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Faculty of Health Sciences
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**EXPERIENCES OF NURSES INITIATING AND MANAGING HUMAN IMMUNE –
DEFICIENCY VIRUS (HIV) INFECTED PATIENTS ON ANTIRETROVIRAL
TREATMENT IN TSHWANE CLINICS**

by

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Magister Curationis (clinical) in nursing science**

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DECLARATION

I Jane Thandi Khotle (student number: 96253593) declare the study titled: **‘Experiences of nurses initiating and managing human immune – deficiency virus (HIV) infected patients on antiretroviral treatment in Tshwane clinics’** is my own original work. Where other people’s work has been used (either from a printed source, Internet or any other source), this has been properly acknowledged and referenced in accordance with departmental requirements.

I have not used work previously produced by another student or any other person to hand in as my own. I have not allowed, and will not allow, anyone to copy my work with the intention of passing it off as his or her own work.

Jane Thandi Khotle

Date

DEDICATION

- A special dedication in memory of my beloved late husband and the father of my children Masiu Elias Khotle. When I started on this venture I knew that if you were granted more days of life you could have supported me throughout as you did with everything that I wanted to do. I will always cherish your memories.
- This study is dedicated to the following people, who were very instrumental in supporting me throughout the course of my study.
- My children Lereng Lerato Khotle, Leamohetsoe Shoeshoe Khotle and Silas Matlala-Khotle
- My sisters Thoko Lekhuleni and Thembi Mahlangu

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ABSTRACT

Experiences of nurses initiating and managing human immune – deficiency virus (HIV) infected patients on antiretroviral treatment in Tshwane clinics

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Background: The implementation of nurse initiation and management of patients on ART in Primary Health setting has increased. This initiative in scaling up, improved patient outcome and improved accessibility to treatment and care. However this large rollout of ART program has created additional workload and challenges for nurses.

Objectives: To explore and describe the challenges and experiences of nurses initiating and managing HIV/AIDS infected patients on ART in the Tshwane North sub-district clinics.

Methods: In this qualitative study the researcher employed qualitative, exploratory, descriptive and contextual design to explore and describe the experiences of nurses initiating and managing human immune deficiency virus (HIV) infected patients on antiretroviral treatment (ART). The population was the NIMART trained nurses actively involved in initiating and managing HIV/AIDS infected patients. A sample of 4 (four) nurses from each of the 4 (four) Tshwane North sub-district clinics were used. Individual in-depth interviews were conducted to collect data. Qualitative content analysis procedure was used to analyse data.

Findings: Four themes were identified: delayed initiation, interference in taking ART, young people infected and living with HIV infection, and patients already on treatment. The identified themes were discussed and supported with literature.

Conclusion: The study highlighted the challenges of nurses initiating and managing HIV infected patients on ART are experiencing. These challenges have negative outcomes on the health of individual patients. Therefore the government came with a strategic plan to put the disease under control.

Key words: Experiences, Initiating, Managing, HIV infected, Antiretroviral

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LIST OF ABBREVIATIONS / ACRONYMS

ABBREVIATIONS / ACRONYMS

Abbreviation / acronym	Meaning
ARV	Antiretroviral treatment/therapy
HIV	Human Immune virus
NIMART	Nurse Initiated antiretroviral treatment
PHC	Primary Health Care
STI	Sexually Transmitted Illnesses
WHO	World Health Organisation
UNAIDS	Joint United Nations programme on HIV/AIDS
NSP	National Strategic Plan
UTT	Universal test and treat
WBOT	Ward Based Tracing Team
PICT	Provider initiated counselling and testing
PCR	polymerase chain reaction
CCMDD	Central chronic medicines distribution and dispensing
WBOT	Ward based Outreach team
PLCHIV	People living with HIV

CHAPTER 1

ORIENTATION OF THE STUDY

1.1 INTRODUCTION/ BACKGROUND

According to the World Health Organization (WHO), 2013 report there were approximately 35 million people initiated on antiretroviral treatment worldwide in 2013 (Joint United Nations Programme on HIV/AIDS (UNAIDS) Global Report Millenium Development Goal (MDG) 6 2013:68). The Sub-Saharan Africa had the highest human immune virus and immunodeficiency syndrome (HIV/AIDS) pandemic in the world. In 2012 approximately 25 million people were infected with the human immune virus (HIV) and they represented nearly 70 percent of the global total of infections. In the same year, there were an estimated 1.6 million new HIV infections and 1.2 million acquired immunodeficiency syndrome (AIDS)-related deaths in Sub- Saharan Africa.

The prevalence of the HIV pandemic represents a major global health crisis. Various clinical policies and programs have been put in place internationally and nationally in reaction to the epidemic. As the world moved towards reaching the target date of the Millennium Development Goals (MDG), the World Health Organization (WHO) was working with its member states to put into effect the Global Health Sector Strategy (GHSS) on HIV/AIDS for the 2011-2015 period (WHO MDG 2011:6). The aims of the strategy were to prevent new HIV infections, and new AIDS. related deaths and also to ensure there was no discrimination against people infected with HIV (WHO GHSS: 2014:1).

Before the introduction of the National Strategic Plan (NSP) of 2007-2011, the statistics of HIV/AIDS was critically escalating. This escalation urged the government of South African to suggest a Strategic Plan envisaged for the 2012-2016 period. The aims of the HIV/AIDS and sexually transmitted infections (STI) Strategic Plan 2007-2011 was to reduce the prevalence of new

HIV infections to half by 2011 and to reduce the impact of HIV and AIDS on individuals, families, communities and societies. This was done through the integration of services to increase access to treatment, care and support to 80% by 2015 (South African National AIDS Council SANAC 2007-2011). In 2012 there was introduction NPS 2012–2016 focused on a long-term vision for the country taking into account the three Zero's supported by UNAIDS. 'The vision for South Africa was: Zero new HIV and Tuberculosis (TB) infections; Zero new infections due to vertical transmission; Zero preventable deaths associated with HIV and TB; Zero discrimination associated with HIV and TB. This would be achieved through governance and institutional arrangements; effective communication; monitoring and evaluation; and research' (National Strategic Plan NSP 2012–2016:13).

The key to a successful outcome in reducing the infection rate of HIV became effective in the hands of the professional nurses tasked with the implementation of HIV tuberculosis (TB) and sexually transmitted infections (STI) policies (Colvin, Fairall, Lewin, Georgeu, Zwarenstein, Bachmann, Uebel, & Bateman 2010: 210.). The implementation of nurse initiated and management of antiretroviral (NIMART) programme in South Africa resulted in increased scaling up, improved patient outcome and improved accessibility of antiretroviral treatment and care. (Ford, Calmy, & Mills 2011:33). Early diagnosis of patients on their first visit to primary health care facilities to test for HIV, implementing (Provider Initiated Counselling and Testing (PICT), and subsequent management of those eligible for care and treatment have enhanced the success rate of controlling the pandemic. (Mutanga, Raymond, Towle, Mutembo, Fubisha, Lule, & Muhe 2012:191).

The recent South African statistics on HIV/AIDS revealed that there is an estimate of 5.51 million patients accessing care and antiretroviral treatment (ART) in all health institutions nationally (UNAIDS Statistics South Africa 2014:303). This statistics impacts on the initiation and management of the HIV ART programme. To expand accessibility and eligibility of ART in South Africa, the South African public health's task shifting model from doctor initiated to nurse initiating and managing HIV infected patient on ART (NIMART) was introduced (Uebel, Timmerman, Ingle, Van Rensburg, & Mollentze 2010:589). The introduction of

HIV ART initiation and management at Primary Health Care level has also added more workload on the nurses scope of practice (Cameron, Gerber, Mbatha, Mutyabule & Swart 2012:98).

This initiation further brought improvement to HIV/AIDS management, accompanied by the scaling up HIV treatment and high volumes of patients accessing treatment (Reis, Heister, Amowitz, Moreland, Mafeni, Chukwuemeka, and Anyamele & Lacopino 2005 10.1371). Nurses initiating treatment and managing these patients' experienced challenges that created an unpleasant working environment. These challenges include among others a lack of human resource (Green, de Azevedo, Patten, Davies, Ibeto & Cox: 2014:229). Davies, Homfray and Venables (2013:12) commented that the government had the highest expectations regarding the ART initiation programme, however, it undermined the quality of care that was essential to deliver to HIV infected patients who are on antiretroviral treatment.

With all the NPS interventions previously introduced to cap HIV infections, the challenge was that the rate of new infections remains high. A new strategy for the prevention of new infections was introduced in 2016 September that is National Guidelines on Universal test and treat (UTT) 2016:22. UTT means everyone testing HIV positive irrespective of the persons CD4 count at the time of testing, they will have to start on (ART) immediately.

1.2 PROBLEM STATEMENT

The introduction of the South African Antiretroviral therapy (ART) programme, known as the Comprehensive Care Management, Treatment and support (CCMTS) program in 2003, achieved much success in managing HIV/AIDS infected patients, however the mortality rate of those infected continued to accelerate. (Koenig, Leandre. & Farmer 2004:24). The accelerated mortality rate was confirmed by HIV/AIDS guidelines (2017).

When the program was started, doctors were responsible for initiating and managing HIV/AIDS infected patients in hospitals (Fairall, Bachmann, Lombard, Timmerman,

Uebel, Zwarenstein, Boulle, Georgeu, Colvin, Lewin, & Faris 2012:889). However, it was observed that doctors who were responsible for the roll-out of the programme had limited capacity to scale up the services (Green et al 2014: 229). To strengthen the capacity of the public health sector to deliver high quality integrated care and wellness services, WHO and UNAIDS 2003 introduced nurse initiated and management of antiretroviral treatment (NIMART) Brennan, Long, Maskew, Sanne, Jaffray, MacPhail, and Fox (2011:111). NIMART is an intervention to improve health care access without compromising the quality of care in resource-limited settings. The purpose was to achieve the best health outcomes in the most cost-efficient manner by decentralizing service delivery to primary health care centres (PHC) (Davis et al 2013:3).

Large scale roll out of (ART) programmes nationally have created an additional workload, responsibilities and challenges for nurses working in Primary health care Centre's (Georgeu, Colvin, Lewin, Fairall, Bachmann, Uebel, & Bateman, 2012:66). These nurses involved in the ART treatment program also experience multiple challenges during the provision of care to HIV infected patients (Colvin, Fairall, Lewin, Georgeu, Zwarenstein, Bachmann, Uebel, and Bateman, 2010:210). These challenges include among others, human resource limitations which affect delivery of services in primary health services (Green et al 2014: 229). Therefore this study is a necessity because it will explore and describe the experiences of nurses initiating and managing HIV infected patients on ART.

1.3 SIGNIFICANCE OF THE PROPOSED STUDY

1.3.1 NURSING MANAGEMENT

This research study may bring the challenges nurses face in providing quality care in a primary health care setting to the attention of the stakeholders. It may also guide Policy makers may be guided on how to formulate new policy guidelines for effective management of HIV infected patients and to also consider the plight of the nurses involved.

1.3.2 NURSING PRACTICE

The findings on experiences of nurses may inform employers on how to address existing challenges in the initiation and management of HIV infected patients in order to improve the working conditions and directly or indirectly contributing to improved patient care.

1.3.3 NURSING EDUCATION

The study may assist the primary health care managers in development programmes to encourage academic growth, and its findings may serve as a platform for future studies.

1.4 RESEARCH QUESTION

The research question for this study was:

What are the experiences of nurses initiating and managing HIV infected patients on antiretroviral treatment in Tshwane North clinics?

1.5 AIM OF STUDY

The purpose of this study is:

To explore and describe the experiences of nurses initiating and managing HIV/AIDS infected patient on antiretroviral treatment in Tshwane North clinics.

1.6 CONCEPT CLARIFICATION STUDY

1.6.1 A nurse

A nurse 'is a person who has successfully completed a programme of education approved by the nursing professional body to practice in health care delivery and continues to meet standard of the professional council' (Webster 2017:370). "nurse" means a person registered in a category under section 31(1) in order to practise nursing or midwifery; (SANC 2005:6). For the purpose of this study a nurse is a professional who is clinically trained to diagnose, and manage treatment of HIV infected patients.

1.6.2 Initiate

Initiate is 'to introduce to something new' or 'to cause or facilitate the beginning of' (Webster 2017:98). In this study initiate means to start newly diagnosed HIV infected person antiretroviral therapy irrespective of the CD4 count.

1.6.3 Manage

Manage implies to taking control of and making a decision about someone's affair (Webster 2017:368). In this study the focus is on managing HIV-infected patients on ART daily and doing follow-up on their progress. Also to take history, assess, do physical examination, and do some tests to be able to and come with diagnoses and start the patients on ART and follow-up care of progress

1.6.4 Human immunodeficiency virus (HIV)

Human immune deficiency syndrome is defined as a blood-borne pathogen that has a direct transmission through blood or body fluids (Corless, Guarino, Nicholas, Tyer-Viola, Kirksey, Brion, Dawson ,Eller, Rivero-Mendez, Kempainen, & Nokes, 2013:364).

1.6.5 Anti-retroviral treatment (ART).

Antiretroviral treatment is class of drugs which inhibits or prevent the replication of human immune deficiency virus in the cell (Van Dyke, Patel, Siberry, Burchett, Spector, Chernoff, Read, Mofenson, and Seage 2011: 166). In this study ART is the treatment administered to HIV infected patients to control HIV from causing AIDS

1.6.6 Experiences

The details of having been exposed to a situation and have gained knowledge through direct observation or participation (Merriam-Webster 2017:66) In this study the participants will describe what they experience in their workplace.

1.7 PHILOSOPHICAL ASSUMPTIONS

1.7.1 Paradigm

A paradigm is a way of observing a natural phenomenon from a world view that includes a set of philosophical assumptions that usher one's approach to investigation (Polit & Beck 2013:736). In this study the paradigm of choice was the constructivist theory. Constructivist paradigm believes that comprehension is decreased when the space connecting the investigator and the subject is decreased (Polit & Beck 2013:12). In this study, the researcher engaged with participants to describe their experiences while managing HIV infected patients on treatment.

1.7.2 ASSUMPTIONS OF THE STUDY

Assumptions are the essential principles that we acquire by faith or assume to be true without proof (Polit & Beck 2012:720). An assumption is also defined by Grove, Burns, and Gray (2013:41) as expression that are taken for granted or are deemed as true despite the fact that they have not been scientifically tested. The following assumptions guided the study ontology, epistemology, and methodology.

1.7.2.1 Ontological assumptions

Ontology is described by Polit and Beck (2013:13) as the nature of authenticity that is numerous and prejudiced, constructed mentally by individuals. Patterns of meaning were identified as participants explain their views on their and experiences in managing HIV infected patients.

1.7.2.2 Epistemological assumptions

Epistemology deals with the nature of knowledge that has to do with methods, theories, concepts, rules and the procedure applied. Botma, Greeff, Mulaudzi and Wright (2010:40). Participants shared their lived nature of knowledge regarding their experiences in managing these patients during interviews.

1.7.2.3 Methodological assumptions

Methodology refers to the rules and mechanisms of how the researcher will study or investigate the topic of interest. Developing awareness based on participant' experiences (Polit & Beck 2013:13). In this study the constructivist method was employed whereby the challenges and experiences of nurses initiating and managing HIV/AIDS infected patients were explored.

1.8 RESEARCH DESIGN

The research design according to Rebar and Cherrie (2011:175) is the overall plan in acquiring new knowledge or confirming existing knowledge. Babbie and Mouton (2014:74) define research design as a proposition of how the research will be conducted. According to Burns and Grove (2011:49) a research design is a plan of the study that directs control over elements that can interfere with the progress leading to the study's outcome. In this study, the qualitative exploratory, descriptive and contextual study was employed. This approach was utilized to explore and describe the challenges and experiences of nurses in their workplace, when initiating and managing HIV infected patients on antiretroviral treatment. The population were the NIMART trained nurses and those who are actively initiating and managing ART to HIV infected patients detailed discussion in 2.4, purposeful sampling method was used and it is discussed in 2.5. In-depth interviews were conducted to collect data and was discussed in details in 2.6 chapter 2.

1.9 ETHICAL CONSIDERATIONS

Ethics is defined as a system of moral values that is concerned with the degree to which research procedures adhere to professional, legal and social obligation with regards to the study participants (Polit & Beck 2013:727).

The research proposal was submitted to the Student Research Ethics Committee, Faculty of Health Sciences, and University of Pretoria for approval before the commencement of the actual research. Permission to conduct the study was obtained from the Department of Health, Gauteng Province, the district office of Tshwane North sub- district clinics, and the clinic managers. Four Ethical

considerations were adhered to. They included beneficence, justice, respect for human dignity and voluntary participation.

1.9.1 BENEFICENCE

The principle of beneficence executes a responsibility on the researchers to decrease harm and increase benefits (Polit & Beck 2013:153). To adhere to this principle the researcher had to ensure the wellbeing of subjects, who have a right to freedom; protection from exploitation discomfort, harm be it physical, emotional, social or legal. . In this study, the researcher took great care and responsibility to ensure that there was no harm to participants and that they were protected from exploitation and discomfort. (Bless, Higson-Smith, and Kagee, 2014.29).

In this study the right to freedom from harm and discomfort was enhanced in this study it was the responsibility of the researcher to ensure that there is no harm and all the participants are protected from exploitation and discomfort. (Bless et al 2014.29).

1.9.2 RESPECT FOR HUMAN DIGNITY

Human rights are claims and demands that have been agreed upon by a group individuals (Grove et al 2013:163). It is having rights for self-respect, dignity and health of an individual (Fry, Veatch & Taylor 2010:98). The human rights that need to be protected in research are the right to self-determination, and the right to full disclosure.

- Right to self determination

Self-determination is explained as a decision by prospective subjects to participate voluntarily in the study (Polit & Beck 2013:154). The participants were given time after the preliminary visit before the actual date of data collection to decide whether to participate or not.

- Right to full disclosure

Polit and Beck (2013:154) explain full disclosure as the responsibility of researcher to describe in details the nature of the study. The subjects were informed about the nature of the proposed study to gain their confidence and allow them to make a choice to participate without pressure.

1.9.3 VOLUNTARY PARTICIPATION

Written informed consent

Written informed consent with accurate and complete information was necessary so that the subjects could fully comprehend on the details of the study and to be able make a voluntary choice about their possible participation (de Vos et al 2014:117).

Deception of participants

Deception usually occurs when participants are misled or intentionally misrepresenting facts or when information is held back from participants (de Vos 2014:118). The researcher ensured that participants are informed of every action taken.

Privacy and confidentiality

The researcher handled information obtained from participants as confidential as possible and their privacy was also protected no names were disclosed and no information was shared with anyone (de Vos 2014:119).

1.9.4 JUSTICE

This principle focuses on the participants right to fair selection, treatment and privacy (Polit & Beck 2012:155). The researcher selected participants the for reasons directly associated with the research problem not because they are easily available (Bothma et al 2010:20). Justice included fair treatment and right to privacy.

Right to fair treatment

Fair treatment means the entire subject to be treated alike (Polit & Beck 2012:155). In this study, the selection of participants was based on the requirements of the study to avoid exploitation.

Right to privacy.

Privacy is explained as keeping confidence and not to interfere with that which naturally not meant for others (de Vos 2013:119). In this study the researcher was sensitive with the information that the participants has shared and did not intrude in their personal space.

1.10 ORGANIZATION OF THE STUDY

The study layout is constructed in the following order:

- Chapter 1: Orientation to the study
- Chapter 2: Research design and methodology
- Chapter 3: Discussion of results and literature control
- Chapter 4: Implications, recommendations, limitations of the study and contribution to the body of knowledge

1.11 SUMMARY

The chapter presented the orientation of the study which comprised of:

Introduction and background, Problem statement, Significance of the study
Philosophical assumptions, Summary of research design and methods
Ethical principles.

2.1 INTRODUCTION

The previous chapter discussed the orientation of this study. This chapter describes the research design and methodology used during the course of the study. The research design is qualitative and it explore and describes the lived experiences of nurses initiating and managing HIV infected patients on antiretroviral treatment. The population, sampling method, data collection method and the measures used to ensure trustworthiness are discussed together with the data analysis.

2.2 RESEARCH DESIGN

The research design according to Rebar and Cherrie (2011:175) is the overall plan in acquiring new knowledge or confirming existing knowledge. Babbie and Mouton (2014:74) defines research design as a proposition of how the research will be conducted. In this study the qualitative exploratory, descriptive and contextual research design was employed. The approach was explore and describe the challenges and experiences of nurses initiating and managing HIV infected patients on antiretroviral treatment in their work place.

2.2.1 Qualitative designs

Qualitative research is the design that progresses throughout the study process (Polit & Beck 2012:487). Offredy and Vickers (2010:86) explain qualitative research as a design that has methods developed which are more suitable to handle the topic of the study. Qualitative design is appropriate for this study as Savin-Baden & Major (2013:11) state that qualitative research is a form of social inquiry that focuses on the way people interpret and make sense of their experiences in their working environment. The participating nurses were able to narrate about their experiences.

2.2.2 Exploratory design

An exploratory study refers to acquiring an understanding into a situation, phenomenon community or individual (Grove et al 2013:370). Exploration begins with a phenomenon of interest, but rather than observing and recording the phenomenon, it aims at exploring the dimension of the phenomenon, the manner in which it is manifested and factors with which it is related (Polit & Beck 2012:640). An exploratory research design provided in-depth information on the experiences of nurses initiating and managing HIV/AIDS infected patients in their work place. This was done with the hope of identifying strategies to improve service delivery towards patients infected by HIV and on treatment. The exploratory research design was relevant for this study as it supplied in-depth information regarding the challenges that influence their service delivery.

2.2.3 Descriptive design

A descriptive design was conducted to observe, describe and document aspect of a situation as it naturally occurs (Polit & Beck 2012:215). Botma et al (2010:194) refer to descriptive research as describing things the way they are, what the actual state of affairs is. In this study the experiences of nurses initiating antiretroviral in clinics were described.

2.2.4 Contextual design

According to Struwig and Stead (2013: 11) “people’s behaviour does not occur from nothingness. It is imperative to provide an all-inclusive description and analysis of the work environment of the research participant” Contextual design puts more importance on different macro and micro contexts of the individual and how they correlate with each other. In this study the experiences of nurses initiating and managing HIV infected patients on treatment were explored.

2.3 RESEARCH METHODOLOGY

The research methodology refers to the process and procedures to be followed to answer the research question (Babbie & Mouton 2014:75). The research methods included the following: the context, population, sampling, data collection and data analysis.

2.3.1 Context

Research setting is explained as a specific location where information was collected (Polit & Beck 2012:49). It is also described by Grove et al (2013:373) as the location where a study was conducted. In this study a natural setting was used to conduct the study. The research was conducted at five clinics, which are located in a semi-rural areas of Tshwane North. These clinics were selected because they offer HIV/AIDS ART (HAART) services. These were clinics that open six (6) days a week, from 7am to 16 pm with a statistic of more than (3000) three thousand patients per month in each clinic. They had the minimum staff allocation of seven (7) professional nurses, two (2) enrolled nurses, two (2) enrolled nursing assistant staff, one (1) administration clerk and two (support staff).

2.4. POPULATION

Population is a total number of persons or objects with similar characteristics (Grove et al 2013:351). The target population is the participants that meet the sampling criteria in the study. Polit and Beck (2012: 738) further explain population as a complete group of individuals having similar attributes. Population is a certain group of people that the research project was centred on. In this study the population was the NIMART trained nurses and those who were actively involved in initiating and managing ART to HIV infected patients in Tshwane North sub-district clinics.

2.5 SAMPLING

Sampling is the process of choosing a part of the population to represent the whole population (Polit & Beck 2012:275). In this study the researcher used Grove, Burns and Gray (2013:365) 'purposeful sampling to select certain participants that were needed for the study. Nurses trained in NIMART and who were also involved in initiating and managing HIV infected patients on ART were selected (Burns & Grove

2011: 40) Four (4) nurses were selected from each clinic. The sample size was determined by the information that the researcher needed.

2.5.1 Inclusion

An inclusion criterion according to Polit and Beck (2012:274) is defined as the criteria of selecting participants with specific characteristics. The researcher selected both male and female NIMART trained nurses who are actively involved in initiating and managing HIV infected patient on ART. The nurses were selected from 5 (five) clinics in Tshwane North district which initiates and manages HIV infected patients.

2.5.2 Exclusion

Polit and Beck (2012:274) defined exclusion criterion as participants with specific characteristics that are not relevant to the study to be under taken. Nurses who were actively involved with initiating and managing HIV infected patient on ART were excluded.

2.6 DATA COLLECTION

Data collection is the gathering of information needed to address a research problem (Polit & Beck 2012:62). Grove et al (2013 45) define data collection 'as a precise, systematic gathering of information relevant to the research purpose or the specific objectives. In this study in-depth interviews were conducted and response to question posed by the researcher was essential. (Polit & Beck 2012: 752). Participants reported the challenges that they come across when managing HIV infected patients on ART.

2.6.1 Recruiting participants

The researcher recruited NIMART trained nurses who were actively involved in initiating and managing HIV infected patient from five (5) clinics in Tshwane North District. During the initial contact with the participants the researcher clarified the topic to be researched and the purpose of the research to gain their trust (Botma et al 2010:203). The researcher also secured an appointment date for the actual collection of data.

2.6.2 Information session

Information session refers to the planning of an interaction between the researcher and the participants prior to the actual interview day (Burns and Grove 2011: 40). The researcher met with participants at their individual clinics in a convenient room. During the information session, the researcher discussed the research topic and issues related to the expectations from the participants, the purpose of the research and the research question. The participant information leaflet was issued and consent form was explained to the potential participants. The participants identified were willing to participate. (de Vos et al 2013). The researcher reminded the potential participants two days before the interview of the scheduled appointment to conduct interview.

2.6.3 Pilot study

Pilot study is defined as the miniature trial of the actual research study (Polit and Beck 2012:737). Before the actual research commences a preliminary interview were conducted. The purpose was to test the research question whether it was clear or not. Information collected will not be utilized in the main study (Botma et al 2010 275). On the day of the interview the venue was prepared. The researcher introduced herself and the research assistance and welcome the participants to allay their anxiety. The topic was introduced.

The following question was posed and was followed by probing question: *What are the challenges and experiences of nurses initiating and managing HIV/AIDS infected patients on antiretroviral treatment in Tshwane clinics?*. Probing questions were asked according to the interview guide.

The researcher employed various communication skills such as listening by not interrupting participants in any way. Probing questions and paraphrasing to obtain enough information and to validate the correctness of the information were used. (Creswell et al 2013:89). The probing question asked were:

- Why do you have challenges?.
- Are the challenges common with most patients
- Do you think that there should be an intervention to curb this challenge?

At the end of the interview the researcher thanked the participants for their contributions.

2.6.4 Individual interviews

An individual interview is defined as method of gathering information in which the researcher ask questions to the participants face to face (Polit & Beck 2013:731). A one on one interview was conducted with each participant involved in initiating and managing HIV infected patients on ART. Each interview lasted thirty minutes. In-depth interviews were conducted to assist the researcher to control and obtain with a list essential questions to be covered to enable extract information for the study (Polit & Beck 2013:537). During this process an assistant researcher accompanied the researcher. Other researchers recommended the assistant researcher for her expertise in research.

The researcher informed the participants that the interview would be recorded to enable the extraction researcher and the co-researcher to transcribe the information word to word to ensure accuracy. Various communication skills were used to inspire the participants to come out with richer information. The communication skills used to extract more information were probing, paraphrasing, and listening skill.

- **Probing**

Probing is explained by Polit and Beck (2013:272) as asking thought inciting questions in a gentle way. This was achieved by requesting participants to give further explanation on what was meant by a statement mentioned in the report. The researcher repeated the participants' comments to gain more clarity and meaning.

- **Paraphrasing**

Paraphrasing refers to the confirmation of what the participant mentioned in another form in a specific area of the report (Burns & Grove 2011:220). The researcher repeated the participants' words in another form but without losing the meaning to gain an understanding. Researcher validated and summarised statements in order to verify what the participants said throughout the interview.

- **Listening**

Listening more and speaking less is of utmost importance for in-depth interviewing and it is also vital not to interrupt the participants when narrating their stories (Burns & Grove 2011:272) The researcher is expected to have good listening skills to be able to inspire participants to talk more. In this study the researcher showed interest by nodding and maintaining eye contact while the participants were expressing their experiences

2.7 DATA ANALYSIS

Data analysis deals with reproducing and organizing data to give it meaning (Grove et al 2013:46). It entails “breaking up information into manageable themes, patterns,trends and relationships” (Babbie & Mouton 2014:108). Qualitative content analysis was used to analyse the data. Qualitative content analysis is the process of scrutinizing the related information to establish important arguments and order among the arguments (Polit & Beck 2012:564). In this study the content of the narrative data was analysed to identify important themes among the themes (Polit & Beck 2012:564). The researcher carefully read through all the transcripts and made notes of prominent themes, arranged similar topics in groups and converted them into sub-themes.

2.8 MEASURES TO ENSURE TRUSTWORTHINESS

Trustworthiness is described by Polit and Beck (2012:582) as a degree of confidence qualitative researchers have in their data, assessed using the criteria of credibility, dependability, conformability and authenticity. Trustworthiness is further explained by Creswell et al (2014:304) as the way in which the researchers captivate and convince the audience to take the study seriously.

2.8.1 Credibility

Credibility is defined as a measure for evaluating honesty and quality in qualitative research, referring to confidence in the truth of the data (Polit & Beck

2013:585). Credibility is the technique researchers used to remain in the field for extended period, using a variety of sources to gather data, peer debriefing as well as searching and accounting for disconfirming evidence (Brink et al 2014:126). The researcher ensured credibility of the research study through prolonged engagement in the field, member checking and triangulation.

- Prolonged engagement

“Prolonged engagement is explained as staying in the field until data saturation was reached” (Brink et al 2014:172). In this study the researcher collected data to the point that there was no new information obtained and redundancy was achieved resulting in data saturation.

- Member checking

The data findings of the research was taken back to the subjects for interpretation and confirmation of the information discussed. This was done to correct errors and provide additional information (Brink et al 2014:172). In this study the researcher had a meeting with the participants to discuss the correctness of the information.

- Triangulation

According to Polit and Beck (2013:543), method triangulation involves using multiple methods of data collection about the same phenomenon. In this study, the researcher used a rich blend of unstructured data collection methods e.g. tape/digital recorded oral interviews.

2.8.2 Confirmability

Confirmability refers to the neutrality of the data and interpretation thereof (Polit & Beck 2012:585). The researcher was interested in establishing that the information at hand represents the facts that the subjects provided, and that the researcher did not create the explanation of data. In this study the audit trail of the individual interview was done. Confirmability was ensured by having a research assistant, a qualified colleague in research, who assisted with transcribing the data and then verified consistency.

2.8.3 Dependability

Dependability refers to trustworthiness of the data over time and condition (Polit & Beck 2012:585). The auditor (usually the peer who will be the supervisor and the co-supervisor) will conduct an audit to follow the process and the activities of the researcher in the study and decided whether they are dependable or not. With this study the same experiences that were uncovered will be found if the study was to be repeated.

2.8.4 Transferability

Transferability 'refers to extent to which the findings can be transferred to other settings (Polit & Beck 2012 585). The researcher provided a thick descriptive data to enable the someone to evaluate the appropriateness of the data to other circumstances (Polit & Beck 2012 585).

2.8.5 Authenticity

Authenticity is explained as the degree to which the researcher fairly and accurately display a range of truthfulness (Polit & Beck 2012:585). In this study authenticity has become visible when a well described report reflects the realities as experienced by nurses.

2.9 SUMMARY

Qualitative, exploratory and descriptive research was conducted to address the research question. In-depth interviews were conducted with female NIMART trained nurses who were actively involved in initiating and managing HIV infected patients on ART in Tshwane North sub district. The next chapter discusses the presentation of the study findings and interpretation thereof.

CHAPTER 3

DISCUSSION OF RESULTS AND LITERATURE CONTROL

3.1 INTRODUCTION

A complete description of the research design and methodology were discussed in chapter 2. Chapter 3 deals with the study findings and interpretations of the raw data collected. The literature will later be used to support the discussion. The interviews were transcribed verbatim and their content coded and analysed to identify core themes. The recorded interviews were listened to repeatedly and compared with the transcripts. The interview transcripts were typed verbatim and not rephrased to be grammatically corrected (Struwig & Stead 2013:178).

3.2 DESCRIPTION OF THE SAMPLE

The sample of this study comprised of 20 professional nurses who were purposely selected. Nurses who were NIMART trained and managing HIV infected patients on antiretroviral treatment were included. The participants were selected from the five (5) clinics in Tshwane North sub-district. Table 3.1 displays the biographical information of the participants.

Table 3.1: Biographic information of participants

Criterion	Characteristics	Frequency	Percentage
Gender	Females	20	100%
Age	20 – 29	2	10%
	30 – 39	8	40%
	40 – 49	7	35%
	50 – 59	3	15%

Qualification	Bachelor of nursing science	03	15%
	Diploma in General Nursing (Psychiatric and Community) and Midwifery	17	85%
Post basic training	Diploma in clinical nursing science health assessment, treatment and care	10	50%
Experience as registered nurse	0 -1	1	5%
	1 – 2	3	15%
	3 – 4	5	25%
	4 – 5	5	25%
	5 and more	6	30%

3.3 PROCESS OF DATA ANALYSIS

The researcher commenced the data analysis by repeatedly listening to the audio sounds interviews reading and re-reading the verbatim transcripts. During this process certain patterns of concepts were identified and grouped into themes that were used as make-up for content analysis. The assistant researcher was given copies of the verbatim transcripts and the analyzed data. The assistant researcher and the researcher sat together to discuss and reach an agreement on the themes and sub-themes identified in the transcripts. Four themes were developed and sub-themes identified. The themes were supported with relevant quotes from participants

A summary of themes and sub-themes on the experiences of nurses initiating and managing HIV infected patients on antiretroviral treatment are indicated in table 3.2

Table 3.2: Framework of data analysis on themes and sub-themes

THEME	SUB THEMES
3.4.1 Delayed initiation	<ul style="list-style-type: none">• Denial of the HIV status due to lack of mental readiness• Fear of Stigma that comes with the illness• Loss to follow up from care
3.4.2 Interference in taking ART	<ul style="list-style-type: none">• Failure to disclose to partners• Disclosure to children living with HIV• Myths about ART• Religion and spiritual beliefs
3.4.3 Young people infected and living with HIV infection	<ul style="list-style-type: none">• Parent denial of children's HIV positive status.• HIV infected teenage girls as teenage mothers.
3.4.4 Patients already on treatment	<ul style="list-style-type: none">• Self-referral of patients.• HIV-positive immigrants' patients.• Defaulting treatment or poor adherence.• Tracing of loss to follow up (LTFUP) patients

3.4 PRESENTATION OF THE STUDY FINDINGS

The data analyzed was grouped into four themes that came with their own sub-themes.

The identified themes are as follows:

3.4.1 Delayed initiation.

3.4.2 Interference in taking ART.

3.4.3 Young people infected and living with HIV infection.

3.4.4 Patients already on treatment.

3.4.1 THEME 1: DELAYED INITIATION

The first theme identified is delayed initiation. Delayed initiation occurs when a person tests HIV positive but postpone entering care (Jenness, Myers, Neaigus, Lulek, Navejas, and Raj-Singh, 2012:1240). Participants mentioned that delayed initiation is one of the most constant operational challenges they come across. The participants indicated that firstly patients must be pre-counselled on the importance of testing for HIV then voluntarily agree to test. HIV infected patients who are eligible for initiation on antiretroviral therapy (ART) are compelled to overcome significant psychological, socio-structural, operational barriers.

With delayed initiation, the following sub-themes emerged denial of HIV status due to lack of mental readiness, fear of stigma that comes with the illness and loss to follow up from care. Three sub-themes identified appear in table 3.3.

Table 3.3 Theme and sub-themes on delayed initiation

THEME 1	SUB-THEME
3.4.1 Delayed Initiation	<ul style="list-style-type: none">• Denial of HIV status due to lack of mental readiness• Fear of Stigma that come with illness• Loss to follow up from care.

3.4.1.1 Sub-theme 1: Denial of HIV status due to lack of mental readiness

Participants mentioned that between testing and initiating patient on antiretroviral (ART) treatment they come across challenges of patients' who report shock from the HIV test result, distress and questions on how they were infected. The participants shared their experiences of patient's lack of mental readiness as follows:

“Yes, the patient is denying the HIV positive results because ... she told me that she has been testing every year to check her status, she did it every year until the last time when she did it she found out that she is positive. She told herself that every year she tested negative and she assumed that even this year she will test negative unfortunately the result was positive” (Participant B)

Another one said:

“Others patients you find that they are still in denial of their HIV status. They are initiated on treatment and when they come back for two weeks follow up they come with the tablets untouched. When you ask them why they are not taking the treatment. They say they are not ready to take them as they are still trying to come to terms with this condition” (Participant J)

One participant expressed that some patients verbalise suicidal thoughts due to denial of HIV status as it appears on the following quote:

“There are so many challenges like for instance one of the patients has just come to me, she was supposed to be initiated today, she was in such a state... She has not admitted her positive status. She told me that she even brought new blades so that she can cut her veins” (Participant B)

It was evident from the findings that most patients are in denial of the diagnosis of HIV positive. Being in denial influenced treatment initiation. Reasons for denial varied from one participant to another however they all impacted on patients' management. The participants indicated that retention of patients following diagnosis and enrolment into HIV care is a prerequisite for the optimal success of HIV scale-up efforts, yet it remains a challenge in most health care facilities. Horter, Thabede, Dlamini, Bernays, Stringer, Mazibuko, Dube, Rusch, and Jobanputra (2017:54) have similar views in their study as the participant indicated that there are patients' who report shock from the HIV test result, distress and questions of how they were infected, as well, as the source of their infection.

Participants reported denial as one of the reasons why some patients diagnosed with HIV delay initiation on antiretroviral treatment (Lyons, Moiane, Demetria, Veldkamp, and Prasad 2016:197). To be told that you are HIV positive is too much some people. The first thing that the patient must do is to accept the diagnosis in order to reach a realistic decision about prioritising care (Geng, Bwana, Muyindike, Glidden, Bangsberg, Neilands, Bernheimer, Musinguzi, Yiannoutsos, and Martin

2013:2). However in this study, participants reported that patients delayed ART initiation due to denial of positive HIV diagnosis.

Horter et al (2017:54) noted in their study that a person needs to be psychologically prepared to accept the outcome of the results he or she that may be HIV positive and make rational choices about prioritizing entering care. It is evident that a patient who tested HIV positive may experience shock from the HIV test result, distress and questions on how they were infected as well as the source of their infection. In support of the discussion Flores, Leblanc and Barroso (2016:128) indicated that in many instances those who have been diagnosed and found to be treatment eligible drop out of care before starting ART. Rosen, Maskew, Fox, Nyoni, Mongwenyana, Malete, Sanne, Bokaba, Sauls, Rohr, and Long (2016:19) indicated that most patients who delays or drop out of care before initiation on ART will eventually come back later with lower CD4 count and being very ill.

In the current study a common response to the diagnosis is that of fear and nervousness. How a person respond to the HIV status depends on how that person perceives the HIV status. The participant noted that it is not uncommon for someone who has just being diagnosed with HIV to be in denial for a while. Human immune deficiency virus denial comes with the shame of stigma and the big question is how he or she contracted it. How am I going to face people?

3.4.1.2 Sub-theme 2: Fear of Stigma that comes with HIV illness

Stigma is described as ‘an element that is intensely disreputable within a distinct social interaction. The justification of stigma pays attention on the public’s attitude towards a person who has a feature that falls short of general society’s expectations Participants mentioned that among the challenges that they experienced was the patient’s fear of stigma that comes with HIV illness. This was expressed as follows:

“Aa... most challenges are about the stigma because some of our clients don’t want to be initiated especially those residing near our clinic. Those that stay in this community prefer to go to other clinics even though we tell them about advantages of collecting treatment at their clinic”. (Participant E)

Patients feel ashamed to be seen by friends, neighbors and relatives coming to clinic regularly to collect their ART treatment. One participant mentioned that the way people perceive the HIV transmission is a guiding force to stigma.

“Mm...I can say the stigma is caused by the way HIV is acquired. Yes, because everyone who knows that through sexual intercourse you can get HIV then they take it as someone is sleeping around and things like that...” (Participant C)

Another participant confirmed by saying:

“Aa... you know when HIV started it was associated with promiscuity and a lot of people were judged so even now people are judging others when they for example lose weight. They already think this person is HIV infected... so... most people move away from the place they are staying and go to live elsewhere”. (Participant K)

The participants highlighted that HIV is the most stigmatized chronic condition because of the way people believe it is acquired. Participants further stated that it makes it difficult for the infected person to speak freely about the HIV status with others. Gilbert and Walker (2010:140) pointed out in their study that most people in the general population do not understand HIV transmissions which result in people being intimidated by the existence of the disease. Participants reported that after testing HIV positive they get worried about what people will say about this. Some may request to be moved to another clinic to avoid being seen by friends and relatives. Therefore fear of stigma delays most people's entry into care especially when the patient has no noticeable signs of illness (Lyimo, Stutterheim, Hospers, de Glee, van der Ven & Bruin 2014:99).

Participants in this study mentioned that people infected with HIV are frequently held responsible for their illness. Some of these peoples believe HIV could be avoided if individuals make better moral decisions. Gilbert and Walker (2010:140) reported that discrimination arising from HIV-related stigma is a reaction to the fears and prejudgments of people and communities and a sense of disgrace and responsibility, respectively and a recurrently troublesome and sometimes disabling fear of being discriminated against. It has become difficult for people to deal with an HIV diagnosis due to how it is perceived in the community. Some patients refused to

start ART because they need to repeat the test, or they transfer to another clinic because their clinic has a lot of familiar people (Losina, Bassett, Giddy, Chetty, Regan, Walensky, Ross, Scott, Uhler, Katz, and Holst 2010:4). The outcome of non-disclosure may result in patient refusal to initiate or not adhering to treatment and possibly poor HIV-related outcomes.

3.4.1.3. Sub-theme 3: Lost to follow up from care

Patient are regarded as lost to follow up (LTFU) when they do not honor their appointments after their last visit without having been transferred to the service of another facility for ART continuity of care. It then not known if the patient has died or has decided to take treatment at other facilities or has stopped taking treatment. Participants in this study mentioned that a significant number of patients are lost to follow up. Most patients do not come back for their baseline bloods results that will determine their eligibility to treatment. The participants additionally noted that other patients who have been on treatment for a period decide to stop coming for follow up. This was expressed in the following quotes:

“Okay some of the patients after being tested they just go. I do not know if they still need to process the positive results or what, but they take longer period to come back to the clinic”. (Participant J)

The following participant also supported the above quotes by saying:

“We take the bloods samples; we explain to them that after testing positive we should take the baseline bloods samples. To prepare for initiation, but they do not come back for the results some take longer to come back to the clinic, and as for others we don’t know if they are still here or they have relocated or what?”. (Participant M)

Participants also mentioned that some of the patients who have been on antiretroviral treatment for some time decide not to come for their follow up visits.

“...Aa... it means ...eh... like yesterday our sister was just reporting to us that most of the patient who are now defaulting ART are from 2011, meaning that they have

been on treatment for about 5 year. So. Maybe they see that they have improve now they leave treatment". (Participant K

"Even after you have initiated them on treatment they take the first bunch of treatment...and never come back". (Participant G)

Patients decide to miss their follow up care after a few years in treatment; this might be because they feel healthy at the time.

The participants in the study expressed higher estimates of delayed entry into care as a challenge. The participants communicated that the most common reasons for delaying initiation are fear of stigma, denial of status and loss to follow up, lack of support from significant others and lack of understanding of the disease and the need for care. The refusal of patients to engage in HIV care, delays initiation resulting in incidence of individuals spreading the disease. The patient is at risk of acquiring multiple co-infections leading to death (Gu, Mao, Tang, Montaner, Shen, Zhu, Detels, Jin, Xiong, Xu, & Ling 2016:1371).

The participants explained further that patients who had undergone the whole process of pre-counselling, testing positive, post-counselling and baseline bloods for CD4 count and other baseline information did not come back for scheduled follow up appointments. Evangeli, Newell and McGrath (2016:358) support the participants concerns, stating that some of the patients get lost to follow up after being diagnosed with HIV or getting the first dose of treatment. They are supposed to come back for review to assess how they are coping with treatment; but unfortunately they do not come back. Loss to follow up also poses barriers to achieving effective treatment outcome (Nordentoft, Engell-Sørensen, Jespersen, Correia, Medina, da Silva Té, Østergaard, Laursen, Wejse, Hønge, & Bissau 2017:188). Participants in this study attested that some patients literally refuse to be started on treatment reporting that they would come back and they did not come.

The participants in this study explained further that patients who have undergone the whole process of pre-counselling, testing positive, post-counselling and baseline bloods for CD4 count and other baseline information do not come back for scheduled follow up appointment. Some of the patients get lost to follow up after

getting the first dose of treatment. The participants further indicated that the patients are supposed to come back for review to assess how they are coping on treatment; unfortunately they no longer come back Mberi, Kuonza, Dube, Nattey, Manda, and Summers (2015:2006) mentioned in their study that retention of patients following diagnosis and enrolment into HIV care is a requirement to the best accomplishment of HIV scale-up effort, yet it remains a challenge in most resource rich and or resource poor surroundings. Flores et al (2015:127) mentioned that enrolling newly diagnosed patients and retaining them to care is important because those on treatment have considerable lower viral loads and lower disease progression than those who are not. The participant mentioned that have a challenge of seeing patient who were lost to follow up coming back when they are very sick with multiple opportunist infections.

3.4.2 THEME 2: INTERFERENCES IN TAKING ART

The Interferences in taking ART was identified as another theme. This interference in accessing HIV care comes as a result of multiple reasons. In this second theme four sub-themes were identified namely: failure to disclose to partners, disclosure to children living with HIV, myths about ARV's and religious and spiritual beliefs. Themes and sub-themes are presented in table 3.4.

Table 3.4: Theme and sub-themes on interferences in taking ARV's

THEME 2	SUB - THEME
3.4.2 Interferences in taking ART.	<ul style="list-style-type: none"> • Failure to disclose to partners • Disclosure to children living with HIV • Myths about ART • Religion and spiritual beliefs

3.4.2.1 Sub-theme 1: Failure to disclose to partners

Failure to disclose to partners emerged as one of the sub-themes that interferes with taking ARV's freely. Despite free availability of HIV information through public awareness campaigns, the participants indicated that disclosing the HIV status to a partner and or family member remains difficult for HIV infected person. The

participants further mentioned that most women diagnosed at antenatal clinic are afraid to talk about their status with their partners because of multiple reasons. This was expressed in the following quotes:

“And then unfortunately some of the women find it difficult to tell their partners because ‘if I tell him that I’m from the clinic, I tested HIV positive he is going to divorce me or we are going to fight or he is going to kill me, therefore it becomes difficult for me to tell him that I have been diagnosed’. (Participant B).

Another participant reported a similar challenge by saying:

“And then some will refuse because the husband does not know the status, so when she goes home with the treatment what is she going to tell the husband? They will tell you that ‘I am not ready to disclose’. (Participant G)

‘Because of men’s negative reactions to HIV, many women fear disclosing their status to their husbands, losing out on an important treatment partner. Out of shame, men may prevent their wives from taking ART’.

“I nurse this woman who was hiding the tablets from the husband saying if he knows that she is on treatment he will leave her’. (Participant O)

The participants noted that individuals who are HIV-positive and have not yet disclosed their status to their partners reported that they adopt different strategies to avoid disclosure, such as moving to other remote facilities, hiding HIV medications, and forsaking care. The participants emphasized that HIV-status disclosure demands careful consideration because of its potential for adverse social consequences, including rejection, abandonment, and even physical assault. These participants further added that most people especially woman experience fear of disclosing their positive HIV status to their partners because of personal implications that may result from doing so. The partners’ response of may vary from supportive to violent.

As pointed out by some participants, women must overcome a number of difficulties when disclosing their HIV infection to their partners, ranging from rejection, being dumped, and fear of being accused of infidelity to fear of loss of economic support from their partners. This may lead to the patient not taking treatment regularly and on time. Failure to disclose the HIV status result in serious implications on the quality of life of the person (Cisse', Diop, Abadie, Henry, Bernier, Fugon, Demdele, Otis & Preau 2016:51).

According to Elopre, Westfall, Mugavero, Zinski, Burkholder, Hook, and Van Wagoner (2016:148, the decision to disclose HIV status is complicated and may entail considering possible sacrifices versus benefits in disclosing to friends, family or sexual partners. Like other chronic illnesses, social support can safeguard the stress associated with living with HIV-infection and can promote a sense of emotional well-being. For people living with HIV infection, receiving social support related to living with HIV requires disclosing their HIV-status. Akilimali, Musumari, Kashala-Abotnes, Kayembe, Lepira, Mutombo, Tylleskar and Ali (2017:137) in their study indicated that some individuals who have tested HIV-positive and disclosed their HIV status have lost social support, and have faced discrimination, stigmatization, rejection, and violent reactions from their significant others (Cisse et al 2015:51.)

The participants highlighted that some women choose to remain silent about their HIV infection. This secrecy may lead to increased risk of HIV transmission to their partners and it may have an impact on treatment success in maintaining viral suppression. On the other hand, the decisions to disclose HIV-status to family members and friends offers advantages to the infected persons in that they can maintain honesty in relationships, ensure relief from the stress associated with concealing one's HIV-status, and access to social support (Maeri, El Ayadi, Getahun, Charlebois, Akatukwasa, Tumwebaze, Itiakorit, Owino, Kwarisiima, Ssemmondo, & Sang 2016:60).

Studies assessing barriers to HIV disclosure among predominantly female PLWHA participants report significant anticipated stigma (Mkwanazi, RoCHAT & Bland, 2015:69) and fear of abandonment, rejection, and violence (Greeff, Phetlhu,

Makoe, Dlamini, Holzemer, Naidoo, Kohi, Uys, and Chirwa 2010:312, Rujumba et al., 2012: 17249). HIV disclosure enables discussion between couples and affords possible sex partners to of HIV-positive individuals the prospect for informed choice about whether to take protective measure during intimacy or abstain from sex at all. The procedure of HIV status disclosure may also assist as an instrument to promote partner testing for HIV.

3.4.2.2 Sub-theme 2: Disclosure to children living with HIV

Disclosure to children continues to be a challenge. Disclosure refers to a child gaining knowledge of his/her HIV status (Jemmott III, Heeren, Sidloyi, Marange, Tyler, & Ngwane 2014:1028). Despite the escalating proof recommending disclosure of human immunodeficiency virus (HIV) status to young people with perinatal acquired HIV as a motivating factor for adherence to antiretroviral therapy, it is a partial event, rather than a process (Bernays, Papparini, Gibb, and Seeley 2016:60). The participant mentioned that some children are born with HIV infection and some of their parents have died due to HIV. Some are raised by their parents and some by guardians/grandparents who find it difficult to explain to the children about the state of their health. This is observed in the following quotes.

“Here was this child who is HIV positive, born with and she was a teenager of fifteen years and the child was always asking the mother at home, why I am taking this medication because I am not sick I am well. And the mother was like duck and diving not telling the child the exact reason, until this child Google, you know they use the advance phones and stuff like that and saying ‘what is maybe fixed dose combination or whatever Nevirapine or blah, blah’, and whereby the child realized that the medication that she is taking is for her HIV status.” (Participant C)

“When you do your physical examination and everything, there would be something telling you that you need to do the HIV test. Then the child is 11 years, she is 12 years and she is positive. After testing you should disclose the positive result to the child.” (Participant J)

“Other challenges right now are concerning children, from the age of 6 years to 16 years ... is a serious problem, because most of my children, I have realized that they

don't know why they are taking their medication. It is like parents are not disclosing ... parents do not disclose to them that they are HIV positive.” (Participant O)

The participants mentioned that most children who were infected perinatal are on treatment although they do not know the reason for taking it. Parents and care givers rely on nurses to disclose their HIV status to their children.

HIV-infected children in developing countries live longer lives if they have access to antiretroviral treatment programs. As they advance in age, their parents or guardians have to confront the difficult decision of disclosing to them, and this includes when, and how to inform the child of his/her HIV status, taking into consideration the age when giving the information (Vaz, Eng, Maman, Tshikandu, & Behets 2010:247). In concurring with the discussion Waugh (2010:174) indicated that most children infected with HIV during the perinatal period and growing up with it present serious challenge to HIV care programmes. Disclosure of a child's HIV status can have significant impact on child's life and family relations. The author further noted that when and how a parent discloses to a child can affect the provision of care for the child and may influence the child's psychosocial adjustment and development.

Disclosure to young people tends to be scanty until the child makes a self-discovery that results in anger (Bernays et al 2014:63). The participant in the study mentioned that some young people responded by doing research of their own, on the Internet, and only a few asked questions to their main care givers, other adults and clinical care staff. Participants also highlighted that some children relied on information from the Google search engines to try and make sense of their own situations. (Kidia, Mupambireyi, Cluver, Chiratidzo, Ndhlovu, Borok, & Ferrand 2014:2) attested in their study that mostly parents will have difficulty in disclosing their children's status to them fearing that the children may develop anger, blame their parent or become rebellious. In some cases, medical providers played a central role in a parent's decision to disclose, as some insisted that the child be informed of the HIV diagnosis prior to treatment, where as others simply advised parents that open disclosure was in the child's best interest.

3.4.2.3 Sub-theme 3: Myths and misconceptions about HIV and ARV's

The concept “myth” is rich in meaning, and can be interpreted in culturally resounding or in negative ways. These authors Picou, Ameen, Maharaj, Ramdath, Quesnel, and Zulaika (2011:18), define myth as ideas or explanations that are widely believed to be true but which are, in fact, untrue and based on ignorance about the subject. A misconception in turn is defined as “a view or opinion that is false or incorrect because it is based on out of order thinking or understanding” (Oxford University Press, 2015), There are various myths and misconceptions that are associated with HIV infection within South African communities that lead to the stigmatization and discrimination against people living with HIV. These myths interferes with testing, prevention and accessing HIV care. Myths are mostly confusing and misleading information. The participants also mentioned that there are myths that are circulating in the community that are related to taking ART. This was expressed as follows:

“...other patients have some myths about the ART, they just believe that when you take ARV's you will die early” (Participant J)

One participant describes it as follows:

“We send them to counselors even we the professional nurse we counsel them. And that's when we hear about that myth whatever that made them be afraid of being started on treatment and try to clear it until the patient understands”. (Participant D)

“There are patients who refuse to be put into care saying that the reason they are sick is because they had a relationship with a widow, ... you know in our black culture a widow needs to be cleansed first and remain for a year before she can start on dating’ (Participant E)

Myths, misconceptions, and superstitions are apparent in many walks of life. Myths concerning HIV/AIDS are a hindrance to accessing care and accomplishing the intended objectives, of treating all HIV infected patients. In this study the participants mentioned that patients listen to community members who have no insight about the disease HIV, what they heard usually impacts on the choices access care.

Participants additionally noted that sometimes the myths originate from religious beliefs and confuse a person more. Kang'ethe and Xabendlini (2014:55) urge that a myth which has lingered far too long in the Southern African countries is the belief that people living with HIV/AIDS can rid of the disease if they sleep with virgins' Myths present misleading and destructive information.

Nleya and Segale, (2015:226) noted that other people believe that HIV/AIDS is a curse for being intimate with a widow. People who trust in traditional healers for help tend to ignore modern medicines like ARV drugs that are offered in facilities. Cameron et al. (2013:382) established that knowledge about myths had no influence on the degree of knowledge, and correct information (Kang'ethe & Xabendlini 2014:60). The beliefs some people hold are disagreeing with medical evidence hence people living with HIV infection become vulnerable to misinformation in their search for answers.

3.4.2.4 Sub-theme 4: Religion and spiritual beliefs

'Religion is defined as an outward formal, institutional expression of the sacred, associated often with a prescribed set of beliefs or dogma.' Religion and or spirituality as revealed by Dalmida, McCoy, Koenig, Miller, Holstad, Thomas, Clayton-Jones, Grant, Fleming, Wirani, and Mugoya, (2017: 23) can have an impact on an HIV infected patient's medical decision-making and adherence treatment. The participants mentioned that some patients refuse to start ARV's because they believe that HIV can be cured at their churches, while others stop taking treatment because they believe they are healed. This was expressed as follows:

'Mh... I think it is with beliefs, you find that there are churches, which are preaching that they can heal HIV so they go to some of the churches, to be prayed for. And then they think that they are healed. (Participant F)

The other one said:

"And then...eh... I think there is some misunderstanding regarding the viral load. If you tell the patient that the viral load is lower than detectable, actually that one I

experience it myself at my church that ...eh...the patient ...eh...just gave a testimony. At the clinic, they told him that...aa... his viral load was lower than detectable. He thought it meant that he was healed, maybe is the way we explain to the patients that your viral load is good now is very low is not detectable they think that they are cured.' (Participant I).

Another one added:

"I say so because God is going to take care of her, actually I want my child to finish the religious medication first" (Participant C)

Based on the above quotes it was evident that patients in their quest to free themselves of the virus do not listen to understand the etiology of the virus during post-test counselling. They go away with little information on the disease and the understanding that on taking medication as ordered the virus will eventually disappear. That's why when they receive the news that viral load is undetected they think they are free of the virus and can stop taking medication believing that they are healed.

The participants indicated that some patients believed that attending religious services, participating in religious rituals, and praying or meditating can result in their HIV positive status changing to the virus being not detected. Vyas, Limneos, Qin, and Mathews (2014 984) reveal that HIV-infected individual who engage regularly in religious practices displays poorer treatment adherence, which may be associated with HIV stigma acquired from religious institutions. It was further emphasized that most patients do not take their time to understand the information that they are given at clinics relating to their HIV positive status and the intake of medication. When a patient is told by the care giver that the viral load is undetectable from the follow up blood result, the patient will be excited and will not ask what the meaning of that is. They usually think they can stop taking the medication because the virus is no longer there. There are those individuals who fall into religious fatalism; they feel that

3.4.3 THEME 3: YOUNG PEOPLE INFECTED AND LIVING WITH HIV INFECTION

Young people living with HIV were identified as a theme. Young adults who have been infected with HIV perinatal and have grown up with it present a challenge to HIV care programmes. In this theme the following sub-themes emerged: Parent denial of children’s HIV positive status and HIV infected teenagers and teenage mothers. Young people living with HIV as a theme and its sub-themes are presented in table 3.5

Table 3.5: Theme and sub-themes on young people infected and living with HIV

THEME 3	SUB-THEMES
3.4.3 Young people infected and living with HIV infection	<ul style="list-style-type: none"> • Parents’ denial of children’s HIV positive status. • HIV infected teenager’s girls as teenage mothers.

3.4.3.1 Sub-theme 1: Parents’ denial of children’s HIV positive status

Parents’ denial of children’s HIV positive status emerged as one of the sub-themes reported on young people infected and living with HIV infection. Parents or caregiver’s failure to admit the HIV test results of child are a result of self-blame and denial. In such cases parents may choose to withhold HIV care throughout the HIV-infected child’s life.

One participant expressed her experience as follows:

‘... they come and reported that the child was having cough ... and remembers we offer HIV test with every visit. The child tested when he was 18 months according the road to health card and was negative but this time around the child tested positive’.

The participants also highlighted that mother of children tested HIV positive are in denial of the children’s HIV results. (Participant J)

Another one expressed that:

“Aa... I had only one challenge with eh...this particular patient, the mother was on ART's she was a defaulter and she even aa... defaulted the child on treatment”.

(Participant G)

‘We did PCR (polymerase chain reaction) test at ten weeks then the baby was...aa... HIV positive. So the mother said that she did not bring the baby back because she did not believe that the baby was HIV positive. She came back when the baby was two years because she saw the symptoms and the baby was not well now. She told me that the baby was

diagnosed HIV positive and she did not believe them then now the baby is not fine now.’ (Participant D)

The participants mentioned that when the mother does not agree or accept the child's HIV test results she will never bring the child for follow up. The child will be susceptible to acquire opportunist infection.

“Ok the first challenge is a recent ...mm..., whereby the mother is a born with HIV, and she gave birth to a baby who is a born with as well. The child was brought to the clinic whenever she is ill with something ... especially something that is visible like the sores, the rash, or maybe the oral thrush or whatever. But in case of bringing this child for regular checkups eh...in terms of the ARV's is concern they did not bring him back. So, it is the challenge that I had. Looking back at the result of this child since 2015 I have observed that the viral load of this child is not suppressed.

(Participant H)

“With malnourished children, we have a challenge that they are from the teenage mothers. The teenage mothers especially who do not want to come to clinics, they don't want to go to the hospital aa... And most of the children who are malnourished are HIV positive. Malnutrition and HIV goes hand in hand and is a challenge mhh... a serious challenge.” (Participant N)

As highlighted in the above, it was evident that the children were neglected and entry into HIV care was denied. Participants reported on babies who had PCR done and whose results were positive but mother failed to take the baby for follow up at the clinic. The condition of children growing up with HIV infection is greatly underestimated. The participants commented that it is the responsibility of mothers to access care and HIV treatment for young children. Participants further highlighted that some mothers do not bring their babies for follow up care and this puts the life of the child at risk. The participants further revealed that the challenge faced by nurses in providing care to the children is denial which is manifested by the significant rate of loss to follow up of both mother and baby postnatal. Bernays et al (2014:1355) reported in their study that children are subjected to the complications that come along with failure to access treatment. Allen, Finestone, Eloff, Sipsma, Makin, Triplett, Ebersöhn, Sikkema, Briggs-Gowan, Visser, and Ferreira (2014:606) indicated that the chronic stresses associated with HIV positive status compromise the psychological well-being of both parent(s) and their children. The authors further stated that as the illness advances from HIV to AIDS, when the child, presents with multiple ailments and failure to thrive, that's when the parents or guardians take their child to clinical facilities for consultation and management. Participants also report that some parents give the responsibility of their children's care to paternal or maternal grandparents.

HIV testing for HIV-exposed infants is available as part of the prevention of mother-to-child transmission programs (PMTCT). Ferrand, Meghji, Kidia, Dauya, Bandason, Mujuru, Ncube, Mungofa, and Kranzer, (2016:25) reported that most vertically HIV infected infants survive to late childhood without being diagnosed. These children will be diagnosed when they are presented with suspicious clinical conditions and diagnosis. Their HIV statuses depend on testing within the health care facilities and the parents or guardian's giving consent for this test to be undertaken (Adeniyi, Thomson, Ter Goon, & Ajayi 2015:98).

One participant mentioned that malnutrition in children who are HIV infected is a challenge due to negligence by their teenage mothers. Jesson, Masson, Adonon,

Tran, Habarugira, Zio, Nicimpaye, Desmonde, Serurakuba, Kwayep and Sare (2015:2) argue that malnutrition is a major problem with HIV infected children especially as it creates a vicious circle with HIV infection. On the other hand malnutrition aggravates HIV disease as it has much the same effects on the immune system as HIV infection. The participant further alluded that this is the result of the young mother not being prepared to deal with the responsibility being a mother.

3.4.3.2 Sub-theme 2: HIV infected teenage girls as teenage mothers

HIV infected teenage girls as teenage mothers also emerged as a sub-theme under young people infected and living with HIV infection. The participants highlighted that children from the age of 6 to 16 are taken into consideration when HIV/AIDS is addressed. This is observed in the following quotes:

“Other challenges right now are; concerning the children eh from the age of 6 years to 16 years hey...There is a serious problem, because most of my children, I have realized that they don’t know why they are taking their medication.” (Participant N)

Another one expressed that:

“With teenage girls who come to the clinic for family planning we are to test them first before issuing contraceptives and when the results are positive joo... it becomes a challenge. You will find that the teenage girl will cry or storm out of the consulting room.” (Participant M)

Another participants mentioned the following challenge with young mothers

“Young mothers book for antenatal care late in their pregnancy ... and give birth before taking ARV’ and this puts the new born baby at risk of being infected. Pregnant women are expected to book for antenatal care at least four weeks before giving birth.” (Participant G)

As mentioned by participants it was apparent that young mothers access antenatal clinic almost at the end of the last trimester which puts the unborn baby at risk of being infected with HIV perinatal.

According to UNCEF, UNAIDS and WHO (2012:6) an estimate of 12.8 million people between the ages of 15 and 25 were living with HIV infection especially women.

Participants indicated that teenage girls accessing contraceptive who also tested positive in the process have difficulty in accepting their HIV status. Karim, Kharsany, Leask, Ntombela, Humphries, Frohlich, Samsunder, Grobler, Dellar, and Karim, (2014:1136) reported in their study that teenage girls come for contraception mainly focusing on preventing unwanted pregnancy other than also prioritizing on protection against sexually transmitted diseases which include HIV.

Bernays, Jarrett, Kranzer and Ferrand (2014:383) mentioned in their study that the HIV infected population is higher among women in their teenage years than among young men of the same age. In concurring with the discussion Harrison, Colvin, Kuo, Swartz and Lurie (2015:298) and Albright and Fair (2014:587) mentioned in their study that the differences in HIV infection rates between young women and men of the same age can be attributed precisely to young women's partnerships with older men, who are more likely to be HIV-infected.

Albright and Fair (2014:587) pointed out in their study that the setback associated with adolescent and young adult living with HIV infection is horizontal transmission due to irresponsible sexual encounters. This may result in unplanned pregnancy with the young mother failing to access anti-natal care early. Teenage girls and women of childbearing age are particularly at high risk of becoming HIV infected because of the challenges they encounter when insisting on sexual protection from partners (Albright and Fair 2014:587). The increase in numbers of children infected with HIV who live until adolescence and becoming sexually active, has a detrimental effect on prevention of new infections. The use of protective measure during sexual encounter is poor among teenagers, and it increases the risk of spreading the disease (Lowenthal, Bakeera-Kitaka, Marukutira, Chapman, Goldrath, K. and Ferrand 2014:632).

Participants reported that the setback associated with adolescents and young adults living with HIV infection is horizontal transmission due to irresponsible sexual encounter. This may result in unplanned pregnancy, with the young mother failing to

access anti-natal care early.so that she can be enrolled early on prevention of mother to child transmission (PMTCT).

3.4.4 THEME 4: PATIENTS ALREADY ON TREATMENT

Patients already on treatment emerged as a theme. In this theme the following sub-themes emerged: self-referral of patients, HIV-positive immigrants’ patients, defaulting treatment and or poor adherence and tracing of loss to follow up (LTFUP) patients. Theme and it,s sub-themes are presented in table 3.6:

Table 3.6: Theme and sub-themes on patients already on treatment

THEME 4	SUB-THEMES
3.4.4 Patients already on treatment.	<ul style="list-style-type: none"> • Self-referral of patients. • HIV-positive immigrants’ patients. • Defaulting treatment or poor adherence. • Tracing of loss to follow up (LTFUP) patients.

3.4.4.1 Sub-theme 1: Self-referral of patients

Participants noted that patients with unknown outcomes are classified as “loss to follow up” while most of them have sought care at a new facility without requesting a formal transfer document (silent transfer) (Geng et al 2016; 935). The participants also reported that they come across patient who come and report that they are on ARV’s but have no document or referral letter to proof that they are on treatment. The participants also reported that there are patients who move from one clinic to another without informing the original clinic. Blevins, Jose, Bilhete, Vaz, Shepherd, Audet, Vermund, and Moon 2015:199). Others come with empty containers requesting refills. This was expressed as follows:

Yes, and again okay I can say with transfer in, eh... self-transfer in clients those that are on ARV’s they will come in without referral letter with nothing. They will just come in with a container of ARV’s saying, sister I am taking this medication... You don’t know if it is true, you don’t know the latest blood result what they are saying,

where he or she started, if this medication is truly his. You don't know anything they just come with a container and say I'm taking this treatment. (Participant P)

"Maybe one or two who just come, and if they come without a referral letter I just take everything. Start him or her as a new client. So, you can't deny the client medication because maybe he does not have money to go and get a transfer the referral. (Participant H)

Participants mentioned walk in as a challenge patients just showing up no official referral letter. These patients just come to request a refill of ARV's.

"And some just relocated without asking for a referral letter and when they ask them for referral letter they decide to remain without treatment. Others just go and visit another province for six months and when the treatment is finished they just remain there and do not come back. (Participant C)

The participants indicated that patients prefer to ignore the guidelines on antiretroviral therapy. They are given an opportunity to request an early refill if they have to go for a visit. This behaviour leads to defaulting of treatment and the risk of developing opportunistic infection that may affect their health. Hickey, M.D. Omollo, Salmen, Mattah, Blat, Ouma, Fiorella, Njoroge, Gandhi, Bukusi, Cohen and Gengh (2016:1387) pointed out in their study, that patients relocation between clinical facilities can take place in ways that are both known (i.e., through official transfer request) or unknown (i.e patients are "lost to follow-up" or LTFU) to the initiating clinic. These movements of patients occurs because individuals need to find employment. The participants reported that patients just come to request treatment without a formal referral letter from the initiating clinic. Estill, Tweya, Egger, Wandeler, Feldacker, Johnson, Blaser, Viscaya, Phiri and Keiser (2015:180) concur with the participants that transfer of patients is an official act, that is, recorded in the patient's record or it may be self-transfer whereby patients decide to continue care at another clinic without informing the original clinic that initiated them. Self-referral can lead to treatment interruption as the nurses will have to treat the patient as new by starting with the baseline to issue treatment. Patients' transfers need to be arranged through formal recording to prevent patients being

recorded as loss to follow up (Harries, Zachariah, Lawn, and Rosen 2010:71). The participants noted that patients who are lost to follow up are often interpreted as being out of care. Many of these patients have simply sought care at another facility without filing formal transfer documentation or maybe dead. Clinical outcomes and retention in care of HIV infected patients on ART will be feasible when patients receive counselling on every visit about the importance of requesting a written transfer letter if they move to another place. The patients will be accepted back if they decide to come back as long as they produce evidence of continuity of care.

3.4.3.1 Sub-theme 2: HIV-positive immigrants patients

Immigrant patients are individuals from other or neighboring countries and who may or may not have legal immigration status, have been diagnosed with HIV or are diagnosed in the country they visit and have to start treatment. Participants indicated that they have a challenge with patients coming in for medical services and going back to their country for a long period. This was expressed in the following quotes:

“We have a challenge with cross border patients especially patients from neighboring states ...I don’t know how we can deal with it they just come and go” (Participant Q)

“Yes. Lots of them, isn’t it that we have a lot of influx in South Africa, so... some of them are the foreigners they will be going back to country of origin and remember in some of these neighboring countries the patients must buy the ARV’s. And most of them are poor. As long as they are well they won’t be taking treatment from that side. Then when they become sick is then they come back”. (Participant M)

The quotes highlight that immigrants’ have predominately a high movement rate from one area to another. These behaviours expose many to difficulties in maintaining appropriately expected adherence to ART for long periods of time.

“We experience a challenge mostly of people from neighboring countries they come with no document with no birth records... with nothing. They will come and report that they are on ARV’S.” (Participant D)

The participants reported that lack of documents to proof what medication the patient is taking is a challenge to the health care providers. This interferes with continuity of care which leads to treatment defaulting. Although it is hoped that a number of immigrant patients who visit or go back to their home country will access care there, it is surprising that they come back only after their health has deteriorated Hallett and Eaton (2013:229), contributing to increase in morbidity and mortality.

Participants reported that they are challenged by patients from neighbouring states that move in and out of the country anytime. They further explained that when the immigrants come back they discover that they have stopped taking treatment several months back. Sumari-de Boer, Sprangers, Prins and. Nieuwkerk (2012:1682) in their study reported that providing care to the population that is continuously moving in and out of the country to neighbouring countries is a health care challenge and a challenge for the health care workers. The challenge is even more extensive when this population needs long term chronic care for disease such as HIV which demands extreme adherence to treatment and frequent follow up visits (Ponthieu & Incerti 2016:98)

Providing health care services to migrant patients has been a long term challenge as people need to see their loved ones more often. People from neighboring countries enter South Africa every day to access medical health care.

3.4.3.2 Sub-theme 3: Defaulting treatment or poor adherence.

Adherence to ART is the strongest predictor of treatment success. Adherence to a medication regimen is defined by Cramer, Roy, A., Burrell, Fairchild, Fuldeore, Ollendorf,. and Wong (2008:46) as “the act of conforming to the recommendations made by the provider with respect to timing, dosage, and frequency of medication taking.’ Participants reported their experiences with patients who fail to come and collect their medications. This was expressed as follows:

“Jaa... the biggest challenge is the defaulter rate, especially patients who were initiated when they were on stage 1 and stage 2 with no symptoms. They just stop coming for follow up.” (Participant R)

Another participant said:

“The other problem with our clients is that when we started them they don’t have symptom but later maybe after two years or three years on treatment they decide to default...’ARV’s” (Participant A)

While one express her view as follows:

“Yes, we do have them those patient who have been taking treatment for sometimes they stop taking the medication because they think they are healed.” (Participant E)

Participants reported that patients who stop coming for treatment follow up are a challenge, especially those who were initiated when they were asymptomatic. This shows that some of the patients who are LTFU were initiated because of their low CD 4 count (i.e. $CD4 \leq 500$ cells/mm), not because of their clinical presentation. According to Sumari-de Boer et al (2012:1681) HIV-infected patients have to take lifetime antiretroviral treatment (ART). High levels of adherence to ART are essential to avoid treatment failure and the development of resistant virus strains. However, many HIV-infected patients have difficulties in keeping with sufficiently high levels of adherence to ART for longer periods of time. Participants highlighted that some patients stop taking treatment after taking it for several years because they believe they no longer have the virus

Decisions to adhere or not adhere to ART depend not only on patients and medical characteristics, but also on psychosocial factors, such as coping, support from family, understanding of HIV as a chronic illness and individual beliefs about ART (Lyimo et al 2014:98). Lower or undetectable viral load resulting from adherence to ART is linked to a lower risk of HIV transmission (Dalmid et al 2017: 23). According to Dahab, Charalambous, Hamilton, Fielding, Kielmann, Churchyard and Grant (2008:93) patients who do not think that HIV is real and that they are infected are probably linked to discontinuing treatment. Feeling healthy after taking ART is also an obstacle to adherence. Participants revealed that some patients fail to take treatment on time and end up defaulting for a week because forgetfulness, being busy or due to side effects. Participants further reported that patients default on taking treatment because they cannot keep clinic appointments, due to being away from home or employers who do not allow monthly absenteeism.

3.4.4.4 Sub-theme 4: Tracing of loss to follow up patients

Back to care tracing teams have been allocated to every clinic where the study was done and it is referred to as Ward Based Tracing Team (WBOT). The participants attested that the success of the tracing team depends on the patients records in the clinic. Some patients are difficult to trace due to movements from one area to another. Participants further mentioned that when the patient is lost to follow up it is difficult to trace them back into care because of the wrong addresses that the patients give or because of movement by patients. This was expressed as follows:

“So...With that the challenge is that aa...addresses you find that they give us wrong addresses. I don't know maybe they don't want to be found.” (Participant D)

Another one said:

“And if you call their phones either they are off or maybe they have change the sim card or someone else answer the call and is not the same person you have tested.” (Participant P)

According to what the participants mentioned it was apparent that it is also difficult to trace patients telephonically.

“You find that they do not reside around our demarcation. So... they use the wrong addresses so that they can access treatment. When they are supposed to come for CD 4 results they don't come because they don't have money for transport to come. And we fail to locate them because of wrong addresses.” (Participant I)

The participants disclosed that some patients, seeking an alternative diagnosis they move from one clinic to another, giving wrong addresses. They further indicated that in most cases it is difficult for the WBOT team to locate patients at the address they provided; it becomes clear that the patient was not honest. Without tracing, the patient will disappear for a long time from the initiating clinic. Patients who have stopped treatment should inform their clinics; unfortunately, this will be known when the outreach team traces the patient (Harries et al 2010:71). Patients moved from

one part of the country to another part of the country searching for a job others are cross border patients who have gone back to their countries. Such patients are difficult to trace. In the process, they are classified as loss to follow up (Bezabhe et al 2014:6). The outreach team, by tracing of patients, reduces the rate of loss to follow. The tracing of patients is not easy for the outreach team because patients do not provide correct addresses and their phone are usually out of order or it is a number used by people who do not know the patient. In this case the facilities end up having a poor attrition rate.

3.5 DISCUSSION OF FIELD NOTES

According to Munhall (2012:308) field notes are notes that assist the researcher to obtain a record of unstructured reflection of the participant under study and to interpret those reflections. These observed reflections are noted during the interview when the participants expressed themselves on their experiences when managing HIV infected patients. In this study the researcher recorded the verbal and non-verbal cues that were portrayed by the participants. Three of the field notes are discussed as follows: Observation notes, methodological notes and personal notes

3.5.1 Observation notes

Participants stated the challenges that they come across when managing HIV infected patients. The participants further explained that it puts strain on the nursing staff if they come across a patient who defaulted but comes back wasted with all the opportunist infections. It was evident that the participants were strained by the behaviour of the patients, evidenced by them sharing the emotions that were bottled up. *"When we see, the patient come back wasted...mm...that is ...it seriously kills you, like something somewhere is missing, you did not do your job"*

They expressed with enthusiasm the role that the outreach team (WBOT) play in tracing the patients back to care. They were also thankful that introduction of universal test and treat (UTT) allows them to test the patients and initiate them on ARV's same day without waiting for the CD4 count results. Some of the participants were unhappy about carrying out UTT because they were afraid of mismanaging the patients if the liver functioning blood results come back abnormal. This was observed

with statement like this, *“And again we test them positive and according to UTT they say you must test and treat, but you cannot test and treat. You cannot test today and treat today what if there are some abnormalities with the liver”*.

3.5.2 Methodological notes

According to Botma et al (2010:218) methodological notes are an expression around strategies and methods identified when collecting data. A challenge to privacy was that the colleagues of the participants interrupted to ask work related questions during the interviews. After these brief interruptions, the interview continued, it was a distraction that changed the mood of the interview. In this study, some of the participants were known to the researcher as she attended NIMART training with them. Adherence to anonymity was emphasized and participants were reassured of confidentiality.

3.5.3 Personal notes

Personal notes are explained by Munhall (2012:309) as personal reactions to information during interview. Thoughts and compassionates are documented for reflection, exploration and analysis. The researcher was amazed at the participant report of mothers who denied their babies treatment but continued breastfeeding them. The situation clearly reflected that mothers are ignorant of the magnitude of HIV infection.

3.6 SUMMARY

The chapter has summarized the main findings using the following themes: delayed initiation, interference in taking ART, young people infected and living with HIV infection and patients already on treatment. Sub-themes for each theme were identified and discussed. Field notes that were noted during the interviews were explored. Conclusions, implications, recommendations and limitations are discussed in chapter 4.

CHAPTER 4

SUMMARY OF FINDINGS, IMPLICATIONS, RECOMMENDATIONS AND LIMITATION OF THE STUDY

4.1 INTRODUCTION

The result of the research findings and literature control were presented in chapter 3 as themes and sub-themes. The researcher in this chapter summarises the findings, formulates the summary of findings, implications, recommendations and limitations of the study. The discussion is guided by the themes identified in Chapter 3.

4.2 AIM OF THE STUDY

The objectives of the study were to explore and to describe the experiences of nurses initiating and managing HIV/AIDS infected patients on antiretroviral treatment and to make recommendations to relevant stakeholders regarding the challenges that nurses managing HIV infected patients experience.

4.3 SUMMARY OF FINDINGS

The following four main themes were identified from the study: delayed initiation, interference in taking ARV's, young people living with HIV and patients already on treatment. These themes were further justified with literature.

4.3.1 Theme 1: Delayed Initiation

Delayed initiation was identified as the first theme. 'Linkage and engagement into HIV medical care are key components of the National HIV/AIDS Strategy; meeting the strategy and the benchmarking will ultimately improve individual-level health outcomes and reduce population-level HIV transmission'. Delayed initiation emerged and the participant highlighted that these patients after testing HIV positive refuse to be initiated on treatment or just disappear. Some patients present themselves at the

clinical facilities during in the fourth stage of HIV when it is too late to help them, even though they have been initiated on treatment earlier. It was highlighted that engaging patients early following HIV diagnoses is essential to monitor clinical outcomes of disease progression and to obtain benefits from antiretroviral therapy (ART). It was also revealed that linkage into treatment and retention in care is a prerequisite for initiation of and adherence to ART. This process reduces the risk of spreading the virus and the progression of the infection by suppressing viral load.

All the participant expressed higher estimates of delayed entry into care as a challenge. The participants communicated that most common reasons for delaying initiation are fear of stigma, denial of status and lack of support from significant others and lack of understanding of the disease and the need for care.

The participants explained further that patients who have undergone the whole process of pre-counselling, testing positive, post-counselling and baseline bloods for CD4 count and other baseline information do not come back for scheduled follow up appointments. It was evident that some of the patients get lost to follow up after getting the first dose of treatment. The patients as articulated by the participants are supposed to come back for review to assess how they are coping with treatment; unfortunately they do not come back.

The participants highlighted that refusal of patients to engage in HIV care delays initiation, resulting in the incidence of spreading the disease. It was featured that the patient is at risk of acquiring multiple co-infections leading to death. Additionally delay in entering care also creates barriers to achieving effective treatment outcome. The study revealed that some patients literally refuse to be started on treatment, reporting that they will come back and they never do. Therefore, enrolling newly diagnosed patients to care is important because those on treatment have considerable lower viral loads and lower disease progression than those who are not. Additionally, early initiation on 'test and treat' of persons found to be HIV positive is crucial in viral suppression because it reduces the likelihood of transmission. Therefore nurses have a challenge of seeing the patients coming back when the disease has progressed to fully blown AIDS.

4.3.2 Theme 2: Interference in taking ART

Interference can be explained as hindering or get in the way of, to make it difficult for an HIV infected patient to access care. Fear of stigma, violence and fear of abandonment or being blamed for bringing the disease are highlighted as the contributors to interference to taking treatment.

Participants stated that it was evident that some of their female patients were afraid to disclose to their partners because of fear of rejection. They commented that disclosure of the HIV-positive diagnosis, is certainly one of the enormous challenges facing HIV infected persons. It was described as a clear decisional conflict. The decision to disclose the HIV status is not a simple phenomenon and it is excruciating to think who to tell, and how and when to do so.

Studies have reported that '40% PLHIV in South Africa had experienced discrimination, and one in five had lost a job or a place to stay after disclosing their HIV status (Maeri et al 2016:58).' Therefore, patients who avoid disclosing to the partner use strategies to keep their diagnoses a secret and seek care in remote facilities to be provided with ART. They hide their medication and or get rid of their medication if possible. Therefore the health care workers remain with a patient who default treatment without seeking help first. The participants expressed that being HIV positive and acquiring AIDS infection is attributed to having a disease of intolerance and ignorance. The participants reported some myths that are circulating in the community about ARV's. This is because people associate HIV/AIDS with frightening myths which bring about stigma and discrimination against people living with HIV infection. These myths are a barrier to testing and prevention of HIV/ AIDS. This is because myths determine an individual's response to the diagnosis, prevention and the decision to seek care. 'A myth which has lingered for far too long in the Southern African countries is the belief that people living with HIV/AIDS can rid of the disease if they sleep with virgins' (Kang'ethe & Xabendlini 2014:55). Myths present misleading and destructive information and actions.

The participants expressed that strong religious beliefs about morality and sin could affect an individual with HIV status possibly. It was further noted that religious beliefs

may influence a decision whether to seek medical treatment for the disease or not. Additionally participants stated that some patients prefer to take the advice of their religious leaders rather than to pay attention to the advice of health professionals when they are faced with potentially life threatening disease. In most cases their decisions bring disrepute to the outcome of their HIV status. The participants mentioned in this study that the patients did the opposite by refusing to take ARV's or claiming to be healed. Considering the beliefs and values that form the patients reaction to illness is a significant quality of humanistic care (Vyans et al 2014:984). Religious belief and practices play an important role in helping persons restructure their lives when they encounter the challenges of serious illnesses. Participants noted that most religious followers rely on their beliefs in making decisions. If a person views being sick or being HIV positive as a harsh punishment from God it was predicted that disease progression is faster. Instead, health care providers must try to understand the role spirituality and religious beliefs plays in their patient's life and respond in a more accepting manner. Spiritual beliefs should be an important part of ART adherence counselling requiring close cooperation between HIV care programmes and religious leaders to identify common goals and ensure successful treatment.

4.3.3 Theme 3: Young people living with HIV

The sustained high HIV incidence among young women in southern Africa represents a significant and important health disparity. There is an increase The participants reported that mothers tend to deny it when their babies test HIV positive by doing so they expose their babies to opportunist infections and disease progression. The participants highlighted that most children have acquired the infection perinatal and some are on treatment, although they do not know why they are taking this treatment. The setback is associated with adolescents and young adults living with HIV infection of horizontal transmission due to irresponsible sexual encounter. The participants alluded that sustained high HIV incidence in young women represents an enormous health disparity that requires appropriate interventions and resources. It poses a threat to the well-being of the next generation, and is a critical factor driving the ongoing HIV epidemic in southern Africa. The literature suggests that pregnancy prevention is a greater concern for adolescents than disease prevention (Dennis, Barrington, Hino, Gould, Wohl, and

Golin 2015:2443).The participants featured that teenage girls who engage in early sexual activity with older partners find themselves testing positive when they request contraceptives. The practice of younger women partnering with older men is common throughout southern Africa, and it is often thought of as the sugar daddy' phenomenon. They further emphasised that it said that young women in such relationships may be less able to negotiate safer sex, due to men's greater relationship power, and they may experience violence for insisting on condom use.

4.3.4 Theme 4: Patients already on treatment

The participants mentioned that patients who are already on treatment give them a challenge of discontinuing treatment. All participants mentioned different reasons for discontinuing treatment. It was reported that most common reasons for discontinuing treatment is patients who started ARV's when they did not have symptoms, as well as patients who were told that the results of their viral load are undetectable.

These patients decide that if they have no signs and symptoms of HIV or AIDS it means that they do not have the disease, therefore they stop taking treatment.

The participants pointed out that some of the patients who learn about the undetectable viral load also assume that they are healed and default treatment. They further commented that access to treatment for chronic illnesses, including HIV and TB is particularly challenging to migrant populations. As stipulated by the South African constitution (1996) access to basic healthcare should be available to everyone nationals as well as foreigners. The lack of access to basic healthcare and the expense that goes with accessing ART in other countries influenced the development of "medical tourism" (Simplice 2014:1244). The participants noted that most immigrants enter South Africa to access health care and treatment of chronic illnesses. This situation is influenced by different factors such as the quality of services in their country of origin, unavailability of free health care in their countries, and the cost of drugs. The participants stated that there is a tendency among immigrants to go back home without requesting extra medication, and this results in a long interruption of treatment. They will later come back when they are already very sick. It was observed that serious and complicated cases, often co-infected with HIV, require treatment, medical equipment, and facilities not always available in the

migrants' home countries. Participants mentioned that a patient reporting to a public health facility in South Africa without transfer documentation from another health facility often had to start the process from the beginning, requiring an HIV test, a CD4 count and preparation for counselling. The process may result in delay to initiate and death due to the extent of the illness.

The participants mentioned that the tracing team which is referred to as WBOT contributes to the tracing of patients and link them back to care using their contact numbers and addresses found in patient's records. The participants emphasised that some patients who are lost to follow up could not be traced due to: incorrect addresses or change of residence and or residence outside the clinics' catchment areas. When tried telephonically it is also a challenge. Patients often do not want to be contacted at home, provide false numbers or numbers that are out of service.

4.4 RECOMMENGATIONS

The study highlighted areas of concern regarding the experiences of nurse managing HIV infected patients. In the light of the research findings the following recommendations on nursing practice and nursing policies were formulated.

4.4.1 Nursing Practice

- The HIV management should be reviewed and scientific discoveries should be implemented in order to improve the nursing practice and patients' retention in ART.
- The guidelines on HIV and STI management need to be reviewed to promote high attrition to care.
- Introduction of collaboration meetings among professional nurses managing HIV infected patients must be held to identify common challenges and how to deal with them effectively to retain patients in care.
- Strategies to support health professionals must be discussed at meetings to encourage a positive attitude among patients who are non-compliant to orders.
- Nurses should try to always apply good communication skill during interaction with HIV infected patients.

4.4.2 Nursing education

- Continuous development of professional nurses when introducing new guidelines should be done.
- The co-ordinators of HAART should follow up to see to it that new guidelines are introduced and practised in clinics for the benefit of the patients.
- Clinical mentors should be acquainted with the new guidelines that are operational in clinical facilities in order to support the learners.
- The curriculum for the basic and tertiary education should introduce the information on common infectious diseases to learners to improve prevention and promotion of health at all levels.
- Continuity of group counselling and health education especially at basic education institution should be encouraged.

4.4.3. Nurses

- The nurses should give counselling to patients on every consultation and not refer them to lay counsellors.
- Counselling should entail questions that ascertains what the patient knows about HIV.
- Multiple group counselling and education sessions prior to initiation are necessary to allow the patients to gain understanding of HIV to ensure retention and adherence.
- The nurses should also encourage patients to talk about HIV as a chronic illness that has to be accepted and teach others about HIV to prevent stigma and encourage disclosure.

4.4.4 Patients

- The patients should be given an opportunity to verbalise their knowledge and understanding of HIV and AIDS.
- The patients should be encouraged to join HIV adherence clubs that work as support groups that were introduced in clinics.
- Patients should always be given a listening ear even outside their scheduled dates of consultation date to promote attrition to care.
- Patients counselling should be continuous at all visits.

- Patients should be kept at the clinics for at least six months before they can be transferred to Pharmacy-Direct to collect medication and should also be encouraged to come for advice when they encounter challenges.

• 4.5 LIMITATIONS OF THE STUDY

In most of the clinics the interviews were conducted in a consulting room used by a professional nurse who consults with the patients. This brought about delays during the interview process. There were a lot of disturbances from other staff members, looking for something, or asking for something from the participants. Noise from the patient in the waiting area was also an impediment to the interview. The interviewer previously worked at one of the clinics in Tshwane North sub-district and most of the participants know her, they have attended the same meetings, same workshops and same in-service training with the interviewer. As a result, the participants may have thought that the interviewer knows their challenges and therefore, they may not have told all.

The participants may have had thought that the interviewer know their challenges and not tell all. Another limitation was that some of the participants had difficulty in expressing themselves in English, because they kept on using Tswana words. The interviewer had to interpret when transcribing the transcripts.

4.6 CONTRIBUTION TO THE BODY OF KNOWLEDE

The study may contribute to the body of knowledge in nursing by using the findings of the experiences nurses' face during rendering of their duties. The information will be added to the existing initiation and management of HIV infected patients on ART..

4.7 FINAL CONCLUSION

The objective, the research method (qualitative), and the research question were clearly answered by the variety of experiences as were elicited by the participants. Several experiences of nurses initiating and managing HIV/AIDS infected patient on antiretroviral treatment (ARV's) featured. The emphasis was on the delayed initiation, Interference in taking ARV's, young people infected and living with HIV infection and patients' already on treatment.

It was strongly emphasised that during initiation of ARV's with the process such as denial of the HIV status due to lack of mental readiness, fear of stigma that comes with the illness and loss to follow up from care interfered with the process as themes that emerged from data analysis.

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ANNEXURE A: Declaration regarding plagiarism

ANNEXURE B: 1st draft of data collection

ANNEXURE C: Participation Information Leaflet Informed consent form

ANNEXURE D: Letter requesting permission to conduct research

Letter of Approval Department In-House Committee University of Pretoria

Clearance certificate from Tshwane Research Committee

Approval Certificate University of Pretoria Research committee

Declaration of intent from clinic managers



1 ANNEXURE

ANNEXURE A

Declaration regarding plagiarism

Full names of student: Jane Thandi Khotle Student number: 96253593

Topic of work: Experiences of nurses initiating and managing human immune deficiency virus (HIV/AIDS) infected patients on antiretroviral treatment in Tshwane North clinics.

Declaration

I understand what plagiarism is and am aware of the University's policy in this regard.

I declare that this research is my own original work. Where other people's work has been used (either from a printed source, Internet or any other source), this has been properly acknowledged and referenced in accordance with departmental requirements.

I have not used work previously produced by another student or any other person to hand in as my own.

I have not allowed, and will not allow, anyone to copy my work with the intention of passing it off as his or her own work.

.....
SIGNATURE

ANNEXURE B

Data collection instrument

Interview questions

Experiences of nurses initiating and managing human Immune-deficiency virus (HIV) infected patient on antiretroviral treatment in Tshwane North clinics.

1. What are the challenges of initiating and managing HIV infected patients?
2. Give examples of such challenges.
3. Do you think it is important that there should be an intervention to deal with the challenges?
4. What interventions do you have in mind?
5. Have you identified any policy put into place to relief your situation?
6. If yes, why are the challenges still being experienced irrespective of available interventions?
7. If not, which interventions would be appropriate to deal with these challenges?

ANNEXURE C

Participation information leaflet and Informed consent form –



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

PARTICIPATION INFORMATION LEAFLET

Researcher's name: MS JT

KHOTLE Student Number:

9625359 Department of

Nursing Science University of

Pretoria

Dear Participant

TITLE OF THE STUDY: CHALLENGES AND EXPERIENCES OF NURSES
INITIATING AND MANAGING IMMUNE-DEFICIENCY VIRUS (HIV) INFECTED
PATIENTS ON ANTIRETROVIRAL IN TSHWANE CLINICS.

INTRODUCTION

I am a Mcur student in Advanced Community Nursing at the Department of Nursing Science, University of Pretoria. You are invited to volunteer to participate in my research project on Challenges and experiences of nurses initiating and managing immune deficiency virus (HIV) infected patients on antiretroviral in Tshwane North Clinics.

The purpose of the study is to Explore and describe the challenges and experiences of nurses initiating and managing HIV/AIDS infected patient on antiretroviral treatment in Tshwane North clinic

What is the duration of this trial?

If you decide to take part you will be one of approximately 10 participants. The study will last for up to 15 minutes.

Has the trial received ethical approval?

The study Protocol was submitted to the Faculty of Health Sciences Research Ethics Committee, University of Pretoria and written approval has been granted by that committee.

What are my rights as a participant in this trial?

Your participation in this trial is entirely voluntary and you can refuse to participate or stop at any time without stating any reason. Your withdrawal will involve no penalty or loss of benefits, but as data is anonymous, you must understand that you will not be able to recall your consent, as your information will not be traceable.

Confidentiality

The implication of completing the questionnaire is that informed consent has been obtained from you. Data that may be reported in scientific journals will not include any information that identifies you as a participant in the study. As all information or data are anonymous, you must understand that you will not be able to recall your consent, as your information will not be traceable. All the information during the course of this study is strictly confidential.

If you have any questions during this study, please do not hesitate to approach me. I sincerely appreciate your help.

Yours truly

Jane Thandi Khotle

INFORMED CONSENT

I hereby confirm that I have been adequately informed by the researcher about the nature, conduct, benefits and risks of the study. I have also received, read and understood the above written information. I am aware that the results of the study will be anonymously processed into a research report. I understand that my participation is voluntary and that I may, at any stage, without prejudice, withdraw my consent and participation in the study. I had sufficient opportunity to ask questions and of my own free will declare myself prepared to participate in the study.

Research participant's name: _____ (Please print)

Research participant's signature: _____

Date: _____

Researcher's name: _____ (Please print)

Researcher's signature: _____

Date: _____



ANNEXURE D

- Letters of approval –

LETTER REQUESTING PERMISSION TO CONDUCT RESEARCH

31 Unit D

Temba

0407

The Manager
Gauteng Department of
Health Private Bag x085
Marshalltown 2107

Date

Dear Ms/Mr

REQUEST FOR PERMISSION TO CONDUCT RESEARCH

I am a registered Master's student in the Department of Health Sciences at the University of Pretoria. My supervisor is Professor MD Peu.

The proposed topic of my research is: Experiences of nurses initiating and managing human Immune-deficiency Virus (HIV/AIDS) infected patient on antiretroviral treatment in Tshwane clinics. The objective of the study are:

- To explore and describe the challenges and experiences of nurses initiating and managing HIV/AIDS infected patients on antiretroviral treatment in Tshwane North clinics.
- I am hereby seeking your consent to conduct a research project at Tshwane North clinics
- To assist you in reaching a decision, I have attached to this letter:
(a) A copy of an ethical clearance certificate issued by the University

(b) A copy the research instruments which I intend using in my research

Should you require any further information, please do not hesitate to contact me or my supervisor. Our contact details are as follows:

Ms. Jane Thandi Khotle 0827866180 thandikhotle@gmail.com

Dr MD Peu 012 354 2133/25 Doricca.Peu@up.ac.za

Upon completion of the study, I undertake to provide you with a bound copy of the dissertation. Your permission to conduct this study will be greatly appreciated.

Yours sincerely,

Signature: _____
Jane Thandi Khotle



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Denkleiers • Leading Minds • Dikgopolo tša Dihlatlefi

DEPARTMENT OF NURSING SCIENCE

PRIVATE BAG X323, ARCADIA, 0007

TEL: (012) 354-2125

Fax: (012) 354-1490

e-mail: isabel.coetzee@up.ac.za

10 December 2015

The Chair: Post Graduate Committee

Dear Prof,

Letter of approval from Departmental In-house committee

The proposal of MCur student, Khotle student number 96253593 served before the in-house committee of the Department of Nursing Science and was approved for submission to the Post Graduate School Committee.

Yours sincerely

Isabel Coetzee

Dr Isabel Coetzee
Senior Lecturer
Department of Nursing Science
University of Pretoria
Cell phone: +2711 589 045
Office: (012) 354-2125
Email: isabel.coetzee@up.ac.za
Fax: (012) 354-1490



Kuyasheshwal Gauteng Working Better

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

427 Hilda Street, 4th floor, The Fields Building, Hatfield Pretoria 0001 South Africa. Tel: +27 12 451 9036
Enquiries: Dr. Molapane Chueu-Shabangu
e-mail: Molapane.Shabangu@gauteng.gov.za

TSHWANE RESEARCH COMMITTEE

CLEARANCE CERTIFICATE

Meeting: N/A

PROJECT NUMBER: 14/2016

Title: Experiences of nurses initiating and managing human immune – deficiency virus (HIV) infected patients on antiretroviral treatment in Tshwane Clinics

Researcher: Ms Jane Thandi Khotle

Supervisor: Dr. D.M Peu

Co-Supervisor: Dr. S. Mataboge

Department: Nursing Science, University of Pretoria

DECISION OF THE COMMITTEE

Approved

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

Date: 20/05/2016

.....
Dr. Molapane Chueu-Shabangu
Chairperson Tshwane Research Committee
Tshwane Health District

.....
Mr. Pitsi Mothomane
Chief Director: Tshwane District Health
Tshwane District

NOTE: Resubmission of the protocol by researcher(s) is required if there is departure from the protocol procedures as approved by the committee.

The Research Ethics Committee, Faculty Health Sciences, University of Pretoria complies with ICH-GCP guidelines and has US Federal wide Assurance.

- FWA 00002567, Approved dd 22 May 2002 and Expires 20 Oct 2016.
- IRB 0000 2235 IORG0001762 Approved dd 22/04/2014 and Expires 22/04/2017.



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Health Sciences Research Ethics Committee

Approval Certificate
New Application

21/04/2016

Ethics Reference No.: 102/2016

Title: EXPERIENCES OF NURSES INITIATING AND MANAGING HUMAN IMMUNE – DEFICIENCY VIRUS (HIV) INFECTED PATIENTS ON ANTIRETROVIRAL TREATMENT IN TSHWANE CLINICS

Dear Jane Khotle

The **New Application** as supported by documents specified in your cover letter dated 18/04/2016 for your research received on the 18/04/2016, was approved by the Faculty of Health Sciences Research Ethics Committee on its quorate meeting of 20/04/2016.

Please note the following about your ethics approval:

- Ethics Approval is valid for 1 year
- Please remember to use your protocol number (**102/2016**) on any documents or correspondence with the Research Ethics Committee regarding your research.
- Please note that the Research Ethics Committee may ask further questions, seek additional information, require further modification, or monitor the conduct of your research.

Ethics approval is subject to the following:

- The ethics approval is conditional on the receipt of 6 monthly written Progress Reports, and
- The ethics approval is conditional on the research being conducted as stipulated by the details of all documents submitted to the Committee. In the event that a further need arises to change who the investigators are, the methods or any other aspect, such changes must be submitted as an Amendment for approval by the Committee.

We wish you the best with your research.

Yours sincerely

Professor Werdie (CW) Van Staden

MBChB MMed(Psych) MD FCPsych FTCL UPLM

Chairperson: Faculty of Health Sciences Research Ethics Committee

The Faculty of Health Sciences Research Ethics Committee complies with the SA National Act 61 of 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 and 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

☎ 012 354 1677

☎ 0866516047

✉ deepeka.behari@up.ac.za

🌐 <http://www.up.ac.za/healthethics>

✉ Private Bag X323, Arcadia, 0007 - 31 Bophelo Road, HWV Snyman South Building, Level 2, Room 2.33, Gezina, Pretoria

Annexure 1: Declaration of intent from the clinic manager or hospital CEO

I give preliminary permission to Jane Phandi Khotle (name of researcher) to do his or her

research on Experiences of nurses initiating and managing HIV/AIDS (with special emphasis on human immune deficiency virus) infection treatment in patients on antiretroviral treatment (research topic) in

MANDISA SHICEKA CLINIC (name of clinic) or

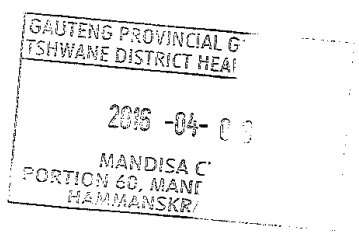
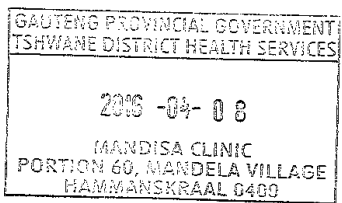
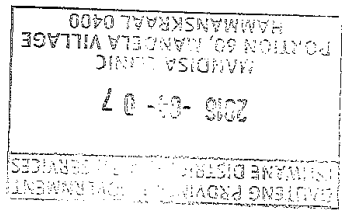
_____ (name of CHC) or

_____ (name of hospital).

I know that the final approval will be from the Tshwane Research Ethics Committee and that this is only to indicate that the clinic/hospital is willing to assist.

Other comments or conditions prescribed by the clinic or CHC manager or hospital CEO:

S. M. M. M. M. M.
Signature
Clinic Manager/CHC Manager/CEO



Annexure 1: Declaration of intent from the clinic manager or hospital CEO

I give preliminary permission to JANE THANY KHOTLE (name of researcher) to do his or her

research on Experiences of nurses initiating and managing Human Immune deficiency virus (HIV) infected patient on antiretroviral treatment in Tshwane District (research topic) in

_____ (name of clinic) or

TEMBA CHC

_____ (name of CHC) or

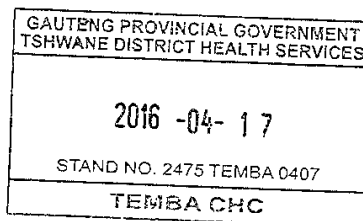
_____ (name of hospital).

I know that the final approval will be from the Tshwane Research Ethics Committee and that this is only to indicate that the clinic/hospital is willing to assist.

Other comments or conditions prescribed by the clinic or CHC manager or hospital CEO:

Jane Thany Khotle (FACILITY MANAGER)

Signature
Clinic Manager/CHC Manager/CEO



Annexure 1: Declaration of intent from the clinic manager or hospital CEO

I give preliminary permission to Jane Thandi Khotle (name of researcher) to do his or her

research on Experiences of nurses initiating and managing Human immune deficiency virus (HIV) infected patients on antiretroviral treatment in Tshwane clinics.
(research topic) in

Suurman clinic (name of clinic) or

_____ (name of CHC) or

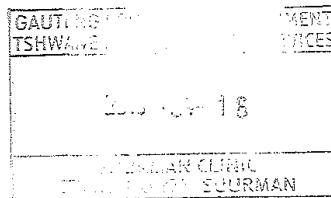
_____ (name of hospital).

I know that the final approval will be from the Tshwane Research Ethics Committee and that this is only to indicate that the clinic/hospital is willing to assist.

Other comments or conditions prescribed by the clinic or CHC manager or hospital CEO:

VM Ratabala

Signature
Clinic Manager/CHC Manager/CEO



Annexure 1: Declaration of intent from the clinic manager or hospital CEO

I give preliminary permission to THANDI JAWE KHOTLE (name of researcher) to do his or her

research on Experiences of nurses initiating and managing Human Immune Deficiency Virus (HIV) infected patients on antiretroviral treatment in Tshwane clinic.
(research topic) in

Ramotse Clinic (name of clinic) or

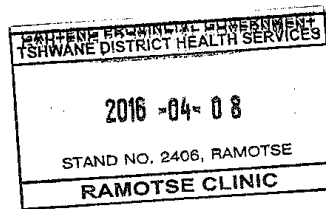
_____ (name of CHC) or

_____ (name of hospital).

I know that the final approval will be from the Tshwane Research Ethics Committee and that this is only to indicate that the clinic/hospital is willing to assist.

Other comments or conditions prescribed by the clinic or CHC manager or hospital CEO:

9/Aladuna R.
Signature
Clinic Manager/CHC Manager/CEO



Annexure 1: Declaration of intent from the clinic manager or hospital CEO

I give preliminary permission to Jane Thandi Khotle (name of researcher) to do his or her

research on Experiences of nurses initiating and managing Human immune deficiency virus (HIV) infected
(research topic) in patients at antiretroviral treatment in Tshwane clinics

Kekanastad (name of clinic) or

_____ (name of CHC) or

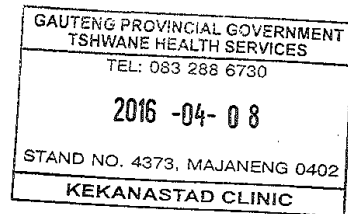
_____ (name of hospital).

I know that the final approval will be from the Tshwane Research Ethics Committee and that this is only to indicate that the clinic/hospital is willing to assist.

Other comments or conditions prescribed by the clinic or CHC manager or hospital CEO:



Signature
Clinic Manager/CHC Manager/CEO



PARTICIPANT J

Researcher : Good morning sister. I 'm Thandi Jane Khotle. I am a student at Pretoria University I came to make contact with you regarding my study in experiences of nurses initiating and managing patients on ARV's. So I know that when you are working you come across challenges and experiences can you tell them to me.

Participant : Ok the challenges that we come across especially when initiating treatment is that eh... firstly it was that not all the patients who are HIV positive are being initiated on treatment but with this new eh...test and treat UTT universal test and treat, you find that most of the patients don't want to be initiated on treatment so even though we've explain to them that now there is this new thing that all patients who are HIV positive must be initiated on treatment you find that most of the patients do not want to be initiated immediately.

Researcher : Why don't they want to be initiated?

Participant : Aa... I think most of them, there are some hearsay in the communities they'll be saying that when you start ARV's you will be sick. That's the thing that they talk jaa...with others. So we will have to clear all those myths.

Researcher : So you don't counsel them?

Participant : We give counseling adherence counseling. It must be a continuous one so that at the end of the game we win them so that we can initiate them all on treatment.

Researcher : So what do you do with the this patients

Participant : With that kind of patients because we cannot force them but what we do, we do adherence counseling continuous one. And then we give them follow up days. We send them to counselors even us the professional nurse we counsel them. And that's when we hear about that myth whatever that made them be afraid of being started on treatment and try to clear it until the patient understands. But fortunately most of them we end up winning them and initiating them all on treatment. Because when they don't want to be initiated immediately

most of them come maybe after two month or three months with diseases like TB. You find that they have already contracted TB and that's when now they agree to be initiated but if they are still strong most of them refuse to be initiated.

Researcher : So meaning they agree when they already see that they are sick?

Participant : Yes

Researcher : What bring them to the clinic until you say that these patients need to be tested?

Participant : Ok what we do in our clinic all the patients who come to the clinic we make sure that we test them for HIV. That's what we do in our clinic. Even though not all of them will agree they will tell you about their rights. But we make sure that all the entire patients who come to the clinic whether they are coming for chronic medication like hypertension or diabetes or whether they are coming because they are sick on that day. We make sure that we test them. That's where we find that most of them are HIV positive. And then when we tell them about the treatment they will tell you that I didn't come here for HIV I come here because I have a headache or I have a stomach pain. I didn't come here for HIV.

Researcher : So when do you tell patients about HIV co infection. Do you tell them?

Participant : We do, immediately when the patient has been tested positive we sit them down. And that's when we start with counseling immediately after they have tested positive then we take bloods, then we also collect the sputum and we also teach them about the opportunist infection that they can contract while they are not yet on treatment.

Researcher : What more challenges do you come across?... You can continue with the others.

Participant : Ok... mm... the other challenge that we come acrossaa... we have been having discussion about it. Because we find most patients being HIV positive and find that already they are very, very weak.

Researcher : Ok

Participant : Those patients that have stayed in the home until the last minute. They come here in wheelchairs and it is very, very difficult to wake that patients.

Researcher : Do you find those kinds of patient more often?

Participant : Yes we do

Researcher : And then when you ask them do they know that there is HIV?

Participant : Others will tell you that they knew their status. They tested maybe in 2012 or in 2009 but they did not do their follow up, like they went to the clinic and they were told because that time there was no UTT was not yet there and they will tell them to come after 6 months ... for bloods. But you know with most patients they did not do that after testing them they then disappear.

Researcher : Even after you have initiated them on treatment they take the first bunch of treatment...?

Participant : No not those ones. The one that are not yet on treatment. You find that the patient knew his status maybe in 2009 but they never come for follow up until the last minute when they come to the clinic being wheeled or being pushed on wheelchairs. And jaa...you find that the patient is very, very ill with all the opportunistic infections in them ... And it becomes difficult for us to help that patient.

Researcher : So what do you do with these patients?

Participant : We try to manage them but mostly we send them to hospital ... we take bloods we collect the sputum. And then you know we try by all means to give whatever we can give and then we can send them to hospital.

Researcher : When you send them to hospital you want them to be admitted

Participant : Jaa... most of them they admitted them. Just...for further management for further jaa... further management but most of them are admitted. And others die, because sometimes you find that the CD 4 is two or one. They have all this opportunistic infections in them ... So it becomes very difficult now.

Researcher : Do you think there should be an intervention to manage that problem?

Participant : ...Jaa... I think there must be a system in place especially now that there is this UTT. All the patient, now is better because when we test the patient we start them on treatment immediately. But previously it was very hard because if you test the patient we didn't have a list of all the patients for follow ups. Because let me say maybe we test the patient today and then we give them an appointment date of after six month that they may come for check the CD 4 again and you find that the patient disappear. So but now is better because when we test them and we find that they are HIV positive we start them on treatment right away.

Researcher : With this system UTT is it successful in such a way that when you have initiated the patient they follow up normally as you have given the dates

Participant : Yes, yes

Researcher : And the other challenges?

Participant : Mm... As I'm working at the TB unit most of my patient who come that side you find that ... 99% of them with TB are HIV positive. Jaa... This is what I was talking about; the patient stay at home until they contract disease is then that they come to the clinic. So there is too much workload, jaa... there is too much work load. But fortunately there are this people from FPD people who come and help us initiate treatment because...

Researcher : So what do they help you with?

Participant : With initiating patients

Researcher : Every patient?

Participant : No the HIV positive patients but with the TB patients I initiate them myself.

Researcher : Ok I want to know do you nurse children?

Participant : Yes

Researcher : Maybe who are HIV infected?

Participant : Yes

Researcher : And do you have challenges with them?

Participant : Yes ...with children there are big, big challenge.

Researcher : Mm...

Participant : Jaa... we have seen many cases whereby you find that the mother, the parents of the child has passed away. And the child is under the care of the grandmother. And most of the grand parents are very old and even though you try counseling them or you try to educate them about the medication ... it's very difficult, . But with this WBOT system that is in place we try to work together with them so that they can do the house visits.

Researcher : And then when they visit the house what do they do there at the house?

Participant : They usually go there if maybe there are challenges ... and they go and check ...if t home and that the granny understands and even the home environment is it conducive for children to stay there.

Researcher : Do WBOT assist in giving these children the medication?

Participant : Yes in the morning but if the children get the medication twice a day it is a problem. Because like if they get them in the morning 8 'o clock and at night.

Researcher : And usually which age do you have a challenge.

Participant : Under-fives, under five. Yes.

Researcher : Ok and then from 13 years?

Participant : Those ones understand and the children. Jaa... we teach the grandparent and the children at the same time. But with the under-fives they don't know anything about the medication even they don't know anything about their illness.

Researcher : And then you mention something that every patient who is HIV positive has contacted TB what do you think is the cause of this?

Participant : No is the obviously their immune system compromised and their CD4 count is very low then, all this... opportunist infection will just come in.

Researcher : With this patient do you still fast track them?

Participant : With the TB...the TB patients

Researcher : The HIV and TB because they go together

Participant : Jaa... with the HIV and TB we start we manage the TB first because we cannot like initiate the TB treatment and ARV's at the same time.

Researcher : How?

Participant : Yes. You have to, we start managing TB first for two weeks and then we have to see the patient if he is stable enough to can take both medication. Because we also have to consider the fact that there are side effects. If the patient can develop side effect we won't even know which medication has caused the side effect, if you initiate both TB treatment and ARV's at the same time.

Researcher : Ok So then you initiate TB first?

Participant : Yes and after two weeks is then that we initiate ARV's.

Researcher : Can you tell me when do you discover that the patient is TB positive

Participant : Ok what we do like I told you that here in our clinic all the patients who come to the clinic we test them for HIV and then immediately after if they tested positive for HIV. Then they send them to me to collection sputum and we collect sputum. Then we wait for the result. But there are those patients where you find that clinically you can see that this patient is not fine. They will complain of chest pain or they will complain about all the signs of TB like night sweat, loss of weight and cough maybe for more than two weeks. And then we don't wait for the result we send them for chest x-ray.

Researcher : Alright so that he can be started on treatment

Participant : Yes

Researcher : Because I was following up on the UTT if the patient is started immediately with treatment and he has TB and we are avoiding that how is it...

Participant : No we don't start them on that day. After they have tested HIV positive on that day, we sit them down and give them counseling, we collect bloods baseline bloods then we collect sputum for GenExpect for TB.... Then we give them follow up maybe after a week and we know that the result are back all the results will be back and that's where we can start them on treatment.

Researcher : Alright meaning you can follow patient much easily?

Participant : Yes.

Researcher : Do you come across patients who have started ARV's and they decide to stop taking them?

Participant : Yes we do have those kinds of patients but ... they are very few

Researcher : Ok the defaulters

Participant : They are very few in our clinic.

Researcher : So Do you also have patients who just come and tell you that I'm on ARV's and I want to continue?

Participant : Jaa... we get those kinds of challenges whereby the patient will bring a container of medication. And we know that this day there this Nyaope and ... they also use ARV's as part of their... So It's a dilemma actually because sometimes we say to the patient that we cannot give you medication because you brought container we need a transfer letter. And so nowadays we are very strict when coming to that one. And some of the patients will tell you that I'm from the Eastern Cape and I cannot go back there now I don't have money. But I'm taking this treatment. And they will come without a letter and but what we do we ask the name of the clinic and then contact them. And find out if they know the patient if the patient is on treatment we ask them to fax us the referral letter if the patient cannot go back there.

Researcher : So meaning that you are having a challenge of nyaope ...people coming and collecting medication?

Participant : Exactly.

Researcher : So it is strictly you don't give patient anything without a prove

Participant : Yes a patient cannot just come with a container saying I'm taking this medication.

Researcher : So does WBOT help you?

Participant : Yes they do, they do help us a lot.

Researcher : What is the other intervention that you utilize in the clinic that assists you tracing the patients?

Participant : The WBOT or the other one?

Researcher : Any one.

Participant : The social workers.

Researcher : What does she do?

Participant : Like in my case I had three patients. They are two sisters who were born with HIV and one of them has a child who is HIV positive. They are staying with their granny because their mother has died. So this child comes to report the granny to me because they were defaulters the three of them I sat them down .I wanted to know why they default so much and then they told me that their grandmother drinks alcohol a lot. And when she is drunk she tells them that they should leave her house because they are the one who make her daughter to die because of HIV.

Researcher : Ok It was a social problem.

Participant : Jaa... I had to intervene and ask the social worker to go and talk to the granny and find out exactly what is the problem.

Researcher : So in your clinic do you group your patients somehow to be managed in groups?

Participant : Yes.

Researcher : What's that?

Participant : We call them clubs they are FPD clubs.

Researcher : Ok how does it help?

Participant : It helps a lot to reduce work load inside the clinic because there is a counselor and a professional nurse. And then they group them in numbers of in twenty, twenty. When they come they don't come to the clinic they sit under the shelter and then they discuss their challenges and everything. So they don't come straight to the clinic. When they come they come to renew their scripts or to take bloods.

Researcher : What do they call that one?

Participant : Aa... I can't remember now ... And then we have recently started with a group for born with children. The children who were born with HIV especially teenagers from 7 years to 18 years. The group has been running for a month now.

Researcher : So do you have a lot of children?

Participant : Yes a lot a lot.

Researcher : Do they understand their condition

Participant : Yes because, the reason we started this group is that with the adults, with, with the adults they know their status, but with the children started their treatment while they were 3 years old. And they did not understand. And most of them when they become teenagers that's when they start to question, why am' i taking this medication. And the parent find it difficult to explain to the children why they are they taking this treatment. They know that they must take this medication for the rest of their life but they don't know ... what their condition is. So...

Researcher : So there is no one to disclose to them?

Participant : You find that the mothers don't want to disclose the condition

Researcher : And then?

Participant : Then children default. They do not want to take the medication any more.

Researcher : It end up being your problem now.

Participant : Yes because now they don't come to the clinic.

Researcher : So is this club that you have opened is it working?

Participant : Yes.

Researcher : It is assisting a lot.

Participant : Yes. It is assisting a lot

Researcher : Do they come these children?

Participant : They come every Friday.

Researcher : After school?

Participant : Jaa... There is a professional nurse a WBOT team leader who is also a professional nurse and social worker and psychologist.

Researcher : They don't have a problem of stigma this children especially because they playing with other children.

Participant : Eh... so far we haven't had a problem.

Researcher : Ok

Participant : Yes

Researcher : Do they work together nicely? How many do you have in your groups?

Participant : Mm... It's a month old. So far we have forty eight.

Researcher : So do they come with the mothers or somebody?

Participant : At first when we started the group. They came with their parent, guardian. And the psychologist and the social worker are the ones who were trying to talk to them. Then after that we started to group them in small group.

Researcher : Thank you for your participation

Participant : Aright