not want to go to the clinics. For example, when you come for testing, then a nurse tells you that she did not send you (meaning you are responsible for your actions, no one instructed you). Just imagine a nurse saying such painful words: 'I did not send you', how would you feel? These days anyone can be on this treatment, it does not matter whether you are a doctor, police, minister, or anyone else; no one is marked. Many people are on treatment, but we do not know, we only know after they pass away. There is this man who is a staff member (gave a description) managing the queue, he talks rudely to us. He is very rude and some of clients cannot tolerate that and end up exchanging words with him" T14C14

"There was a time when I did not attend the clinic in July. This date was highlighted with a red pen on my appointment card, but I did not know that I was supposed to collect blood on that day. The person who wrote it did not explain to me, so I thought that because I have been referred to collect treatment at the post office, I can only go back to the clinic at the next appointment date. So, I missed the blood collection month and collected in August instead of July. It was just a misunderstanding because there was this date on my card that I did not know what it meant, yet I still had treatment" T7C7

The results of the study conducted in Zimbabwe support the findings of this study. The study cited negative staff attitudes of health care workers and long waiting time in ART clinics as some of the barriers in HIV management which led to clients' disengagement from care (Tafuma *et al*., 2018:5). The same study indicated that long queues and time spent at health care facilities disrupted other aspects such as work and social life of clients seeking medical attention. Additional delay was caused by poor management of medical records which resulted in lost files or blood results (Mwamba *et al*., 2018:6; Maughan-Brown *et al*., 2018:8). As a result, clients would have to start afresh or even re-visit the health facility to repeat some procedures, and this discouraged them from continuing with care.

Mwamba *et al*., (2018:7) further supported the study findings by revealing that despite the health care workers' attitudes and respect towards clients being the pillar of clients' engagement or disengagement from care, some clients still experienced public humiliation through being shouted at. Similarly, Shabalala *et al*., (2018:55) mentioned that clients perceived lack of empathy from health care workers who would speak harshly and not provide them with the required care.

Some participants felt that they had poor understanding of HIV treatment because education and counselling support were not provided to them by health care workers (Ahmed *et al*., 2019:35; Buregyeya *et al*., 2017:6). Instead, clients were sent from one consulting room to another without receiving the necessary health education. Dapaah (2016:5) added that health care workers had overall control over the decisions affecting clients' care and this is in line with the study findings where a client was not allowed to send a buddy to collect treatment on his behalf or choose a suitable appointment date as highlighted under the work constraints' quotations in the next subtheme.

6.2.2.4.2 SUBTHEME 4.2: Client-related barriers

The participants indicated that they missed appointment dates because they forgot to check appointment cards, went to work, were ill-informed and walked for a long distance to get to the facility. Quotations are presented below:

"I missed the date once because I did not realise that it was my date, but I went to the clinic the next day. So, it was not deliberate, I forgot to check my appointment card" T9C9

"And at work, they also used to refuse to give me time to collect treatment, plus there were no letters to show that you attended the clinic, you see? So, it was difficult for me to collect treatment" T1C1

"I skipped the appointment because I was at work and couldn't request for some time to go to the clinic. I usually go to the clinic when I am off, but this time my appointment was not aligned to my day off" T4C4

"However, I know that I still have to come back to the facility for renewal of the prescription or blood monitoring. So, I wish I can be given a chance to choose a suitable date, I would look at the calendar and identify my off days then choose from them so that I do not have a challenge at work" T4C4

“There was a time when I found work far from the clinic and could not come back on time for my scheduled clinic appointments, though I still had treatment. I did not know what to do, but I visited the clinic as soon as I arrived” T2C2

“I stay in this township; it is just that this area is big, and I walk for almost 6 km to get to the clinic. But I hear other people on the queue mentioning other townships and that they prefer this clinic. I do not know why they do that and maybe this is why our queue is always long this side” T9C9

Two participants highlighted clients’ misinterpretation of undetectable virus as cured, as well as being misled by friends, as per quotations below:

“One may take advantage that, what is this, the CD4 count is okay during monitoring, maybe he/she is told that ‘the virus does not exist anymore’ or ‘it cannot be detected’, then he/she believes that he/she is healed. This person then decides to stop treatment, thinking that when they say they cannot see the virus anymore he/she is healed, and this ‘truth’ is kept away from him/her by the clinic staff. Anyway, I do not know, that is just my thought” T2C2

“She stopped treatment because of friends who gave her wrong information that she does not have HIV” T10C10

The study findings are supported by Mukumbang *et al.*, (2017:5) who found that clients missed appointments due to being at work and not being able to take time off to go to the health care facility. However, Lowane *et al*., (2022:4) explained that the clients’ next ART refill or return dates were not aligned to their availability, but to the number of scripts and tablets inside the containers. Therefore, lack of clear communication and discussion regarding suitable dates, by health care workers and clients will lead to missed appointments if dates clash with clients’ work or other schedules.

Buregyeya *et al.,* (2017:5) identified other factors that negatively affected adherence and retention, such as clients’ forgetfulness to take medication or attend the clinic, travelling away from home and lack of transport to go to the health facility. Similarly, Mukumbang *et al.,* (2017:7) and Tafuma *et al*., (2018:4) found that the distance from clients’ homes to the clinic was very long, with some clients walking for more than an hour as they did not have transport or money thereof. The discussed studies concur with the current study findings in terms of clients' forgetfulness and walking for long distances to the facility.

Li *et al*., (2017:4) discovered that participants lacked satisfactory knowledge that enabled them to get access to HIV care, such as what services and where to get access, benefits, and potential risks. This resulted in ignorance of dealing with their illness, or made them confused and scared. This concurs with the findings of the study where one of the barriers to retention was misinformation and misinterpretation of undetectable viral load as 'healed' and not requiring ART anymore.

6.2.2.4.3 SUBTHEME 4.3: Fear of HIV positive status disclosure and its consequences

Clients alluded that another barrier is fear of HIV status disclosure due to its negative impact on their relationships. Some clients even attend the furthest clinics where they are not known to avoid the stigma. While most participants have disclosed to their families, one participant had not disclosed to her partner until her family did, without her consent, which destroyed the relationship and made her to stop treatment out of anger. The same client revealed that she has a new partner but has still not disclosed. Another client indicated a strained marriage, while the other one expressed the pain of being ill-treated and mocked by church members and further emphasized the importance of acceptance and ignoring gossip as the first steps towards the healing process. Quotations are presented below:

"I have not experienced this, but some people, what I hear is that people are scared to go to the local clinic because they say that some nurses will tell people their status since they live in their neighbourhood. As a result, they attend far away clinics, or they just stay at home without collecting treatment. It has never happened to me and there is a nurse who is my neighbour and works in the clinic, but I have never heard anything like this, all is well" T4C4

"I told my family not everyone. Isn't that when you tell other people they mock you? But I do not care about that, I know that one day I'll meet the same person at the clinic and ask her/him what he/she is doing there. The clinic is for everyone" T14C14

"Some people have a problem because they are concerned about being seen by others, especially those known to them. This is a problem that kills many people. It is easy to

identify people on this treatment because we queue at this area; however, I do not mind being seen on the queue. For the sake of my life, I have to be patient for that day. If people see me, it is fine, it is up to them how they want to handle it, all of us have different challenges. What matters to me is my survival. Others buy treatment at the chemist, but it is expensive there. I will never buy my treatment there because I do not see the importance of doing that. Besides the expenses, no blood is collected at the chemist. Like yesterday, the nurse told me that my kidneys are functioning well, and I do not think that they do this at chemists. I do not have money as I am not working, but the clinic is providing good services to me" T15C15

"One of my family members disclosed my status without permission to my boyfriend in December 2020. My boyfriend was angry at me and accused me of planning to make him sick as well. I told him that I did not make him sick and that I kept quiet about my status because I was waiting for the right time. As a result, we broke up" T12C12

"I was very angry to the extent that I stopped taking my treatment. I did not understand why my family had to tell my boyfriend about my status. I felt like dying because they were interfering in my life, I was waiting for the right time to tell him. In June 2021, I visited my new boyfriend at (name of place which is ±54 km from home). I skipped school on Monday, so my friends called my family because they were worried. I think that is how they got to know; my family disclosed. Now most grade 12 learners know about my status" T12C12

"Long pause...This is a difficult one, but I'll find a way. Maybe I can take few pills, wrap them in a tissue paper and place in the bag. Then I'll go to the toilet to take them and also make sure that I reduce the sleep-over visits. I am not ready to disclose" T12C12

"After this whole thing of my family informing people that I have HIV, I stopped taking treatment for a while. My guardian was called two times to take me to the clinic. I told her that I would do so when I am done with my preparatory exam. But she insisted that I go to the clinic as soon as possible after school, then I decided to do that" T12C12

"There was no negative reaction from my family, except for my husband. It was too difficult, but we tried to correct it. We are on separation currently, but we do talk on daily basis. I just don't know how to explain it. I think he was blaming me, but I started reading

and researching on HIV. I also looked at history and found that his 2 previous partners passed away. I used to look at these partners and realise that they were positive, the signs were there. I could just see that they were sick, but I think they were in denial. I accepted myself wholly when I read and discovered that some partners are carriers who transmit HIV without them testing positive. I do not know how true this is. I think he is the one who brought the virus because I never cheated on him. Also, my previous partners are all alive, anyway I don't know, but I don't think that they are sick. I continued searching the internet for more information and it showed that this case indeed exists. I just wonder how he managed to survive when all his past partners passed away and me being sick as well. Anyway, I have accepted and moved on because my motto is that my life comes first" T15C15

"Yes, I experienced it. When I was sick, some people went as far as going to the tailors to design dresses in preparation for my burial ceremony. They told me straight to my face that they were preparing to come and have breakfast at my place during my burial ceremony. I remember that time very well. Then in 2015 in September when I felt better, I went back to church (name of church and Bishop). All the people who mocked me were surprised to see me alive and recovering. They could not believe it and kept on asking if it was me indeed and how I pulled through. They still mentioned that they had hoped to come and eat at my burial ceremony. I did not let their comments get to me because I have accepted my status fully" T14C14

"It was very painful, but unfortunately, I cannot control what other people do. I can only control myself, so I prayed to God to give me the strength to accept my status and move on. Accepting the situation and ignoring gossip are the first steps to help in the healing process. I thank God that I have fully recovered" T14C14

"Some of my friends are distancing themselves from me, especially those in grade 12, but there is no problem with learners from other grades. There was a time when the teachers were encouraging us to come forward when we had problems. I raised my hand and informed them that other learners were treating me unfairly. The learners denied it, but one girl agreed with me. The teachers advised us to avoid being judgemental and that we need to care for each other. The situation is better now but I want to prove the learners wrong" T12C12

"Sometimes we hide our status from our partners because we do not meet the same people, including the family, their characters are different. Sometimes you tell him, and he abandons you. When you find another partner, you decide to keep him in the darkness and not tell him anything. You just decide to leave everything because the same thing will happen" T8C8

"Sometimes the family ill-treats you, but mine has accepted me. I informed them the first time and at times when I am unable to go to the clinic, I ask one of them to go on my behalf. They are supportive. However, I have seen some families neglecting sick members, it is painful. When you are sick you need support because it gives you the strength to go on" T8C8

Becker *et al*., (2020:8) conducted a study in Eswatini and discovered that fear of revealing the HIV status to the family or other social structures was a barrier in HIV management. Though nearly all women in the study had disclosed their HIV positive status to at least one person, these women were worried about inadvertent disclosure to other members of their social group or community. Some participants experienced conflict with partners after disclosing the HIV diagnosis, with others blaming and accusing each other of promiscuity or even dissolving the relationship (Becker *et al*., 2020:8; Maeri *et al*., 2016:62). Furthermore, some participants would avoid disclosure by attending remote facilities so that they could not be seen by known people when going to collect ART, while others were hiding medication or stopping treatment altogether.

In addition, Spangler *et al*., (2018:7) conducted a study in Kenya and found that non-disclosure lasted for a few days to months. Although participants agreed that there is fear of disclosure, they emphasised the need to overcome fears of stigma, break the secrecy and talk openly about HIV. Dapaah *et al*., (2016:41) further discovered that stigmatisation occurred in different forms both in the community and health care facilities where even the mere presence of a person at the HIV counselling area or clinic is enough for that person to be suspected to be HIV positive. Unfortunately, this serves as a barrier for the HIV programme and clients' access to testing and antiretroviral therapy, which agrees with the study findings.

6.2.2.5 THEME 5: RECOMMENDATIONS TO STRENGHTEN RETENTION TO HIV CARE

The recommendations to improve retention to HIV care were presented by the participants and are classified into two subthemes which are presented together with supporting quotations and literature control below.

6.2.2.5.1 SUBTHEME 5.1: Improving health care facility processes and clients' experiences

Clients revealed that in terms of addressing the challenge of lost clinic files, the filing system needs to be improved to avoid delays. Again, participants suggested that communication, counselling against defaulting, and referral of clients to external treatment pick up points be strengthened. Quotations are posted underneath:

"Number 1, the issue of files needs to be sorted. There is no one who is willing to attend the clinic for 3 days, maybe you were off for the 3 days, then you queue until 4 o'clock because of a file and they tell you that they are knocking off. Even last time, there were some women that I found in the clinic so I was helped together with other people left those who we found at the clinic behind because their files were missing, and they could not be helped. So, the file issue is a problem, you can go back home without treatment just because they could not find your file. They do not have your information, today they open a new file, tomorrow when you come back, they retrieve that other one that was used in the past 3 months, you see, it is just chaos. So, I do not know what they can do about their filing system, they need to try and sort it out. Because the file challenge is a big issue, even when I was still collecting treatment from the mother and child side, it was still the same issue, same as this general side" T4C4

"You see these files must be arranged alphabetically if they want to minimise the loss" T14C14

"I do not know how to answer that one. They work okay at the clinic, but there is some delay. This delay is sometimes caused by us the clients because we default and the workload increases, so they need to tighten the rules against defaulting. Again, they must stick to this system of registering us for treatment collection at some external pharmacies, this is what makes us motivated to collect treatment" T10C10

"Eish, I do not understand if many people who queue there are new or those who have been long on treatment. If they are new, there is something called billboard, they must be shifted to it to reduce the queue. Another problem is that some people do not attend correctly on their appointment dates. Again, the files are a challenge, they get lost. I do not understand why every now and then we are told that the files are lost. This is a challenge for other people as well. These files really get lost and once your file gets lost, you will never find it again. I do not understand if this file is still there or not, and how does it get lost, we really do not understand this. But like I said, collecting treatment at pharmacies is a better option because it reduces overcrowding. People are discouraged by long queues and now they are also afraid of COVID-19" T11C11

"But I am lucky because I do not collect treatment at the clinic anymore, they sent me to this pharmacy (stated the name)" T4C4

"For now, the system of taking treatment at external pharmacies and post offices is the right one. To be honest, going to the clinic at times... (pause), people have different jobs, you request for permission at work promising them you would be back by 12:00 then you stay for the whole day at the clinic. The following day when you go back to work, they ask why you did not return as promised and the employers do not believe you when you explain that the queue was long. And now since there is COVID-19, the clinic procedure is long, you have to screen first in order for you to get to the consulting room. So, for now, it is nice to collect treatment at the post office. When you get there, no one knows what you came to collect, we are all there to collect parcels. So, at the clinic, you meet many people, sometimes your neighbours, that is why some people are shy. And you know if it is your neighbour, once he/she sees you he/she will tell others that you are collecting HIV treatment, yes" T7C7

"I am not sure if I am using the correct term when I say billboard, but it is situated right next to the clinic entrance. People collect their medication there, so it is better to register new people there so that it becomes easy for them to collect their medication. "Like they will want to take their medication there and not inside the clinic. I think it is better there because they will avoid these long queues. The queue is what annoys most people" T11C11

“No, no, I am happy collecting at the external pharmacy. Like I said, I do not want to go to the clinic because it is overcrowded there. Sometimes people queue on the side of that box because it is next to the entrance, so it is not conducive if I want to collect treatment in the morning. I am afraid of this crowding, so the pharmacy remains the best option for me” T11C11

“In fact, I am tired with the clinic, I wish it was possible to remain at the chemist because it is better there. The queue is there but not too long like at the clinic and I go there at a time that is convenient for me” T14C14

Other recommendations were related to the health care workers performing thorough examinations, fast-tracking and helping clients first before they break for lunch. The quotations are presented underneath:

“Also, when we come for check-up, we must be examined thoroughly, like checking if you eat well, treatment is working, etc. I sometimes ask them to check my blood sugar because my blood pressure is always high, and I know that it normally goes together with high blood sugar” T10C10

“I think they must improve their service and refrain from keeping people at the clinic for a long time without staff to assist. They really need to push the queue, some of us reside far and start queueing at 5 in the morning but only get helped at 4 in the afternoon, which is not good. They must help us on time and also go for lunch at intervals, not all at once. Sometimes we sit and wait for them to come back from lunch when we are also hungry. It feels as if we are not people as well. People will be encouraged if they are helped on time and can also attend to other commitments thereafter. And sometimes you just go there to get a date or results, but you still stay for a long time as if you are starting; you go from one queue to the other. According to me they are too slow” T9C9

“*(Deep breath) Yeah, at the clinic, when one starts treatment, or rather let me say that when I started, I got the encouragement but there are some challenges along the way like long queues. I think we have spoken about this already that it depends on the time that you have been on treatment for you to qualify for the option of collecting treatment elsewhere. But if there was a way to reduce waiting time as from the reception up to the* *treatment collection point, it would be better. A person must not stay in the clinic until he/she becomes impatient (repeated), I think this can make things better" T1C1*

Participants indicated that they would like to receive communication when there are challenges in the health care facility, and also be informed or referred to credible sources of HIV information. Quotations below represent client's voices:

"If there is a problem, they need to inform us and not wait for us to complain. Like the last incident, the sister who was supposed to assist us had gone to the workshop and there was no one to assist us. Patients will understand" T9C9

"I just don't know how to say it but these days there are many things. I think there are groups, even on the phone there are HIV websites where you can visit. There is also WhatsApp. I visit these sites to read more about HIV. Even at the clinics, there are counsellors. You can just go to the clinic to get the information" T3C3

"Yes, it helps, it helps. Sometimes when you are sitting at home you can read and read. We also encourage each other, you see. So, it helps. You can also read further, reminding yourself of what the counsellors or health care workers advised you on. So not only the information on the phones is important, every legit information, like from the clinic, media, etc., empowers us and we are able to take charge of our health" T3C3

Marutha *et al*., (2017:7) conducted a study regarding the role of medical records in the public sector in Limpopo province and revealed that missing medical records negatively affected timely and effective service delivery because it led to increased clients' waiting time, with clients being treated without medical history sometimes. Therefore, an effective record management system, continuous training and filling of vacant posts of the administrative personnel need to be invested on. This concurs with the findings of the study where participants indicated that poor management of medical records is a critical problem and in order to improve service delivery and retention to care, it must be improved.

Mulqueeny and Taylor (2017:5) highlighted that the Centralised Chronic Medicine Dispensing and Distribution programme allows clients to collect their chronic medication from designated external pick-up points in an attempt to alleviate challenges of ARV stock-outs, transportation costs and long waiting time. Also, these external facilities operate after hours, including weekends, which is convenient for clients and improves access even for working clients. This concurs with the study findings, which recommended that this method be used to promote clients' motivation and retention.

Eyassu *et al*., (2016:7) mentioned that health care workers must provide regular feedback to clients regarding the benefits of ART as well as the importance of viral load and CD4 count to promote clients' trust on the medication and retention to care. Again, the health care workers need to be trained on ways of providing information at the appropriate level of the clients' understanding. The USAID HIV Reform in Action Project (2017:53) indicated that in addition to training the health care workers on post-test counselling, managers can conduct exit interviews with clients to assess the counselling and testing offered.

Bisnauth *et al.*, (2021:12) emphasized that value clarification that enhances mutual understanding among health care workers and clients, as well as friendly health talks, information, education, and communication, can promote acceptability attitudes and retention to HIV care. The above discussions concur with the current study findings.

6.2.2.5.2 SUBTHEME 5.2: Promoting clients' acceptance, responsibility, and disclosure

Participants indicated that they value their lives and emphasized acceptance, independence and taking responsibility because it is not possible to control other people's actions. However, they still mentioned the importance of disclosing the HIV positive status to those close to them. Participants' quotations are posted below:

"I do not know how people who default treatment really think. They must realise that the life is theirs and take treatment at the correct time. I do not have much to say on this one. Challenges will always be there but like I said earlier, one has to be self-motivated and determined to take responsibility of own health" T13C13

"Generally, you cannot control how the other person acts, so you just have to be independent and find a way to create your happiness" T6C6

Health comes first and we really have to take responsibility for taking treatment correctly. Yes, challenges are there, but it does not mean that you must stop treatment completely" T11C11

"So, you need to accept yourself, if not you will become sicker, have stress and pressure. If you know you are sick it is better because you know how to take care of yourself. People must not be afraid to talk about their status, at times you can help someone who has been helpless all along. And again, people must not be ashamed of taking treatment and they will live freely and healthy" T10C10

"My life comes first, yes. I must not listen to other people, but I have to be responsible for my health" T2C2

"People must just take their treatment and stop worrying about what others think or say about them. We all have our lives and each and every one must care for his/hers. I am not afraid to take my treatment, even in front of my relatives and if they ask what I take it for I gladly respond that it is for HIV. Isn't it that they also take their treatment, be it for high blood pressure, diabetes? People must also eat well, now it is easier because there are some government grants that assist us. The problem is that people buy alcohol instead of food with this money" T5C5

"(Laughter) I don't know how to answer this one. But what I can say is that this is my life, my life comes first. Do not please other people, make yourself comfortable first. You cannot reverse other things; we did not choose to be in this situation, and we have different reasons that led to that. Being informed and then accepting yourself are important and that is what people must focus on and stop complaining about other things" T6C6

"People must just take treatment and stop making excuses. Why are people, especially the elderly taking their hypertensive and diabetes treatment so well? What is different with HIV treatment because it is taken daily just like other chronic illnesses? We should not be ashamed of this treatment and even carry it everywhere with us. I am not ashamed, if I am at your place and need to take treatment, I'll just ask for bread, eat, and take my treatment, just like that. We have to be open and free, ignore people because they always gossip, and we cannot control them" T14C14

Clients alluded that health care workers should encourage clients to disclose their HIV positive status to their loved ones. See quotations below:

"With me, when my partner informed me that she tested HIV positive at the doctor, I did not waste time, I went for testing the next day. I also found that I was positive, I was counselled and referred to this clinic because where I tested treatment was not offered yet as the facility is small. Since that day until today I have been on treatment continuously. So, it all depends on acceptance and determination, even if there are challenges, you can overcome them" T3C3

"You have to accept; in this world we are advised to accept. You have to sit down with your relatives and explain to them, narrate your journey so that they understand where you come from. I do not believe that all your family members can abandon you, it is not possible. If you meet a new partner, you have to disclose your HIV status and it will be up to the partner if he/she stays or abandons you. If you get diagnosed with HIV while in a relationship, you have to tell your partner immediately. It is wrong not to disclose to your partner. If there is partner violence you need to go to the police station or even the clinic to get help, they will never chase you away" T5C5

"Most of us with this condition, we are afraid to disclose to partners. We fear that they may abandon us if we tell them. In my case, my partner was there for me from day 1 until today. So, I think that if you are open towards people close to you, there is nothing that can push you to default; you are open and not hiding anything. So, when you meet a new partner, then you visit him for a month without taking your treatment along because you are afraid to disclose, it means you do not value your life. I agree that you cannot disclose to everyone, but you need to disclose to someone close to you and be willing to accept the consequences" T6C6

"The partner will choose whether he stays with you or not, but you have to disclose. If a person cares about you, he will stay in your life no matter the situation you face, even if it it's not HIV. It is important to disclose, you become free and do not feel guilty for being dishonest. People need to accept themselves and not rely on their partners because it is not good to base your happiness on a partner" T6C6

“I do not know. But the first time I knew my status, I felt like I did not have a choice but to inform them. I felt that even if I kept quiet, one way or the other they would still find out. I knew that they would not go around telling other people, but because we stay in the same house, they’ll eventually see me” T8C8

“Hiding treatment, how would it have worked? If it is time for treatment, like 8 o’ clock, I’ll be taking a glass of water and going to my room. My family would have enquired about this. And again, telling them helped me to be free to take my treatment without hiding” T8C8

“I first became alert when he was not well: he was wasted, coughing, like he had lost weight and looked weird. After a few months I also became sick around December, I was coughing and realised that I was not well. I considered his appearance and mine and became suspicious. Then I went to the clinic alone, got tested and counselled. That same day they advised me to disclose to my partner and come back to the clinic with him. They also advised me that if he refuses, I can give them his contact numbers so that they can call him. Luckily when I got home, I informed my mother who then informed my partner. He refused initially and I told him that it will be better for us to separate because I am willing to take treatment while he is not willing to go to the clinic. The next day, he asked me to accompany him to the clinic and we went to the same room that I was tested at. He was tested, was also not okay and got counselled. He then started treatment. Since then, we have been supporting each other” T10C10

Oh, I forgot to tell you, after recovering, he proposed. He told me that I made him who he is and wanted the world to know how important I am to him. Yes, we had a big wedding ceremony and even those who gossiped about us came to witness how beautiful we were. We both had no sign of illness at all because of the treatment. We had killed the stigma and conquered this illness, and we are still going strong even today” T10C10

Acceptance of the HIV positive status varies from person to person and is regarded as contextual, but clients can be assisted through exploring and discussing factors specific to them (Horter *et al.,* 2017:57). These factors include the clients’ perceived risk of contracting HIV, judgement, and self-association with HIV infection, all which can promote transition towards acceptance if discussed intensively. However, Horter *et al*., (2017:57) further cautions that clients’ follow up must not be done just to bring them back to care as this may cause distrust and demotivate them; rather, the counsellors must demonstrate that they value clients' lives, and that treatment is for their own well-being.

The health care workers and key stakeholders need to conduct campaigns that focus on addressing stigma, and also consider a family approach to HIV management as ways of promoting family and community support (Eyassu *et al*., 2016:7). Additionally, psychosocial care needs to be strengthened after HIV diagnosis, and health care providers must not only focus on clinical aspects of care (Thapa *et al*., 2018:1223). Some HIV positive clients wish to belong to peer support groups to share their feelings, therefore, they must be encouraged to do so.

Similarly, Spangler *et al*., (2018:13) mentioned that in order to promote acceptance and disclosure, as well as to reduce stigma and clients' isolation, it is important to improve communication, create support groups, offer facilitated disclosure sessions, and routinely cascade messages that normalise HIV in the community.

6.3 CONCLUSION

This chapter presented the findings from clients on ART and concludes the first stage, that is, the empirical phase. Clients explained the emotions that they went through after the HIV diagnosis, the support and knowledge received, their motivation to keep up with the clinic appointments as well as barriers and possible interventions to improve retention. Although clients experienced barriers such as negative experiences at the health facilities, fear of stigma and strained relationships after disclosure of the HIV status, limited knowledge, and communication, they had a good relationship with LHWs and also emphasised that self-acceptance remains key to taking ownership of their health and remaining in HIV care.

CHAPTER 7

CONCEPT ANALYSIS: SUPPORT FOR LAY HEALTH CARE WORKERS

7.1 INTRODUCTION

The demand for HIV services has been increasing over the years and retention in care is vital for treatment continuation, monitoring and reduction of new infections, which in turn has put more strain on the health care professionals (Moosa *et al*., 2019:10; Crowley *et al.*, 2015:2). South Africa is among the countries that introduced task shifting from nurses towards the LHWs to reduce the workload, increase the communities' access to health care services and possibly reduce the number of clients who are lost to follow up (Aithal *et al*., 2017:35; Crowley *et al.,* 2015:3). To provide guidance, the WHO released the task shifting guidelines wherein different tasks that are essential in HIV management were outlined across the 4 common levels of health care service delivery, that is the physicians, non-physicians, nurses and CHWs who fall under the LHWs (WHO, 2008:51).

The success of task shifting from the nurses towards LHWs hinges on training, mentoring, supervision, reorganization of services and ongoing support from the existing heath care workforce (Crowley *et al*., 2015:4). Again, limited health system resources and support, ineffective guidance from managers as well as remuneration, equipment and infrastructure issues are some of the barriers to effective task shifting implementation identified by some countries.

The study conducted derived interest from the support provided to LHWs amidst task shifting. The aim of the study was therefore to develop an integrated support model for LHWs to improve retention to HIV care. After conducting the interviews with both LHWs, their supervisors and nurses, as well as clients on ART, support emerged as a concept of interest as it was also commonly cited and described by the participants. Risenga and Davhana-Maselesele (2017:215) mentioned that the selected concept must be significant, relevant, and important to contribute to the research. Therefore, the support, as experienced by the LHWs appears relevant in finding meaning and contributing to the identified research problem.

The LHWs understood and experienced support differently. They described the support received from colleagues, supervisors, nurses, and the Department of Health in terms of the provision of working materials, incentives, direct patient care, staff interactions, the review of their performance, as well as challenges affecting task performance.

7.2 BACKGROUND

The study conducted indicated that the LHWs experienced no support while some had sufficient support in performing HIV care duties that aim to retain patients in care and improve the outcomes. The LHWs revealed that their performance and motivation are negatively affected by lack of continued training and debriefing, insufficient resources such as transport for outreach activities at distant areas, limited communication and respect which made them feel unappreciated, low stipends, as well as lack of work collaboration between them and other health care workers, e.g., traced clients not being seen by professional nurses immediately and clients' contact details not captured correctly on medical records to assist the CHWs and tracers during tracing of defaulters.

However, there was some form of support among the lay counsellors in terms of counselling difficult clients for HIV, but different categories of LHWs such as lay counsellors, tracers, CHWs and health promoters interviewed, worked in silos. Letsoalo *et al*., (2017:35) similarly found that the lay counsellors experienced different levels of support from their supervisors and other health care professionals, ranging from adequate to inadequate, and others felt belittled.

Additionally, Assegaai *et al.,* (2022:36) found poor support and coordination of the ward-based outreach activities which negatively influenced the confidence and trust relationships between the front-line health care workers and the CHWs. Hodgins *et al*., (2016:5) alluded that the support of LHWs is crucial and must be individually tailored because they have little formal training. Also, there is a need for constructive engagements and respect which improve the CHW programme outcomes as opposed to focusing on performance versus set standards or targets only (Ludwick *et al*., 2018:7; Assegaai *et al.,* 2022:36).

Yazdani *et al.*, (2016:46) and Abdolrahimi *et al.*, (2017:4969) mentioned that concept analysis is a rigorous approach in which an abstract concept is explored, defined, clarified, and differentiated from similar concepts for theory formulation, through the search and analysis of relevant literature. Support will be discussed within the primary health care context; with the supervisors, nurses, co-workers, and the Department of Health being the sources or providers, and LHWs as the recipients.

The guiding question was: what does support entail? The aim of this concept analysis was to explore the attributes and dimensions of support to clarify its meaning and understand its use. The benefit of this concept analysis is that it will establish a common understanding of LHWs' support within the health care contexts and possibly guide the HIV management and retention activities amidst task shifting towards the LHWs.

7.3 METHODS

After identifying support as the concept of interest, literature review was conducted. The Cumulative Index to Nursing and Allied Health Literature (CINAHL) and Google Scholar databases provided a variety of peer-reviewed articles that were relevant to assist in the achievement of the aim of this concept analysis, and also, they are widely used. Therefore, these two databases were chosen as ideal to provide sufficient information on the concept of support (Rodgers *et al*., 2018: 452). The search commenced by typing the key words "support" AND "concept analysis", to search for articles with these terms either in the titles or abstracts. Articles that discussed closely-related terms, such as "care", "advocacy", and "influence" were also considered.

The initial search produced 2481 articles, then limits were set to peer reviewed, freely accessible and English articles. The refined search produced 240 articles, which were then sorted by relevance not year, because the researcher, who is orientated to the nursing field, wanted to determine how this concept which is an inherent part of the nursing practice, has been evolving. The abstracts were individually screened for relevance, thereafter, 32 articles were selected. However, the screening stopped after 10 more articles were found to be irrelevant.

The articles were read and re-read individually to obtain the relevant information as per Walker and Avant steps of concept analysis, that have been used widely for different concepts and include:1) selecting a concept; 2) determining the aim of analysis; 3) identifying all possible uses of the concept; 4) determining concept defining attributes; 5) constructing a model case; 6) constructing additional case; 7) identifying antecedents and consequences of the concept; and 8) defining empirical referents of the concept

(Abdolrahimi *et al*., 2017:4969; Liu *et al*., 2016:85). The literature search and analysis were conducted for a month, from the 16th of May to the 13th of June 2022.

7.4 RESULTS

The presentation of results is as follows:

7.4.1 Selecting a concept: The concept "support" was selected and presented in the introduction section.

7.4.2 Determining the aim: The aim of this concept analysis is to explore the attributes and dimensions of support to clarify its meaning and understand its use and was presented in the background section.

The remaining 6 steps are discussed below:

7.4.3 Identifying all possible uses of the concept

a) Dictionary definitions

Support can be used as a noun or verb. When used as a noun, it means "a person who gives someone a practical or an emotional help"; or "a thing that carries the weight of an object from below"; and has synonyms such as "pillar", "mainstay" and "backbone" (Collins Thesaurus). The importance of support is also seen in an example of building a house, where other bricks may be removed without damage but removing those that support or bear the weight may lead to the collapse of the entire structure (Vocabulary.com).

Again, as a verb, some support synonyms that can be used are "boost", "reinforce", "sustain" and "strengthen" and it means "to give encouragement to someone or something because you want the person or thing to succeed"; "to provide the right conditions for life" or "to provide someone with money or physical things that are needed" (Cambridge Dictionary).

According to Merriam Webster Dictionary, support means to:

- "Keep from losing courage"
- "Promote the interests of or to vote for"
- "Provide the basis for existence or subsistence of"

- “Endure bravely”
- “Serve as a foundation”

Furthermore, support synonyms may include “advocate”, “maintain”, “assist”, “endorse” and “champion”.

The dictionary definitions above show that support can be used in two ways. Firstly, in the form of a noun where a person or an object provides support to the recipient. In this study, the LHWs’ supervisors, nurses, co-workers, and the Department of Health emerged as the support for LHWs. Secondly, support can be used as a verb or action. In this study, the positive actions that the supervisors, nurses, co-workers, and Department of Health undertake to encourage the LHWs are regarded as support.

These actions as described by the LHWs during the interviews include training on updated HIV information, effective communication, work collaboration, provision of working materials, two-way client referrals and performance reviews as part of feedback, as well as being respected and appreciated. The afore-mentioned actions were mostly directed to senior personnel, that is, the health care professionals and supervisors or managers, except collaboration which was also directed to the co-workers, and availability of working material which is provided by the organization.

b) Literature definitions

Support involves human interactions and is termed social support in most literature and can further be explained in terms of the type, source, context, and amount; however, there has not been a consensus on these aspects, so different approaches exist (Mikulincer *et al*., 2015:351; Williams *et al*., 2004: 947). Bashirian *et al*., (2019:225) endorsed four types of social support as emotional, instrumental, informational and appraisal. *Emotional support* includes empathy, care, and trust*; instrumental* relates to tangible assistance; *informational* refers to information and advice, while *appraisal* relates to provision of information for the purpose of self-evaluation.

Mikulincer *et al*., (2015:351) explained that the types of support have also been identified as emotional, network, esteem, material, instrumental and active; sometimes as emotional, companionship, informational and tangible; however, there have been suggestions to collapse these multiple categories to two, that is, emotional and instrumental. Mathieu *et al.*, (2018:2) stated that the *emotional support* includes listening and showing esteem, encouragement, affection, and sympathy to others, while *instrumental support* entails task assistance, information, and other tangible aspects.

Kayed and Moghadam (2021:440) described social support as the most powerful shield that facilitates endurance and coping with stressful situations, thereby increasing self-esteem, while Ilmalwa & Hlatywayo (2022:23) regarded it as a job resource. The sources of support, adequacy, and the context within which it occurs vary, and may be from parents to their children at home, or from spouses, family members and friends to adults in different social environments, or from co-workers, supervisors, and the organization to employees in the workplace; and may be perceived as less or sufficient (Gariepy *et al*., 2016:284; Zhai *et al*., 2020:3).

In the workplace, employees value the support from co-workers in the form of job-sharing and teamwork, but the empathy and assistance from supervisors, including the flexibility of the organization's protocols and procedures to accommodate personal life, seem to be crucial (Boakye *et al.,* 2021:6). Additionally, workplace social support is a set of actions carried out by co-workers, supervisors, and the organization, including sources outside the workplace such as family, to help employees, and may include emotional support, mentoring, problem-solving or even communicating the organization's hierarchies (Pelin & Osoian, 2021:75; Nasurdin *et al*., 2018:367).

In the nursing field, social support is defined in multiple ways: as occupational, where workplace support from both co-workers and supervisors is emphasized, and also as specific to the context or illness. It is the intentional human interaction that provides affection e.g., respect and sense of security; affirmation, e.g., feedback and reinforcement; and tangible aid, e.g., spending time assisting someone or providing material such as money (Donovan & Greenwell, 2021:3). The same authors further provided an example of an antenatal-oriented definition which relates to being non-judgmental and listening to women's pregnancy-related needs as well as providing relevant information and referrals to other professionals.

In a theoretical perspective provided by Feeney and Collins (2015:5), social support was regarded as a relational process that does not only promote coping during adverse circumstances but also focuses on thriving through non-adversity to facilitate individuals' growth. Moreover, reciprocity between both the support providers and recipients is key as they all have roles to play in order for social support to be successful; however, the support must also be responsive and sensitive to the needs.

Similarly, Caesens *et al.,* (2020:1) stated that in organizational psychology and management, the theory of social exchange and reciprocity are adopted in explaining support. So, the organizational support theory states that when the organization provides positive resources to its employees, the employees' perceived support is increased and they want to help the organization to achieve its goals, while experiencing self-enhancement as well.

Lakey and Cohen (2000:36) indicated that from a social constructivist perspective, there may not be a clear consensus among individuals and groups in terms of what social supportive behaviours entail, and that the self is inseparably linked with the social world, including social support. Therefore, the individual's characteristics such as the personality traits, perceptions and interpretation influence social support, and that as people self-regulate through applying the group's standards, self-esteem and identity are created and maintained. The individual's recognition of non-acceptance by the social group and the perception that the group would not help when needed, play an important role in social support (Lakey *et al*., 2000:43). So, the types of social support identified are *perceived* (perception of available support in times of need) and *enacted* (actual support received) support as well as *social integration* (social relations or membership).

The above reviewed literature supports the study findings. The study participants had different views on the support received and this may be attributed to the individual traits or the view of incongruence between the support provided and the one needed. Some viewed ART provided to clients by professional nurses after being counselled by lay counsellors as support, while others did not. Other participants felt that they would not say they are supported because the support was limited to a certain aspect of patient care only, while other aspects like provision of materials and information were lacking.

Participants who felt unappreciated and not part of the facility team felt unsupported because they would refer clients from the community to the clinic, but the referral would not be considered by nurses, who would even make belittling remarks in front of clients. Also, lay counsellors feared that the nurses would regard them as incompetent if they called for assistance during HIV counselling; therefore, they preferred to rather assist each other. Despite the LHWs recognizing the need to collaborate their efforts as co-workers, they viewed organizational or management support as key.

In line with the organizational support theory, the study participants highlighted that they still felt like volunteers as their stipend was too low to keep up with the standard of living and they had no benefits like funeral assistance, which contributed to them either releasing their anger on clients or contributing to clients defaulting treatment. The performance of CHWs was also affected by lack of: transport to hard-to-reach areas, supportive supervision and information which made them feel unequipped to address the community's needs. One other aspect highlighted by participants was the way in which support was provided by some supervisors, specifically those from the developmental partner that supports the health facilities. The participants stated that these supervisors provided HIV viral load job aids to their lay counsellors only, which made them feel discriminated. Moreover, patient care would negatively be affected because either they would refer clients to counsellors with resources or they would work sub optimally.

Lastly, Stoltz *et al.,* (2007:1482) stated that the variability and complexity of the definition of support is sometimes due to the prefixes attached to the term, such as financial-, family-, social-, emotional-, nursing-, child-; as well as the suffixes, e.g. -group, -network, -organisation, etc. Furthermore, support in nursing has been mainly on caring for patients, however, literature shows that the use or meaning is different in other fields, for example, courts of law, where it is used to refer to child or spouse financial provision; or in computers for programs that assist in system's operations; or in environmental sciences where it refers to preventing the soil from moving along the slope; or in construction where it refers to keeping trees upright. The context is therefore important when defining support.

7.4.4 Determining concept defining attributes

Attributes refer to the most comprehensive aspects that the concept is characterized with or related to, and are useful in operationalizing the concept (Abdolrahimi *et al*., 2017:4970; Foley & Davis 2017:72; Arabi *et al*., 2014: 317). Both the *support providers or agents and recipients* are the means to the support processes and outcomes; and will be discussed first.

- Providers’ or agents’ characteristics and responsibilities

The providers must be competent, motivated, interested, receptive and emotionally stable (Maqsood, 2019:2; Feeney *et al*., 2015:25). Also, competent, and selflessly motivated providers will be able to transfer the knowledge and skills accurately, confidently, freely, and optimally without egoistic motives. In the current study, the LHWs’ supervisors and other health care professionals need to be knowledgeable about HIV management, from diagnosis until maintenance of clients on treatment; be able to identify performance gaps and quality issues; be willing and interested to support the LHWs and also, be able to acknowledge and regulate own feelings that may interfere with positive interactions (Feeney *et al*, 2015:25).

Issues like the high workload or other stressors, either at work or home may affect the motivation levels of providers (Kavga *et al*., 2022:151). In the current study, the supervisors and nurses cited that they shifted the focus towards the COVID-19 activities which had resulted in more work and lack of time to supervise the LHWs, with the CHWs working in the community being mostly affected. Another challenge indicated was the termination of contracts for some OTLs who were supervising CHWs, which increased the OTL-CHW ratio to about 1:30, and though the situation was resolved, the newly appointed OTLs were also redirected to COVID-19 activities.

Moreover, being receptive and emotionally stable can also be promoted by some individual aspects such as positive moods or having energetic and agreeable personalities (Pelin *et al*., 2021:83; Feeney *et al*., 2015:26). Some LHWs indicated positive attitudes from other nurses who were always willing to assist them, while some stated the opposite. Again, one participant indicated that she had observed a negative attitude from a particular CHWs’ supervisor who was unapproachable and harsh, which made the CHWs scared to open up and lose trust, thereby hindering the support processes.

- Recipients’ characteristics and responsibilities

The support recipients also have to acknowledge the need for support, be interested and emotionally stable (Kayed *et al*.,2021:440). When the LHWs acknowledge their needs and show interest, support will be promoted. However, negative moods or self-perception and certain personality types such as neuroticism where individuals cry more often even with the slightest adversities, may hinder the support (Restrepo *et al*., 2022:111; Kayed *et al*., 2021:438; Udayar *et al*., 2020:17; Fiori *et al*.,2013:54; Swickert *et al*, 2010:736). In the study, participants were willing to be supported, even those who had training, yearned for continued information.

- The attributes of support

Literature showed that there are multiple definitions of support, and no consensus on how many categories are ideal to classify it, as discussed above in section 7.4.3 of identifying its possible uses, however, there are some consistencies identified in the attributes, as summarised in table 7.1 below.

TABLE 7.1: LITERATURE COMPARISON OF SUPPORT ATTRIBUTES

Concept analysed	Source	Attribute	Explanation
Support in nursing	Stoltz *et al.,* (2007:1483).	- “Tangible, concrete and impersonal dimensions”,	“Support entails the provision of general tangibles such as information, education, economic or financial aid, goods and external services.”
		- “Intangible, abstract and highly individual dimensions”, - “Reciprocity between the care-giver and receiver - “Protection.”	- However, support is also created when individuals feel protected and are able to share emotions and experiences.
Peer support within a health care context	Dennis (2003:325)	“Emotional”	- Peer’s availability to listen to, and discuss personal challenges may reduce threats to self-esteem.
		“Informational”	- Relates to the provision or exchange of knowledge necessary for problem-solving.
		“Appraisal”	- Providing the encouragement and motivation to endure during problems.
			- Peer support can continue without instrumental support, however, the current study found that both instrumental and emotional support were necessary in the LHW-supervisor relationship.
Developmentally supportive care in congenital heart disease	Peterson & Evangelista, (2017:5)	“Adapted to unique individual’s needs”; “Inter-relational”	Supportive care must be adapted to the needs of the individuals, including when these needs change. The environment must be developmentally supportive.

Women's experiences of their maternity care	Beecher, *et al*., (2020:423)	Care is: - "Context-dependent", - "Interpreted subjectively.	- Care is influenced by how it is organised and delivered. - The interpretation depends on the individual's needs, expectations and circumstances.
Care partner	Bennett *et al*., (2017:187).	- Care is characterised by "providing assistance." - It also depends on the "nature of relationships."	- Assistance can be in a form of providing information and supervision, while having a positive relationship and commitment towards each other.
Care dependency	Boggatz *et al*., (2007:567).	- Care needs to assess the following from recipients: "Functional limitation" "Care dependency" and "Unmet needs"	- "What are you able to do?" - "How much support do you need?" "Do you get this support?"
Human caring	Ghanbari-Afra *et al*., (2022:246)	- "Establishing therapeutic communication", - "Presence at the patient bedside", "Empathy" and "Subjectivity", "Providing scientific care", - "Dynamicity", "Art and creativity", "Respecting the patient's rights and ethics of care", - "Helping the patient achieve a feeling of well-being."	Quality nursing care requires nurses' responsiveness to the patients' needs. The current study was focused on the support for LHWs, not necessarily the patients, but the attributes are similar.
Continuity in care of chronic diseases	Hu *et al*., (2020:515).	- "Care over time", - "Relationship between an individual patient and a care team", - "Information transfer", - "Coordination", - "Meeting the changing needs."	- "Continued care is a continuous process of mutual medical assistance that involves healthcare management, cooperation, and ongoing relationship." -The interpretation is similar to that of the current study.
Spiritual nursing care	Monareng (2012:3).	- The caring presence characterised by the "compassion", "empathy", "hope", "concern" and "respect."	- "Caring presence means availability, listening and showing concern for meeting the needs of patients physically, psychologically and spiritually." - These attributes were also identified in the current study under the provision of emotional and instrumental support.
Family-centred care of children and young people in the acute hospital setting	O'Connor *et al.,* (2019:3362).	- "Participation", - "Respectful" and - "Trusting" relationships	-Mutually-agreed upon goals, commitment and shared responsibility can be facilitated by communication, information and negotiation.

After reviewing the literature, the attributes of support were synthesized to form four characteristics, namely *responsiveness, provision, reciprocity, and integration*. These attributes are discussed below and illustrated in figure 7.1.

Responsiveness: Support must be perceived as available, then delivered sensitively during times of need. When the recipients feel that help will be available when needed, their perception of support becomes high, and the support processes are facilitated (Restrepo *et al*., 2022:111; Kayed *et al*., 2021: 440; Feeney *et al.,* 2015:29). Caesens *et al*., (2020:1) further indicated that the support must be appropriate or responsive to the recipients' needs, otherwise it may be meaningless or viewed negatively. Furthermore, in individuals with low socioeconomic needs, high support perception may threaten their self-esteem or be viewed as an indication of incompetence or lack of managers' confidence in them. So, supervisors must assess the LHWs' individual needs to be able to plan and deliver the relevant support.

Provision: Although there have been multiple types of support in literature, emotional support is regarded as the most effective, followed by the instrumental; therefore, these two types were selected as the most comprehensive for the context of this study (Jones & Koerner, 2015:5; Mikulincer *et al*., 2015:351). Furthermore, Mathieu *et al.*, (2018:2) stated that the emotional support incorporates expressive intangible aspects such as respect, listening and care while the instrumental aspects include tangible aspects such as the provision of resources, money, information, and assistance, as well as problem solving. The LHWs expressed the need for emotional support such as debriefing and appreciation, as well as instrumental support such as the working material, transport for outreach services at distant households, updated information, and better stipends.

Reciprocity: Support is not unilateral; it involves exchange of actions, so both the support agent and recipient need to have a good relationship and focus on the positive aspects of their interaction. Supported individuals must respond appropriately to the support provided, express gratitude and communicate their needs properly and in a less demanding manner, as a way of reciprocating the support (Pelin *et al*., 2021:81; Feeney *et al*., 2015:27; Dow & MacDonald, 2003:10).

The LHWs who participated in the study mentioned that they were not initially involved when new programmes such as the HIV index testing started, only to be asked to implement it later. As a result, they have not been implementing the programme consistently and would sometimes just refer clients to other lay counsellors from the developmental partner as they were the ones who initiated it and were better equipped with knowledge. The LHWs expressed the need to be supported with updated information so that they can reciprocate by improving the HIV outcomes.

Integration: Acceptance by co-workers, and a sense of belonging facilitate group cohesion and collaborative efforts (Lundqvist *et al*., 2018:11; Pelin *et al*., 2021:83; Boakye *et al*., 2021:6). Also, during times of demand, tasks can be shared among the workers and then completed with ease. The LHWs indicated the importance of integrating their work and that of the co-workers and health care professional. They alluded that proper counselling and collection of clients' information by lay counsellors or administrative clerks would help the CHWs to know which clients accepted home visits. This would possibly protect the CHWs from being unwelcomed by clients at the community as they would only visit clients who consented.

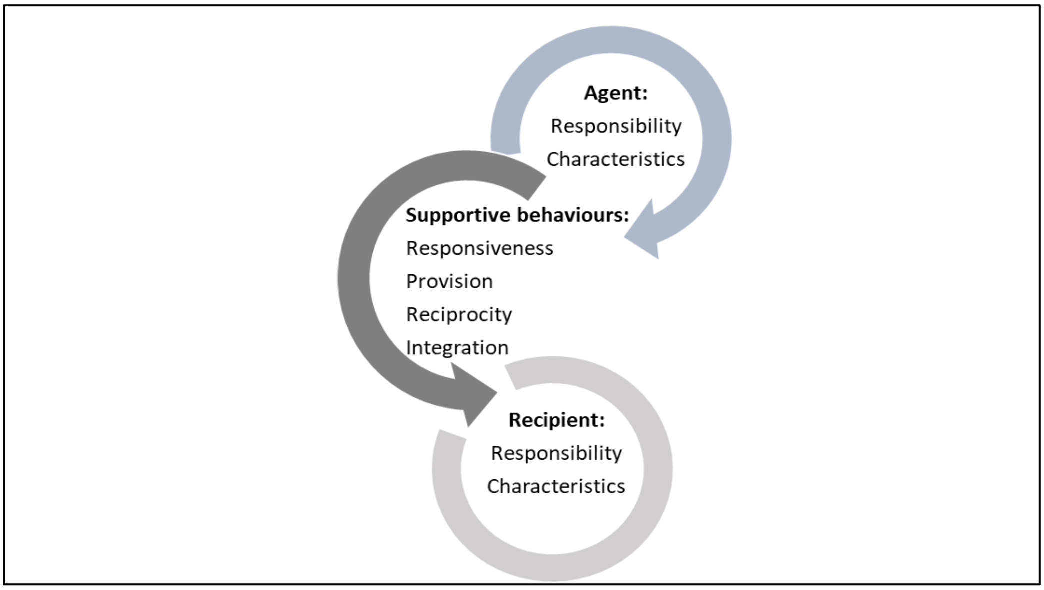


Figure 7.1: Attributes of Support

7.4.5 Constructing a model case

A model case is an example of the concept with its attributes, which makes it practical and enhances its understanding (Foley *et al*., 2017:72; Abdolrahimi *et al*., 2017:4970). The support concept will be illustrated using the quotations from the LHWs who participated in the study.

"To be honest, I receive good support from the clinical nurse mentor. She is helpful and explains things that I do not understand. Even though I am not clinical, she is able to explain in a manner that I understand. I am really happy with her support and when I go to work in the morning, I am motivated and looking forward to it. So, I am capable of doing my work, through her consistent support" T3F3E

The above case exhibits ***responsiveness*** where the nurse mentor addressed the identified or verbalised need of the LHW; ***provision*** of instrumental support such as clear information and ***reciprocity*** where the LHW is able to work effectively through the consistent support. The LHW has a high perception that support is continuously available during non-adverse periods and would probably also be there during adverse times.

Other examples below show instrumental support (availability, information and skills transfer) during difficulties with clients' management:

"I get support from the manager in terms of dealing with the non-disclosure cases that I referred to earlier on. She assists me in counselling these clients. That is where we both provide the information to the partner who is not disclosing that if he/she continues with unprotected intercourse with the negative partner, it is the same as intended murder." T1F1A

"You know with the previous OTLs, they would accompany us to the households, or we would call them when we have challenges. They would teach us and even show us how to check infants" T2F2D

The case below shows emotional support where the lay counsellors were debriefed and felt good about it:

"Yes, the colleagues are telling the truth. Fortunately, I had a debriefing session together with some of the counsellors and a psychosocial trainer sometime this year and it was good. We talked about our experiences, shared ideas and motivated each other away from our work environment" T4F4D

Integration is illustrated in terms of sharing information, recognizing the interrelatedness of tasks performed by different staff categories, collaborating efforts, and coming together for feedback and improvement of retention to HIV care and other activities.

"Teamwork from colleagues. If someone is good or knowledgeable, he/she must assist those that are struggling so that we can improve. We must be aware of each other's activities as LHWs so that we can understand how our work is interrelated and work effectively" T2F2A

"The integration is minimal yes, but we can still find a way to start collaborating as LHWs. We can approach the managers and suggest that we have our weekly or fortnightly feedback sessions so that we can improve our working relationship" T1F1A

"It is not only the tracers and CHWs who need to come together and integrate their activities, even the counsellors must be included. I am saying this because adherence counselling starts with the counsellors and continues throughout" T4F4D

"In terms of skills, I feel confident about them. I can communicate well with clients because I was once a counsellor. However, for my skills to be effective, we need to come up a strategy to reduce defaulter rate. A client must be given an appointment date and immediately be attached to the relevant CHW either physically or by being provided with phone numbers so that he or she can report any challenges. The CHW will then inform me and together we can come up with a way to assist the client to get treatment" T4F4B

7.4.6 Constructing additional case

An additional case can either be borderline or negative. A borderline case has some but not all attributes of a concept, whereas a negative case has none. Identifying these additional cases is important as they help to differentiate between the ideal and non-ideal situations of the concept of interest (Abdolrahimi *et al*., 2017:4971). Examples of negative cases will be provided and similar to the model case, quotations from the participants are used.

LHWs indicated **poor provision** of both instrumental and emotional support which **negatively affected responsiveness, integration, and reciprocity,** where some LHWs would refuse to carry out particular tasks due to being excluded from the communication and planning of HIV services. They were not well-informed about HIV treatment changes, while others were excluded from implementation when the index testing programme was started. Moreover, the supervisor from the developmental partner would visit the workplaces and communicate with their lay counsellors only, excluding those from the Department of Health. These actions made other LHWs to feel sad, lost and discriminated. Low salaries were also mentioned as an issue, except for developmental partner’s LHWs whose salaries were perceived as better by other participants.

“We do not get support in the sense that when treatment changes no one informs us, like when Dolly (Dolutegravir) came in, we were not informed. We have to gather the information ourselves. Sometimes you become exposed in front of a patient that you do not know the new treatment. I think they forget that we are the first face the clients encounter at the facility when they must be put on treatment, and even when on treatment, these clients still come back to us for more information because we explain things better. At times the nurses issue treatment without explaining thoroughly to the patient and this patient turns to me for explanation, at that time I do not have a clue of this new tablet. So, I think as new things are being introduced, they forget that we are also part of it and do not empower us” T1F1B

“It is the same as index, it is only now that they want us to do it. Sometimes I refuse and let the lay counsellors from the developmental partner continue with it, isn’t it that they started it without involving us? But again, the salary issue is adding to it, I would also like to earn a better salary and be like them, maybe I will be motivated” T3F3A

“For me I am used to the low salary, my main issue now is this discrimination. Why are we not treated the same? Why must I refer a client to another lay counsellor when I am also one?” T3F3C

“We really want to work and do the correct things, but we are sad. How can we work effectively when we are sad? It is not possible. Our supervisor also does not support us. The one from the developmental partner visits the clinic but mainly communicates with their lay counsellors. We feel lost, the problem is that when we started to work as lay counsellors, we were volunteering. Even now we are still treated as volunteers and volunteers do not have any form of support” T3F3A

Apart from limited collaborative efforts among the LHWs and the feeling of still being treated as volunteers, **lack of integration** with other health care workers is also illustrated. Participants revealed poor working relations characterized by lack of both communication and recognition of LHWs as part of the health care workforce. In turn, it may negatively affect the trusting relationship between the community members and the CHWs.

"Indeed, communication is a problem. Sometimes as a CHW, I refer a client to the facility and when the client gets to the facility, the staff informs her/him that they do not know me (other participants concurred). So how is the community going to trust us CHWs, if the clinic staff deny knowing us? We tell the community that we work for the Department of Health and indicate the name of the clinic, but the clinic staff say they do not know us. Do you think that when I go back to the same patient, he/she will believe me when I say I work at a particular clinic? No! We refer clients expecting to get a back-referral (feedback) so that I can get a copy and have evidence that I did my job, but this is not happening" T2F2D

LHWs felt pressurized and not appreciated despite their efforts. They are not given a chance to voice their challenges, instead they are blamed for not tracing the defaulters. As a result, their moods become negative as they become angry, discouraged, and demotivated to work since there is no benefit.

"It angers me because they expect miracles from us. And no matter how hard we work, no one appreciates or commends us for our hard work (Other participants agreed: yes). Instead, they keep on putting pressure on us, they complain and complain. And when they do this, we end up being demotivated and discouraged to work, what is the use of trying to do your best when no one notices or appreciates? A 'thank you' once in a while will do" T2F2A

The quotation below has aspects of both a borderline and a negative case. It shows that initially, LHWs had some support as they were able to meet with other staff members to voice their challenges without any fear of being oppressed. However, the situation changed when problems were no longer explored to understand the real causes, instead LHWs were blamed for poor retention of clients to HIV care.

“We used to have these meetings, but since 2020, everything changed. Every month we were given a chance to voice our challenges and the clinic staff would do the same. We were not oppressed, like now we are told that we are not tracing properly and the missed appointments are high. They blame us for these high missed appointments whereas they are the ones who do wrong things by not updating files after the clients’ visit to the clinic or obtaining traceable contact details. They point fingers at us, but the other fingers are pointing at them for not updating the files correctly” T2F2D

7.4.7 Identifying antecedents and consequences of the concept

Antecedents are incidents that must occur before the actual occurrence of the concept and are related to the context, while the consequences refer to results brought by the concept’s occurrence (Abdolrahimi *et al*., 2017:4969; Liu *et al*., 2016:88; Arabi *et* al., 2014:319).

Feeney *et al*., (2015:9) advised that social support should not only focus on assisting individuals during stressful situations but must be available even during non-adverse events to promote individual participation and growth; thus, providing meaning in human relations. The antecedents and consequences will therefore be discussed under two contexts: during adversity and non-adversity. Antecedents occur in both the support recipient, agent as well as the environment as created by the organization and supervisors.

During adversity, the support provided aims to reduce the effects of a stressful situation through putting it into perspective and redefining it in a way that helps the affected individual to endure and identify opportunities (Feeney *et al*., 2015:9). Furthermore, when there are no adverse events, support still needs to occur with the aim of creating opportunities for growth and maintaining positive human relations. Table 7.2 below outlines the antecedents and consequences of the support concept:

TABLE 7.2: ANTECEDENTS AND CONSEQUENCES OF SUPPORT

Context	Antecedents	Support functions	Consequences	Sources
During adversity	**Support recipient:** • Stressful situation leading to: ○ Inability to cope ○ Lack of motivation • Acknowledgement of a problem • Acceptance of assistance **Support agent:** • Willingness to support • Emotional stability • Safe venting space	• Stress buffering. • Reconstruct after stress.	• Positive coping mechanisms • Motivation to rebuild • Self-acceptance • Endurance • Sense of control • Psychological well-being	Feeney *et al*., (2015:9). Lakey *et al*., (2000:34). Maqsood, (2019:6). Jones *et al*., (2015:4). Agarwal *et al.,* (2020:62) Stoltz *et al.,* (2007:1484).
During non-adversity	**Recipient/ Agent** • Communication of needs • Positive mood • Emotional stability • Willingness to engage in a supportive relationship • Competence of the agent **Environment** • Resources, e.g., HIV test kits, teaching/ counselling aids • Adequate workspace • Peaceful climate	• Provide opportunities for growth • Create and maintain meaningful relations	• Thriving • Self-worth • Motivation • Competence • Self-reliance • Job satisfaction • Commitment • Trust • Respect • Work-family enrichment • Positive relations • Improved patient care, including retention • Providers' feeling of accomplishment	Kayed *et al*., (2021:439). Tufail *et al*., (2016:1219). Lundqvist *et al*., (2018:18). Pelin *et al*., (2021:83). Caesens *et al.,* (2020:2). Morelli *et al.,* (2015:12). Nguyen *et al.,* (2020:18).

The examples of antecedents and consequences are evident from the quotation of a study participant below, indicating willingness to engage in a supportive relationship between the LHW and a nurse mentor, the communication of needs and the provision of relevant assistance, as well as the consequences on the LHW, namely, job satisfaction, motivation, and competence:

"To be honest, I receive good support from the clinical nurse mentor. She ***is helpful*** *and* ***explains things that I do not understand****. Even though I am not clinical, she is* ***able explain*** *in a manner that I understand. I am really* ***happy*** *with her support and when I go to work in the morning****, I am motivated*** *and look forward to it. So, I am* ***capable of doing my work****, through her consistent support" T3F3E*

7.4.8 Defining empirical referents of the concept

Empirical referents are the measures of an abstract concept; and their presence suggests that the concept is occurring or has occurred (Abdolrahimi *et al*., 2017:4971; Liu *et al*., 2016:88; Arabi *et al*., 2014:320). Support is an interpersonal process; however, its measurement seems to be mostly intrapersonal where individuals are asked to provide subjective experiences or perceptions (Feeney *et al.,* 2015:28). Several instruments have been developed; however, this study discusses measures as guided by a multidimensional scale known as the Comprehensive Evaluation of Social Support (CESS) (Boyar *et al*., 2014:918).

According to Boyar *et al*., (2014:901) the CESS tool has 52 items that measure emotional and instrumental types of support from organizations, supervisors, co-workers, and family, as well as across domains such as the organization's, supervisors', and co-workers' support for employees' family-related aspects on a 5-point Likert scale ranging from strongly disagree to strongly agree. Furthermore, these domains are distinctly outlined, which helps organizations to diagnose potential support-related challenges per source and type, and then design appropriate interventions (Boyar *et al*., 2014:901). Also, the tool can be adapted to include items that are applicable to a particular context such as the workplace.

As a result, CESS tool was found to be in line with this study which sought to understand the supervisors', co-workers' and Department of Health's support as described by the LHWs. Extracts of support measures from the CESS tool (Boyar *et al*., 2014:918) are summarized under the three sources of support, that is, the supervisor, co-worker, and organization, while also attempting to identify the four attributes of support that were discussed in 7.4.4 above as responsiveness, provision (of emotional and instrumental support), reciprocity and integration.

- Supervisor's support measures

In terms of work-related support, examples of measures include:
"I can depend on my supervisor for help on the job"- **Emotional, responsiveness**
"*My supervisor is understanding or sympathetic on the job"*- **Emotional, responsiveness**

“My supervisor reduces my workload when it is too much”- **Instrumental, responsiveness, reciprocity**

“When my workload is heavy, my supervisor will assign extra help”- **Instrumental, responsiveness, reciprocity, integration**

The following items relate to support from the supervisor that considers family-related aspects:
“My supervisor is understanding of my family situation”- **Emotional, responsiveness**

“My supervisor is understanding of my family responsibilities”- **Emotional, responsiveness**

“My supervisor lets me leave work early to accommodate family responsibilities”- **Instrumental, reciprocity, responsiveness**

“My supervisor lets me adjust my schedule to accommodate my family responsibilities”- **Instrumental, reciprocity, responsiveness**

The study participants did not mention the supervisors’ support for their families; however, they focused on work-related aspects. While other LHWs cited the availability of nurses to assist them with patient care, some felt that they were overburdened with work, with those working in the communities citing that they carried out difficult tasks on their own and could not respond to the community’s needs at times. The findings indicate the need to measure the support received by LHWs, encourage them to verbalize challenges or needs and initiate custom-made interventions.

- Co-workers’ support measures

In terms of work-related support, examples of co-workers’ measures include:

“My co-workers listen to my work-related problems”- **Emotional, responsiveness**
“*My co-workers help me to figure out how to solve work problems*”- **Emotional/instrumental, responsiveness, reciprocity**

“*If I get behind on my work, my co-workers will help me out”*- **Instrumental, responsiveness, integration, reciprocity**

“*When my workload is heavy, my co-workers will help”*- **Instrumental, responsiveness, reciprocity, integration**

Examples of co-workers’ support for family measures include:
“My co-workers are understanding of my family responsibilities”- **Emotional, responsiveness**

“My co-workers provide a family-friendly work environment”- **Emotional, responsiveness**

“My co-workers will switch schedules to accommodate my family responsibilities”- **Instrumental, responsiveness, integration, reciprocity**

“My co-workers will volunteer to pick up the slack if I have to attend to family needs”- **Instrumental, responsiveness, reciprocity, integration**

The study participants revealed that they sometimes helped each other in counselling difficult clients or couples for HIV, but there was no collaboration among different categories of LHWs such as the lay counsellors, tracers, CHWs, health promoters, etc. Again, the LHWs indicated that there was no support from other facility workers such as administrative clerks who would capture incomplete contact details of clients on ART, making it difficult to trace if a need arises. There was also no constructive feedback which allowed for identification of gaps across all categories of staff, instead, the LHWs were blamed for poor performance and high ART missed appointments. Once again, assessing the support would guide efforts to improve interpersonal working relations. Although the LHWs in the study did not mention family-related support, it may be necessary to consider it when assessing support.

- Organization’s support measures

Examples of the organization’s work-related support measures include:

“My organization strongly considers my goals and values”- **Emotional, responsiveness**

“My organization cares about my opinions”- **Emotional, responsiveness, reciprocity**

“In general, organizational policies are fair”- **Instrumental**

“My organization provides the tools necessary for doing my job”- **Instrumental, responsiveness, reciprocity**

In terms of family support by the organization, support measures examples include**:**
“My organization understands that I have a life outside of work”- **Emotional, responsiveness**

“Help is available from my organization when I have a family problem”- **Emotional, responsiveness**

“My organization lets me leave work early to accommodate family responsibilities”- **Instrumental, responsive, reciprocity**

“The organization’s attendance policy allows me to accommodate family needs”- **Instrumental, responsive, reciprocity**

The study participants said that they had working materials, though fairness in distribution especially among lay counsellors was questionable as patient educational aids were given to developmental partner’s counsellors only. Moreover, other concerns raised by the LHWs were about lack of transport for outreach services at distant areas, debriefing, training as well as low salaries and no funeral assistance.

The organization’s support is the only source of support that had family-related aspects highlighted by the study participants, that is, low salaries/stipend and no assistance with the funeral should the LHW pass on. Some participants further indicated that the family would struggle alone in times of bereavement, while others were worried about being treated as volunteers even after many years of serving the Department of Health. Again, LHWs who were receiving social support grants that assisted them to take their children to school had been stopped because they were regarded as government employees.

7.5 CONCLUSION

The aim of this concept analysis was to explore the attributes and dimensions of support to clarify its meaning and understand its use, which would in turn establish common understanding of LHWs' support within the health care contexts and possibly guide the HIV management and retention activities amidst task shifting towards the LHWs. In addition to the *concept selection and aim*, the analysis also provided the following: *the uses of support*; *attributes*; *model cases; additional cases; antecedents and consequences;* as well as *empirical referents.*

The analysis was applied to the support concept as described mainly by the LHWs who participated in the study that aimed to develop an integrated support model for LHWs to improve retention to HIV care. Literature review was conducted to obtain the relevant information and thereafter, the researcher came up with the following conceptual definition:

"Support is a context-based reciprocal process from different actors, characterized by expressive and instrumental actions provided either during times of adversity to promote endurance, or as a routine in the absence of adversity to create opportunities for growth and maintain positive human relations."

Lastly, the researcher acknowledges that other articles that discuss support were not reached. However, the literature review from CINAHL and Google Scholar considered a random selection of both older (published more than 10 years ago) and newer sources to obtain the concept's evolution, as well as data saturation where new or unique aspects were no longer emerging.

CHAPTER 8

LAY HEALTH CARE WORKERS' SUPPORT MODEL DEVELOPMENT

8.1 INTRODUCTION

HIV infections in South Africa accounted for nearly 20% of the global prevalence, which made it a hyperendemic country that requires urgent response (Allinder, 2020:1). Furthermore, the magnitude of the HIV burden was exacerbated by continuing new infections, challenges in treatment initiation and retention to care, as well as low viral suppression and sustainability. According to the UNAIDS, PLWHIV were lost between diagnosis and treatment initiation, as well as between treatment initiation and continued care (UNAIDS, 2019:20).

Osler *et al*., (2018: 122) and Johnson *et al., (2017:5)* emphasized that the focus should be on adherence and retention to HIV care strategies, as well as sustained drug availability to improve ART initiation and continuation, thereby achieving viral suppression and reducing new HIV infections. As HIV care occurs along a continuum, the integration of activities and guidance of different lay and professional health care workers are crucial to successfully achieve the outcomes (UNAIDS, 2019:20). Hodgins *et al*., (2016:5) further alluded that the LHWs needed more support as they have little formal training as compared to health care professionals.

The researcher observed that previous studies focused largely on the experiences and roles of lay counsellors and CHWs as well as the HIV testing procedures, excluding other categories of LHWs such as tracers and health promoters. Moreover, LHWs had different experiences of support, varying from none to adequate, and the CHW outreach programmes were poorly integrated into the health facilities' processes (Letsoalo *et al*., 2017:35; Mundeva *et al*., 2018:1; Assegaai *et al*., 2022:36).

So, the problem identified was that the researcher did not find a support model that considered different categories of LHWs as they work along the HIV care continuum to promote retention to HIV care and other outcomes.

The study was therefore conducted with the aim of developing an integrated support model for LHWs to improve patients' retention to HIV care. The objectives of the study were to:

- Describe how the lay health care workers interact with PLWHIV.
- Describe the views of health care professionals on the support provided to lay health care workers in carrying out their duties relating to PLWHIV.
- Explore and describe how PLWHIV experience their interaction with lay health care workers.
- Develop the integrated support model for lay health care workers to improve patients' retention to HIV care.

This chapter explains the milestones that were undertaken by the researcher to reach the above-stated study aim of the support model development.

8.2 METHODOLOGY OF THE SUPPORT MODEL DEVELOPMENT

The study commenced after obtaining ethical clearance from the College of Human Sciences Research Ethics Committee of the University of South Africa, with reference number 44434960_CREC_CHS_2021, in annexure A; and permission from different governance levels of the Department of Health, as shown in annexures B and C. It was conducted in two phases: the empirical and model development.

8.2.1 Empirical phase

The study followed an exploratory, descriptive, and contextual research design to understand HIV care and retention experiences of LHWs, LHWs' supervisors, nurses and PLWHIV, as they occur in their natural setting. As a result, the study participants included three groups: 1) different categories of LHWs such as lay counsellors, CHWs, tracers, health promoters; 2) their supervisors and nurses; 3) and clients on ART at a health centre situated in Rustenburg sub district, Bojanala district, South Africa. Following the recruitment of participants, written consent to participate was obtained, and data collection started. In-depth individual interviews were conducted with LHWs' supervisors, nurses, and clients on ART while the focus group discussions were conducted with LHWs. The study methodology was discussed in detail in chapter 3.

Data analysis started with transcribing data obtained from the participants and then analysing through thematic analysis. Clients on ART had good experiences with LHWs but cited multiple health facility-related challenges that affected their retention to HIV care, such as lost medical records, negative staff attitude, inflexible appointment dates, and inadequate information. The LHWs' supervisors and nurses acknowledged the important roles played by the LHWs but also cited challenges around the support provided to LHWs which may affect their correct implementation of HIV management guidelines.

Similarly, LHWs had different experiences of support, with others feeling supported and others not. Those who felt unsupported cited lack of appreciation, recognition, collaboration, educational aids, transport; as well as low stipends and other benefits such as funeral assistance. Detailed findings of the study were presented in chapter 4 (LHWs), chapter 5 (LHWs' supervisors and nurses) and chapter 6 (clients on ART).

8.2.2 Model development phase

The model was developed using literature and the study findings, and was guided by the four steps of theory development, namely, *concept analysis and classification*, *constructing relationship statements*, *description,* and *critical reflection of the model,* as proposed by Chinn and Kramer (2011:164). The first step of concept analysis followed the eight processes of Walker and Avant (Abdolrahimi *et al*., 2017:4969; Liu *et al*., 2016:85), and was fully discussed in chapter 7. "Support" was chosen as a main concept and then analysed to clarify meaning through defining its use and exploring the attributes, dimensions, and related concepts, which would in turn establish common understanding of LHWs' support within the health care contexts and possibly guide the HIV management and retention activities amidst task shifting towards the LHWs. The remaining steps of the model development are discussed fully in the results section below.

8.3 RESULTS: SUPPORT MODEL DEVELOPMENT

8.3.1 Classification of concepts

The classification of concepts related to support was guided by the Dickoff survey list (Dickoff *et al*., 1968:423; Dube & Rakhudu 2021:3; Towell *et al*., 2015:3). The survey list has six items: the context, agent, recipient, dynamics, procedure and terminus or outcome.

8.3.1.1 Context

The context refers to the environment in which the activity is carried out. The study included the LHWs working in a primary health care facility and households in the community. However, the LHWs work in multiple settings to provide HIV care: there are *lay counsellors* who provide testing and counselling on HIV and adherence in private and government **hospitals**, **primary health care facilities**, **non-governmental organizations, mobile clinics** as well as **community sites** and **households** during outreach campaigns; *community health care workers* linked to the health care facilities, who conduct household registrations, tracing of defaulters and provide HIV education and care in the community; *tracers* who trace clients who defaulted ART telephonically; *health promoters* and *mother-mentors* who provide health talks in the health care facilities and encourage the general population and pregnant women to test for HIV and remain in care.

The success of the HIV programme and retention depends on the clients' access to services along the HIV care continuum; and the above-stated roles of the LHWs are an inherent part of the HIV care continuum (Hall *et al*., 2017:2). Moreover, if clients are well-managed and retained to HIV care, morbidity and mortality will be reduced as the virus becomes suppressed. Hodgins *et al*., (2016:5) emphasized that the LHWs' support was crucial because they had little formal training as compared to health care professionals. Furthermore, Bemelmans *et al*., (2016:3) revealed that the work of the lay counsellors was not regulated by any professional body, except in Zambia, where the counsellors' council has been established and psychosocial counsellors are recognized as formal health care workers.

Sam-Agudu *et al*., (2018:9) also emphasized the importance of support by stating that the integration and recognition of LHWs were vital to optimise the impact of their roles in health care, while Engelbrecht *et al*., (2017:6) recommended continuous training, support, collaboration, and linkage of home-based carers to health care facilities. Although the work of the LHWs is not yet formally regulated, their HIV care and retention activities are governed by the National Consolidated HIV guidelines (SANDoH, 2020a) and the National Adherence guidelines for HIV, TB, and Non-Communicable diseases (SANDoH, 2020b), while the Policy Framework and Strategy for Ward-based Primary Healthcare Outreach Teams (SANDoH, 2018) provide additional guidance to the CHWs and their supervisors.

Different health care facilities are summarized below:

8.3.1.1.1 Hospitals

Hospitals have multiple wards where clients are treated as in- or out- patients (Now health International, 2022:1). Examples include adult medical, orthopaedic, and surgical wards, maternity, and paediatric units, where clients are admitted for one or more days, and the outpatient departments where clients visit for follow up or specialized services such as eye and dental care, then go back home on the same day, and casualty units. There are lay counsellors placed in most of these units to counsel and test clients for HIV. HIV positive clients are then linked or referred to either the nurse or doctor depending on the procedures of individual hospitals; thereafter, clients can be referred to primary health care centres for continuation of ART, except when it is not feasible.

It is important for clients in the hospital setting to be tested for HIV so that appropriate care can be provided to them, thereby reducing morbidity and mortality, and improving the quality of life; and LHWs placed in this context need support as well, in order to provide effective counselling and testing (Hall *et al*, 2017:2).

8.3.1.1.2 Primary health care facilities

Primary health care facilities refer to 8-, 12- and 24-hour clinics and health centres that provide care on an out-patient basis; however, 24-hour centres can observe clients overnight (Seladi-Schulman, 2020:1). In these facilities, there are adults who consult for acute, chronic, preventive, reproductive or maternity care as well as children who consult for illness or immunization. The mentioned categories need to be counselled, tested, and treated if HIV positive, then retained in care to prevent new infections to partners and children and reduce HIV-related morbidity and mortality (Hall *et al*, 2017:2).

Most HIV care services are rendered in these facilities since there are lay counsellors who provide counselling and testing; tracers who trace clients who defaulted ART; CHWs who conduct home visits, tracing, pre-packed medication delivery and household registrations; as well as health promoters and mother-mentors who provide health education to clients. The study was conducted in this setting, in a 24-hour health centre as it has many categories of LHWs.

8.3.1.1.3 Non-governmental organizations

The expansion of health care services to improve access has led to an increase in the number of organizations offering health care services. (Zihindula *et al*., 2019:15). These organizations include home-based or community-based organizations that provide rehabilitation and chronic care, preventive, and health promotion services to in- or out-patients, as well as developmental partners who also provide prevention, promotion, chronic care services and research. Clients in these settings also require to be tested for HIV, put on treatment, and retained in care if HIV positive. LHWs in these organizations include lay counsellors, retention or linkage officers and community or home-based carers, and require support to carry out their duties effectively.

8.3.1.1.4 Mobile clinics

Mobile clinics are similar to primary health care clinics but provide limited community outreach services because they are not fixed at one point and are linked to specific health centres. Seladi-Schulman, (2020:1) defines a mobile clinic as a customized vehicle that goes to different sites to provide medical services to communities with health access barriers. Services provided may include acute and chronic care as well as preventive services such as immunizations or reproductive health. Lay counsellors provide counselling and testing, while CHWs mobilize the community; so, they also require support.

8.3.1.1.5 Community sites and households

Community sites refer to spaces in the community areas that are occupied with gazebos or mobile vehicles by lay counsellors and linkage officers during campaigns or outreach HIV testing services; therefore, the LHWs offer the same services as those working in the mobile clinics. Households are the homes where the CHWs visit to trace ART and TB clients who defaulted treatment; and carry out registrations where families are profiled, educated, treated or referred for appropriate care at health facilities (SANDoH, 2018, 10). So, CHWs interact with all age groups, including antenatal and postnatal clients as well as their babies to provide health education, check the HIV status and encourage treatment continuation. The CHWs need both remote and on-site support especially because they are far from fixed heath facilities and are sometimes confronted with difficult client problems which they cannot handle.

The context is displayed in figure 8.1 below.

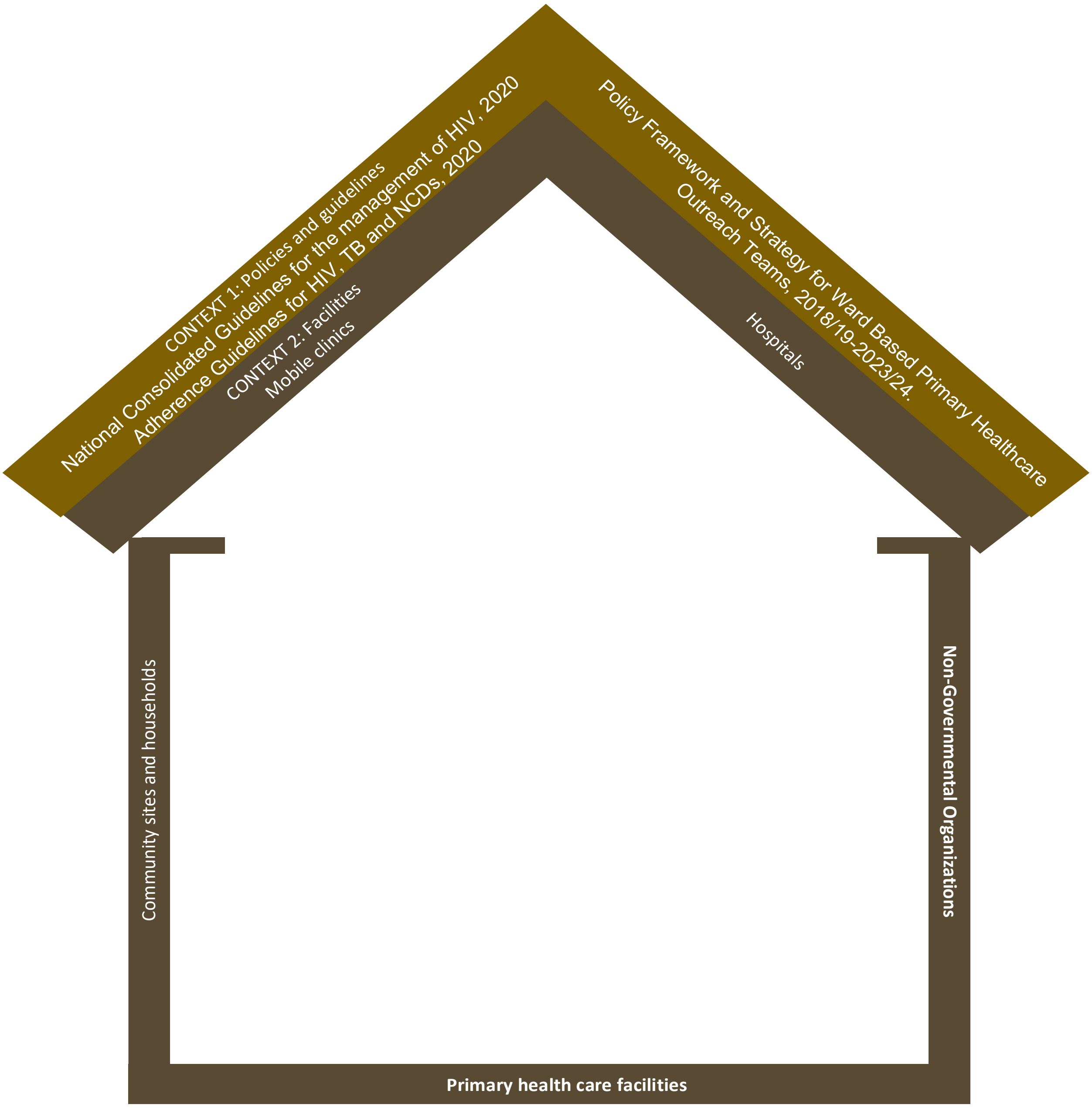


Figure 8.1: Context

8.3.1.2 Agent

The agent refers to a person or people responsible for carrying out a particular activity. In this study, the LHWs indicated the need to be supported by the co-workers but the support from the nurses, supervisors, and the Department of Health emerged as the most crucial. The agents therefore are the health care professionals, such as nurses, LHWs' supervisors, and the Department of Health. The nurses and LHWs' supervisors interact directly with the LHWs and must be competent, motivated, interested, receptive and emotionally stable to be able to provide emotional and instrumental support to the LHWs (Maqsood, 2019:2; Feeney *et al*., 2015:25).

Scott *et al*., (2018:10) further found that although educational materials, job aids and training contribute to effective work, they need to be followed by supportive supervision to facilitate the effectiveness of CHWs. The nurses and supervisors who participated in the study expressed their willingness to support the LHWs but regarded competing priorities and increased workload brought by COVID-19 activities as a hinderance.
The supportive actions by different agents may overlap and are outlined below:

- Nurses

Nurses need to provide the LHWs with updated HIV information and also mentor them according to the identified needs. Also, when the LHWs are struggling with certain patients, nurses need to assist and provide guidance. As lay counsellors provide Pre-ART counselling, they collaborate with nurses who will then initiate clients on ART afterwards. The CHWs must be able to refer clients from the community to the clinic for nurses to continue with the management and provide feedback to the CHWs as well. Quotations below present examples of support provided by the nurses who participated in the study:

"For retention, the counsellors link patients to treatment. But patients are different, there will be one who is not accepting his/her status so the counsellor will refer accordingly to the psychologist or professional nurse or the case facilitator" T8HP8

"In most cases when the CHWs bring patients back to the clinic, I avail myself to assist so that these patients do not wait for a long period of time or are moved up and down. Also, when CHWs are out in the field, they are able to call and discuss matters with me where necessary. I then assist them where I can, that is how I support them. When I identify that they lack knowledge, I train them or arrange with the relevant personnel to train them" T3HP3

- LHWs' supervisors/managers

The supervisors need to identify the needs of the LHWs and address them appropriately. New LHWs must be orientated and trained on their roles, while the existing ones need to receive refresher courses which include the updated HIV information. The working materials such as HIV test kits, reference tools, client educational aids, national guidelines and other relevant resources need to be provided to LHWs; however, availability depends on the Department of Health as well. The provision of resources needs to be accompanied by supervision and assessment of the correct use, e.g., in the current study, the incorrect and inconsistent use of HIV and adherence guidelines were identified. Again, supervisors can arrange debriefing for LHWs to prevent burnout.

Quotations below are from the LHWs' supervisors:

"I oversee the work of lay counsellors, identify the need for training and arrange accordingly. I also review their performance in line with the set targets and provide the necessary working material. I conduct performance monitoring, so when a lay counsellor does not perform well, I communicate with him/her to understand the challenges. I also observe her work closely then after understanding the gaps, I recommend in-service training or refresher course. I also provide mentoring while the counselling is in progress" T7HP7

"We empower them in terms of giving them the updates because we all have to follow the updated adherence guidelines, consolidated HIV guidelines and other available standard procedures. So, the lay health care workers must continuously be updated on the latest developments, they don't have to work with old information" T10HP10

"And then emotionally, we need to check their well-being. As much as we health professionals can communicate that we are emotionally drained, we need to include the LHW in our debriefing activities" T3HP3

- The Department of Health

Provision of working material is the responsibility of both the supervisors and the Department of Health. The supervisors are responsible for ordering material needed and distributing to the LHWs after receiving them; however, the budget, which is beyond the supervisors' control, needs to be available for the resources to be procured. Also, the LHWs need improved work benefits such as transport, better stipends, and overtime incentives to motivate them. They also work for few hours per day due to their contracts and there is a lot of work, so human resource shortage needs to be addressed so that tasks can be balanced. Quotations below are from the LHWs' supervisors:

"I think if there can be delegation, e.g., if there are several counsellors, they can take turns to complete other tasks. But it's also a human resource issue, they need to increase staff, there is no other way" T5HP5

"I think their stipend must be increased; they are doing a good job. And occasionally, let them be transported, especially those who visit hard-to-reach areas, those working locally are okay. And then I wish that in their contract, they can have overtime allowance, for example, if a patient can only be found on Saturday, the CHW can go there on that day and be paid for overtime. Like our TB clients, we must from time-to-time check and support them. So even if the CHWs work on Saturday, they do not receive any incentive, and this demotivates them. If they are motivated, they will do their work whole heartedly and be flexible" T9HP9

The relationship between the agent and recipient is posted in figure 8.2.

8.3.1.3 Recipient

The recipient refers to a person or people who will benefit from receiving a particular service. The different categories of LHWs are the recipients of the support that will help them to improve the retention of patients to HIV care. Although support is provided by the agents, it is a two-way process that requires active participation of the recipient as well. The recipient must acknowledge and indicate the need for support and be interested and emotionally stable (Kayed *et al*., 2021:440). The LHWs who participated in the study expressed their need for support as follows:

- Fairness in the distribution of working materials and information

LHWs indicated that working materials, including the patient educational aids, will assist them to offer health education on viral load. The working materials were provided but not as the LHWs wished because lay counsellors from the developmental partner would receive patient educational material for viral load, except those employed by the Department of Health, leading to feelings of discrimination, and the offering of different education to patients. Furthermore, the lay counsellors wished to be involved in new programmes and receive information from the beginning, not when the programmes have long been implemented. Quotations below represent the LHWs' needs:

"On the other hand, supervisors are good at providing working material, yes, they are trying their best in this regard" T1F1B

"Yes, it is true. For example, lay counsellors from the developmental partner were given these small bags with bottles inside and these bottles will help them to teach clients about the viral load. Their supervisor came to orientate them on these bottles, but he stated that the bags are for their lay counsellors only not us. It just happened that I got into the room that they were in, otherwise I wouldn't have known about this" T3F3B

"Exactly, so do you expect us to be involved? It means when I get an HIV positive client, I must send her/him to the lay counsellors from the developmental partner for viral load education, it is their work. It means we do not have any important role to play there but next time we will be told to take over. How do we take over when we were initially discriminated? The index and HIV self-screening programmes started just like that, they were for the lay counsellors from the developmental partner and now we are told to implement them. We are just doing a favour when we conduct HIV self-screening. Everything is about the developmental partner. They were also taught about the new medication" T3F3A

- Training on relevant skills and updated information on HIV

LHWs expressed the need to continuously receive communication and information on updated HIV management so that they are able to offer correct information to clients. They also indicated a need to be trained on mental health issues and couple counselling to assist in non-disclosure challenges.

"We, in fact, I feel that if there is something new, they must engage us. Like you see the new drug, Dolly-Dolly and the previous one - FDC (Fixed Dose Combination), I for one do not know which patients receive what. So, it is difficult to explain the 2 options to patients because I do not understand this new one. If there is something new, they must tell us whether a particular treatment is for pregnant women only and so forth. They are not sharing information enough" T1F1D

"I need a refresher training on adherence counselling because I was trained long time ago when I was a counsellor at another province, that is why I do not even know the adherence tools used. In service training must be a continuous thing and not done once. Other HIV-related topics must also be discussed so that we can gain the necessary skills and have the updated information. I also agree with my colleague that counsellors are the only ones trained on the updated adherence counselling, but we also interact with clients during tracing; therefore, adherence counselling skills are much needed" T4F4C

"I am not trained to pick up warning signs of mental health issues. And like my colleague said, I never thought it is important. And yes, we see challenging situations at the households, but I normally inform the clinical mentor if I see a client who cannot walk or a client who has social problems. Nothing around mental health issues but I would really love to be trained if there is such a training as this will improve my skills. I am very happy about this interview, sometimes we just wish to have someone who can just listen to us narrating our field work. Otherwise, we just bottle our feelings inside which is not right" T4F4A

"But going back to the non-disclosure issue, it is a challenge, and it is difficult for me as well. It is not safe for us because sometimes the couple starts to argue. We just don't know how to deal with non-disclosure among couples" T3F3C

- Mentoring and supervision on patient care

LHWs stated that they felt alone at the field and indicated a need for on-site mentoring and supervision, as per quotations below:

"You know with the previous OTLs, they would accompany us to the households, or we would call them when we have challenges. They would teach us and even show us how to check infants. So, it means these activities stopped when they left, then we remained with just 1 OTL and there was no way that she could supervise all of us" T2F2D

"But I still have hope that when everything settles the supervision will improve and there will be time for us to be mentored at the households or at the clinic" T2F2F

- Allocation and balancing of activities

LHWs felt that more tasks which were not even within their activities' plan, such as COVID-19 tasks, were allocated without creating a balance to also allow LHWs to perform their main tasks. As a result, they were concerned that their main activities such as tracing, were neglected, and that the LHWs would forget how to perform their duties. Other participants gave an example of the lay counsellors' daily HIV testing targets which have been increased, resulting in them striving to mainly reach these targets, while losing focus for other tasks.

"They need to balance the activities; the other half can focus on COVID-19 while others continue with the CHWs' activities, and we can rotate monthly. Sometimes I promise the client that I'll bring his/her medication, then I am allocated to do something else. It means I am failing the client because now he/she will be on the missed appointment list. We cannot all focus on COVID-19 activities and abandon other duties, otherwise we will have problems of other areas not performing well" T2F2A

"Yes, we are no longer doing our CHWs' activities. We will end up forgetting how the activities are done. So, after COVID-19 becomes controlled, all other activities will be far behind and it will be a struggle to catch up" T2F2E

"It is true, I support what the colleagues are saying. And to add, from time to time we are allocated other tasks in the clinic and our tracing work is left behind. Then when they are being flagged by the higher authorities for high numbers of missed appointments or defaulters, they blame us for not tracing accordingly whereas they are the ones who gave us other tasks" T2F2F

"The other challenge is our daily HIV testing target. It used to be 8 but now it is 12 and we work for 6 hours due to our contract (other counsellors concurred). So, we end up striving to reach the target before we knock off, at the same time losing focus on other tasks" T1F1C

"If our targets can be reduced and more lay counsellors appointed, we can focus on quality not quantity. I really would not mind to physically follow up my clients if I cannot find them telephonically" T1F1B

- Debriefing and discussion of challenges

LHWs feel burdened as they provide psychosocial support to HIV diagnosed patients; therefore, they require debriefing, discussion of their challenges and assistance with problem solving. Quotations from LHWs are posted below:

“We are not debriefed regularly. The last time I was debriefed was in 2020 after demanding it. In most cases, tracers are not included in debriefing activities, only counsellors are” T4F4A

“True, even the CHWs are not debriefed routinely. And actually, we do not require a big thing, if we can just meet as colleagues, have a professional person, and then talk about our work and how to cope, it will be good” T4F4E

“This is where the problem is. There is no time for meetings in our facility. I believe that we must have monthly meetings with the managers to discuss our challenges, but this is not happening because they are always busy. And I believe that they must make time for us because we have challenges, we are burdened. And how will I do my work effectively when I feel burdened? No, I will not be effective. It is clear that if I am not happy, there will not be production” T2F2C

- Communication and collaboration

The LHWs indicated a need to improve their communication and working relationship with the clinic staff which are essential not only for patient care but also to improve clients’ trust in LHWs. Correct documentation of clients’ details and clinic visits, as well as proper file management would also contribute to the LHWs’ retention efforts. These needs are expressed by the quotations below:

“Indeed, communication is a problem. Sometimes as a CHW I refer a client to the facility and when the client gets to the facility, the staff informs her/him that they do not know me (other participants concurred). So how is the community going to trust us, CHWs, if the clinic staff deny knowing us? We tell the community that we work for the Department of Health and indicate the name of the clinic, but the clinic staff say they do not know us. Do you think that when I go back to the same patient, he/she will believe me when I say I work at the particular clinic? No! We refer clients expecting to get a back-referral

(feedback) so that I can get a copy and have evidence that I did my job, but this is not happening" T2F2D

"I have also realized that sometimes nurses do not document on the file that remains in the clinic, especially at maternity or child welfare sections and it appears as if a client defaulted. As a result, some clients become angry when I trace them because they did not actually default, one client threatened to even sue me. But then again if the contact numbers are wrong, I won't be able to call the client and correct this error" T4F4C

"File flow is indeed a challenge. Filing needs to be improved so that file loss can be minimised. Sometimes clients wait for a long time because the files are not found, and this leads to frustration. Duplicates are then created and sometimes the information is not captured on the system or nurses do not document on the files accordingly. I think that when a file is lost, there must a register of some kind to document the clients' names, file number and return dates and then we can continue to look for a file after helping the client. We agreed on this previously, but it never materialised" T4F4E

- Better work contracts and recognition

LHWs wished that their stipends would be increased, and titles changed from lay to professional counsellors considering the amount of work that they do. These are some of their quotations:

"The salary issue is a sad one, but I still treat my patients well. We have been working for a long time but there is nothing to show for it. If I happen to die, my family is the one that will make arrangements for me to get home (mentioned the place ± 100km away). There won't be any cent from my workplace, my kids will not get anything. Yes, I continue to help patients but I am sad" T3F3B

*"I remember that we were on go-slow the last time and we were hopeful that our issue (*salary*) will be resolved. Now the people who were helping us are driving nice cars, have forgotten about us and are no longer saying anything on the media. Who will ever help us? Since January, now we are heading to December, it is the same story throughout, our matter is forever being postponed" T3F3C*

"We really want to work and do the correct things, but we are sad. How can we work effectively when we are sad? It is not possible. Our supervisor also does not support us. We feel lost, the problem is that when we started to work as lay counsellors we were volunteering. Even now we are still treated as volunteers and volunteers do not have any form of support" T3F3A

"We are doing a good job and have been working for a long time, I just wish our title can be changed from lay to professional counsellors (laughter from participants)" T3F3A

Figure 8.2 below represents the relationship between the recipients and the agents.

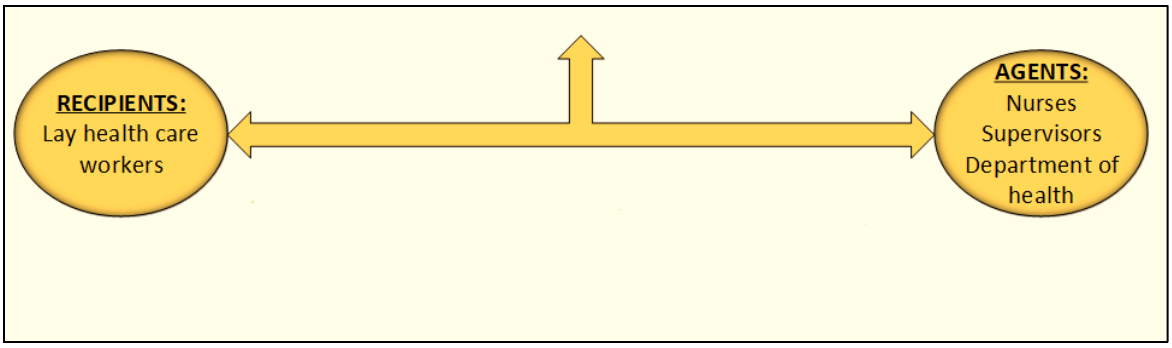


Figure 8.2: Reciprocity between the agents and recipients

8.3.1.4 Dynamics

The dynamics are the driving forces of the activity. Support is an interpersonal activity that requires **positive relationships**, **communication**, **willingness,** and **emotional stability** from both the agent and recipient (Pelin *et al*., 2021:81; Feeney *et al.,* 2015:28). These drivers foster trust, appreciation, respect as well as collaboration and free participation of employees, thereby facilitating the support. On the other hand, the LHWs experienced challenges that demotivate them to work optimally and negatively affect retention to HIV care. These challenges include **power imbalances** and **low self-esteem** of LHWs, stemming from the superiority of supervisors versus lower positions of LHWs as well as no formal recognition of LHWs, which then impact negatively on communication; **lack of respect** and **trust** which hinder positive relations and work collaboration. Quotations below reflect these challenges:

"*It angers me because they expect miracles from us. And no matter how hard we work, no one appreciates or commends us for our hard work (Other participants agreed: yes). Instead, they keep on putting pressure on us, they complain and complain. And when* *they do this, we end up being demotivated and discouraged to work, what is the use of trying to do your best when no one notices or appreciates? A 'thank you' once in a while will do" T2F2A*

"We used to have these meetings, but since 2020, everything changed. Every month we were given a chance to voice our challenges and the clinic staff would do the same. We were not oppressed, like now we are told that we are not tracing properly and the missed appointments are high. They blame us for these high missed appointments whereas they are the ones who do wrong things by not updating files after the clients' visit to the clinic or obtaining traceable contact details. They point fingers at us, but the other fingers are pointing at them for not updating the files correctly" T2F2D

The above-identified challenges need to be carefully considered and addressed, and sometimes addressing one of them improves the others as well, as discussed below:

8.3.1.4.1 Power imbalance

LHWs occupy low positions as compared to other health care workers; therefore, the power imbalances may occur and they become scared to speak up or voice their opinions. The facility managers and supervisors need to address this challenge in order for support activities to be successful. Joseph-Williams *et al.,* (2014:2) stated that the managers need to firstly, be aware of the disadvantages of power imbalances, and specifically mentioned poor task sharing. Thereafter, the culture in the facility needs to be changed through educating all staff about the importance of task sharing and showing the importance of everyone in the HIV care continuum and other health services.

LHWs also need to be assured of a safe environment for them to participate actively and provide suggestions. When the primary health care services were reengineered, the LHWs, especially the CHWs, started working closer to the community than facility-based staff, so they understand the needs of the communities better and can provide valuable practical inputs (NDoH, 2018:10; Scott *et al*., 2018:11).

8.3.1.4.2 Low self esteem

Self-esteem relates to the personal judgement of worthiness and the confidence in the ability to think and cope with challenges (Branden, 2021:8). Furthermore, the environment where individuals are humiliated, regarded as less important or are not accepted, can serve as an obstacle to self-esteem development and maintenance. In this study, LHWs felt unappreciated and blamed for poor performance, which demotivated and discouraged them to work.

Branden (2021:10) further mentioned that high self-esteem helps an individual to form therapeutic relationships and also strive during adversities. The interventions to improve self-esteem are similar to those mentioned under the power imbalances above. LHWs' supervisors and managers need to emphasize the importance of LHWs to them and to the facility staff members as well. They need to encourage acceptance of LHWs as an inherent part of the health workforce that play a crucial role in HIV management.

8.3.1.4.3 Lack of respect

Respect is a two-way interpersonal process that refers to the worth accorded to an individual by others (Rogers & Ashforth, 2017:7). Furthermore, respect leads to improvement of self-related outcomes such as self-esteem and a sense of belonging, which then facilitates individual and group performance. The LHWs in the study felt unappreciated and oppressed by the health care professionals who could not listen to their views and challenges but rather, labelled them as not performing optimally.

Managers can encourage respect by treating all employees fairly, expressing sympathy and support according to the individual's needs, as well as valuing contributions from all employees irrespective of their positions (Rudolph *et al*., 2021:3; Rodgers *et al*., 2017:7). Also, respect is one of the values in most organizations, so managers need to constantly remind employees about such values and also lead by example.

8.3.1.4.4 Lack of trust

Trust is a psychological phenomenon that develops over time when an individual or team members perceive that the future behaviours from others will be desirable (Costa *et al*., 2018:11). Also, trust is influenced by the context and reciprocity among team members or individuals, and if it is lacking, employees reserve their valuable inputs which then impacts negatively on teamwork. Retention to HIV care is an interrelated activity, so if there is no teamwork, it will be poor. In the current study, one nurse mentioned her lack of trust towards the CHWs because they did not seem to know their clients as much as the lay counsellors do; so, she could support the CHWs by outlining the expectations and discussing the impact of their actions. Therefore, managers can facilitate trust by keeping their promises, encouraging the sharing of common information and tasks among all staff, as well as involving employees in decisions that affect the facilities' performance.

Afsar and Masood (2018:21) further explained that trust can be built by transformational leaders who are approachable, create safe environments, consider employees as unique individuals and allow them to be innovative and take risks without fear, thereby improving their performance.

Figure 8.3 below illustrates the dynamics.

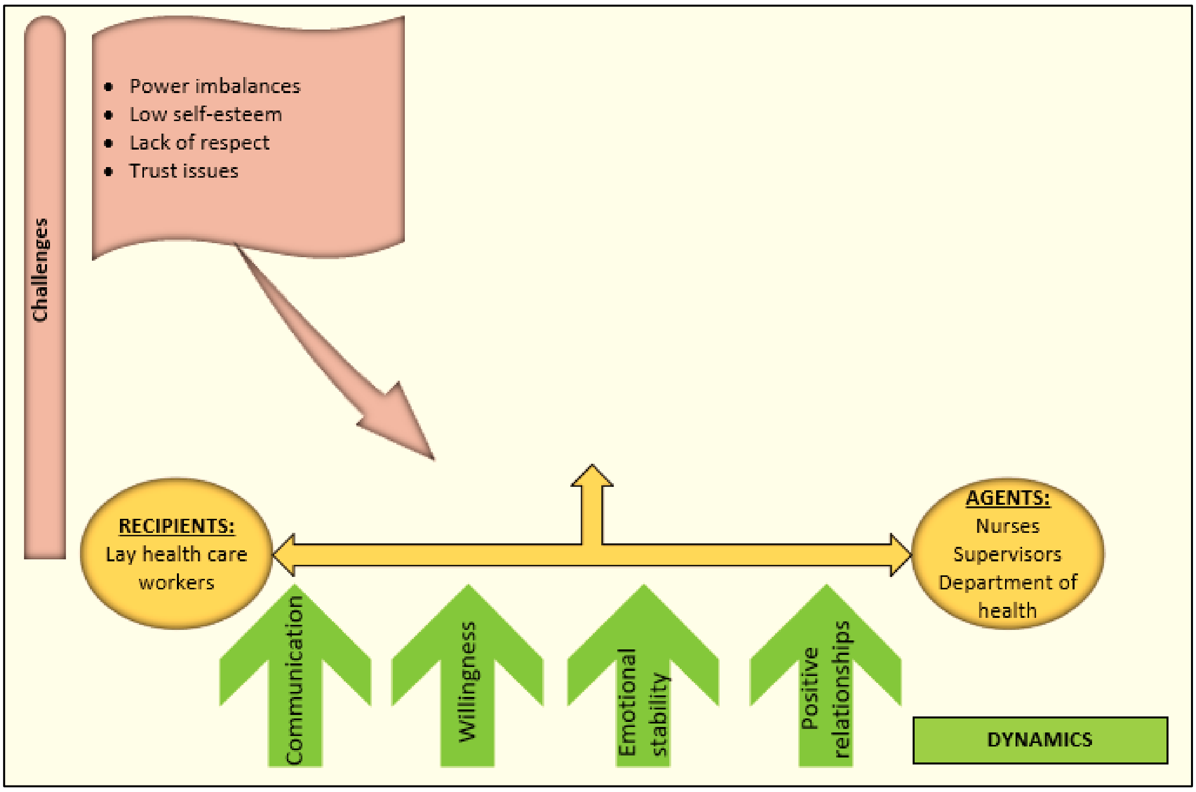


Figure 8.3: Dynamics that drive support

8.3.1.5 Procedure

The procedure refers to how the activity occurs. Support is an unending activity which can be implemented in 5 steps; however, some steps, especially the last three may not necessarily occur as per outlined sequence, e.g., fostering mutual dependence may occur throughout or before the provision of emotional and instrumental support:

- Step 1: Create a positive climate

Support activities start with the creation of a positive climate so that the LHWs can open up. Facility managers need to encourage good relationships by showing appreciation and acceptance of LHWs as part of the health care team and encouraging all workers to do the same. Challenges need to be addressed fairly and objectively by giving all staff members an equal opportunity to state their facts and not taking sides.

Also, LHWs must be allowed to come up with ideas for improvement while acknowledging their valuable experiences in working closely with the community. Busza *et al*., (2018:1) indicated that the CHW programmes are valuable in improving HIV services and adherence to treatment, but effectiveness of these programmes relies on providing enabling work environments for CHWs.

- Step 2: Identify individual needs of LHWs

The individual LHWs' needs can then be identified either through verbalization or assessment by the supervisor or health care professional. Support checklists can be designed with the LHWs, supervisors and nurses, and then be used in assessing the supportive behaviours. Also, individual improvement plans can be compiled, and progress monitored by both the LHWs and supervisors. Examples of needs include updated information, refresher courses, orientation, supervision, debriefing, better stipends, and were provided in detail under the recipients above. This will ensure that the support provided is appropriate to the needs identified, thereby increasing the LHWs' perceptions of support and fulfilment.

The assessment of individual needs was supported by Hodgins *et al*., (2016:5) who emphasized that the LHWs needed support that is individually tailored to enable them to offer effective health programmes. Again, Caesens *et al*., (2020:1) further indicated that the support must be appropriate to the recipients' needs otherwise it may be meaningless or viewed negatively, further revealing that individuals with low socioeconomic needs may perceive high support as a threat to their self-esteem, an indication of incompetence or lack of managers' confidence in them.

- Step 3: Provide emotional and instrumental support

Supervisors and nurses can proceed to offer the support based on the identified needs and work requirements. The emotional support includes: the supervisors and nurses assisting LHWs with difficult clients, problem solving, fair distribution of resources to avoid feelings of discrimination, arranging debriefing sessions and discussion of field challenges, as well as the Department of Health's improvement of working conditions such as stipend increment, incentives, and other labour-related benefits which all impact on the LHWs' emotions.

The instrumental support includes actual assistance with patient care*, e.g.,* nurses to assist working clients as soon as possible to facilitate their return to work; provision of refresher courses and updated HIV information such as new ART, working material like HIV test kits, gloves and visual educational aids that promote patient adherence counselling*;* identification of implementation gaps *such as HIV guidelines' use, then* mentoring accordingly*;* job-orientation for new LHWs; and supportive supervision. These types of support were stated by the LHWs during the focus group discussions.

Mathieu *et al.*, (2018:2) stated that emotional support includes listening and showing esteem, encouragement, affection, and sympathy to others, while instrumental support entails task assistance, information, and other tangible aspects and these are in line with the above-stated examples. While the health care system is still struggling to regulate and absorb the LHWs, interventions such as debriefing, training, supervision and follow up can help the LHWs to feel recognized as part of the health care team, thereby boosting their morale and improving the quality of counselling (Mkhabele *et al*., 2016:326).

- Step 4: Foster mutual dependence

The LHWs' supervisors and managers need to encourage collaboration among all facility workers by clarifying the roles, sharing of tasks, and explaining how all activities are interrelated to improve retention to HIV care and other health outcomes. The LHWs stated the importance of working together and also understanding what other categories of staff are working on. They emphasized the importance of clinic staff in capturing and updating correct contact details of clients which assist during tracing, as well as the linking of HIV positive clients to CHWs to visit them even before they default treatment. Moreover, lay counsellors need to intensify the counselling and education right from diagnosis of HIV to facilitate retention, and not view retention as the responsibility of the tracers and CHWs only.

Other issues that were emphasized by the LHWs were the improvement of staff attitudes and the filing system to minimise the loss of clients' medical records, which lead to clients' frustration and discontinuation of care. Kok *et al*., (2015:8) mentioned that to improve the effectiveness of CHWs, there must be clear operating procedures and guidelines as well as clearly defined roles and relationships with other health care workers. Likewise, Scott *et al*., (2018:11) alluded that integration that promoted respectful collaboration and communication between CHWs and other health care professionals encouraged and motivated the CHWs to share their unique, practical knowledge; therefore, contributing positively to patient care.

- Step 5: Provide constructive feedback

Constructive feedback can be facilitated through two-way client referrals between the LHWs and facility staff, including the LHWs in staff meetings and discussing performance and gaps in a respectful manner without belittling or blaming others. Also, feedback in terms of positive and negative performance can be provided to individual LHWs to motivate them and also guide further decisions regarding the required support. Supervisors must be careful how they treat or correct the LHWs and not do it in front of patients, or if urgent and critical, it needs to be done in a way that does not embarrass the LHW. The quotations below indicate the LHWs' need for constructive feedback and not blame:

"Yes, she said it all. There is no time for feedback and this is really affecting our work negatively. We are just working, not knowing if we do the right or wrong things (others agreed: "yes")" T2F2F

*"We refer clients expecting to get a back-referral (*feedback*) so that I can get a copy and have evidence that I did my job, but this is not happening" T2F2D*

"It angers me because they expect miracles from us. And no matter how hard we work, no one appreciates or commends us for our hard work (Other participants agreed: yes). Instead, they keep on putting pressure on us, they complain and complain. And when they do this, we end up being demotivated and discouraged to work, what is the use of

trying to do your best when no one notices or appreciates? A 'thank you' once in a while will do" T2F2A

Ludwick *et al*., (2018:7) indicated that it was imperative for the supervisors and health care workers to find ways that support constructive engagements and relationships, such as referral systems and respect, thereby contributing to improved CHWs' programme outcomes. Figure 8.4 below depicts the support procedure.

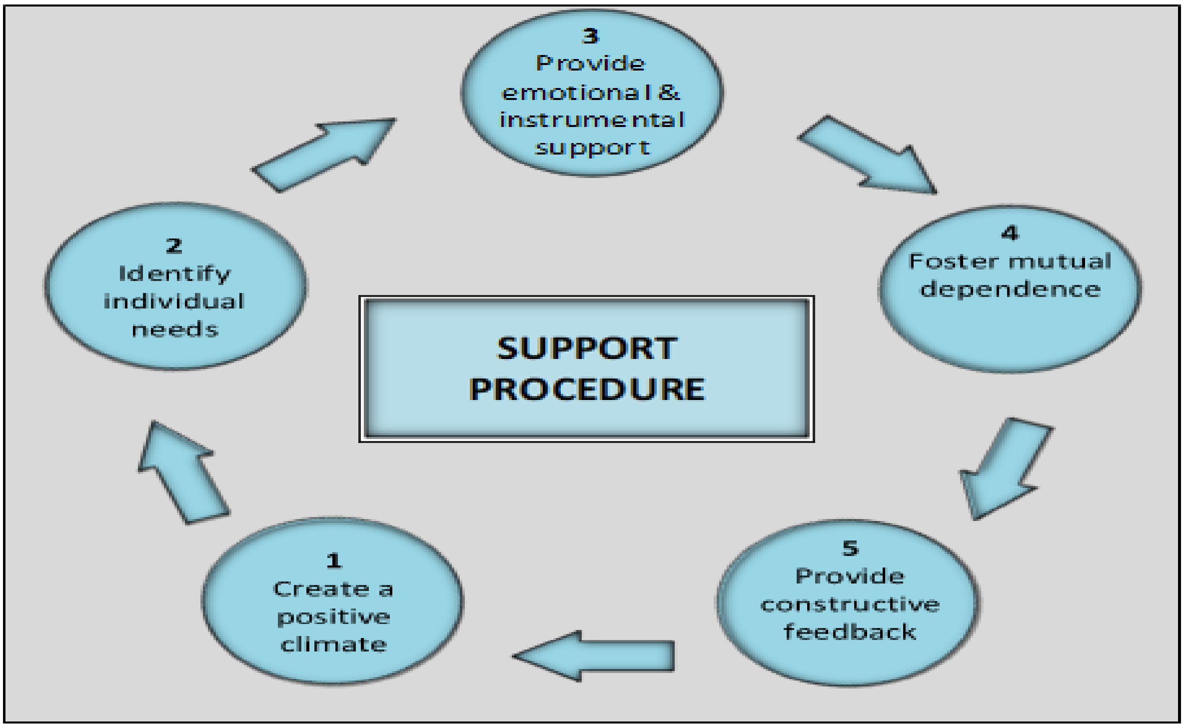


Figure 8.4: Support Procedures

8.3.1.6 Terminus/Outcome

The terminus refers to the outcome of the activity and is reflected in figure 8.5 below. Support provision will improve the LHWs' motivation, job satisfaction, competence and also promote thriving, which will in turn improve the retention of patients to HIV care and viral suppression, then possibly reduce new infections.

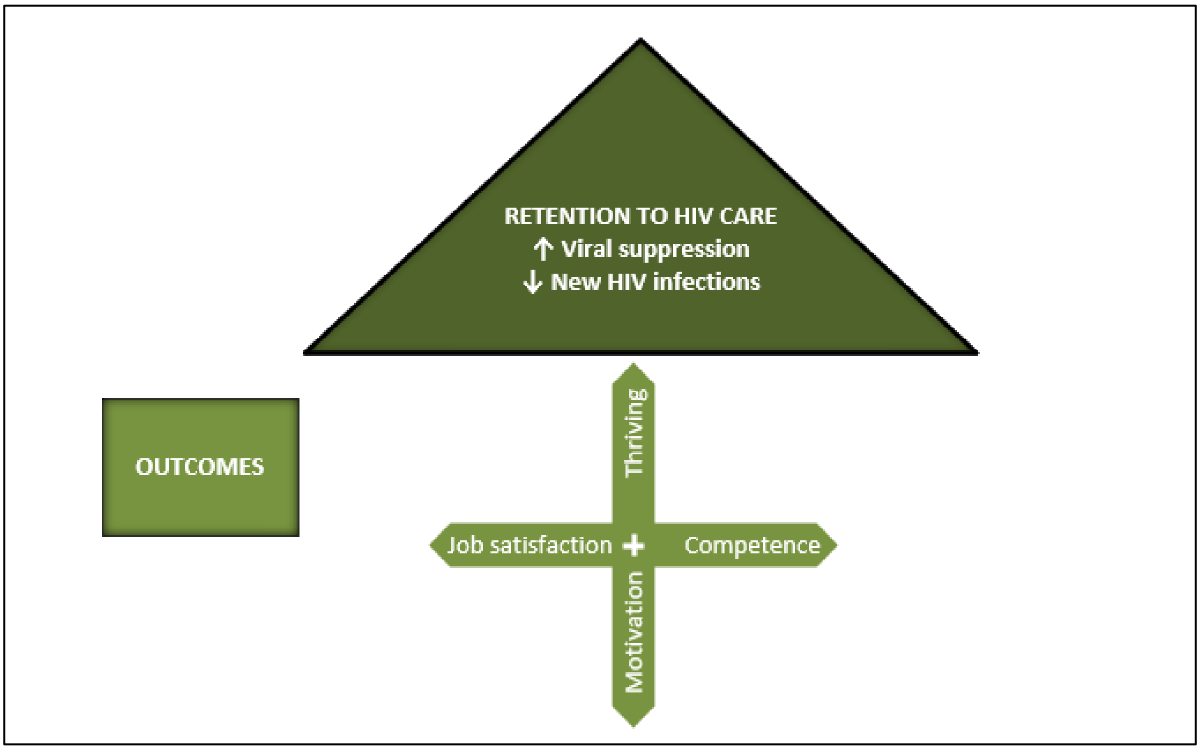


Figure 8.5: Support Outcomes

8.3.2 Relationship statements

The relationships between the concepts were constructed as follows:

- Support is an interrelated activity between the recipient and agent, that is, the LHWs and their supervisors, health care professionals and the Department of Health, that requires emotional stability, positive relations, willingness, and communication.
- The exchange of support between the LHWs and supervisors may occur in different context such as the primary health care facilities, mobile clinics, hospitals, community, and NGOs.
- The Department of Health, other organizations and supervisors need to create a safe environment for the LHWs to verbalize the needs for support and perform their work freely without fear of being judged.
- The dynamics identified as willingness, communication, emotional stability, and positive relationships are necessary to facilitate the support procedures.
- The support procedures will lead to the achievement of the outcomes which include thriving, improved motivation and competence on the LHWs, as well as improved retention to HIV care, viral suppression, and the reduction of new HIV infections.
- Although the dynamics and procedures may result in positive outcomes, they are threatened by challenges that negatively affect the LHWs' efforts to retain clients to HIV care, e.g., missing medical records; negative staff attitude towards clients; lack of

collaboration, appreciation, and recognition of LHWs; increased workload and unfavourable work contracts.

8.3.3 Description of the support model

According to Chinn and Kramer (2012:185), the model can be described in terms of the purpose, structure, and assumptions.

8.3.3.1 Purpose of the model

The purpose of this model is to assist the health care organizations, professionals, and LHWs' supervisors to support the LHWs in improving patients' retention to HIV care.

8.3.3.2 Structural description of the model

The integrated support model for LHWs to improve patients' retention to HIV care is presented in figure 8.6 below and thereafter described in terms of the shape, colours used and the components.

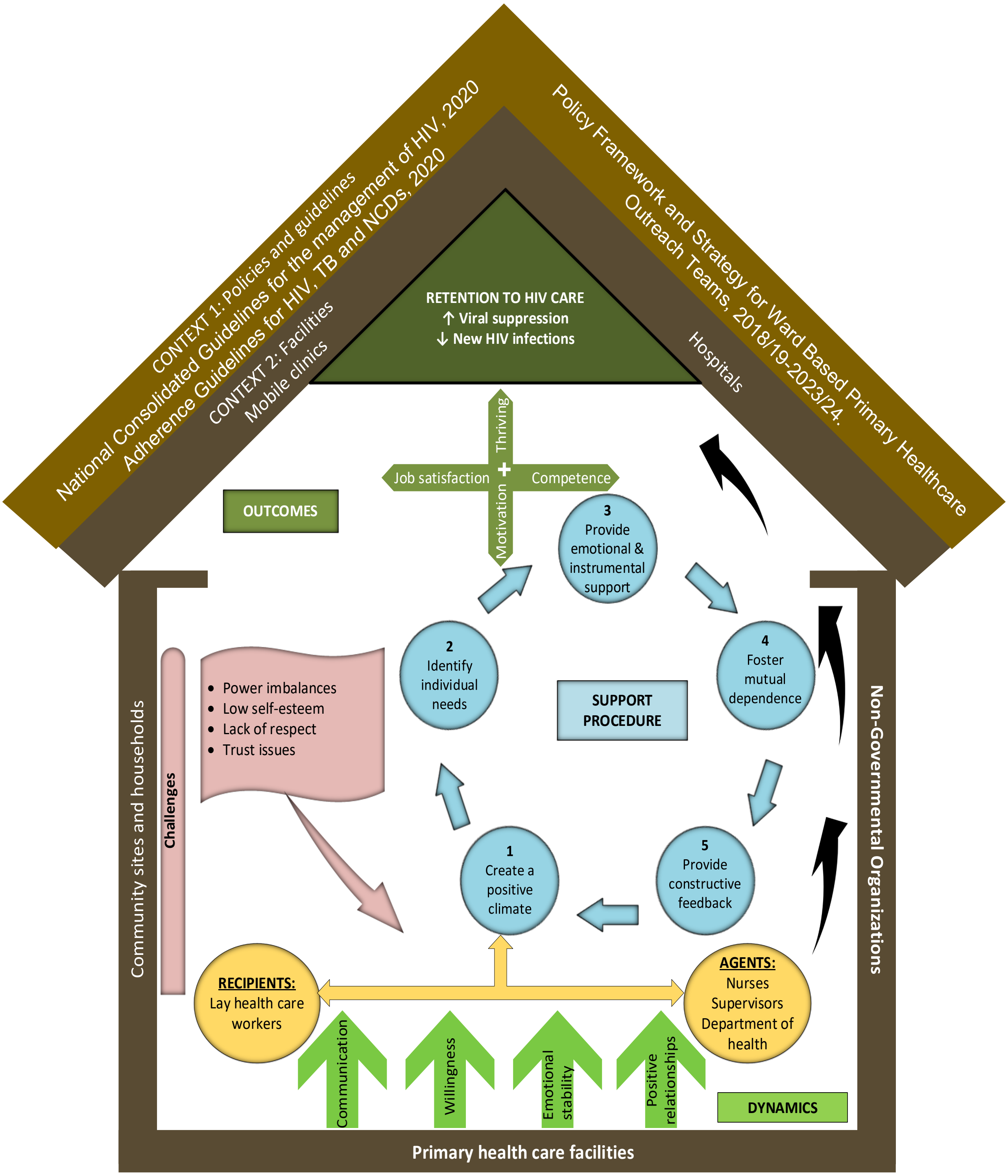


Figure 8.6: An integrated support model for LHWs to improve retention to HIV care

The model consists of six elements, namely, the context, agent, recipient, dynamics, procedures, and outcome. The symbolic meaning is as follows:

- The overall shape resembles a house, with the contexts as outer walls and coloured in brown which signifies the structure or earth. The house is a shelter and indicates that supportive interactions also require a safe and positive climate, as well as a sense of belonging.

- The dynamics are at the base to show that they are a foundation for supportive interactions and are represented by upward light green arrows, where green is regarded as the colour of hope.
- The agents and recipients are represented by light orange oval shapes and joined by a two-way arrow to show reciprocity of support.
- Challenges are represented as a pink flag and arrow on the left side to show caution as they need to be closely monitored and addressed as much as possible to promote support procedures.
- The procedures are represented in a light blue cyclic shape, showing the continuous and interrelated nature of the support activities that facilitate retention. Non-execution of either one or more of these procedures would impede retention to HIV care efforts. However, it does not necessarily mean that all the steps occur as per outlined sequence, others can run concurrently or precede each other, like provision of support and fostering mutual dependence.
- The outcomes are represented by a dark green colour: the retention outcome is on the topmost triangle, while the LHWs' outcomes of motivation, job satisfaction, thriving and competence are just beneath the retention. The outcomes are at the top to signal actualization for both the LHWs and the health care system.
- Lastly, the black arrows facing upwards on the right side show the desired direction of the flow, which is from the dynamics through to the outcomes.

8.3.3.3 Assumptions of the model

Assumptions refer to the accepted truths on which the model is based and are related to the relationship statements discussed above (Dube *et al.*, 2021:6). The assumptions are based on the stress and coping, social constructivist and relationship perspectives as outlined by Lakey *et al.,* (2000:29):

- The stress and coping perspective assumes that the provision of supportive actions will help individuals to cope with stress, while the perception of available support will assist individuals to interpret threatening situations as less negative.
- The social constructivist perspective assumes that people construct concepts about the world that reflects their contexts and there may not be clear consensus on what constitutes supportive actions among different individuals or groups.

- Furthermore, the social environment promotes the well-being of individuals by helping them make sense of self as they self-regulate in line with the group standards, then create and maintain the identity and self-esteem.
- The relationship perspective assumes that the quality of relationships between people is associated with strong social support. Positive ties are characterized by sharing, low conflict and social skills, while negative ties are accompanied by criticism, conflicts, fighting for limited resources and breaking the promises.

The last two assumptions were extracted from the LHWs' quotations:

"Yes, communication is really important. Without communication, nothing will improve" T2F2A

"This (meetings and feedback) *can work for us because our activities are interrelated, and we depend on each other to be successful in improving retention" T1F1F*

8.3.4 Critical reflection of the support model

The model must be critically evaluated to assess for clarity, simplicity, generality, accessibility, and importance (Chinn *et al*., 2012:204). The evaluation by independent experts was not done, but these criteria are discussed below. Also, the model was reviewed by the researcher's supervisor, who then provided recommendations accordingly.

- Clarity

The understanding of the model was promoted by sticking to the same identified concepts without introducing new ones, and classifying these concepts using clear steps of Dickoff *et al., (1968:423)* as well as the steps of model development by Chinn *et al.*, (2011:164).

- Simplicity

The model does not look complex as it was designed to simply reflect its components, the relationships between them, the driving forces, challenges, and the outcomes (Chinn *et al.*, 2012:205).

- Generality

This model was designed within the context of a primary health care setting, in one of the largest health centres in the North-West province; however, it can be applied to support

LHWs' HIV retention activities in other provinces of South Africa and countries who have similar contextual factors. Also, it can facilitate support for other health care programmes in which LHWs are involved, not only HIV.

- Accessibility

Accessibility of the model will be promoted by submitting a copy of the study findings to the North-West Health Research, Monitoring and Evaluation Directorate and presenting at the quality improvement summits or conferences. Moreover, the findings will also be disseminated through thesis write-up and loading on the university's repository, as well as publishing manuscripts in accredited journals.

- Importance

The model is significant as it has the potential to address the identified problem of inadequate support of LHWs, thereby increasing their skills and motivation levels, then contributing to improved retention to HIV care, viral suppression and other outcomes, as well as possible reduced new infections.

8.4 CONCLUSION

This chapter explained how an integrated support model for LHWs to improve retention of patients to HIV care was developed. The model was developed in two phases: the empirical, where LHWs, supervisors, nurses as well as clients on ART were interviewed to obtain their HIV care experiences. The second phase was the model development which followed the Dickoff survey list (Dickoff *et al*., 1968:423; Dube *et al.,* 2021:3) and model development guidelines by Chinn *et al.,* (2011:164). The components of the model include:

- The LHWs as the recipients of support.
- The supervisors, nurses, and Department of Health as agents.
- The primary health care facilities, hospitals, mobile clinics, community, and non-governmental organizations as well as the HIV policies and guidelines as the contexts.
- The dynamics, which include positive relations, communication, emotional stability, and willingness, and challenged by power imbalances, low self-esteem, lack of respect and trust issues.

- The procedures include the creation of a positive climate, individual needs identification, provision of emotional and instrumental support, fostering mutual dependence and providing feedback.
- The outcomes include the improvement of the LHWs’ motivation, job satisfaction, competence, and promotion of thriving, which will in turn improve the retention of patients to HIV care and viral suppression; thereby, potentially contributing to the reduction of new infections.

CHAPTER 9

DISCUSSION OF FINDINGS, RECOMMENDATIONS AND CONCLUSIONS

9.1 INTRODUCTION

This chapter concludes the study report and provides an overview of the research; summary of findings; recommendations for practice, policy and governance, and research; study limitations and conclusions. The experiences and support for LHWs in their HIV management and retention roles were researched to develop a support model.

9.2 OVERVIEW OF THE STUDY

The background of the study was done through reviewing the relevant international, regional and national literature on retention to HIV care to determine the importance, facilitators and challenges of retention, as well as the support provided to LHWs as they provide most of the HIV services such as testing, counselling, health education and tracing. Previous studies focused more on the experiences of lay counsellors and CHWs, excluding other categories of LHWs but also, the researcher did not find any support model for LHWs to improve retention to HIV care. The study was therefore conducted to develop an integrated support model for LHWs to improve patients' retention to HIV care. The objectives of the study were to:

- Describe how the lay health care workers interact with people living with HIV (PLWHIV).
- Describe the views of health care professionals on the support provided to lay health care workers in carrying out their duties relating to PLWHIV.
- Explore and describe how PLWHIV experience their interaction with lay health care workers.
- Develop the integrated support model for lay health care workers to improve patients' retention to HIV care.

9.2.1 Methodology

The study followed a qualitative approach and an exploratory, descriptive and contextual design. It was conducted in two phases, namely, the empirical, where the participants were interviewed, and then model development. The setting was a community health centre situated in Rustenburg sub-district, Bojanala Health District in the North-West Province, South Africa. The LHWs, their supervisors and health care professionals (professional nurses) as well as clients on ART formed the population of this study and those who met the inclusion criteria were sampled using purposive non-probability sampling. Data saturation determined the study sample across the 3 groups: 22 LHWs, 10 supervisors and nurses who work with LHWs as well as 15 clients who have been on ART for at least a year.

The ethical aspects that were considered before commencement of the study included safety and advocacy where the ethical clearance was obtained from the University of South Africa’s College of Human Sciences Research Ethics Committee, and permission was sought from the Department of Health; written informed consent was obtained from the participants; and confidentiality, privacy, anonymity and non-maleficence were promoted throughout. An interview guide with open-ended questions was used to collect data from the participants. Four focus group discussions were conducted with the 22 LHWs; in-depth individual interviews were conducted with 10 supervisors and nurses as well as 15 clients on ART. The audio recorder was used to record and transcribe data from the participants and thematic analysis was used to analyse data. All steps that were taken throughout the study were outlined to ensure trustworthiness which is a measure of rigour.

9.3 SUMMARY OF FINDINGS

The findings from the three groups of participants will be summarised separately and then common retention barriers cited across the groups highlighted at the end.

9.3.1 Lay health care workers

Objective 1: Describe how the lay health care workers interact with people living with HIV

- LHWs’ experiences in HIV care and contribution to retention

Participants understood their roles such as general HIV and treatment adherence counselling, index testing, health education, tracing, household registrations and delivery of pre-packed medication; however, some viewed HIV counselling and adherence as separate duties, while others especially lay counsellors, did not understand how their activities contributed to retention to HIV care. They also highlighted the importance of the welcome back campaign in returning defaulted clients back to care, and index programme in improving the testing and non-disclosure of couples, though it posed challenges as re-testing was sometimes done for index clients.

- HIV tools and guidelines implementation by LHWs

The study participants indicated different practices in terms of the tools that guide them to perform their duties. Outreach teams mentioned the use of household registration forms, pregnancy, STI and TB screening tools as well as phones to capture outcomes after tracing. However, participants indicated that they did not have specific tools that guide them on what to say during telephonic or physical tracing. Also, while lay counsellors mentioned that they used adherence plans, stopwatches, HIV testing algorithms and visual teaching aids, some indicated that they used information from their heads because they have memorized the testing procedure. Again, some participants completed the adherence plans in one day, which they found overwhelming for the clients.

- LHWs’ perceptions of HIV testing and same day treatment

The participants emphasised the importance of clients’ preparation and acceptance, which they felt that the national HIV policy did not consider when mandating the same day treatment initiation for new HIV positive clients. The participants indicated that it is not easy at times for clients to accept taking ART immediately after diagnosis, without undergoing thorough counselling, with others even absconding after testing positive. Furthermore, the participants highlighted the difficulty of spreading and completing the adherence sessions over a number of days, rather, they completed them in one day, which is overwhelming for clients and also breaks the counsellor-client bond.

- LHWs’ experiences of support

The participants had varying experiences of support, ranging from none to adequate. Those who felt supported indicated assistance in terms of patients being initiated on ART immediately after counselling; provision of work material and training, while those with limited or no support cited lack of orientation or in-service training; incorrect capturing of patient contact details which are supposed to be used during tracing; and feeling discriminated by not receiving teaching aids the same way as counsellors from the developmental partner. Lay counsellors assisted each other in terms of counselling but they never met to discuss their work as LHWs. Also, they feared to be labelled as incompetent; therefore, they did not call nurses to assist with counselling difficult clients except those who refused ART initiation. The LHWs also stated that they were not included in the staff meetings to discuss their performance and challenges, therefore communication and feedback were lacking.

- Barriers and suggestions to promoting retention to HIV care

Multiple factors that are related to clients, health facility and LHWs were mentioned. *Client related factors* included non-acceptance of the HIV positive status, dependence and lack of ownership. Clients did not incorporate HIV care into their lives and depended on LHWs to either trace or deliver medication to their homes. Lack of acceptance also resulted in non-disclosure of the HIV positive status; however, fear of stigma from the family or community also contributes to non-disclosure which was said to be common in clients aged 24-35 years. Participants also stated that some clients provided wrong contact details which made it difficult to trace them after defaulting.

The participants explained that in order to improve retention, more efforts must be directed at preparing the clients for lifelong HIV treatment and not only striving to reach the HIV testing targets. Client preparation needs to start right from counselling to promote acceptance and must include expectations, responsibilities and advantages of independence, or disadvantages of dependence on other people for motivation.

Health facility-related factors included lack of communication and information about medication side effects and HIV management; inflexible appointment dates, as well as previous negative experiences such as negative staff attitudes, lost medical records and long queues. Participants suggested that clients be allowed to choose appointment dates; be well-educated on side effects, blood collection and HIV management; receive intensive adherence counselling and be decanted to external pick-up points. Another issue that was highlighted was the improvement of the filing system to minimise the loss of medical records.

Factors related to the LHWs and the health system or workers included lack of supervision, collaboration, feedback and training on updated HIV information; high workload and unbalanced tasks; as well as low stipends. They expressed frustration caused by lack of updated information such as changes in HIV or other chronic medication which makes them to look uninformed when interacting with clients. Participants further stated that even if they are trained, they wish to receive refresher training, and the training duration must be adequate to enable them to process the information effectively. The participants also agreed that their work is interrelated and it is important for them to work collaboratively.

Another issue is lack of feedback meetings to discuss performance, gaps and remedial actions. Instead, the LHWs felt that the facility staff blamed them for the high HIV missed appointments, which made them feel angry, discouraged and unappreciated. LHWs stated that their testing targets of 12 daily made them to rush through the work and also overlook other tasks such as adherence counselling, therefore they suggested that their targets be reduced so that they can focus on quality not quantity. Participants were also worried about their low stipends which sometimes made them to release their frustrations on clients and therefore wished to receive better stipends which will motivate them.

9.3.2 Key findings: LHWs' supervisors and nurses

Objective 2: Describe the views of health care professionals on the support provided to LHWs in carrying out their duties relating to PLWHIV.

- The role and contribution of LHWs in HIV management and to retention to care

The participants described the LHWs' role as crucial because they are the HIV care entry points and sources of support to clients as they offer testing, adherence counselling and health education, and later when clients default treatment, they trace either telephonically or physically and also remind clients of their clinic appointments and conduct routine visits at the households. As a result, they regarded the LHWs as complementing the nurses and reducing their workload so that they can focus more on clinical tasks and critical clients.

- Support provided to LHWs

The participants indicated good working relationships with LHWs, and continuous interactions to monitor the performance, discuss patient care and challenges encountered in the facility and community, as well as to brainstorm improvement ideas. They also provided ART to clients tested by lay counsellors and helped to identify clients who defaulted treatment so that tracing can be done accordingly.

The other form of support is the provision of working material to the LHWs. The supervisors visit the LHWs' workstations to identify gaps and provide mentoring, training and supportive supervision; however, supervision of CHWs has been a challenge due to the focus on COVID-19 prevention activities.

- Barriers experienced by LHWs in promoting retention and possible interventions

Client and community-related barriers included non-disclosure of the HIV status; missing clinic appointments due to forgetting dates, traveling, lack of responsibility or limited information; congested housing arrangements which makes it difficult to locate the addresses; and safety issues where one CHW was bitten by dogs and there was an incident of criminals robbing CHWs of the work phones. Sometimes there is dishonesty from clients who provide wrong contact details. The participants emphasized that continuous counselling was needed to improve clients' knowledge and promote acceptance of the HIV status. In terms of safety, CHWs work in pairs when they go to the community.

Health facility-related barriers affecting clients were indicated as the clients' negative experiences where they would be yelled at or not given information. Long queues, clinic operating hours that clash with the clients' work schedules, as well as language barriers, were mentioned. Improvement suggestions included compiling a list of interpreters to assist in language barrier cases, offering client-oriented care that includes discussing clinic appointments and scheduling weekend dates, extending clinic operating hours, offering continuous health education, the use of different treatment collection modalities suitable for individual clients, and client profiling. Improvement of filing and staff attitudes, as well as warmly welcoming clients who defaulted ART, and reducing waiting time were also suggested.

Health facility barriers affecting LHWs' functioning included lack of transport for outreach services at distant areas, increased workload of the LHWs versus the quality of their work where the HIV testing target is 12 clients per day, with those from the developmental partner expected to test 16. Other concerns were around the provision of working material such as tracing phones and tools that guide LHWs, especially tracers when communicating with clients; as well as collaboration; training and supervision which have the potential to impact negatively on their skills, knowledge and compliance with the national HIV management guidelines.

Participants indicated that the some LHWs do not have a good relationship with their supervisors, and there were also trust issues from the health care professionals towards LHWs. Good working conditions are essential to improve LHWs' motivation and performance. The participants cited the importance of debriefing, training, supervision, reducing the workload, increasing the stipend for LHWs and improving interdependence among health care workers, including functional clinic committees.

9.3.3 Key findings: Clients on ART (PLWHIV)

Objective 3: Explore and describe how PLWHIV experience their interaction with lay health care workers.

- Experiences of HIV positive clients postdiagnosis

Clients experienced different emotions such as confusion, sadness, shock, guilt, being scared, non-acceptance and worry over the kind of life they would have after HIV diagnosis. However, they reported good counselling and connection with the lay counsellors. They also indicated that the care received was very good and it made them feel accepted, encouraged, and motivated to take treatment and be responsible for their own health. Although clients reported that they received the necessary information, most of them indicated that the health care workers do not explain the blood monitoring purpose clearly, so they just followed instructions. The participants also understood the benefits of ART, such as good health, and consequences of defaulting treatment such as becoming very sick or dying, or failing to continue with work and caring for family.

- Motivation to keep up with clinic appointments and treatment

Clients mentioned that they continue to take ART because they want to remain healthy and take care of their families, and they had also witnessed the suffering that people who defaulted treatment go through, and did not wish to see themselves in that state. Also, they are self-determined, value their lives and have social support. Some clients were motivated by collecting treatment at external pharmacies; taking just one pill per day; being provided with clinic attendance proof to submit at work and reminders such as appointment cards.

- Barriers and suggestions to improve retention to HIV care

Barriers related to the health facility included lost medical records, long waiting time and queue, rules that did not allow buddies to collect treatment on behalf of clients and negative staff attitudes. The lost files would sometimes not be found, resulting in clients going home without the medication irrespective of the long time that the clients waited for.

Clients revealed that in terms of addressing the challenge of lost clinic files, the filing system needs to be improved to avoid delays. Again, participants stated that counselling on defaulting must be strengthened, and the referral of clients to external treatment pick up points needs to continue. Participants indicated that they value their lives and emphasized acceptance, independence and taking responsibility because it is not possible to control other people’s actions; however, disclosure remains important. In terms of *client-related barriers*, the participants indicated that they missed appointment dates because they forgot to check appointment cards, went to work, were ill-informed into interpreting suppressed viral load as cured, and walked for long distances to get to the facility. Participants feared to disclose due to stigma and negative consequences on relationships. Some clients even attend the furthest clinics where they are not known to avoid the stigma.

The interviews were conducted separately but there are most common cited barriers across the three groups of participants as outlined in table 9.1 below.

TABLE 9.1: MOST COMMON RETENTION BARRIERS CITED BY THE 3 GROUPS OF PARTICIPANTS

Most common retention barriers cited	LHWs	Nurses	Clients
Lost medical records	x	x	x
Long queues	x	x	x
Negative staff attitude	x	x	x
Lack of client information	x	x	x
Inflexible appointment dates	x	x	x
Non-disclosure of HIV status	x	x	x
Non-acceptance of HIV status	x	x	x
Lack of client preparation, which may also be exacerbated by same day ART initiation	x	x	-
Limited orientation, supervision, training and updated information for LHWs	x	x	-
High HIV testing targets and workload	x	x	-
Lack of collaboration	x	x	-
No transport for CHWs	x	x	-
Low stipends	x	x	-

9.3.4 Model development

Objective 4: Develop the integrated support model for lay health care workers to improve patients' retention to HIV care

The support model was then developed using the findings and literature review. It was developed in two phases: *concept analysis* which was presented in chapter 7; and the *model structure* which consists of six components, namely, the context, agent, recipient, dynamics, procedure, and outcome, as presented in chapter 8.

9.4 RECOMMENDATIONS FOR PRACTICE, POLICY AND GOVERNANCE AND FUTURE RESEARCH

9.4.1 Recommendations for practice and patient care

9.4.1.1 Lay health care workers

- More emphasis to be directed to counselling and education done at the HIV care entry points to promote client preparation and self-acceptance. It may be difficult to promote acceptance when the client is already defaulting.
- Adherence counselling to focus on clients' concerns, not only the general aspects. Clients at risk for defaulting can then be identified and their support intensified.
- LHWs (and other health care workers) need to emphasize the importance of viral suppression through the use of undetectable=untransmittable (u=u) messages and also integrate the decanting information with the initial and follow up counselling to motivate clients.

9.4.1.2 Health care professionals and supervisors

- All LHWs need to be equally trained on adherence counselling as they all at some point need to use those skills.
- Debriefing to be provided to all LHWs, not only lay counsellors, and inexpensive and innovative ways can be explored.
- Health care workers need to implement patient-centric care, provide information and treat clients as partners who discuss their health care and appointment dates.
- Integrate the supervision activities of supervisors from the developmental partner and Department of Health to provide information and educational aids to all lay counsellors without discriminating others, to promote quality patient care and sustainability of projects.

- Managers and supervisors need to encourage respect, collaboration and feedback because retention activities are interrelated.
- The supervisors need to check the implementation of HIV and adherence guidelines, then address the identified gaps.
- The supervisors need to assess the support perceptions of individual LHWs using either the available checklists or adapting them and then addressing the needs accordingly.
- Managers to check the implementation of the national guidelines for filing in order to determine how clients' files are managed to minimise their loss.

9.4.2 Recommendations for policy and governance

9.4.2.1 Department of health and managers

- The Department of Health needs to explore the possibility of recognising the LHWs as part of the health workforce, considering the crucial role that they play in HIV management, by revising their stipends and benefits, and designing a formal training path for them.
- Also, there is a need to investigate file loss at the facility and explore feasible options for a facility with >7000 clients on ART.
- The lay counsellors' HIV testing targets need to be reviewed to enable them to spend more time on adherence activities.
- The adherence guidelines outline the procedures that are followed when clients have defaulted treatment but there is a need to design tracing tools or checklists that guide tracers on how to communicate with clients who defaulted treatment.
- Mental health issues are contributing negatively to retention, so, there is a need to explore the feasibility of designing mental health screening checklists and level-appropriate training for LHWs to be able to identify warning signs and refer appropriately.

9.4.3 Recommendations for future research

- More research has been done on retention or disengagement from care patterns, which sometimes showed a skewed picture due to high mobility of clients and duplication at multiple health facilities. Therefore, future research needs to focus on strategies that empower clients to minimise both false and true lost to follow up since there is no centralised HIV care database.
- Investigate the costs of establishing electronic medical records.
- The participants mentioned preparation and acceptance frequently, so their impact on retention can be explored. This can also include the impact of providing HIV testing incentives on retention to care.

9.5 LIMITATIONS OF THE STUDY

The study was conducted in a community health centre in Bojanala district and may not be generalised to all districts, provinces and countries; however, the methodology and context were clearly explained to facilitate replication. The study findings were also compared with those from other provinces and countries. Also, the researcher acknowledges that not all literature on support and retention was reached; however, the procedures for searching and selecting the articles was explained. Also, the aspect of data saturation, where new or unique information was no longer emerging, was considered.

9.6 CONCLUSION

The findings of the study were discussed as per objectives. The ultimate aim of developing an integrated support model for lay health care workers to improve retention to HIV care was achieved. It can be concluded that support is a resource that needs to be continuously available and provided to facilitate the LHWs' knowledge, skills, motivation, and job satisfaction. Retention to HIV care needs to be promoted throughout the HIV care continuum in order to improve the HIV outcomes.

REFERENCES

Abdolrahimi, M., Ghiyasvandian, S., Zakerimoghadam, M. & Ebadi, A. 2017. Therapeutic communication in nursing students: A Walker & Avant concept analysis. *Electronic Physician, 9(8),* p.4968. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5614280/

Afsar, B. & Masood, M. 2018. Transformational leadership, creative self-efficacy, trust in supervisor, uncertainty avoidance, and innovative work behavior of nurses. *The Journal of Applied Behavioral Science, 54(1),* p.36-61. https://journals.sagepub.com/doi/abs/10.1177/0021886317711891

Agarwal, B., Brooks, S.K. & Greenberg, N. 2020. The role of peer support in managing occupational stress: a qualitative study of the sustaining resilience at work intervention. *Workplace Health & Safety, 68(2),* p.57-64. https://journals.sagepub.com/doi/pdf/10.1177/2165079919873934

Ahmed, S.I., Farooqui, M., Syed Sulaiman, S.A., Hassali, M.A. & Lee, C.K. 2019. Facilitators and barriers affecting adherence among people living with HIV/AIDS: a qualitative perspective. *Journal of Patient Experience, 6(1),* p.33-40. https://journals.sagepub.com/doi/pdf/10.1177/2374373518770805

Aithal, A. & Aithal, P.S. 2017. Task-Shifting–An Alternative Survival Strategy for Health-Care Organizations. *International Journal of Scientific Research and Modern Education (IJSRME), 2(2),* p.34-48. https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3042536

Akintola, O. & Chikoko, G. 2016. Factors influencing motivation and job satisfaction among supervisors of community health workers in marginalized communities in South Africa*. Human Resources for Health*, 14(1), p.1-15. https://human-resources-health.biomedcentral.com/track/pdf/10.1186/s12960-016-0151-6.pdf

Allinder, S. M. 2020. South Africa's Future at the Brink: Emergency in the World's Largest HIV Epidemic. *Center for Strategic & International Studies (CSIS):* Washington. https://www.csis.org/analysis/south-africas-future-brink-emergency-worlds-largest-hiv-epidemic Date of access: 16 June 2022.

Al Shamsi, H., Almutairi, A. G., Al Mashrafi, S., & Al Kalbani, T. 2020. Implications of Language Barriers for Healthcare: A Systematic Review. *Oman Medical Journal*, *35*(2), e122. https://doi.org/10.5001/omj.2020.40

Alsharari, N.M. & Al-Shboul, M. 2019. Evaluating qualitative research in management accounting using the criteria of "convincingness". *Pacific Accounting Review*, pp. 1-21. https://doi.org/10.1108/PAR-03-2016-0031

Ames, H., Glenton, C. & Lewin, S. 2019. Purposive sampling in a qualitative evidence synthesis: A worked example from a synthesis on parental perceptions of vaccination communication. *BMC Medical Research Methodology, 19(1),* pp.1-9. https://bmcmedresmethodol.biomedcentral.com/articles/10.1186/s12874-019-0665-4

Amin, M.E.K., Nørgaard, L.S., Cavaco, A.M., Witry, M.J., Hillman, L., Cernasev, A. and Desselle, S.P. 2020. Establishing trustworthiness and authenticity in qualitative pharmacy research. *Research in Social and Administrative Pharmacy, 16(10),* pp.1472-1482. https://www.sciencedirect.com/science/article/abs/pii/S1551741119309155

Arabi, A., Rafii, F., Cheraghi, M.A. & Ghiyasvandian, S. 2014. Nurses' policy influence: A concept analysis. *Iranian Journal of Nursing and Midwifery Research*, 19(3), p.315. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4061635/

Arias-Colmenero, T., Pérez-Morente, M., Ramos-Morcillo, A.J., Capilla-Díaz, C., Ruzafa-Martínez, M. & Hueso-Montoro, C. 2020. Experiences and attitudes of people with HIV/AIDS: a systematic review of qualitative studies. *International Journal of*

Environmental Research and Public health, 17(2), p.639. https://www.mdpi.com/1660-4601/17/2/639

Arifin, S.R.M. 2018. Ethical considerations in qualitative study. *International Journal of Care Scholars*, 1(2): 30-33. https://journals.iium.edu.my/ijcs/index.php/ijcs/article/view/82

Assegaai, T. & Schneider, H. 2022. Factors associated with workplace and interpersonal trust in the supervisory system of a community health worker programme in a rural South African district. *International Journal of Health Policy and Management, 11(Special Issue on CHS-Connect),* pp.31-38. https://www.ijhpm.com/article_4006_59c47b0bdd435c76ede4f6afc4e7e5cf.pdf

Augstein, M., Neumayr, T., Pimminger, S., Ebner, C., Altmann, J. & Kurschl, W. 2018. Contextual Design in Industrial Settings: Experiences and Recommendations. *In ICEIS (2),* pp. 429-440. https://pdfs.semanticscholar.org/88c5/57746f641ab3b3f8d1f40797a5f081f6ee7e.pdf

Austin-Evelyn, K., Rabkin, M., Macheka, T., Mutiti, A., Mwansa-Kambafwile, J., Dlamini, T. & El-Sadr, W.M. 2017. Community health worker perspectives on a new primary health care initiative in the Eastern Cape of South Africa. *PLoS One*, 12(3), p.e0173863. https://doi.org/10.1371/journal.pone.0173863

Avert. 2020, August 24. South Africa 90-90-90 progress. Global information and education on HIV and AIDS [Blog post]. https://www.avert.org/infographics/south-africa-90-90-90-progress

Ayuttacorn, A., Tangmunkongvorakul, A., Musumari, P.M., Srithanaviboonchai, K., Jirattikorn, A. & Aurpibul, L., 2019. Disclosure of HIV status among Shan female migrant workers living with HIV in Northern Thailand: A qualitative study. *PLoS One*, 14(5), p.e0216382.

https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0216382

Bashirian, S., Barati, M., Shoar, L. M., Mohammadi, Y. & Dogonchi, M. 2019. Factors affecting Breast Self-examination Behavior among female Healthcare Workers in Iran: The Role of Social Support Theory, *Journal of Preventive Medicine and Public Health, vol. 52* (4), p. 224–233. https://www.jpmph.org/upload/pdf/jpmph-52-4-224.pdf

Becker, N., Cordeiro, L.S., Poudel, K.C., Sibiya, T.E., Sayer, A.G. & Sibeko, L.N. 2020. Individual, household, and community level barriers to ART adherence among women in rural Eswatini. *PLoS One 15(4):* e0231952. https://doi.org/10.1371/journal.pone.0231952

Beecher, C., Devane, D., White, M., Greene, R. & Dowling, M. 2020. Women's experiences of their maternity care: A principle-based concept analysis. *Women and Birth, 33(5)*, pp.419-425. https://www.sciencedirect.com/science/article/pii/S1871519219303622

Bemelmans, M., Baert, S., Negussie, E., Bygrave, H., Biot, M., Jamet, C., Ellman, T., Banda, A., van den Akker, T. & Ford, N. 2016. Sustaining the future of HIV counselling to reach 90-90-90: a regional country analysis. *Journal of the International AIDS Society, 19(1)*, p.20751. https://onlinelibrary.wiley.com/doi/epdf/10.7448/IAS.19.1.20751

Bender, M. & Feldman, M.S. 2015. A practice theory approach to understanding the interdependency of nursing practice and the environment. Advances in Nursing Science, 38(2): 96-109. https://escholarship.org/content/qt382122zb/qt382122zb.pdf

Bennett, P.N., Wang, W., Moore, M. & Nagle, C. 2017. Care partner: A concept analysis. *Nursing Outlook, 65(2),* pp.184-194. https://www.sciencedirect.com/science/article/abs/pii/S0029655416303529

Besada, D., Goga, A., Daviaud, E., Rohde, S., Chinkonde, J.R., Villeneuve, S., Clarysse, G., Raphaely, N., Okokwu, S., Tumwesigye, N. & Daries, N. 2018. Roles played by community cadres to support retention in PMTCT Option B+ in four African countries: a qualitative rapid appraisal. *BMJ open, 8(3),* p.e020754. https://bmjopen.bmj.com/content/bmjopen/8/3/e020754.full.pdf

Bishop, G. & Blake, J. 2007. Reflective practice: a guide to reflective practice with workbook: for postgraduate and post experience learners. Working Paper. University of Huddersfield, UK: 1-48. http://eprints.hud.ac.uk/id/eprint/19114/1/bishopPost_Grad_guide-_final_doc.pdf

Bisnauth, M.A., Davies, N., Monareng, S., Buthelezi, F., Struthers, H., McIntyre, J. & Rees, K. 2021. Why do patients interrupt and return to antiretroviral therapy? Retention in HIV care from the patient's perspective in Johannesburg, South Africa. *PLoS one, 16(9),* p.e0256540. https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0256540

Boakye, A. O., Dei Mensah, R., Bartrop-Sackey, M. & Muah, P. 2021. Juggling between work, studies and motherhood: The role of social support systems for the attainment of work-life balance. *South African Journal of Human Resource Management, vol. 19 (*1), p. 1–10. https://sajhrm.co.za/index.php/sajhrm/article/view/1546

Bock, P., Gunst, C., Maschilla, L., Holtman, R., Grobbelaar, N., Wademan, D., Dunbar, R., Fatti, G., Kruger, J., Ford, N. & Hoddinott, G. 2019. Retention in care and factors critical for effectively implementing antiretroviral adherence clubs in a rural district in South Africa. *Journal of the International AIDS Society, 22(10),* p.e25396. https://onlinelibrary.wiley.com/doi/full/10.1002/jia2.25396

Bogart, L.M., Shazi, Z., MacCarthy, S., Mendoza-Graf, A., Wara, N.J., Zionts, D., Dube, N., Govere, S. & Bassett, I.V. 2022. Implementation of South Africa's Central

Chronic Medicine Dispensing and Distribution Program for HIV Treatment: A Qualitative Evaluation. *AIDS and Behavior*, pp.1-13. https://link.springer.com/article/10.1007/s10461-022-03602-y

Boggatz, T., Dijkstra, A., Lohrmann, C. & Dassen, T. 2007. The meaning of care dependency as shared by care givers and care recipients: a concept analysis. *Journal of Advanced Nursing, 60(5),* pp.561-569. https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1365-2648.2007.04456.x

Boru, T. 2018. Chapter Five Research Design and Methodology. Pretoria. University of South Africa (Thesis-PHD). http://dx.doi.org/10.13140/RG.2.2.21467.62242

Boyar, S.L., Campbell, N. S., Mosley Jr, D. C., Carson, C. M. 2014. Development of a work/family social support measure. *Journal of Managerial Psychology, 29 (7).* p.901-920. https://doi.org/10.1108/JMP-06-2012-0189

Boyce, M.R. & Katz, R. 2019. Community health workers and pandemic preparedness: current and prospective roles. *Frontiers in Public Health, 7*, p.62. https://www.frontiersin.org/articles/10.3389/fpubh.2019.00062/full

Branden, N., 2021. The power of self-esteem. *Health Communications, Inc*. http://dspace.vnbrims.org:13000/jspui/bitstream/123456789/5039/1/The%20Power%20of%20Self-Esteem.pdf

Breger, T.L., Newman, J.E., Mfangam Molu, B., Akam, W., Balimba, A., Atibu, J., Kiumbu, M., Azinyue, I., Hemingway-Foday, J. & Pence, B.W. 2017. Self-disclosure of HIV status, disclosure counseling, and retention in HIV care in Cameroon. *AIDS care, 29(7),* pp.838-845. https://drive.google.com/file/d/1kIqPEp7dyg30y4aOzYQzyNfD5THfd1T7/view

Buregyeya, E., Naigino, R., Mukose, A., Makumbi, F., Esiru, G., Arinaitwe, J., … & Wanyenze, R.K. 2017. Facilitators and barriers to uptake and adherence to lifelong antiretroviral therapy among HIV infected pregnant women in Uganda: a qualitative study*. BMC pregnancy and childbirth, 17(1),* p.1-9. https://bmcpregnancychildbirth.biomedcentral.com/articles/10.1186/s12884-017-1276-x

Busza, J., Dauya, E., Bandason, T., Simms, V., Chikwari, C.D., Makamba, M., … & Ferrand, R.A. 2018. The role of community health workers in improving HIV treatment outcomes in children: lessons learned from the ZENITH trial in Zimbabwe. *Health Policy and Planning*, 33(3), p.328-334. https://academic.oup.com/heapol/article/33/3/328/4788356?login=true

Caesens, G. & Stinglhamber, F. 2020. Toward a more nuanced view on organizational support theory. *Frontiers in Psychology, 11*, p.476. https://www.frontiersin.org/articles/10.3389/fpsyg.2020.00476/full

Cassidy, T., Grimsrud, A., Keene, C., Lebelo, K., Hayes, H., Orrell, C., Zokufa, N., Mutseyekwa, T., Voget, J., Gerstenhaber, R. & Wilkinson, L. 2020. Twenty-four-month outcomes from a cluster-randomized controlled trial of extending antiretroviral therapy refills in ART adherence clubs. *Journal of the International AIDS Society, 23(12),* p.e25649. https://onlinelibrary.wiley.com/doi/epdf/10.1002/jia2.25649

Caulfield, J., 2020, August 14. How to do thematic analysis [Scribbr Blog post]. https://www.scribbr.com/methodology/thematic-analysis/ Date of access: 25 Feb 2021.

Chammartin, F., Zürcher, K., Keiser, O., Weigel, R., Chu, K., Kiragga, A.N., ...Tweya, H. 2018. Outcomes of patients lost to follow-up in African antiretroviral therapy programs: individual patient data meta-analysis. *Clinical infectious diseases*, 67(11):1643-1652. https://academic.oup.com/cid/article/67/11/1643/5034717

Chauke, P., Huma, M. & Madiba, S. 2020. Lost to follow up rate in the first year of ART in adults initiated in a universal test and treat programme: a retrospective cohort study in Ekurhuleni District, South Africa. *The Pan African Medical Journal*, 37(198):1-14. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7813655/

Chen, J., Mullins, C. D., Novak, P., & Thomas, S. B. 2016. Personalized Strategies to Activate and Empower Patients in Health Care and Reduce Health Disparities. *Health Education & Behavior: the official publication of the Society for Public Health Education*, *43*(1), 25–34. https://doi.org/10.1177/1090198115579415

Cherutich, P., Golden, M.R., Wamuti, B., Richardson, B.A., Ásbjörnsdóttir, K.H., Otieno, F.A., & Bukusi, D. 2017. Assisted partner services for HIV in Kenya: a cluster randomized controlled trial. *The Lancet HIV, 4(2),* p.1-19. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5291815/

Chibanda, D. 2017. Depression and HIV: integrated care towards 90-90-90. International health, 9(2), pp.77-79. https://academic.oup.com/inthealth/article/9/2/77/2937781?login=true

Chinn, P.L. & Kramer, M.K. 2011. Integrated theory and knowledge development in nursing. 8th edition. St-Louis, MO: Mosby Elsevier.

Chinn, P.L. & Kramer, M.K., 2012. Integrated theory & knowledge development in Nursing 9th edition. Elsevier-Mosby, St Louis

Chinyandura, C., Jiyane, A., Tsalong, X., Struthers, H.E., McIntyre, J.A. & Rees, K. 2022. Supporting retention in HIV care through a holistic, patient-centred approach: a qualitative evaluation*. BMC Psychology*, 10(1), pp.1-9. https://link.springer.com/article/10.1186/s40359-022-00722-x

Chirambo, L., Valeta, M., Banda Kamanga, T.M. & Nyondo-Mipando, A.L. 2019. Factors influencing adherence to antiretroviral treatment among adults accessing care from private health facilities in Malawi. *BMC Public Health, 19(1),* p.1-11. https://doi.org/10.1186/s12889-019-7768-z

Costa, A.C., Fulmer, C.A. & Anderson, N.R. 2018. Trust in work teams: An integrative review, multilevel model, and future directions*. Journal of Organizational Behavior, 39(2),* p.169-184. https://bradscholars.brad.ac.uk/bitstream/handle/10454/16836/Costa_Anderson_%20JOB.pdf?sequence=1

Crowley, T. & Mayers, P. 2015. Trends in task shifting in HIV treatment in Africa: Effectiveness, challenges and acceptability to the health professions. *African Journal of Primary Health care & Family medicine, 7(1)*, p.1-9. http://www.scielo.org.za/pdf/phcfm/v7n1/41.pdf

Dapaah, J.M. 2016. Attitudes and behaviours of health workers and the use of HIV/AIDS health care services*. Nursing research and practice*, 2016. https://www.hindawi.com/journals/nrp/2016/5172497/

Dapaah, J.M. & Senah, K.A., 2016. HIV/AIDS clients, privacy and confidentiality; the case of two health centres in the Ashanti Region of Ghana. *BMC medical ethics*, 17(1), pp.1-10. https://doi.org/10.1186/s12910-016-0123-3

Daskalopoulou, M., Lampe, F.C., Sherr, L., Phillips, A.N., Johnson, M.A., Gilson, R., & Hart, G. 2017. Non-disclosure of HIV status and associations with psychological factors, ART non-adherence, and viral load non-suppression among people living with HIV in the UK. *AIDS and Behavior, 21(1),* p.184-195. https://link.springer.com/content/pdf/10.1007/s10461-016-1541-4.pdf

Davey, D.J., Wall, K.M., Serrao, C., Prins, M., Feinberg, M., Mtonjana, N., … & Malone, T. 2019. HIV positivity and referral to treatment following index testing of partners and children of HIV-infected patients in public sector facilities in South Africa.

Journal of Acquired Immune Deficiency Syndromes (1999), 81(4), p.365. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6637406/pdf/nihms-1036828.pdf

Dawson-Rose, C., Cuca, Y.P., Webel, A.R., Báez, S.S.S., Holzemer, W.L., Rivero-Méndez, M., … & Reyes, D. 2016. Building trust and relationships between patients and providers: an essential complement to health literacy in HIV care. *Journal of the Association of Nurses in AIDS Care, 27(5),* pp.574-584. https://www.sciencedirect.com/science/article/pii/S1055329016300012

Deliktas, A., Korukcu, O., Aydin, R. & Kabukcuoglu, K. 2019. Nursing Students' Perceptions of Nursing Metaparadigms: A Phenomenological Study. *The Journal of Nursing Research, 27(5)*:1-9. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6752693/

Dennis, C.L. 2003. Peer support within a health care context: a concept analysis. *International Journal of Nursing Studies, 40(3),* pp.321-332. https://www.sciencedirect.com/science/article/abs/pii/S0020748902000925

DiCarlo, A., Fayorsey, R., Syengo, M., Chege, D., Sirengo, M., Reidy, W., …& Abrams, E.J., 2018. Lay health worker experiences administering a multi-level combination intervention to improve PMTCT retention. *BMC Health Services Research,* 18(1), pp.1-13. https://doi.org/10.1186/s12913-017-2825-8

Dickoff, J., James, P. & Wiedenbach, E. 1968, ‘Theory in a practice discipline. Part 1: Practice orientated theory’, *Nursing Research 17(5),* 415–435. https://www.semanticscholar.org/paper/Theory-in-a-practice-discipline-part-I-%3A-Practice-Dickoff-James/a546b7f4340253326625e973a07f7d3d45f6c71f

Donovan, E.E. & Greenwell, M.R. 2021. Social Support in Nursing: A Review of the Literature. *Nursing Communication, 1(1),* p.2. https://repository.usfca.edu/cgi/viewcontent.cgi?article=1012&context=nursingcommunication

Dorward, J., Msimango, L., Gibbs, A., Shozi, H., Tonkin-Crine, S., Hayward, G., … & Garrett, N. 2020. Understanding how community antiretroviral delivery influences engagement in HIV care: a qualitative assessment of the Centralized Chronic Medication Dispensing and Distribution programme in South Africa. *BMJ open, 10(5),* p.e035412. https://bmjopen.bmj.com/content/bmjopen/10/5/e035412.full.pdf

Dow, B. & McDonald, J. 2003. Social support or structural change? Social work theory and research on caregiving. *Australian Social Work, 56(3),* p.197-208. https://core.ac.uk/download/pdf/213002255.pdf

Doyle, L., McCabe, C., Keogh, B., Brady, A. and McCann, M., 2020. An overview of the qualitative descriptive design within nursing research. *Journal of Research in Nursing, 25(5),* pp.443-455. file:///C:/Users/sampi/Downloads/1744987119880234.pdf

Drainoni, M.L., Baughman, A.L., Bachman, S.S., Bowers-Sword, R., Davoust, M., Fortu, K., ...Sprague Martinez, L. 2020. Integrating community health workers into HIV care teams: Impact on HIV care outcomes. *Journal of HIV/AIDS & Social Services*, 19(3): 204-219. https://www.tandfonline.com/doi/abs/10.1080/15381501.2020.1785364

Dube, A. & Rakhudu, M.A. 2021. A preceptorship model to facilitate clinical nursing education in health training institutions in Botswana. *Curationis, 44(1*), pp.1-9. http://www.scielo.org.za/scielo.php?script=sci_arttext&pid=S2223-62792021000100006

Engelbrecht, J.G., Letsoalo, M.R. & Chirowodza, A.C. 2017. An assessment of the HIV/TB knowledge and skills of home-based carers working in the North-West province in South Africa: a cross-sectional study. *BMC health services research, 17(1),* p.1-7. https://link.springer.com/content/pdf/10.1186/s12913-017-2238-8.pdf

Etoori, D., Wringe, A., Renju, J., Kabudula, C.W., Gomez-Olive, F.X. & Reniers, G. 2020. Challenges with tracing patients on antiretroviral therapy who are late for clinic appointments in rural South Africa and recommendations for future practice. *Global Health Action, 13(1),* p.1755115. https://www.tandfonline.com/doi/pdf/10.1080/16549716.2020.1755115

Eyassu, M.A., Mothiba, T.M. & Mbambo-Kekana, N.P. 2016. Adherence to antiretroviral therapy among HIV and AIDS patients at the Kwa-Thema clinic in Gauteng Province, South Africa. *African Journal of Primary Health Care and Family Medicine, 8(2),* p.1-7. http://www.scielo.org.za/pdf/phcfm/v8n2/24.pdf

Farghaly, A., 2018. Comparing and Contrasting Quantitative and Qualitative Research Approaches in Education: The Peculiar Situation of Medical Education. Education in Medicine Journal, 10(1). https://doi.org/10.21315/eimj2018.10.1.2

Feeney, B.C. & Collins, N.L. 2015. A new look at social support: A theoretical perspective on thriving through relationships. *Personality and Social Psychology Review, 19(2),* p.113-147. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5480897/pdf/nihms863739.pdf

Fiori, K.L., Consedine, N.S., Denckla, C.A. & Vingerhoets, A.J.J.M. 2013. Crying in context: Understanding associations with interpersonal dependency and social support. *Interpersonal: An International Journal on Personal Relationships, 7(1),* pp.44-62. https://interpersona.psychopen.eu/index.php/interpersona/article/view/3355

Fleischer, L. & Avery, A., 2020. Adhering to antiretroviral therapy: A qualitative analysis of motivations for and obstacles to consistent use of antiretroviral therapy in people living with HIV. *SAGE open medicine, 8*, p.1-10. https://journals.sagepub.com/doi/pdf/10.1177/2050312120915405

Foley, A.S. & Davis, A.H. 2017. A guide to concept analysis. *Clinical Nurse Specialist, 31(2)*, p.70-73. https://journals.lww.com/cnsjournal/Citation/2017/03000/A_Guide_to_Concept_Analysis.4.aspx

Fox, M.P., Bor, J., Brennan, A.T., MacLeod, W.B., Maskew, M., Stevens, W.S. & Carmona, S. 2018. Estimating retention in HIV care accounting for patient transfers: A national laboratory cohort study in South Africa. *PLoS Medicine*, 15(6):1-21. https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1002589

Gammie, E., Hamilton, S. & Gilchrist, V. 2017. Focus group discussions. In The Routledge companion to qualitative Accounting Research methods (p. 372-386). Routledge. https://rgurepository.worktribe.com/preview/299500/GAMMIE%202017%20Focus%20group%20discussions.pdf Date of access: 17 July 2022.

Gariepy, G., Honkaniemi, H. & Quesnel-Vallee, A., 2016. Social support and protection from depression: systematic review of current findings in Western countries. *The British Journal of Psychiatry, 209(4),* p.284-293. https://doi.org/10.1192/bjp.bp.115.169094

Garrard, J. 2020. Health sciences literature review made easy. Available from Google e-books: https://books.google.co.za/books?hl=en&lr=&id=eOcLEAAAQBAJ&oi=fnd&pg=PP1&dq=literature+review&ots=06C9tDJOYb&sig=nWnLVjApecvu7D8-Enr2RhueJ5U&redir_esc=y#v=onepage&q=literature%20review&f=false

Geldsetzer, P., De Neve, J.W., Boudreaux, C., Bärnighausen, T. & Bossert, T.J. 2017. Improving the performance of community health workers in Swaziland: findings from a qualitative study. *Human Resources for Health, 15(1),* p.1-9.

https://link.springer.com/content/pdf/10.1186/s12960-017-0236-x.pdf

Ghanbari-Afra, L., Adib-Hajbaghery, M. & Dianati, M., 2022. Human Caring: A Concept Analysis. *Journal of Caring Sciences, 11(4),* pp.246-254. https://scholar.google.com/scholar?hl=en&as_sdt=0%2C5&q=Human+Caring%3A+A+Concept+Analysis&btnG=

Gopal, T. 2019. In-depth: The problem of stopping or not starting HIV treatment. *Spotlight*, 6 Mar. https://www.spotlightnsp.co.za/2019/03/06/in-depth-the-problem-of-stopping-or-not-starting-hiv-treatment/ Date of access: 30 June 2022.

Gouse, H., Robbins, R.N., Mellins, C.A., Kingon, A., Rowe, J., Henry, M., …& Joska, J.A., 2018. Empowering lay counsellors with technology: Masivukeni, a standardized multimedia counselling support tool to deliver ART counselling. *AIDS and Behavior, 22(10),* pp.3345-3356. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7726217/pdf/nihms-1026780.pdf

Graham, S.M., Micheni, M., Secor, A., van der Elst, E.M., Kombo, B., Operario, D., ... Simoni, J.M. 2018. HIV care engagement and ART adherence among Kenyan gay, bisexual, and other men who have sex with men: a multi-level model informed by qualitative research. *AIDS care*, 30(sup5): S97-S105. https://www.tandfonline.com/doi/full/10.1080/09540121.2018.1515471

Graham, I.D., Logan, J., Harrison, M.B., Straus, S.E., Tetroe, J., Caswell, W. & Robinson, N. 2006. Lost in knowledge translation: time for a map? *Journal of continuing education in the health professions*, 26(1):13-24. https://onlinelibrary.wiley.com/doi/pdfdirect/10.1002/chp.47

Grimsrud, A., Lesosky, M., Kalombo, C., Bekker, L.G. & Myer, L. 2016. Community-based adherence clubs for the management of stable antiretroviral therapy patients in

Cape Town, South Africa: a cohort study. *J Acquired Immune Deficiency Syndromes, 71(1),* p.e16-23. https://journals.lww.com/jaids/Fulltext/2016/01010/Implementation_and_Operational_Research_.18.aspx

Gugsa, S., Potter, K., Tweya, H., Phiri, S., Sande, O., Sikwese, … & O'Malley, G. 2017. Exploring factors associated with ART adherence and retention in care under Option B+ strategy in Malawi: A qualitative study. *PLoS One,* 12(6), p.e0179838. https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0179838

Gyamfi, E., Okyere, P., Enoch, A. & Appiah-Brempong, E. 2017. Prevalence of, and barriers to the disclosure of HIV status to infected children and adolescents in a district of Ghana. *BMC International Health and Human rights, 17(1),* pp.1-8. https://doi.org/10.1186/s12914-017-0114-6

Hall, B.J., Sou, K.L., Beanland, R., Lacky, M., Tso, L.S., Ma, Q., Doherty, M. & Tucker, J.D. 2017. Barriers and facilitators to interventions improving retention in HIV care: a qualitative evidence meta-synthesis. *AIDS and Behavior, 21(6),* pp.1755-1767. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5332336/pdf/nihms831901.pdf

Haas, A.D., Zaniewski, E., Anderegg, N., Ford, N., Fox, M.P., Vinikoor, M., ...Tanon, A. 2018. Retention and mortality on antiretroviral therapy in sub-Saharan Africa: collaborative analyses of HIV treatment programmes. *Journal of the International AIDS Society*, 21(2):1-7. https://onlinelibrary.wiley.com/doi/pdf/10.1002/jia2.25084

Hartzler, A.L., Tuzzio, L., Hsu, C. & Wagner, E.H. 2018. Roles and functions of community health workers in primary care. *The Annals of Family Medicine*, 16(3), pp.240-245. https://www.annfammed.org/content/annalsfm/16/3/240.full.pdf

Hennink, M. & Kaiser, B.N. 2021. Sample sizes for saturation in qualitative research: A systematic review of empirical tests. *Social Science & Medicine*, pp. 1-10. https://www.sciencedirect.com/science/article/pii/S0277953621008558

Hennink, M., Hutter, I. & Bailey, A. 2020. Qualitative research methods. *Sage*. https://books.google.co.za/books?hl=en&lr=&id=_InCDwAAQBAJ&oi=fnd&pg=PP1&dq=qualitative+research+methods&ots=3ueMkRt_iA&sig=vlbfN6pBoT72d8OUbO350hFM_MY&redir_esc=y#v=onepage&q=qualitative%20research%20methods&f=false

Hill, J., Peer, N., Oldenburg, B., & Kengne, A. P. 2017. Roles, responsibilities and characteristics of lay community health workers involved in diabetes prevention programmes: A systematic review. *PLoS one*, *12*(12), e0189069. https://doi.org/10.1371/journal.pone.0189069

Hodgins, F., Gnich, W., Ross, A. J., Sherriff, A., & Worlledge-Andrew, H. 2016. How lay health workers tailor in effective health behaviour change interventions: a protocol for a systematic review. *Systematic reviews*, *5*(1), 102. https://doi.org/10.1186/s13643-016-0271-z

Holtzman, C.W., Brady, K.A. & Yehia, B.R. 2015. Retention in care and medication adherence: current challenges to antiretroviral therapy success*. Drugs, 75(5),* pp.445-454. https://link.springer.com/article/10.1007/s40265-015-0373-2

Horter, S., Thabede, Z., Dlamini, V., Bernays, S., Stringer, B., Mazibuko, S., … & Jobanputra, K. 2017. “Life is so easy on ART, once you accept it”: acceptance, denial and linkage to HIV care in Shiselweni, Swaziland. Social Science & Medicine, 176, p.52-59. https://www.sciencedirect.com/science/article/pii/S0277953617300072

Hu, J., Wang, Y. & Li, X. 2020. Continuity of care in chronic diseases: a concept analysis by literature review. *Journal of Korean Academy of Nursing*, *50(4),* pp.513-522.

https://koreascience.kr/article/JAKO202025356104728.pdf

Igumbor, J.O., Ouma, J., Otwombe, K., Musenge, E., Anyanwu, F.C., Basera, T., … & Schmitz, K. 2019. Effect of a Mentor Mother Programme on retention of mother-baby pairs in HIV care: A secondary analysis of programme data in Uganda. *PLoS one, 14(10),* p.e0223332. https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0223332

Ilesanmi, O.S. & Afolabi, A.A. 2021. Causes of defaulting from antiretroviral therapy and their prevention: a qualitative study of adherent clients and defaulters in Nigeria. HIV & AIDS Review. *International Journal of HIV-Related Problems, 20(2),* p.136-143. https://doi.org/10.5114/hivar.2021.107240

Ilmalwa, W. & Hlatywayo, C. K. 2022. Meaning of Work, Satisfaction with Life, Happiness and Work Engagement, among Nurses at Selected State Hospital, Windhoek, Namibia. *Health & Research Journal, 8(1),* p. 23–34. https://doi.org/10.12681/healthresj.29377

Institute of Medicine. 2013. Evaluation of PEPFAR. Washington, DC: The National Academies Press. https://nap.nationalacademies.org/read/18256/chapter/14 Date of access: 11 March 2021.

Isaacs, P.O. 2014. The psycho-social challenges faced by HIV/AIDS lay counsellors at health facilities in the Eastern Cape (Doctoral dissertation). http://scholar.sun.ac.za/handle/10019.1/86441

Ismail, N., Kinchin, G. & Edwards, J.A. 2018. Pilot study, does it really matter? Learning lessons from conducting a pilot study for a qualitative PhD thesis. *International Journal of Social Science Research, 6(1),* pp.1-17. https://eprints.soton.ac.uk/416716/1/11720_44548_1_PB.pdf

Jackson, J.I. 2015. Nursing paradigms and theories: A primer. https://sigma.nursingrepository.org/bitstream/handle/10755/338888/Nursing+Paradigms+and+Theories,+A+Primer.pdf?sequence=1

Jacobs, Y., Myers, B., van der Westhuizen, C., Brooke-Sumner, C. & Sorsdahl, K. 2021. Task sharing or task dumping: Counsellors experiences of delivering a psychosocial intervention for mental health problems in South Africa. *Community Mental Health Journal, 57(6)*, p.1082-1093. https://link.springer.com/content/pdf/10.1007/s10597-020-00734-0.pdf

Jasper, M. & Rosser, M., 2013. Reflection and reflective practice. *Professional development, reflection and decision-making in nursing and healthcare.* Chichester: Wiley-Blackwell, p.41-82. https://books.google.co.za/books?hl=en&lr=&id=XTxKEAAAQBAJ&oi=fnd&pg=PA41&dq=Reflection+and+Reflective+Practice.&ots=oGEqw7-Mhn&sig=ouvQfXfjHA-QXC2DtWWq5U1YtYU&redir_esc=y#v=onepage&q=Reflection%20and%20Reflective%20Practice.&f=false

Jensen, N., Lund, C. & Abrahams, Z. 2022. Exploring effort–reward imbalance and professional quality of life among health workers in Cape Town, South Africa: a mixed-methods study. *Glob Health Res Policy* 7 (7). https://doi.org/10.1186/s41256-022-00242-6

Johnson, L.F., Dorrington, R.E. & Moolla, H. 2017. Progress towards the 2020 targets for HIV diagnosis and antiretroviral treatment in South Africa. *Southern African journal of HIV medicine*, 18(1):1-8. https://journals.co.za/doi/abs/10.4102/sajhivmed.v18i1.694

Jones, S., Koerner, A. 2015. Support Types. *In The International Encyclopedia of Interpersonal Communication*. 1st Edition*: John Wiley & Sons Inc.*

https://www.researchgate.net/publication/314706225_Support_Types

Joseph-Williams, N., Edwards, A. & Elwyn, G. 2014. Power imbalance prevents shared decision making. *BMJ,* 348. https://www.bmj.com/content/348/bmj.g3178.short

Jubilee M, Park FJ, Chipango K, Pule K, Machinda A, Taruberekera N. 2019. HIV index testing to improve HIV positivity rate and linkage to care and treatment of sexual partners, adolescents and children of PLHIV in Lesotho. *PLoS One* 14(3): e0212762. https://doi.org/10.1371/journal.pone.0212762

Kaplan S. R., Oosthuizen C., Stinson K., Little F., Euvrard J., Schomaker M., ...Meintjies, G. 2017. Contemporary disengagement from antiretroviral therapy in Khayelitsha, South Africa: A cohort study. *PLoS Med, 14* (11): 1-24. https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1002407

Kaushik, V. & Walsh, C.A. 2019. Pragmatism as a research paradigm and its implications for social work research. *Social Sciences*, 8(9):1-17. https://www.mdpi.com/2076-0760/8/9/255

Kavga, A., Kalemikerakis, I., Konstantinidis, T., Tsatsou, I., Galanis, P., Karathanasi, E. & Govina, O. 2022. Factors associated with social support for family members who care for stroke survivors. *AIMS Public Health, 9(1),* p.142. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8755957/

Kay, E.S., Batey, D.S. & Mugavero, M.J. 2016. The HIV treatment cascade and care continuum: updates, goals, and recommendations for the future*. AIDS Research and Therapy*, 13(1): 1-7. https://aidsrestherapy.biomedcentral.com/articles/10.1186/s12981-016-0120-0

Kayed, H. & Moghadam, K. K. 2021. Causal relationship between personality traits and psychological well-being with quality of working life through perceived social support in nurses. *Journal of Fundamentals of Mental Health,* p. 433–442. https://jfmh.mums.ac.ir/article_19330.html

Kibaara, C., Blat, C., Lewis-Kulzer, J., Shade, S., Mbullo, P., Cohen, C.R. & Bukusi, E.A. 2016. Treatment buddies improve clinic attendance among women but not men on antiretroviral therapy in the Nyanza region of Kenya. *AIDS Research and Treatment, 2016*. https://www.hindawi.com/journals/art/2016/9124541/

Kivunja, C. & Kuyini, A.B. 2017. Understanding and applying research paradigms in educational contexts. *International Journal of higher education*, 6(5): 26-41. https://files.eric.ed.gov/fulltext/EJ1154775.pdf

Knettel, B.A., Fernandez, K.M., Wanda, L., Amiri, I., Cassiello-Robbins, C., Watt, M.H., Mmbaga, B.T. & Relf, M.V., 2021. The role of community health workers in HIV care engagement: A qualitative study of stakeholder perspectives in Tanzania. *The Journal of the Association of Nurses in AIDS Care: JANAC, 32(6),* p.682. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8548405/pdf/nihms-1718520.pdf

Kok, M.C., Kane, S.S., Tulloch, O., Ormel, H., Theobald, S., Dieleman, M., … & de Koning, K.A. 2015. How does context influence performance of community health workers in low-and middle-income countries? Evidence from the literature. *Health Research Policy and Systems*, 13(1), pp.1-14. https://link.springer.com/article/10.1186/s12961-015-0001-3

Kok, M.C., Broerse, J.E., Theobald, S., Ormel, H., Dieleman, M. & Taegtmeyer, M. 2017. Performance of community health workers: situating their intermediary position within complex adaptive health systems. Human resources for health, 15(1), pp.1-7. https://doi.org/10.1186/s12960-017-0234-z

Kokolakis, S., 2017. Privacy attitudes and privacy behavior: A review of current research on the privacy paradox phenomenon. *Computers & security, 64*, p.122-134. https://www.sciencedirect.com/science/article/pii/S0167404815001017

Korstjens, I. & Moser, A. 2018. Series: Practical guidance to qualitative research. Part 4: Trustworthiness and publishing. *European Journal of General Practice*, 24(1): 120-

124.https://www.tandfonline.com/doi/pdf/10.1080/13814788.2017.1375092?needAcce

Kram, N.A., Yesufu, V., Lott, B., Palmer, K.N., Balogun, M. & Ehiri, J., 2021. ‘Making the most of our situation’: a qualitative study reporting health providers’ perspective on the challenges of implementing the prevention of mother-to-child transmission of HIV services in Lagos, Nigeria. *BMJ open, 11(10),* p.e046263. https://bmjopen.bmj.com/content/bmjopen/11/10/e046263.full.pdf

Krubiner, C.B., Keller, J.M. & Kaufman, J. 2020. Balancing the COVID-19 response with wider health needs: key decision-making considerations for low-and middle-income countries. https://www.jstor.org/stable/pdf/resrep29626.pdf

Kutnick, A.H., Gwadz, M.V., Cleland, C.M., Leonard, N.R., Freeman, R., Ritchie, A.S., … & Belkin, M. 2017. It’s a process: reactions to HIV diagnosis and engagement in HIV care among high-risk heterosexuals. *Frontiers in Public Health, 5*, p.100. https://www.frontiersin.org/articles/10.3389/fpubh.2017.00100/full

Kwame, A. & Petrucka, P.M. 2020. Communication in nurse-patient interaction in healthcare settings in sub-Saharan Africa: A scoping review. *International Journal of Africa Nursing Sciences, 12*, p.100198. https://www.sciencedirect.com/science/article/pii/S2214139119301490

Laforest, M.E., Krol, P.J. & Leblanc, N. 2017. Theoretical and ethical issues using Heidegger’s hermeneutics in a research project with children living with physical, intellectual or social disabilities. *Journal of Nursing Education and Practice*, 7(10):46-55. https://www.sciedupress.com/journal/index.php/jnep/article/view/11371/7085

Lakey, B. & Cohen, S. 2000. Social support theory and measurement. https://psycnet.apa.org/doi/10.1093/med:psych/9780195126709.003.0002

Laurenzi, C.A., Skeen, S., Coetzee, B.J., Notholi, V., Gordon, S., Chademana, E., … & Tomlinson, M. 2021. Instructive roles and supportive relationships: client perspectives of their engagement with community health workers in a rural South African home visiting program. *International Journal for Equity in Health*, 20(1), p.1-12. https://equityhealthj.biomedcentral.com/articles/10.1186/s12939-020-01377-z

Leon, C., Koosed, T., Philibert, B., Raposo, C. & Benzaken, A.S. 2019. HIV/AIDS health services in Manaus, Brazil: patient perception of quality and its influence on adherence to antiretroviral treatment. *BMC health services research, 19(1),* p.1-11. https://bmchealthservres.biomedcentral.com/track/pdf/10.1186/s12913-019-4062-9.pdf

Letsoalo, M.R. & Ntuli, B. 2017. The perceptions of HIV lay counsellors with regard to their experiences at primary health facilities in Ekurhuleni North Subdistrict, South Africa (Doctoral dissertation, Sefako Makgatho Health Sciences University). https://repository.smu.ac.za/bitstream/handle/20.500.12308/553/M%20R%20Letsoalo%20Dissertation.pdf?sequence=1&isAllowed=y

Leavy, P. 2022. Research design: Quantitative, qualitative, mixed methods, arts-based, and community-based participatory research approaches. Guilford Publications. https://books.google.co.za/books?hl=en&lr=&id=yj2VEAAAQBAJ&oi=fnd&pg=PP1&dq=research+approach&ots=Yki5fCzsO8&sig=bcH1ThbxDjc02eR1BR9nGwyhm0o&redir_esc=y#v=onepage&q=research%20approach&f=false

Li, H., Wei, C., Tucker, J., Kang, D., Liao, M., Holroyd, E., … & Ma, W. 2017. Barriers and facilitators of linkage to HIV care among HIV-infected young Chinese men who have sex with men: a qualitative study. *BMC Health Services Research*, 17(1), pp.1-8. https://doi.org/10.1186/s12913-017-2158-7

Lilian, R.R., Rees, K., McIntyre, J.A., Struthers, H.E. & Peters, R.P. 2020. Same-day antiretroviral therapy initiation for HIV-infected adults in South Africa: Analysis of routine data. *PLoS One, 15(1),* p.e0227572. https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0227572

Limbani, F., Thorogood, M., Gómez-Olivé, F.X., Kabudula, C. & Goudge, J. 2019. Task shifting to improve the provision of integrated chronic care: realist evaluation of a lay health worker intervention in rural South Africa. *BMJ Global Health, 4(1),* p.e001084. https://gh.bmj.com/content/4/1/e001084.abstract

Lippman, S.A., Shade, S.B., El Ayadi, A.M., Gilvydis, J.M., Grignon, J.S., Liegler, T., ...Barnhart, S. 2016. Attrition and opportunities along the HIV care continuum: findings from a population-based sample, North-West Province, South Africa. *Journal of Acquired Immune Deficiency Syndromes*, 73(1):91-99. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4981507/

Liu, Y., Aungsuroch, Y. & Yunibhand, J., 2016. Job satisfaction in nursing: a concept analysis study. *International Nursing Review, 63(1),* pp.84-91. https://doi.org/10.1111/inr.12215

Lowane, M.P. & Lebese, R.T. 2022. Missing appointments by patients on antiretroviral therapy: Professional nurses' perspective. *Curationis,* 45(1), p.1-7. http://www.scielo.org.za/pdf/cura/v45n1/03.pdf

Ludwick, T., Turyakira, E., Kyomuhangi, T., Manalili, K., Robinson, S. & Brenner, J.L. 2018. Supportive supervision and constructive relationships with healthcare workers support CHW performance: use of a qualitative framework to evaluate CHW programming in Uganda. *Human Resources for Health, 16(1),* pp.1-8. https://human-resources-health.biomedcentral.com/articles/10.1186/s12960-018-0272-1

Lundqvist, D., Fogelberg Eriksson, A. & Ekberg, K. 2018. Managers' social support: Facilitators and hindrances for seeking support at work. *Work, 59(3),* p.351-365. https://www.diva-portal.org/smash/get/diva2:1201638/FULLTEXT02

Madhvani, N., Longinetti, E., Santacatterina, M., Forsberg, B.C. & El-Khatib, Z. 2015. Correlates of mobile phone use in HIV care: Results from a cross-sectional study in South Africa*. Preventive Medicine Reports, 2,* p.512-516. https://www.sciencedirect.com/science/article/pii/S2211335515000820

Maeri, I., El Ayadi, A., Getahun, M., Charlebois, E., Akatukwasa, C., Tumwebaze, D…, & Sang, N. 2016. "How can I tell?" Consequences of HIV status disclosure among couples in Eastern African communities in the context of an ongoing HIV "test-and-treat" trial. *AIDS care, 28*(*sup3*), pp.59-66. https://www.tandfonline.com/doi/pdf/10.1080/09540121.2016.1168917

Maguire, M. & Delahunt, B. 2017. Doing a thematic analysis: A practical, step-by-step guide for learning and teaching scholars. *All Ireland Journal of Higher Education*, 8(3):1-14. https://ojs.aishe.org/index.php/aishe-j/article/view/335

Majid, U. 2018. Research fundamentals: Study design, population, and sample size. *Undergraduate Research in Natural and Clinical Science and Technology journal*, 2:1-7. https://www.urncst.com/index.php/urncst/article/view/16

Mantell, J.E., Masvawure, T.B., Mapingure, M., Apollo, T., Gwanzura, C., Block, L., … & Rabkin, M. 2019. Engaging men in HIV programmes: a qualitative study of male engagement in community-based antiretroviral refill groups in Zimbabwe. *Journal of the International AIDS Society, 22(10),* p.e25403. https://onlinelibrary.wiley.com/doi/epdf/10.1002/jia2.25403

Manti, S. & Licari, A. 2018. How to obtain informed consent for research. *Breathe, 14(2)*, p.145-152. https://breathe.ersjournals.com/content/breathe/14/2/145.full.pdf

Maqsood, S. 2019. Social support and work-family life enrichment: the mediating role of emotional intelligence. *Pakistan Journal of Social Sciences, 39(1),* p.1-8. https://www.bzu.edu.pk/PJSS/Vol.%2038,%20No.%202,%202018/Vol.%2039,%20No.%201,%202019/PJSS-Vol39-No1,%202019-01.pdf

Marutha, N.S. & Ngoepe, M. 2017. The role of medical records in the provision of public healthcare services in the Limpopo province of South Africa, *South African Journal of Information Management* 19(1), a873. https://journals.co.za/doi/epdf/10.4102/sajim.v19i1.873

Mathieu, M., Eschleman, K.J. & Cheng, D. 2018. Meta-analytic and multiwave comparison of emotional support and instrumental support in the workplace. *Journal of Occupational Health Psychology, 24(3),* p.387. http://www.eschleman.com/uploads/9/2/8/0/92800488/johp_2018.pdf

Matseke, G., Peltzer, K., & Mohlabane, N. 2016. Clients' perceptions and satisfaction with HIV counselling and testing: A cross-sectional study in 56 HCT sites in South Africa. *African journal of primary health care & family medicine*, *8*(1), e1–e7. https://doi.org/10.4102/phcfm.v8i1.1173

Maughan-Brown, B., Kuo, C., Galárraga, O., Smith, P., Lurie, M.N., Bekker, L.G. & Harrison, A. 2018. Stumbling blocks at the clinic: experiences of seeking HIV treatment and care in South Africa. *AIDS and Behavior, 22(3),* pp.765-773. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5815960/pdf/nihms907267.pdf

May, C.R., Cummings, A., Girling, M., Bracher, M., Mair, F.S., May, C.M., Murray, E., Myall, M., Rapley, T. & Finch, T. 2018. Using normalization process theory in feasibility studies and process evaluations of complex healthcare interventions: a systematic review. *Implementation Science*, 13(1):1-27. https://implementationscience.biomedcentral.com/articles/10.1186/s13012-018-0758-1

McCombes. 2019a, March 09. How to write a literature review [Scribbr Blog post]. https://www.scribbr.com/author/shona/page/5/ Date of access: 22 March 2021.

McCombes, S. 2019b, 3 September. Descriptive research. [Scribbr Blog post] https://www.scribbr.com/methodology/descriptive-research/ Date of access: 22 March 2021.

Mhlongo, E. M., & Lutge, E. 2021. Facility Managers' Perceptions of Support and Supervision of Ward Based Primary Health Care Outreach Teams in National Health Insurance Pilot Districts in KwaZulu-Natal, South Africa. A Qualitative Study. *Healthcare (Basel, Switzerland)*, *9* (12), 1718. https://doi.org/10.3390/healthcare9121718

Mikulincer, M.E., Shaver, P.R., Simpson, J.A. and Dovidio, J.F., 2015. APA Handbook of Personality and Social Psychology, Volume 3: Interpersonal Relations. *American Psychological Association.* https://perpus.univpancasila.ac.id/repository/EBUPT191189.pdf#page=382

Min, R.M. & Abdullah, T.N.T. 2017. People affected with HIV: Experience of counselling contributes to emotional support. *Asian Social Science, 13(1).* https://pdfs.semanticscholar.org/7426/8d2289937302794bfe8f494d5190052352a9.pdf

Mkhabele, C. & Peu, D. 2016. The experiences of lay counsellors regarding HIV and AIDS care and support in Tshwane clinics. *The Social Work Practitioner-Researcher, 28(3),* pp.316-329. https://repository.up.ac.za/bitstream/handle/2263/58261/Mkhabele_Experiences_2016.pdf?sequence=1

Mody, A., Sikombe, K., Beres, L.K., Simbeza, S., Mukamba, N., Eshun-Wilson, I., … & Bolton-Moore, C. 2021. Profiles of HIV care disruptions among adult patients lost to follow-up in Zambia: a latent class analysis. *Journal of Acquired Immune Deficiency Syndromes (1999), 86(1),* p.62. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7722465/

Monareng, L.V., 2012. Spiritual nursing care: A concept analysis. *Curationis*, *35(1),* pp.1-9. http://www.scielo.org.za/pdf/cura/v35n1/13.pdf

Moosa, A., Gengiah, T.N., Lewis, L. & Naidoo, K. 2019. Long-term adherence to antiretroviral therapy in a South African adult patient cohort: a retrospective study. *BMC infectious diseases, 19(1)*, p.1-12. https://bmcinfectdis.biomedcentral.com/track/pdf/10.1186/s12879-019-4410-8.pdf

Morelli, S.A., Lee, I.A., Arnn, M.E. & Zaki, J., 2015. Emotional and instrumental support provision interact to predict well-being. *Emotion, 15(4),* p.484. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4516598/pdf/nihms686863.pdf

Motloba, P.D. 2019. Non-maleficence-a disremembered moral obligation. *South African Dental Journal*, 74(1):40-42. http://www.scielo.org.za/scielo.php?pid=S0011-85162019000100009&script=sci_arttext&tlng=es

Mphahlele, M. & Zandamela, H. 2021. Local Government Capacity Development: A Case Study of a South African District Municipality. *Journal of Public Administration and Governance, 11(2),* p.156-177. https://pdfs.semanticscholar.org/aec3/afc25312d8544a5f1a52f2fdd2c9c179d70a.pdf

Mshweshwe-Pakela, N., Mabuto, T., Ntombela, N., Hlongwane, M., Kubeka, G., Kerrigan, D.L. & Hoffmann, C.J. 2022. Facilitators and barriers to implementing provider-initiated HIV counselling and testing at the clinic-level in Ekurhuleni District, South Africa. *Implementation Science Communications, 3(1),* pp.1-9. https://implementationsciencecomms.biomedcentral.com/articles/10.1186/s43058-022-00269-3

Mshweshwe-Pakela, N., Hansoti, B., Mabuto, T., Kerrigan, D., Kubeka, G., Hahn, E., …& Hoffmann, C.J. 2020. Feasibility of implementing same-day antiretroviral therapy initiation during routine care in Ekurhuleni District, South Africa: Retention and viral load suppression. *Southern African Journal of HIV medicine, 21(1),* pp.1-6. http://www.scielo.org.za/pdf/sajhivmed/v21n1/31.pdf

Mudavanhu, N. & Schenck, R. 2014. Substance abuse amongst the youth in Grabouw Western Cape: Voices from the community. *Social Work*, 50(3):370-392. http://www.scielo.org.za/scielo.php?pid=S003780542014000200004&script=sci_arttext&tlng=es

Mudavanhu, M., West, N.S., Schwartz, S.R., Mutunga, L., Keyser, V., Bassett, J., …& Hanrahan, C.F. 2020. Perceptions of community and clinic-based adherence clubs for patients stable on antiretroviral treatment: a mixed methods study. *AIDS and Behavior, 24(4),* p.1197-1206. **Abstract retrieved from** https://link.springer.com/article/10.1007/s10461-019-02681-8

Mukumbang, F.C., Mwale, J.C. & Van Wyk, B. 2017. Conceptualizing the factors affecting retention in care of patients on antiretroviral treatment in Kabwe District, Zambia, using the ecological framework. *AIDS research and treatment*, (2017):1-12. https://downloads.hindawi.com/journals/art/2017/7356362.pdf

Mukumbang, F.C. 2021. Leaving no man behind: how differentiated service delivery models increase men's engagement in HIV care. *International Journal of Health Policy and Management, 10(3),* p.129. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7947905/

Mulumba, M., London, L., Nantaba, J. & Ngwena, C. 2018. Using health committees to promote community participation as a social determinant of the right to health: lessons from Uganda and South Africa. *Health and Human rights, 20(2),* p.11. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6293345/pdf/hhr-20-011.pdf

Mulqueeny, D.M. & Taylor, M., 2017. Patients' recommendations for a patient-centred public antiretroviral therapy programme in eThekwini, KwaZulu-Natal. *Southern African Journal of HIV medicine, 18(1).* https://www.ajol.info/index.php/sajhivm/article/view/154906

Mundeva, H., Snyder, J., Ngilangwa, D.P. & Kaida, A. 2018. Ethics of task shifting in the health workforce: exploring the role of community health workers in HIV service delivery in low-and middle-income countries. *BMC Medical Ethics*, 19(1), pp.1-11. https://bmcmedethics.biomedcentral.com/track/pdf/10.1186/s12910-018-0312-3.pdf

Mwamba, C., Sharma, A., Mukamba, N., Beres, L., Geng, E., Holmes, C.B., … & Topp, S.M. 2018. 'They care rudely!': resourcing and relational health system factors that influence retention in care for people living with HIV in Zambia. *BMJ Global Health, 3(5),* p.e001007. https://gh.bmj.com/content/bmjgh/3/5/e001007.full.pdf

Mwisongo, A., Mehlomakhulu, V., Mohlabane, N., Peltzer, K., Mthembu, J. & Van Rooyen, H. 2015. Evaluation of the HIV lay counselling and testing profession in South Africa. *BMC health services research*, 15(1): 2-7. https://doi.org/10.1186/s12913-015-0940-y

Naidoo, N., Zuma, N., Khosa, N.S., Marincowitz, G., Railton, J., Matlakala, N. ...Peters, R.P. 2018. Qualitative assessment of facilitators and barriers to HIV programme implementation by community health care workers in Mopani district, South Africa. *PLoS one*, 13(8): 2-17. https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0203081

Nasurdin, A.M., Ling, T.C. & Khan, S.N. 2018. Linking social support, work engagement and job performance in nursing. *International Journal of Business & Society, 19(2).* *http://www.ijbs.unimas.my/images/repository/pdf/Vol19-no2-paper8.pdf*

Ndambo, M.K., Munyaneza, F., Aron, M.B., Nhlema, B. & Connolly, E. 2022. Qualitative assessment of community health workers' perspective on their motivation in community-based primary health care in rural Malawi. *BMC Health Services* research, 22(1), pp.1-13.https://doi.org/10.1186/s12913-022-07558-6

Ndou, T. V., Maputle, S. M., & Risenga, P. R. 2016. HIV-positive patients' perceptions of care received at a selected antiretroviral therapy clinic in Vhembe district, South Africa. *African Journal of Primary Health care & Family medicine*, *8*(2), e1–e6. https://doi.org/10.4102/phcfm.v8i2.926

Ngangue, P., Gagnon, M.P. & Bedard, E. 2017. Challenges in the delivery of public HIV testing and counselling in Douala, Cameroon: providers perspectives and implications on quality of HTC services. *BMC International Health and Human rights, 17(1),* p.1-9. https://link.springer.com/article/10.1186/s12914-017-0118-2

Nguyen, D.T., Teo, S.T. & Dinh, K.C. 2020. Social support as buffer for workplace negative acts of professional public sector employees in Vietnam. *Public Management Review, 22(1)*, p.6-26. https://www.tandfonline.com/doi/abs/10.1080/14719037.2019.1638438

Now health International. 2022, June 17 [Blog post]. https://www.now-health.com/en/blog/what-is-in-patient-vs-out-patient-healthcare/ Date of access: 01 July 2022.

Nowell, L.S., Norris, J.M., White, D.E. & Moules, N.J. 2017. Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative methods, 16(1)*, p.1-13. https://journals.sagepub.com/doi/full/10.1177/1609406917733847

Nsiah, C., Siakwa, M. & Ninnoni, J.P. 2019. Registered nurses' description of patient advocacy in the clinical setting. *Nursing Open, 6(3),* p.1124-1132. https://onlinelibrary.wiley.com/doi/epdf/10.1002/nop2.307

Nyumba, T. O., Wilson, K., Derrick, C.J. & Mukherjee, N. 2017. The use of focus group discussion methodology: Insights from two decades of application in conservation. *Methods in Ecology and Evolution*, 9(1), p.20-32. https://besjournals.onlinelibrary.wiley.com/doi/full/10.1111/2041-210X.12860

O'Connor, S., Brenner, M. & Coyne, I. 2019. Family-centred care of children and young people in the acute hospital setting: a concept analysis. *Journal of Clinical Nursing, 28(17-18),* pp.3353-3367. https://doi.org/10.1111/jocn.14913

Öktem, P. 2015. The role of the family in attributing meaning to living with HIV and its stigma in Turkey. *SAGE Open, 5(4),* p.2158244015615165. https://journals.sagepub.com/doi/pdf/10.1177/2158244015615165

Omonaiye, O., Nicholson, P., Kusljic, S. & Manias, E. 2018. A meta-analysis of effectiveness of interventions to improve adherence in pregnant women receiving antiretroviral therapy in sub-Saharan Africa. *International Journal of Infectious Diseases, 74,* p.71-82. https://www.sciencedirect.com/science/article/pii/S120197121834462X

Onoya, D., Mokhele, I., Sineke, T., Mngoma, B., Moolla, A., Vujovic, M., …& Fox, M.P. 2021. Health provider perspectives on the implementation of the same-day-ART initiation policy in the Gauteng province of South Africa. *Health Research Policy and Systems, 19(1),* p.1-12. https://health-policy-systems.biomedcentral.com/track/pdf/10.1186/s12961-020-00673-y.pdf

Ormel, H., Kok, M., Kane, S., Ahmed, R., Chikaphupha, K., Rashid, S.F., … & Taegtmeyer, M. 2019. Salaried and voluntary community health workers: exploring how incentives and expectation gaps influence motivation. *Human Resources for Health, 17(1*), pp.1-12. https://doi.org/10.1186/s12960-019-0387-z

Osler, M., Hilderbrand, K., Goemaere, E., Ford, N., Smith, M., Meintjes, ... Boulle, A. 2018. The continuing burden of advanced HIV disease over 10 years of increasing antiretroviral therapy coverage in South Africa. *Clinical Infectious Diseases*, 66(2): S118-S125. https://academic.oup.com/cid/article/66/suppl_2/S118/4918989

Patten, M.L. & Newhart, M. 2017. Understanding research methods: An overview of the essentials. Routledge. https://www.researchgate.net/profile/Michelle-Newhart/publication/321154617_Understanding_research_methods_An_overview_of_the_essentials_tenth_edition/links/5fb40af8a6fdcc9ae05e5e1d/Understanding-research-methods-An-overview-of-the-essentials-tenth-edition.pdf

Pelin, I. I. & Osoian, C. 2021. Co-Workers Support and Job Performance. Studia Universitatis Babes-Bolyai. *Oeconomica, 66(2),* p. 74–86. https://doi.org/10.2478/subboec-2021-0010

Peterson, J.K. & Evangelista, L.S. 2017. Developmentally supportive care in congenital heart disease: a concept analysis. *Journal of Pediatric Nursing, 36*, pp.241-247. https://www.sciencedirect.com/science/article/abs/pii/S0882596316301737

Petersen, I., Fairall, L., Egbe, C.O. & Bhana, A. 2014. Optimizing lay counsellor services for chronic care in South Africa: a qualitative systematic review. *Patient Education and Counseling*, 95(2): 201-210. https://www.sciencedirect.com/science/article/pii/S0738399114000524

Pezaro, S., Clyne, W. & Gerada, C. 2018. Confidentiality, anonymity and amnesty for midwives in distress seeking online support–Ethical? *Nursing Ethics, 25(4)*, pp.481-504. https://journals.sagepub.com/doi/pdf/10.1177/0969733016654315

Plowright, A., Taylor, C., Davies, D., Sartori, J., Hundt, G.L. & Lilford, R.J. 2018. Formative evaluation of a training intervention for community health workers in South Africa: A before and after study. *PLoS one, 13(9),* p.e0202817. https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0202817

Pratap, A. 2019, 22 September. Research design and its types: Exploratory, descriptive and causal [Blog post] https://notesmatic.com/2018/07/research-design-and-its-types-exploratory-descriptive-and-causal/ Date of access: 24 Feb 2021.

Pretorius, Z., 2019. The perceptions and experiences of HIV testing service counsellors with providing HIV counselling and testing at three community sites in South Africa (Doctoral dissertation). https://wiredspace.wits.ac.za/handle/10539/28215

Raberahona, M., Lidamahasolo, Z., Andriamamonjisoa, J., Andriananja, V., Andrianasolo, R.L., Rakotoarivelo, R.A. & de Dieu Randria, M.J. 2019. Knowledge, attitudes, perception and practices regarding antiretroviral therapy among HIV-infected adults in Antananarivo, Madagascar: a cross-sectional survey. *BMC health Services Research*, 19(1), pp.1-9. https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-019-4173-3

Rahi, S. 2017. Research design and methods: A systematic review of research paradigms, sampling issues and instruments development. *International Journal of Economics & Management Sciences*, 6(2):1-5. https://pdfs.semanticscholar.org/d957/e1a07a961a572ce70f7d5845cb423ac8f0be.pdf

Ramukumba, M.M. 2020. Exploration of Community health workers' views about in their role and support in primary health care in Northern Cape, South Africa. *Journal of community health, 45(1)*, p.55-62. https://link.springer.com/content/pdf/10.1007/s10900-019-00711-z.pdf

Ravindran, V. 2019. Data analysis in qualitative research. *Indian Journal of Continuing Nursing Education, 20(1)*, p.40. https://www.ijcne.org/temp/IndianJContNsgEdn20140-4405381_121413.pdf

Restrepo, J.E., Ospina-Bran, Z.E. & Cuartas-Montoya, G.P. 2022. Mood and perceived social support of Colombian older adults with chronic obstructive pulmonary disease during the pandemic: A cross-sectional descriptive study. *Gac Méd Caracas, 130(1)*, p.105-113. http://saber.ucv.ve/ojs/index.php/rev_gmc/article/view/23594

Riley, R.D., Ensor, J., Snell, K.I., Harrell, F.E., Martin, G.P., Reitsma, J.B., …& Van Smeden, M., 2020. Calculating the sample size required for developing a clinical prediction model. *BMJ*, pp 1-12. https://eprints.keele.ac.uk/id/eprint/7880/1/bmj.m441.full.pdf

Risenga, P.R. & Davhana-Maselesele, M. 2017. A concept analysis of young adults; Perception of HIV Counselling and Testing. *Health SA Gesondheid*, 22, p.213-220. https://www.ajol.info/index.php/hsa/article/view/159808

Rogers, K.M. & Ashforth, B.E. 2017. Respect in organizations: Feeling valued as "we" and "me". *Journal of Management, 43(5),* p.1578-1608. https://epublications.marquette.edu/cgi/viewcontent.cgi?article=1299&context=mgmt_fac

Rodgers, B.L., Jacelon, C.S. & Knafl, K.A. 2018. Concept analysis and the advance of nursing knowledge: state of the science. *Journal of Nursing Scholarship, 50(4),* p.451-459. https://sigmapubs.onlinelibrary.wiley.com/doi/full/10.1111/jnu.12386

Roscoe, C., Hachey, D. M. 2020, September 10. Retention in HIV care [National HIV curriculum].https://www.hiv.uw.edu/go/basic-primary-care/retention-care/core-concept/all Date of access: 11 Mar. 2021.

Rosen, M. A., DiazGranados, D., Dietz, A. S., Benishek, L. E., Thompson, D., Pronovost, P. J., & Weaver, S. J. 2018. Teamwork in healthcare: Key discoveries enabling safer, high-quality care. *The American Psychologist*, *73*(4), 433–450. https://doi.org/10.1037/amp0000298

Roy, M., Czaicki, N., Holmes, C., Chavan, S., Tsitsi, A., Odeny, T., ...Geng, E., 2016. Understanding sustained retention in HIV/AIDS care and treatment: a synthetic review. *Current HIV/AIDS Reports*, 13(3):177-185. https://link.springer.com/article/10.1007/s11904-016-0317-9

Rudolph, C.W., Katz, I.M., Ruppel, R. & Zacher, H. 2021. A systematic and critical review of research on respect in leadership. *The Leadership Quarterly, 32(1),* p.101492. https://www.sciencedirect.com/science/article/pii/S1048984320301193

Saddki, N., Sulaiman, Z., Abdullah, S., Zakaria, N., Mohamad, N., Ab Razak, A. & Zainan Abidin, Z. 2016. HIV-related knowledge among people living with HIV/AIDS in Kelantan, Malaysia. *Journal of HIV/AIDS & Social Services, 15(2),* p.216-233.

https://www.tandfonline.com/doi/abs/10.1080/15381501.2013.816648

Sam-Agudu, N.A., Odiachi, A., Bathnna, M.J., Ekwueme, C.N., Nwanne, G., Iwu, E.N. & Cornelius, L.J. 2018. “They do not see us as one of them”: a qualitative exploration of mentor mothers’ working relationships with healthcare workers in rural North-Central Nigeria. *Human resources for health, 16(1),* p.1-12. https://human-resources-health.biomedcentral.com/articles/10.1186/s12960-018-0313-9

Samuel, K. 2020. Pros and cons of disclosing your HIV status. *National AIDS Manual Publication, England*.

https://www.aidsmap.com/about-hiv/pros-and-cons-disclosing-your-hiv-status

Date of access: 15 May 2022.

SANDoH (South African National Department of Health). 2017. National Guideline for Filing, Archiving and Disposal of Patient Records in Primary Health Care Facilities. https://www.knowledgehub.org.za/elibrary/national-standard-operating-procedure-filing-archiving-and-disposal-patient-records

SANDoH. 2018. Policy Framework and Strategy for Ward Based Primary Healthcare Outreach Teams, 2018/19-2023/24.

https://www.health.gov.za/wp-content/uploads/2020/11/policy-wbphcot-4-april-2018_final-copy.pdf Date of access: 21 June 2022.

SANDoH. 2020a. National Consolidated Guidelines for the management of HIV in adults, adolescents, children and infants and prevention of mother-to-child transmission. https://www.knowledgehub.org.za/system/files/elibdownloads/2020-07/National%20Consolidated%20Guidelines%2030062020%20signed%20PRINT%20v7.pdf Accessed: 21 June 2022.

SANDoH. 2020b. Adherence Guidelines for HIV, TB and NCDs: SOPs: Minimum Package of Interventions to support linkage to care, adherence and retention in care, 2020. https://www.tbhivinfosys.org.za/doc/adherence-guidelines-sops-march20-revision-final-ndoh-print/ Accessed: 21 June 2022.

Schmitz, K., Basera, T.J., Egbujie, B., Mistri, P., Naidoo, N., Mapanga, W., ... Igumbor, J. 2019. Impact of lay health worker programmes on the health outcomes of mother-child pairs of HIV exposed children in Africa: A scoping review. *PLoS One*, 14(1): 1-21. https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0211439

Scott, K., Beckham, S.W., Gross, M., Pariyo, G., Rao, K.D., Cometto, G. & Perry, H.B. 2018. What do we know about community-based health worker programs? A systematic review of existing reviews on community health workers. *Human Resources for Health, 16(1),* p.1-17. https://link.springer.com/content/pdf/10.1186/s12960-018-0304-x.pdf

Seelandt, J.C., Walker, K. & Kolbe, M. 2021. “A debriefer must be neutral” and other debriefing myths: a systemic inquiry-based qualitative study of taken-for-granted beliefs about clinical post-event debriefing. *Adv Simul* 6, (7). https://doi.org/10.1186/s41077-021-00161-5

Seladi-Schulman, J. 2020. 10 Types of Health Clinics and the Services Provided. *Healthline* (Blog post). https://www.healthline.com/health/types-of-health-clinics Date of access: 23 June 2022.

Shabalala, F.S., Vernooij, E., Pell, C., Simelane, N., Masilela, N., Spiegelman, D., ...Reis, R. 2018. Understanding reasons for discontinued antiretroviral treatment among clients in test and treat: a qualitative study in Swaziland. *Journal of the International AIDS Society*, 21(S4):53-59. https://onlinelibrary.wiley.com/doi/epdf/10.1002/jia2.25120

Shah, M., Risher, K., Berry, S.A. & Dowdy, D.W., 2016. The epidemiologic and economic impact of improving HIV testing, linkage, and retention in care in the United States. *Clinical infectious diseases*, 62(2): 220-229. https://academic.oup.com/cid/article/62/2/220/2462686

Shahmalak, U., Blakemore, A., Waheed, M.W. & Waheed, W. 2019. The experiences of lay health workers trained in task-shifting psychological interventions: a qualitative systematic review. *International Journal of Mental Health Systems*, 13(1), pp.1-15. https://doi.org/10.1186/s13033-019-0320-9

Showkat, N. & Parveen, H., 2017. In-depth interview. Quadrant-I (e-Text). http://www.uop.edu.pk/ocontents/Lecture%204%20indepth%20interview.pdf Date of access: 17 July 2022.

Sim, J., Saunders, B., Waterfield, J. & Kingstone, T. 2018. Can sample size in qualitative research be determined a priori? *International Journal of Social Research Methodology*, 21(5):1-18. https://www.tandfonline.com/doi/abs/10.1080/13645579.2018.1454643

Sineke, T., Mokhele, I., Langa, J., Mngoma, B. & Onoya, D. 2021. HIV and ART related knowledge among newly diagnosed patients with HIV under the universal-test-and-treat (UTT) policy in Johannesburg, South Africa. *AIDS care,* p.1-8.

https://www.tandfonline.com/doi/pdf/10.1080/09540121.2021.1902927?needAccess=true

Skovdal, M., Wringe, A., Seeley, J., Renju, J., Paparini, S., Wamoyi, J., ...Bernays, S. 2017. Using theories of practice to understand HIV-positive persons varied engagement with HIV services: a qualitative study in six Sub-Saharan African countries. *Sexually transmitted infections*, 93 (3):1-7. http://orcid.org/0000-0002-2068-1814

Smith, L. 2013. HIV Care Utilization: A Theory-Based Approach to Retention in Care (Doctoral dissertation). https://opencommons.uconn.edu/cgi/viewcontent.cgi?article=6379&context=dissertations

Spangler, S.A., Abuogi, L.L., Akama, E., Bukusi, E.A., Helova, A., Musoke, P…, & Turan, J.M., 2018. From 'half-dead' to being 'free': Resistance to HIV stigma, self-disclosure and support for PMTCT/HIV care among couples living with HIV in Kenya. *Culture, Health & Sexuality, 20(5)*, p.489-503. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5815954/pdf/nihms902153.pdf

Stahl, N.A. & King, J.R. 2020. Expanding approaches for research: Understanding and using trustworthiness in qualitative research. *Journal of Developmental Education, 44(1)*, p.26-28. https://files.eric.ed.gov/fulltext/EJ1320570.pdf

Stenfors, T., Kajamaa, A. & Bennett, D. 2020. How to… assess the quality of qualitative research. *The Clinical Teacher*, 17(6), pp.596-599. https://onlinelibrary.wiley.com/doi/pdfdirect/10.1111/tct.13242

Stoltz, P., Andersson, E.P. & Willman, A. 2007. Support in nursing—An evolutionary concept analysis. *International Journal of Nursing Studies, 44(8),* p.1478-1489. https://doi.org/10.1016/j.ijnurstu.2006.07.014

Sudsawad, P., 2007. Knowledge translation: introduction to models, strategies and measures. Austin, TX: Southwest Educational Development Laboratory, National Centre for the Dissemination of Disability Research. https://ktdrr.org/ktlibrary/articles_pubs/ktmodels/ktintro.pdf

"Support". 2022. Cambridge Dictionary. Cambridge University Press. https://dictionary.cambridge.org/dictionary/english/support Date of access: 03 June 2022.

"Support". 2022. Collins English Thesaurus. https://www.collinsdictionary.com/dictionary/english-thesaurus/support Date of access: 03 June 2022.

"Support." 2022. Merriam-Webster.com Dictionary. https://www.merriam-webster.com/dictionary/support Date of access: 04 June 2022.

"Support". 2022. Vocabulary.com. https://www.vocabulary.com/dictionary/support Date of access: 04 June 2022.

Swickert, R. J., Hittner, J. B., & Foster, A. 2010. Big Five traits interact to predict perceived social support. *Personality and Individual Differences, 48(6),* 736–741. https://doi.org/10.1016/J.PAID.2010.01.018

Tafuma, T. A., Mahachi, N., Dziwa, C., Moga, T., Baloyi, P., Muyambo, G…, & Lew, K. 2018. Barriers to HIV service utilization by people living with HIV in two provinces of Zimbabwe: Results from 2016 baseline assessment. *Southern African Journal of HIV medicine*, *19*(1), 721. https://doi.org/10.4102/hivmed.v19i1.721

Thapa, R. & Yang, Y. 2018. Experiences, Emotions, and Adjustments of HIV-Infected Men in HIV-Concordant Marital Relationship in Cambodia*. American Journal of Men's Health, 12(5),* p.1215-1225. https://doi.org/10.1177/1557988318784155

Tomaszewski, L.E., Zarestky, J. & Gonzalez, E. 2020. Planning qualitative research: Design and decision making for new researchers. *International Journal of Qualitative Methods*, 19, pp. 1-7. https://journals.sagepub.com/doi/pdf/10.1177/1609406920967174

Topp, S.M., Carbone, N.B., Tseka, J., Kamtsendero, L., Banda, G. & Herce, M.E. 2020. “Most of what they do, we cannot do!” How lay health workers respond to barriers to uptake and retention in HIV care among pregnant and breastfeeding mothers in Malawi. *BMJ Global Health, 5(6),* p.e002220. https://gh.bmj.com/content/bmjgh/5/6/e002220.full.pdf

Torija, C. S. T., Vázquez, G.V, Montijo, S.S. R. & Romo, L.L. E. 2015. The information and motivation and behavioral skills model of ART adherence among HIV-positive adults in Mexico. *Journal of the International Association of Providers of AIDS Care*, 14(4): 335-342. https://journals.sagepub.com/doi/pdf/10.1177/2325957415581903

Towell, A., Nel, W.E. & Muller, A. 2015. Model of facilitation of emotional intelligence to promote wholeness of neophyte critical care nurses in South Africa. *Health SA Gesondheid, 20(1)*, p.1-10. https://www.sciencedirect.com/science/article/pii/S1025984815000022

Tseng, Y.H., Griffiths, F., de Kadt, J., Nxumalo, N., Rwafa, T., Malatji, H. & Goudge, J. 2019. Integrating community health workers into the formal health system to improve performance: a qualitative study on the role of on-site supervision in the South African programme. *BMJ open, 9(2),* p.e022186. https://bmjopen.bmj.com/content/9/2/e022186.abstract

Tshuma, N., Mosikare, O., Yun, J.A., Alaba, O.A., Maheedhariah, M.S., Muloongo, K. & Nyasulu, P.S. 2017. Acceptability of community-based adherence clubs among health facility staff in South Africa: a qualitative study. *Patient Preference and Adherence, 11*, p.1523. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5602677/

Tufail, M.S., Ismail, H. & Zahra, S. 2016. The Impact of Work Social Support on Firm Innovation Capability: The Meditational Role of Knowledge Sharing Process and Job Satisfaction and Moderating Role of Organizational Trust. Pakistan *Journal of Social Sciences, 36(2)*. https://media.teckiz.com/pakistan-journal-of-social-sciences/pjss-bzu/2020/05/31/5ed3db7269aec.pdf

Udayar, S., Urbanaviciute, I. & Rossier, J. 2020. Perceived social support and Big Five personality traits in middle adulthood: A 4-year cross-lagged path analysis. *Applied Research in Quality of Life, 15(2),* p.395-414. https://serval.unil.ch/resource/serval:BIB_ECB11B6FD55C.P001/REF

Umeokonkwo, C.D., Onoka, C.A., Agu, P.A., Ossai, E.N., Balogun, M.S. & Ogbonnaya, L.U. 2019. Retention in care and adherence to HIV and AIDS treatment in Anambra state Nigeria. *BMC infectious diseases*, 19(1):1-11. https://link.springer.com/article/10.1186/s12879-019-4293-8

UNAIDS (the joint United Nations programme on Acquired Immune Deficiency Syndrome). 2017. Ending AIDS. Progress towards the 90–90–90 targets: 1-198. https://www.unaids.org/sites/default/files/media_asset/Global_AIDS_update_2017_en.pdf Date of access: 30/06/2022.

UNAIDS. 2019. UNAIDS Data 2019: 1-471. http://rstesa.unaids.org/publications/global-publications/2019/item/208-unaids-data-2019 Date of access: 30/06/2022.

UNAIDS. 2020a. Seizing the moment: Tackling entrenched inequalities to end epidemics. *Global AIDS update*. https://www.unaids.org/sites/default/files/media_asset/2020_global-aids-report_en.pdf Date of access: 11 Mar. 2021.

UNAIDS. 2020b. UNAIDS data 2020. https://www.unaids.org/sites/default/files/media_asset/2020_aids-data-book_en.pdf Date of access: 11 Mar. 2021.

USAID (The United States Agency for International Development) HIV Reform in Action Project. 2017. Perceived quality of HIV care across different service providers: Understanding what drives client satisfaction with HIV/AIDS services in three oblasts of Ukraine. Kyiv: HIVRIA. https://www.researchgate.net/publication/318325526_Perceived_quality_of_HIV_care_across_different_service_providers_Understanding_what_drives_client_satisfaction_with_HIVAIDS_services_in_three_oblasts_of_Ukraine

Uwishema, O., Taylor, C., Lawal, L., Hamiidah, N., Robert, I., Nasir, A., …& Mwazighe, R.M. 2022. The syndemic burden of HIV/AIDS in Africa amidst the COVID-19 pandemic. *Immunity, Inflammation and Disease, 10(1),* p.26-32. https://onlinelibrary.wiley.com/doi/full/10.1002/iid3.544

Venables, E., Edwards, J.K., Baert, S., Etienne, W., Khabala, K. & Bygrave, H. 2016. "They just come, pick and go." the acceptability of integrated medication adherence clubs for HIV and non-communicable disease (NCD) patients in Kibera, Kenya. *PLoS One, 11(10),* p.e0164634. https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0164634

Venkatesan, P. 2020. COVID-19 diagnostics—not at the expense of other diseases. *The Lancet Microbe, 1(2),* p.e64. https://www.thelancet.com/journals/lanmic/article/PIIS2666-5247(20)30041-0/fulltext

Vermeir, P., Vandijck, D., Degroote, S., Peleman, R., Verhaeghe, R., Mortier, E., …H & Vogelaers, D. 2015. Communication in healthcare: a narrative review of the literature and practical recommendations. *International Journal of Clinical Practice*, *69*(11), 1257–1267. https://doi.org/10.1111/ijcp.12686

Visser, M. & Mabota, P. 2015. The emotional wellbeing of lay HIV counselling and testing counsellors. *African Journal of AIDS Research*, 14(2):1-5. https://repository.up.ac.za/bitstream/handle/2263/49818/Visser_Emotional_2015.pdf?sequence=1

Westgate, C., Musoke, D., Crigler, L. & Perry, H.B. 2021. Community health workers at the dawn of a new era: 7. Recent advances in supervision. *Health Research Policy and Systems, 19(3),* pp.1-18. https://doi.org/10.1186/s12961-021-00754-6

WHO (World Health Organization). 2008. Task Shifting: rational redistribution of tasks among health workforce teams: Global Recommendations and Guidelines. WHO Publications: Switzerland. https://apps.who.int/iris/bitstream/handle/10665/43821/9789?sequence=1 Date of access: 11 June 2022.

WHO. 2016. Global health sector strategy on HIV 2016-2021. Towards ending AIDS: 1-60. https://apps.who.int/iris/bitstream/handle/10665/246178/WHO-HIV-2016.05-eng.pdf Date of access: 30/06/2022.

WHO. 2019. Ethical considerations for health policy and systems research. https://apps.who.int/iris/bitstream/handle/10665/330033/9789241516921-eng.pdf Date of access: 25/1/2021.

WHO. 2020a. Maintaining essential health services: operational guidance for the COVID-19 context. https://www.who.int/publications/i/item/WHO-2019-nCoV-essential_health_services-2020.2

WHO. 2020b. Health policy and system support to optimize community health worker programmes for HIV, TB and malaria services: an evidence guides. https://apps.who.int/iris/bitstream/handle/10665/340078/9789240018082-eng.pdf?sequence=1

Williams, P., Barclay, L. & Schmied, V. 2004. Defining social support in context: a necessary step in improving research, intervention, and practice. *Qualitative Health Research, 14(7),* pp.942-960. https://journals.sagepub.com/doi/abs/10.1177/1049732304266997

Williams-McBean, C.T. 2019. The value of a qualitative pilot study in a multi-phase mixed methods research. *The Qualitative Report, 24(5)*, pp.1055-1064. https://media.proquest.com/media/hms/PFT/1/56tQ9?_s=isrpk1bxz4lpvYI8%2F8x4UgUsAgQ%3D

Wolpaw, B.J., Mathews, C., Mtshizana, Y., Chopra, M., Hardie, D., Lurie, M.N..., Jennings, K. 2014. Patient experiences following acute HIV infection diagnosis and counselling in South Africa. *PLoS one*, 9(8):1-5. https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0105459

Wringe, A., Moshabela, M., Nyamukapa, C., Bukenya, D., Ondenge, K., Ddaaki, W., ...Hosegood, V. 2017. HIV testing experiences and their implications for patient engagement with HIV care and treatment on the eve of 'test and treat': findings from a multicounty qualitative study. *Sexually Transmitted Infections*, 93(Suppl 3):1-6. https://sti.bmj.com/content/sextrans/93/Suppl_3/e052969.full.pdf

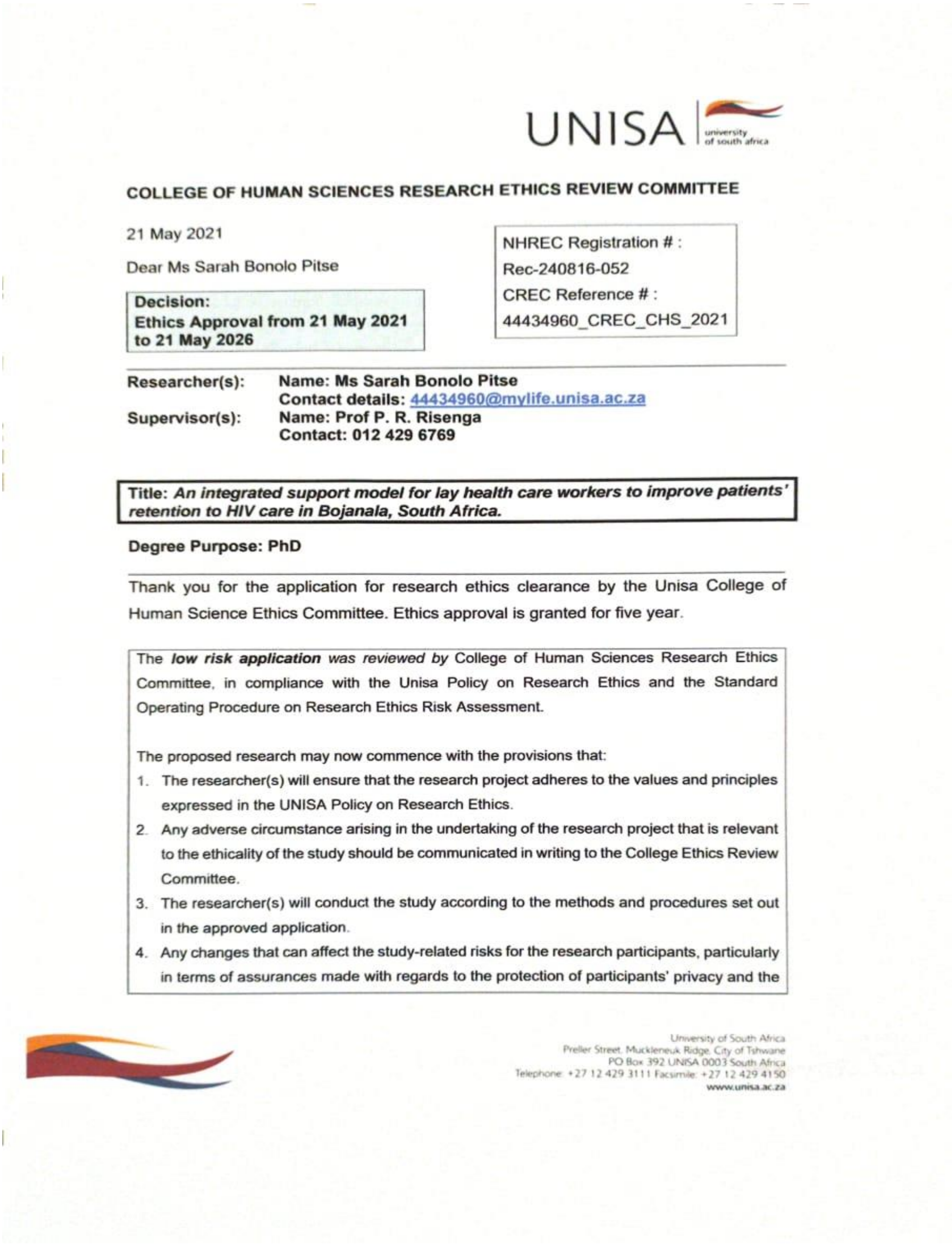
Xie, Z. & Or, C. 2017. Associations between waiting times, service times, and patient satisfaction in an endocrinology outpatient department: a time study and questionnaire survey. INQUIRY: *The Journal of Health Care Organization, Provision, and Financing,* 54, p.0046958017739527. https://doi.org/10.1177/0046958017739527

Yazdani, S., Hosseini, F. & Ahmady, S. 2016. System based practice: a concept analysis. *Journal of Advances in Medical Education & Professionalism, 4(2),* p.45. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4827756/

Zhai, Q., Wang, S. & Weadon, H. 2020. Thriving at work as a mediator of the relationship between workplace support and life satisfaction. *Journal of Management & Organization, 26(2),* p.168-184. https://doi.org/10.1017/jmo.2017.62

Zihindula, G., John, R. A., Gumede, D.M. & Gavin, M. R., 2019. A review on the contributions of NGOs in addressing the shortage of healthcare professionals in rural South Africa. *Cogent Social Sciences, 5(1),* p.1-19. https://www.tandfonline.com/doi/full/10.1080/23311886.2019.1674100

ANNEXURE A: Ethical clearance



UNISA
university
of south africa

COLLEGE OF HUMAN SCIENCES RESEARCH ETHICS REVIEW COMMITTEE

21 May 2021

Dear Ms Sarah Bonolo Pitse

Decision:
Ethics Approval from 21 May 2021 to 21 May 2026

NHREC Registration # :
Rec-240816-052
CREC Reference # :
44434960_CREC_CHS_2021

Researcher(s): **Name: Ms Sarah Bonolo Pitse**
Contact details: 44434960@mylife.unisa.ac.za

Supervisor(s): **Name: Prof P. R. Risenga**
Contact: 012 429 6769

Title: ***An integrated support model for lay health care workers to improve patients' retention to HIV care in Bojanala, South Africa.***

Degree Purpose: PhD

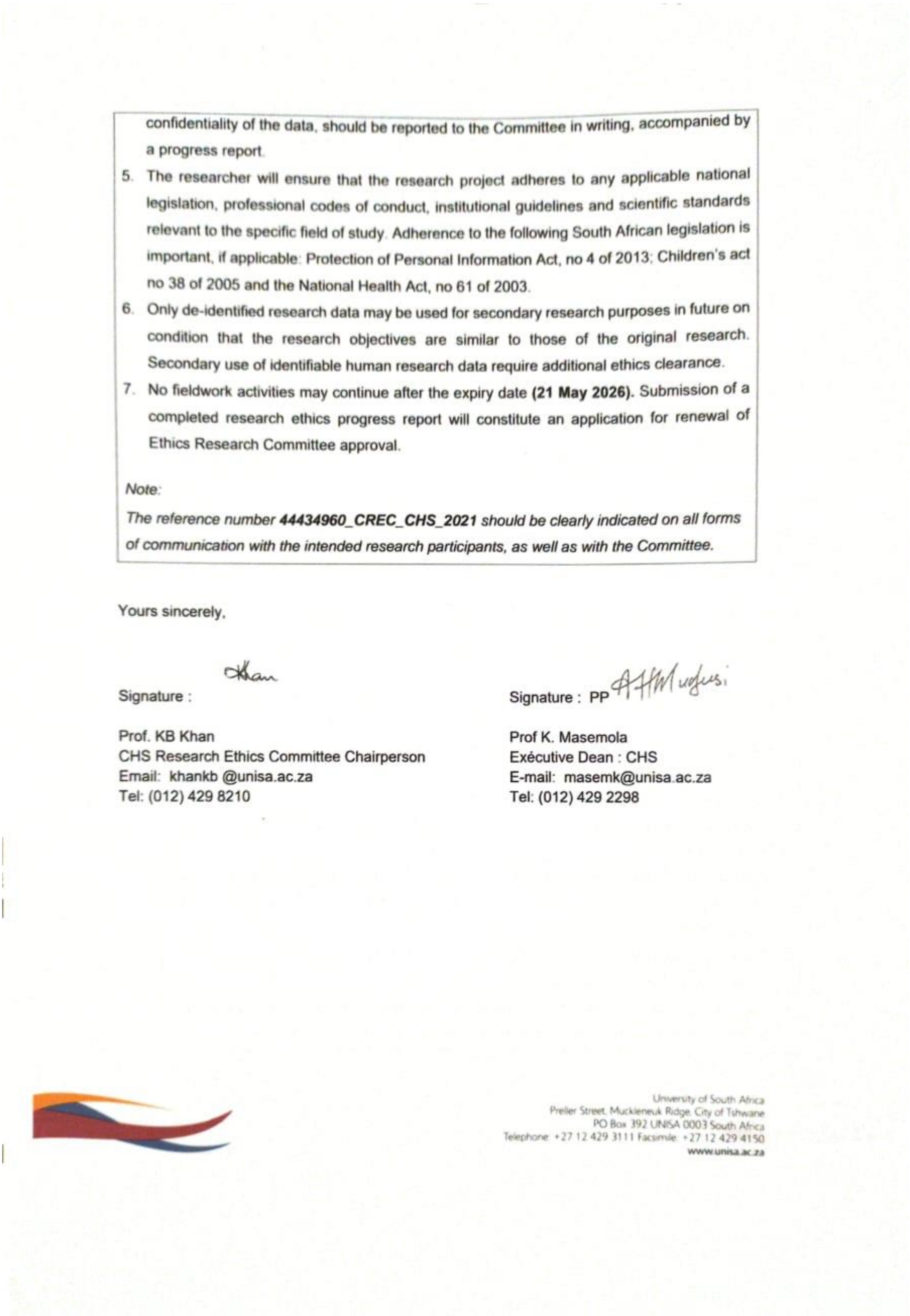
Thank you for the application for research ethics clearance by the Unisa College of Human Science Ethics Committee. Ethics approval is granted for five year.

The ***low risk application*** *was reviewed by* College of Human Sciences Research Ethics Committee, in compliance with the Unisa Policy on Research Ethics and the Standard Operating Procedure on Research Ethics Risk Assessment.

The proposed research may now commence with the provisions that:

1. The researcher(s) will ensure that the research project adheres to the values and principles expressed in the UNISA Policy on Research Ethics.
2. Any adverse circumstance arising in the undertaking of the research project that is relevant to the ethicality of the study should be communicated in writing to the College Ethics Review Committee.
3. The researcher(s) will conduct the study according to the methods and procedures set out in the approved application.
4. Any changes that can affect the study-related risks for the research participants, particularly in terms of assurances made with regards to the protection of participants' privacy and the

University of South Africa
Preller Street, Muckleneuk Ridge, City of Tshwane
PO Box 392 UNISA 0003 South Africa
Telephone: +27 12 429 3111 Facsimile: +27 12 429 4150
www.unisa.ac.za



confidentiality of the data, should be reported to the Committee in writing, accompanied by a progress report.

5. The researcher will ensure that the research project adheres to any applicable national legislation, professional codes of conduct, institutional guidelines and scientific standards relevant to the specific field of study. Adherence to the following South African legislation is important, if applicable: Protection of Personal Information Act, no 4 of 2013; Children's act no 38 of 2005 and the National Health Act, no 61 of 2003.
6. Only de-identified research data may be used for secondary research purposes in future on condition that the research objectives are similar to those of the original research. Secondary use of identifiable human research data require additional ethics clearance.
7. No fieldwork activities may continue after the expiry date **(21 May 2026).** Submission of a completed research ethics progress report will constitute an application for renewal of Ethics Research Committee approval.

Note:

*The reference number **44434960_CREC_CHS_2021** should be clearly indicated on all forms of communication with the intended research participants, as well as with the Committee.*

Yours sincerely,

Signature : Khan

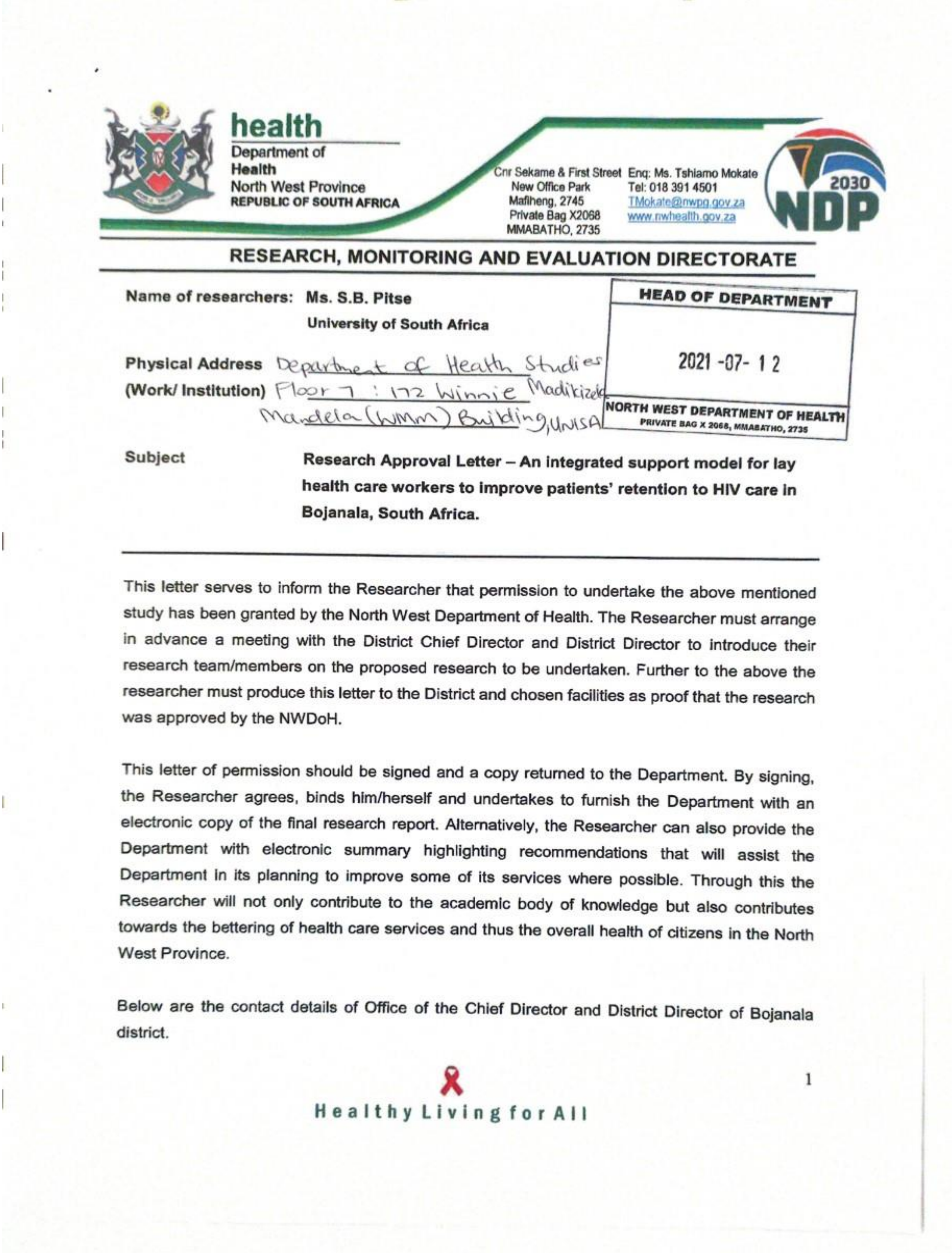
Prof. KB Khan
CHS Research Ethics Committee Chairperson
Email: khankb @unisa.ac.za
Tel: (012) 429 8210

Signature : PP

Prof K. Masemola
Exécutive Dean : CHS
E-mail: masemk@unisa.ac.za
Tel: (012) 429 2298

University of South Africa
Preller Street, Muckleneuk Ridge, City of Tshwane
PO Box 392 UNISA 0003 South Africa
Telephone: +27 12 429 3111 Facsimile: +27 12 429 4150
www.unisa.ac.za

ANNEXURE B: Permission from NW Research, Monitoring & Evaluation Directorate



health
Department of
Health
North West Province
REPUBLIC OF SOUTH AFRICA

Cnr Sekame & First Street
New Office Park
Mafikeng, 2745
Private Bag X2068
MMABATHO, 2735

Enq: Ms. Tshiamo Mokate
Tel: 018 391 4501
TMokate@nwpg.gov.za
www.nwhealth.gov.za

2030 NDP

RESEARCH, MONITORING AND EVALUATION DIRECTORATE

HEAD OF DEPARTMENT
2021 -07- 12
NORTH WEST DEPARTMENT OF HEALTH
PRIVATE BAG X 2068, MMABATHO, 2735

Name of researchers: **Ms. S.B. Pitse**
University of South Africa

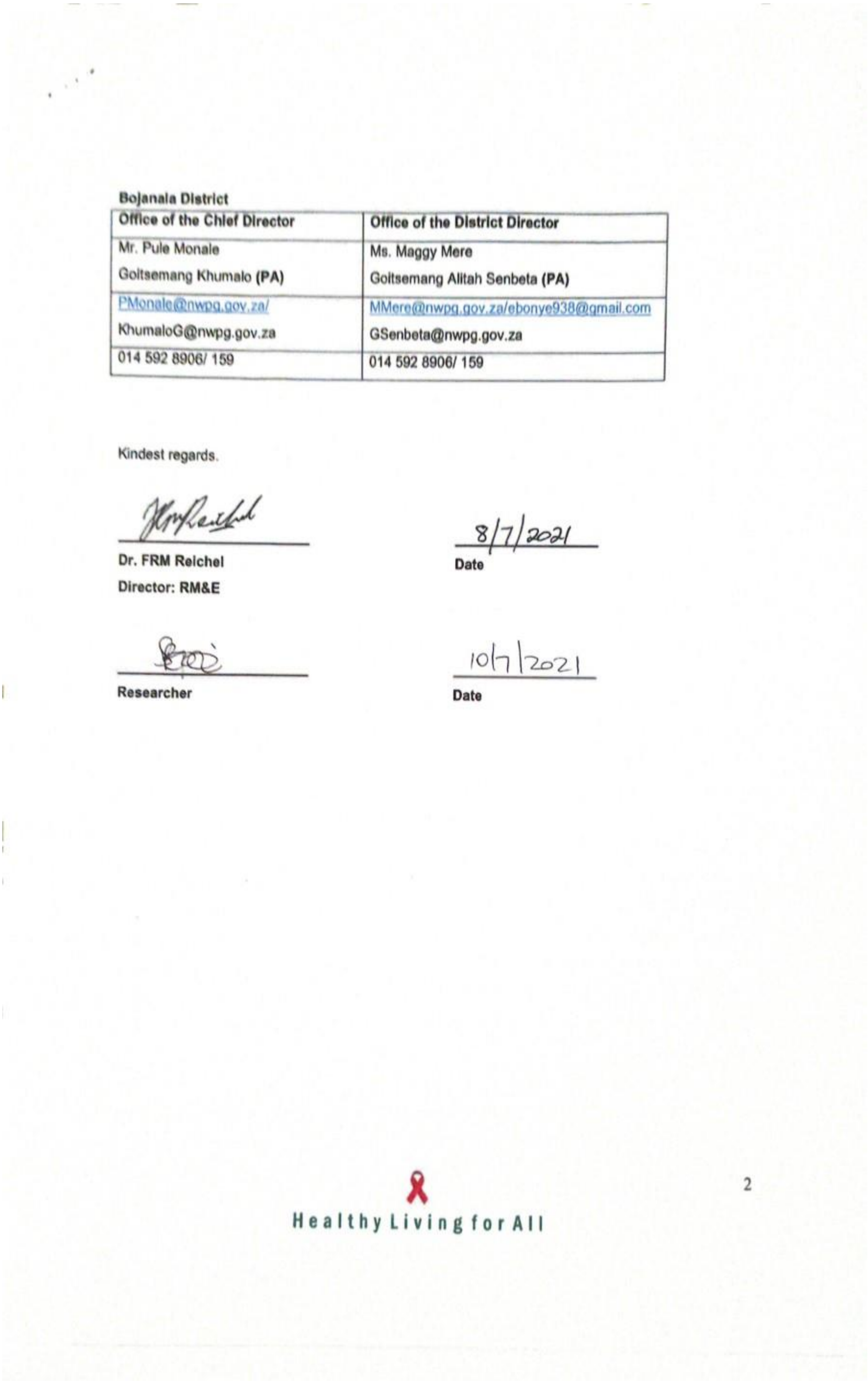
Physical Address (Work/ Institution) Department of Health Studies Floor 7 : 172 Winnie Madikizela Mandela (WMM) Building, UNISA

Subject **Research Approval Letter – An integrated support model for lay health care workers to improve patients' retention to HIV care in Bojanala, South Africa.**

This letter serves to inform the Researcher that permission to undertake the above mentioned study has been granted by the North West Department of Health. The Researcher must arrange in advance a meeting with the District Chief Director and District Director to introduce their research team/members on the proposed research to be undertaken. Further to the above the researcher must produce this letter to the District and chosen facilities as proof that the research was approved by the NWDoH.

This letter of permission should be signed and a copy returned to the Department. By signing, the Researcher agrees, binds him/herself and undertakes to furnish the Department with an electronic copy of the final research report. Alternatively, the Researcher can also provide the Department with electronic summary highlighting recommendations that will assist the Department in its planning to improve some of its services where possible. Through this the Researcher will not only contribute to the academic body of knowledge but also contributes towards the bettering of health care services and thus the overall health of citizens in the North West Province.

Below are the contact details of Office of the Chief Director and District Director of Bojanala district.



Bojanala District

Office of the Chief Director	Office of the District Director
Mr. Pule Monale Goitsemang Khumalo **(PA)**	Ms. Maggy Mere Goitsemang Alitah Senbeta **(PA)**
PMonale@nwpg.gov.za/ KhumaloG@nwpg.gov.za	MMere@nwpg.gov.za/ebonye938@gmail.com GSenbeta@nwpg.gov.za
014 592 8906/ 159	014 592 8906/ 159

Kindest regards.

Dr. FRM Reichel
Director: RM&E

8/7/2021
Date

Researcher

10/7/2021
Date

ANNEXURE C: Permission from Bojanala health district

health
Department of
Health
North West Province
REPUBLIC OF SOUTH AFRICA

Boom street
1st Floor, Absa Building
P/Bag X82079
Rustenburg
0300

Enq: N Masango
Tel: (014) 592 8906

email:
JTumbo@nwpg.gov.za
NMasango@nwpg.gov.za

2030
NDP

BOJANALA DISTRICT

To: Ms Bonolo Pitse

5 Manitoka Avenue

Geelhout Park Rustenburg

15/July/2021

REF: PERMISSION TO UNDERTAKE RESEARCH IN FACILITIES IN BOJANALA DISTRICT

Permission is hereby granted to Ms. Bonolo Pitse to undertake research entitled “An integrated support model for lay health care workers to improve patients' retention to HIV care in Bojanala, South Africa” at selected Facilities in Bojanala district.

The research protocol has been granted ethical clearance by the UNISA and permission by the director, Policy Planning and knowledge management of Health North West Province.

Please facilitate access of the researchers to the targeted participants and information.

Thank You

Prof J M Tumbo District

Family Physician and research coordinator

ANNEXURE D: Consent form

CONSENT TO PARTICIPATE IN THIS STUDY

Title: An integrated support model for lay health care workers to improve patients' retention to HIV care in Bojanala, South Africa.

I, ________________ (participant name), confirm that the person asking for my consent to take part in this research has told me about the nature, procedure, potential benefits, and anticipated inconvenience of participation.

I have read (or the researcher explained to me) and I understood the study as explained in the information sheet.

I have had sufficient opportunity to ask questions and am prepared to participate in the study.

I understand that my participation is voluntary and that I am free to withdraw at any time without penalty (if applicable).

I am aware that the findings of this study will be processed into a research report, journal publications and/or conference proceedings, but that my participation will be kept confidential unless otherwise specified.

I agree to the audio recording of the interview.

I have received a signed copy of the informed consent agreement.

Participant Name & Surname………………………………………… (please print)

Participant Signature……………………………………………. Date…………………

Researcher's Name & Surname……………………………………… (please print)

Researcher's signature…………………………………………...Date…………………

ANNEXURE E: Interview Guide for lay health care workers

Title: An integrated support model for lay health care workers to improve patients' retention to HIV care in Bojanala, South Africa

Biographical information:

Age:………………………………………………………………………………………….
Gender:……………………………………………………………………………………….
Job title:..
Years of experience:..

Grand tour Question

Describe your role in working with HIV infected clients.

Probing Questions

- How do you contribute to the retention of HIV clients to care?
- What are the barriers that you experience in promoting retention to HIV care?
- What kind of support do you receive from other health care professionals, colleagues, and supervisors?
- What suggestions would you recommend that will strengthen your HIV care retention skills?

ANNEXURE F: Interview Guide for health care professionals interacting/supervising lay health care workers

Title: An integrated support model for lay health care workers to improve patients' retention to HIV care in Bojanala, South Africa.

Biographical information:
Age:……………………………………………………………………………………….
Gender:……………………………………………………………………………………
Job title:...
Years of experience in HIV care:...

Grand tour Question

Describe your working relationship with lay health care workers.

Probing Questions

- How can you describe the role of lay health care workers in HIV care?
- How do lay health care workers contribute to retention of HIV clients to care?
- What are the barriers that the lay health care workers experience in promoting retention to HIV care?
- How do you provide support to lay health care workers?
- What suggestions would you recommend for effective retention to HIV care?

ANNEXURE G: Interview Guide for clients

Title: An integrated support model for lay health care workers to improve patients' retention to HIV care in Bojanala, South Africa.

Biographical information:

Age: ……………………………………………………………………………………….

Gender: ……………………………………………………………………………………..

Employment status...

Geographical area (urban, rural, township) ....

Mobility (mobile, permanent) ....

Grand tour Question

How long have you been receiving HIV care?

Probing Questions

- How was your journey in relation to receiving HIV care?
- How was your relationship with lay health care workers?
- What are the factors that motivate you to keep up with clinic appointments?
- What are the challenges that have led to you (may lead you to) skipping clinic appointments?
- What suggestions would you recommend that will strengthen your retention to HIV care?

ANNEXURE H: PARTICIPANT INFORMATION SHEET

Study title: An integrated support model for lay health workers to improve patients' retention to HIV care in Bojanala, South Africa.

Dear Prospective Participant

My name is Bonolo Pitse and I am conducting a Doctoral Research under the supervision of Prof P. R. Risenga, a Professor in the Department of Health Studies at the University of South Africa. I hereby invite you to participate in a study entitled '**An integrated support model for lay health workers to improve patients' retention to HIV care in Bojanala, South Africa'**.

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of the study is to explore the experiences of people living with HIV (PLWHIV) and lay health workers and the support provided to lay health workers by health professionals, thereafter, develop an integrated support model for lay health workers to improve retention to HIV care. The study is expected to collect vital information that will contribute positively to the improvement of the lay health workers' retention skills of PLWHIV, contribute to the United Nations' goals of achieving 90-95% viral load suppression and retention of patients to HIV care and quality of life. The Department of health can also adapt the model towards retention to care for other chronic conditions.

WHY AM I BEING INVITED TO PARTICIPATE?

You have been chosen to participate in this study because you are either a lay health worker or health professional who interacts with lay health workers or a client who has undergone counselling or has interacted with a lay health worker at a health facility. Your wealth of experience will assist in reaching the objectives of the study. Permission to conduct the study was obtained from the North West Health Policy, Planning, Research, Monitoring and Evaluation and Bojanala health district, thereafter, the study information and screening questionnaire was distributed to your health facility or office.

Lay health workers, health professionals or clients who answered 'yes' in the screening questionnaire and are willing to participate in the study will document their cell numbers to be contacted and invited to participate. A researcher will communicate with you to check if you wish to take part and then request you to complete a consent form while maintaining confidentiality, provided that you agree. We anticipate interviewing about 15 to 20 clients and 10 to 12 health professionals or supervisors and 10-15 lay health workers.

WHAT IS THE NATURE OF MY PARTICIPATION IN THIS STUDY?

You will be interviewed either telephonically or face to face, depending on your preference. We request that you describe your experiences either as a client who interacts or has interacted with lay health workers, or as a lay health worker, or as a health professional who supervises the lay health workers. The interviews, telephonic or face to face, will be recorded with your consent, in order to correctly represent your experiences. An interview guide will be used to facilitate the data collection process and questions will be open-ended to allow you to express yourself adequately. The interview may last approximately 20 to 30 minutes.

CAN I WITHDRAW FROM THIS STUDY EVEN AFTER HAVING AGREED TO PARTICIPATE?

Participating in this study is voluntary and you are under no obligation to consent to participation. If you decide to take part, you will be given this information sheet to keep and be asked to sign a written consent form. You are free to withdraw at any time and without giving a reason. There will be no penalty for withdrawing.

WHAT ARE THE POTENTIAL BENEFITS OF TAKING PART IN THIS STUDY?

The findings of this study will improve the lay health workers’ retention skills of PLWHIV, contribute to the United Nations’ goals of achieving 90-95% viral load suppression and retention of patients to HIV care and quality of life. The Department of health can also adapt the model towards retention to care for other chronic conditions. As a result, there are no immediate individual benefits, but the benefit will be at the level of the public health.

ARE THERE ANY NEGATIVE CONSEQUENCES FOR ME IF I PARTICIPATE IN THE RESEARCH PROJECT?

For a client, there is a chance that you may experience emotional distress caused by narrating past experiences. Should this happen, the interview will be stopped immediately, and you will be referred for counselling at the facility. You may also be inconvenienced if there are network challenges which may result in interruptions and longer interviews. Confidentiality will be maintained and there will be no information that directly links or reveals your identity.

WILL THE INFORMATION THAT I CONVEY TO THE RESEARCHER AND MY IDENTITY BE KEPT CONFIDENTIAL?

You have the right to insist that your name must not be recorded anywhere and that no one, apart from the researcher and identified members of the research team, will know about your involvement in this research. Your answers will be given a code number, or a pseudonym and you will be referred to in this way in the data, any publications, or other research reporting methods such as conference proceedings.

The only people who will have access to the data are the transcriber and /external coder, all who will sign a confidentiality agreement. Your answers may be reviewed by people responsible for making sure that research is done properly, including the transcriber, external coder, and members of the Research Ethics Review Committee. Otherwise, records that identify you will be available only to people working on the study, unless you give permission for other people to see the records. A report of the study may be submitted for publication, or for conference proceedings but individual participants will not be identifiable in such a report.

HOW WILL THE RESEARCHER(S) PROTECT THE SECURITY OF DATA?

Hard copies of your answers will be stored by the researcher for a minimum period of five years in a locked cupboard/filing cabinet in the researcher’s office, in South Africa, for future research or academic purposes. The electronic information will be stored on a password protected computer. The future use of the stored data will be subject to further Research Ethics Review and approval if applicable. After the stated five years, hard copies will be shredded and/or electronic copies will be permanently deleted from the hard drive of the computer using a relevant software programme.

WILL I RECEIVE PAYMENT OR ANY INCENTIVES FOR PARTICIPATING IN THIS STUDY?

There will be no incentives provided to you for taking part in the study.

HAS THE STUDY RECEIVED ETHICS APPROVAL?

This study has received written approval from the UNISA College of Human Sciences Research Ethics Committee. A copy of the approval letter can be obtained from the researcher if you so wish.

HOW WILL I BE INFORMED OF THE FINDINGS/ RESULTS OF THE RESEARCH?

If you would like to be informed of the final research findings or you require any further information relating to the study, please contact Bonolo Pitse, cell phone number: 082 850 1384, email address: bonolo.pitse@yahoo.com .

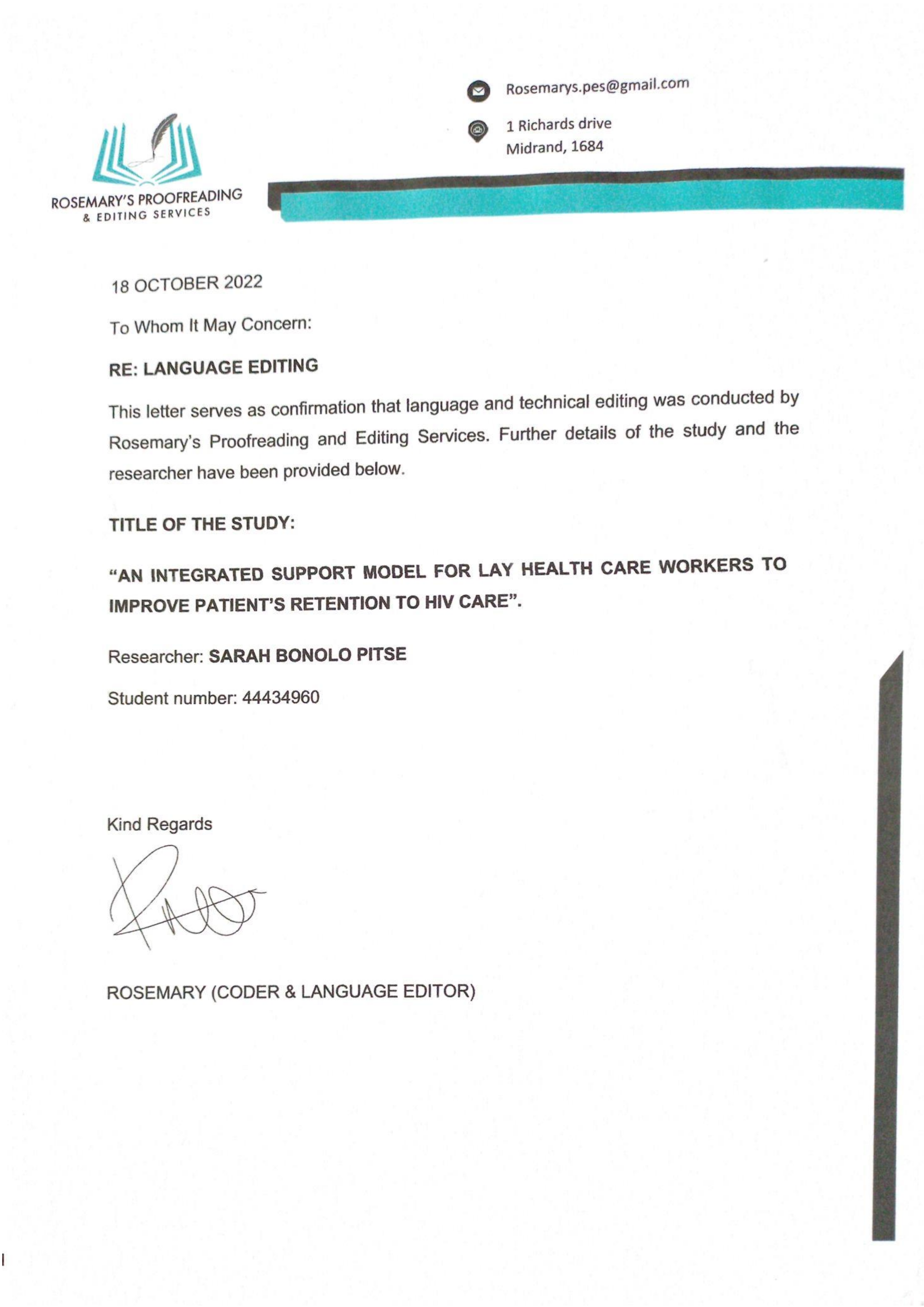
Should you have concerns about the way in which the research has been conducted, you may contact Prof P. R. Risenga on cell phone number: 083 381 9745, Telephone number: 012 429 6769, email address: risenpr@unisa.ac.za

Thank you for taking time to read this information sheet and for participating in this study.

Thank you.

Bonolo Pitse

ANNEXURE I: Language editing certificate



Rosemarys.pes@gmail.com
1 Richards drive
Midrand, 1684

ROSEMARY'S PROOFREADING
& EDITING SERVICES

18 OCTOBER 2022

To Whom It May Concern:

RE: LANGUAGE EDITING

This letter serves as confirmation that language and technical editing was conducted by Rosemary's Proofreading and Editing Services. Further details of the study and the researcher have been provided below.

TITLE OF THE STUDY:

"AN INTEGRATED SUPPORT MODEL FOR LAY HEALTH CARE WORKERS TO IMPROVE PATIENT'S RETENTION TO HIV CARE".

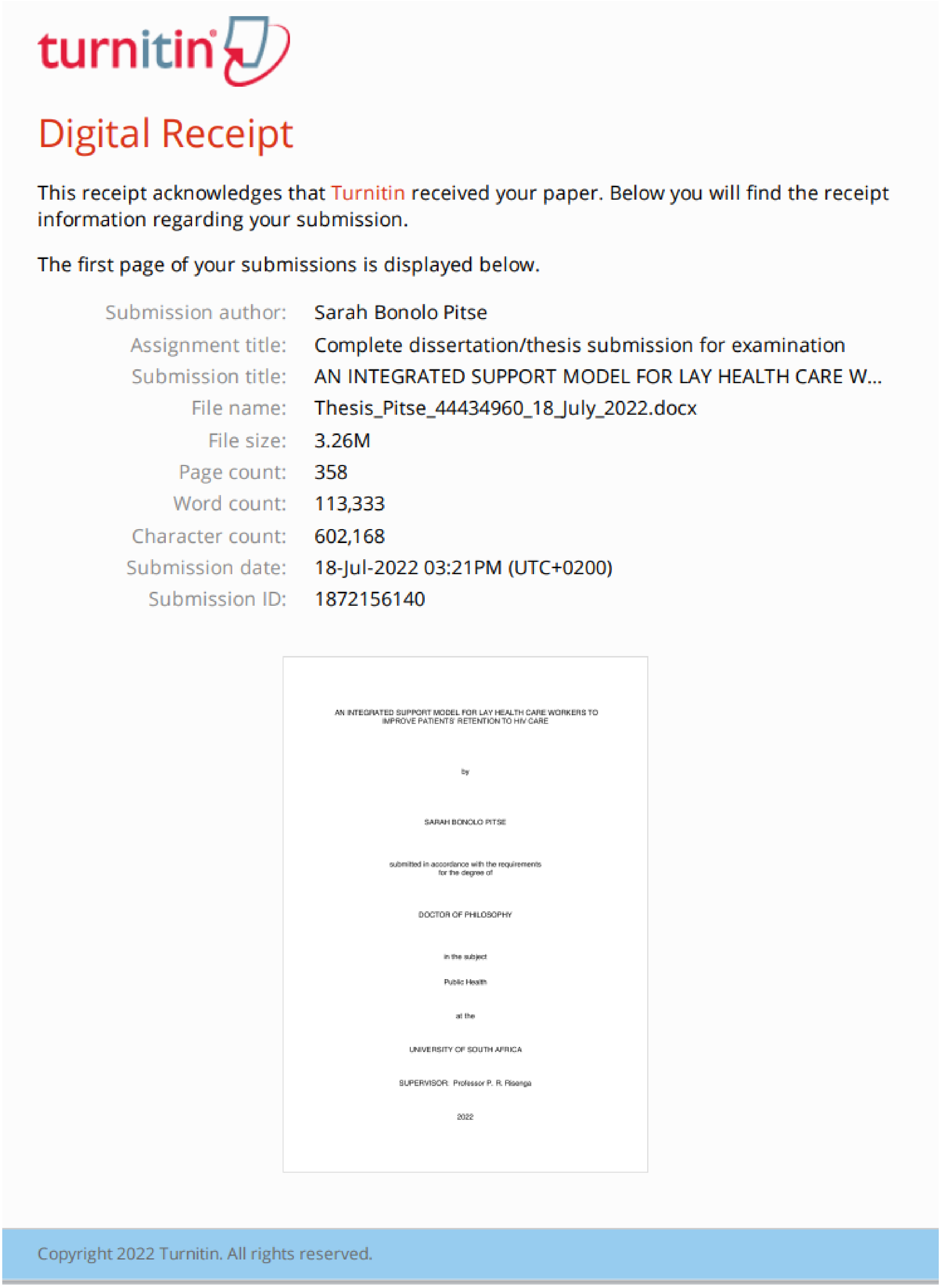
Researcher: **SARAH BONOLO PITSE**

Student number: 44434960

Kind Regards

ROSEMARY (CODER & LANGUAGE EDITOR)

ANNEXURE J: Turnitin report



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Submission author: Sarah Bonolo Pitse
Assignment title: Complete dissertation/thesis submission for examination
Submission title: AN INTEGRATED SUPPORT MODEL FOR LAY HEALTH CARE W...
File name: Thesis_Pitse_44434960_18_July_2022.docx
File size: 3.26M
Page count: 358
Word count: 113,333
Character count: 602,168
Submission date: 18-Jul-2022 03:21PM (UTC+0200)
Submission ID: 1872156140

AN INTEGRATED SUPPORT MODEL FOR LAY HEALTH CARE WORKERS TO
IMPROVE PATIENTS' RETENTION TO HIV CARE

by

SARAH BONOLO PITSE

submitted in accordance with the requirements
for the degree of

DOCTOR OF PHILOSOPHY

in the subject

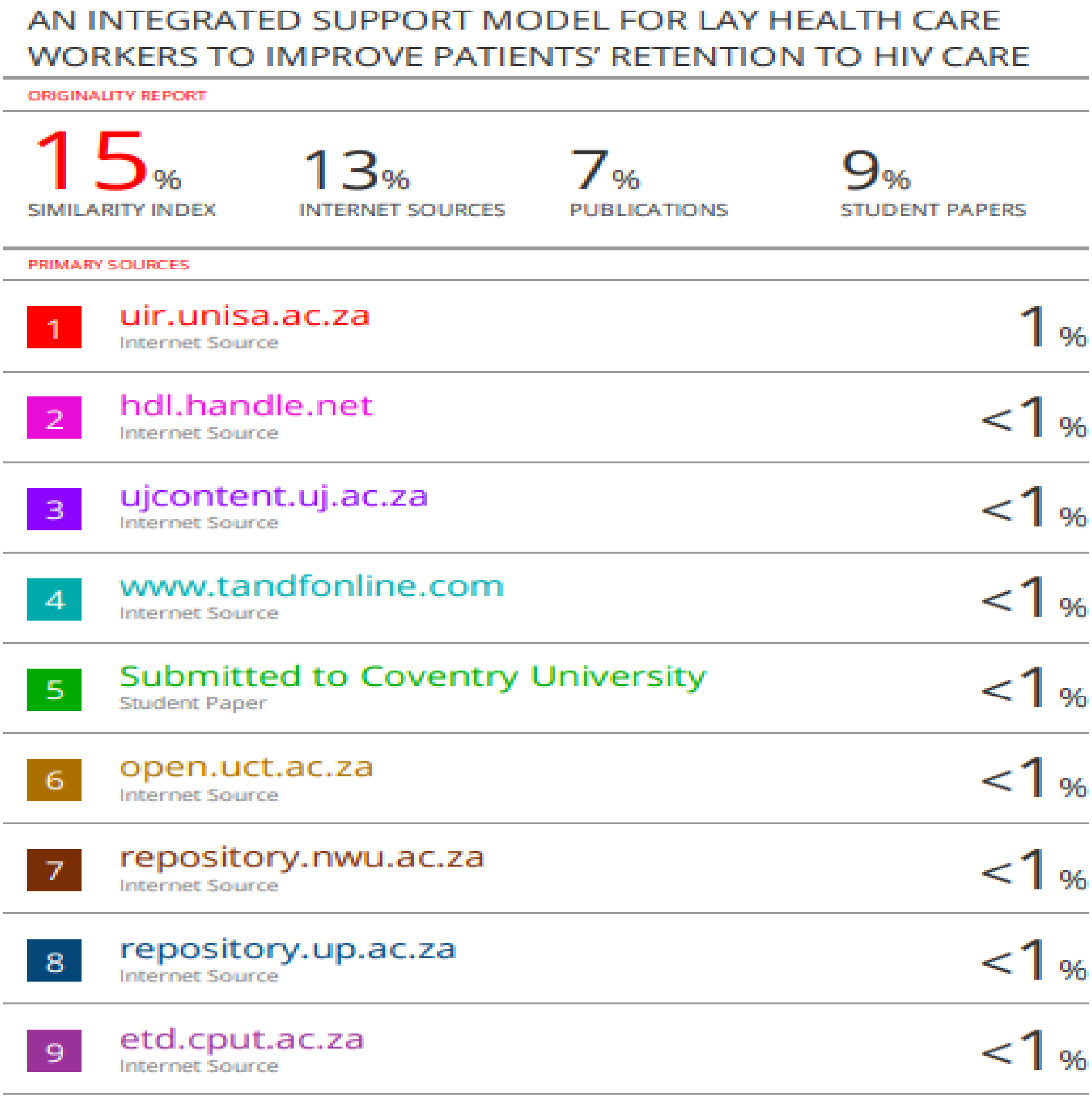
Public Health

at the

UNIVERSITY OF SOUTH AFRICA

SUPERVISOR: Professor P. R. Risenga

2022



AN INTEGRATED SUPPORT MODEL FOR LAY HEALTH CARE WORKERS TO IMPROVE PATIENTS' RETENTION TO HIV CARE

ORIGINALITY REPORT

15%	13%	7%	9%
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

PRIMARY SOURCES

1	uir.unisa.ac.za Internet Source	1 %
2	hdl.handle.net Internet Source	<1 %
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