PERCEPTION OF STIGMA EXPERIENCED BY PEOPLE LIVING WITH HIV AT A HEALTH FACILITY IN KHAYELITSHA SUB-DISTRICT, CAPE TOWN.

This full thesis is submitted in fulfilment of the requirements for the Degree of Master in Nursing (RESEARCH) in the School of Nursing, Faculty of Community and Health Sciences, University of the Western Cape.

BY

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LIST OF ABBREVIATIONS

AIDS:	Acquired Immune Deficiency Syndrome
ART:	Antiretroviral Therapy
CAQDAS:	Computer Assisted Qualitative Data Analysis Software
DOH:	Department of Health
HAART:	Highly Active Antiretroviral Therapy
HIV:	Human Immune Deficiency Virus
MOH:	Ministry of Health
MSF:	Medicine sans Frontiers
NSP:	National Strategy Plan
SANAC:	South African National Aids Council
PLHIV:	People Living with HIV
UNAIDS:	United Nations Programme on HIV/AIDS
WHO:	World Health Organisation

DECLARATION

I, Alobwede Samuel Muabe, declare that “Perceptions of stigma experienced by People Living with HIV at a health facility in Khayelitsha Sub-District Cape Town” is my own work, and that it has not been submitted for any degree in any University, and that all sources of information used or quoted have been indicated and acknowledged appropriately as complete references.

Full name: Alobwede Samuel Muabe

Signed

Date: Nov 2018

Dedication

This thesis is dedicated to my late parents, Alobwede Max Masonge and Alobwede Tickla Nyake, for not giving up on me even when life was very harsh. I thank them for the love, care and support they gave me while they were both alive. The values they instilled in me will remain

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The Lord is my shepherd; I shall not want. He makes me to lie down in green pastures. He leads me besides quiet waters, He restores my soul, and He guides me in the paths of righteousness for His name's sake. Even though I walk through the valley of the shadow of death, I will fear no evil for you are with me. Your rod and your staff comfort me in the presence of my enemies. You anoint my head with oil, my cup overflows. Surely, the goodness of the Lord will follow me all the days of my life, and I will dwell in the house of the Lord forever (Psalm 23).

To my loving wife, Olive Mejane Alobwede, you encouraged and stood by me during the difficult moments of this journey. Even though I was battling with work, studies and travelling, you still encouraged me to spur on. You took the responsibility of the head of the family, and you did it to perfection. Through your patience and support, I was able to walk towards this achievement.

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ABSTRACT

HIV stigma is still affecting People Living with HIV (PLHIV) despite biomedical and structural interventions to reduce this phenomenon. Stigma, particularly health facility related stigma, experienced by PLHIV is reported to fuel poor access to services. As a result, considerable interventions to reduce the stigma among PLHIV have been proposed. However, poor HIV indicators are still reported. Little is reported about PLHIV's lived experiences of stigma, especially at health facilities, which might be the contributor to poor health outcomes. Hence, this study sought to explore and describe the stigma experienced by PLHIV at a health facility in Khayelitsha Sub-District, Cape Town, South Africa.

A qualitative approach, using an exploratory design was followed. Participants were purposively selected, and unstructured interviews were conducted. In total, 15 participants were anticipated to be interviewed. However, saturation occurred after 12 participants were interviewed, but the researcher went further to interview 14 participants. Audiotaped interviews were transcribed *verbatim* by the researcher (those in English) and assistant researchers (isiXhosa and Afrikaans). Data were then organised and entered into ATLAS.Ti version 8, a Computer Assisted Qualitative Data Analysis Software (CAQDAS) used for analysis of large sets of data. An independent coder was given raw data, and the two outcomes were discussed to reach a consensus on generated themes. The supervisor reviewed the analysed data.

Rigour was ensured through the criteria of credibility, dependability, transferability and conformability. The ethical clearance for this study was obtained from the Biomedical Research Ethics Committee (BMREC) at the University of the Western Cape and the City of Cape Town. Six themes emerged from the data because of participants' experience of stigma at the facility. These include: existence of stigma triggers, participants' experience of stigma at the clinic, direct stigmatising behaviour, and PLHIV's characterisation of stigma types, PLHIV's directed health outcomes, and activism as a secondary health outcome. The results of the study revealed that stigma was perpetuated in the health facility in numerous forms. These were: physical demarcation of the facility, negative behaviour of nurses towards People living with HIV and incompetence of the nurses. This gave rise to recommendations in nursing practice, to policymakers and a need for further research on the topic.

Keywords: HIV, AIDS, stigma, discrimination, ARV, adherence

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Chapter 1: Overview of the study

1. Introduction

Acquired Immune Deficiency Syndrome (AIDS) is one of the most serious conditions in the world. According to the United Nations Programme on AIDS (UNAIDS, 2016) and the World Health Organisation (WHO, 2017), it is estimated that worldwide, about 36.7 million people are living with HIV. This is a significant public health concern in sub-Saharan Africa where there are 69% of People Living with HIV (PLHIV). More so, the region accounts for three-quarters of AIDS-related deaths (WHO, 2017).

In South Africa, it is reported that about 7.1 million people are living with HIV, of this number the Western Cape accounts for about 5.96% (Statistics South Africa, 2016). As a result, antiretroviral drugs were rolled out as one of the ways to reduce and prevent the devastating impact and consequences of the epidemic. From 1 April 2016, the South African government and the Western Cape Government, in particular, embarked on the provision of antiretroviral therapy to all HIV positive patients, irrespective of their CD4 count (Western Cape Department of Health, 2016). In Khayelitsha, a sub-district in the Western Cape and the focus of this study, it is reported that more than 20 000 people are on antiretroviral treatment (ART) (Western Cape Department of Health, 2016). Despite this and the various interventions to reduce the HIV disease burden, the epidemic is still not controlled, with Khayelitsha being among one of the highly burdened in the country (SANAC, 2015) with a prevalence rate of 28.1% (Western Cape Department of Health, 2016).

It is worth noting that stigma has been identified as one of the contributing factors that impact negatively on the HIV treatment outcome (SANAC, 2015). HIV stigma remains a complex concept (Mbonye, Birung and Shabbar, 2013) associated with blame, shame, disgrace and social unacceptability. Unfortunately, stigma is still rife in communities and health facilities (Phetlhu and Watson, 2011). Hence, there is a need to explore the perceptions of PLHIV regarding their experiences of stigma in health facilities that still present poor indicators on HIV management.

1.1 Background

The fear surrounding the emerging HIV epidemic in the 1980s still persists nowadays. At that time, very little was known about how HIV is transmitted, which made people scared of those infected due to fear of the disease being contagious (Mbonye et al., 2013). This fear, coupled with the belief that HIV is associated with death, made many people to disapprove behaviours of homosexuality, drug users, sex work or infidelity. This triggered stigma in many communities worldwide (UNIADS, 2015). This fear is not only experienced by the general communities but by those who work as health workers. Health workers experienced some negative attitudes from the public, and this presented as stigma triggers (Mbonye et al., 2013). The consequence of these triggers is discrimination and prejudice towards PLHIV and the quality of care provided to them (Phetlhu and Watson, 2011).

HIV stigma acts as a powerful barrier to accessing healthcare as it inhibits HIV testing and disclosure of HIV status as well as adherence to medication (French, Greeff, Watson & Doak, 2014). Stigma often heightens existing prejudices and inequalities. HIV related stigma tends to be most debilitating for people who are already socially marginalised and closely associated with HIV and AIDS, such as sex workers, homosexuality, injecting drug users, and prisoners

(Gagnon, 2015). Various types of HIV related stigmas have been identified, which include internalised stigma, perceived/anticipated stigma and associated stigma (Herek et al., 2013). Some of these types of stigmas are manifested in health care facilities, thus impacting on the health care to PLHIV. Therefore, with this becoming a reality, both government and communities are seeking interventions.

Many of the PLHIV are mostly vulnerable to the face of stigma, prejudice and discrimination in their daily lives. This negative impact pushes them to the margin of society where poverty and fear make accessing health care and HIV services difficult (Matima et al., 2018). Consequently, they begin to develop negative thoughts about themselves as a result of these prejudices (Herek et al., 2013). According to the same authors, this type of stigma is called internalised stigma. In contrast, HIV stigma can also be enacted thus called enacted stigma. For instance, in South Africa, a study carried out by Phetlhu and Watson (2011) revealed that HIV stigma manifested itself through continued conflict that characterised the relationship between health care workers and PLHIV. The authors indicated that these stigmatising behaviours by health workers included impatience, harshness and serving the PLHIV out of obligation and not choice.

One of the best interventions in South Africa was carried out in all the nine provinces by the South African National AIDS Council (SANAC, 2015). The mandate was to establish the causes of stigma as well as to seek intervention strategies. Despite these interventions, stigma in health care facilities seems not to have changed as it is still being identified as one of the main contributors to poor health outcomes of PLHIV ((SANAC, 2015). Hence, the researcher assumes that areas with poor HIV indicators such as Khayelitsha might be grappling with this phenomenon; thus there is a need to explore the status quo. PLHIV's experiences and their perceptions thereof, could shed light on the phenomenon and allow for more understanding on the triggers and types of stigma, as well as responses used by them to cope with the daily challenges.

1.2 Problem Statement

HIV stigma is still affecting PLHIV despite biomedical and structural interventions to reduce it over the years. Health facility related stigma has been reported to contribute to the stigma experience of PLHIV. This has led many people to seek testing and treatment services late in the progression of their disease (Nyblade et al., (2018). In South Africa, despite being the home of many intervention programmes and antiretroviral therapy, the HIV prevalence rate is still high. About 7.1 million people are living with HIV, and of this number, the Western Cape accounts for about 5.96% (Statistics South Africa, 2016). However, Khayelitsha and Gugulethu/Nyanga had HIV rates of approximately 30% in 2015(Western Cape Health Report, 2017). This is in contrast to 28.1% in 2016 (Western Department of Health, 2016).

Stigma has been identified as one of the critical drivers to poor or delayed access to health care facilities by PLHIV (MSF, 2011). Stigma is worse when perpetrated by health care workers where PLHIV face discrimination, exclusion and rejection in the facilities where they expect to find acceptance, care and support. Their experience often results in behaviour that is detrimental to their wellbeing (Jain, Carr and Nyblade, 2015). Therefore, it is imperative to understand all forms of PLHIV related stigma to educate the health care workers better and improve service delivery to the affected.

However, current inadequate data regarding what PLHIV perceive as they interact with the health care workers in the facilities regarding stigma might prove to be detrimental to good quality health care. Studies have been conducted regarding stigma in different settings (Phetlhu and Watson, 2011; French, Greeff, Watson, and Doak, 2014). Nevertheless, there is limited information regarding the perceptions of PLHIV regarding their experiences of stigma in the Khayelitsha Sub-District. Therefore, it has become imperative to explore the perceptions of PLHIV regarding experienced stigma at a health facility in this context, to understand the extent of this phenomenon in the era of drug availability.

1.3 Research Question

Following the above rationale of the study, the following question was posed: What are the perceptions of PLHIV regarding stigma at a health facility in Khayelitsha Sub-District?

1.4 Aim and Objectives of the Study

This study aimed to explore and describe perceptions of PLHIV who receive treatment at a health care facility in Khayelitsha Sub-District regarding their experiences of stigma. The following objectives, as guided by the four domains defined by the adopted Model of dynamic HIV /AIDS stigma (Holzermer at al., 2007), were explored:

- To explore and describe the perceived triggers of stigma experienced by PLHIV at a health care facility in Khayelitsha Sub-District;
- To explore and describe the various stigmatising behaviour experienced by PLHIV at a health care facility in Khayelitsha;
- To explore and describe the various types of stigmas experienced by PLHIV at a health care facility in Khayelitsha;
- To describe the outcome of stigma and its influence on PLHIV and their health in general.

1.5 Significance of the Study

Most studies conducted on stigma in Khayelitsha focus on societally perpetuated stigma (Matima et al., 2018). However, this study focused on the health services based on reports such as the South Africa National AIDS Council (2017) and the National Strategic Plan for TB, HIV and STI (2017-2022). These reports are an indication that the presence of stigma could be a barrier to access and treatment adherence. Therefore, the results of this study will form part of a baseline data for future research and intervention plans on stigma related to health care services in this context. Additionally, in the advent of ARVs and the increase in individual disclosure, the assumption often made is that the availability of medication has reduced stigma towards patients infected with HIV. However, this assumption has not been tested in Khayelitsha. The results of this study will indicate what stigma really is in the era of ARVs, particularly in the health services that render the services to these patients. This data might be used as a baseline for stigma trends research and impact in the changing phase of HIV management. This study might give a voice to PLHIV because sharing their perceptions based on their experiences of stigma can highlight their plight and give impetus on the implementation of stigma-reducing interventions for health care workers and the health system in general.

1.6 Paradigmatic Perspective

A paradigmatic perspective may be defined as a paradigm whereby a researcher uses a model or a framework for observation and understanding which shapes both what is observed or seen and how we understand it (Creswell, 2014). Over and above, according to Creswell (2014), the paradigmatic perspective describes how the researcher views and explains the research material. The following meta-theoretical, theoretical and methodological statements define the paradigmatic perspective within which the researcher conducted this research.

1.6.1 Meta-theoretical Statements

In this study, the researcher's meta-theoretical assumptions are based on co-constructive knowledge of the interpretation of participants' perceptions on social justice in health and include the following meta-theoretical statements as defined within the researcher's view of health: human being, health environment and health care workers (nurses). The researcher's assumptions are as follows:

1.6.2 Health

The continuum of health is a complete state of physical, mental and social wellbeing and not merely the absence of disease or infirmity (WHO, 1978). Health can be qualitatively described on a continuum from maximum health to minimum health. The patterns of interaction of PLHIV with their internal environment, that is, their body, mind and soul play an important role in establishing their continuum of health. This implies how patients who are PLHIV take care of their bodies, how they cope with stress and anxiety and how they attend to their emotional needs. In addition, the pattern of interaction with the external environment, meaning their interaction with the health workers in the health setting, their perceptions of the health services and their involvement with their emotional denominations, determines their state of health on the health continuum. The PLHIV's way of recognising and acknowledging their illness and accepting the responses from the health worker and the community, determine their state of health.

1.6.3 Human Being

Human beings are created as complex and unique in that they are made up of three components namely the body, mind and soul (WHO, 2015). However, the researcher holds a strong view that for all these components to be in harmony, social justice needs to be well carried out. It is from this meta-theoretical view that PLHIV in this research are viewed as individuals who deserve caring, support, dignity and being treated equally and holistically such that their physical, mental and emotional health is addressed to create harmony holistically.

1.6.4 Environment

The environment is the sphere and surrounding in which human beings can live and share with fellow human beings (Oxford dictionary, 2009). The environment where PLHIV receive care is at a health facility in Khayelitsha Sub-District in Cape Town**.** The researcher believes that all PLHIV have a right to be treated equally in the environment in which they seek healthcare and that no one should be denied the possibility to be healthy or feel stigmatised due to being labelled according to a disease or condition they have. Therefore, health facilities in Khayelitsha Sub-District in Cape Town are health care environments where PLHIV should receive adequate care of excellent quality, irrespective of their social standing, race, religion or political affiliation.

1.6.5 Health Care Workers

Health care workers in this study, refer to individual men and women who are well trained both theoretically and practically in the field of health. They are required to offer care, support and services to the patients in order to promote health, prevent and cure illness and assist patients in managing chronic illnesses such as HIV, as in the case of this study. In providing services to patients, health care workers (mostly nurses) act as advocates for those under their care and treatment. Thus, health care workers are obliged under social justice, to give holistic care to PLHIV in their quest to achieve good health.

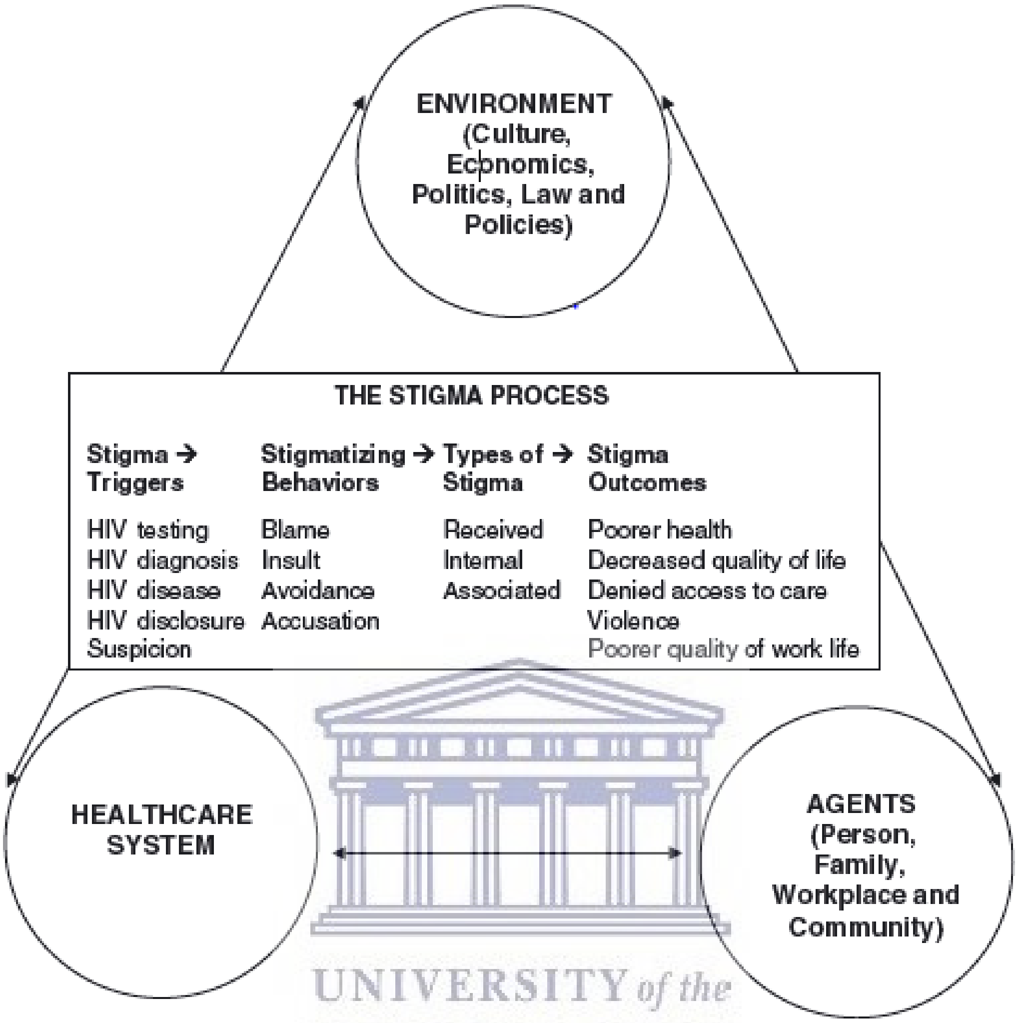
1.7 Theoretical Statements

The theoretical statements of this research include the theoretical framework, the central theoretical argument as well as conceptual definitions of core concepts applicable to this research.

1.7.1 Theoretical framework

A theoretical framework is a structure that can hold or support a researcher's study source. It also introduces and describes the theory which explains the research problem under which the study exists (Hargreaves et al., 2016). The theoretical framework adopted for this study is the "Model of dynamic HIV /AIDS stigma" (Holzemer et al., 2007). This model focuses on the dynamics of HIV/AIDS stigma which explains the stigma process domains specific to HIV in Africa. The model explains that the process of stigma is based on four dimensions: triggers of stigma, stigmatising behaviours, types of stigma and the outcomes of stigma. The model suggests that HIV triggers influences the players' (stigmatiser and stigmatised) behaviours, thus causing different categorisations of stigma based on individuals' perceptions within a context. These perceptions ultimately result in an outcome that impacts on both the PLHIV and the health system. This model was chosen for this study because it is grounded on the African perspective, thus emphasising on context's specificity as well as the health system stigma as an essential contributor to the PLHIV's health outcomes (Uys et al., 2009).

Figure 1: Model of dynamic HIV /AIDS stigma (Holzemer et al., 2007)



This model is grounded on three pillars, that is, the environment that consists of culture, economics, policies, law and politics; the health care system comprises mainly service providers, and the last pillar is the agent. The agent comprises of a person, family workplace and community. For the stigma process to apply well in this model, these three phenomena: the environment, the health care system and the agent, need to interplay to achieve the intended results. The framework purports that a health care system that achieves significant gains in these facilities would be far better at meeting patients' needs. Patients would experience care; support that is safer, more reliable where patient-centred views are listened and responded to. In return, patients would work with health workers (nurses) to manage their care, and this may improve the outcomes of their health and ultimately, the outcomes of the health of the community at large (WHO, 2015).

When applied to PLHIV in this study, the model suggests that for PLHIV to recognise that they are receiving good quality care, and not being stigmatised because of their disease, they need to be treated in a safe facility with strong confidentiality norms. Consequently, they will not be afraid to disclose their health status or of being harmed through illegal disclosure or stigma that may lead to them defaulting on their clinic visits. The facility needs to have healthcare workers (nurses) who are knowledgeable in the management of HIV and follow the evidence-based guidelines in managing HIV patients through ensuring that the necessary drugs are available, coupled with good professional attitude towards patients. The facility also needs to have an environment where patients can talk to the healthcare workers and be listened to regarding their problems with their treatment and any other problems that may be linked to treatment. Over and above, if concerns are raised regarding nurses' performance as evidence of stigma, intervention needs to be put in place.

1.7.2 Central Theoretical Argument

The understanding of the perception of stigma experience by People Living with HIV at a health facility in Khayelitsha Sub-District in Cape Town will assist in forming recommendations that may be used to develop appropriate stigma-reducing interventions relevant to the study context.

1.7.3 Theoretical Definitions

The following concepts are central in this research and are defined as follows:

- **HIV stigma:** A social process that can be manifested by exclusion, rejection, blame, or devaluation, labelling, stereotyping and separation that occurs as a result of experience or anticipation of an adverse social judgement (Hargreaves et al., 2016). In this study, the definition means the same because its application was observed**.**
- **Perception:** Is how something is regarded, understood or interpreted by an individual (Wringer et al., 2017). In this study, perceptions denote how PLHIV see and interpret the care they receive from the facilities they receive treatment from.
- **HIV:** Human Immune Deficiency Syndrome virus is a virus that affects all other organs and if not followed up with treatment, may result in death (WHO, 2015).
- **Lived experience:** Is an emotional expression through the senses or mind. In this study, the mindset and emotional expression of either the health care worker or the PLHIV may reflect stigma behaviour (WHO, 2015).
- **ART**: Antiretroviral Therapy is medication or drugs used in the treatment of HIV patients (WHO, 2015). In this study, participants who are PLHIV access this clinic mostly for their ARVs and other health care services.

1.8 Methodological Statement

This study focused on a better understanding of the perceptions of stigma experienced by People Living with HIV at a health facility in Khayelitsha Sub-District in Cape Town. Through the generation of new knowledge in the lived world of PLHIV in Khayelitsha Sub-district health facilities, the researcher believes that the study will provide a framework within which the healthcare workers (nurses) will be able to generate new ideas to improve quality of care to satisfy the needs of the HIV patients and avoid issues that can generate stigma.

Since the main aim of the study was to gain understanding about the perceptions of stigma experienced by People Living with HIV at a health facility in Khayelitsha Sub-District in Cape Town and how these could be used to make recommendations, the researcher used a qualitative, explorative and descriptive study design (Grove and Gray, 2018). The following section gives an overview of the study methodology and all the related techniques and procedures.

1.9 Research Methodology

Research methodology is the process or plan for conducting the specific steps of the study (Burns and Grove, 2013). In this chapter, the research design and method are discussed briefly, and a more detailed discussion follows in Chapter 2.

1.9.1 Research Design

A research design is used to plan and structure the research project in such a way that the eventual validity of the research findings is maximised through minimising or where possible, eliminating potential error (Creswell and Poth, 2017). The researcher adopted a qualitative approach with an explorative, descriptive and contextual design to explore and describe the perceptions of stigma experienced by People Living with HIV at a health facility in Khayelitsha Sub-District, Cape Town.

1.9.2 Qualitative Approach

Qualitative research is a systematic subjective approach used to describe life experiences and situations to give them meaning (Burns and Grove, 2013). It focuses on the experiences of people as well as stressing the uniqueness of the individual (Camlin et al., 2018). The approach allows the study of things in their natural settings in order to make sense of phenomena in terms of the meanings people bring to them. This approach was, therefore, chosen because it assisted the researcher in being successful in the quest to explore and describe the perceptions of stigma experienced by People Living with HIV at a health facility in Khayelitsha Sub-District.

1.9.3 Exploratory Design

Explorative studies are undertaken when a new area is investigated or when little is known about an area of interest (Grove and Gray, 2018). The researcher chose the exploratory design with an intention to gain more insight into the perceptions of stigma experienced by People Living with HIV who receive treatment at a health care facility. Little is known about the patients' perceptions of HIV stigma in the study context.

1.9.4 Descriptive Design

Descriptive research accurately describes the characteristics of persons, situations or groups and the frequency within which certain phenomena occur (Brink et al., 2012). The researcher chose the descriptive design to be able to accurately describe how PLHIV perceive the experience of stigma while taking treatment at the health facilities in Khayelitsha Sub-district.

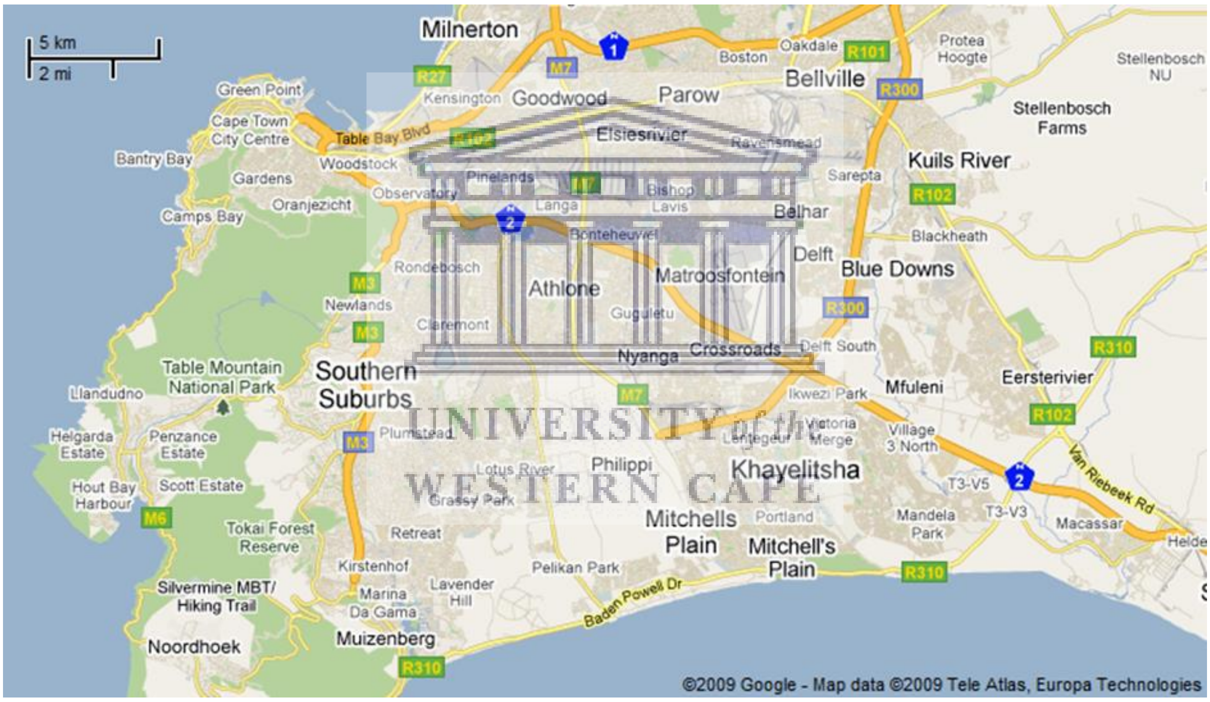
1.9.5 Contextual Design

Contextual designs focus on the specificity of the study context which might denote the geographical location of the study (Grove and Gray, 2018). The research took place within the context of the Khayelitsha Sub-District in the province of the Western Cape. The research findings are only generalised contextually within the parameters of the studied phenomenon.

1.9.6 Study Setting

This study was conducted at a health facility in Khayelitsha Sub-District (Figure 2). This health care facility provides integrated primary health care services to the community including HIV care. The facility was purposively selected because it services the highest number of PLHIV as far as headcount is concerned and has one of the highest numbers of ‘loss to follow up’ of PLHIV on ART (Massyn et al., 2016). In addition, Khayelitsha carries one of the highest burdens of HIV in the Cape Metro (Western Cape Department of Health, 2016). The economic hardships faced by the inhabitants of Khayelitsha Sub-District render them impoverished. Many households rely on casual jobs and government grants and become consequently vulnerable to stigma. A more detailed description of the setting is provided in Chapter 3.

Figure 2: Map depicting the geographical location of Khayelitsha



Source: 2009-Map data, Tele Atlas, Europa Technology

1.9.7 Study Population

The population is defined as, “the entire group of persons or objects that are of interest to the researcher, or that meet the criteria the researcher is interested in studying” (Brink, 2012).

The target population in this study were patients who met the inclusion criteria. At the time the research was conducted, the target population were People Living with HIV who received their care at the health facility. The accessible population were those who volunteered to take part in the study.

- **Inclusion criteria**: The targeted population were patients of all races and gender living with HIV and who were capable of making informed decisions. They were all 18 years and above and received treatment at the health facility. Over and above, they had to be able to communicate in English, Xhosa or Afrikaans, and their participation was purely voluntary.
- **Exclusion criteria:** The study excluded People Living with HIV younger than 18 years of age and who were not attending the chosen health facility.

1.9.8 Sampling Technique and Size

According to Grove and Gray (2018), sampling is the process of selecting a group of people, events or behaviour of the population being studied.

1.9.9 Sampling Technique

In this study, the sampling method was purposive. This sampling method is a non-probability sampling, where researchers use their judgement to select the subjects to be included in the study based on their knowledge of the phenomenon (Creswell and Poth, 2017). Purposive sampling was used to select PLHIV who could give their perceptions of stigma as they experience it at a health facility in Khayelitsha Sub-District in Cape Town. Only PLHIV who met the set criteria were purposively chosen to participate in this study.

1.9.10 Sample Size

A qualitative study does not seek generalisation, and data is often collected until saturation occurs, that is, when new data does not generate new knowledge (Burns and Grove, 2013). In this study, the researcher recruited 15 participants to provide in-depth interviews regarding their perceptions of stigma as they experienced it at the health facility. Data collection was only stopped when the researcher saw that the data were not yielding any new information and in this case, after fourteen (14) interviews.

1.9.11 Participant Recruitment

After permission was received from all the relevant authorities, the researcher contacted the facility manager to request her to act as a mediator in order to assist in identifying potential participants who were willing to participate in the study. The purpose of the study was explained to her so that she could, in turn, explain it to the potential participants. The researcher also used the opportunity to introduce the research assistant who assisted with some of the interviews. The research assistant chosen for the data collection was able to communicate fluently in the three chosen languages (English, Afrikaans and isiXhosa). The process of informed consent, confidentiality as well as the importance of anonymity was also explained. The researcher, together with the research assistant, set up appointments with the potential participants who agreed to participate in the study. Interview dates, places and times were agreed upon at the convenience of the participants and the venues of their choice.

1.10 Data Collection

Data were collected using unstructured interviews where one open-ended question was asked, and probes were used to encourage the conversation. This method was chosen because it allows the participants to respond in their own spoken words and gave room for more flexibility (Murphy and Dingwall, 2017). Before the commencement of the interviews, the researcher introduced himself to the participants and explained to them the aim of the study. He also informed them of their voluntary participation and the importance of their responses. The researcher also told them of their right to withdraw at any time without any consequences. They were also informed that the interview would be audio recorded once a participant agreed to commence with the interview. An informed consent form was signed before the commencement of the interview. Once the interview began, the interviewer switched off his cell phone and asked the participant to do the same in order to prevent any interruptions from either party until the interview was completed.

The interviewer started by asking the participants to choose the preferred language for the interview from the three languages mentioned earlier. The research assistant labelled each clip (self-recording) with codes such as "PLHIV1" with the letters representing the participant's gender and language and the interview number. The date and time were also included. The interviews began with demographic information of the participants, and this included age, gender, employment and marital status. The question asked was: *"Tell me about your experience regarding stigma since the period you started to access care as a PLHIV in clinic X?"*

Each interview lasted about 45-60 minutes, and at the end of each interview, permission was granted for field notes. Field notes were written during the interview process. The purpose of the field notes was to write essential observations during the interviews. At the end of the interviews, audio recording with associated field notes was then uploaded into a computer with a password protected folder only accessible to the researcher.

1.11 Data Analysis

The audiotaped interviews in English were transcribed *verbatim* by the researcher. The research assistant translated the data from isiXhosa to English before giving it to the researcher for transcription. Data were organised and entered into Atlas. Ti version 8.1. This is a Computer Assisted Qualitative Data Analysis Software (CAQDAS) used to analyse qualitative data to increase the rigour and credibility of the study. Thematic analysis techniques were used whereby patterns were identified and grouped into themes and categories (Burns and Grove, 2013). An independent coder was given raw data, and the two outcomes were discussed to reach a consensus on generated themes. The analysed data were reviewed by the supervisor.

1.12 Trustworthiness

The goal of rigour or trustworthiness in qualitative research is to report the study participants' experiences accurately. According to Creswell and Poth (2017), the four criteria for developing trustworthiness of a qualitative study are credibility, conformability, transferability and dependability. In this study, trustworthiness was ensured by adhering to the criteria below.

- **Credibility**: Credibility was achieved through the use of member checking where generated themes were given to three of the participants (randomly chosen) to verify if they captured the intended meanings.
- **Conformability:** Conformability was achieved by ensuring that data findings and conclusions represented the information provided by participants. Hence, thick descriptions of the research process were recorded, and an audit was kept. Additionally, the researcher also kept a reflective trail to ensure reflexivity.
- **Transferability:** In qualitative research, there is situational uniqueness whereby a study may not relate to another and conclusions may not be transferable (Lincoln & Guba, 1985). To ensure transferability, a thick description of the study setting and participants' characteristics were provided (Brink et al., 2012).
- **Dependability:** An audit trail of the study is kept, including the thick description of the study processes and procedures, to achieve dependability. In addition, an independent coder was used. Other colleagues and experts (peer examiners) also examined the research plan and implementation to ensure dependability.

1.13. Ethics

The ethical clearance for this study was obtained from the Biomedical Research Ethics Committee (BMREC) from the University of the Western Cape and the City of Cape Town. Permission was also sought from the health care facility management and the participants (See Annexures A, B and C). Proceedings were guided by basic ethical principles such as respect for human subjects, beneficence and justice, as described by Hickey (2018).

Each participant was given an information sheet explaining what the study is about, the purpose, procedure, benefits and risks as well as the expectations of both the researcher and the participants (Annexure D). Participants were informed of their rights and that if there were any problems with the researcher, they could notify the researcher's supervisors. The supervisors' telephone numbers were provided. The researcher adhered to the ethical principles discussed below.

1.13.1 Informed Consent

The study was described to participants in a language they understood, and questions about the study were answered. Participants agreed to participate of their own free will. They were assured of confidentiality and that their identities would not be disclosed to anyone. They were also informed of the right to withdraw from the study at any time without giving any reason and without fear of negative consequences. Participants were informed of their rights to report the researcher to the faculty dean or supervisor on the provided telephone numbers, should they experience any problems with the researcher during the interviewing process. Participants were assured of a standby clinical psychologist counsellor or a social worker in case of distress in the course of the interviews. This clinical psychologist and social worker were part of the staff at the health facility. However, their service was not used as the participants were comfortable throughout the interviews.

1.13.2 Confidentiality

To maintain confidentiality, participant data were first decoded not using their names, and all audio information was loaded in a password protected computer folder. All information on paper such as transcripts was locked in a separate cabinet in safe storage in the researcher's personal bank safe. All the information was accessible only to the researcher and the supervisor. Over and above, the participants were reassured of the safety of the collected information which will be kept in the researcher's bank safe for five years, after which it will be destroyed (Burns and Grove, 2013; Hichey, 2018).

1.13.3 Justice

This principle involves fairness in participant selection and treatment. Therefore, the researcher's selection criteria were fair as participants for this study were selected based on their willingness to participate freely.

1.14 Limitations of the Study

The shortcomings of this study included the lack of sponsorship and the languages being limited to English, Afrikaans and IsiXhosa. These two issues had severe limitations in that the research setting had people from other provinces and different nations who use the services of the facility. However, they could not add value to the study because of the language limitations.

1.15 Chapter Outline

Chapter 1: Overview of the study, including the background, aims, objectives, methodology and trustworthiness.

Chapter 2: The literature review of the study.

Chapter 3: Research Methodology and data analysis of the study.

Chapter 4: Discussions of the results findings and literature alignment.

Chapter 5: Recommendations, conclusions and study limitations

1.16 Summary of the chapter

This chapter provided a brief introduction and the overview of the study which included; a brief discussion on the study background and problem statement, aims and research question of the study, the significance of the study, definitions of concepts, the theoretical framework, the methodology, trustworthiness and ethics adhered to during the study. Chapter 2 provides a literature review on studies in the field of stigma.

Chapter 2: Literature Review

2.1 Introduction

Chapter 1 gave an overview of the study as well as the research design and ethical principles that were adhered to while conducting the study. Chapter 2 focuses on reviewing literature related to the concept of stigma as well as existing knowledge related to the aim of the study. A literature review, according to Groves and Gray (2018), is aimed at contributing to a clearer understanding of the nature and meaning of the problem under study and perpetuated stigma. Literature review searches were done in different search engines. These included: Science Direct, EBSCOhost, SAGE Journal Online, Google Scholar, and PubMed Central. As well as peer-reviewed journal articles, reports and books that focused on HIV stigma by health care workers. Keywords and phrases such as stigma; health workers and stigma; PLHIV and stigma; nurses and stigma; stigma and health care facilities were used to search for the literature sources.

2.2 Overview of HIV

Human Immunodeficiency Virus (HIV) is a virus that attacks and weakens the human immune system such that it makes a person’s body vulnerable to opportunistic infections such as Tuberculosis (TB), cancer, and hepatitis B, while AIDS stands for Acquired Immune Deficiency Syndrome (WHO, 2017).

HIV can be spread through infected blood, breast milk, semen, and anal or vaginal fluids contaminating the bloodstream (WHO, 2015). No effective cure currently exists, but with proper medical care, HIV can be controlled. The medicine used to control HIV is called antiretroviral therapy (ART). (WHO, 2017). Before the introduction of ART in the mid-

1990s, People Living with HIV could progress to AIDS in just a few years. However, nowadays, someone diagnosed with HIV may start treatment on the same day of diagnosis (SANAC, 2017; WHO, 2017).

According to WHO (2017), there were approximately 36.9 million people worldwide living with HIV at the end of 2017, with Africa having 25.7 million, America 3.4milliom, South and East Asia 3.5 million, Europe 2.3 million, East and Mediterranean 0.35million and Western Pacific 1.5 million people. Of these, 2.1 million were children (<15 years old). An estimated 1.8 million individuals worldwide became newly infected with HIV in 2016 with about 5,000 new infections per day. This includes 160,000 children (<15 years). Most of these children live in sub-Saharan Africa and were infected by their HIV positive mothers during pregnancy, childbirth or breastfeeding. The UNAIDS (2017) reported that approximately 70% of People Living with HIV globally were aware of their HIV status by December 2017, while the remaining 30% (over 11 million people), still needed access to HIV testing services (UNAIDS, 2017).

According to UNAIDS (2015), HIV testing is an essential gateway to HIV prevention, treatment, care and support services. As of June 2017, 20.9 million People Living with HIV were accessing antiretroviral therapy (ART) globally, up from 15.8 million in June 2015, 7.5 million in 2010, and less than one million in 2000. Despite these numbers of people on ART, 1 million people died from AIDS-related illnesses in 2017, bringing the total number of people who have died from AIDS-related illnesses since the start of the epidemic, to 35.0 million, with Africa having the highest number (UNAIDS, 2017).

HIV related stigma and discrimination have been acknowledged as impediments to mitigating the HIV epidemic since its early days (Cloete et al., 2011). However, this could be changed if programmes and activities on television and radio, workshops in communities, community engagement with churches, sporting bodies all strive to reduce stigma and discrimination (Cloete et al., 2011).

2.3 HIV in Africa and South Africa

HIV is a major public health concern and cause of death in many parts of Africa. Although the continent is home to about 15.2 per cent of the world's population (WHO 2015), more than two-thirds of the 35 million PLHIV worldwide are Africans. Sub-Sahara Africa alone accounts for an estimated 69% of all PLHIV (WHO, 2017) with 70 per cent of all AIDS-related deaths occurring around 2017/2018 (UNIAIDS, 2017) in this region. North African countries have significantly lower prevalence rates as their populations typically engage in fewer high-risk cultural patterns that have been implicated in the virus (UNAIDS, 2016).

According to SANAC's (2016) report, South Africa has the biggest and most high-profile HIV epidemic in the world, with an estimated 7.1 million People Living with HIV in 2016. The same report indicates that South Africa accounts for a third of all new HIV infections in Southern Africa. In 2016, there were about 270 000 new HIV infections, and 110 000 South Africans die from AIDS-related illnesses yearly (ibid).

Nonetheless, South Africa has the most substantial antiretroviral treatment (ART) programme in the world. These efforts have converted HIV infection from an almost universally fatal illness to a manageable chronic disease (Kgasi, 2017). The financing pattern was noted in the Western Cape Government Health Report (2016) where it was stated that the country would invest more than $1.8 billion annually to run its HIV programmes as of 2017-2018 financial years. The success of this ART programme is evident in the increases in national life expectancy, rising from 61.2 years in 2010 to 67.7 years in 2015. However, South Africa is still profoundly affected by the Human Immunodeficiency Virus (HIV) infections. More than 15% of the country's population aged 15 to 49 years are living with the disease. The total number of persons living with HIV in the country has increased from an estimated 4,72 million in 2002 to 7,03 million by 2016 (Kgasi, 2017). Moreover, it is reported that in 2015 the HIV prevalence was high (18.9%) among the general population although it varied remarkably between the regions. For example, HIV prevalence is almost 12.2% in KwaZulu Natal compared to 6.8% and 5.6% in the Northern Cape and the Western Cape, respectively (SANAC, 2015). Statics South Africa (2017) data shows that according to provinces, KwaZulu Natal has the highest prevalence (18%), followed by Mpumalanga (15%). The Northern Cape and Western Cape have the lowest HIV prevalence, at 6.8% and 6.6% respectively (SANAC, 2017). Overall, the country had an estimated 7.1 million PLHIV and nearly 270 000 people were newly infected in 2016. This reflects a prevalence rate of about 12.8% among the entire population, or 19.1% among those aged 15-49 years (ibid).

2.4 HIV in the Western Cape

In South Africa, despite being the home of many intervention programmes and antiretroviral therapy, the national HIV prevalence rate is still high. However, provinces such as the Western Cape have relatively low prevalence rates accounting for about 6.6% of the national prevalence ((SANAC, 2017). Khayelitsha Sub-District carries one of the highest burdens of HIV in the Western Cape Province with a prevalence rate of 28.1% (Western Cape government health, 2016). It is in these areas with a high prevalence of HIV in the Western Cape where high unemployment rates and rampant poverty are the norm.

2.5 HIV stigma as a barrier to positive health outcomes

In 2000, when the 16 Millennium Development Goals were set, one of the objectives was to reduce the prevalence rate of HIV by 2015 (WHO, 2015). As of 2014, the number of new HIV infections and AIDS-related deaths had declined by 40% and 42%, respectively (WHO, 2015). This is an indication of some level of success, despite the target not having been achieved as envisaged. South Africa played a leading role in this achievement even though the country is home to 7.1% of PLHIV (WHO, 2017). This progress has been attributed to massive improvement in funding which enhanced broader coverage of antiretroviral treatment, innovative approaches to treatment and prevention interventions. In addition, there was the introduction of programmes such as the"90, 90, 90 strategy". The objective of this strategy was to ensure that 90% of the country's population know their status; 90% of those who tested positive are on treatment, and 90% of all the HIV positive people stay and remain on treatment (SANAC, 2017).

Irrespective of this progress, stigma is still reported as one of the key challenges that needs to be dealt with in the fight against HIV (UNAIDS, 2017). To confront these challenges and build on the excellent progress so far recorded, one of the health targets under the new Sustainable Development Goals (SDG) is to end the HIV/AIDS epidemic by 2030 (UNAIDS, 2016). However, to attain this achievement, the key impediments such as stigma, cannot be ignored. In pursuit of this, the Joint United Nations Programme on HIV/AIDS (UNAIDS) has proposed a global strategy whose target is to reduce the number of new HIV infections by 90% and the number of AIDS-related deaths by 80% by the year 2030 and zero new HIV infections and zero stigma (UNAIDS, 2016). Hence it is important to highlight stigma as a barrier to positive health outcomes and develop stigma reduction strategies in South Africa in general and the Western Cape in particular.

2.6 The concept of stigma

The word “Stigma” comes from a Latin/Greek word *stigma*, which refers to marks made on the body from being burnt with a hot iron or being cut, designed to expose something unusual and wrong about the moral status of the person burnt. The bearer of such a sign was considered a slave, a criminal or a traitor. Thus, a blemished person who was ritually polluted had to be avoided, especially in public places (Goffman, 1963). In the present day, stigma can be referred to as a social process that can be manifested by exclusion, rejection, blame, devaluation, labelling, stereotyping and separation that occurs as a result of experience or anticipation of an adverse social judgement (Chirdwadi et al., 2016).

Holzmeer et al., (2007) describe HIV stigma in their conceptual model as a cyclical process within a specific context (the environment, the healthcare system and agents). According to the authors, the stigma process includes four dimensions, namely, triggers of stigma, stigmatising behaviours, types of stigma and the outcomes of stigma (Holzemer et al., 2007). Stigma can be characterised into four types:

a) Internal stigma refers to a person’s endorsement of prejudicial beliefs about a devalued characteristic (Jain, Carr & Nyablade, 2015);

b) Anticipated (perceived) stigma, by contrast, is a negative response PLHIV expect to receive from their families and communities if others know their HIV positive status. It is the fear of people’s prejudice and discrimination once they know that one is living with HIV (Jain, Carr & Nyblade, 2015).

c) Enacted (received) stigma is discrimination which involves actual acts or omissions that disadvantage a person, and it is the society's perception that an individual is socially unacceptable (Jain, Carr & Nyblade, 2015).

d) Associated stigma involves examples of stigma that results from a person's association with someone living with, working with or otherwise associated with People Living with HIV. This can include, for example, having a family member who is living with HIV or working with people who are living with HIV (Jain, Carr & Nyblade, 2015; Prinsloo et al., 2017).

2.7 Factors and manifestation of stigma in PLHIV

According to the UNAIDS (2015), in about 35 countries with available data, over 50% of men and women reported having discriminatory attitudes towards PLHIV. Moreover, the PLHIV Stigma Index indicates that, roughly, one in every eight PLHIV is denied health services because of stigma and discrimination (UNAID, 2015). Nyblade et al., (2018) reported that besides the fact that PLHIV experience stigma every day in their lives, stigma experience within the health system is detrimental. For instance, in Thailand, the Ministry of Public Health reported that over 80% of healthcare workers had at least one negative attitude towards PLHIV, while approximately 20% knew colleagues who were unwilling to provide services to PLHIV or provided them with substandard services (Pudpong et al., 2014). This implies that not much of success has been achieved regarding stigma reduction within the health system.

Almost a decade ago, in a study conducted in five African countries, namely Lesotho, Malawi, South Africa, Swaziland and Tanzania, stigma was demonstrated through actions such as extensive verbal and physical abuse and neglect in health services, as was reported by the PLHIV (Uys et al., 2009). Noteworthy, the perpetuation of stigma in health care services cannot be looked at in isolation, as in most cases, health workers mirror the communities they live in. Factors such as poverty and law that criminalise PLHIV, also contribute to the increase in HIV stigma (Victoria AIDs Council, Australia 2015). For example, although the Constitution of Ghana protects all citizens from discrimination in employment, education and housing and ensures their right to privacy, there was ambiguity in the way these provisions apply to People Living with HIV. As a result, by September 2015, 32 cases of stigma and discrimination that included violence, blackmail, abuse and denial of healthcare services were recorded by PLHIV, with only 13 resolved (Williamson et al., 2014). Such behaviour impacts on PLHIV and as a result, the fear of rejection and non- disclosure is fuelled. The snowballing effect results in PLHIV's delay or hesitation in accessing health facilities, resulting in dire health outcomes.

2.8 Impact of stigma

The consequences of stigma and discrimination are wide-ranging. Families, peers and the wider community shun some people, while others face poor treatment in healthcare and educational settings. This erosion of PLHIV's rights often leads to psychological damage; hence it is tantamount to social injustice. According to Pudpong et al., (2014) in 2012, half of all PLHIV in Thailand started treatment very late and had CD4 counts under 100. The authors reported that HIV stigma was identified as a significant barrier to service uptake. In a survey conducted in South America, it was revealed that HIV related stigma was associated with adverse health outcomes, including poor medication adherence and a lower viral load (Reif, Wilson & Allster, 2017).

Stigma and discrimination in the health care setting and elsewhere contribute to keeping people, including health providers, from adopting HIV preventive behaviours and accessing needed care and treatment. Fear of being identified increases the likelihood for people to avoid testing for HIV, disclosing their HIV status to healthcare providers and family members or seeking treatment and care, thus compromising their health and wellbeing (UNAIDS, 2014).

Another impact of stigma among PLHIV is considerable fear of the consequences of revealing their HIV status. In a study by Stahlman et al. (2017), nearly half of the participants (48.2%) agreed with the statement "It is easier to avoid friendships than worry about revealing that I have HIV". Nearly two-thirds of participants (65%) agreed that "I worry that people may judge me when they know about my HIV status". This implies that the more stigma is perpetuated on PLHIV, the more those who are newly diagnosed internalise stigma and believe that they will receive the same treatment as their peers.

In the South African context, the stigma index survey which was commissioned and undertaken by the Human Sciences Research Council (SANAC) in 2015, gathered information from more than 10 000 People Living with HIV in two districts in each of the nine provinces. The findings revealed that more than 40% of PLHIV suffer from internalised stigma and feel shame and inferior, and 11% contemplated suicide. In some cases, people refused to get married because of stigma and others stopped their treatment because of the attitude of the health care providers (SANAC, 2015). Additionally, the PLHIV Stigma Index indicates that roughly one in every eight PLHIV is denied health services because of stigma (ibid). This indicates the rifeness of stigma even in an era where HIV is no longer perpetuated as a death sentence. Research has demonstrated that the experience or fear of stigma often results in postponing or rejecting care, seeking care far from home to protect confidentiality and the non-adherence to medication. For example, in Cape Town, men who have sex with men and injecting drug users, respectively, often avoid or delay accessing HIV related services, including treatment for other sexually transmitted diseases (Stahlman et al., 2017; Jain, Carr & Nyblade, 2015; Pudpong et al., 2014).

2.9 HIV stigma in health facilities

This study focused on the perception of stigma experienced by PLHIV receiving treatment at a health facility. Close to a decade now, there has been growth in literature on HIV stigma in health facilities (Nyblade et al., 2018; Earnshaw et al., 2013; Phetlhu & Watson, 2011; Cloete et al., 2011). On the same subject, other authors have conducted quantitative studies as a means to measure stigma at health facilities (Jain, Carr & Nyblade, 2015; Stangl et al., 2017; Boyers et al., 2011). All these studies demonstrated the prevalence of stigma in health care facilities globally. The prevalence of stigmatising experiences varied widely in health services. Two separate studies in the US, one of housing project clients and the other of ART clients, found that approximately 40% of their respondents had experienced stigma and discrimination in the health care system (Stahlman et al., 2017). In a study conducted at a tertiary health facility in Southern Nigeria and a Teaching Hospital in the North Central region by Owolabi et al., (2012) 25% of ART patients reported that they had experienced stigma or discrimination by family members, at hospitals, at the community level and the workplaces.

Forms of stigma experienced included being blamed for being HIV positive and name-calling (prostitute, skeleton and unfaithful person, among others). Discriminatory practices against PLHIV in hospitals included selective use of gloves, poor quality care and isolation from other patients. A study conducted in Cameroon, a wide range of discriminatory and stigmatising practices at a health care facility was experienced by PLHIV, categorising them broadly into neglect, differential treatment, denial of care, testing and disclosing HIV status without consent and verbal abuse/gossip (Boyers et al., 2011). Similarly, findings from a study in Ethiopia found that conventional forms of stigma in health facilities were designating patients as HIV positive on charts or in wards, gossiping about patients' status, verbally harassing patients, avoiding and isolating HIV positive patients and referring patients for HIV testing without counselling (Pudpong et al., 2014). The same trends were reported in Indian hospitals where stigma and discrimination manifested as health workers informed family members of patients' HIV status without their consent. The following stigmatising behaviours were also perpetuated to PLHIV: burning their bedding upon discharge, charging them for the cost of infection control supplies and using gloves during all interaction, regardless of whether physical contact had occurred (Pudpong et al., 2014).

In a study of directors of non-governmental organisations providing HIV related services, it was reported that the majority believed that HIV positive women were especially vulnerable to adverse treatment, such as refusal of access to family planning services. There was a general trend which depicted behaviours that impeded their access to a range of services, including their ability to report to the facility for their antiretroviral treatment (ART) (Earshaw et al., 2016). More alarming, is the physical nature that is sometimes experienced by PLHIV in health services. Earshaw et al., (ibid) state that the manifestation of stigma in health services included traumatic assault, residential separation and medical mistrust. Although all these studies were conducted in different parts of the world, including the developed countries, it is of concern that the patterns of stigma perpetuated in health facilities is similar, and the trends of stigma do not seem to be decreasing over time and with new knowledge on HIV. Stigma in health facilities has been discussed as a case, but nothing much in terms of interventions has been developed. Hence, health indicators such as poor adherence to treatment by PLHIV are still a challenge as the underlying contributors are not dealt with. Therefore, it has become imperative that stigma in health facilities be investigated and interventions directed at the reduction of such behaviours, be developed. The lack of such interventions means the trend will still prevail in the next decade and health outcomes of PLHIV will still be the same, despite the introduction of biomedical interventions.

2.10 Summary of chapter

This chapter focused on HIV and its relation to the concept of stigma perpetuated in the health services, families and communities. Chapter 3 will give a detailed process of the research methodology.

Chapter 3: Research methodology

3.1 Introduction

Chapter 2 provided a full literature review on HIV trends globally, in Africa, South Africa and the Western Cape. It also outlined the stigma concept, its manifestation in health care facilities, families and communities, as well as the impact of this stigma in relation to People Living with HIV. In addition, the theoretical framework for the study was also highlighted.

Chapter 3 discusses the detailed methodology followed in the study. Research methodology is the application of all the steps and procedures for gathering and analysing data in a research investigation, logically and systematically (Grove & Gary 2018). The methodology of this study embraces the research design, population and setting where the research took place, instruments used to collect data and the data collection process, data analysis as well as methods used to ensure trustworthiness and ethical consideration. According to Burns and Grove (2013), the methodology chosen for a research study must be determined by the research question, which is the case in this study.

3.2. Aim and Objectives of the Study

This study aimed to explore and describe the perceptions of PLHIV who receive treatment at a health care facility in Khayelitsha Sub-District regarding their experiences of stigma.

The following objectives, as guided by the four domains, defined and adopted from the Model of dynamic HIV /AIDS stigma as described by Holzemer et al., (2007).

- To explore and describe the perceived triggers of stigma experienced by PLHIV at a health care facility in Khayelitsha Sub-District.

- To explore and describe the various stigmatising behaviour experienced by PLHIV at a health care facility in Khayelitsha.
- To describe the various types of stigma experienced by PLHIV at a health care facility in Khayelitsha.
- To describe the outcome of stigma and its influence on PLHIV and on health in general.

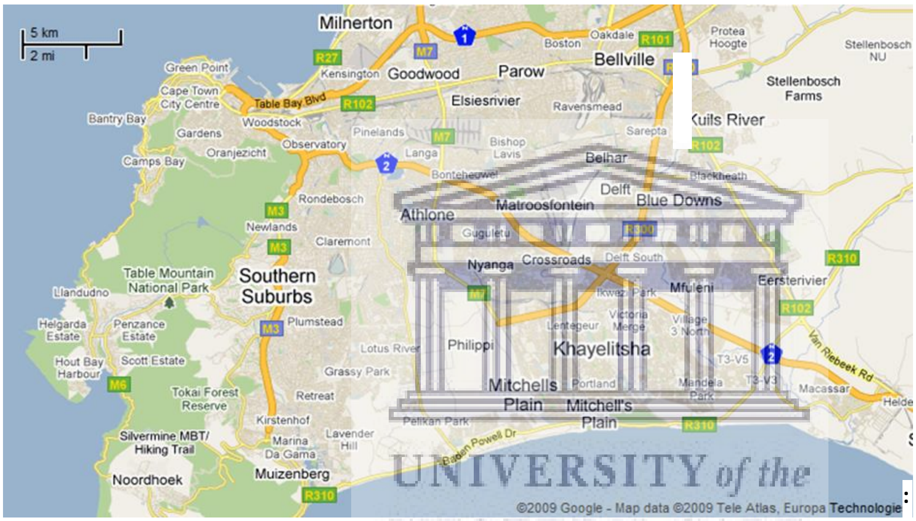
3.3 Study Setting

The research setting can be described as the physical, social and cultural site in which the researcher conducts a study (Grove & Rray, 2018). The study took place at a health facility in Khayelitsha Sub-District in the Cape Metro district. There are 30 municipalities in the Western Cape and all fall under six central districts, which include the West Coast District, Cape Winelands District, Overberg District, Eden District Central Karoo District, and Cape Metropole District. Cape Metropole is divided into five rural districts and one metropolitan sub-district, which is the City of Cape Town (Statistics South Africa, 2016). Khayelitsha Sub-District falls under the City of Cape Town metropolitan district. Two sub-districts in the metro, Khayelitsha and Gugulethu/Nyanga, had HIV rates of approximately 30% in 2016 (Western Cape Health Report, 2017), compared to 28.1% in 2015 (Western Department of Health, 2016).

The chosen health care facility provides integrated primary health care services to the community. It is a day clinic that runs from 8 am to 5 pm. However, because of its strategic location, it is always very crowded, with less than eight professional nurses servicing the population. The headcount per nurse is more than 40 patients per day leading to anecdotal accounts of staff burnout. The facility was purposively selected because it services the highest number of PLHIV as far as headcount is concerned and treats about ten newly diagnosed HIV cases every month (Massyn et al., 2016). According to the district barometer report, Khayelitsha has one of the highest numbers of loss to follow up care of PLHIV on ART with approximately one (1) to three (3) new cases lost to follow-ups every month (ibid).

The economic hardships faced by the inhabitants of Khayelitsha Sub-District render them impoverished, thus vulnerable to stigma. Many households rely on casual jobs and government grants. Many of the people are unemployed living in the township, and the majority of the residents depend on the public health system when seeking health care.

Figure 3: Map depicting the geographical location of Khayelitsha.



Source: 2009-Map data, Tele Atlas, Europa Technology.

3.4 Research Design

A research design is a systematic way of conducting a study with the aim of maximising control over factors that could interfere with the validity of the findings. The purpose of the design is to maximise the possibility of obtaining a valid answer to the research question (Creswell & Poth, 2017). According to Grove and Gray (2018), research design is a unique, flexible and detailed outline of how the study is conducted. A qualitative, exploratory, descriptive and contextual design was adopted to answer the research question for this study.

3.4.1 Qualitative Approach

A qualitative research approach is a systematic, interactive, subjective approach used to describe the experiences of participants (Grove & Gray, 2018). It stresses the importance of peoples' interpretations of events and circumstances, rather than the researcher's interpretation, and emphasises that subjectivity is essential for the understanding of the human experience. The collection of information is often conducted through formally structured instruments and analysed narrative information is illustrated in an organised but intuitive fashion (Brink et al., 2012). The rationale for choosing this approach was that it allowed the researcher to explore the participants' emic perspectives and make an interpretation based on their perceptions and not those of the researcher. The perceptions of PLHIV seeking health services at the chosen facility were unknown. Thus the qualitative approach ensured that the subjective data from the participants was unearthed.

3.4.2 Exploratory design

An exploratory research design is defined by Grove and Gray (2018) as research conducted to gain new insights, discover new ideas and increase knowledge about the phenomenon. In this study, an exploratory design was chosen because it allowed the openness and flexibility that the researcher needed to explore the perceptions of PLHIV regarding stigma as they experience it at a health facility in Khayelitsha Sub-District, Cape Town. This allowed the researcher to get in-depth information on a phenomenon that is relatively new in the context of this research.

3.4.3 Descriptive Design

Descriptive research accurately describes the characteristics of persons, situations or groups and the frequency within which certain phenomena occur (Brink et al., 2012). According to Grove and Gray (2018), a descriptive design is intended to gain more information about a variable within a particular field of study. It is used to describe the phenomenon of interest in real life situations. The researcher chose the descriptive design to be able to accurately describe how PLHIV perceive the experience of stigma while taking treatment at the health facilities in Khayelitsha Sub-District.

3.4.4 Contextual Design

A contextual design focuses on the specificity of the study context which might denote the geographical location of the study (Brink et al., 2012). Grove and Gray (2018), stress that a contextual design describes the uniqueness of the research setting or the context in which the study took place. The research took place within the context of the Khayelitsha Sub-District in the Western Cape Province. The research findings are only generalised contextually within the parameters of the phenomena being studied.

3.5 Research Methods

This section discusses the techniques and procedures followed in this study. This will include discussions about the population and sample, the sampling technique used as well as the sample size, the data collection and data analysis procedures as well as the study rigour and ethics.

3.5.1 Population

Creswell and Poth (2017) refer to the population as a specific type of individuals or elements, entire groups of people or subjects that are of interest to the researcher. The authors also state that the population could be the entire aggregation of cases that meet the specific criteria as set out by the researcher. Since the researcher did not have access to the entire population, the accessible population comprised those individuals who conformed to the eligibility criteria and were available for the study. In this research, the population comprised of People Living with

HIV who received care and treatment at a clinic in Khayelitsha Sub-District. They were chosen because they had experiences about the phenomenon under study and could thus share their perceptions. The accessible population were those who volunteered to take part in the study, irrespective of their race, sexuality, religion, language, culture or disability, as well those who met the inclusion criteria.

3.5.2 Inclusion Criteria

The inclusion sampling criteria are those characteristics that a subject must possess to be part of the target group (Grove & Gray, 2018). The following inclusion criteria were applied in this study:

- Participants of all races and gender who are living with HIV and who are capable of making informed decisions. This means people with disabilities willing to participate and make informed decisions, were equally eligible to participate;
- People who were 18 years of age and above and receiving treatment in the chosen health facility; and
- Participants who were able to communicate in any one of the three languages spoken by the majority of persons in the Western Cape. These were English, isiXhosa and Afrikaans.

3.5.3 Exclusion Criteria

This study excluded People Living with HIV younger than 18 years of age and those who were not receiving treatment in the study site, as well as patients who could not communicate in Afrikaans, IsiXhosa or English.

3.5.4 Sampling Method

A sample is part or fraction of a whole, or a subset of a broader set, selected by the researcher to participate in a research, and is representative of the population from which it is selected, if the aggregate characteristics of the sample closely approximate those same aggregate characteristics in the population (Brink et al., 2012; Burns & Grove, 2013). On the other hand, sampling refers to the researcher's process of selecting the sample from a population to obtain information regarding a phenomenon in a way that represents the population of interest (Brink et al., 2012). A purposive sampling technique was used to select participants who volunteered to be part of this study. Purposive sampling is a non-probability method of sampling in which the researcher selects participants who are the typical population (Creswell & Poth, 2017).). According to Creswell (2014), purposive sampling is used to recruit a sample of participants who have the experience and information required to satisfy the aim of the study. This method was selected because it allowed the researcher the opportunity to focus on individuals who had an in-depth knowledge of the phenomenon that was being investigated (Brink et al., 2012).

3.5.5 Sample size

The determination of the sample size in qualitative research is mostly based on the purpose of the study (Burns & Grove, 2013). In the case of this study, it was anticipated that 15 participants would provide the researcher with sufficient data for analysis, while at the same time providing sufficient interviewing experience. In order to reduce any gender bias, an equal number of males and females was anticipated to be interviewed. However, nine (9) females and five (5) males were interviewed. During data collection, after the researcher interviewed 12 participants, the responses and ideas began to replicate themselves. Therefore, by the thirteenth interview, no new ideas were emerging, and the pattern became saturated. The researcher did not stop there; he went on to interview one more participant to confirm data saturation.

The researcher recognises the importance of data saturation in qualitative research, and it was hoped that in this study, data saturation would occur, that is, the pattern would begin to repeat itself, and no new ideas would emerge (Creswell, 2014; Burn & Groove, 2013).

3.6 Data Collection

This section will discuss data collection from the process of participants' recruitment, pilot interview and the main data collection process. The discussion will also include the physical setting where the interviews were conducted and the type of field notes that were taken.

3.6.1 Recruitment Process and the Researcher's Role

The researcher first obtained ethical clearance from the Biomedical Research Ethics Committee (BMREC) of the University of Western Cape (Annexure 1), and permission from the City of Cape Town (Annexure 2). After permission was granted from both the university and the City of Cape Town, the researcher went to the clinic and met with the clinic manager to seek the permission to conduct the study at that clinic. The researcher explained the purpose of the research and presented the ethical clearance approval as well as the permission letter from the City of Cape Town. The clinic management gave verbal consent to proceed with the data collection. The following day, the researcher and the research assistant returned to the clinic and were taken to the counsellor's room. The clinic manager introduced the researcher and the research assistant to the possible participants, who were all PLHIV. She briefly told them the reason for the visit and gave us the platform to explain the research study to the attendees. The researcher and the researcher assistant introduced themselves to the attendees in the room. The researcher explained the aim of the project and the importance of their contribution (see Appendix 4). The attendees were assured of their anonymity and confidentiality, as well as the safety of collected information should they volunteer to participate. The participants were informed of the consent forms and their importance as well as the right to withdraw from the project at any time they felt like doing so.

After a detailed presentation of the study to the participants, they were given the opportunity to ask questions. Some of them asked mostly around anonymity, privacy and confidentiality, to which the researcher provided clarity. Participants asked the researcher to leave his cellular number with them so that those who were interested would contact him privately. After the meeting, the researcher and the clinic manager agreed that the researcher should make posters informing all clinic attendees of the research project with the researcher’s contact details on the poster (Annexure 3) so that those who wanted to participate could contact him and meet at a private venue that best suits them.

After a couple of days, two participants volunteered to take part in a pilot interview and were given the information sheet and the informed consent forms (Annexure 4 and 5).

A list of activities that explains the role of the researcher before and during data collection was as follows:

1) The researcher obtained ethical clearance from the Biomedical Research Ethics Committee of the University of the Western Cape (Annexure 1);
2) The researcher requested permission from the clinic manager as well as permission for an approval letter from the City of Cape Town, which was granted (Annexure2);
3) The researcher made an appointment with the clinic manager to meet the prospective participants and explained the purpose of the study and handed out the information sheet and the informed consent forms (Annexure 4 and 5);

4) The researcher made posters, with permission from the clinic manager (Annexure3) and advertised the study in the clinic with the full title of the study and all necessary information needed as well as the contact details of the researcher,
5) Participants who were willing to take part contacted the researcher privately;
6) The researcher made appointments with participants, most of whom called the researcher, indicating their interest to participate in the study following the presentation;
7) The researcher always respected the venue and times of the interviews for the participants, even those who wanted to be interviewed after hours;
8) The researcher met with the participants at a venue that was safe for participants as agreed at the first meeting;
9) The researcher outlined the whole study process by informing the participants that interviews would last from 45 to 60 minutes at most as well as assure them of a user-friendly physical environment.
10) The researcher explained the availability of support to the potential participants should they experience any discomfort during the interviews. Participants were told that there was a standby clinical psychologist or social worker working at the facility in the event of distress in the process of the interviews.
11) The researcher conducted most interviews, with the research assistant helping with field notes and operating the tape recorder. The assistant researcher interviewed three participants who wanted to be interviewed in isiXhosa which added credibility and quality assurance to the research.

3.6.2 The Physical Environment

The researcher met with the participants at a venue and time of their choice as agreed on during the recruitment stage. The setting chosen was private, quiet, comfortable and easily accessible to participants. Tags with a message ‘do not disturb or interview in progress’ were put on the door to avoid interruptions. The seating was arranged in a closed position and face-to-face as it encouraged a positive, supportive connection among the participants and the researcher. This seating arrangement also encouraged involvement and interaction between the researcher and the participants. The researcher ensured that the participants were given an opportunity to speak freely. The participants felt relaxed and calm and were able to interact with the researcher without fear. Water to drink was made available, to make the environment comfortable.

3.6.3 Data Collection Process

Groves and Gary (2018) define data collection as “the precise, systematic gathering of information relevant to specific research objectives or questions”. Data can include a variety of methods. However, the research objective must be accomplished with the instrument used (Murphy & Dingwall, 2017). There are several data collection methods in qualitative research. In this study, personal interviews were selected as the most appropriate way to collect data because the researcher wanted to explore the perceptions of the participants.

Brink et al., (2012) describe interviews as a flexible technique that involves verbal communication between the researchers who wishes to explore meaning in greater depth. These authors further explain that the interview is the most commonly used method in qualitative studies, and it can be conducted by using a variety of approaches, including unstructured or semi-structured interviews (Murphy & Dingwall, 2017).

Unstructured interviews were selected for this study because of the qualities as outlined in data collection techniques above, as well as the exploratory nature of this research. With this method, the researcher was able to gather in-depth responses of participants as well as their experience regarding stigma at the clinic.

3.6.4 Unstructured Interviews

Unstructured interviews are interviews that are organised around areas of particular interest, while still allowing considerable flexibility in scope and depth (Grove & Gray, 2018). Unstructured interviews are mostly based on one question and probing, with open- ended questions that encourage participants to give detailed information. In this study, the researcher was particularly interested in gaining some understanding of the participant's perception of stigma in the process of taking their ART at the clinic. The question posed was: *"Tell me about your experience regarding stigma since the period you started to access care as a PLHIV in clinic X?"* The researcher, furthermore, facilitated the interviews by using communication techniques such as:

- Probing: an open-ended question that would encourage the participant to give more information, such as "Tell me more about that' 'How does that make you feel?" "Do you feel respected?"
- Reflecting: Verbalising the concerns and perspectives of the participant to show understanding.

The researcher was able to redirect questions when the participants went off topic and in so doing, remained in control of the interview (Brink et al., 2012). The duration of each interview was approximately 45 to 60 minutes for each participant. Initially, it was anticipated to take one hour, but because most of the participants had a good insight of the research topic, they responded effortlessly with no doubt or without delay (Camlin &Seeley, 2018).

The first two interviews with the clinic participants described in the data collection techniques above were used to pilot the interview technique. The participants did not have any difficulty in answering the questions. The collected data were not included in the final results. This practice helped the researcher to overcome his doubts and gain more confidence. The supervisor listened to the two pilot interviews as well as transcribed these pilot interviews in order to evaluate the researcher’s technique. She was satisfied with it and approved the actual data collection. The research assistant labelled each clip with codes such as “PLHIV1” with the letters representing the participant’s gender and language. The date, number allocated to the interview and time were also included.

3.6.5 Field Notes

Field notes can be described as detailed notes and observations taken by the researcher or the research assistant. They consist of everything that is said and done during the interviews (Brink et al., 2012). The researcher wrote down field notes immediately after each interview (Annexure 8). The field notes included:

- Descriptive notes: These were the reports on the portraits or descriptions of the participants, the physical setting, the interviewer's account of particular events that occurred and activities that took place during the interview. The body language and eye contact or any other mannerism were also included.
- Reflective notes: This was the information written immediately after each participant was interviewed in reflecting the participants’ ideas.

3.7 Data Analysis

According to Gagnon (2015), data analysis begins with listening to participants’ verbal description on the audio recorder followed by reading and re-reading the verbatim transcriptions. The recorded interviews were transcribed *verbatim* (Annexure 6) and a set of raw data was given to an independent co-coder for analysis. Open coding was used to code the transcribed interviews into an ATLAS.Ti version 8. The thematic analysis method using inductive reasoning was employed where codes were grouped into code families (categories) and then into major themes. A detailed description of the process follows in the next sub-section. Initially, Nivo version 8 was planned for analysing the data, but it was unavailable, and the university offered ATLAS.Ti version 8, which was accessible on campus and also easy to use.

3.7.1 Thematic Analysis

A conventional process of thematic analysis was used in this study. This method was selected because the primary aim of the study was exploratory (Maguire & Delahunt, 2017). This is an inductive approach where the researcher begins the data analysis without any preconceived ideas. The six steps of thematic analysis as highlighted by Clarke and Braun (2013) were followed in this study:

- **Familiarisation with the data:** In this study, the researcher immersed himself and became intimately familiar with his data by reading and re-reading the data and listening to the audio recorded data at least two to three times and noting any initial analytic observations.
- **Coding:** Coding is not merely a method of data reduction; it is an analytic process; codes capture both the semantic and conceptual reading of the data. In this study, the researcher used open coding to code segments of the data (Maguire & Delahunt, 2017). At the end of the coding similarities, codes were merged to form a new code and then grouped according to their similarities.
- **Searching for themes:** A theme is a coherent and meaningful pattern in the data relevant to the research question. If codes are the bricks and tiles in a brick and tile

house, then themes are the walls and roof panels (Clarke & Braun, 2013; Maguire & Delahunt, 2017). In this study, searching for themes was like coding codes to identify similarities in the data. The researcher did this 'searching' as an active process. The researcher constructed the themes. He created smart codes into code groups in order to group similar co-groups to form sub-themes and their relevant categories.

- **Reviewing themes:** This involves checking the themes 'work' in relation to both the coded extracts and the full data sets. In this study, the researcher reflected and concentrated on whether the themes tell a convincing and compelling story about the data. Then he began to define the nature of each theme and the relationship between the themes. In some instances, two themes were collapsed together, and a theme was split into two themes.
- **Defining and naming themes:** This requires the researcher to conduct and write a detailed analysis of each theme (the researcher should ask 'what story does this theme tell?' and 'how does this theme fit into the overall story about the data?'), identifying the 'essence' of each theme and constructing a concise, punchy and informative name for each theme. In this study, the researcher carefully looked and relooked at what theme fitted into the overall story of the data and where needed, renamed the theme.
- **Writing up**: Writing is an integral element of the analytic process in the thematic analysis in most qualitative research. Writing up involves weaving together the analytic narrative and vivid data extracts to tell the reader a coherent and persuasive story about the data and contextualising it in relation to the existing literature.

Each code's family was then reviewed to identify themes and merging themes and categories were classified according to the priorities. Some codes were attached to the comments to further elaborate the content of the code (Creswell, 2013). An independent coder, experienced in the field of qualitative research, coded a copied set of the raw data that was given to him. Meetings were held between the researcher and the independent coder to verify themes and categories that had emerged between the two analyses.

3.8 Trustworthiness

Qualitative research is trustworthy when it accurately represents the perspectives of the participants. In this study, the perceptions of stigma by People Living with HIV at a health facility in Khayelitsha Sub-District in Cape Town were represented and not those of the researcher. The method of establishing trustworthiness was adopted from that of Lincoln and Guba (1985) as cited by Krefting (1990). The strategies utilised to ensure trustworthiness included conformability, dependability, transferability and credibility.

Table 1: Criteria for trustworthiness

Standards	**Strategies**	**Criteria**
Neutrality	Conformability	Audit trail, reflexive notes
Consistency	Dependability	Dense description of the research process, audit trail
Applicability	Transferability	Dense description of the research process
Truth value	Credibility	Independent co-coder, member checking, reflexive notes adapted from Krefting (1990)

3.8.1 Conformability

Conformability is the extent to which the participants shape the findings of the study and not the researcher's bias or interest (Brink et al., 2012). Conformability refers to the objectivity or neutrality of data such that there is an agreement between two or more independent people about data relevance or meaning (Krefting, 1990). Conformability guarantees that the findings, conclusion and recommendations are supported by data (Brink et al. 2012). Its goal is to determine whether two or more researchers can agree on the interpretations made during a study. In this study, an inquiry audit was used (Krefting, 1990). The audit included all documents which included raw data such as field notes, interview transcripts and report drafts (Grove & Gray, 2018). The co-coder ensured that the necessary audit was conducted.

3.8.2 Dependability

Dependability is the strategy which relates to the consistency of findings. According to Krefting (1990), there is no validity without reliability. Dependability is a criterion that requires an audit. The enquiry auditors (the supervisor and co-supervisor) followed the process and procedure used by the researcher in the study and determined whether it was acceptable (Brink et al., 2012). The dependability of the study was also enhanced through a dense description of the research method (ibid). An independent coder was requested to assist in coding and verifying the coded data to serve the purpose of maintaining dependability. In addition, the supervisor reviewed the procedure employed by the researcher. All interview material, transcriptions, documents, findings, interpretations and recommendations were kept, and any other material relevant to the study was made available and accessible to the supervisor and the co-coder for conducting an audit trail.

3.8.3 Transferability

Transferability is showing that the findings have applicability in another context (Brink et al., 2012). Transferability was ensured through a thick description of the study and its process during the enquiry. Enough information is available to enable transferability should it be requested. A literature control was conducted with similar findings from other reported studies in this field of work. The research provided a dense description of the research methodology, the participants, background and research context to enable readers interested in making a transfer, to make a conclusion.

3.8.4 Credibility

Credibility is viewed as having confidence in the truth value of the findings. Credibility is demonstrated when participants recognise the reported research findings as their own experiences (Grove & Gray, 2018). To ensure credibility, the researcher used the following measures:

- All participants were taken through full details of what the study is all about. They were informed in advance that it would be open-ended questions with probes to get their insight into the research questions;
- The interviews were tape-recorded, and transcriptions were played at the end of every interview for confirmation that that is the information they gave and if corrections needed to be done, these were done in their presence;

The researcher went back to the participants to ascertain whether the transcribed data were an accurate version of their perceptions. Three randomly selected participants were given the interpreted data to confirm if it represented their views.

The services of a research assistant were employed to help in the interview in cases where certain participants wanted to be interviewed only in isiXhosa or Afrikaans. Only three participants requested to be interviewed in isiXhosa. Therefore, during data collection, the reflexivity of the study was ensured by going into an interview with an open mind to prevent influencing the participants’ responses and the study’s findings. The researcher exposed himself to peer review from both the supervisor and the independent coder whereby he was probed for any biases, and clarification of the researcher’s interpretation to ensure the credibility of this study (Creswell, 2013).

The researcher recognised that member checking is an important part to ensure credibility in qualitative research. This was not done in this study. Because the research assistant was proficient in the language of the participants, the transcriber and translator was also proficient in the participants' language as well as English. This made the study to have two independent coders and thus enhanced the credibility of the study.

3.9 Ethics

Ethics refers to the quality of research procedures with regard to their adherence to professional, legal and social obligations to the research participants (Hickey, 2018). As this study involved human participants and a very sensitive and emotional topic, it was essential to adhere to ethical principles. Therefore, the fundamental ethical principles of justice, beneficence and respect of persons were taken into consideration during the proposed study. According to Hickey (2018), these fundamental ethical principles are based on the right to self-determination, privacy, anonymity, confidentiality, fair treatment and prevention of any form of harm or discomfort.

3.9.1 Permission

The researcher obtained permission to conduct this study from the University of the Western Cape Biomedical Research Ethics Committee (BMREC). The researcher also obtained permission from the City of Cape Town Research Ethics Committee, the clinical management and as well as from the participants (Annexures 1, 2, 5).

3.9.2 Principle of Respect for Persons

As far as this study is concerned, all participants were autonomous; thus, they had a right to self-determination. This means that the participants had a right to voluntarily decide whether to participate in the study or not (Hickey, 2018). A participant information sheet (Annexure 4) and consent forms (Annexure 5) were disseminated to explain the purpose and guidelines for participation in the study. Signed consent forms were requested from the participants before the commencement of data collection. They all went through the consent forms and were only allowed to sign if they were satisfied with the contents and the interview process. All the participants signed the consent forms.

3.9.3 Principle of Beneficence

All participants have a right to be protected from discomfort and harm (Hickey, 2018). The researcher explained to the participants that they had a right to withdraw from the study at any time if they felt uncomfortable, without any prejudice and penalty meted against them. The researcher made the necessary counselling arrangements with a clinical psychologist and social worker working at the facility and further referral in cases where a participant required counselling for emotional distress. However, no participant in this study expressed the need for this service during and after the interviews.

3.9.4 Principle of Justice

All participants have the right to fair selection and treatment (Hickey, 2018). Participants were selected for reasons related directly to the study’s experiences and knowledge. The researcher respected any agreements made with the participants. The researcher respected the participants’ right to privacy by ensuring that they chose a private area, which was best suited for the interview and not asking intrusive questions not related to the study. Confidentiality was also ensured by not using participants’ names and not sharing access to information with anybody except the supervisors and the co-coder. Additionally, information was saved in a password protected file on my private computer, with the researcher being the only person with access. Hard copy documents were saved in a locked cupboard, with only the researcher having access. The participants were informed that this information would never be used with their names on it and the information would be destroyed after five years. All participants indicated that they did not want to be interviewed at the clinic premises. This right was respected, and the participant’s wishes were granted. A suitable venue away from the clinic was selected for all the interviews.

3.10 Limitations

This study included only a small sample of participants from one clinic and thus reflects only the experiences of HIV stigma of participants attending this geographic clinic and not those of the other clinics in the sub-district**.** Over and above, the shortcomings of this study included a lack of sponsorship and the languages being limited to English, Afrikaans and IsiXhosa. People from different provinces formed part of the setting and nations who live in this sub-district who made use of this clinic’s services, could have benefited from this study.

3.11 Summary of the Chapter

The researcher covered a detailed description of the research design and methods that included the population identification decisions and applied sampling strategies. A detailed exposition of the role of the researcher and the data collection process were presented. The results and interpretation of the study are presented in the next chapter.

Chapter 4: Results and Discussion

4.1 Introduction

In Chapter 3, the analysis process was described. The current chapter presents the findings and discussions thereof.

4.2 Presentation of data

As described in Chapter 3, data analysis was done using a conventional process of thematic analysis (inductive approach) and guided by the steps outlined by Maguire and Delahunt (2017). At the end of the analysis process, six themes were identified as presented in Table 2 below. Fourteen participants formed the sample in this study. The researcher used the acronym PLHIV and numbers one to fourteen (1 to 14) to designate the participants' identity in the interview transcripts. The participants' excerpts have been used within the discussions of themes to add value to the description. These quotes appear in italics followed by the participant's identification number from which the excerpt was taken. The verbatim excerpts are not edited because the researcher wanted to preserve the meanings and non-verbal cues as they appeared.

4.2.1 Description of the Sample

The sample in this study comprised 14 participants. All participants were PLHIV taking treatment at the research site. The ages of the participants ranged from 20 to 40 years. Most of the participants were between the ages of 30 to 40 years old and were predominantly of the Black race (*n*=14; 100%). Both males and females participated in the study. Table 2 below presents the full details of the population's demographics.

Table 2: sample characteristic

Criteria	**Characteristics**	**Number of participants**	**Percentage of participants**
Age	20 - 30 years 31 – 40 years	4 10	28.5% 71.4%
Race	Black	14	100%
Gender	Female Male	9 5	64.2% 35.7%

Table 3: Objectives, themes, categories and subcategories that emerged from the data

Objectives	**Themes**	**Categories**	**Sub-Categories**
1. To explore and describe the perceived triggers of stigma experienced by PLHIV at a health care facility in Khayelitsha Sub-District	Theme 1: Existence of stigma triggers	1.1.Overt markers of stigma	1.1.1 Different cards for HIV patients 1.1.2 Different HIV medication packaging 1.1.3 Physical demarcation of space
		1.2. Unintended stigma triggers	1.2.1 Lack of proper health education 1.2.2 Inadequate nurses' competence in HIV management
		1.3. Quality of service as a trigger	1.3.1 Comparison between nurses and lay counsellors' service 1.3.2 Focus on numbers as compared to the quality of service 1.3.3 Inadequate support service 1.3.4 Lack of feedback about raised concerns regarding stigma
Objective 2: To explore and describe the various stigmatising behaviour experienced by PLHIV at a health care facility.	Theme 2: Participants' experience of stigma at the clinic	2.1 PLHIV's characterisation of stigma	2.1.1 Stigma is the fear of being maltreated at a health facility 2.1.2 Stigma is killing someone's self-confidence 2.1.3 Stigma is labelling and judging someone 2.1.4 Stigma is rejection by peers based on your condition.
		2.2. Behavioural concepts associated with stigma.	2.2.1 Racism, discrimination and negative criticism
	Theme 3: Direct stigmatising Behaviour	3.1 Nurses' negative attitudes towards HIV patients	3.1.1 Lack of respect 3.1.2 Rudeness to patients 3.1.3 Disclosure without permission to colleagues 3.1.4 Punitive service associated with one's HIV status

		3.2 Peers' (PLHIV) behaviours towards newly diagnosed PLHIV	3.2.1 Mocking behaviour 3.2.2 Discerning body language
		3.3 Community members' behaviour towards PLHIV	3.3.1 Provocative behaviour
Objective 3: To describe the various types of stigma as experienced by PLHIV at a health care facility in Khayelitsha	Theme 4: PLHIV's characterisation of stigma types	4.1 Personal induced stigma	4.1.1 Not accessing the health facility within their immediate community.
		4.2 Peers (PLHIV) induced stigma	4.2.1 Mocking behaviour from other PLHIVs when you are newly diagnosed.
		4.3 Stigma from health providers	4.3.1 Negative attitudes and behaviour of nurses towards PLHIV
		4.4 Stigma from the community members at the clinic	4.4.1 Gossiping, back chatting, mockery and laughter
Objective 4: To describe the outcome of stigma and its influence on PLHIV and their health in general	Theme 5: PLHIV direct health outcomes	5.1 Generated negative feelings	5.1.1 Anger, rebellious and unhappiness 5.1.2 Feeling disrespected 5.1.3 Unfairly treated 5.1.4 Dissatisfaction with the service
		5.2 Impact on the quality of PLHIV health	5.2.1 Strong inclination to stop treatment 5.2.2 Inability to cope with the stigma
		5.3 Economic Impact on PLHIV	5.3.1 Change health facilities

	Theme 6: Activism as an indirect health outcome	6.1 Health workers directed propositions	6.1.1 Need for improvement in nurses' attitudes at the clinic 6.1.2 Nurses' continuous training regarding HIV management
		6.2 Infrastructure directed proposition	6.2.1 Need to improve the general clinic set up
		6.3 Continuous involvement of PLHIVs in HIV care	6.3.1 Involvement in a research study on stigma 6.3.2 Continuous feedback on the outcome of research and decision made on HIV

4.3 Discussion of the Research Finding Related To Literature

The discussion focuses on the themes, categories and subcategories of data as it appears in Table 4 above. Direct quotes from participants support the findings according to the transcripts and how the responses relate to the research objectives.

4.3.1 Theme 1: Existence of Stigma Triggers

Table 4: Summary of Existence of Stigma Triggers

Categories	**Sub-Categories**
1.1.Overt markers of stigma	1.1.1.Different cards for HIV patients 1.1.2 Different HIV medication packaging 1.1.3 Physical demarcation of space
1.2.Unintended stigma triggers	1.2.1 Lack of proper health education 1.2.2 PLHIV's perceptions of inadequate nurses competence in HIV management
1.3. Quality of service as a trigger	1.3.1Comparison between nurses and lay counsellors' service 1.3.2 Focus on numbers as compared to the quality of service 1.3.3 Inadequate support service 1.3.4 No feedback about raised concerns regarding stigma

Under this theme, three categories emerged, namely, overt markers of stigma, unintended stigma triggers and quality of service as a trigger of stigma at the facility. Each category is discussed with its subcategories below.

4.3.1.1 Overt markers of stigma

Participants indicated that there are labels of stigma that are discriminatory at the health facility. These include the use of different cards for PLHIV, the medication package and the physical demarcation of the facility's rooms.

- **Different cards for HIV patients**

From these findings, participants indicated that their clinic cards are different from those of the other patients who come for other services. The fact that PLHIV carried different cards distinguished them from other patients and exposed them to everyone who enters the clinic. Therefore, these different colored cards are perceived as an instrument that discloses their status to other clinic attendees and hinders their privacy. The participants' perceptions were expressed in the following quotes;

> *"The cards are very different from the other cards, it's like (thinking) if any person comes to the clinic and they see your card, they already know in their mind that this person is HIV positive or like this person come for a certain treatment at the clinic."* **(PLHIV9)**

> **"***The cards are the same, they are not the same as others though and people are treated like they are not people (thinking)…because they are separated from other. Separation of cards (hesitant)… if everything can be one, then people can understand and take their ARV. Look proper, because now people are…(thinking)… Those things are different. Therefore, you know when you carry a blue card it means that one must go for ARV. If you are carrying a white card that one is going for other stuff."* **(PLHIV 13)**

Different HIV medication package

Participants reported that the ARV treatment package, as indicated above with the cards, also exposes them to the public and therefore discloses their status to people even if they did not want people to know. This compromises their privacy and confidentiality. They also reported that the ARV treatment package was a threat to their lives because they felt that from the ARVs advertisement on media, the public was aware of the container and color, especially those that abuse substances and use ARVs as their drug of choice. Moreover, the tablets in the containers produce a specific noise due to the packaging thus making them identifiable to these substance abusers. As a result, participants reported that these substance abusers come to the clinic to monitor the HIV patients' section. When they walk in the street after collecting the ARVs, the medication makes noises in their pockets. They are then robbed when they leave the clinic in the street where there is no security. Some participants reported that they put masks in their container to stop the noise and ensure that their medication is safe.

"*Sir, I say here the packaging is extremely wrong for me, but I don't have a problem with the packaging since maybe I am a man, I can put it somewhere or maybe I can hide it. However, it is a huge problem to the Tucks (unscrupulous characters) who are smoking it because they always say …"thaima [Old man], we know you come from the clinic"... I never told this tucks that I am HIV positive. I never told them, but they always say "thaima [Old man] aren't you coming from the clinic?" Now I am very afraid to tell them because they robbed my friend last month… they robbed his package. Now we had to go back to the clinic, and that is when the nurses shouted us. However, we did not lose that treatment. That treatment was robbed by the thugs who are smoking it":* **PLHIV 10**

"Yeah yeh (coughing), the containers are the issues because those pills are big and those containers are little bit thick so when you go around, they like qwasha (making the noisy sound)... So that noise is a problem." **PLHIV 13**

This information regarding the noise made by the packaging was perceived as a tool that stigmatises PLHIV. This phenomenon was of great interest as never has a perspective such as this been presented before. Participants highlighted that not only does the packaging trigger stigma, but it endangers their lives two fold. First, when they are being robbed, they are compelled to disrupt treatment. This could lead to the development of resistance. In addition, as reported by the above participants, when they return to the clinic after experiencing such an incident, they are shouted at by the nurses. This implies that the nurses might not believe them and might not issue another package of treatment. This disrupts treatment for a month. This emerges as a serious issue that could have repercussions on HIV control and prevention. Secondly, when they are attacked by substance users who want to rob them of their medication, the attackers can cause physical injuries, which could result in death. Hence, there is a need to carry out further research, regarding the medication package and the noise linked to it.

Although this issue has not been reported in this manner in previous research studies, the Positive Future Project (De Klee, 2016.) recently started to design a new human-friendly medication packaging for ARVs in Africa, as a means to reduce the negative stigma associated with HIV. It is not clear if this new packaging design is associated with noise.

- **Physical demarcation of the clinic space**

The participants expressed their discontent regarding the clinic set up, and they perceived this demarcation as a stigma trigger. All the participants highlighted that the physical demarcation of clinic space was designed in a manner such that PLHIV have their waiting room at the back of the clinic. This was obvious to the community attending the same clinic that people entering that particular room were PLHIV. Similarly, PLHIV have a club room at the clinic which is used on specified dates for support group activities. The participants reported that those entering the club room on those specified dates are easily identified as PLHIV. Thus the confidentiality of their status is compromised resulting in stigma. However, the participants acknowledged that the original plan to divide the clinic had no malicious intent. The intention was to facilitate easy patient flow in the clinic and speedy assistance for PLHIV. Unfortunately, this turned out to be a label of HIV and thus a trigger for stigma. As a result, some participants revealed that they move away from their communities to seek treatment in different residential areas to avoid identification by their community members. Another participant reported that it is embarrassing to know that at the clinic there is a section for patients like "them". This, according to the participants, was stigmatizing and inhibited their continued access to ART.

"It's there wena buti [you my brother], and it will always be there. The thing is that maybe the nurses do not see that they are stigmatizing. I don't know how to put it in any way... Because if you are HIV positive, you have your side, if you have TB you know your side where to go." ***PLHIV 13***

*"…like I said the demarcated area make HIV known. It is known that this area is for HIV even if they have not labelled it yet. Therefore, I feel that on its own, it stigmatises us as HIV people. Because we need to be treated like any other patient that come in. I feel that even with the date that they give us to come to the clinic, it makes it obvious to everyone that on this date, it is for HIV support group which is a club for HIV people. We do not need to be stigmatised for a certain date to conduct our own support session. I think that doing that is stigma on its own. However, somewhere somehow, in the system people got the information that in this part of the clinic, it is where the HIV client goes. Even with pre-counselling and post counselling, they will just say go to room 5. They never change rooms, so now everyone knows if you are going for HIV you are going to room 5."****PLHIV1***

"But even that club… I am not there yet but they know once you are in the club, there is a club room there, all the people who go there are there to take their HIV treatment."

PLHIV14

Similar reports have been presented where incidences of separation and isolation were perceived as triggers for stigma in a study conducted in Southern Nigeria (Owolabi et al., 2012). Wringer et al. (2017) wrote on a similar topic in a gross section study in several African states on stigma perpetrated by health care worker towards their patients.

In the mentioned study, HIV patients who came for treatment were also demarcated to a certain area of the hospital and subjected to isolation. Their medical records were different from the other patients who came for other services. Similar studies by Pudpong et al., (2014) reported that PLHIV in Thailand did not want to attend clinics because of the open separation of PLHIV from other patients, coupled with the negative attitude of the health care providers. As a result, their findings indicated that PLHIV started treatment very late and most of them had CD4 counts of less than 100. Such studies reaffirm the dangers associated with subtle markers that can trigger different types of stigma towards PLHIV.

4.3.1.2 Unintended stigma triggers

- **PLHIV perceptions of inadequate nurses' competencies in HIV management**

Participants reported that nurses' behaviour towards PLHIV at the facility could be attributed to the lack of necessary HIV education. It can also be attributed to nurses' familiarity with patients since some nurses gave preferential treatment to patients that they know well. These contributed to the increased negative "vibe" at the clinic, as explained by one of the participants. Participants emphasised that nurses should be continuously educated about HIV management through workshops and further training. Although it may look as an unintended stigma trigger, the actions of nurses are stigmatising, and participants felt that in order to compensate for their lack of skills in managing PLHIV, nurses' resort to the stigmatisation of PLHIV.

"They act like that because also on their side they don't have enough information. I think so because they also need to be trained about HIV because with HIV, there is a lot of changes, and I think the nurses need to be kept on par about it." ***PLHIV 5***

"I don't know because these are professional people you are dealing with. Now if the professional can behave in such a manner who is going to educate them? It is becoming a mystery to us because they are the one who should be educating us and the community. But now it seems they are the one who need workshops about HIV and AIDS." ***PLHIV 8***

This view is supported by a study in Kenya which revealed that there was a gap in nurses' training, perceived competence, and practice in HIV care and treatment. The study recommended further intervention to build nurses' competence and prepare them to provide effective quality care to patients living with HIV (Smith et al., 2016). According to Happell et al., (2014) factors that influence nurses' knowledge and attitude towards PLHIV include education, previous experience of caring for PLHIV or knowing someone who is infected, and the willingness to provide care to PLHIV. The authors recommended that supplementary education is needed to strengthen the nurse's knowledge and competency. Training of nurses in HIV management is essential in the nursing education curriculum.

A study by Ouzouni and Nakakis (2012) indicated that the attitude and behaviour of nursing students towards People Living with HIV were influenced by their knowledge of HIV and its management.

- **Lack of proper health education**

Participants reported that they do not receive enough counselling and good health education from the nursing staff. The only time they feel like they have gained some knowledge is when counsellors from the HIV club talk to them. However, as far as the nurses are concerned, participants reported that some of them are always in a rush and mostly work hard only after lunch. Participants reported that some nurses do not give health education unless someone asks them a question, and only then will they have a brief talk with the person. The participants indicated that this behaviour, although unintended, triggers stigma, particularly internalised stigma. PLHIV reported that the lack of health education was perceived as an avoidance mechanism used by nurses because they do not want to spend a prolonged period with them.

“You have to ask questions because if you don’t ask questions they just think maybe you know everything. However, if you ask questions, that is when they seat with you and talk with you. That is why you need to talk. If you don’t talk and you just say yes yes, when you say this yes yes, then they say ok you look like you are fine then they leave you like that. This is sad because it is like they don’t want to spent time with you.” ***PLHIV13***

“They just do what they have to do so that they can get rid of you. That’s the only thing; they just do the job just to get finished otherwise they are not giveng us that full knowledge of “okay what do we do now.” ***PLHIV 14***

4.3.1.3 Quality of service as a trigger

Participants expressed satisfaction and acknowledged the excellent work done by lay counsellors at the facility. They highlighted that lay counsellors displayed a sense of professionalism when compared to the counselling and health education they received from the nurses. Participants highlighted that lay counsellors treated them with sensitivity and sympathy. They educated them and counselled them regarding many issues in their treatment journey. Meanwhile, participants expressed dismay and dissatisfaction with the nurses' counselling and working attitude. This was perceived as a trigger to stigma as the same is not done to other patients who attend the same facility.

"I will say the HIV counsellor understand HIV, understand the support part of HIV, the emotion that goes with you, the shock and the trauma that you go through. So they are able to probe and talk more about your illness and the phases that you go through. Then if it was just you dealing with the nurse, they just give medication and say drink this at this time. But you do not know what type of medication you are drinking, what side effect it contains. Now with this lay counsellor, even when you come back and say "I keep on vomiting, I am keep on having dizziness", they will say to you "certain medications have side effect. It is this and this and this… So I think the lay counsellors are giving us more information, more support than the nurses do. They see a human first before my illness." ***PLHIV 1***

- **Inadequate support service**

Some of the participants reported that they hope the situation at the clinic could improve and that nurses could learn to accept HIV patients and give them the support they need. Participants reported being treated with disrespect and others with disrespect. Again, the quality of services and behaviour of the nurses was reported to trigger stigma. According to the participants, stigma exists at the clinic, and that is why poor quality of services is given to them. The quote below affirms the report:

"Once we hear that this is a professional nurse we expect the service to be at least of the highest order. However, when we get this thing (stigma) from the professionals, then we don't know where we must go to now. We do not know. They always tell us that they know what they are doing. However, they are saying what they are doing with us in front of everyone. This is a problem to us; that is not good service; that is not giving support."

PLHIV 5

- **No feedback about raised concerns regarding stigma**

These findings indicated that participants were very concerned about the situation at the clinic regarding the negative attitudes of the nurses, the quality of the service and the support they received. However, most of them did not raise these concerns with the clinic management. The reasons given were that although there is a complaint box at the clinic, those who wrote complaints, never received feedback, so for them, it is a waste of time because they never receive feedback. In addition, they reported that nurses always tell them that they know what they are doing, which confirms that indeed, the quality of service acts as a catalyst for stigma towards PLHIV.

"*One of my friends has written a complaint because there is a box there by the clinic that if you want to write any complaint, you can drop it there. However, one of my friends has written a note to say her mind and drop it there but up till now, there is no response. I asked her; I think last month if she got any feedback. She said nothing yet, but I know maybe if there is a meeting they have already talked about it*." ***PLHIV 12***

Guma (2011) supports the notion that health workers in the health care system (doctors, nurses and other HIV management staff) are the prime agents of HIV related stigma and discrimination. Although many studies spell out the stigmatising behaviours, the findings of this study were clear that some actions or lack thereof can trigger perceptions of stigma by those at the receiving end such as PLHIV.

4.3.2 Theme 2: Participants Experience of Stigma at the Facility

Table 5: Summary of participants' experience of stigma at the facility

Categories	**Subcategories**
2.1 PLHIV's characterisation of stigma	2.1.1Stigma is the fear of being maltreated at a health facility 2.1.2 Stigma is killing someone's self-confidence 2.1.3 Stigma is labelling and judging someone 2.1.4 Stigma is rejection by peers based on your condition.
2.2. Behavioural concepts associated with stigma.	2.2.1 Racism, discrimination and negative criticism

In this theme, participants explained their understanding of the concept of stigma to demonstrate that what they perceive in their experiences, is indeed stigma. They reported various definitions of stigma as well as concepts associated with stigma. These are grouped under two subcategories.

4.3.2.1 People living with HIV characterization of stigma

This category was further broken down into subcategories.

- **Stigma is the fear of being treated unfairly at a health facility**

Participants defined stigma according to their understanding and how they felt it is perpetuated in the health facility, where they collect their medication. They reported that their perception was that they would be treated unfairly and think everybody knows their status, even before they experience the actions. This type of stigma is called perceived stigma or anticipated stigma.

"That room is designed for us and only that room. We are not mixed with the other people that are going there for headache or for other illnesses. That makes us believe that we will be treated differently from other people." **PLHIV 10**

The participants reported that because of their fear of being identified due to the use of a separate room, causes them to run away from their community and get their ARVs elsewhere. This is because they do not want to be seen by members of their community or their family. The participants' characterized stigma is the inability to disclose their status due to the fear of being discriminated against, should people find out about their positive HIV status.

"There are people that come from far away that stay far away. They come and take their ARV here because of stigma that it happening there. However, when they see their family members in the clinic, they get scares because they know that the family member now knows that the person is coming to take ARVs. That is stigma, fear of being found out." **PLHIV2**

Some participants reported that once the community discovers a person is living with HIV, they become belittled and labelled and in most cases the society becomes judgmental towards them. They reported that they are humiliated by name-calling from the nurses, peers and the society at large. As a result, some reported that the name-calling is equivalent to being dehumanized, which ultimately impacts negatively on their self-confidence. The following is an expression made by one participant;

> *"Sometimes we are told that, "that is how you people will die". The word "you people" feels like we HIV people are different from the next patient who is not HIV positive. The wording itself from the nursing staff when they say "you people" as if we are different kind of human race is dehumanizing."* **PLHIV 1**

Furthermore, some participants based their understanding of stigma on how their peers perceive them. They described stigma as isolation or rejection by friends, once they become aware of their HIV status. The participants related their description from an instance that was perpetuated in the clinic whereby a patient did not want to come back for treatment because she overheard peers gossiping about her in the health facility. This patient was eventually isolated by those who used to sit with her.

> *"Stigma is something like you cannot like euh (Thinking pensively), how can I put it? I don't know how to put it now. Stigma is a situation where people tend to run away from you; because of that situation that you are in. That is the meaning of stigma. That is how I see it. People don't want to get along with you because they know you are positive. Even those you were a friend to before, the moment they realized that you are in this situation, they tend to stay away from you."* **PLHIV12**

These findings suggest that PLHIV understand what stigma is and they experience stigma in the facility. Participants' understanding of stigma parallels the definition of many authors regarding stigma (Reif, Wilson & Allster, 2017).

These authors agree that the concept of stigma can be manifested by exclusion, rejection, blame, devaluation, labelling, stereotyping and separation that occur as a result of experience or anticipation of an adverse social judgement (Jain, Carr & Nyblade., 2015; Earnshaw et al., 2013).

4.3.2.2 Behavioural concepts associated with stigma behaviour

- **Stigma is discrimination, criticism or racism**

Discrimination and negative criticism were two of the concepts which were commonly used interchangeably with stigma. Discrimination has been considered as an attribute to stigma, that is, the way people portray an act of stigma. What was interesting, however, was the equation of stigma to racism is this study. Nonetheless, Earnshaw et al., (2013) report that an enduring legacy of institutional racism is a fundamental cause of racial disparities in health. Hence, those who have experienced racism will easily relate the unjust treatment of stigma to the concept of racism. However, it seems that there is limited research associating stigma with racism, particularly from a PLHIV perspective and HIV context. This new association indicates the need to study the relationship between HIV stigma and race within the health service parameters. The following quote expresses the views of the participants;

"Stigma, I can say stigma, is the (Thinking)… I want to call it criticism, or (pause) racism towards the kind of a person or that kind of a gender, or that kind of a culture, that one people discriminate others against. In my experience in this clinic, the disrespectfulness of the staff makes me describe stigma as that": **PLHIV 10**

This finding was similar to a study in Cameroon which documented a wide range of discriminatory and stigmatising practices and categorised them broadly into neglect, differential treatment, denial of care, testing and disclosing HIV status without consent, including criticism, verbal abuse and gossip (Boyers et al., 2011: Pretorius et al., 2016).

4.3.3 Theme 3: Direct Stigmatizing Behavior

Table 6: Summary of direct stigmatising behaviour

Categories	**Subcategories**
3.1 Nurses' negative attitudes towards HIV patients	3.1.1 Lack of respect 3.1.2 Rudeness to patients 3.1.3 Disclose without permission to colleagues 3.1.4 Punitive service associated with one's HIV status
3.2 Peers (PLHIV) behaviours towards newly diagnosed PLHIV	3.2.1 Mocking behaviour and 3.2.2 Discerning body language
3.3 Community members' behaviour towards PLHIV	3.3.1 Provocative behaviour

This theme explained participants' experience of the stigma that is, how the nurses, peers or members of the community treat them at the facility. These experiences are grouped into three categories: nurses' negative attitude towards HIV patients, peer behaviour towards newly diagnosed patients and community members' behaviour towards PLHIV.

4.3.3.1 Nurses' negative attitudes towards HIV patients

- **Lack of respect**

Participants were very disappointed with the nurses' attitudes towards them. According to them, the nurses at the clinic stigmatized them in various ways. These include their body language which is perceived as being looked down on as if they are nothing. The immense portrayal of disrespect was reported by most of the participants. In addition, they reported that at the clinic, the nurses lacked professionalism and gossiped about their status with their colleagues.

"As I said before there is no respect, they don't welcome people, they don't make you feel comfortable in the clinic. If you miss your date, they just shout at you (raising her voice) they say, "Guys! Come and put your card here". If you don't put your card there, they just shout at you (raising her voice) and say "why are you sitting there and you don't put your card at the window; how are we going to get you your file if you are just sitting there with your card and everything like that?" **PLHIV 9**

The participants further reported that nurses at the clinic abuse them verbally and are rude to them. They indicated that the nurses call them names such as "you people". The excerpt below demonstrates the report by the participants;

"*When you were supposedly to come to clinic maybe for check-up or you were busy with something else and couldn't make it to the clinic; this is how the nurse react to you "that is how you people will die". The words "you people" feels like we HIV people are different from the next patient who is not HIV patient."* **PLHIV 4**

Participants reported that in some instances, the nurses gossip about them to their colleagues and disclose their status, including private and essential aspects of their lives.

"If I am going there for my HIV treatment as well as for my family planning, but I don't want to take the family planning, they will shout and laugh. They say things like "Do you want to have a lot of children? Your boyfriend is going to leave you with these lots of children. You cannot have many boyfriends while you are HIV positive" and stuff like that. It is not their problem if I have too many children or not (anger). That doesn't concern them": **PLHIV 9**

*"Because it has been a long time that I am taking treatment, I know most of the nurse. So because of that… I am treated nicely now than before. Before I was scared... I did not want to go and take my treatment because I was scared that the nurses are going to shout at me when I missed my date."***PLHIV7**

However, some participants also reported that not all nurses portray these negative attitudes. They disclosed that some nurses were helpful and of good character, depending on the relationship they have with some of the patients. Others also reported that patients sometimes push the nurses to behave in a certain way, for instance by arriving late for their appointments.

"I am respected in the facility because the nurses are doing their job very well. They can't change anything because it is the government that made the facility how it look like. So they are doing their job, they are trying to do their job in many ways. So I can say that I am respected because I get my service there." **PLHIV 5**

"Yes if you are coming there on time, there will be no problem. That is why I hate it where I am coming from. When it is the time for your appointment, you must make sure that you are

there. It is your body. It is you who wants help. Therefore, you must consider everything. It is better to be early than being late.” **PLHIV 11**

Some of the stigmatising behaviours were similar to those reported in a study conducted in South Sudan in 2011. This study revealed that participants’ experiences of stigma and discrimination at the health facilities were characterised by behaviours such as being tested without consent and lack of confidentiality (Guma, 2011).To add to stigmatising behaviours experienced by PLHIV at this facility, some participants mentioned that the behaviour of the service providers, mostly nurses, rendered their services as punitive. They reported that the nurses were often not very sensitive and blamed the patients of being “mischievous”. Those who missed their appointment on a particular due date struggled to get a new appointment date. This behaviour, according to the participants, felt like punishment for situations that are often beyond their control. One participant said;

> *“You know the nurses crucify us; they call us names. I just missed one appointment, and they crucified me like I kill a person or something. It is the professionals that have this stigma.”***PHIV10**

“The service providers themselves are not sensitive when it comes to HIV clients especially young people like me who are the age of 28. They automatically assume that you are mischievous so you deserve to be HIV positive. So they have that perception of how you contracted the virus hence you are mischievous and (pensive pause)... So there is already a negative aura towards you when you are fetching your treatment or when you come for check-up.” **PLHIV 6**

Some of them added that when they come to the clinic for other health-related conditions, the nurses refuse to treat them assuming that their current state of health (that brought them to the clinic at that point,) is a result of their HIV status. Hence, the participants feel stigmatised and sometimes do not want to return to the facility. One participant said:

> *"They will be harassing you in front of the other people. You are coming for HIV now you asking something else. You are not supposed to ask. You are supposed to focus on what you are coming for."* ***PLHIV11***

These reports support a study conducted by the South African National AIDS Council, where it surfaced that many participants stopped their treatment because of the attitude of the health care providers (SANAC, 2015). This attitude of treating patients harshly because they miss their appointment is a clear indication of the violation of patients' rights, thus direct stigmatisation in the facility. Although some participants, as indicated above, reported that some nurses are good to them, it was not encouraging that this study still reveals the negative behaviour of some nurses towards PLHIV. Nurses, especially at primary health care facilities, are the first health professionals who interact with patients. Hence, they are supposed to understand that patients need more care. It is equally important to understand the circumstances of PLHIVs because they are subjected to ART for the rest of their lives. Wringer et al., (2017) found similar results in their study. However, ten years later, it seems that nothing has changed, despite major stigma reduction programmes.

4.3.3.2 Peers' (PLHIV) behaviour towards newly diagnosed people

Over and above the behaviour of nurses, PLHIV are subjected to stigmatising behaviours from their peers. Some participants reported that newly diagnosed patients are sometimes mocked and ridiculed by their fellow PLHIV at the clinic. The participants reported that when a new PLHIV comes for treatment, fellow PLHIV laugh, gossip and whisper statements such as "*welcome to the club or you also".* The reaction of some of their fellow HIV positive peers makes them very uncomfortable, thus resulting in stigmatisation.

> *"But then the fellow patient that also comes for their treatment gossips about you when you came out of that room or certain room that is mostly for HIV patient. The way they look at you, the way they whisper when you pass, the giggle, and the laughing when you just pass by (disappointed look). That is the type of behaviour that you get from the other HIV clients."*
>
> ***PLHIV 1***

The stigma perpetrated by peers in this study is similar to that in a study conducted by Earnshow et al., (2016). The study reported that associated stigma was identified mostly among people who are all HIV positive. It was reported that every time a new member joins the support group, he or she feels stigmatised by his peers because they never expected him or her to be in the same situation.

4.3.3.3 Stigma perpetrated by the community members at the clinic

Participants reported that the demarcation of the clinic was designed in a way that PLHIV were identified easily by community members who also access the clinic for other health care services. This was perceived as a source of embarrassment by PLHIV. They indicated that once community members associate them with the "HIV room", then gossiping and isolation becomes the norm when they meet PLHIV at the clinic. This behaviour often makes PLHIV to shy away from the clinic thus missing their appointments. Some participants highlighted the intention to seek treatment in other facilities, which was more strenuous and expensive because of the distance they have to travel. The following are some of the quotes that demonstrate the existence of these behaviours;

“That is why I was not taking treatment in this clinic. It is stigma because they know me and I know the people that are there. Those women, (pause) they are in the same community that I live in. They live in the same street that I live in. I use to take my treatment very far away but because I sometimes don’t have taxi fare, I come back here.” ***PLHIV 10***

“The way they look at you, the way whisper when you pass, the giggle, and they gossip about you in your area. When you pass by the conversation stop and they start laughing.” ***PLHIV1***

This finding is similar to that of Pretorius et al., (2016) where the participants defaulted from treatment because of fear of prejudice and discrimination from family and community members who attended the same health facility.

4.3.4 Theme 4: PLHIV’s Characterisation of Stigma Types

Table 7: Summary of PLHIV's characterisation of stigma types

Categories	**Sub-categories**
4.1 Personally induced stigma	4.1.1 Not accessing the health facility within their immediate community
4.2 Peers (PLHIV) induced stigma	4.2.1 Mocking behaviour from other PLHIV when one is newly diagnosed.
4.3 Stigma from health providers	

4.4 Stigma from the community members at the clinic	4.3.1 Negative attitudes and behaviour of nurses towards PLHIV 4.4.1Gossiping, back chatting, mockery and laughter

In this theme, participants reported stigma as they experience it at the facility. For them, stigma is induced by the PLHIV themselves, their peers, the nurses and the community members. This theme is grouped into four categories and subcategories.

4.3.4.1 Personally induced stigma

- **Not accessing the health facility within their immediate community**

Participants indicated that the fear of the attitude of the nurses, peers and community members who also access the clinic, subjected them to self-stigma. According to participants, this affects their self-esteem, and as a result, they internalise this perception of negative behaviour at the clinic and develop constant fear about what will happen when they go to the facility. This quote from data collected backs this statement.

> *"I didn't like to take treatment from this clinic. First, I never wanted to take my treatment from this clinic. It is just that currently I am not working so I do not have that taxi fare every time. However, if it was up to me I will still be going to that other clinic. I am scared of what will happen to me and who I will meet here before I even come":* ***PLHIV 10***

PLHIV's experience of stigma (experienced previously or observed from others' experiences) has great repercussions on their belief about themselves. Fear becomes the order of the day and dictates the actions that they take regarding accessing care. From the findings of this study, it is clear that enacted stigma leads to internalised and anticipated stigma. This category shows the anticipated stigma or (perceived) stigma. Anticipated stigma is a negative response that PLHIV expect to receive from their health care providers, family and community when their HIV positive status is exposed. This is fear of people's prejudice and discrimination even before the actual act happens (Jain, Carr & Nyblade, 2015: Earnshaw et al., 2013). The findings in this study are supported by Reinius et al., (2018) in Sweden where it was revealed that anticipated stigma and internalised stigma were related to lower physical functioning and lower emotional well- being. In line with this perception, a survey by Sahltman al., (2017) indicates that personally induced stigma is associated with adverse health outcomes, such as poor medication adherence and lowered viral load. These findings add to the growing evidence of the need to address stigma to improve the wellbeing of individuals living with HIV.

4.3.4.4 Peer (PLHIV) induced stigma

In this sub-category, participants expressed shock and disappointment from the reaction and negative behaviour of fellow peers who are also HIV positive. Participants indicated that this mostly happened when an influential member of the community is newly diagnosed and joins the club. The giggling body posture, laughing and mocking behaviour of their peers sometimes discourages them from returning for treatment. This may be characterised as an actual action of stigma from old to the new patients. As a result, this type of behaviour among fellow PLHIV indicates a lack of compassion and sympathy towards one another. Hence, participants reported discomfort and distrust of the club as they perceive it to be another form of stigma.

> *"Stigma is always there because if you are new and you meet someone who knows you, they will be surprise to see you there. They ask questions like "you are also joining us? Are you now taking treatment with us?" They make statements "like I never thought you will get HIV."* **PLHIV 5**

"You get stigma through your fellow (euh) client. Through people who come to the clinic to take their own medication or their own different treatment. Now they treat you (pause) or distance themselves from you." **PLHIV 1**

4.3.4.5 Stigma from health providers

Even though some participants reported that the nurses try to do their jobs to the best of their ability, most of them expressed their discontent about the negative behaviour portrayed by nurses.

Participants reported that they do not receive any form of support from the nurses. This results in a situation where most participants reported that nurses' behaviour towards them sometimes pushes them to stop coming to the facility for treatment.

"*When they shout like that, it feels like dropping this clinic and going to the other clinic. However, the reason why I stick with them is because they are the closest to me. Because the clinic is in the same street as I live. That is the reason why I come to this clinic. The other clinic is far from me I am going to have to take a taxi and travel but sometime I am not going to have money for taxi."* **PLHIV 9**

"The nurse don't care about you, they shout and just give you ARV to drink. They don't tell you how and when you should drink them, so you must read from the box. They don't care about you as a person. They don't respect you, they talk as they want, they shout at you as if you are not a human being" **PLHIV 2**

This category is line with a study conducted by Gilbert and Walker (2010) on stigma experienced by HIV patients at a clinic in Johannesburg. The findings of that study revealed that the participants in that study were afraid that the health workers will disrespect them and would disclose their status to their colleagues. Another study on the stigma index surveyed two districts in each of the nine provinces of South Africa. It revealed that some people stopped their treatment because of the attitude of health care providers (SANAC, 2014). In contrast, a study in Namibia revealed that PLHIV did not perceive any experience of stigma and discrimination at their ARV clinic (McMahon et al., 2017).

4.3.4.6 Stigma from the community members at the clinic

Participants mentioned that because of the physical design of the clinic, community members are aware that patients who attend the clinic on a specific date and carry a particular colour of the clinic card and those who attend clubs in a particular room, are PLHIV. This subjects them to gossip, provocative laughter and back chatting from the community. This makes it difficult for PLHIV to return for treatment at the clinic.

> *“That is why I was not taking treatment in this clinic. Those women are in the same community that I live in. They gossip. That, made me go to take my treatment very far away.”*
>
> ***PLHIV 6***

This finding was similar to that of a study conducted by Pretorius et al., (2016) in which participants defaulted from treatment because they perceived fear of prejudice and discrimination from family and community members who attend the same health facility. In another study conducted in Namibia, participants reported experiencing enacted stigma and discrimination as a result of their HIV status from within their community and families. (McMahon et al., 2017; Nghifikwa, 2011).

4.3.5 Theme 5: PLHIV Directed Health Outcomes

Table 8: Summary of PLHIV directed health outcomes

Categories	Sub-Categories
5.1 Generated negative feeling	5.1.1 Anger, rebelliousness and unhappiness 5.1.2 Feeling disrespected 5.1.3 Unfairly treated 5.1.4Dissatisfaction with the service
5.2 PLHIV's Impact on the quality of health	5.2.1 Strong inclination to stop treatment 5.2.2 Inability to cope with the stigma
5.3 Economic Impact on PLHIVs	5.3.1 Change health facilities

In this theme, participants explained the repercussions stigma could have on their personal feelings and their general health. This is grouped under three categories.

4.3.5.1 Generated negative feeling

Some of the participants expressed their disappointment concerning the way they have been treated at the facility. The situation led to emotional responses mostly characterized by anger, unhappiness, rebellion and feelings of disrespect, as shown in the quote below.

> *"I am unhappy because it is embarrassing, it does not keep you fine. Sometime you ask yourself but why me? You ask yourself what if you can change the situation but it is too late.*

> *You cannot change the situation; you need to live like that. Therefore, the situation can also make you (pause)… not to be strong; to feel like stressed out. Maybe it is time of the When the times of the appointment come, you start to ask yourself "Do I need to go?" Sometimes you do not feel like going there."* **PLHIV 12**

Sahltman et al., (2017) reported similar findings where approximately 40% of their respondents had experienced stigma and discrimination at the health care facilities and due to that; they were engulfed with feelings of anger, unhappiness and mistrust. The behaviour of the nurses and the facility set up entirely made participants in this study angry and rebellious, which was a consequence of the outcome of stigma at the facility.

- **Feeling disrespected**

Another familiar feeling experienced by PLHIV due to stigma was disrespect. The quote below demonstrates the reported experiences;

> ***"I** feel disrespected. We are shouted at, (louder)I feel disrespected."* **PLHIV 4**

> *"I feel bad now because they disclose your status to people. You don't want your stamp in green. That is why feel disrespected."* **PLHIV11**

- **Unfairly treated**

Participants reported that they were separated from other patients and sometimes were forced to wear masks all the time. In addition, they are not treated equally with the same empathy or consideration as other patients. Some blame their condition of not receiving proper care at the facility when they present with other health problems because they are told that their situation is a consequence of their HIV status.

"People living with HIV are not treated like other people, the don't belong to the community, because of the way people treat us." **PLHIV 14**

"If there will be equality. There is not equality in that clinic. They treat us based on our sicknesses. To them the virus is something like I don't know (Looking upset). Stigma does exist, I don't know how they treat us. It is not equal; it is not the same." **PLHIV 3**

- **Dissatisfaction with the service**

Participants in this study reported that they are not happy with many things in the facility starting with the facility set up, the nurses' behaviour and the inadequacy in the service provided and lack of professionalism.

"It makes me angry and sick every time I go there. I know there will always be an attitude. Every time I go there, I am not happy. I am supposed to be happy because I am going to the clinic. They are supposed to help us by giving us counselling. There is no counselling there the way they treating people who are sick…(doesn't complete the sentence and appear saddened." **PLHIV 3**

This finding is supported by a study conducted in Tennessee which revealed that more than half of the participants in the study expressed dissatisfaction with how the nurses perceived them. This sometimes forced to them to request self-medication and isolate themselves from family and friends, which leads to depression at times (Audet, McGowan, Wallston, & Kipp, 2013)

4.3.5.2 PLHIV impact on the quality of health

Participants reported that the stigma they experience at the clinic from the nurses, their fellow PLHIV and community members has a negative impact on their wellbeing. Firstly, this leads them to internalise fear of certain people's reaction when they know about their status. The verbal abuse contributes to lower their self-confidence. Consequently, some desire to stop treatment and others travel extra miles to change the health facility in order to get their treatment at another facility. Stress was also reported as a consequence that impacts on PLHIV's wellbeing. This demonstrates a significant struggle and inability to cope with stigma. The quote below affirms this assumption.

> *"You can default for things like that. Because you are not happy and you are stressed out just by thinking of going there."* **PLHIV 12**

> *"I try to manage (stress), I try, but at first it was hard"* **PLHIV 14**

4.3.5.3 Economic impact on PLHIV

Participants in this study mentioned that because of their experiences of stigma, some prefer to seek treatment from another facility where nobody knows them. This means extra costs for them, and it is challenging because most of them are unemployed. As a result, some reported that they end up stopping their treatment. This disruption in their treatment could lead to the development of resistance and make them more vulnerable to opportunistic infections.

> *"I wanted to take my treatment at a faraway clinic. However when I was taking my treatment very far, it was tough financially. I don't have taxi fare you know."* **PLHIV 6**

This category elucidates that as a result of stigma at the facility, PLHIV were forced to go from facility to facility far from their area of residence for fear of stigma. This results in an inadequate follow-up and retention to care. As participant ten highlighted, high financial constraint impacts negatively on their treatment as they need to travel by taxi to different health facilities.

To support this finding and ways to overcome this situation, mapping interactions between multiple factors that influence long-term engagement and retention of PLHIV in the health care facilities suggests the development of strategies. These strategies aim to minimise disengagement and facilitate re-engagement through more flexible attendance policies, improved client-provider interactions and outreach and support for disengaged clients and could help to improve retention and re-engagement in lifelong HIV care and treatment programmes, and ultimately improving health outcomes (Topp et al., 2018).

4.3.6 Theme 6: Activism as an indirect health outcome

Table 9: Summary of Activism as an indirect health outcome

Categories	**Subcategories**
6.1 Health workers' directed propositions	6.1.1 Need for improvement in nurses' attitudes at the clinic
6.2 Infrastructural directed proposition	6.2.1 Nurses' continuous training regarding HIV management 6.2.1 Need to improve the general clinic set up
6.3 Continuous involvement of PLHIVs in HIV care	6.3.1 Involvement in a research study on stigma 6.3.2 Continuous feedback on the outcome of research and decisions made on HIV

Participants in this theme reported that despite all the negativity they experience at the facility as a result of stigma, they are still hopeful that things will change for the better, and they will be accepted and cared for like other patients. They reported that their HIV status and stigma has resulted in a need for them to take matters into their own hands by becoming active citizens, who can raise their concerns. They reported that they needed a platform where they could express their frustration. Hence they would like to become activists for social justice and their human rights. The participants made propositions that could be adopted by the health system to reduce stigma. The following is discussed according to the patterns that were uncovered.

4.3.6.1 Health workers' direct proposition

Based on their experiences, the participants felt the need to present recommendations that can improve their relations with the service providers, particularly nurses. They strongly believed that if these were considered, there would be change and stigma would be reduced. The following quotes sum up the observation;

> *"Anyway, I just want change. We that are sick, we just want change. Let us be like.. Honour us also.. Treat us like others."* ***PLHIV 12***

However, the participants emphasised that for the change to happen, health workers need to be provided with continuous knowledge about HIV and how to care for PLHIV. The reasons given were that nurses give the tablets without explaining the procedure or its side effects to the patients. As a result, participants suggested that continuous training and updates in HIV education would be beneficial to both the health workers and the public.

"They act like that because also on their side they don't have enough information. I think so. They also need to be trained about HIV because there are lots of changes about it, and I think the nurses need to be kept up to date." **PLHIV 5**

To support this finding, studies conducted in South Africa, indicated the need for continuous training of service providers in the field of HIV, due to rapid changes and the dynamic nature of the condition (Earnshaw, Bogart, Zanoni, Bangsberg, Orrell, Goggin, & Katz, 2016).

4.3.6.2 Infrastructural direct proposition and category

Participants made recommendations directed at structural improvements as they believed that the demarcation of the clinic space contributes to stigma. The following sub-category was generated:

This finding indicated that participants were not happy about the clinic set up which subjected them to stigma and unintelligently disclosed their status to others. Therefore, they recommended that the clinic setup be improved in order to be user-friendly without the discriminatory demarcation.

> *If they can change the way they give the tablets and put them in a brown paper, and then if I come to the clinic if we can sit in the same room like the other patients. They must not separate us. I think they must respect us like the other people."* **PLHIV 4**

4.3.6.3 Continuous involvement of PLHIV in HIV care

All the participants indicated their need to be continuously involved with their care at the clinic. They happily indicated that they are willing to participate in further research regarding the same topic in order to bring about this change. In addition, they reported that platforms aimed at facilitating engagement between them and the health system would be appreciated so that they can raise their concerns as well as receive feedback on issues that they raise as PLHIV.

> *"Will love to see a change in our local clinic. As I have being directly affected by stigma, so if the is future research or future study that come along I am willing to participate. "***PLHIV 1**

4.4 Summary of the chapter

This chapter addressed the research findings according to the identified categories and themes. This chapter dealt with the way the data were analysed. Relevant literature was used to collaborate with the findings of the study. In addition, the results of the study were presented and discussed in relation to the literature. Chapter 5 presents the conclusions and recommendations based on the findings in this chapter.

Chapter 5: Conclusions, limitations and recommendations of the study

5 .1 Introduction

The conclusions derived from the study are based on the findings yielded from interviews that were conducted. The study aimed to explore and describe the perceptions of stigma as experienced by PLHIV at a health care facility in Khayelitsha Sub-District. Data were collected and analysed by the researcher using an inductive approach. The steps of thematic analysis were followed to analyse the data using ATLAS.Ti version 8. At the end of the analysis, six themes emerged namely; existence of stigma triggers; participants' experience of stigma at the clinic; direct stigmatisation behaviour, PLHIV characterisation of stigma types and PLHIV direct health outcome. The conclusions pertaining to these themes are discussed below in relation to the objectives of the study.

5. 2 Objective 1: To explore and describe the perceived triggers of stigma experienced by PLHIV at a health care facility in Khayelitsha sub-district

This objective was addressed by the emergence of one theme namely, the existence of stigma triggers. The following is the conclusion derived from this theme.

5.2.1 Existence of stigma triggers

In establishing if there was the existence of stigma in the health facility, the study findings revealed that all the participants perceived the rife existence of stigma perpetuated by the nurses. The participants' perception of stigma was based on triggers in the form of different coloured cards, the type of packaging that is used for ARVs as well as the structural setup of the clinic that perpetuates separation of PLHIV from the general clinic attendees. Aspects such as the physical demarcation of consulting and club rooms with special dates were not only perceived as triggers of stigma from the nurses but also as conditions that trigger stigma from community members who attend the health facility. The identified activities are overtly conducted, resulting in the exposure and the infringement of PLHIV privacy. Identifying symbols expose PLHIV to danger from drug users, in an area where it is known that there are substance abusers who favour ARVs as their drugs of choice.

However, PLHIV acknowledged that some of the triggers of stigma in the facilities were not purposely intended to trigger stigma. Participants reported that nurses at the clinic do not give them proper health education and they attribute this to the lack of knowledge regarding HIV management. Therefore, participants perceived nurses as incompetent, as far as HIV management is concerned. They even compared nurses to the lay counsellors and stated that the lay counsellors understood their responsibilities better than the nurses. As a result, the participants' general perception was that the quality of the service provided to them at the facility was poor and riddled with stigma triggers. The lack of adequate support systems and feedback when stigmatising behaviours are reported, contribute to the participants' view regarding the quality of service for PLHIV as compared to the rest of the clinic attendees. This study, therefore, concludes that stigma was present in the health facilities and as highlighted in the model of dynamics of HIV/AIDS (Holzemer et al., 2007) in which this study is grounded. The presence of stigma triggers, be it intentional or unintentional leads to stigmatising behaviour.

5.3 Objective 2: To explore and describe the various stigmatising behaviour experienced by PLHIV at a health care facility

In addressing this objective, two themes emerged, and the conclusions thereof are discussed below.

5.3.1 Participants understanding of stigma as perpetuated in the clinic

In order for the researcher to determine if participants understood what is meant by stigma, he gave them an opportunity to share their understanding of the concept "*stigma*". The findings of this study revealed that the participants had a significant understanding of stigma. They characterised stigma in different forms based on how they experienced it at the facility. For some participants, stigma is the fear of being maltreated in a health facility, destroying someone's self-confidence, as well as labelling and being judgemental. Some of the participants even looked at stigma's definition from a behavioural perspective and equated it to racism.

From the participants' definitions, the research concluded that all the participants had an understanding of the concept of *stigma*. Therefore, what they perceived as stigmatising behaviour in the health facilities is indeed stigma as defined by Goffman (1963). This confirms the existence of stigma by health workers towards PLHIV in the study site.

5.3.2 Direct stigmatising behaviour

Participants reported that they experienced stigma from three levels at the facility namely, the nurses, community members attending the clinic, and from their fellow PLHIV who have been attending the health facilities for a lengthy period. Stigma from the peers emerged as a new finding as often one expects that peers will be sympathetic and give support.

Stigmatising behaviours from the nurses were characterised by rudeness, disrespectfulness and discussion of the PLHIVS' results with colleagues without consent. The participants complained about the negative treatment they received when they missed their appointment dates. Peer stigmatisation was characterised by teasing and laughing at newly diagnosed

PLHIV. The participants saw the behaviour as patronising and infuriating, to say the least, as they expected more support from their peers. Some participants also experienced some stigmatising behaviour from the community members who attended the same clinic.

These findings confirm that participants were experiencing various stigmatising behaviours at the facility and provided answers to the second (2) research objective. All these experienced attributes from the health workers, peers and community members, were perceived as stigmatising behaviour which is in line with the constructs of stigma as per the Model of dynamics of HIV/AIDS (Holzemer et al., 2007). Therefore, the study concludes the existence of stigma in the study setting.

5. 4 Objective 3: To identify the various types of stigma as experienced by PLHIV at a health care facility in Khayelitsha

In addressing this objective, one theme emerged, and the conclusions are as follows.

5.4.1 Characterisation of stigma types

There was a need to group the findings into the different stigma domains or characterisation of stigma types to compare the findings with the adopted model’s constructs. Based on the participants’ responses, four types of stigmas were displayed in the study setting.

Personal induced stigma: The participants reported that because of the clinic set up and the nurses’ behaviour (enacted stigma), they were scared and did not feel like reaccessing treatment in the facility. This fear happens spontaneously, even if the PLHIV has not experienced stigma in his/her capacity. This finding is characteristic of internalised stigma.

Peer PLHIV induced stigma: Participants indicated that newly diagnosed patients always find it difficult to cope during their first few club visits because of mocking behaviour, laughing and gossiping they received from their peers. Although little is known about peer to peer stigma, this finding can be characterised as a form of personal induced stigma or internal stigma.

Stigma from health providers (nurses): The participants reported different forms of despising behaviour towards PLHIV. Negative attitudes from nurses and disrespect were meted out to PLHIV. Hence a conclusion could be made that anticipated (perceived) stigma from the nurses, family and community members exists in the study setting.

Stigma from community members: Participants reported that they experience stigma from their communities within the parameters of the health facilities. This implies that PLHIV do not only experience stigma from the communities they live in, but they are also subjected to it in the health facility, where they all attend to get health care services. Hence enacted stigma was observed.

These findings revealed various types of stigma as experienced by participants and answered objective three of the study while demonstrating the construct that confirms the existence of stigma as per the Model of dynamics of HIV/AIDS.

5. 5 Objective4: To describe the outcome of stigma and its influence on PLHIV and their health in general

In addressing this objective, two themes emerged, and the conclusions thereof are discussed below.

5.5.1 PLHIV Direct Health Outcome

The findings from this study revealed that stigma experienced by PLHIV has multiple adverse effects on them. These manifested as general negative feelings which subsequently impacted on the quality of PLHIV's health. PLHIV reported feelings of anger, unhappiness, disrespect, unfair treatment and dissatisfaction with the service. Consequently, PLHIV experienced increased stress which impacts negatively on their mental wellbeing. Participants reported the physical demarcation of the facility, coupled with the harmful nature of the nurses' behaviour, prompting some of them to consider stopping treatment in that facility. Other participants shared their frustration of not being able to cope with stigma at the facility. This left them with no choice but not to default their medication. This could subject them to opportunistic infections and eventual drug resistance.

Stigma is linked to economic implications for PLHIV. The findings revealed that participants sometimes had to pay transport fees to attend a clinic far away for fear of stigma in the clinic nearest to them in their community. This subjected them to extra expenses and could have a devastating effect on their income.

5.5.2 Activism as an Indirect Health Outcome

Another theme that emerged from this study was the participants' need to raise their voices and be heard. The participants reported that there is a need for a platform where they could make suggestions or propositions to mitigate the existence of stigma at the facility. One of their suggestions was the need for continuous HIV training and education for nurses and the public in general, as well as being up to date with new developments and interventions in the field of HIV.

Participants reported that participation in this research made them happy because it gave them a chance to voice their experiences of stigma in the facility. They expressed their willingness to participate in further research projects, thus adding their voice on the solution of stigma at the health facility and being activists as citizens.

Based on the findings of this study, the researcher concluded that all the constructs of stigma as outlined in the Model of dynamics of HIV/AIDS exist in the study setting. Therefore, stigma exists in this health facility.

5.6 Limitations of the study

It is acknowledged that this study took place within a specific health facility in Khayelitsha Sub-District and may not be generalised. Moreover, this study focused only on perceptions of PLHIV's experience regarding stigma in one health facility in the Western Cape Province. The findings, therefore, will not be generalised to all health facilities in Khayelitsha Sub-District nor the Cape Metro. However, the researcher believe that more research sites could have given a clearer picture regarding the state of stigma in different sub-districts in the Cape Metro.

Over and above that, this study was only restricted to PLHIV who could speak only English, isiXhosa and Afrikaans. Cape Metro has other residents who speak languages other than the three listed above, particularly foreign national. Their inclusion could have contributed immensely to the study and probably shed a light if differences were experienced.

5.7 Recommendations

From the findings of this study, recommendations are made for nursing practice, policymakers, and research.

5.7.1 Recommendations for nursing practice

It was most disturbing to find that in this study, all participants agreed that stigma exists at the chosen facility. As a result, the following recommendations are suggested:

- Approaches in the management and care of PLHIV, including structural issues, should be reviewed frequently;
- Nurses need to be updated through continuous training and workshops on HIV management;
- Messages to the public on HIV stigma and its related impact need to be continuous;
- Opportunities should be created for nurses to attend conferences, where they can get to learn how to treat and care for PLHIV;
- Presentations of strategies that demystify HIV and reduce HIV stigma should be made regularly at health facilities;
- Continued engagement with HIV patients and the creation of platforms where management and clients could exchange views, should be made. Doing so would revitalise their trust in the services because this could be used as a platform to give feedback when complaints are raised; and
- In-service training on patient-client relations and the Bathos Pele principle training need to be ongoing.

5.7.2 Recommendations for policymakers

- The study recommends that from the provincial or national level, HIV stigma reduction programmes should be prioritised because biomedical solutions only have proven to be ineffective in the control of HIV.;

- Strategies' workshops and intervention programmes for PLHIV should be put in place as a way of facilitating trust relations with the health care providers including nurses and management;
- Deterrent strategies should be developed for those who are employed in the health sector.

5.7.3 Recommendations for Further Research

The study was conducted utilizing a qualitative approach and with a small sample; thus, it is not generalizable. Hence it is recommended that;

- The research topic be replicated using other areas in the province to see if stigma is a general trend, using a qualitative approach;
- The following topics should be considered
    - Exploration of the effect of health education on the stigmatization of People Living with HIV.
    - An investigation of the degree of stigma on PLHIV in the Western Cape health care facilities.
    - Comparisons of HIV stigma among different ethnicities in the Cape Metro health district.

5.8 Conclusion of the study

This study assisted the researcher in understanding the perceptions of PLHIV experiences with regards to stigma at a health care setting. The use of a qualitative design and purposive sampling, during data collection, enabled the researcher to obtain good descriptions of PLHIV's perceptions of stigma at a health care facility, thus helping the researcher to synthesise the findings, conclusions and recommendations. The findings of this research suggest that although there were circumstances that unintentionally triggered stigma, the attitude of nurses and the physical demarcation of the facility were the most important triggers of stigma that are overt and can be changed. Therefore, health services should strive to create and provide an environment that is conducive to PLHIV. All nurses and health care workers in health institutions should strive to reduce stigma in all the facilities they work in.

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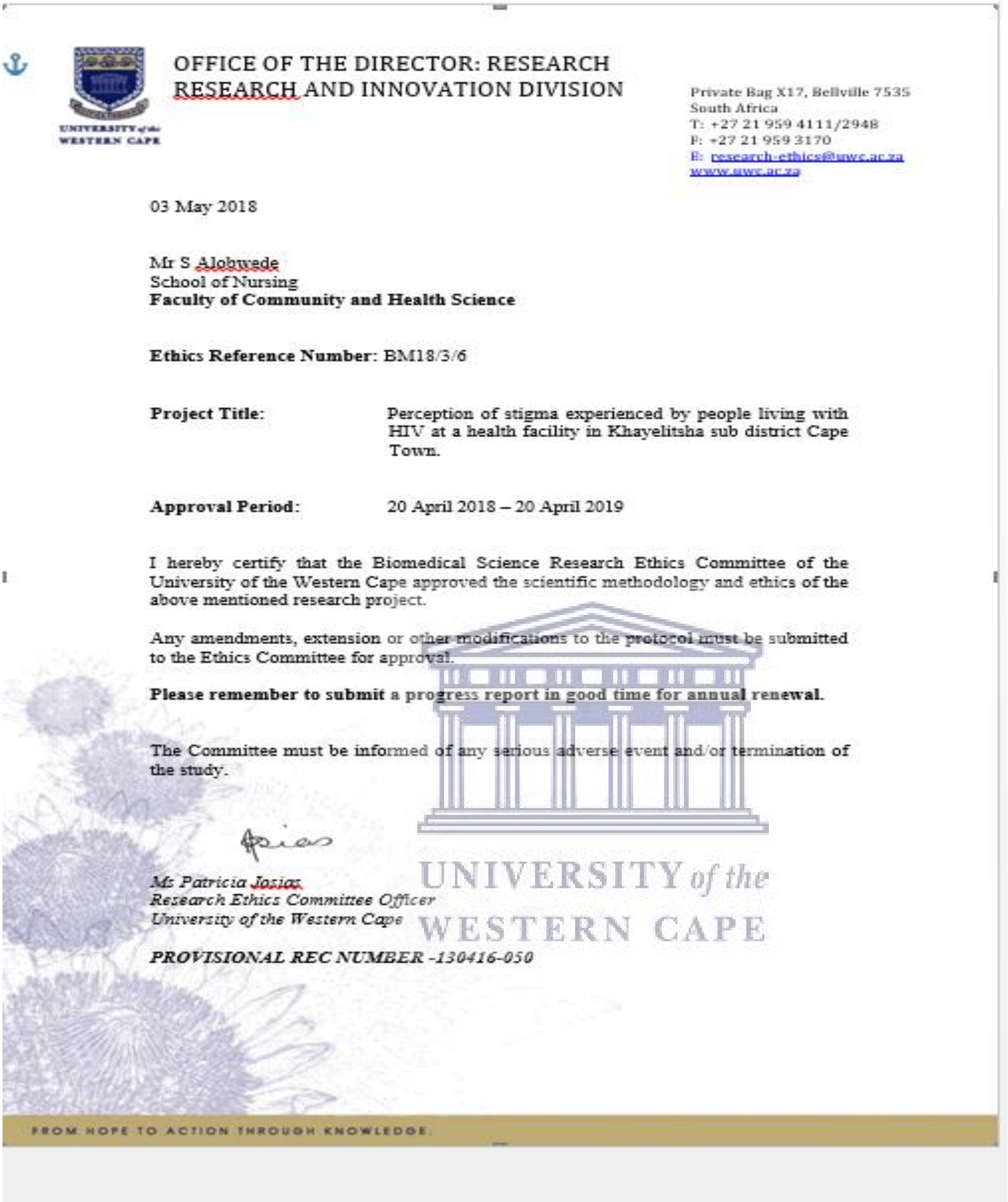
Annexure 1: BMREC ethic clearance



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03 May 2018

Mr S Alobwede
School of Nursing
Faculty of Community and Health Science

Ethics Reference Number: BM18/3/6

Project Title:	Perception of stigma experienced by people living with HIV at a health facility in Khayelitsha sub district Cape Town.
Approval Period:	20 April 2018 – 20 April 2019

I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific methodology and ethics of the above mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

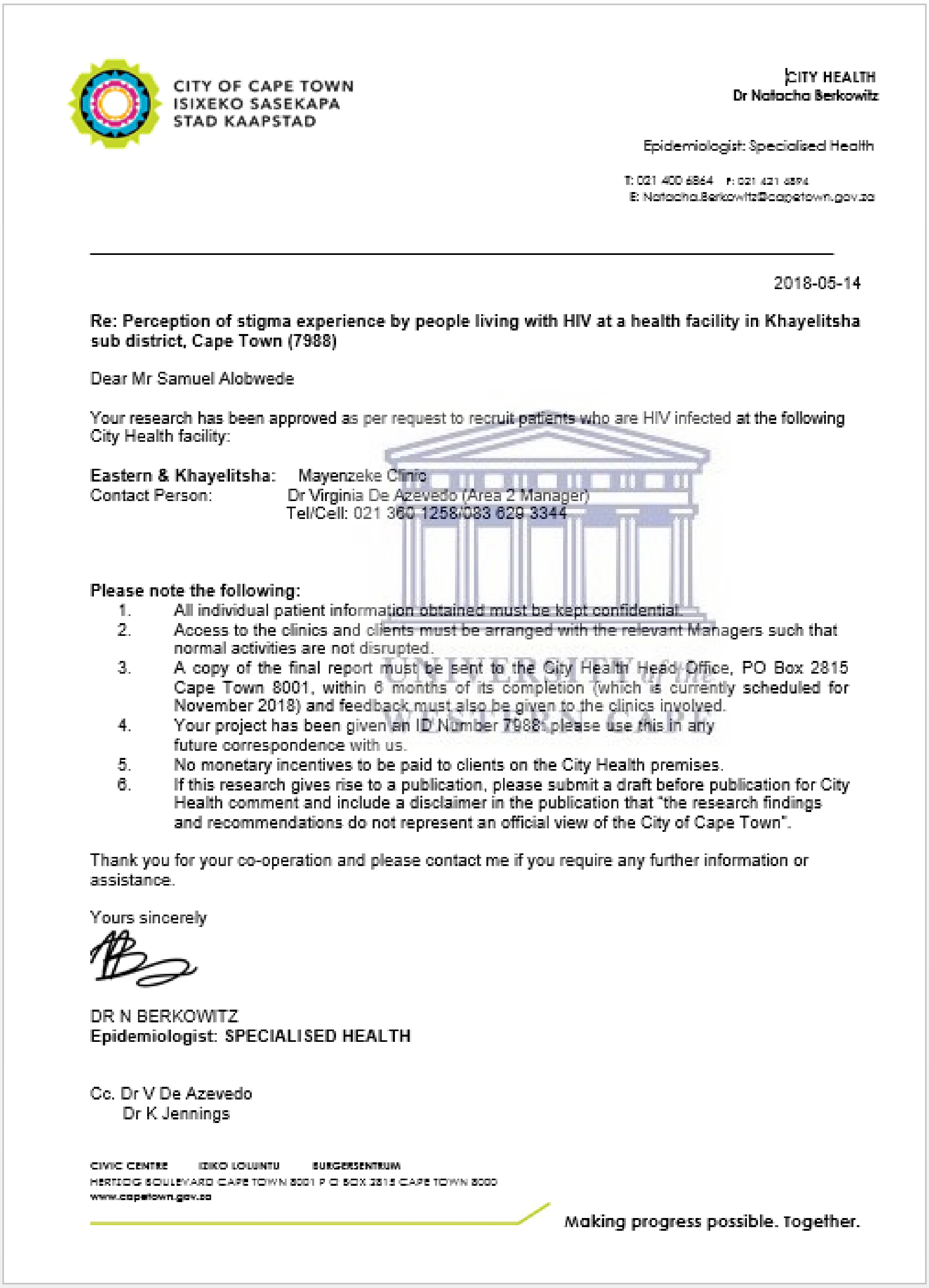
Please remember to submit a progress report in good time for annual renewal.

The Committee must be informed of any serious adverse event and/or termination of the study.

Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape

PROVISIONAL REC NUMBER -130416-050

Annexure2: Ethic Approval City of Cape Town



CITY OF CAPE TOWN
ISIXEKO SASEKAPA
STAD KAAPSTAD

CITY HEALTH
Dr Natacha Berkowitz

Epidemiologist: Specialised Health

T: 021 400 6864 F: 021 421 4894
E: Natacha.Berkowitz@capetown.gov.za

2018-05-14

Re: Perception of stigma experience by people living with HIV at a health facility in Khayelitsha sub district, Cape Town (7988)

Dear Mr Samuel Alobwede

Your research has been approved as per request to recruit patients who are HIV infected at the following City Health facility:

Eastern & Khayelitsha: Mayenzeke Clinic
Contact Person: Dr Virginia De Azevedo (Area 2 Manager)
Tel/Cell: 021 360 1258/083 629 3344

Please note the following:

1. All individual patient information obtained must be kept confidential.
2. Access to the clinics and clients must be arranged with the relevant Managers such that normal activities are not disrupted.
3. A copy of the final report must be sent to the City Health Head Office, PO Box 2815 Cape Town 8001, within 6 months of its completion (which is currently scheduled for November 2018) and feedback must also be given to the clinics involved.
4. Your project has been given an ID Number 7988, please use this in any future correspondence with us.
5. No monetary incentives to be paid to clients on the City Health premises.
6. If this research gives rise to a publication, please submit a draft before publication for City Health comment and include a disclaimer in the publication that "the research findings and recommendations do not represent an official view of the City of Cape Town".

Thank you for your co-operation and please contact me if you require any further information or assistance.

Yours sincerely

DR N BERKOWITZ
Epidemiologist: SPECIALISED HEALTH

Cc. Dr V De Azevedo
Dr K Jennings

CIVIC CENTRE IZIKO LOLUNTU BURGERSENTRUM
HERTZOG BOULEVARD CAPE TOWN 8001 P O BOX 2815 CAPE TOWN 8000
www.capetown.gov.za

Making progress possible. Together.

Annexure 3: Poster of the project

PERMISSION HAVE BEEN GRANTED BY THE UNIVERSITY OF THE WESTERN CAPE AND THE CITY OF CAPE TOWN TO CARRY OUT A RESEARCH ON THIS FACILITY ON THE TOPIC:

- Perception of stigma Experienced by people living with HIV at this health facility.

- Those who voluntary want to participate in this Study must contact:

Mr SAM on cell:

082 629 5011

Their I.D and information will be kept confidential.

Annexure 4: Information sheet

University of the Western Cape
Faculty of Community and Health Sciences
P/Bag X17, Bellville 7535, South Africa Tel.: +27 21 959 2163
Fax: +27 21 959 2755 Email: 2731600@myuwc.ac.za

INFORMATION SHEET

Project Title: Perception of Stigma Experience by People Living with HIV at a Health Facility in Khayelitsha Sub-District in Cape Town.

What is this study about?

The aim of this study is to explore and describe the perception of stigma as experienced by PLHIV who receive treatment at a health care facility in Khayelithsa sub-district.

Describe why the person reading the consent form is a possible research subject for your project.

This is a research project conducted by Alobwede Samuel Muabe at the University of the Western Cape. You are invited to participate in this research project because you are 18 years and older and you are receiving antiretroviral treatment in this health facility. You can voluntarily participate in the study if you want to. Over and above, you stand a better chance to give us your perception of stigma while attending this health facility.

What will I be asked to do if I agree to participate?

You will be asked to participate in an in-depth interview with the researcher at a time and place that suits you. This study is being conducted for a master’s degree and permission has been granted by the University of the Western Cape Biomedical Research Ethics Committee, the City of Cape Town as well as the clinic manager. Prior to the interviews, the principle researcher will explain the purpose and procedures of the study, your rights, especially that your participation is voluntary; you can withdraw at any time without coercion. Everything you say will remain confidential, and you will be given a code number to maintain your anonymity. Each interview will last about 45 to 60 minutes. You will be asked for permission to record the interview, and you will be requested to sign the consent form if you agree to participate. All your recorded information will be stored in a computer with a password only known to the researcher for a period of five years. The researcher start by asking a broad question "***Tell me about your experience regarding stigma since the period you started to access care as a PLHIV in clinic X."*** Then, as you proceed with the interview, more probing and asking more questions according to the stigma domains.

Would my participation in this study be kept confidential?

The researchers undertake to protect your identity and the nature of your contribution. To ensure your anonymity, your name will not be mentioned at any time during the interview. I and the research assistant will use a code number that will help to designate your recorded information. To ensure your confidentiality, your recorded information with a designated code number will be stored in a computer with a password only known to me (researcher) for a period of five years after which it will be deleted. If we write a report or article about this research project, your identity will be protected.

What are the risks of this research?

All human interactions and talking about self or others, carry some amount of risk (fear, fatigue or embarrassment). We will minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, a clinical psychologist or social worker will be placed on standby to assist. An appropriate referral will be made to a suitable professional for further assistance or intervention.

What are the benefits of this research?

There will not be any monetary benefit to participant. However, the Project may give the participant a way to express their feelings. The results may help the investigator and learn more about how stigma affecting PLHIV. We hope that in the future, other people might benefit from this study through improved understanding of stigma and interventions to reduce it. The results of the study may influence the nursing curriculum by providing a better understanding of who PLHIV are and may inform student nurses who will be called to deliver nursing care to these communities, of how to reduce stigma and above all, care for PLHIV.

In addition, the results may contribute to assist policy makers to plan and develop strategies aimed at reducing stigma towards PLHIV perpetrated by those who care for them at home and at the health facilities. Importantly, the results may provide new information regarding this key population who is marginalised. The consequences may be a contribution to scientific knowledge on stigma between PLHIV and a baseline for more research regarding this population. Results of this study will give direction for future research and intervention plans on stigma in this and other similar contexts because the results will be disseminated through conferences and publications.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalised. In the event that you experience an emotional breakdown during the interview, the research assistant will stop the interview and call the appropriate assistance available at the facility. If need be, we will refer you to the appropriate health facility for further support.

This research is being conducted by Alobwede Samuel Muabe from the School of Nursing at the University of the Western Cape. If you have any questions about the research study itself, please contact Alobwede Samuel Muabe, phone number 0826295011 and via email: oliveasabo@gmail.com or 2731600@myucw.ac.za .

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Prof J Chipps
Director of the School of Nursing.
University of the Western Cape
Private Bag X17
Bellville 7535
jchipps@uwc.ac.za

Prof Anthea Rhoda
Dean of the Faculty of Community and Health Sciences
University of the Western Cape
Private Bag X17
Bellville 7535
chs-deansoffice@uwc.ac.za

The Western Cape University Information Statement Committee has approved this study.

Annexure 5: Inform consent form

University of the Western Cape
Faculty of Community and Health Sciences
P/Bag X17, Bellville 7535, South Africa Tel.: +27 21 959 2163
Fax: +27 21 959 2755 Email: 2731600@myuwc.ac.za

CONSENT FORMS

Title of Research Project:

Perceptions of stigma experience by People Living with HIV at a health facility in Khayelithsa sub-district in Cape Town.

The study has been described to me in a language that I understand. My questions about the study have been answered. I understand what my participation will involve, and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences and also understand that audio tapes will be recorded in the process of the interview.

Participant's name………………………..

Participant's signature……………………

Date………………………

Annexure 6: Interview transcript

First interview: 24 May 2018

Participant= PLHIV

Researcher= Re

Interview number 1

Re: Good afternoon Sir, how are you?

PLHIV1: I am very well sir and you?

Re: Sir, we would like to use this opportunity to thank you for participating in this research study.

PLHIV1: My pleasure.

Re: Sir before we continue with this interview, which language do you prefer? Afrikaans English or Xhosa?

PLHIV 1: I prefer English.

Re: sir mm I want to reassure you that … as I explained to you last week, this information that you will give in this interview will.. Mmm your ID will remain anonymous and all the information that you will give will be kept confidential, your information will be kept in the computer with a password that only the researcher goanna know; secondly, it is to reassure you that this record will be kept for five years and after that, it will be destroyed.. Is that fine with you?

PLHIV 1: No problem sir

Re: Sir I also want to say once more that we are grateful that you voluntarily participate in this research work... For the fact that you accepted that we should use audio tape to do this interview, we are grateful. Is that still fine with you?

PLHIV 1: Yes, it is fine.

Re: Sir we also want to make you understand that we are grateful you have …you went through the consent form, read it and now that we want to start the interview, would you like to go through it again, re-read it and sign it if you are still happy with it. Is that fine with you?

PLHIV 1: Yes, it is fine.

Re And... We just want to use this opportunity to make you understand that HIV is a very sensitive topic. Therefore, for your safety, there is a standby psychologist whereby if you feel distressed, the clinical psychologist will counsel you and if there is need for a referral, the clinical psychologist will do the referral for you. Is that fine with you?

PLHIV 1: Yes sir its fine.

Re: Thank you very much ….so tell me how old are you?

PLHIV 1: I am 28 years of age

Re: are you married?

PLHIV 1: No

Re: Do you have kids?

PLHIV 1: Yes

Re: Are you working

PLHIV 1: Yes I am

Re: How many kids do you have?

PLHIV1: I have two

Re: beautiful. Sir when did you discover that you are HIV positive?

PLHIV 1: Five years ago.

Re: five years ago…for how long have you been taking medication in this clinic?

PLHIV 1: It has been three years now that I am taking medication from this clinic.

Re: Thank very much for that information. Sir what is your experience as regards to stigma since you started taking medication from this clinic?

PLHIV 1: It felt at first like. Mmm. When you. Mmm when you get to the clinic, it felt as everyone knows. Because they will say TB client this side, those who come for their pregnancy this side. You feel like everyone knows. Moreover, they will keep on looking at you in the certain way knowing where you are going. That is when stigma came in …even when you receive medication, the amount of medication that will come through. The packaging itself because it was in the see through packaging so people will be looking at you. So people will say he is eh…he must be ee, he is now taking medication for HIV. Most of the time, it was never something you could feel like literally hearing from someone. But you could feel it in the atmosphere... sometimes euh even euh the way the clinic card will look, people will automatically assume that you taking HIV treatment and it will feel bad when you now go sit there with them.

Re: So are you saying is this your perception or something that you know?

PLHIV 1: This is how (raising his voice) I felt. This is how I experience it… I have not heard it from other people somewhere else.

Re: What do understand by stigma?

PLHIV1: Stigma is how people judge, or perceive you or a situation in a negative form some sort of prejudice or discrimination of one according to one situation... That is my understanding of stigma.

Re: tell me….. (Pause)..Do you think stigma exist in this clinic, do you think there is stigma in this clinic where you are taking your medication?

PLHIV 1: Yes

Re: By whom or how do you experience it?

PLHIV 1: ONE you get through your fellow..Euh client through people who come through the clinic for there to take their own medication or their own different treatment. How they treat you euh or distance themselves from you. Actually the vibe around them. The vibe that they give you it seem at time. People taking treatment for HIV first we have to go to the other side and go eat before we come and take our treatment on this side. So they will also even do not want to take the soup that is provided by the clinic. Because they think it just for HIV people. However, that soup is provided for everyone who is hungry at the clinic. In addition, some time when you miss your date. When you were supposedly to come to clinic may be for check-up or you busy with something else you could not make at the clinic. How the nurse react to you talking things like "that is how you people will die" the word you people itself feels like we HIV PEOPLE are different from the next patient who is not HIV patient. The wording itself from the nurses staff when they say you people as if we are different kind of human race

Re: ok if I understand you well. Are you saying that there is a negative attitude a negative behaviour coming from the service provider?

PLHIV 1: Yes

PLHIV 1: The service providers itself are not sensitive when it comes to HIV clients especially young people like myself who are the age of 28...They automatically assume that you mischievous you are pro.. So you deserve to be HIV positive... so they rather have that perception how you contracted the virus itself so you are mischievous and... Therefore, there is already a negative aura towards you when you are fetching your treatment or when you come for check-up.

Re: So does this come from the service provider or from the other patients?

PLHIV 1; mostly the wordings. The bad words come from the nurses when you missed your treatment date or your check-up date. But then. With your fellow... Your fellow client that also come for their treatment, it is more of gossip. When you came out of that ward or certain room that is mostly for HIV patient. The way they look at you, the way whisper when you pass, the giggle, and they go gossip about you in your area or when you pass by the conversation stop and they start laughing, when you just pass by. So is that type of behaviour that you get from the clients.

Re: So if I understand you well, are you saying that the area where people with HIV take their medication is different from the area where others who are not HIV positive take their medication?

PLHIV 1: Not per se different, but it easily demarcated within the clinic itself. We know exactly if you come for TB treatment where you supposed to go, if you come for HIV treatment fetching or counselling where you supposed to go. Therefore, everyone in the clinic knows if you are going to room 5, you automatically going for HIV. If you are going to room 12 you automatically going for TB. So people can easily read the system itself and they look at you in a certain way.

Re: In this system, are there labels in the HIV clinic or is not labelled?

PLHIV 1: It is not label.. However, somewhere somehow, in the system people got the information that in this part of the clinic that is where our HIV client goes.. Even with pre-counselling and post counselling they will just say go to room …? They never change the room. So now everyone knows if you are going for HIV you are going to room 5. So if a group of us come in and say we having our meeting at room 5, so they know it is our support group for HIV because that part of the clinic is really segregated and set apart for HIV.

Re: Ok. Thank you very much for this information. Do you feel respected when you come to take your medication?

PLHIV 1: Now yes, before no. Like I said, the packaging was transparent and with the word commonly used like *you people* the things that are commonly used. Since then, the packaging is silver, which is neutral to everyone whether the patient come for HIV, TB or whatever high blood pressure or hypertension. The packet itself is compulsory; it is branded by the Department of Health. Therefore, it does not feel like everyone knows what is inside my medication itself. So I felt that is the part of respect I get. Moreover, with the professionalism within the lay counsellor now that are in the clinic. It is they are more of support adherent lay counsellor that when it it was the nurses itself just talking more medically than to dealing with you as a person.. Someone who is going through emotions and being unable to adhere to your treatment. Because it is all new to you. So now, the lay counsellor talk more and give support. Therefore, I feel I have being respected. They see a human first before my illness. Moreover, before they will treat as mischievous ill people.

Re: In your opinion, between the nurses or the lay counsellor, who do you think treat you with love and respect?

PLHIV 1: I will say the HIV lay counsellor understands HIV, understand the support part of HIV, the emotion that goes with you, the chock and the trauma that you go through. Therefore, they are able to probe and talk more about your illness and the phases that you go through. When it was just you dealing with the nurse the just give medication and say drink this at this time, but you do not know what type of medication you are drinking, what size effect it contains. Now with this lay counsellor …even you come back and say I keep on vomiting.. I keep on having dizziness.. They say certain medications’ side effects is this and this and this.. Now I am going to refer you to the doctor to actually explain what you need to do. So I think the lay counsellor are given us more information, more support than the nurses do.

Re: So in your view, if you want to score the nurses out of ten in term of their services, how would you score them?

PLHIV 1: I would give them 4/10 4’5/10.

Re: Not even 5/10?

PLHIV 1: Not even 5/10 because they are not even 50% there yet. Even us now we are clients with HIV, we are educating them on what we go through, what type of medication, support we undergo. However, for them, it is just medical, doing their basic. They register what is to register in your folder, submit it and then they move on to the next client. Nevertheless, the lay counsellors give support. They are more adherent to you, also talking more about your medication, proper use of your medication and what needs to be done in the holistic approach to your illness.

Re: How do you feel about this attitude from the nurses?

PLHIV 1: I feel...that...partly...

Re: Or how does this make you feel?

PLHIV 1: It makes me feel rebellious coming to the clinic itself if I am going to be dealing with a nurse than a counsellor. Because the nurse will just treat me like a … I am to do.. I need her to explain more as if she just wants to be done with it. For me, I feel rebellious coming to the clinic. I feel it is a waste of time coming to the clinic dealing with a nurse who won’t listen to my problems or actually sympathise with me or when it comes to my illness and treat it with sensitivity because for them, it is just a joke.

Re: Do you sometimes skip your medication or skip going to the clinic because of this attitude or do you still adhere to your medication?

PLHIV 1: With the support now and the support group in place and people coming into our house to check, I am consistently adhering to my medication, but at first, there were days that you come to the clinic and find that a certain nurse is working today and you prefer not to go in and attend those services because that certain nurse does not give proper treatment or proper respect that you deserve or proper approach that you deserve then you rather come back when a certain nurse that understands what you go through. Then you sit there waiting for that certain nurse.. Therefore, it’s a matter of this person compared to that person. So now, I adhere to my treatment because I understand my illness better and I adhere to my treatment.

Re: So if I understand you quite well. This negative attitude does not come from all the nurses, just from specific nurses.

PLHIV 1: Specific nurses with specific attitudes towards a specific age group.

Re: If you talk of a specific age group, what do you mean?

PLHIV 1: euhm we young people between 16-30. We are experiencing a lot of discrimination stigma because whenever you are at the clinic, they treat you as if you are mischievous, promiscuous… you sleeping around... The things they talk about in school and say why are not using condom?. However, forgetting that there is other way to contracting the virus itself. Even not, even listening to how you contracted the virus itself. They just have a preconception on how you contracted the virus. So sometimes, it just make me feel like I do not want to. But when I sit in our support group, most of us sit on our own because we deal with the same challenge than those who are 35 years and older who are experiencing the same challenge that we experience at the clinic when we are being charged or words are thrown to us.. That drinking problem caused you to contract this. You drink a lot that is why you forget to take your medication. It is something that we do as all young people.

Re: Tell me does this happen, especially to you or to other people?

PLHIV 1: At first, it felt as if it was specific for me. I felt the nurse and service providers had an issue with me... Now as we sit in this support group, we understand that it is a pattern. However, for us young people, we experiencing it the especially at a certain specific clinic.

Re: We hear some people saying that there is stigma in this particular clinic, what is your opinion about this?

PLHIV 1: For me, it is a yes. Yes. Because like I said, the demarcated area where HIV is known... That this area is for HIV even if they have not labelled it yet. So I feel that on its own, it stigmatises us as HIV people because we need to be treated like any other patient that comes in because I feel that even with the date that they give us to come to the clinic, it is obvious to everyone that on this date, it is for the HIV support club group for HIV people. We do not need to be stigmatised for a certain date to conduct our support session... I think that is a stigma on its own.

Re: Thank you very much.. Now tell me, have you ever raised this with the nurses, lay counsellors or the management of the clinic?

PLHIV 1: They always have that suggestion box in the clinic. You write something and you do not get the response back. So I have done that twice and I didn’t get a response so I felt that whom should I talk to? Because when you come to the clinic, the security person directs you where to go. The consulting nurse direct you where to go. Then you find out that if you started to complaint about the consulting nurse because I have never seen the facility manager, this where I have to complain. In addition, the procedure on how to complain, we only know about the suggestion box. We do not know if there is another way to go and put our complaints.

Re: Thank you very much sir. I am quite grateful with this information. Do you have any question for me?

PLHIV 1: We listen to people and people come to listen to our story on how we are being treated. What is the implementation part to make sure that our emotions and feelings at this clinic are dealt with?

Re: this is why this research is being carried out. Basically, this research is an academic purpose research; and again like I explained to you last week when I came, it is for us to find out if there is availability if medication. Therefore, we are still realising that although there is medication available, there are still a lot of people that are adhering to their treatment. They are not feeling like continuing with treatment and there is a new case of HIV every day. That is why we want to find out. What is the reason? Is it stigma or what? That is why we conduct this research, and from the information that we are getting from you guys then we shall use it to make recommendations to policy makers on how they can change the system. Are you fine with that?

PLHIV 1: Yes, I am fine so you want to influence the policy makers to change the situation in our service? Ok I am satisfied with that sir thank you.

Re: Is there any other question for me?

PLHIV 1: No, I am good sir thank you.

Re: If at all there is further research on this research topic, will be willing to participate?

PLHIV 1: I would love to see change in our local clinic. As I have been directly affected by stigma, so if there is future research or future study, I am willing to participate.

Re: Thank you very much

PLHIV 1: Thank you sir

Re: My pleasure

Anexxure 7; Field note extract

Field notes

A gentle lady living with HIV accepted to participant in the study voluntarily, he looks calm, relaxed and composed, he displayed interest and a good knowledge of his HIV status.

Which help the interviewer not to struggle with the participant to talk.

Probes were used to encourage the participant to talk more and give more detail of the topic in question. Often non-verbal communication was used as well as direct eye contact to show the participant you share his concern as well as you are paying attention to him.

The interview was held in a private space where the environment was therapeutic that is it calm, relaxed and convenient.

The interviews were mostly in the afternoon after 12pm and the interviews lasted for about 45 to 60 minutes the researcher gave full attention to the participant to express himself.

Reflective notes

Participant was very passionate about the research topic and showed a mastery of his condition, he spoke openly about what he like and what he is not happy about.

Annexure8: Editor's Report

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6 March 2019

DECLARATION OF PROFESSIONAL EDIT

I declare that I have edited and proofread the Master in Nursing Dissertation entitled: **PERCEPTIONS OF STIGMA EXPERIENCED BY PEOPLE LIVING WITH HIV AT A HEALTH FACILITY IN KHAYELITSHA SUB-DISTRICT, CAPE TOWN by Mr ALOBWEDE SAMUEL MUABE.**

My involvement was restricted to language editing: contextual spelling, grammar, punctuation, unclear antecedent, wordiness, vocabulary enhancement, sentence structure and style, proofreading, sentence completeness, sentence rewriting, consistency, referencing style, editing of headings and captions. I did not do structural re-writing of the content. Kindly note that the manuscript was not formatted as per agreement with the client.

No responsibility is taken for any occurrences of plagiarism, which may not be obvious to the editor. The client is responsible for ensuring that all sources are listed in the reference list/bibliography. The editor is not accountable for any changes made to this document by the author or any other party subsequent to my edit. The client is responsible for the quality and accuracy of the final submission/publication.

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