



**NURSE SUPPORT FOR YOUNG ADULTS DURING A FIRST ANTIRETROVIRAL
THERAPY VISIT AT AN URBAN PRIMARY HEALTH CARE CLINIC IN MALAWI**

By

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Signed

Date

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DEDICATION

I dedicate this thesis to my husband, Macdonald Nkhalamba.

KEY WORDS

- Antiretroviral therapy
- Retention
- Primary health care (PHC)
- Patient experiences
- Adolescent
- Young adult

ABBREVIATIONS

ALHIV:	adolescent living with HIV
ANC:	antenatal clinic
ART:	antiretroviral therapy
AYA:	adolescent and young adult
CHTC:	couple HIV testing and counselling
FDC:	fixed-dose combination tablet
HIV:	human immunodeficiency virus
HTC:	HIV testing and counselling
IRIS:	immune reconstitution inflammatory syndrome
PHC:	primary health care
PITC:	provider-initiated testing and counselling
PLHIV:	people living with HIV
PMTCT:	prevention from mother-to-child transmission
SDGs:	sustainable development goals
TB:	tuberculosis

OPERATIONAL DEFINITIONS

Antiretroviral therapy

This term refers to the lifelong use of the combination of three or more antiretroviral drugs for treating HIV/AIDS infections (WHO, 2016: xiii).

Primary health care (PHC)

An approach of providing frontline health care with the emphasis on the promotion of health through a partnership between nurses and other health care professionals and the community in treatment, with a focus on being curative and preventing various conditions (Macdonald, 2013:9; Thomas, 2017; Pratt & Rowland, 2018). In this study, the focus is on nurses providing ART at an urban primary health care (PHC) clinic.

Experience

An occurrence or event which leaves an impression on a person (Calvillo-Gómez, Cairns & Cox, 2015:37). In this study this term refers to a patient's visit to a PHC clinic.

Patient experiences

Events and occurrences that happen collectively and independently during health care (Wolf, Nelderhauser, Dianne & Lavela, 2014:1154).

Adolescent

The stage of development between childhood and adulthood (from 13–19 years of age) (Martin, 2015:13).

Young adult

The researcher concurs with the definition that people aged from 19 to 25 years are young adults (Yonker et al., 2015).

ABSTRACT

Primary health care (PHC) is a frontline health care approach. It is the point of contact where people are kept well and where their quality of life is improved. All people diagnosed as HIV- positive are retested prior to antiretroviral therapy (ART) initiation to verify their serostatus. ART initiation is seen as a non-emergency treatment that provides many benefits if its initiation is accelerated, for example following up pregnant women after being diagnosed with HIV. However, accelerated initiation may lead clients to start treatment before they are ready to adhere to treatment outcomes.

The purpose of this study was to describe the nurse support for young adults during a first antiretroviral therapy visit at an urban primary health care clinic in Malawi. A descriptive phenomenological design was followed at an urban setup in Zomba city, Malawi. The sample was selected through purposive sampling until data saturation was obtained. Individual semi- structured interviews were conducted with young adults aged 19–25 who have visited the clinic for their first ART according to an interview schedule and field notes for around 30 minutes in a private room.

The data was analysed using distinctive process and a consensus meeting was held between the researcher and independent coder. The findings of the study could help the PHC services to retain and re-engage the young adults in HIV care and aid the Government of Malawi in achieving its Sustainable Development Goal (SDG) 3. Principles of trustworthiness and ethics were adhered to throughout the research process.

Six themes, each with separate categories, emerged from the data analysis on the experience of young adults during their first visit for ART at an urban PHC clinic in Malawi. The results indicated the need for an environment that enhances a client-orientated approach with a focus on holistic well-being. Knowledge management should be used to provide relevant and sufficient information to a newcomer while maintaining ethics under difficult circumstances. The legal environment should have a focus on supporting clients that need comprehensive ART treatment. Motivation of the patient regarding taking antiretroviral treatment (ART) is thus essential. Young adults express the need to be supported by nurses with relevant information, privacy and confidentiality and the trusting client/nurse relationship which could help them to retain in ART care.

Recommendations of this study was that nurses should be offered in-service training on youth-friendly programmes which focuses on the health care of young adults during their HIV/ART

services. Nurses need to create trusting relationship for the young adults and providing in door game at the waiting area to keep them busy as they are waiting for the services. Nursing managers to lobby for funding to extend the clinic and be role models in providing relevant information to young adults.

It was concluded that a first visit was both positive and challenging to the participant s; however, they experienced the health providers on the first visit to be caring and supportive.

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CHAPTER 1

1.1 INTRODUCTION AND BACKGROUND

Primary health-care (PHC) is an approach through which frontline health-care is provided by emphasising the promotion of health through a partnership between nurses and other health care professionals and the community in treatment. Curative measures and the prevention of various conditions are priorities. It is the first point of contact, and the aim is to keep people well and improve their quality of life (Macdonald, 2013:9; Thomas, 2017; Pratt & Rowland, 2018). A strong, accessible PHC system reduces pressure on hospitals as it promotes health, prevents disease and cures and rehabilitates by supporting people to manage their health issues in their society. PHC organises health services around people's needs and expectations (Agarwal, Jain, Ghosh & Parihar, 2017:6), such as antiretroviral therapy (ART) treatment for patients with HIV/AIDS.

Initiating and managing ART patients at PHC systems may potentially produce equally good outcomes, at a lower cost, as those obtained in hospital-based HIV clinic care (Long, Rosen, Brennan, Moyo, Sauls, Evans, Modi, Sanne & Fox, 2016). During the first visit to a PHC clinic, all patients diagnosed as being HIV-positive are retested prior to ART initiation to verify their serostatus. The retesting should be done by a different provider with the same testing algorithm (WHO, 2016:19).

Health-care providers should also assess the willingness and readiness of patients to start with ART, and discuss the drug regimen, scheduling, dosage, benefits, possible adverse and side effects, safe sex, follow-up and monitoring visits with patients (WHO, 2016:72). Nearly half of the adolescents living with HIV (ALHIV) at Zomba and Baylor College of Medicine ART clinics in Malawi reported non-adherence to ART treatment (Kim, Mazenga, Yu, Ahmed, Paul, Kazembe & Abrams, 2017), yet efficacy of ART treatment depends on patient adherence to daily medication regimen (Finitis, Pellowski & Johnson, 2014:1). Medication nonadherence can affect patient health outcomes and health worker/patient relationships and can increase health resource consumption when the patient develops resistance to the drug (Donald & Kola, 2017: 2,6; Hommel, McGrady, Peugh, Zacur, Loreaux, Saeed, Williams & Denson, 2018:4). It is important that nurses should understand the needs of patients so that they can provide support and care and help to make patients' lives as normal and productive as possible (Komatsu & Yagasaki, 2014:419).

The United Nations (UN) Sustainable Development Goal (SDG) 3, in Vision 2030, is focused on healthy lives and the promotion of wellbeing of all (at all ages), including young adults, while being commitment to address HIV (WHO, 2016:1). A young adult age range is considered to be 15 to 29 years of age (Bleyer & Albritton, 2003; Rosenberg, 2015:3-4). Simpson (2008:1) states that young adulthood is considered as 18 to 25 years of age, as also assumed in this study.

With the latest treatment protocol, more people are eligible for treatment and live longer; nevertheless, the expansion of services to difficult-to-reach areas and vulnerable populations is urgently needed (Mehra, De Pee & Bloem, 2017:665). A new strategy and fast-track approach of UNAIDS reinforces the visions of Three Zeros and 90-90-90 (Zero new infections, Zero AIDS-related deaths and Zero discrimination) (Mehra et al., 2017:665). The 90-90-90 targets will need continued efforts from governments and international agencies to end HIV/AIDS as a public health threat by 2030. It is aimed to have 90% people living with HIV/AIDS know their status, 90% of those to be treated with ART, and 90% of those receiving treatment achieving viral load suppression (Wang, Wolock, Carter, Nguyen, Kyu, Gakidou, Hay, Mills, Trickey, Msemburi & Coates, 2016:361). The low rates of HIV/AIDS diagnosis and treatment initiation among adolescents and young adults (AYA) between the ages of 15–24 years, pose a great challenge to efforts to control the epidemic, therefore efforts should be made to improve the first two 90s among AYA and to improve HIV testing and diagnosis and linkage to care and treatment (Wong, Murray, Phelps, Vermund & McCarragher, 2017:191).

Globally, HIV prevalence has been steadily increasing and has reached 38.8 million in 2015. At the same time, HIV/AIDS mortality has been declining at a steady pace, from a peak of 1.8 million deaths in 2005, to 1.2 million deaths in 2015 (Bill & Melinda Gates Foundation, 2016:361). Of the 38.8 million people infected, about 70 percent were from Sub-Saharan Africa (UNAIDS, 2014). In the third decade of the HIV/AIDS epidemic, of the 34 million people living with HIV/AIDS in the world by December 2013, five million were aged between 15 and 24 years (Kim, Gerver, Fidler & Ward, 2014).

The 2015 report of the Global Burden of Disease Study (GBD, 2015) assessed the burden of HIV/AIDS, including the HIV/AIDS incidence, prevalence, coverage of ART and mortality for 195 countries and territories from 1980 to 2015 (Wang et al., 2016:361). The estimates indicated that globally 38,802,500 people were living with HIV and that only 40.60% of them are on ART. Sub-Saharan Africa has 29,439,540 people living with HIV of whom 42.35% are

on ART treatment. In Malawi, 1,126,770 people are living with the virus and 49.50% of them are on ART treatment (Wang et al., 2016:361).

About 20% of all people living with HIV (PLHIV) in the Sub-Saharan Africa region are aged between 15–24 years, and about 40% of all youth and children infected by their mothers during birth are reaching adulthood (Lamb et al., 2014:559). In 2015, only 10.3 million people in Eastern and Southern Africa had access to antiretroviral therapy (ART), representing 54% of all PLHIV in the region. Preventive and HIV care programmes have resulted in the reduction of mortality rates among HIV-infected adults (Church, Machiyama, Todd, Njamwea, Mwangome, Hosegood, Michel, Oti, Nyamukapa, Crampin & Amek, 2017). Malawi has a HIV prevalence rate of 11.7% (Macpherson, 2015). ART is critical to the economic future of the region, therefore the optimisation of outcomes across the HIV/AIDS care among the youth is crucial (Lamb, Fayorsey, Nuwagaba-Biribonwoha, Viola, Mutabazi, Alwar, Casalini & Elul, 2014:559).

1.1.1 Orientation to the study

Malawi is one of the low-income countries in the south east of Africa. It has a population of about 16 million people of whom 20% live in the urban areas and 70% of them in slums. HIV prevalence among young people aged 15–24 years is higher in women than in men (5.2% and 1.9% respectively). Malawi's HIV prevalence is higher in urban areas (nearly double than in rural areas) (Kamndaya, Kazembe, Vearey, Kabiru & Thomas, 2015:90; Kamndaya, Vearey, Thomas, Kabiru & Kazembe, 2016:295). The incidence of HIV/AIDS has been a heavy burden on Malawi since early 1980s. People who are living with the virus fear dehumanisation due to the stigma associated with HIV. In Malawi, sex-related issues are not usually discussed in public and stigmas could be created because HIV is a sexually-transmitted disease (Chimbatata Zhou, Chimbatata & Xu, 2017:60). The National AIDS Commission has been providing overall leadership and coordination of the response to HIV and AIDS in Malawi since 2001. Antiretroviral therapy (ART) is provided free of charge in public, private and faith-based hospitals and health centres controlled by the Ministry of Health (McKinney, Pearce, Banta, Mataya & Muula, 2016:2). As of 2017, Malawi has 730 sites offering ART to clients (Government of Malawi, 2017:9). A study conducted by the government in 2017 revealed that about 88% of PLHIV knew their status, 78% of them were on ART, and the viral load of 86% who were on ART was suppressed (Government of Malawi, 2017:3).

Health-care in Malawi faces many challenges, which include the shortage of resources (including human resources), poor roads and long travel distances to the nearest health-care facility (Chimbatata et al., 2017:60). Malawi has a ratio of 2.03 physicians and 36.8 nurses for every 100,000 people (Ritchie et al., 2016:54). The decentralisation of HIV/ART care from hospitals to primary health facilities was meant to reduce the travel distance for clients and to improve the health delivery outcomes.

The population of the urban area of Zomba is over 164,000 (Smith, Eigenbrod, Hudson, Kafumbata & Schreckenber, 2015). ART care in the Zomba district was decentralized from central hospitals to 40 health facilities, with nurses and non-physician clinicians providing the services (Government of Malawi, 2017:5).

Clinic B (unfenced, situated alongside the road) is located in the city of Zomba and provides outpatient primary care. Some of the services use corridors as their waiting area, but these corridors are small and have no windows, making it to be too hot, dark and uncomfortable for the clients. Clients who have come for HIV services have to move around the clinic as the treatment and testing rooms are not close to one another, e.g. clients have to go for HIV testing and counselling, from there (if the results are positive) for pre-ART counselling, and thereafter they move to the ART treatment room.

12 LITERATURE REVIEW

A vast number of studies have been conducted on HIV/AIDS. Worldwide, more than three million children and young adults are infected with HIV, 90% of whom live in Sub-Saharan Africa (Lowenthal, Bakeera-Kitaka, Marukutu, Chapman, Goldrath & Ferrand, 2014:627). A study done in 50 health-care facilities (HCFs) and 25 boarding schools in Homa Bay County, Kenya, included participants who were HIV-infected adolescents (15–19 years) and young adults (20–21 years), and investigated fast-track peer-navigated services, peer-counselling and psychosocial support at HCFs and schools in 2016. Training was implemented in HCFs and boarding schools. Within six months of the programme rollout, 559 adolescents and young adults (481 females; 78 males) were newly diagnosed with HIV (15–19 years, n = 277; 20–21 years, n = 282) and the majority (n = 544; 97.3%) were linked to care, compared to 56% at pre-implementation of the programme. All 559 adolescents and young adults received peer-counselling and psychosocial support, and the majority were initiated on treatment. Compared to pre-implementation, the proportion of adolescents and young adults who were retained in treatment increased significantly from 66.0% to 90.0% at three months and from 54% to 98% at six months (Ruria, Masaba, Kose, Woelk, Mwangi, Matu, Ng'eno,

Bikeri & Rakhmanina,, 2017). This indicates that patients receiving antiretroviral therapy (ARV) treatment should be supported by nurses. Support from health-care workers, including nurses, at ART clinics is one of the facilitators of adherence to ART (Kim et al., 2014). There is a significant relationship between support from health professionals and adherence to treatment, as poor communication leads to lack of information to clients (Hanghøj & Boisen, 2014:121).

Nurses provide support by verbal (counselling and listening) and non-verbal communication (being physically present and touching) (Hockenberry, Wilson & Rodgers, 2016:9). They also support clients to undergo behavioural and lifestyle modification and identifies options for achieving health promotion goals (Vannet, Hawley, Wegner, Falk, Harward & Kshirsagar, 2015:250).

A study in Nigeria on the use of Adolescent Coordinated Transition (ACT), to improve health outcomes among young people living with HIV, indicated that training in ALHIV-specific treatment and care is urgently needed for health care workers. Limited training can have a negative impact, including causing poor rapport between providers and their adolescent patients (Sam-Agudu, Pharr, Bruno, Cross, Cornelius, Okonkwo, Oyeledun, Khamofu, Olutola, Ereka & Menson, 2017:595). Training could be beneficial for the provision of support to patients receiving ARV treatment.

In a qualitative study in Zambia, the experiences of children and adolescents living with HIV aged 10–19 (n = 58) in Kitwe, Kalomo and Lusaka were examined. Furthermore, the operating hours of the clinics, staff shortages and a lack of health policies relating to ALHIV presented ongoing limitations to adolescents' ability to access relevant support services (Mburu, Ram, Oxenham, Haamujompa, Iorpenda & Ferguson, 2014:9).

A study in Finland on customers' first impression of a fine-dining restaurant indicated that first impressions had an impact on whether customers would come back or not (Amelia & Garg, 2016:107). Another study was done in Madang, New Guinea, on factors affecting attendance at and timing of formal antenatal care from February 2010 to January 2011. The results showed that previous negative experiences of health care providers and service delivery at the clinic could discourage women from attending clinics more than once or twice (Andrew, Pell, Angwin, Auwun, Daniels, Mueller, Phuanukoonnon & Pool, 2014).

Patients' experiences are referred to as the sum of all interactions, events and occurrences that happen collectively and independently and could influence their perception during health care.

Experiences could be influenced by meeting basic client needs (Jason, 2014:236 & 238; Wolf Nelderhauser, Victoria, Dianne & Lavela, 2014:1154; Calvillo-Gámez, Cairns & Cox, 2015:37). Good patient-care experiences may be associated with higher levels of adherence to treatment processes (Anhang, Elliott, Zaslavsky, Hays, Lehrman, Rybowski, Edgman-Levitan & Cleary, 2014:522). The relationship with staff members during health care delivery played an important role in the experience of inpatient care (Gill, Butler & Pistrang, 2016:60).

In a systematic review and meta-analysis of adherence to ART for adolescents and young adults (AYA), it was reported that support from health-care workers, including nurses, at ART treatment sites was one of the factors that was associated with ART adherence (Kim et al., 2014). In another study on adolescents' needs for nurses' support when initiating breastfeeding, the participants indicated that they value nurses' support, which included answering their questions and providing the information they needed (Pentecost & Grassley, 2014:224).

During 2004–2012 a study was conducted in seven African countries (Côte d'Ivoire, Nigeria, Swaziland, Mozambique, Zambia, Uganda and Tanzania) on ART enrolment characteristics and outcomes of HIV-infected young adults and older adults. The findings indicate that the lost to follow-up (LTFU) rates were high among young adults in all seven countries. The higher risk of LTFU among young adults (ART enrollees) increases their risk for death and transmission of HIV to seronegative sex partners. Effective interventions and support from health professionals could reduce LTFU and mortality for AYA and could lower the HIV incidence in this age group (Auld, Agolory, Shiraiishi, Wabwire-Mangen, Kwesigabo, Mulenga, Hachizovu, Asadu, Tuho, Ettiegne-Traore & Mbofana, 2014:1097).

A survey was undertaken in Uganda during 1999 to 2008 on behavioural, biological and demographic risks for and protective factors against new HIV infections among the youth. There were 15,904 participants aged from 15 to 24 years who have had sexual intercourse. The average proportion of sexually experienced 15 to 19-year-olds was 59% in men and 72% in women; and for 20 to 24-year-olds it was 95% in men and 99% in women. Although Uganda has made notable progress in reducing HIV prevalence, the youth continue to face a considerable risk of HIV infection in Uganda (Santelli, Edelstein, Mathur, Wei, Zhang, Orr, Higgins, Nalugoda, Gray, Wawer & Serwadda, 2013:393). In the Southern African setting, young females aged 15–24 years contribute to nearly 30% of all new HIV infections. The percentage translates to 113,000 new infections in young women per year; more than four-times that of their male peers. Young women acquire HIV around five to seven years earlier

than young men, often synonymously with their sexual debut (Dellar, Dlamini & Karim, 2015). This outlines the need for health care support from nurses to young adults receiving ART treatment.

13 PROBLEM STATEMENT

Between January and August 2012, nearly half of the adolescents at Zomba and Baylor College of Medicine clinics in Malawi reported nonadherence to ART treatment (Kim et al., 2017). Children and adolescents (10–19 years) and young adults (20–24 years) continue to be vulnerable to HIV infection despite efforts like voluntary medical male circumcision, condom provision, and antiretroviral therapy (ART) by the Malawian government (Sanga, Kapanda, Msuya & Mwangi, 2015; AVERT, 2017). Between 2005 and 2012, HIV/AIDS related deaths among adolescents in the Sub-Saharan Africa region increased by 50%, while the global number of HIV/AIDS-related deaths in the same period fell by 30%. This increase in deaths was due to poor prioritisation of adolescents in planning, inadequate provision of accessible and acceptable HIV testing and counselling (HTS) and treatment services, and a lack of support for adolescents to remain in care and adhere to ART (Denison, Pettifor, Mofenson, Kasedde, Marcus, Konayuma, Koboto, Ngcobo, Ndleleni, Pulerwitz & Kerrigan, 2017).

Currently, about 50% of new HIV infections in Malawi occurred in young adults – more in young women than in young men aged between 15 and 24 years are living with the virus, hence the need for retention and reengagement of them in care (AVERT, 2017; Lowenthal et al., 2014). All people who are diagnosed as HIV-positive are retested prior to ART initiation to verify their serostatus. This retesting is done by a different provider with the same testing algorithm (WHO, 2016:19).

Health-care providers' discussion with the clients' center's around their willingness and readiness to initiate ART, involves details about drug regimen, scheduling, dosage, benefits, possible adverse and side effects, safe sex, follow-ups and monitoring visits (WHO, 2016:72). ART initiation is seen as a non-emergency, but it is supportive and beneficial if the initiation is accelerated, for example in pregnant women to avoid LFTU after the HIV diagnosis. However, accelerated initiation may lead clients to start treatment before they are ready to commit to it (WHO, 2016:74). Support from health-care workers, including nurses at an ART clinic, is one of the factors that support adherence to ART (Kim et al., 2014). Nurses use several strategies to promote young adults' retention in care, which includes teaching them how to schedule their clinic appointments (Hockenberry & Wilson, 2014:759). Clients need to be supported by nurses (e.g. through advice) to commit to ART treatment. It has been observed at a clinic in Malawi that

a lot of young adults do not return for ART care after their first visit. It is therefore unclear how clients experienced the first visit. First impressions are crucial for building relationships, and when expectations are not met, patients can automatically withdraw from such a relationship (Amelia & Garg, 2016:104). The first visit, the initiation of the ART for HIV patients, is therefore very important.

The main research questions of the study were:

- What are young adults' lived experiences of their first visit for ART treatment at an urban PHC clinic in Malawi?
- How should the nurse support young adults during a first antiretroviral therapy visit at an urban primary health care clinic in Malawi.

1.4 PURPOSE

The purpose of the study was to describe the nurse support for young adults during a first antiretroviral therapy (ART) visit at an urban primary health care (PHC) clinic in Malawi.

1.5 RESEARCH OBJECTIVES

The objectives of the study were:

- To explore and describe the lived experience of young adults with HIV/AIDS on the treatment and care received during their first visit at an urban PHC in Malawi; and
- To describe nurse support for young adults during a first ART visit at an urban PHC clinic in Malawi

1.6 RESEARCH DESIGN

A qualitative methodology in a postmodern paradigm was followed in this study. Qualitative research is an approach that seeks to understand through exploration of beliefs, motivation, perception, human experience, intentions and behaviour, in order to understand social life through the study of targeted populations or places (Parahoo, 2014:56). A research design is a series of

approaches used in collecting and analysing measures of the variables specified in the research problem (Ary, Jacobs, Irvine & Walker, 2018:380; Gravetter & Forzano, 2018:37).

A descriptive phenomenology design was followed. Phenomenology is a design of inquiry in which the researcher describes the individual's experience of a phenomenon as described by participants (Kim, 2015). Descriptive phenomenology is used to investigate the characteristics of a group of people in a given situation (Sekaran & Bougie, 2016:43), while an interpretative phenomenology is used to describe the social phenomena of the participants, e.g. how they make sense of their personal world (Smith, 2015:2; Eatough & Smith, 2017:9).

The study was contextual in nature. Contextual research is situated within the setting of the participant in order for the researcher to understand the contextual features and their influence on the experience (Creswell & Poth, 2017:44). The study was conducted in the context of an urban clinic in Malawi to generate rich information on the phenomenon.

1.7 SETTING

The study included a health centre, located within the urban Zomba city. Its catchment area has a population of above 32,000, but some clients come from surrounding rural areas. The adolescent population in this area is estimated at about 6000. Since 2010, this health facility has been managing a cohort of over 3000 (all ages) patients on ART, with an average of 150 people of all ages initiated on ART treatment every year. The health centre is one of the busiest health facilities in the Zomba urban region, with an average of 400 clients attending the outpatient facility daily.

1.8 POPULATION AND SAMPLING

The study population included 15 young adults aged between 19 and 25 years (both male and female) who were HIV-positive and who had their first visit for ART treatment at an urban PHC clinic in Malawi between January and February 2018.

Purposive sampling was used to select participants. Participants were selected based on the features or characteristics that helped to explore the research questions (Riff, Lacy & Fico, 2014:76). Eligibility criteria were used to describe the characteristics participants must have in order to be included in the study (Shivade, Hebert, Lopetegui, De Marneffe, Fosler-Lussier & Lai, 2015:211).

Inclusion criteria refer to the characteristics of the target population (Card, 2015:38). The participants were:

- Young adults from 19 to 25 years;

- Males and females;
- Having their first visit for ART treatment at an urban PHC clinic in Malawi; and
- Were HIV/AIDS positive (contracted during the adolescent period).

An exclusion criteria is a list of factors that prevents eligibility of the potential participant into the study (Card, 2015:38). This study excluded:

- Young adults who have visited the clinic more than once for their ART treatment;
- Any young adult with mental health problems; and
- A young adult who was infected with HIV by the mother during pregnancy and breastfeeding.

Data saturation determined the sample size and was established by continuing to collect data and asking probing questions until no new gaps, new categories or themes emerged (Corbin Strauss & Strauss, 2014:139). Data saturation was obtained with the 15th participant.

19 METHOD

19.1 Data gathering

19.1.1 Preparation of the field

The preparation of the field includes spending time studying the topic guides, thinking through the work in practice and how to approach the field, identifying potential problems, thinking of any additional materials and how to use them, and obtaining comments from the supervisor (Wolshon & Pande, 2016:110). Conducting qualitative research interviews did not only require skills such as intensive listening and note taking, but also assisted in developing expertise in the topic area (Hartas, 2015:236; Merriam & Tisdell, 2015:122).

Permission was requested from the clinic to use a private room to conduct the semi-structured individual interviews according to interview schedules without disturbance. During the period of data gathering, the researcher asked the facility manager in charge of the clinic on a daily basis for the list of clients who came for ART treatments for the first time and then selected those who met the eligibility criteria. To ensure confidentiality, the participants' information and clinical notes were not accessed by the researcher. After the first visit, eligible participants were told about

the benefits of the research and their right to withdraw, after which they were asked to complete written consent forms.

1.9.1.2 Pilot interview

A pilot study is a small study conducted prior to a larger investigation (Eldridge, Lancaster, Campbell, Thabane, Hopewell, Coleman & Bond, 2016). In this study, as a departure, one pilot individual interview was conducted to ensure that the interview questions address the purpose and research questions. A pilot interview was useful for refining the interview schedule and research questions (Marshall & Rossman, 2014).

1.9.1.3 Data collection method

The researcher is the primary instrument for data collection in the semi-structured interviews as she extends the questions and pursue the participants' descriptions (Brinkmann, 2014:277). The method of data gathering was through phenomenological interviews that are used to study lived experiences of individuals, and they help to understand those experiences and to develop a worldview (Marshall & Rossman, 2014). The interviews were semi-structured. Two research questions were posed using an interview schedule (Annexure C). In a semi-structured interview, the researcher uses an interview guide, but works flexibly to allow room for participant's descriptions and narratives (Brinkmann, 2014:277). Semi-structured interviews explored the lived experiences and offered an opportunity to attend to complexities of the research theme. Probing questions were furthermore used to obtain an in-depth understanding of the problem (Bryman & Bell, 2015:213). All interviews were digitally recorded, and the device was tested beforehand to ensure that it was in good working order.

Verbal and non-verbal interactions between the researcher and participants shaped the data collected (Hong, Taylor-Lange, D'Oca, Yan & Corgnati, 2016:694). The interviews were conducted in a private room until data saturation was reached, i.e. when no new information was attained (Fusch & Ness, 2015:1408). The duration was, no longer than 30 minutes. The local language of the targeted area is Chichewa, which was spoken by the researcher. The local language was used to ensure that participants who did not understand English would be able to express themselves freely. Field notes were also taken. Triangulation of data was established by using multiple sources to collect data and to gain an understanding of the experiences shared. Methods of data collection included interviews and field notes (Cope, 2014:89). The researcher used the method of triangulation of individual interviews and field notes.

1.9.1.4 Data analysis

Data analysis involves working with data, organising it, breaking it down to discover what is important and deciding on what to report to others (Ravitch & Carl, 2015). All interview data of the interviews and field notes were coded together as soon as the interviews were concluded. The interviews in the local language were translated into English by the researcher and back-translated by an editor who also spoke both languages. The data was analysed using IPA with an open, inductive approach (open coding). This method was chosen because it is an effective way of analysing qualitative data obtained from semi-structured interviews. IPA is an approach which aims to provide detailed examinations of lived experiences in its own terms, rather than those prescribed by pre-existing theoretical conceptions (Smith & Osborn, 2015:42). This method of analysis was used because it is valuable when examining emotionally laden topics (Smith & Osborn, 2015:42). Phenomenological analysis indicates the commonality of findings by placing importance on bracketing in order to be open to what is in the data. It involves spending time reflecting on data and reducing data to discern the horizon of meaning and construct findings through writing (Roulston, 2014:303).

The steps in the Colaizzi (2015) descriptive phenomenological approach were followed, namely familiarisation with the data, identifying significant statements from the data, formulating meanings from the data, clustering themes from the data, developing an exhaustive description of the data, producing the fundamental structure from the data and seeking verification of the fundamental structure from the participants (Morrow, Rodriguez & King, 2015:643).

1.10 TRUSTWORTHINESS

The trustworthiness of a study refers to the degree of confidence in the data, interpretation and methods used to ensure the quality of a study (Connelly, 2016:435). The trustworthiness of the results depends on the availability of appropriate, well-saturated and rich data (Elo, Kääriäinen, Kanste, Pölkki, Utriainen & Kyngäs, 2014:9). Credibility refers to how well the data collection method and the data answer the research questions of interest (Elo et al., 2014:3). In this study, the data from the interviews and field notes was triangulated in order to obtain accurate information. A pilot interview was important to ensure that the research questions were clear. In order to obtain in-

depth descriptions after posing the research questions, data was collected until data saturation was reached. In order to establish credibility, consensus was reached by the primary researcher and the independent coder before the final themes were generated. Dependability refers to the stability of the criteria and principles used to select participants for the study was conducted (Elo et al., 2014:4). The supervisor was involved to oversee the decisions taken at each stage of the research process (Cope, 2014:90). Transferability occurs when the findings of a study can be transferred to other settings or groups (Elo et al., 2014:6). The researcher collected sufficient and detailed data about the context, and sufficient information on the participants in the research context is provided in the report to enable another researcher to assess the findings and methods and decide if the environment is similar to other situations to which the results can justifiably be applied (similar study in another similar settings) (Cope, 2014:90). Conformability implies that the data accurately represents the participants' information, and that interpretations are not invented by the inquirer or influenced by the researcher's perspective (Elo et al., 2014:5). This was achieved by providing adequate quotes from all the participants to depict each emerging theme (Cope, 2014:90). An independent coder served as an external auditor in assessing the qualitative data analysis of the study (Pieterse, Lawrence & Friedrich-Nel, 2016:386) in order to promote conformability. A consensus meeting was held with the researcher.

1.11 ETHICAL PRINCIPLES

Ethics refers to participants' dignity, safety, rights and wellbeing during a study (Holloway & Galvin, 2016:51). Ethical considerations are standards and norms of conducting a study that are considered to help determine acceptable and unacceptable conduct (Ary et al., 2018 :449). As this study utilised human participants, certain ethical issues were addressed to ensure the privacy and security of the participants. The issues included the use of passwords to protect the electronic data for security purposes. Confidentiality and privacy of participants were respected, and names were not included on the transcripts. Only identification numbers e.g. P 1 were used.

Ethical considerations were adhered to in the course of this study. Permission to undertake the study was sought from the Senate Research Ethics Committee of the Cape Peninsula University of Technology (reference number: CPUT/HW-REC 2017/H41), the Ministry of Health in Malawi, the Zomba District Health Office in Malawi and the particular clinic. Participants were asked to participate voluntarily and were advised of the right to withdraw from the study at any point should they feel uncomfortable. The participants were made aware that a counsellor at the clinic was

available during and after the interviews should they wish to consult her. After explaining the process of the interviews and the benefits, all participants signed a written informed consent form.

Privacy refers to controlling when, what and how someone's information can be communicated to others (Nelson & Stagers, 2016:635). Privacy is important in qualitative research as it involves participants' intimate feelings and thoughts (Holloway & Galvin, 2016:60). All the interviews were conducted in a private room to avoid disturbances and also to make participants feel free to respond to the interview. Every precaution was taken to respect the privacy of the participants and their information in order to prevent social, mental and physical impacts on their integrity (Holloway & Galvin, 2016:54). In this study, only numbers and no names were used on transcripts.

Beneficence means that the research should benefit the participant and the society at large (Parahoo, 2014:102). The benefits of this study are that the findings will contribute towards improving ART adherence among young adults and will contribute towards improving the PHC services to retain and reengage young adults in HIV care.

Non-maleficence was taken into consideration to avoid causing any physical or psychological harm to participants (Parahoo, 2014:102). The researcher, as a trained HTC counsellor and ART provider, was able to select words which did not cause psychological harm. The availability of a counsellor on the premises was explained to the participants. *Fidelity* means building trust between the researcher and the participants (Parahoo, 2014:103) before the interview by asking background demographical information. *Justice* is being fair by not giving preferential treatment to some participants while depriving others the care they deserve (Parahoo, 2014:103).

Beneficence and non-maleficence demand that the researcher use the best practices that do not inflict harm on participants (Carter & Lubinsky, 2015:23). It is researcher's responsibility to minimise harm and maximise benefits to study participants and to mitigate any unexpected harm that could affect participants or others involved in the study (Cox, Drew, Guillemin, Howell, Warr & Waycott, 2014:10).

Qualitative researchers mostly work with a small sample, which makes it difficult to protect participants' identity. Even small details about the participants could lead to a loss of *anonymity*, therefore the researcher needs to be sensitive towards the participants' identity (Holloway & Galvin, 2016:59).

Confidentiality refers to the practice of keeping participants' information secret and private throughout the study and to report dissemination (Ary et al., 2018;450). It furthermore relates to the objective of protecting participants and the researcher-participant relationship. Breach of confidentiality limits participants' willingness to proceed with the study (Cox et al., 2014:9). In qualitative research, participants' words and ideas are used, which makes it difficult to promise full confidentiality, especially when the report contains participants' quotes. The researcher should keep the information that participants do not wish to share with other people, confidential (Holloway & Galvin, 2016:60).

Confidentiality was maintained by respecting information that the participants shared (Parahoo, 2014:103). All transcripts, field notes and audio tapes will be placed under lock and key for five years after publishing the results, in a safe room, after which it will be destroyed by shredding it. All electronic data on the computer is password-protected. The participants thus have the right to complete information on the study, self-determination of participation, privacy, anonymity, confidentiality and to not be harmed (Parahoo, 2014:103).

Informed consent: Consent-participant information sheets need to be written in the language of the lay person so that it can be clear and unambiguous. Both consent forms (Annexure B) and information sheets (Annexure A) should be provided to the participants in order to obtain informed consent (Holloway & Galvin, 2016:60). Participants were informed about the purpose of the study and the interview as the method of data collection and were assured that there were no potential risks if they participate. Participants signed informed consent forms before the interview, and they were informed of their rights to voluntarily participate and to withdraw from the study at any time they wish. Participants in the study should voluntarily consent based on sufficient information on the purpose of the study (Cox et al., 2014:12).

During the study period, the researcher was on study leave so the interviews were not part of her departmental workload. The interviews were conducted when the participants were done with their clinic activities, received their medication and were about to leave the facility. This was done in order not to disturb the service delivery and patients' management.

1.12 SIGNIFICANCE OF THE STUDY

The results of the study contribute towards more knowledge on and insight into the experiences of young adults during their first visit to a clinic, thereby improving the care rendered by nurses in supporting these patients. Guidelines could be formulated to disseminate to the government,

stakeholders and other nongovernmental organisations in the development of strategies or

policies that could help to retain and reengage the young adult in HIV care. The finding could also contribute towards setting a baseline for the involvement of young adults in self-care and treatment adherence.

1.13 LIMITATIONS OF THE STUDY

The study was qualitative in nature and the findings cannot be generalised to the broader population of young adults in Malawi. The researcher translated the findings from Chichewa into English, although speaking both languages herself. The independent coder therefore was also able to speak the language in which the interviews were conducted.

1.14 OUTLINE OF THE STUDY

The report is organised as follows:

Chapter 1

Introduction and background to the study: This chapter provided an introduction to all the chapters in the study. A detailed description of the participants and the study setting was given. The purpose of the study and an overview of the lived experience of young adults and the nurse support for young adults during a first antiretroviral therapy visit at an urban primary health care clinic were outlined.

Chapter 2

In this chapter, an outline of the literature which helped the researcher to understand other researchers' contribution to the topic was given. This literature provided the researcher with the background on the current knowledge and helped to identify knowledge gaps.

Chapter 3

In this chapter, the research methodology is discussed. The reason for using a qualitative approach is described and the limitations of using this approach highlighted. The phenomenological research design was used to explore the lived experience of young adults with HIV/AIDS on the treatment and care received during their first visit for ART. Details of the study design, sampling

method, data collection and data analysis is presented and the measures to ensure trustworthiness of the research described.

Chapter 4

This chapter outlines and discusses the research findings. The participants' demographic data as well as the summary of themes that emerged from the research will be presented. The six main themes will be discussed in detail and quotes from the transcripts are included to give a direct voice to the participants. Findings of the study will be supported by literature.

Chapter 5

This chapter concludes the study. Recommendations to nurses to support young adults with HIV/AIDS on the treatment and care received during their first visit for ART is made and the nursing education. The implications of this study on further research and the limitations of the study outlined.

1.15 SUMMARY

In Chapter 1, an overview was provided on the background of the nurse support for young adults during a first ART visit at an urban primary health care clinic in Malawi. The purpose of the research study was to provide an in-depth understanding of the lived experience of HIV positive young adults on ART during their first visit at an urban PHC clinic in Malawi. Nurse support for young adults during a first antiretroviral therapy visit at an urban PHC clinic in Malawi was described.

CHAPTER 2

LITERATURE REVIEW

INTRODUCTION

A literature review is an organised, written argument that supports a thesis by providing a case based on the presentations of what the previous researchers publish on this or related topics (Machi & McEvoy, 2016:5). It aids in understanding other researchers' contribution to the topic and provide the background about the current knowledge. It furthermore facilitates the identification of knowledge gaps (Thomas, 2015:236; Yawar & Seuring, 2017:627).

This chapter only provides a broad overview of the topic. The purpose of a qualitative research project is to place the study in the context of others and to avoid duplicating other work, which facilitates the development and implementation of the study and defines the research question (Holloway & Galvin, 2016). Through a literature review, the researcher can describe how the study could contribute to existing knowledge.

The chapter is not specifically reporting on only nurses' provision of ART but on health workers in general. The following will be addressed:

- The primary health care (PHC) environment;
- The impact of client impressions on visits to clinics;
- The general procedure of HIV testing;
- ART procedures;
- ART adherence; and
- Retention in care.

2.1 PRIMARY HEALTH CARE

Primary health care (PHC) is a basic approach of providing structured frontline health care for simple and common health problems, with an emphasis on the promotion of health through a partnership between nurses, other health care professionals and the community (Macdonald,

2013:9; Bitton, Ratcliffe, Veillard, Kress, Barkley, Kimball, Secci, Wong, Basu, Taylor & Bayona, 2017:566). Integrating HIV treatment and care into the existing PHC system improves access to care and reduces the time between an enrollment and ART initiation, though with higher risk of late attrition. This integration of HIV care into PHC services improves patients' access to integrated services and comprehensive PHC packages (Mathibe, Hendricks & Bergh, 2015:1; Tso, Best, Beanland, Doherty, Lackey, Ma, Hall, Yang & Tucker, 2016:1639; Bitton et al., 2017:571).

According to the literature, men do not want to go to clinics which are integrated with reproductive services because of its identity as a place for women (Treves-Kagan, Steward, Ntswane, Haller, Gilvydis, Gulati, Barnhart & Lippman, 2015:87; Horter et al., 2017:57). Therefore, it is difficult for them to find HIV care. Women find it easier to access HIV care because, unlike men and youth, they can do so under the reproductive health services umbrella. Decentralisation of HIV care, from hospitals to PHCclinics, has improved patients' access to and retention in HIV care, with the same clinical outcomes that hospitals are obtained (WHO, 2016:267; Agaba et al., 2018).

In some of the studies done in Africa on the decentralisation of HIV/AIDS treatment services, participants were not happy with the decentralisation of ART services, claiming that, even though they have to wait long at the current facility, they cannot be comfortable getting the treatment at the PHC facility close to where they live due to fear of disclosure and discrimination (Onwujekwe, Chikezie, Mbachu, Chiegil, Torpey & Uzochukwu, 2016; Roy et al., 2016:177).

2.2 IMPACT OF FIRST IMPRESSION ON SUBSEQUENT VISITS

The results of a study done in Texas between 26 August 2013 and 18 November 2013 show that clients who had a good experience with an HIV provider on their initial visit were more likely to remain in care compared to those with negative experiences (Dang, Westbrook, Hartman & Giordano, 2016: 2482). The relationship between the first experience and retention in care was, however, of short term (Dang et al., 2016:2482).

Results of a study done in Finland show that first impressions have an impact on the customers' decision-making behaviour, on whether they wish to come back or not (Amelia, & Garg, 2016:107). In another study from February 2010 to January 2011 in Madang, New Guinea, on antenatal care it was found that previous negative experiences with health care providers and service delivery at the clinic could discourage women from attending the clinic more than once

or twice (Andrew et al., 2014).

2.3 HIV TESTING

Voluntary counselling and testing (VCT) occur when clients initiate the testing themselves (Mwangala, Moland, Nkamba, Musonda, Monze, Musukwa & Fylkesnes, 2015). People can go for testing just to know their status, although a social facilitator and the fact that its free could enhance motivation (Logie et al. 2017). Most people only get tested when there is something which has pushed them to do so. Clients who had HIV/AIDS knowledge and perceived themselves to be at low risk of HIV were more likely to receive voluntary counselling and testing compared to those who lacked knowledge and thought they had no risk of HIV at all. Clients who discussed HIV issues with their partners were likely to make use of VCT. Also, clients with positive attitudes towards testing were more likely to go for HIV testing than those who were stigmatised by their families (Teklehaimanot et al., 2016:239).

In a study done in Tanzania, it was found that demographics, e.g. age and sex, play a role in the uptake of HIV testing. Males were less likely to test for HIV than females, and adolescents older than 18 years were more likely to be tested than those below 18 years (Sanga et al., 2015). In another study done in Ethiopia, it was found that more youths than ever had been tested for HIV. This was very positive as the youth has the highest risk of HIV acquisition of all age groups (Teklehaimanot, Teklehaimanot, Yohannes & Biratu, 2016:239). The HIV testing uptake is lower in the areas where there was stigma due to a fear of discrimination by the community. Furthermore, clients who stay away from the health facility were less likely to undertake the VCT because of a difficulty in organising transport to the testing centre (Teklehaimanot et al., 2016:239). People who spoke openly about their experience after being tested for HIV encourage other people to go for testing (Teklehaimanot et al., 2016:239).

Although some of the clients said they did not get tested because they fear a positive result, stigma and discrimination, they were not ready for testing or needed to consult their partner (Abdurahman et al., 2015:157).

A confirmatory test is the retesting of newly diagnosed HIV-positive individuals, preferably conducted by a different provider on new specimen using the same testing algorithm. The aim of retesting is to rule out technical or clerical errors, including specimen mix-up through transcription errors and mislabelling (WHO, 2016:3). For positive results it is advisable to use more than one test kit to confirm the result, as one participant pointed out that more than one test was needed to come up with their positive result. After giving them their results, the clients should be given

the time to consider the consequences and cope with the emotion arising from these results (WHO, 2015:27).

2.3.1 Testing for safe sex counselling

Couple HIV testing and counselling (CHTC) could be used to discuss prevention of transmission to HIV-negative partners. Some people believe that their HIV-positive partners had suppressed viral loads and therefore had a minimal chance of contracting the virus. Many of the HIV-negative partners were interested in pre-exposure prophylaxis and regular condom use. The counselling was also aimed at reducing HIV transmission to the HIV-negative partner and to encourage them to have safe sex with outside partners (Wall et al., 2016:1).

2.3.2 Accepting the HIV-positive results

Clients who had not accepted their HIV status do not adhere to the ART treatment because they are afraid that by visiting the clinic, their HIV status would be revealed when they are seen queuing for the ART service. They also fear a breach of confidentiality by health providers (Makanjuola, Taddese & Booth, 2014; Horter et al., 2017:57).

2.4 ART PROCEDURE

Recently the WHO issued a recommendation that anti-retroviral treatment should be made available to all persons newly diagnosed with HIV at the time of their diagnosis, regardless of the CD4 count (Kresina et al., 2016:15). ART initiation is not necessarily conducted on the same day as testing but should be done soon thereafter to give the clients time to be ready themselves for the treatment and to do all the adherence counselling processes, which promote retention in care and treatment adherence (WHO, 2016:73). During their first visit to a PHC clinic, all clients diagnosed as being HIV-positive are retested prior to ART initiation to verify their serostatus. The retesting should be done by a different provider who uses the same testing algorithm (WHO, 2016:19).

Before initiation on ART, the clients and their guardians undergo group and individual counselling sessions. A study indicated, that patients identify a guardian whom they had trusted with their serostatus information who accompanies them to the clinic on their first visit for antiretroviral treatment, counselling and education on the disease condition and treatment (MacPherson et al., 2015:414; McKinney et al., 2015:553).

Health care providers should also observe the clients' willingness and readiness to initiate ART, and discuss the drug regimen, scheduling, dosage, benefits, possible adverse and side effects, safe sex, follow-up and monitoring visits with patients. The need for psychosocial support is also assessed to optimise adherence and to obtain a baseline disease status of the client (Samuel, Crumb, & Duba, 2014:357; WHO, 2016:72). Before the initiation of ART, clients must be screened for tuberculosis (TB) and renal function, as the use of tenofovir in patients with renal problems could complicate the condition (Koenig et al., 2017).

2.5 PATIENTS' RIGHTS

Patients' dignity in all areas of health care should be preserved. This includes communicating relevant information, ensuring their autonomy and privacy and interacting with them in a respectful manner as a basic foundation of each care activity and treatment (Ferri, Muzzalupo & Di Lorenzo, 2015:41). The dignity of all clients in all phases of health care is important, as it permits clients to tolerate the physical and psychological vulnerability of their condition and/or diagnosis (Ferri et al., 2015:41). A study conducted in Cameroon found that nurses who had negative attitudes towards the clients and were not respecting clients' dignity were negatively affecting client adherence to treatment (Wung, Peter & Atashili, 2016:280). Sagar and Prakash (2016:496) found that equality was an important element of dignity. Health providers have a moral obligation to advocate non-discriminatory care to vulnerable groups.

In some sub-Saharan African settings, pregnant women believe HIV testing and treatment were obligatory parts of attending an antenatal clinic, although they had the right to opt out. (McClean et al., 2017).

2.6 STIGMA AND DISCRIMINATION

Stigmatisation in the health care system discourages the HIV-positive clients from seeking health service (Ahamuza et al., 2016:41). In a study done in Eastern Africa, it was found that long waiting periods and stigmatisation were some of the reasons which made the clients stop taking ARVs or move to other clinics. The evaluation was done over the period of 2.5 years in 14 clinic sites (Geng et al., 2015:935).

Denison et al. (2015:3) found that the fear of unintended disclosure of HIV status affects adolescents' adherence to treatment. When the adolescents were at school or social events, they did not take their medication in an effort to avoid being seen with the drugs. They also wanted to keep their HIV status a secret, because it could lead to stigmatisation by the community.

Disclosure of clients' HIV status to close friends and family members facilitated adherence to treatment as it reduces fear of stigmatisation and discrimination and means that they do not need to hide obtaining, taking and keeping medication (Bezabhe et al., 2014).

Treves-Kagan et al. (2015:87) state that clients were stigmatised by health care providers when they seek HIV care. Both men and the youth felt at risk of stigmatisation when the HIV care was integrated with reproductive healthcare services, as the facility was seen as a clinic for females, while married women had an easier time accessing care for HIV because they can do so under the reproductive health services' guise, or children's health care needs (Treves-Kagan et al., 2015:87). Male clients often postpone their visits to health facilities in fear of being seen at the clinic as they could risk exposing their HIV status (Treves-Kagan et al., 2015:87).

Clients do not disclose their HIV status to their families because they are afraid of being abandoned or accused of wrongdoings, and their HIV-positive status may not be accepted by their relatives (Treves-Kagan et al., 2015:87). Adolescents do not want their mates and even their HIV-negative siblings to know that they are taking ARV medicines due to the fear of stigmatisation and discrimination, (Nabukeera-Barungi et al., 2015:520; Ankrah et al., 2016:329).

2.7 ART ADHERENCE

Patient adherence to treatment is the degree to which clients follow prescribed treatment recommendations and advice from their health care provider (Miller et al., 2016:1079). Non-adherence to medical treatment may have serious consequences for one's health and increase morbidity and mortality, while good adherence to treatment has positive effects on the treatment outcomes (Viswanathan et al., 2015:601; Miller et al., 2016:1079). According to Kim et al. (2014), the sustained effect of ART depends on good adherence (>95%) to daily medication. The adherence rate of above 95% is necessary to achieve viral load suppression (Viswanathan et al., 2015:601). Clients should be informed that the first ART regimen offers an opportunity for effective viral suppression and immune recovery and that successful ART requires good adherence to medications (WHO, 2016:72).

Rates of adherence vary across different clients' populations, disease types and treatment regimens.

Adherence to treatment is better in acute, non-chronic conditions as compared to chronic conditions where nearly 50% of clients with chronic diseases do not adhere to their treatment and medical

directives (Sharma et al., 2014:40; Miller et al., 2016:1079). Adherence to chronic disease treatment is complex as clients are sometimes asymptomatic. It is further complicated by the costs associated with required clinic visits (Hamine et al., 2015; Harris et al., 2017:170). Up to 50% of the HIV-infected adolescents and young adults adhere poorly to chronic medication compared to other age groups. This is due to behavioural challenges, psychological factors and complex ART regimes (Viswanathan et al., 2015:601).

When adherence was measured using pill counts, it was found that those using once-daily ART regimens had better adherence than those using twice-daily regimens (Scott Sutton, Magagnoli & Hardin, 2016). A PubMed database study, found that there was a reduction in the risk of nonadherence in the clients using the fixed-dose combination tablet (FDCs) compared to those using non-FDCs (Van Galen, Nellen & Nieuwkerk, 2014). Hanna et al. (2014:587) and Nachege et al. (2014:1297) also found that a single-tablet regimen was more strongly correlated to good adherence to treatment than following a twice-daily regimen (adherence was measured using pill counts). In a study on the meta-analysis of single- and multi-tablet fixed dose HIV treatment regimens, Clay et al. (2015) found that adherence to a single-tablet regimen was 2.37 times higher than adherence to a multiple-tablet regimen (whether administered once a day or twice). Starting Isoniazid preventive therapy (IPT) and ART simultaneously in HIV-positive clients helps to reduce the incidence of TB by 80%, mainly during the first six months when there is a high risk of contracting as a result of immune reconstitution inflammatory syndrome (IRIS) which occurs when CD4 count is very low (Yirdaw et al., 2014; Makhandu, 2018:8).

Although approximately three-quarters of PLHIV's Tuberculosis Skin Test (TST) was negative when screened for TB, it is still less expensive to administer IPT than the costs of operational challenges, which include training outreach workers to read TST results consistently (Smith et al., 2015). Clients who take ART and IPT concurrently are less likely to adhere to treatment because they experience toxicity and have a high pill burden (Makanjuola et al., 2014).

2.7.1 Family support

Families provide psychological, physical, emotional and economical support. This mutual Helpfulness and cooperateon is necessary to help individual members of the family to overcome their weaknesses (Handel et al., 2017:225; Lamanna, Riedmann, & Stewart, 2014:5).

Families could affect adherence in a positive way if there is support, good communication between family members and parental involvement, while little support and poor communication

could have a negative effect on adherence (Wolf et al., 2014:1154; Mokwele & Strydom, 2017:34). Partners, family and close friends could promote adherence by giving emotional and financial support, as well as advice and encouragement when participants are weak (Maixenchs et al., 2015; Levison et al., 2017). Family and friends could be a good source of support if clients disclose their HIV status to them. They can encourage them to stay in care and adhere to treatment, and friends who are also living with HIV could give advice on where to seek care (Bratt et al., 2015; 171; Barrington et al., 2016). Although disclosing an HIV status to partners is an obligation, clients fear the negative reactions, abandonment and intimate partner violence, which involves emotional and physical violence that could result from assumptions that they were unfaithful to their partners. Clients avoid disclosure because of the anticipated negative reaction associated with a positive HIV status from the community at large (Ashaba et al., 2017). The families provide support to HIV-positive clients, which includes emotional support and reminding the clients to take their drugs and to visit the clinic for an appointment (although the reminders were sometimes infrequent). This depends upon whether the family member lived with or visited the client frequently (Denison et al., 2015:4). Partners of patients who provided good support were usually those who were also HIV-positive and on treatment themselves. This support includes transportation and covering food costs (Bezabhe et al., 2014). Maixenchs et al. (2015) found that partners were a great source of support if both were HIV-positive. In serodiscordant couples, however, it was found that if the woman is negative, she supports the partner, but if the man is negative, his family and friends often influence him to abandon his wife.

2.7.2 Religious beliefs

Religious rituals like using holy water and fasting were also found to influence medication adherence in Ethiopia. During fasting seasons in both Islam and Christianity, some patients were unable to take their medications as prescribed. Clients were also lost to follow-up when they went to monasteries for holy water and to be baptised, and also when the religious leaders discouraged the clients to take the pills and told them that they can be cured by taking holy water and praying to God for a complete cure from HIV/AIDS (Bezabhe et al., 2014).

Some clients were not adhering to ART because they had received prophecies from church leaders and/or fellow faithful believers that they would be healed from HIV. According to these prophecies, they had to discontinue taking the ART increase their religiosity and continue to pray to God for healing (Vyas et al., 2014:817). In the same study, it was found that the religious beliefs can also help to improve the adherence of some participants. This group said that they believed in

God but still took their ART because they know that human beings are given wisdom and autonomy by God to help them chart their destiny in life by acting independently. These patients furthermore received adherence counselling from religious leaders, clinic counsellors, family members and friends (Vyas et al., 2014:817). Some participants felt that their faith grew after adhering to the ART treatment and seeing great improvements in their physical health. Participants with good ART adherence and high levels of religiosity said they had never seen a person being healed from HIV after receiving prayers, so they cannot rely on prayers alone (Vyas et al., 2014:817).

2.8 RETENTION IN CARE

Retention in care refers to clients' visits to the clinic for refilling their drugs and the routine care received by clients enrolled in a programme in accordance with their needs (WHO, 2016: xv; Nosyk et al., 2014:41). Poor patient retention in HIV care undermines positive patient outcomes such as achieving and sustaining viral suppression (WHO, 2016:251). Adolescents diagnosed as HIV-positive often experience poor linkage to HIV treatment and care and their retention in HIV care is lower than that of other age groups. This suboptimal adherence leads to lower rates of viral suppression (Murray et al., 2017).

2.8.1 Clinic appointments compete with other activities

Most of the young adults are preoccupied with life events and lifestyles that conflict with adherence and lead to them forgetting to take their medication (Ankrah et al., 2016). In their study, Yehia et al. (2015:246) found that regular attendance to HIV clinics was not a priority for some clients who had other activities such as school and work. It was difficult for them to request time off for clinic appointments, and, as a result, they missed some appointments.

2.9 SUMMARY

This chapter provided a general background on literature that focus on the phenomena of nurses' support of HIV patients within clinics. Factors that affect adherence to medications and retention in care as per findings from different studies were reviewed.

CHAPTER 3

METHODOLOGY

3.1 INTRODUCTION

Methodology refers to various choices made by the researcher on how to conduct the research and includes the method of data collection and analysis. Methodology is decided on during the planning phase of the study (Silverman, 2015). The main aim of this study was to describe the nurse support for young adults during a first antiretroviral therapy (ART) visit at an urban primary health care clinic in Malawi.

Paradigm refers to a model for understanding, shared by a community, and is an attempt to explain a specific behaviour (Arend & Beck, 2014:204; Ferraro, 2018:5). It forms part of the assumptions that guide the thinking and actions of a person (Mertens, 2014:8). In this study, a post-modern paradigm was followed in order to appreciate the phenomena and to understand the lived experiences of participants around the phenomena (Lash, 2014:42; Hatch, 2018:386).

3.2 RESEARCH DESIGN

3.2.1 Differences between qualitative and quantitative designs

The qualitative approach of this study used non-numerical data to understand phenomena through an exploration of participants' lived experiences. Qualitative studies focus on beliefs, motivation, perceptions, human experiences and intentions, and have no predetermined hypothesis (Parahoo, 2014:56; Ary et al., 2018:372). In a qualitative study, the researcher is flexible, and models interviews on a normal conversation; thus, in this study the researcher did not use a formal question-and-answer approach (Taylor, Bogdan & DeVault, 2015:8). Quantitative research, on the other hand, answers the hypothesis being tested by using controlled procedures to gather numerical data (Ary et al., 2018:373). The quantitative research is more formal in approach and fairly limited in what it can achieve. In both approaches, the researcher/participant relationship comes into play, with the researcher having to distance himself or herself from the study participants (McNabb, 2015:226).

Quantitative research derives its hypothesis from related literature in the early stage of the research, so that the researcher has a framework with which to begin and some direction for the study (Silverman, 2015:54; Ary et al., 2018:31). Quantitative analysis begins with structuring

the general problem into an understandable, specific problem (Anderson et al., 2018:6). Qualitative study, on the other hand, seeks to understand the perceptions and experiences of people (Silverman, 2015:41), but data collection should still be rigorous, systematic, disciplined, methodical and carefully documented. Qualitative data analysis in this study began at the outset of data generation, as outlined by Schwandt (2014:385).

The researcher selected a small sample for the qualitative research because the aim was to acquire rich information, useful for understanding the complexity, variation, depth and context surrounding the phenomenon, not to represent whole populations, as in a quantitative study (Gentles et al., 2015:1782). In a quantitative study, random sampling remains the golden standard (Orcher, 2016).

Qualitative methods are intended to achieve depth of understanding (Etikan, Musa & Alkassim, 2016:2), while quantitative researchers base their studies on things which can be measured or counted and thus need a larger sample (Berger, 2015). Qualitative researchers attempt to control or minimise their effects on the people they study. In this case the researcher made every effort to understand the participants on their own terms when collecting and interpreting their data (Taylor et al., 2015:9). Qualitative researchers aim at making a theory to fit the data by operating within theoretical frameworks (Taylor et al., 2015:8). Qualitative methods are used to evaluate programmes and policy research, because of their ability to study people in their context and in the situations in which they are found (Taylor et al., 2015 :7-9). It is thus not only a set of data-gathering techniques; it is also an approach to the empirical world. This study produces descriptions from observable behaviour, and participants' own spoken or written words. The research study was inductive in nature, against a background of the broader topic under investigation.

The researcher had to choose between depth and breadth in the approach taken, and chose depth, using a small sample. The researcher endeavoured to be sensitive and to show self-knowledge during the research process and with regards to the topic of the study (Haahr, Norlyk & Hall, 2014:6). A sensitive researcher is attentive to participants' cues and makes the necessary choices during the unstructured research interview. Qualitative researchers also need to be flexible to minimise the influence of their own previous knowledge on the study (Sorsa, Kiikkala & Åstedt-Kurki, 2015:8). The researcher was interested in understanding an in-depth of the topic, not for generalisation (Bengtsson, 2016:14). The study employed the qualitative methodology within a postmodern framework, and a descriptive, phenomenological design was used to achieve the research objectives in a specific, natural context.

3.2.2 Phenomenology

Phenomenology is a qualitative approach to research that aims to develop a new understanding of lived experiences, obtained through participant interviews. It relies on first-person accounts, gaining insights and generating meanings (Ormston et al., 2014:18; Gentles et al., 2015:1773). Phenomenology is the philosophical study of participants' experiences and consciousness and yields insights into people's lived experiences or life-worlds. The phenomenological approach is a strong method for understanding subjectivity and personal knowledge and emphasises the personal interpretation and perspective. Phenomenological research aims to observe from a perspective free of hypotheses, and rather to explain phenomena (Van Scoy & Evenstad, 2015:338).

In an interpretive phenomenological approach, the researcher focuses on gaining a deep understanding of participants' experiences (Ormston et al., 2014:271). On the other hand, description refers to capturing a phenomenon exactly the way it is; to look at things the way they really are without interpreting (Bengtsson, 2016:9). Descriptive phenomenology enables an understanding of the characteristics of a group of people in a given situation and describes their lived experiences very carefully (Sekaran & Bougie, 2016:43,44; Eatough & Smith, 2017:180). In this study the descriptive design helped to answer questions pertaining to the experiences of young adults. Interpretative phenomenology explores the lived experiences of the participants, attempting to understand how they make sense in their personal and social worlds. It focuses on what the experience was likely to mean to a particular young adult (Smith, 2015:2). Descriptive analysis understands the meaning based on data presentation (Vagle, 2016:55).

Descriptive phenomenology mainly requires exploring, describing and analysing the phenomenon while maintaining its depth, breadth and richness, to reveal something close to its real nature (Matua & Van Der Wal, 2015:25). It aims to 'unveil' how the experience presents itself, without adding or subtracting anything (Matua et al., 2015:25). This creates deep insights to describe phenomena thoroughly. Descriptive phenomenologists suspend and put aside (bracket) their previous understanding of the topic to focus on the participants' views completely (Bengtsson, 2016:9).

Descriptive phenomenology was used in this study because it allowed the participants to express their own experiences as lived by them. The researcher used bracketing when speaking

to the participants in order to suspend any personal expectations or prejudices when interviewing participants.

3.2.2.1 Exploratory design

This research explored the lived experience of young adults with HIV/AIDS on the treatment and care received during their first visit at an urban PHC in Malawi. Exploratory design refers to the process of familiarising oneself with what the data will cover. It is flexible and can direct the research process (Robson & McCartan, 2016:414; Suresh, 2014:496). Data collection and the development of themes in an exploratory design help to generate new ideas or meanings (Bernard, Wutich & Ryan, 2016:18). Exploratory design in this study did not provide a conclusion for the researcher, but helped to define the problem (Zikmund et al., 2017:21).

3.2.2.2 Contextual design

A principle of contextual design is to go where the participants are and observe them doing ‘their thing’ while they are doing it. The researcher collects data on ongoing experience and motives, so that data is concrete (Holtzblatt & Beyer, 2016:50). This study was conducted in the participants’ natural setting, with interviews conducted at an urban PHC clinic where patients were receiving ART treatment.

3.3 STUDY SETTING

Zomba is the fourth largest city in Malawi. It is located in the southern part of the country and has a population of about 88,000. According to Malawi National Statistics Office’s report (2015:425), only 18% of men and 26% of women aged 15 to 24 years in Zomba are employed, while 21% of men and 53% of women have an income. Among people in this age group, 20% of men and 34% of women attend school. In total, 77.8% of women and 53.3% of men in the age group have tested for HIV and know their results, and 58.9% of women and 56.2% of men know the three ways of transmitting the virus from mother-to-child. In addition, 97.45% of women and 87.4% of men know where they may be tested for HIV (NSO 2015:409 & 411; Mulwafu et al., 2017:2). A clinic set up for HIV care needs to be able to ensure confidentiality for its clients. Some clinics separated clients coming for HIV care from clients seeking other health services (Logie et al., 2017). This can adversely affect the willingness of clients to attend such clinics.



Figure 3.1: Map of Malawi

The health centre for this study is located within the urban area of Zomba city. The catchment area of clinic B has a population of over 32,000, with many additional clients coming from surrounding rural areas. The clinic has seven nurse midwives; three males and four females.

One nurse had a bachelor's degree, four of them had diplomas and two had certificates. Five of them were trained ART providers but none of them was an HTC counsellor. There were two medical assistants; one an ART provider and one clinical officer who was also qualified to administer ART.

The ART clinic was run by nurses, as the medical assistants were always busy with consultations. This finding is in line with that of Zakumumpa et al. (2017:45), who found that HIV care in Uganda was nurse-centred because of a shortage of clinicians.

On every clinic day there are two nurses working in the ART clinic. The ART clinic operates on Tuesdays and Fridays only, as the facility does not have sufficient rooms. This same room is used for an antenatal clinic on Mondays and Wednesdays, and also for mother and infant pairing on Thursdays. On each ART clinic day, there are on average 50 clients who come for their drug refills, with an average of two ART initiations per week. Malawi has a nurse/patient ratio of 38 nurses per 100,000 population (Msiska, Smith & Fawcett, 2014:35). The majority of health facilities in Malawi have a median of 2.1 per 10,000 of medical officers, clinic officers, assistants, and nurses for the served population, and a median ratio of 15.2 per 10,000 of health surveillance assistants (HAS) per served population (Gunda et al., 2017).

Some of the nursing duties at the ART clinic are done by health surveillance assistants (HSAs) and long-term clients (expert clients) due to the chronic shortage of nurses. A long-term client is someone living positively with HIV, taking antiretroviral drugs as prescribed, with good adherence, who is willing to disclose his or her status and encourage other HIV-positive clients to do the same. Such a person shares the experience of living with HIV (Dlamini-Simelane & Moyer, 2017:20). Testing and counselling at the clinic is done by HIV Testing Services (HTS) counsellors who are HSAs. Pre-ART counselling is done by long-term clients who have attended a two-day training course on counselling. These two groups are supervised by nurses, although it is difficult for them to supervise the testing and counselling because no nurse at the facility has trained in testing and counselling.

3.4 POPULATION AND SAMPLE

The study population comprises all the sampling elements for inclusion in the study (Riff, Lacy & Fico, 2014:72). Population refers to all members of a well-defined class of people, objects or events (Ary et al., 2018:171). In this study, the study population was young HIV-positive adults aged between 19 and 25 years (both male and female) who had visited the clinic for ART. The transition to adulthood is associated with various developmental stages, including living independently (Maturro et al., 2015).

3.4.1 Sampling

Sampling refers to the process used to select a sample suitable for study from the population (Ary et al., 2018:381). Sampling in qualitative research refers to the selection of data sources which may provide the data to address the research objective (Gentles et al., 2015:1775). Non- probability

sampling deviates from the principles of probability, with most of the units having unknown probabilities (Vehovar, Toepoel & Steinmetz, 2016:329). Non-probability sampling can be biased, as the researcher has control over the choice of the sample, while in probability sampling the process is unbiased because each unit has an equal chance of being selected, and there is no room for subjectivity (Lynn, 2016:249; Thrusfield, 2018:272). To minimise the risk of bias in non-probability sampling, researchers may use purposive sampling (Lynn, 2016: 248). Non-probability sampling is easily accessible, cost effective and has administrative benefits (Lynn, 2016: 248). Purposeful sampling is a technique used in qualitative study to identify and select individuals or groups of individuals that are experienced or knowledgeable. Individuals provide information-rich cases for the effective use of limited resources (Palinkas et al., 2015:534). The purposive sampling technique is used in qualitative studies only, and participants are chosen due to certain qualities they possess (Etikan, Musa & Alkassim, 2016:2). Purposive samples are participants chosen from the population using non-probability techniques; those that the researcher believes will be able to provide relevant information (Ary et al., 2018: 382). On the other hand, the convenience sampling technique is used in both qualitative and quantitative studies, however mostly used in quantitative studies (Etikan et al., 2016:2).

Sampling for the semi-structured interviews was purposive. Participants were selected because of their particular perspectives, experiences or expertise, and were not necessarily demographically representative (McIntosh & Morse, 2015). Phenomenological research uses purposive sampling to get data from people who are knowledgeable and have had experiences in the phenomenon under study. In phenomenological studies, sample size is determined by data saturation (Ellis, 2016: 41). Sampling was done based on the eligibility criteria.

3.4.2 Sample

A sample is a small portion of the population, chosen to provide data (Ary et al., 2018:171). Phenomenological studies usually have a small sample size, as the interviews require detailed, individual transcript analysis, which takes time (Lyons & Coyle, 2016:54). Sample size is determined by data saturation (Sekaran & Bougie, 2016:226). Data saturation in qualitative research refers to reaching a point where no new information or themes emerge during data collection or when there is nothing new to add to the study (Corbin et al., 2014:139; Gentles et al., 2015:1781). Saturation has become widely recognised as an indicator or guide that

sufficient data collection has been achieved (Gentles et al., 2015:1781). This study sample depended on data saturation. A total of fifteen young adults were selected as participants, with whom semi-structured, one-on-one interviews were conducted.

Eligibility criteria refers to the shared characteristics of participants which make them eligible for inclusion in the study (Shivade et al., 2015:211). Clear criteria help to guide the selection of the sample and reduce subjectivity. They define the population which will lead to the study's conclusion and they promote transparency, which must be considered when reporting the findings (Card, 2015:38).

Inclusion criteria is a set of statements of the features of the population to be included in the study (Card, 2015:38). In this study inclusion criteria were:

- Male and female young adults between the ages of 19 and 25 years who were HIV-positive. The researcher chose this age group, as for teenagers younger than 18 parents would had to have provided consent before the interviews could be conducted;
- Clients who had completed a first visit for ART treatment at an urban PHC clinic in Malawi, who had gone through the process of ART initiation.

Exclusion criteria are features of the population which preclude them from participating in the study (Card, 2015:38). These were:

- Young adults who had visited the clinic more than once for ART treatment;
- Young adults with mental deficiencies or psychiatric problems, which might influence their experiences and necessitate someone to give consent for them; and
- Clients who were infected by their mothers during pregnancy, who may have known about their status since an early age and may have been coming to the clinic for opportunistic infections (their experiences could be different from others').

3.5 DATA GATHERING

3.5.1 Gaining access to the participants and preparing the field

Permission to undertake the study was gained by submitting a proposal to the Senate Research Ethics Committee of the University (Annexure D), the Ministry of Health in Malawi, the Zomba District Health Office in Malawi (Annexure E), and the particular clinic involved to

brief them on the purpose and outline of the study and of the ethical clearance obtained.

The researcher visited the clinic after permission was granted by the Zomba District Health Office. The process and benefits of the study were explained, and the proposal given to the nursing in-charge. The nursing in-charge informed the nursing staff members, so that all were informed about the study and its benefits for the clinic and the broader community. They were also informed about the inclusion and exclusion criteria for study participants, so that they might identify and refer possible participants to the researcher. The staff members informed the possible participants of the nature of the study and asked them whether they would like to participate in the research. In effect, the nurses served as gatekeepers; the rationale was that they could identify clients through their registers, since the researcher could not access the registers for confidential client information.

The researcher engaged in a discussion with the nurse in-charge so that the researcher understood the routine activities of the clinic, the numbers and qualifications of staff members and the task allocations for all who worked at the ART clinic, since all of this information affected service delivery and patients' experience of the health care they received. A time and place to conduct the study was arranged.

3.5.2 Pilot interview

A pilot study is an initial small-scale trial done with a percentage of the participants from the population to assess the practicability of the procedure and test the data collecting instrument. It obtains systemic feedback from individuals who have used the tool and who have experienced the assessment, so that these may be altered as necessary according to feedback (Taylor, 2017:92; Ary et al., 2018:563). A pilot study helps to improve the efficiency and the quality of the main research (Hazzi & Maldaon, 2015:53). The pilot interview helped to facilitate decision-making on whether and how to launch the study, helping the researcher to evaluate whether the research project was feasible and whether the research questions would be adequately answered through the interview guide designed for this (Eldridge et al., 2016). A pilot also allows the researcher to become familiar with the technique of asking probing questions, since she rehearses the interview schedule and performance; skill is gained in building rapport with the participants, and information is yielded on the interviewer's level of interviewing skills. It also helps the researcher to find out whether the participants' responses to the questions elicit the intended information, so that amendments may be made in advance of the actual interviews (McIntosh & Morse, 2015). One pilot interview, using the eligibility criteria of the study, was conducted at clinic A, to

ensure that the research questions addressed the purpose of the study. The research questions were then slightly modified so that clients would understand them and give appropriate information.

The clinic A had no private room, so interviews were conducted in the room used for pre-ART counselling. This meant that there was no privacy; health workers moved in and out of the room, preventing participants from answering some questions for fear of being heard by the health providers. The researcher then decided to collect data from clinic B where there was an unused room.

3.5.3 Data gathering method

Phenomenological interviews involve conducting more individual interviews with the same or different participants who have experienced the phenomenon in which the researcher is interested (Ellis, 2016:42; Morse, 2016:112). Open-ended questions are used to allow participants to direct the discussion in directions that are important to them and not necessarily to the researcher (Marshall & Rossman, 2014).

3.5.3.1. Structured and semi-structured interviews

Structured interviews are those where the interview schedule is constantly referred to by the researcher, so that all participants are asked the same questions and given identical cues, with the aim of aggregating participants' responses (Bryman & Bell, 2015:211). Semi-structured interviews are based on an interview schedule, but the sequence of questioning and the cues may vary. The researcher may ask further questions probing following a particular response, as may seem relevant at the time. The researcher has an interview guide (Annexure C). The questioning was informal, and phrasing and sequencing varies from interview to interview (Bryman & Bell, 2015:214). The advantages of semi-structured interviews are:

- The approach is less structured;
- The researcher is very flexible;
- Questions are general and phrased according to a frame of reference;
- Insight is gained as to what is important or relevant to the participant;

- Interviews may depart from the interview guide when the researcher asks new questions based on a participant's response; and Interview guide is somewhat structured (Marshall & Rossman, 2014; Thomas, 2017:324).

Semi-structured interviews were decided upon in this study because:

- They allowed for flexibility for more detailed descriptions and narratives (Brinkmann, 2014).
- They have the potential to attend to complex themes (Brinkmann, 2014).
- The focus was on participants' points of view (Bryman & Bell, 2015:201).
- The researcher sought rich and detailed answers (Bryman & Bell, 2015:201).

The role of the interviewer in the semi-structured interviews was to:

- Control the conversation so that issues that are important to the study were discussed;
- Use the interview's potential to produce a 'knowledge dialogue' by allowing leeway in answers, so that angles which are important to the participant may be covered;

In semi-structured interviews there is a greater chance of producing knowledge during the interview process than when the interviewer 'hides behind the interview guide' (Brinkmann, 2014:285).

The local language of the targeted area was used by the researcher so that participants who did not understand English could express themselves freely. Both verbal and non-verbal interactions between researchers and participants shaped the quality of data collected and affected the results of the study in turn (Bengtsson, 2016:10). Appropriately formulated verbal or written questions helped the researcher to understand the phenomena being studied (Bengtsson, 2016:10). The data for the study was collected through semi-structured interviews by the researcher during January and February 2018.

Field notes were used. Field notes refers to the raw data or daily entries made, based on observations in the field, which may contain reflections (Schwandt, 2015). The field notes in this case described observations made during the interviews and documented non-verbal cues such as

gestures, tone of voice, repetition, etc., so that a full picture of the interview was provided.

3.5.3.2 Conducting the interviews

Once a client agreed to participate in the study, the researcher took the person to a private room in the clinic identified for the purpose of conducting interviews. The main objective was to ensure a relatively quiet and private space where the participants could talk freely without the risk of being overheard or seen by others. After introducing herself, the researcher explained the purpose of the study and provided an information sheet (Annexure A). Participant information was given on the form so that participants understood well, both verbally and in writing, what the process would involve, and thereafter their informed consent was sought by means of a signature (Moule, Aveyard & Goodman, 2016:106). When starting the interview, the researcher asked for demographic information so that participants felt less intimidated and more at ease. All interviews were conducted when the participants had just completed a session with ART services, which was their main purpose for visiting the clinic. If a participant was in a hurry on the day of the clinic visit, an alternate arrangement was made for interviewing at a later date. A box of tissues and a glass of water was made available for the participants during interviews. The participants were informed that the interviews would take no more than 30 minutes.

At the beginning of the interview the participants were asked to provide their demographic information (see Chapter 4) and were informed about confidentiality. They were assured that the interview notes, forms and final report would not contain their names anywhere, and that information would be stored in a safe cabinet, under lock and key, to which only the researcher and the supervisor would have access. General questions were asked (Bryman & Bell, 2015:480). The questions were: ‘What is your experience of your first visit for ART treatment at the urban PHC clinic that you attended?’ ‘How can other young adults be supported by nurses when they first visit the clinic for ART treatment?’ After each initial question, probing, questions were asked that encouraged participants to give their independent thoughts about their experiences at the clinic (Adams, 2015:493). Probing questions provide more significant information and vary from participant to participant (Hoevemeyer, 2017:18-19).

Probing questions were:

- ‘How is it for you to ...’
- ‘Tell me more about ...’

- ‘What is your overall impression of the support from nurses to you during your visit to the clinic?’
- ‘How was the treatment and education plan supportive to you?’
- ‘What information did you receive?’

3.5.3.3 Bracketing

In bracketing the researcher suspends his or her assumptions about the world to understand what is essential to the phenomenon without prejudice (Sorsa, Kiikkala & Åstedt-Kurki, 2015:10; Bengtsson, 2016:9). The researcher’s role differs according to the various research methods used, in terms of planning, interview structure and attitude during interviews. In a descriptive study, the researcher uses bracketing to suspend his or her knowledge and assumptions, in order to focus on participants’ viewpoints. Participants’ experiences are described without adding anything to the phenomena. In an interpretative study, previous knowledge is used by the researcher to create new understanding through the research (Bengtsson, 2016:9 & 10). In the current study, the researcher ensured that her preconceived ideas did not contaminate or interfere with the data collected or the resultant findings. The researcher did some contemplation before each interview to limit bias as much as possible. The researcher refrained from engaging too much with the literature on the phenomenon prior to the interviews, to avoid affecting data through her own prior knowledge. Once data collection and analysis were complete, the researcher read as much of the literature as was available.

Bracketing is used to guide how the researcher should behave and reflect during the analysing process (Bengtsson, 2016:14). The researcher should know the context and be aware that this knowledge should not affect the process or outcome of the study (Bengtsson, 2016:14). Researchers should be non-judgemental when conducting interviews. By building trust during interviews, the researcher allows participants to uncover emotions and adjust their storytelling in light of the researcher’s responses and feedback (Bengtsson, 2016:11). Researchers need to have the skill to recognise how bracketing could affect their choices during the interview, and remain focused, while being sensitive to cues during interviews (Bengtsson, 2016:11). All of these the researcher endeavoured to do.

3.5.4 Data analysis

3.5.4.1 Process

Data analysis is the process of breaking down, organising, reducing and describing components of data through drawing conclusions and making interpretations so that sense is made of the data (Schwandt, 2014). Qualitative analysis is an iterative and ongoing process; it begins soon after data collection starts and continues throughout the data collection period (Gelling, 2015:46).

Data from the audio recorder was transcribed exactly as it was (word for word), not paraphrased, and any information which may have compromised participants' privacy was removed to maintain confidentiality. Square brackets, for example, [fearfully] were utilised to indicate the tone of the voice (e.g., tears, laughter, expletives) of the participants during the transcribing process (McIntosh & Morse, 2015). All pages of the transcript were numbered, and the participant's number was placed on them. Once each transcript was typed, the content was checked against the audio recorder to ensure accuracy of the data (McIntosh & Morse, 2015).

All interview data and field notes were coded as soon as the interviews were concluded. The data was analysed using IPA, which enables examination of the topic and the detailed, personal, lived experiences (Eatough & Smith, 2017:193). This method was chosen because:

- It is one way of analysing qualitative data obtained from semi-structured interviews (Smith & Osborn, 2015:42).
- It is valuable when examining emotionally laden topics (Smith & Osborn, 2015:42).
- It is cost effective as it does not use technologically expensive or sophisticated equipment for data collection and analysis (Denscombe, 2014:102).

Colaizzi's (2015) seven-step distinctive process for data analysis was used (table 3.1).

Table 3. 1: Steps in Colaizzi’s descriptive phenomenological method

Step	Description
Familiarisation	The researcher reads the participant’s account several times to become familiarised with the data.
Identifying significant statements	The researcher identifies from the data all statements which are directly pertinent to the phenomenon under study.
Formulating meanings	The researcher identifies meanings from significant statements which are pertinent to the phenomenon. The researcher must instinctively ‘bracket’ his or her assumptions from the phenomenon.
Clustering themes	The researcher clusters the meanings he/she has identified into themes. Bracketing is crucial, to avoid influencing existing theory.
Developing an exhaustive description	The researcher writes a description of the phenomenon, including all the themes produced in step 4.
Producing the fundamental structure	The researcher compresses the description to a short statement that captures the essential aspects of the phenomenon.
Seeking verification of the fundamental structure	The researcher returns the structured statement to participants to check if it captures their experience. He or she may modify earlier steps depending on the feedback.

Source: Morrow, Rodriguez & King (2015:643)

3.5.4.2 Data triangulation

Triangulation is the process of using multiple sources of data collection to confirm the findings (Ary et al., 2018:442). Data triangulation is used for confirmation from the sources (Elsbach & Kramer, 2015:287). Triangulation analysis can be performed by independent coders to validate the study findings and minimise subjectivity in the results (Bird, Menzies & Zimmermann, 2015:49). In this study both the data collected from the interview and the field notes were included for data analysis, and an independent coder and the researcher came up with the themes. The researcher used triangulation of individual interviews and field notes. During or soon

after each interview, the researcher wrote field notes in summary of any event or behaviour observed, noting any interesting words heard, and combining these with the transcript of the digital recorder interview to obtain an accurate record of each interview (Bryman, 2015:440).

3.6 TRUSTWORTHINESS OF THE STUDY

Trustworthiness refers to the degree of confidence that an outsider may have in the qualitative research, and encompasses credibility, confirmability, dependability, transferability (Ary et al., 2018:442). Trustworthiness refers to the thoroughness and competence of the qualitative study (Holloway & Galvin, 2016). An independent coder, referred to as an external auditor, should help to assess and analyse the qualitative data in order to promote the trustworthiness of the analysis (Pieterse, Lawrence & Friedrich-Nel, 2016:386). The trustworthiness of this study was established by ensuring its credibility, which corresponds to its validity, dependability, reliability and transferability of the findings to generalisation (Bengtsson, 2016:14). Data was analysed independently by an independent coder to promote confirmability. Consensus was reached by the primary researcher and the independent coder before the generation of the final themes, to promote credibility. Translation and back translation of the transcripts was also done to promote the credibility of the study.

3.6.1 Credibility

Credibility refers to the process of establishing correct data analysis procedures, to ensure that relevant data has not been excluded (Bengtsson, 2016:14). Credibility is a term used in qualitative studies to describe the accuracy or trustworthiness of the research findings (Ary et al., 2018:442). Credibility demonstrates to readers why they should have confidence in the study findings (Geling, 2015:43). Credibility is concerned with the data collection stage of a qualitative study and involves checking to see if data is complete and accurate for the researcher to use in the study (Roller & Lavrakas, 2015:22). To improve a study's credibility, the researcher needs to design data collection strategies that will solicit accurate representations and design the coding process to be transparent when conclusions are drawn (Zhang & Wildemuth, 2016:323). In this study, the researcher ensured credibility by using the direct words of the participants, and supplementing these with information recorded in the field notes in which the interactions were noted - including the reactions to various events or information. These notes formed part of the data analysis (triangulation). The findings were confirmed by the researcher's supervisor and an independent coder.

3.6.2 Dependability

Dependability refers to the level of stability of the data, since data can subtly change over time through alterations made by the researcher during the analysing procedure (Bengtsson, 2016:14). Dependability demonstrates to readers that the study findings are consistent and repeatable (Gelling, 2015:43). Dependability refers to the consistency of the internal process and how the researcher explains the phenomena under study. The main technique for ensuring dependability and confirmability is the auditing of the study processes and findings. Checking the study processes for consistency is helpful for determining the dependability of the research (Zhang & Wildemuth, 2016:324). The supervisor assisted with it. Dependability was ensured by using data triangulation and included the use of field notes for a more nuanced record of events than the recordings alone would have provided.

3.6.3 Confirmability

Confirmability refers to the neutrality or objectivity of the data (Bengtsson, 2016:14). Confirmability is a term used in qualitative studies and describes the degree to which the findings of the study may be corroborated by another researcher in the same situation (Ary et al., 2018:448). Confirmability demonstrates to readers that the study findings have emerged from the participants' experiences and have not been influenced by the researcher's ideas (Gelling, 2015:43). The researcher ensured confirmability by documenting all procedures, enabling her to check data throughout the study, and also by using direct quotes from participants in the final report.

3.6.4 Transferability

Transferability refers to the degree to which the results are applicable to other groups or settings and is related to the number of study objects or participants. The sample representative will determine the generalisation of the results (Bengtsson, 2016:14). Transferability demonstrates to readers how the study findings may be transferred to another setting or group of people (Gelling, 2015:43). This study provided a detailed description of a qualitative nature about the population and the study setting in question; that is, about young HIV-positive adults who had just completed their first visit for ART treatment at an urban PHC clinic. The strategies used to ensure transferability in this study were:

- Using participant's quotations in the report;
- Selecting participants purposefully, to increase the chances of getting specific information relevant to the study question - participants had to have knowledge about the phenomena under study; and
- Conducting semi-structured interviews and probing for additional information, until data saturation was reached.

3.6.5 Reflexivity

One of the skills needed for researchers is reflexivity, which is used to respond to ethical conflicts appropriately and to react ethically to unexpected situations. Qualitative researchers also use reflexivity to minimise the influence of previous knowledge on the study and to enable them to use their theoretical backgrounds intentionally during interviews (Sorsa, Kiikkala & Åstedt-Kurki, 2015:8). The research topic became of interest to the researcher after she had worked as an ART provider at an urban clinic for over a year.

Participants were frustrated because clinic waiting times were long. The researcher remained open to both positive and negative feedback, although she was aware of the power-relation between herself and the participants, which might have subconsciously influenced participant s' reactions (Lee et 2016:49). While it was an advantage for the researcher to understand participants' experiences and what could possibly emerge from the study, the researcher needed to understand her own role as an interviewer and not a professional nurse at the clinic. Reflexivity refers to a researcher's awareness and level of engagement in shaping the research process (Dalal & Priya, 2016).

3.7 SUMMARY

The researcher used a qualitative, descriptive study design. Semi-structured interviews were conducted by the researcher to collect data from a purposively selected sample of fifteen (including pilot) participants. The interview used open-ended questions, allowing participants to volunteer more detailed descriptions and narratives. Inclusion criteria were that participants had to be young, HIV-positive adults aged between 19 and 25 years, who had completed their first visit to an urban PHC clinic for ART treatment in Malawi.

Permission was obtained from the Ministry of Health and Zomba District Health Office in Malawi.

Consent was obtained from the participants themselves. Anonymity, privacy and confidentiality were ensured during the interviews and report writing.

This chapter described the research methodology, including the population, sample, data collection instruments and the strategies used to ensure the ethical standards, reliability and validity of the study. Consensus was reached by the primary researcher and an independent coder before the final themes were generated, to promote the study's trustworthiness.

CHAPTER 4

DISCUSSION OF THE FINDINGS

4.1 INTRODUCTION

This chapter presents and discusses the findings of the study. The purpose of this study was to explore and describe the lived experiences of young adults with HIV/AIDS regarding the treatment and care they received during their first visit to an urban primary health-care clinic (PHC) in Malawi. The aim was to describe the nurse support for young adults during a first antiretroviral therapy visit at an urban primary health-care clinic in Malawi. Data analysis resulted in the emergence of six major themes:

- Environment: An environment is needed that enhances a client-orientated approach, with a focus on holistic wellbeing.
- Knowledge management: Knowledge management needs to be optimally operated to provide relevant and sufficient information.
- Ethics: There are many ethical dilemmas associated with the provision of counselling for new HIV/AIDS patients.
- Legal matters: Nurses need to be aware of the legal environment surrounding their work.
- ART treatment: The comprehensiveness of treatment is sometimes an issue.
- Motivation: Patient motivation plays a role in effective ART treatment.

4.2 DEMOGRAPHIC PROFILE OF PARTICIPANTS

Sixteen clients were considered for participation in semi-structured interviews, held during January and February 2018. One of the potential participants was excluded because she did not consent to the study. This resulted in a sample of fifteen purposively selected participants.

Participants in the study were identified as being on their first visit if they had not been to the clinic before, or if it was their second visit but they had not yet met with the nurses during the second visit at the time of the interview. In this study there were eleven females and four males (pilot interview

included). See Table 4.1. The gender imbalance may be because there are more new infections in females; Idele et

al. (2014:144) found in that in sub-Saharan Africa, about two-thirds of all new HIV infections in adolescents occur in girls. In 2012, the HIV prevalence in Ugandan girls was nearly double that of boys of the same age, 15–19 years (Ideleal., 2014). After ten years of ART scales up in rural Malawi; it has been found that HIV prevalence in women is higher than men of the same age (Maman et al., 2016).



The mean age of the participants was 22 years, with ages ranging from 19 to 25. Seven participants were married, six were single, one was a widow and one was divorced. Seven of the participants were tested because ART providers urged them to get tested, while eight had done so voluntarily. In the table below, ANC stands for antenatal clinic, OPD stands for out-patient department and PITC stands for ‘provision of initial testing and counselling’ and indicates that treatment was initiated at the suggestion of a healthcare provider when the clients come for other services. VCT stand for voluntary testing and counselling and indicates that testing and treatment was initiated at the clients will.

Table 4.1: Demographic information and triggers for participants’ HIV testing

	SEX	AGE IN	MARITAL	SERVICE	TEST &
P1(pilo)	female	19	Married	ANC/PITC	Yes
P2	Male	25	Married	OPD/PITC	Yes
P3	Female	25	Widow	OPD/PITC	Yes
P4	Female	20	Single	OPD/PITC	Yes
P5	Male	24	Single	VCT	Yes
P6	Female	21	Married	VCT	Yes
P7	Female	23	Married	ANC/PITC	Yes
P8	Female	24	Single	ANC/PITC	Yes
P9	Male	23	Married	OPD/PITC	Yes
P10	Male	20	Single	OPD/PITC	Yes
P11	Female	19	Divorced	VCT	Yes
P12	Female	24	Married	VCT	Yes
P13	Female	25	Single	FP/PITC	Yes
P14	Female	20	Married	OPD/VCT	Yes
P15	Female	21	Single	VCT	Yes

Table 4.2 shows the themes that emerged during semi-structured interviews.

Table 4.2 Themes that emerged during semi-structured interviews

THEMES	CATEGORIES	SUB-CATEGORIES
1. Environment: Creating an environment that enhances a client-orientated approach with a focus on holistic well-being	1.1 Preconceived ideas around the clinic and services rendered	
	1.2 Inviting and flexible environment at the initial engagement	1.2.1 Hearty and warm reception by staff
		1.2.2 Advised to promptly initiate ART
	1.3 User-friendliness; space for different generations or ages of clients	1.3.1 A need for separate waiting areas for various age groups
2. Knowledge management: Use of knowledge management to provide relevant and sufficient information to a newcomer of antiretroviral therapy (ARV)	2.1 Work experience and skills to support clients' needs as a newcomer to the world of ARV	
	2.2. Delivering quality information management	2.2.1 Pre-test counselling with a newcomer
		2.2.2 Pre-ART counselling for every newcomer
		2.2.3 Subjects that are important to address during counselling of the newcomer
	2.3 Role of the patient during counselling to support	2.3.1 Opportunity to ask questions to ease the path ahead
3. Maintaining ethics under difficult circumstances	3.1 Context of professional, ethical behaviour towards clients	

	3.2 Clients are stigmatised by health workers	
4. Acknowledging the legal environment of supporting clients	4.1 Limitations in privacy and confidentiality in the clinics	
	4.2 Incorporating the rights of patients during the first visit	
	4.3 Looking into the quality of services	
5. Comprehensiveness of ART treatment	5.1 Planning services to care for patients	5.1.1 Clients move around different departments
	5.2 Organising and leading appropriate activities in the clinic	5.2.1 Amount of time clients spend at the clinic
6. Motivation of the patient regarding taking antiretroviral treatment (ART)	6.1 Motivation to approach the clinic for support	6.1.1 Provision of initial testing and counselling (PITC); offer to conduct HIV testing
		6.1.2 Clients go for voluntary counselling and testing
	6.2 Motivation to take antiretroviral treatment (ART)	6.2.1 Confirmation test to promote acceptance
		6.2.2 Motivation for adherence
		6.2.3 The role of living examples in promoting acceptance
		6.2.4 Clients are given many types of medication
	6.3 Moving forward in partnership	6.3.1 Involvement of partners and guardians

4.2 THEME 1: ENVIRONMENT: CREATING AN ENVIRONMENT THAT ENHANCES A CLIENT-ORIENTATED APPROACH WITH A FOCUS ON HOLISTIC WELLBEING

The physical environment may affect clients' perceptions of the quality of care they receive, although clients evaluate the environment differently according to their unique expectations and interpretations. The image of the clinic environment can be affected by the nurse/client relationship and the quality of services delivered (Carpman & Grant, 2016:6; Rapoport, 2016:26). The holistic approach in health care includes a comprehensive physical, psychological, spiritual and social assessment of a client's needs rather than a focus on diseases alone. However, this is quite challenging because of the shortage of skilled nurses, resources and infrastructure (Siouta et al., 2016:8). HIV counselling is one of the core elements of health care in this HIV era (Chippindale & French, 2018:145). Client-centred care refers to nursing care which is focused on clients' specific needs and preferences and helps to increase clients' self-management (Kieft et al., 2014:249). The client-centred approach involves an assessment of needs which may extend beyond those directly related to their illness. Clients need to be helped to focus on what is important to operate their everyday lives and deal with uncertainty (Komatsu & Yagasaki, 2014:423).

4.3.1 Category 1: Preconceived ideas around the clinic and services rendered

Clients choose a clinic because they have received information about the clinic and health providers from other people or have done their own survey before deciding where to go for HIV care. Sometimes clients are motivated to go for health care because they have been exposed to information about the services offered (Sanga et al., 2015).

One participant said she had been referred to the clinic by others, and came on the basis of their recommendations:

'I came here just to differentiate between this place and the other clinics ... some people were recommending this clinic; that they know how to treat patients - that's the goodness of this place.' (P 2)

Participants heard that the clinic focused only on specific services that provided a form of privacy:

(Avoiding eye contact): *'The place is nice, unlike other clinics where they combine with those on malaria treatment, some people can see you and spread the messages that you are on ARV treatment, as a result you may feel disgraced to people who knows*

you. ' (P 11)

'In other hospitals everybody is able to see them when they are queuing at ART department while at this clinic is a hiding place and people can't know that you have gone there to collect medication.' (P 14)

If clients have positive preconceived ideas about a clinic they are more likely to seek care there, based on the information they have received. Treves-Kagan et al. (2015) found that men and youth who knew that a clinic delivered integrated HIV care together with reproductive health care services would avoid seeking care at such a facility, viewing it as for females only.

4.3.2 Category 2: Inviting and flexible environment at the initial engagement

Apart from experiencing the normal anxiety and fear associated with being diagnosed HIV-positive, many newly diagnosed patients fear the nurses who treat them (Dang et al., 2017:32). A patient's first experience with nurses has the most impact for a client with HIV, because during this visit patients form lasting impressions of the nurses and the clinic and are at their most vulnerable. They need urgent reassurance at the first visit that they will be able to control their disease (Dang et al., 2017:32). Participants in this study mostly experienced an inviting environment in which staff members were flexible in their approach to care.

4.3.2.1 Sub-category: Hearty and warm reception by staff

Participants reported having received an overall positive reception at the clinic. Koirala (2017) says that clients who are satisfied with the quality of communication from nurses regarding their HIV infection and ART treatment usually adhere well to their ART regimens. Participants in this study reported that they were warmly welcomed by the nurses:

'Everyone was flexible and free to help me. That was known by the friendly faces they showed me, they were smiling and were not shouting at me.' (P 12)

'She welcomed me very well and she encouraged me.' (P

13) A participant was happy with the care provided at the clinic:

(Smiling while talking) *'They treated me very well.'* (P 6)

A client felt that patients needed a warm welcome to feel encouraged to revisit the clinic, and to recommend the care to their friends to attend:

'To say the truth they assist us, I'm saying this because what brought me here is that some people were recommending this clinic that they know how to treat patients - that's the goodness of this place.' (P 2)

If clients are properly taken care of, they are likely to feel satisfied and to recommend the service to other people. This was confirmed by McLean et al. (2017) who found that clients sought care at a particular clinic based on recommendations from friends and/or relatives who had had positive experiences with the providers and the facility (McLean et al., 2017:4). A warm reception by clinic staff, including the HIV/ART nurses, was mentioned by most of the participants as a factor that built a trusting relationship. Yahia et al. (2015:246) suggest that positive relationships with nurses increase the sense of trust and confidence in the nurses' recommendations and advice. Lam(2016) confirmed that good communication with nurses motivates clients to make appointments and remain on their medications.

4.3.2.2 Sub-category: Advised to promptly initiate antiretroviral therapy(ART)

Health services are effective when they are backed up by skilled and evidence-based care, which meets clients' needs and expectations (Barr & Dowding, 2015:229-232). Delivering an effective service helps to improve health outcomes with reduced costs for both the clients and the health delivery system (Stanhope & Lancaster, 2015: 67).

Some nurses thought ART ought to be initiated on the same day of HIV diagnosis. It was mentioned that prompt medication was seen by nurses as essential:

'... And he told me to start treatment immediately.' (P 2)

'That day when I came they tested me and the result came positive; then I was given medication.' (P 3)

'Then they told me nowadays when someone test positive he/she must start the treatment right away.' (P 8)

Immediate initiation of treatment after a positive HIV test could help to capture clients who become lost to the health system when they are given an opportunity to go home and possibly decide against being treated. A participant felt positive about being forced to start medication straight away:

'To me it was compulsory as they said when found positive I should receive ARVs at the same time. It's good to continue with the strategy because these days many people can promise to come back for ARVs yet change the decision according to their nature.'

(P 9)

Apart from reducing the viral load and improving the immunity of the infected individual, ART treatment also reduces the risk of infecting others due to viral suppression (Günthard et al., 2016:201). ART reduces the mortality rate among people living with HIV (PLWHIV) due to its retarding effect on the disease's progression (Tymejczyk et al., 2018).

A participant also said that the strategy of same-day testing and treatment should continue because it reduced the number of visits to the clinic that clients had to make:

'I thought of getting tested, then I went on though it was during lunch time but still more they assisted me after getting my results. That sister (the counsellor) took me where the pre-ART counselling took place, after that I was given all the medication. Now am on my way home.' (P 4)

Natoli et al. (2015) suggest that the advantage of same-day treatment is the reduction of time between testing and treatment provision. However, Atanga et al. (2017:161) point out that same-day treatment initiation may not give the clients enough time to prepare and become ready to commit themselves to lifelong ART treatment.

4.3.3 Category 3: User-friendliness; space for different generations or ages of clients

When old and young people were given health education in the same room and at the same time because of limited space, the environment was experienced as uncomfortable. The situation could end up with younger clients being uncomfortable about asking questions because of fear of being teased by the older people (Ahamuza et al., 2016:41).

4.3.3.1 Sub-category: Need for separate waiting areas for various age groups

Culturally in Malawi, discussing sex issues is taboo, with the issue frequently tied to pressures from older people and religious leaders (Newton-Levinson, Leichliter & Chandra-Mouli, 2016:7). This

attitude could be responsible for the discomfort young adults feel when among older people for HIV care, which to some extent cannot be discussed without mentioning sexuality. Parents are mostly against youth sexual activity and do not discuss or educate them about sex, while young people are in need of this information (Newtong-Levinson et al., 2016:7). Traditional, conservative beliefs with regard to sexuality prevented young adults from accessing the necessary information about sex, due to a sense of shame and adult reluctance to discuss sexual matters - although they could be a good source of information (Yari et al., 2015:278).

Some participants disliked the small size of the waiting room and many disliked the mix of ages present together in the small space. They indicated a preference for separate waiting areas for clients of different age groups. A male participant advised that the clinic needed to have different waiting areas for different age groups:

'Maybe it could be better if you could have separate place like adults should have their own place and youth too should have their own place. Maybe there are other people who feel uncomfortable when they are mixed.' (P 5)

Another participant thought it would be better to have different clinic days:

'My concern is about these young children, my opinion is, it could be better if these young children should have their own day. Children should have their own room and adults, too, they should have their separate room, because there is no respect when both of us we are collecting medication at the same place.' (P 14)

Sometimes nurses do not understand the needs of HIV-positive young adults and are judgmental towards young adults who are sexually active (Nabukeera-Barungi et al., 2015:520).

Not only were the clients looking for separate spaces for age groups, they also expressed a need for separate spaces for different conditions. A participant suggested that clients with different conditions should have different waiting areas.

(Separating the hands while talking): *'Queues to receive ARVs, people should not mix, every condition should have its queue, malaria and to receive ARV treatment supposed to be different queues.'* (P 11)

Many participants reported the need for a separate waiting area for youth and adults. This finding supports that of a recent study conducted in Nyanza, Kenya, where it was found that the use of youth-friendly services is not, in and of itself, sufficient to improve patient retention in care,

with some young adults reporting stigma and a fear of disclosure to the community as a reason for their disengagement (Wolf et al., 2014:1154).

4.4 THEME 2: KNOWLEDGE MANAGEMENT: USE OF KNOWLEDGE MANAGEMENT TO PROVIDE RELEVANT AND SUFFICIENT INFORMATION TO A NEWCOMER OF ANTIRETROVIRAL THERAPY

Information refers to data which informs intellectual concepts, which can be developed for the purpose of understanding something (Pearlson, Saunders & Galletta, 2016:11; Webb, 2017). The desire to attain knowledge is a personal, self-modifying state which can change following acquisition of information (Webb, 2017). Relevant information refers to organised and processed data which should be valuable, be read and should match a person's specific needs (Stair & Reynolds, 2017:481; Wager, Lee & Glaser, 2017:23).

4.4.1 Category 1: Work experience and skills to support clients' needs as a newcomer to the world of ARV

Nurses' knowledge, technical skills and communicative capabilities are important for providing high quality, effective and safe patient care (Kieft et al., 2014:249).

A participant mentioned that when the nurses had experience in nursing, they performed their work faster than novices did:

'The other problem is people who work there. Others are new, as a result, they are slow. At the same time, there are others who have been working there for so long and they are very fast so we as patients we have to understand them.' (P 8)

Nkhata et al. (2016:660) found that tasks which were previously performed by nurses have sometimes been undertaken by untrained personnel such as health surveillance assistants and long-term clients. These tasks may include drug distribution, HIV testing and counselling.

Experience makes a difference. This experience may be in providing HIV care or in the use of computers, as electronic medical records are used in ART departments. Clients who receive care from competent nurses who listen to them and treat them as individuals are likely to adhere to treatment (Ndou, Maputle & Risenga, 2016:1).

Other participants felt that the use of technology contributed to the long waiting times:

'Then you go for registration - this is where the file is opened. After that, they have to

record the information in the computer, so it takes time.' (P 13)

'I know of course that there is too much process because of this technology but still more we need to be served faster.' (P 12)

Some participants seemed unaware that some of the healthcare providers serving them were not nurses; they thought they had been counselled by a nurse while in fact they had interacted with a cadre of untrained people. Providers without skills in computers can take a lot of time to capture the clients' details, delaying the entire process. The use of technology in healthcare is most helpful if the users are competent and skilled (Korhonen, Nordman & Eriksson, 2016).

4.4.2 Category 2: Delivering quality information management

Young adults want information on the nature of their disease, about manageability and survival rates, and about how they can prevent premature death by adhering to treatment protocols. A deeper knowledge of the disease and their responsibilities in managing it would facilitate greater adherence, and for this reason, counselling coupled with the provision of information should be ongoing (Mathibe et al., 2015; Ankrah et al., 2016:329).

4.4.2.1 Sub-category: Pre-test counselling with a newcomer

Pre-test counselling with accurate and up-to-date information helps clients to give informed consent for testing (Chippindale & French, 2018:145). One of the participants disliked the questions in the testing room:

(Stretching the hands and stay quiet for some seconds before speaking):

'Just imagine! I was asked, why have you decided to come for testing? This question can make someone to go back home. Whoever has decided to come here for testing it means that he or she has already made the decision at home, so that's not a good question.' (P 8)

Clients do not want their providers to use verbal or non-verbal language which is insensitive and judgmental. Kind and non-judgement response from their providers makes clients take note of the advice given (Dang et al., 2017:32). Sometimes there are no test kits in the clinics, leading to clients having to return at a later stage. For some clients, it is difficult or impossible to come back later for testing, as pointed out by this participant:

(Opening the hands while talking): *'I have been coming here, but I was told that there*

were no test kits, and with my piece work it is very difficult to come now and then.' (P 5)

Lack of resources in the clinic leads to lost opportunities for clients to be tested and treated in time. Where test kits are in short supply, PMTC clients receive higher priority than others. Chitete and Puoane (2015) found that the intermittent supply of HIV test kits was affecting delivery of HIV testing.

4.4.2.2 Sub-category: Pre-ART counselling for every newcomer

Pre-ART counselling is very important, as it offers an opportunity to support clients on an arduous emotional journey that requires strict and regular medication to be taken for life. Counselling should be individualised (Chippindale & French, 2018:147). Participants said that they had undergone a pre-ART counselling session before they received the drugs. Some comments on pre-ART counselling were:

(Speaking assertively and looking straight into the interviewer's eyes): *'I was told that nowadays when a person tested positive, he or she is supposed to start the treatment right away. Before that, we were required to go for treatment counselling, then after that we can provide you with the medication. What's your opinion?'* (P 8)

'We attended treatment counselling and we were given instructions on how to take medication because we are positive.' (P 7)

(While swinging a leg repetitively): *'We attended treatment counselling and we were told instructions which will be followed when taking medication because we are positive.'* (P 9)

Topics discussed at an ARV clinic range from side effects to drug resistance. Bezabhe et al. (2014) found out that ART nurses generally do provide counselling to motivate patients to take their pills. Abdurahman et al. (2015:157) say that counselling from well-trained, skilled and competent personnel had significant positive effect associated with it and led to increased self-acceptance by clients of their conditions. Many new clients are given only brief counselling by long-term clients who have attended a two-day, standardised Ministry of Health training course for ART counselling (Landes et al., 2017:341). If clients attend more than one counselling session, they could be greatly helped to assimilate and process information, since they would be more likely to discuss their issues with nurses when exposed to counselling over a period of time (Dlamini-Simelane & Moyer, 2017:20).

4.43 Category 3: Subjects that are important to address during counselling of the newcomer

4.4.3.1 Sub-category: Side effects

Almost all participants received the information that they might experience some side effects of the drugs, especially during the first days of their treatment. Clients were encouraged to report all such side effects to the clinic. Side effects have been associated with ART non-adherence and even discontinuation in some clients (Phillipset al., 2016). First-line therapy for ART has relatively short-lived side effects; however, these early side effects may disrupt initial adherence to treatment which is very important in setting long-term adherence, retention in care and treatment success in general (Phillips et al., 2016).

Participants were informed about side-effects they may experience:

(Looking down): 'When you are just starting the treatment there are so many side effects, for example other people have bad dreams. Sometimes you could dream someone chasing you, secondly other people feel dizziness, others develop a rash on the whole body or have strange sickness, like mental disorder. I was told that if I experienced any of these side effects I should report to the hospital for treatment.' (P 8)

'We went to another room where they told us the side effects of the drugs. He said if we experience any side effects we should come to meet him again.' (P 9)

The value of informing clients about expected side effects is that it tends to reduce anxiety when such effects occur. Clients who had experienced side effects were able to understand what was happening to them:

'It was true, for the first three days I felt dizziness, sometimes I felt fever at night, and was urinating too much. After three day I recovered.' (P 10)

The first months of treatment are especially important as viral suppression and immunologic a l improvement are expected during this time. Early adverse drug reactions, opportunistic infections and/or immune reconstitution inflammatory syndrome (IRIS) may develop in the first three months of this lifelong treatment (WHO, 2016:74).

4.4.3.2 Sub-category: Stress

Stress refers to an emotional experience that leads to failure to manage threats following changes in social or personal situations. Stress can affect the physical or psychological being of an individual, leading to changes in the cognitive functions (Cassel, 2017:8). Stress affects people in different ways. HIV-positive people are subject to increased stress, with many having started treatment therefore counselling on the effects of stress became part of standard ART counselling. If a clients' cognitive functions are affected by stress, their ability to take medication and remain in care are likely to be affected. Hence there is a need to provide proper stress management to clients before the initiation of ART (Brion & Kempainen, 2017:181).

Participants spoke of the effects of stress during ART treatment:

'When one has stress and is taking medication, nothing can happen, when someone has stress it is easy to forget to take the medicine, but when you don't have stress and you taking medicine at the right time, this can result to good health.' (P 5)

'I was also told that when you are positive, avoid stress, if you have stress your body doesn't look good. At the end you lose weight, though you're not sick.' (P 8)

Another participant knew the importance of avoiding stress:

(Bending forward while talking): *'I was told that I should avoid stress if possible so that I can have good health.'* (P 2)

Most clients experience shock and distress after receiving HIV-positive results, increasing the need for proper counselling, support and reassurance about life after the diagnosis (Horter et al., 2017:54-56). Simply telling people to avoid stress is not enough; counselling is needed to reduce the stresses already being experienced and to provide clients with strategies to maintain a healthy life.

4.4.3.3 Sub-category: Prevention of mother-to-child transmission (PMTCT)

As all female participants were of childbearing age, it was important to give them information on PMTCT (Peltzer et al., 2018:9). Nurses need to provide counselling on PMTCT, which includes waiting for the CD4 count to be high before conceiving, initiating the woman on ART during pregnancy, encouraging adherence to ART, and explaining the importance of attending ANC, having a hospital delivery and breastfeeding (Matthews et al., 2014). HIV-positive pregnant

women should be encouraged to deliver at a health facility to ensure access to PMTCT services and safety for both mother and infant (WHO, 2015:30).

A participant told she was advised of the need to initiate ART while pregnant:

(Taking a deep breath): *'Because both of us are positive and we are also expecting a baby, that's why we should start treatment and we should also use condoms.'* (P 7)

For those who are single, this information gives hope for future families. A male participant said:

(Seeming shy and looking down while speaking): *'When we are together we should use condoms. This doesn't mean that people who are on treatment cannot have children. No, they can have children but must use condoms at certain stages. Pregnant mothers are given medication which prevents unborn baby from getting infection.'* (P 5)

(Leaning forward, looking very serious and covering the mouth with one hand): *'We should always use condoms when a woman is pregnant to avoid infecting the unborn baby.'* (P 9)

Participants showed courage in receiving ART treatment while going ahead with starting a family, ensuring that their children would be free from the virus. Although PMTCT counselling is mostly focused on contraceptives, methods of preventing perinatal transmission and condom use, but safer conception were not discussed during counselling. This is mainly because nurses were not comfortable discussing these topics. Nurse training on handling pregnancy while reducing HIV transmission to a partner is needed (Matthews et al., 2016:7). Such training could help clients to reach their fertility goals while protecting their partners and their unborn children. Tenthani et al. (2014) found that women who enroll on ART during antenatal care and while breastfeeding to prevent infection of the child are generally not prepared for life long treatment, since they are initiated on treatment on the same day as diagnosis (Tenthani et al., 2014:589).

4.4.3.4 Sub-category: Safe sex

Advice on safe sex, condom use, prevention of re-infection and prevention of infecting others should be given to clients before initiating them on ART (WHO, 2016:72). Many participants had information on safe sex and reinfection when on ART treatment.

A participant knew how to avoid re-infection:

'If you have sex with someone who is positive, and that person is not on treatment, there are very high chances to transmit the disease to the one who is on treatment.'
(P 6)

A participant had information on the need for both partners to know their status:

(Rubbing the hands while talking): *'Before having sex, we have to visit the hospital for testing. I know I am positive, so he should do that. It's very bad to have unprotected sex because the chances of increasing viruses can be high.'* (P 11)

Discordant couples (where one is HIV-positive, and another is HIV-negative) were encouraged to protect the uninfected partner during sex. Couples who are given adequate information on ways to do this may be helped to remain together despite the HIV-positive status of one partner.

A participant was told to practice safe sex to protect her partner:

(Avoiding eye contact): *'As I am positive while my husband is negative, so we should use condoms when having sex so that I should not infect him.'* (P 14)

Discordant couples need comprehensive information on safe sex to protect the partner who is negative and to protect their unborn baby (Del Romero et al., 2016).

4.4.3.5 Sub-category: Lifelong treatment

ART is a lifelong treatment and requires high levels of client commitment (WHO, 2016:74). It was noted that the participants knew that the treatment should be taken every day, but none made specific statements which indicated awareness that this was a lifelong treatment. It is possible that clients adhere to taking medication every day for a specific period, and then stop.

Participants knew that the treatment should be taken daily:

'The health worker asked me if I'm ready to use ARVs, he explained about its effects, and he also told me to take drugs every day.' (P 12)

'I was told that I should not stop taking medicine.' (P 4)

Another participant indicated that he felt free to go to the clinic to replenish his medication even before his appointment date, saying:

'I was told that whenever I'm going away but I don't have enough pills, I'm allowed to come here and do the refilling.' (P 5)

Clients should be given information on the benefits of early initiation, the requirement of lifelong commitment to treatment, the availability of adherence support and the risks of delaying treatment (WHO, 2016:74).

4.4.3.6 Sub-category: Drug resistance

Poor adherence to ART could lead to the development of drug resistant proviruses (Muri et al., 2017:68). Nurses need to ensure that clients do not skip doses, as this can lead to drug resistance. Participants had information that skipping doses could lead to drug resistant viruses:

'This can also happen to the human body - if missing doses of ARV, it could lead to drug resistance.' (P 13)

'Skipping pills is not recommended. In so doing it allows the virus to be active, so this can result to high viral load.' (P 5)

'I was told that missing doses of ARVs lead to disease progression.' (P 7)

ART adherence is not only critical for good health but also to prevent infection of others, to reduce HIV viral load and to prevent drug resistance (Clay et al., 2015). Gunda et al. (2017) state that clients should take ART every day for life and should avoid skipping a single dose to prevent worsening the HIV. If clients get enough information on how ART works and the schedule for taking ART, they could prolong their lives.

4.4.3.7 Sub-category: Nutrition counselling

PLWHIV in low-income settings are at high risk of micronutrient deficiencies due to their diets, which tend to be low in essential vitamins and minerals. Micronutrients help to boost the immune system (Visser et al., 2017). Good nutrition promotes quality of life and increases the effectiveness of antiretroviral treatment, while malnutrition facilitates immunosuppression and disease progression in PLHIV (Abgaryan, 2015). The most frequently mentioned issue regarding nutrition among participants in this study was the importance of a well-balanced diet; however, none could list an example of a balanced meal, nor the recommended amounts of specific food categories. The

clients simply knew that a balanced diet could promote their good health.

Participants indicated that their level of knowledge about a balanced diet was fairly limited:

(Taking off one shoe while talking): *'I was told that when you're positive it's important to eat balanced diet food. This helps to build the body.'* (P 8)

'I was told that we should eat balanced diet food.' (P 4)

'I was told that I should eat more fruits like banana, oranges and mangoes. I was told to eat vegetables, fish, meat and beans.' (P 14)

Ezechi et al. (2016:10) found that there is a gap in nutritional knowledge among HIV-positive clients. Clients need nutritional knowledge to improve their diets. SS, Srivastava and Verma (2015:7), however, found that there is much improvement in knowledge, attitudes and practices regarding nutrition after HIV-positive clients have been properly counselled.

4.4.4 Category 4: The role of the patients during counselling to support

Clients are supposed to be involved directly in their health management and encouraged to be responsible for their own health needs. Clients should express their views during counselling, even if these differ from those of the counsellor (Bond, 2015:104; Gable & Herrmann, 2015:10).

4.4.4.1 Sub-category: Opportunity to ask questions to ease the path ahead

Clients should be offered opportunities to ask questions and the nurses should respond to questions in simple language so that clients understand.

Clients in this study were given the opportunity to seek clarification in areas where they did not understand:

'She [the nurse] was very friendly. She even gave me a chance to ask her questions. Had it been that she was not friendly she could not have done that ... I was satisfied with her answers.' (P 8)

'I was given a chance to ask questions.' (P 5)

Although clients had a chance to ask questions during counselling sessions, some clients were not satisfied with the way their questions were answered:

(Shaking the head): *'I asked them about the time to take drugs they did not explain very well to me.'* (P 9)

Clients were given counselling before ART initiation; however, it seems that the information provided was not sufficient. Providing inadequate information reduces opportunities for clients to make informed decisions (Mwangala et al., 2015). Mwangala et al. (2015) found that task shifting in health service provision affected quality of information provided to clients.

4.5 THEME 3: MAINTAINING ETHICS UNDER DIFFICULT CIRCUMSTANCES

4.5.1 Category 1: Context of professional, ethical behaviour

Professionalism is an attitude towards one's work that leads a group of people to come together to make and keep promises to the society they serve, and to decide how best they can deliver this service in an ethically correct way (Wynia et al., 2014:712). The need for nurses to be professional was highlighted by a participant. According to participants, some nurses behaved unprofessionally.

A participant was frustrated by the absence of attention provided by a nurse:

(Speaking a high-pitched voice): *'The nurse who was on duty to say the truth, I was very disappointed the way she treated me. She didn't take care of me. You could tell by the way she was responding. She wasn't all that attentive. Just imagine, I came here at 8 o'clock, but till 11 o'clock was not yet attended to.'* (P 2)

Participants' information was discussed by health workers outside the counselling room:

(Voice becoming hoarse): *'It's like we were discussed that in a secret room and I was surprised that they were discussing that outside ... It's not all who act like that, there some who are professional, and they do everything very confidential.'* (P 15)

It was not only nurses' attitudes towards confidentiality that were problematic, but also their punctuality.

A participant noted that nurses started their work late:

(Looking at wrist watch): *'The health workers start their work late especially that department. For example, today patients came here early in the morning around 8 o'clock but still. You could find that cleaners have not yet cleaned the place and we*

were chased away and they started working around 9 o'clock. To add on that, the process is too long. For example, other people work and they make their plans that after collecting their medication it's when they will go to work. It could be better if workers could start their work in good time.' (P 13)

Nurses need to be committed to the ethics of their profession for them to provide proper care to clients (Dehghani, Mosalanejad & Dehghan-Nayeri, 2015:61). Nurses should be aware of the sensitivities surrounding HIV infection and treat clients in a way that encourages them to return for more medication. Nurses should develop a sense of responsibility for their behaviour, since a good nurse/client relationship is an element of professional ethics. Without a positive attitude, patient care is affected (Dehghani et al., 2015:61).

4.5.2 Category 2: Clients are stigmatised by health workers

Stigma is a social construct that reduces an individual from the usual person to an imperfect one (Major et al., 2017:4). A sense of stigma attached to the clinic or in the health care system discourages HIV-positive clients from seeking health services (Ahamuza et al., 2016:41; Levison et al., 2017:1749; Wachila et al., 2017:646). Some young adults may avoid ART clinics because they fear that they might encounter familiar people who might spread news of their status.

A participant did not want to be seen by familiar people around the clinic:

(Moving the chair backwards while talking): 'I cannot feel comfortable to be seen by someone who comes from where am living. I would be very worried.' (P 13)

Another participant felt comfortable among clients with the same condition:

'It was well since we are the same, both on ARVs treatment, I would be worried if they would not be on ARV treatment.' (P 11)

This finding regarding stigma is confirmed by Wachira et al. (2014:646) who state that stigma is often associated with the department or clinic providing HIV care. On the other hand, nurses may also stigmatise clients. It is stated by Treves-Kagan et al. (2015:8) that gossip by nurses may lead to many clients avoiding HIV services at their nearest clinic and choosing rather to receive care in a distant community. The presence of health workers in the counselling room who are not part of the counselling could promote this stigma.

A participant was emotional and upset by a nurse's comment:

'They were so friendly but there was someone who said, 'I don't take that', so I was very upset, I even thought that maybe It's because am the only one who is in that condition.' (P 4)

Fear of stigma and discrimination from nurses and the community is one of the problems which lead people to stop taking ART (Atanga et al., 2017:161). Similarly, in a study by Yehia et al. (2015:246), participants were afraid to be seen by people they knew due to uncertainty about how they would respond to their status. These fears may well affect their willingness to attend appointments. Shubber et al., (2016) also state that stigma is one of the barriers to adherence.

Stigma and discrimination cause clients to avoid taking medication in the presence of others who don't know their status and affects their obtaining and keeping medications (Bezabhe et al., 2014). Stigma also leads some people to limit the number of friends and relatives who know their HIV status (Treves-Kagan et al., 2015:8).

4.6 THEME 4: ACKNOWLEDGING THE LEGAL ENVIRONMENT OF SUPPORTING CLIENTS

In the health environment the law of the governing practice assists nurses to make decisions about patient care (Cherry & Jacob, 2016:121). These legal and professional issues impact on nurses' responsibilities with regard to effective communication and confidentiality, and their assessment of clients' mental capacity to consent to treatment (Arnold & Boggs, 2015:446; Dougherty & Lister, 2015:102). Clients have the right to make informed decisions related to their health needs after receiving sufficient information (Arnold & Boggs, 2015:285).

4.6.1 Category 1: Limitations in privacy and confidentiality in the clinics

Clients fear that nurses who lack confidentiality may disclose their HIV status to the community (Wachila et al., 2014:646). The findings showed that there was a need for privacy in the care of HIV clients, with many participants emphasising the importance of a waiting area which could provide privacy.

One participant felt comfortable with the environment at the clinic because people would not know the reason for her visit there:

(Smiling while talking): *'At other hospitals everybody can see them when they are queuing at ART department, while at this clinic, it is discreet. People can't know that you have gone there for ART.'* (P 14)

The risk of being seen at the HIV-specific waiting room could lead to clients' HIV status becoming known in the surrounding community (Treves-Kagan et al., 2015:8). The existence of a specific department for ART can stigmatise clients. Even when confidentiality and privacy are maintained during counselling, the mere fact that a clinic or section of a clinic is set aside for ART would compromise confidentiality and possibly prevent people attending.

One participant said privacy was also compromised when clients were given their drugs in the waiting area in the presence of other clients:

'Upon reaching the hospital this morning we were given our medication in the corridor and people were shouted if they were not taking medication properly.' (P 9)

The use of a waiting area for ART services not only affected clients' privacy but could also discouraged them from discussing the problems they were facing with nurses. This is confirmed by Church & et(2015), who stated that privacy is particularly impeded in some ART clinics where drugs were distributed on chairs in the corridor. Clients could not discuss their personal matters. For clients who did not adhere to protocols, nurses should empower them rather than discipline them (Dlamini-Simelane & Moyer, 2017:20).

A participant was not comfortable discussing his problem when there was limited privacy:

(Appearing shy and looking down): *'While everybody is watching at me, there is lack of respect. Sometimes you may happen to have a problem and you don't want everybody to hear what's going on, but you are forced to shout and everybody can hear you. That's not good.'* (P 14)

Another participant stated her appreciation that, in her case, counselling and drug administration were done in the same room to promote privacy:

'There was no problem because medication was given in the private room and none knew about what was going on.' (P 7)

The issue of using a private room for drug refilling was quite prominent among all participants. The use of the same room for counselling and drug administration would promote privacy and instil greater trust among clients. In part, failure to ensure privacy in this clinic could be attributed to

the limited space available for providing services. Ahumuza et al. (2016:41) suggest that expanding the space available would help address this ethical issue.

Confidentiality among some nurses is also perceived as a problem. Clients felt that confidentiality was violated when their information was shared with another health worker. One participant said that some of the nurses shared clients' information with the public. Clients feared that nurses would disclose their status to other people (Wachira et al., 2014:646). However, other researchers have also found that this breach in confidentiality and privacy are sometimes due to limited space (Mwangala et al., 2015).

A participant overheard a health worker sharing her information:

'After the counselling when I was passing that corridor, one of the people who gave me her testimony was telling her friend, a workmate, that "that girl was crying after learning that she was positive." I heard that.' (P 6)

Ensuring confidentiality for clients with adherence problems is essential. Breaches of confidentiality could be regarded as a demotivating factor for retention in care for young adults (Ahumuza et al., 2016:41).

4.6.2 Category 2: Incorporating the rights of patients during the first visit

Clients' dignity in all areas of health care should be preserved in all phases of their care. This includes the communication of information, respect for clients' autonomy, physical privacy, and respectful interactions, all of which help clients to tolerate the physical and psychological vulnerabilities of their condition and/or diagnosis (Ferri, Muzzalupo & Di Lorenzo, 2015:41).

A female participant felt nurses did not respect their rights:

'I'm saying this because other children are school-going children and yet they are on treatment. When their dates are due for refilling, for example, they supposed to come for refilling on 5th, that's on Monday, Wednesday or Friday its obvious that child will be absent from school. Let's say it's during exams- it means that child will miss exams in order to come here for refilling. Do you think the teacher of that child will give her exams? No, it can't happen! If this child chose to go to school to write exams it's obvious that this child will miss his appointment.' (P 4)

Clients have the choice to accept or decline ART; if they choose to defer ART initiation, it can be offered to them again at subsequent visits (WHO, 2016:72). ART treatment should be initiated based on a client's informed decision (WHO, 2016:74). HIV-positive clients also have the right to be treated if they have other problems. Treatment should not be limited to ART treatment (Ferri, Muzzalupo & Di Lorenzo, 2015:41).

A participant felt the right to agree to treatment was not respected:

(Shaking the head while speaking): *'To me it was compulsory, as they said when found positive I should receive ARVs at the same time, yet when having some other disease, they did not give me treatment at the same time.'* (P 9)

'I complained that I have painful bones, so I was told to go and collect Brufen. I refused and told them that I get better when I take Diclofenac, but they forced me to take Brufen.' (P 4)

If clients have been forced to take ART, there is a likelihood that they will not take the medication as prescribed (McLean et al., 2017:3). Sometimes nurses expect all clients to accept their decisions without question; if the client is not submissive to nurses, they are labelled 'uncooperative' and may be punished for it (Ondenge et al., 2017:4).

Campbell et al. (2015) found that sometimes nurses thought HIV-positive clients did not deserve prescriptions for other medications they may need. If clients' dignity is not respected, treatment adherence could be compromised (Wung, Peter & Atashili 2016:280).

4.6.3 Category 3: Looking into the quality of services.

Bezabhe et al. (2014) suggest that poor healthcare services could discourage clients from remaining on ART.

A participant thought the counselling process was repetitive:

(Drawing a circle in air with the hand while talking): *'I noticed many redundancies. I went to many offices giving me the same advice, and I was worried and asked myself why they can't just send me to a particular place where I can receive drugs and the advices regarding the ARVs at the same time, instead of moving around for three hours repeating the same things.'* (P 9)

Sometimes clients were sent back from the clinic without ART because the providers were not

present on that particular day or nobody wanted to care for those clients:

'I was told that everything will be done on Tuesday because those people who are responsible for that were not around ... I was told that people who dispense medication were not available, that's why I was told to come again on Tuesday.' (P 2)

'I have a problem of itching around my private part, I was told to meet the doctor, when I went there the doctor send me to another person, then I end up giving up without collecting medication for that.' (P4)

Wachira et al. (2014:646) state that health facilities lack proper linkage systems between HIV testing and care. Clients can return home without being assisted because of clinic layout and procedures.

47. THEME 5: COMPREHENSIVENESS OF ANTIRETROVIRAL THERAPY (ART)

The HIV/AIDS comprehensive care package includes HIV testing, preventive strategies, timely ART initiation, the management of opportunistic infections and the care provided to people at risk of acquiring the infection from their families (WHO, 2016: xiv).

4.7.1 Category 1: Planning services to care for patients

Clients who present for ART services for the first time are required to undergo history taking and full clinical examination to rule out signs of opportunistic infections such as TB and meningitis before ART initiation is offered (WHO, 2017:20). The speed of ART initiation, which includes same-day ART, increases the possibility of care professionals missing clinical conditions which require management before the initiation of ART. However, it also increases the number of cases initiated, reduces mortality, and reduces the chances of transmission to HIV-negative sex partners and unborn babies (WHO, 2017:22).

4.7.1.1 Sub-category: Clients move around different departments

Clients may experience discomfort if they pass through too many hands and different processes at a

clinic before they receive the services they are looking for (Dlamini-Simelane & Moyer, 2017:20).

One participant felt that the clinic was too small for the number of clients who attended for ART:

(Putting her hands together): *'The space it's too small to accommodate more people and you could end up standing.'* (P 3)

A participant advised on the need to improve the infrastructure:

'My suggestion is you should improve the infrastructure as you can see there are a lot of patients and the hospital is too small.' (P 13)

Another participant thought that if the waiting area was reserved for ART clients only, the situation would be much better:

'Queue to receive ARVs people should not mix, every condition should have its queue, malaria and to receive ARV treatment supposed to be different queues.' (P 11)

A participant believed that one waiting area for clients with different conditions not only reduced the space but also reduced ART clients' privacy:

(Fiddling with bag while talking): *'I think the best way to improve this is for those who come for family planning, they should have their own special place, for example other people they come here just to peep and they say that, this queue belongs to ARV patients, that's not good.'* (P 4)

Another participant preferred a mixed waiting area, not specific to ART clients:

'There is one queue to family planning and ART, other people are happy with it because these two sections are very close to each other...is a hiding place and people could not know that you have gone there to collect medication.' (P 12)

Several waiting areas for different conditions may end up being confusing for clients. However, Church et al. (2015) state that the presence of a variety of services in the same location, apart from ART, could be a positive development as it facilitates the integration of services.

4.7.2 Category 2: Organising and leading appropriate activities in the clinic

4.7.2.1 Sub-category: Amount of time clients spend at the clinic

Delays in service delivery and long queues contribute to poor retention of clients in ART (Wachira et al., 2014:646).

A participant noted that the services were slow:

(Playing with fingers while speaking): 'Let me give you an example. When a patient comes here and the services are not that good and he is late for work, next time he will choose to be at work instead of coming here to collect his medication. If this happens that person automatically will miss his doses and this will lead to drug resistance ... all the health passport books should be collected according to arrival of the patients. By so doing, those people, they may be able to know their turn, or you can distribute numbers, other people they came here early but you could see them they are the last ones to be helped this is so because there is no proper arrangement, and this makes other patients to worry.' (P 13)

ART clients were served later in the day, after clients who had come for other services, which could make clients feel disregarded.

A participant was told to wait for the antenatal women before being served:

'I was told that I have to wait for pregnant women to be assisted first then I waited again until all of them were assisted they were not willing to help me and I even thought that I was not important to them.' (P 2)

Naburi et al. (2016) and Wung et al. (2016:280) found that queues at clinics were too long and that clients became disillusioned as a result. Spending many hours at a clinic for appointments interferes with clients' employment and can deter people in need from attending future appointments (Lam et al., 2016). Requesting time off work is difficult for some clients (Yehia et al., 2015:246). Clinic waiting times invariably compete with clients' other priorities, leading to dilemmas. The nurses need to implement a queuing system which is fair and fast, ensuring that early arrivals are served first and that none are forced to spend whole days queuing.

48 THEME 6: MOTIVATION OF THE PATIENT REGARDING TAKING ANTIRETROVIRAL THERAPY (ART)

Patients are motivated to adhere to ART treatment by both extrinsic and intrinsic factors (Wildavsky, 2017:85).

4.8.1 Category 1: Motivation to approach the clinic for support

Feeling sick was one of the problems which brought clients to the clinic for testing. Some participants in this study made the decision on their own, voluntarily, while others were tested at the suggestion of a health provider, because of their condition, as part of PITC (provision of initial testing and counselling).

4.8.1.1 Sub-category: Provider- initiated testing and counselling: offer to conduct HIV testing

Most clients who come for out-patient department services, antenatal clinic, family planning and sexual transmitted infections are sent for HIV testing by their providers.

Clients who first test through provider-initiated testing may find it difficult to accept ART immediately. They need time to process the results. Acceptance of positive results may take a long time and may happen only after several 'confirmation' tests over a period of time (McLean et al., 2017:3). Antenatal mothers who test positive sometimes accept ART in order to protect their unborn child, but many of these women stop taking the drugs once they have weaned the baby (McLean et al., 2017:2).

Participants were asked to take an HIV test by nurses:

'I came here for family planning. I was asked if I was ever tested, then I said no. So I was requested to go for testing at VCT. They asked me if I was ready to start treatment or I would wait.' (P 13)

(Touching the fundus while talking) 'When I come here for antenatal clinic they sent me for blood testing, then I was told that am positive.' (P 6)

Another participant was sent for testing because of illness, and the providers made the decision to test, so that clients would know their HIV status:

'I thought I was to be given drugs to treat my malaria, instead I was found positive and directed to receive ARVs. This was fine because if they could give me drugs like Bactrim and Panado I wouldn't have known the cause of my suffering. I welcome the idea, that's the way they operate ... it's difficult for me to understand.' (P 9)

PITC is routinely offered in health facilities to all clients for all services, depending on the

population served, facility capacity and symptoms or medical conditions that might indicate HIV infection (WHO, 2016:26). This PITC model should not be perceived as mandatory by the nurses; clients have the right to opt out of HIV testing (Mwangala et al., 2015). Clients who test through PITC sometimes accept ART as a requirement for accessing other services (McLean et al., 2017:3). This acceptance may be misleading and not indicative of long-term retention in care, because after receiving the service they want, clients may well decide to stop coming for ART appointments (McLean et al., 2017:3).

4.8.1.2 Sub-category: Clients go for voluntary counselling and testing

Voluntary counselling and testing means clients initiate the testing themselves (Mwangala et al., 2015). People can go for testing just to know their status, although social facilitators such as the availability of a testing place and the lack of fees associated with testing do enhance motivation (Logie et al., 2017).

Participants decided to be tested on their own for various reasons:

(Swinging a leg continuously): 'I was not feeling well, I was not healthy at all. I had body pains and prolonged headaches. I decided to come for testing.' (P 11)

'At first when I came here I told them that I want to get tested.' (P 8)

'I came here to be tested.' (P 14)

These clients are likely to be ready and willing to start ART treatment when found positive. An asymptomatic client who starts ART may miss doses or discontinue treatment when they experience side effects, as they lack a serious, felt motivator to adhere to ART (Bezabhe et al., 2014).

4.8.2 Category 2: Motivation to take antiretroviral therapy (ART)

Personal values may influence a client's motivation to take ART treatment (Mokwele & Strydom, 2017:31).

4.8.2.1 Sub-category: Confirmation test to promote acceptance

The confirmation test promotes acceptance of the results as it rules out testing errors (WHO, 2016:3).

A participant was tested more than once to confirm her positive results:

'At first the result came positive. They did for second time - it was also positive, then they did it for the last time, and the result came positive again. So, they told me my result that am positive.' (P 8)

Another participant needed the use of more than one test kit to promote acceptance of her positive result:

'I was tested on 8th December last year and was found positive. My husband did not accept his results, so he said we should come another day ... I went for testing again and they used two types of testing and found that I am positive.' (P 12)

Clients sometimes find it difficult to accept a positive result, distrusting the accuracy of the test kits and the skill of the provider (Choko et al., 2015; WHO, 2016:3,20).

Participant mentioned:

'I have just decided to get tested because nowadays things are changing because today you can be tested, and results comes negative. If you go for the same test tomorrow, the result can be positive.' (P 8)

Clients clearly do not always trust their initial results and need to be tested more than once to accept their condition.

4.8.2.2 Sub-category: Motivation for adherence

Those who start ART because of ill health are more likely to adhere to treatment than those who experience no symptoms before they initiate treatment (Bezabhe et al., 2014). Kingkaew et al. (2017:218) found that clients who have been confirmed HIV-positive following long-term sickness adhere to ART because of their heightened trust in the medications; they experience the effects of the ARVs in the form of improvements in their health. Most participants believed that ARTs would improve their health and mentioned good health as the reason for their acceptance of the ARVs (Denison et al., 2015:4; Russell et al., 2016:10).

A participant believe that ART would prolong her life:

'Now I'm going to use ARVs to prolong my life.' (P 11)

Another participant said that ART would improve her health status:

(Looking at her hands): *'I receive the ARVs to reduce the disease in my body and also to boost up my immunity.'* (P 9)

The results highlight good health as one of important motivators for ART adherence. Some participants were already unwell when they initiated testing or when they were sent for testing by the nurses. Denison et al. (2015) wrote that those clients who were severely sick when they initiated ART perceived good health as a motivator to adhere to treatment.

A participant thought of the responsibilities she had:

'Actually, I'm a widow and I have small children to take care of so if am not careful I may end up dying and leave my children behind.' (P 3)

Childcare responsibilities clearly enhanced acceptance of and commitment to treatment, a finding which concurs with that of Bezabhe et al. (2014).

4.8.2.3 Sub-category: The role of living examples in promoting acceptance

Sharing personal experiences with and getting support from other people such as long-term clients who have experienced similar situations may be viewed as crucial (Bratt et al., 2015:171).

Some participants appreciated the involvement of long-term clients who were positive about ART treatment, and who helped to motivate them to accept the ART and take their medications regularly:

'They called someone who is also on treatment, she narrated her testimony. She said, as you can see, I'm also positive, I'm not worried because I started taking this medication a long time ago. She had encouraged me that I should not get disappointed or having stress. Then I was given the medicine ... because of the testimony which was given by that long-term client and she said that she was found positive long time ago. She looks healthy, that was why I was encouraged.' (P 6)

If newly diagnosed clients are able to talk to someone who understands what they are going through and encourages them, they gain the motivation they need to accept the treatment and adhere to it (Bratt et al., 2015:171).

When a client encounters another client on treatment, they become aware that the condition is common and can be managed. A participant was encouraged when he realised that there were others who were positive and doing well on treatment:

'I'm not the first one to be on treatment. There are so many people who started long time ago and they are still alive up to now in good health. Others could even give birth to children while in that condition.' (P5)

Macpherson et al. (2015:1015) suggest that young adults who receive peer counselling have a higher retention rate for clinic attendance, which could lead viral suppression over time. Using long-term clients who are doing well on ART treatment, and who are supported by adequate training and ongoing supervision, could be of tremendous help to these young adults and to the healthcare system (Lands et al., 2017:341).

4.8.2.3 Sub-category: Clients are given many types of medication

Initiating ART in first-line treatment with a fixed-dose combination of Tenofovir (TDF) + lamivudine (3TC) + Efavirenz (EFV) is recommended by WHO (2016:98). This combination is known as Option 5 for adults (5A). In areas where bacterial infections and malaria are highly prevalent, co-trimoxazole prophylaxis therapy should be initiated and continued in all clients who are HIV-positive, regardless of CD4 cell count or WHO clinical stage (WHO, 2016:193). During initiation of ART, clients may also get prophylaxis treatment for TB, cryptococcal meningitis if antigen-positive, malaria or severe bacterial infection (WHO, 2017:9).

Clients in this study were receiving more than one type of drug, whether or not they were experiencing problems. Two participants were given four types of drugs:

(Showing the drugs): *'I have been given four types of medication. I was given 5A which is supplied to those who are just starting the treatment ... these [the four types] include all the medicines which I am given for ARV, Bactrim and the medications which are meant to prevent TB and the other one to relieve the pain of legs.'* (P 4)

'Four types ... small pills, and the other one was medium in size, the other medication was Bactrim, then ARV.' (P 6)

Scott et al. (2016) suggest that there may be a significant negative association between adherence and pill burden, while Van Galen et al. (2014) and Clay et al. (2015) found that using fixed drug combinations reduced non-adherence.

A participant was given TB prophylaxis:

'I was also given medication which prevents from TB.' (P 5)

Combining IPT and ART reduces the incidence of TB and has a significant impact in reducing death in PLWHIV (Smith et al., 2015:84). The incidence of TB is higher in the first six months of ART because of immune reconstitution inflammatory syndrome (IRIS), which occurs if there is a very low CD4 count (Yirdaw et al., 2014). The high acceptance of IPT in patients in another study indicated that people living with HIV were ready to accept any intervention that might improve their health (Shayo et al., 2015).

4.8.3 Category 3: Moving to the future in partnership

Once participants in this study were initiated on ART, they began thinking of the new life which they would live with the virus while taking the medication long term.

A participant was encouraged to live positively:

'I was encouraged that I should not be afraid because I'm like this and this is not the end of everything. No, I have courage that I can do everything as other people can do.'
(P 13)

Another participant was hoping to live long because of ART:

'Now I'm going to use ARVs to prolong my life.' (P 11)

A participant felt that he could plan for a future with his status known:

'I will be able to plan my life because I know my status.' (P 5)

The idea that treatment prolongs life is clearly a motivating factor for clients in initiating treatment on ART. Lifson et al. (2017: 953) confirm that clients who are initiated on ART reduce the risk of HIV disease progression and increase their chances of survival.

4.8.3.1 Sub-category: Involvement of partners and guardians

Partners and all family members of clients who are enrolled in HIV care and treatment should be offered routine HIV testing at the clinic. Information on prevention could also be offered to uninfected partners or couples who might be infected (WHO, 2016:44).

A participant was encouraged to involve her partner in HIV care prevention:

'If you are married, it is good to be open to your husband and tell him. It's good to tell the partner to get tested so that both of you should be on treatment.' (P 8)

Participants were reluctant to take medication before informing their partners, for fear of being suspected of knowing about their HIV status and hiding it:

'I tested positive and they said I should start receiving ARVs, I said no, I had to go back to discuss with my wife. I should not go back home with medication, it would be like I knew that I'm positive and was hiding from her.' (P 9)

The same participant wanted to discuss his status with his partner:

'Rather we should put matters on the table to discuss and agree either to move on with life or to separate or we are both HIV-positive, so we can be using condom.' (P 9)

Clients who start the ART treatment immediately after counselling do not have the opportunity of disclosing their HIV status to spouses or relatives. Those who disclose early may have improved ART adherence because of an increased likelihood of receiving much-needed support at home (Tenthani et al., 2014:589).

A participant planned to inform her family members about her status:

'They asked me about my guardian, I told them that when I go home I will tell my niece so that she should know, in case if I may happen to fail sick she can come here and collect medicine on my behalf.' (P 3)

Family members can be a great source of emotional and instrumental support to HIV-positive people (Denison et al., 2015). Guardians can support clients both emotionally and physically, reminding them of clinic appointments, and facilitating and supporting patients to take their medications at home (MacPherson et al., 2015:1015; McKinney et al., 2015).

4.9 SUMMARY

This study found that nurses need to increase their support of young adults during their first visit to the ART clinic to retain them in care. The support should include improvements to the physical environment, which should be modified to allow comfort, privacy and confidentiality. It should also include the provision of adequate information which would help young people to understand the treatment procedures and their responsibilities in care. These young adults have experiences which can affect their retention in positive or negative ways. From their experiences, it is clear that nurses ought to maintain absolute professionalism and respect for every individual, and not become careless in the way they treat clients. In addition, effective use should be made of long-term clients who are doing well on treatment. These can be asked to counsel and encourage HIV-positive people newly initiated on ART. The first visit is the most crucial, setting the tone for long-term management of the condition.

CHAPTER 5

CONCLUSIONS, RECOMMENDATIONS AND LIMITATIONS

5.1 INTRODUCTION

This chapter describes the conclusions, recommendations and limitations of the study. The question posed in the study was: How can nurse support young adults during their first antiretroviral therapy visit at an urban primary health-care clinic in Malawi.

5.2 CONCLUSIONS

The insight gained from this research has given insight into the young adults' experience of their first ART visit. The findings of this study suggest that young adults are confronted with challenges on their first visit to the ART clinic, such as the social stigma associated with the disease, the daily intake of medications, the need for frequent clinic visits for more drugs and fear of poor health associated with reduced immunity (Ramaiya et al., 2016; Ryan et al., 2016; Van der Heijden et al., 2017).

During their first experience at the clinic, young adults who are HIV-positive should form a positive impression of the nurses and the clinic and need strong reassurance that they can control their disease (Dang et al., 2017). This study indicated that young adults need support from nurses to be able to cope with the diagnosis.

From the lived experiences of the interviewed participants, six themes emerged. The themes focused on an environment that enhances a client-orientated approach and that has a focus on holistic wellbeing in a legal and professional context. Information pointed out as important was the use of knowledge management to provide relevant and sufficient information, as well as motivating patients to receive ART treatment. Holistic care is needed in managing clients through ethical dilemmas and comprehensive ART treatments.

5.2.1 Environment of the client

One of the aspects participants believed could contribute positively or negatively to their experience during their first ART visit is an environment that can enhance a client-orientated approach, with a focus on holistic wellbeing. Clients' preconceived ideas of the clinic and service could contribute to

their decision on whether they should seek HIV care and where they can access this care. An inviting and flexible environment gives the young adults the freedom to share their information with nurses at the initial engagement and could help them to trust the services at the clinic and the care nurses provide. This type of environment could also encourage the young adults to remain in HIV care as they could feel accepted and supported. According to Wong et al. (2017:192), young adults are confronted with challenges when seeking care, and even when they have managed to seek HIV care, they will often not engage in lifelong care due to multiple factors which include their adulthood stage and a lack of privacy and confidentiality.

Some of the participants did not like the clinic environment as they thought their HIV status would accidentally be disclosed while they were receiving the drugs in the waiting area. Nurses should try their best to provide privacy to the young adults during the HIV care. When a clinic is not supportive to different generations/ages, young adults could be discouraged to discuss their health needs as they fear older people would laugh at them. If there are different waiting areas for different age groups, the young adults could feel comfortable as they can use that opportunity to discuss their challenges and ways to help them to move forward with their life and HIV-positive status in a positive way. If the environment cannot accommodate different waiting areas, the management could think of using separate clinic days for different age groups.

5.2.2 5.2.2 Holistic care

Participants thought the care at the clinic was insufficient due to an absence of nurses who are skilled at and experienced in supporting young adults' needs. Nurses should have the skill and expertise to assess the young adults' physical and psychological needs during their clinic visit. Participants felt that nurses were just interested in their HIV infection but lacked a holistic nursing-care approach, which could include a proper physical assessment of clients before initiating them on ART, treating the opportunistic infection and/or referring the clients to other care if needed. Participants thought they were just encouraged to begin with ART treatment and were denied the care for other opportunistic infections.

Another cause of dissatisfaction was the amount of time spent at the clinic. This could be due to the necessary movement around different departments. The clinics should have recreation material and facilities for example, posters, indoor games and TVs to keep the clients entertained and provide information at the same time. Nurses could book the client's appointment for a specific time so that the client could come to the clinic closer to their time and spend less time at the clinic. Some of the participants had to be absent from work or school

for more than a day as they could not access the HIV/ART services on the same day because the nurses were not available at the clinic on the day they came. This could disturb clients' daily activities. Making a duty roster and following it closely could increase the chances of having enough nurses on duty at the ART clinic.

Sometimes clients had negative experiences of HIV care due to unprofessional conduct of the nurses, which includes their untimely report for duties and failure to meet standards of confidentiality (Topp et al., 2018). When young adults were not treated with dignity at the clinic and their confidentiality and privacy not ensured when they come for ART on their initial visit, they could be unwilling and reluctant to return for more drugs and clinic appointments. The conservation of dignity allows young adults to tolerate the physical and psychological vulnerability of the HIV/AIDS diagnosis (Ferri, Muzzalupo & Di Lorenzo, 2015:41). Nurses should ensure that young adults are given appointments with the same nurse with whom they have built trust during all their appointments for them to have confidence that their information is kept confidential and not shared with other nurses.

This study found that some respondents felt stigmatised by nurses, which could discourage the HIV-positive clients from seeking health service and taking ARV treatment, or cause them to move to other clinics where they do not feel stigmatised (Geng et al., 2015:935; Ahamuza et al., 2016:41). Nurses should avoid judgemental verbal and non-verbal communication as it could be perceived by clients as stigmatisation and discrimination.

This study found that nurses encourage their clients to involve the partners and family members to provide them with the needed support and encouragement. This could be important for keeping the young adults in care, in addition to their own willingness and readiness for ART. Hosting an open day could lead to sensitisation in communities, and by involving the community and church leaders, information about the importance of supporting the family member who is HIV-positive could be emphasised.

5.2.3 Information

Participants experienced the nurses to be emotionally supportive when they were providing information regarding HIV/AIDS and its treatment and explaining how to take the medication and what its possible side effects are. This information could make the young adults confident to follow the treatment regime given to them. This study found that when the clients were given enough information, they felt that nurses were friendly and had a caring attitude. Pre-test and Pre-ART

counselling could be important for addressing the client's health and psychological needs. This study found that all the participants had pre-ART counselling before initiation, during which different topics were discussed. However, none of them indicated that the treatment is lifelong. This lack of information could lead the clients to stop taking the medication when they feel healthy and to be unmotivated to continue with the treatment.

Clients also have their roles to play during counselling, which includes providing the counsellor with the information about their condition and asking questions when they don't understand something. This could help nurses to identify the clients' needs and to identify the strategies which clients could use to manage their own problems (Horter et al., 2017:54–56). The nurses should provide complete information and use language which the lay persons could understand. A clinic should also have a support group for young adults who are HIV-positive as it could help to reinforce the information and support the young adults to remain in care.

Although PITC offer HIV testing opportunities for clients who have reported to the clinic for other services, some of the clients could not understand the reason for testing; more specifically, when they spent more time at the clinic they started blaming the nurses for delaying them. There is a need for proper explanations to clients about why they need to be tested and why testing, in relation to the services they were seeking, were important. Nurses should provide information to clients on the importance of testing, benefits of starting ART treatment before the immunity is very low and the availability of the treatment and support when one is positive. Without these explanations, these clients could just accept the ART treatment (even though they were not ready for it) in order to get the services, they intended to get, thinking that if they opted out of the HIV testing and treatment, they couldn't get the other services (Denison et al., 2015:4). Clients should also know that they have the choice to opt out if they don't want to be tested on that day so that they could make an informed decision on HIV testing and counselling.

This study found that knowing someone living with HIV who is doing well on treatment could play an important role in facilitating acceptance and motivating clients to initiate ART treatment. These findings support the finding of Mupambireyi et al. (2014) which showed that involvement of long-term clients in pre-ART counselling encourages clients as they get information from persons who have real-life experience of being HIV-positive and have to deal with the challenge of taking medication daily.

5.3 RECOMMENDATIONS

The findings of the study provided information on the young adults' lived experience during their first visit to an ART clinic. Overall experiences of the HIV-positive young adults at this clinic was positive. Accordingly, based on the findings, the researcher made recommendations for professional nurses on the support given to young adults during their first visit to an ART clinic. Recommendations around nursing practice, nursing education, nursing management and research are outlined.

5.3.1 Recommendations for nursing practice

The study has shown that young adults who are HIV positive need motivational support from nurses on their first visit for ART to retain them in care.

Nurses should try their best to provide privacy to the young adults during the HIV care. When a clinic is not supportive to different generations/ages, young adults could be discouraged to discuss their health needs as they fear older people would laugh at them. If there are different waiting areas for different age groups, the young adults could feel comfortable as they can use that opportunity to discuss their challenges and ways to help them to move forward with their life and HIV-positive status in a positive way. If the environment cannot accommodate different waiting areas, the management could think of using separate clinic days for different age groups.

Good interpersonal relationships are essential. The nurses at an urban PHC clinic could create a good rapport with young adults on initial contact to win their trust by engaging in appropriate conversation in a peaceful environment without distractions. Nurses should provide a positive atmosphere for young adults by guiding and supporting them. They should furthermore make them feel comfortable by asking about other things like work or school and how they are feeling in general, and not only talk about their HIV. The nurses need to create a trusting relationship with the young adults by providing them with enough and relevant information about their condition and the medication they are getting. Nurses should ensure that young adults are given appointments with the same nurse with whom they have built trust during all their appointments for them to have confidence that their information is kept confidential and not shared with other nurses.

Ethical considerations should be taken into account. Privacy should be provided to the young adults by seeing them in a private room and respecting their dignity during the nursing care, despite heavy workloads and limited space. Nurses should keep clients' information confidential and ask for consent when they need to share it with other health professionals for the sake of caring for the client. Nurses should advocate the protection of young adults' rights during care. They should furthermore help and support young adults, especially when they are vulnerable and lack the strength to fight for their rights during HIV care.

The nursing process should be conducted scientifically. Nurses need to do a proper assessment of any client before initiating him/her on ART treatment. This means that every aspect of the client as a person should be explored through a thorough history taking and assessment of their physical, psychosocial and emotional needs, and, where needed, laboratory investigations should be conducted. These assessments could help nurses to isolate individual clients' needs and provide the young adults with specific care and counselling, so that when they leave the

ART clinic, they are not only provided with the ART treatment but are also encouraged to manage their HIV condition in a positive manner and are ready to adhere to treatment and to remain in care.

HIV-positive clients are at risk of developing opportunistic infections due to reduced immunity, and any infection could be severe, so proper assessment and treatment or reference is needed before complications develop (Ignatavicius & Workman, 2015:333). Nurses need to be knowledgeable and skilled and need to make time for their clients so that they get holistic care. Procedures and standard for the physical assessment of clients before ART initiation should be put in place for the nurses and doctors who are working in HIV/ART clinics to equip them to be able to assess clients' needs holistically. All nurses, especially those in the ART clinics, need to abide by those procedures.

Effective time management can support clients. The nurses should make time to interview and counsel the young adults to ascertain emotional stability before they let them go home. As small as this intervention may seem, it is very valuable to the clients. This could be routine practice in the HIV/ART clinics as clients that present there are in distress due to the diagnosis. This could be incorporated in the care the nurses provide while handing out the medication and interacting with the client and could have a huge impact on the emotional outcomes of the participants and ensure their retention in care (Kourkouta & Papathanasiou, 2014:142; Dures et al., 2016).

Beyond the ART treatment on the first day at the clinic, HIV-positive young adults may need a full physical and psychological assessment and psychological support. Nurses spend quite a

significant time with the clients, therefore they could use this opportunity to assess the psychosocial needs of young adults and the support they receive from family, spouses, friends and significant others. The provision of informed, non-judgemental and reliable support could help the young adults to remain in HIV care. The introduction of couple counselling services at the clinic could also promote the support from a spouse. Nurses could help the young adults to plan their care and time for clinic appointments. The young adults' mood, level of anxiety and self-esteem should also be assessed in order to work with them and identify their strengths and coping strategies. Nurses also need to provide stress management to all HIV-positive clients.

A client-centred communication style could provide a positive client-nurse relationship, desired by young adults (Ignatavicius & Workman, 2015:336). During counselling, nurses should use language and terminology that their clients would understand.

Preventive orientated counselling remains a primary function of a nurse, even in the HIV/ART clinic. Information about what they should do if they forget to take their medication should be provided, as young adults are always busy with other activities and could easily miss treatment time. It is evident that many clients have minimal information about HIV/AIDS or misunderstand HIV/AIDS and its treatment (Van Hoof et al., 2015:163). It is important that the nurses give them enough information in order for them to understand the disease and to adhere to the treatment from the time they are initiated into care.

However, a need exists for regular information sessions on the ART so that clients understand how the drugs work and know why they need to take them for life. Establishing online forums might provide young adults with the needed information about HIV/AIDS and its treatment, which they can access in their own time. Enough and quality information could help young adults make informed decisions and plan and manage their care appropriately. The nurses should provide complete information and use language which the lay persons could understand. A clinic should also have a support group for young adults who are HIV-positive as it could help to reinforce the information and support the young adults to remain in care.

Young adults need positive reinforcement and encouragement by nurses to give them hope for life after HIV diagnosis.

5.3.2 Recommendations for nursing management

The staffing levels of the clinic should be increased to reduce the workload, give them more time to spend with each client and to help the nurses to provide holistic care to young adults. The nurses in charge should make sure that there is a well-distributed work schedule in the clinic and that it is followed, so that the clients are not sent home without being attended to as this could discourage the young adults.

The nurses in charge should act as role models to encourage all the nurses at the clinic to act professionally and ethically in providing care to young adults. They should furthermore arrange in-service training to ensure that nurses are competent to assess the physical and psychosocial needs of young adults and provide the needed care and listen to clients in a caring and non-judgmental

manner. Continuous education helps to develop a sense of responsibility, accountability and commitment to professional and ethical practices. Professionalism and nursing ethics should be monitored by the nurses in charge as these attributes are necessary qualities for nursing practice, even in the situation where there are too many patients and/or staff shortages. The nurses in charge should ensure that all nurses protect patients' rights and uphold client dignity. Nurses should also not breach patients' rights when providing care (Dehghani et al., 2015:61; Griffith & Tengnah, 2017:67–72). When clients know that their dignity is not respected, they avoid seeking care from that facility.

Adequate resources are needed to expand the clinics so that they can have enough rooms and space for the services they provide and can ensure that all clients are comfortable. Equipment which could be used to provide information and recreation to the clients at the waiting area (for example posters, indoor games, TVs) should be purchased. Integrating HIV services with medical care and treatment, psychological evaluation and psychotherapy could promote the holistic care to young adults. When the services are integrated, clients would not have to spend time on moving around the departments.

The formation of a support group for HIV-positive young adults close to their homes can provide them with information, support and encouragement they need to remain in HIV care. Exchange visits between support groups should furthermore be organised so that they can learn how to support the members who have poor adherence to treatment from other groups.

A yearly open day for the clinics must be arranged during which the community is made aware of all the services the clinics provide and the benefits of those services to the clients and the community at large. The community and church leaders should also be involved in sharing this information where ever there is a gathering so that their communities know about the services at the clinics and what is expected from them in their support of their relatives who are HIV- positive.

A policy which promotes the use of separate waiting areas for different age groups at the ART clinic should be developed, as this could make the young adults feel comfortable and promote their willingness to remain in care. Health workers who share patients' information, stigmatise or mismanage the clients at the ART clinic should be subjected to disciplinary action in order to reinforce professional conduct during care.

Another recommendation is to put up a suggestion box at the exit of the clinic which clients can use to submit their views. This feedback can then be used for the improvement of client care. The clients' feedback on the services could also help during the evaluation and re- planning of the

services rendered at the clinic. Anonymous, toll-free lines could be set up for clients to report any mismanagement at the clinic.

5.3.3 Recommendations for nursing education

Continuous skills development in the form of short courses is needed, especially with regards to youth-friendly ART services and electronic data management skills. Nurses should read articles to give them enough information to disseminate to clients on the importance of treatment, good adherence to ART and retention in care during their counselling sessions before and after initiating the clients on treatment. Educational opportunities should be provided to ART nurses to increase their knowledge of planning and delivering the care to young adults.

Nurses should have in-service training on the information and care to be provided to young adults who are HIV positive. Mentorships to novice nurses on the care of HIV-positive young adults could help them to be confident when providing the care to this group. The nursing colleges could include modules on specific care for HIV-positive young adults on all year levels in undergraduate nursing curricula so that even novice nurses would be able to provide the needed care to this age group.

5.3.4 Recommendations for further research

The researcher recommends that further research is conducted on the overall impact of the first visit to a clinic on young adults' experience and retention in HIV/ART care.

The researcher also recommends a study on the quality of information provided by long-term clients during counselling. It was observed that long-term clients were doing most of the pre-ART counselling; however, they are not sufficiently trained to do this. It would be important to understand the impact of using long-term clients in HIV care.

Further, the practices, attitudes and knowledge of nurses who provide ART to young adults need to be explored, as the nurses may also need some form of support to effectively care

5.4 CHALLENGES AND LIMITATIONS OF THE STUDY

The study has several limitations. The study was done at one clinic which is situated in an

urban area. Therefore, these findings could not be generalised to other ART clinics. The study was limited to lived experiences and did not research the overall impact of advice on young adults' retention in HIV care.









Qualitative studies are always difficult and sometimes impossible to replicate as their data are from a specific context (Bengtsson, 2016:14). The qualitative design adopted in this study makes it difficult to quantify the highlighted experiences. However, the exploratory nature of the study facilitated an in-depth understanding of young adults' experience of their first visit to an ART clinic. The other challenge (and potential weakness) in this study was that the sample was small. Quantitative researchers sometimes criticise the small sample sizes of qualitative studies as being unscientific and unrepresentative of the population. However, the principle in qualitative research is data richness, not quantity.

Another possible limitation might be that the sample consisted mostly of females – eleven out of fifteen participants were females. Although the inclusion criteria included males and females who were HIV-positive, most of the clients who came to the clinic for various reasons and were referred for HIV testing through the PITC programme and willing to participate in the study were female.

The researcher noticed that some participants needed to be encouraged to talk; however, as far as possible, the researcher attempted to ensure scientific rigour in the study (see Chapter 3).

5.5 CONCLUSION

This qualitative study described the support nurses need to render to young adults during a first visit for ART at an urban PHC clinic in Malawi. Participant's lived experiences varied – some had positive experiences, while some had negative experiences. All participants mentioned that they had a warm reception at the clinic and that they had pre-ART counselling, but there is still a need for more and accurate information. The participants felt that they needed support regarding their right to choose to defer or delay the ART initiation, so that they could disclose their status to their partners. They therefore did not want to be forced to start with the treatment on the same day as the diagnosis. Support to young adults should be addressed in practice, through nursing education, by nurse managers and further research. Ethics and trustworthiness were maintained throughout the study.

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ANNEXURE A: INFORMATION SHEET



PO 1906, Bellville, 7535

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E-mail: kupatsac@gmail.com

PARTICIPANT'S INFORMATION SHEET

Project Title: Nurse support for young adults during a first antiretroviral therapy visit at an urban primary health care clinic in Malawi

Dear Participant

Introduction

My name is Kupatsa Chigona and I am a registered master's student in Nursing Science at the Cape Peninsula University of Technology. I would like to ask you to offer me an opportunity to explain the research that I wish to undertake, and to ask you to kindly participate in an individual interview. Please note that you are allowed to any question at any time you may have.

Purpose of the research study

In Malawi nearly half of ALHIV in two ART clinics reported non-adherent to ART treatment, yet efficacy of ART treatment depends on patient adherence to daily medication regimen. Nurses understand the needs of patients, so they can provide support and care to make patients' lives as normal and productive as possible including those with HIV. PHC organises health services around people's needs and expectations, such as antiretroviral therapy (ART) treatment for patients with HIV/Aids. The purpose of the study is to describe nurse support for young adults during a first antiretroviral therapy visit at an urban primary health care clinic in Malawi.

Description of study procedures

Individual semi-structured interviews will be conducted in a private room at the clinic with the participant as agreed. The interview will take not more than 30 minutes of your time to participate in during the research. The interview will be recorded with your permission. The reason for recording is to allow the researcher to analyse the interviewee's experiences to gain insight, to listen to the interview more than once, and share the data obtained with only the supervisor. The researcher will also take notes so that at the end of interview she can reflect on the interview to identify gaps that might need to be explored in a follow-up interview. The interview schedule will include questions such as: What are young adults' lived experiences of their first visit for ART treatment at an urban PHC clinic in Malawi? How can nurse support for young adults during a first antiretroviral therapy visit at an urban primary health care clinic in Malawi could promote the retention in care?

Risks or discomfort

Should you decide to participate in the study, you may feel emotional about your HIV status, however there will be no physical risk. In the event of any unforeseen circumstance, the interview will be stopped, and the necessary assistance will be offered by a counsellor that will be available within the clinic.

Benefits to the participant or others

The results of the study may contribute towards the retention and re-engagement of young adults in HIV treatment and care.

Privacy and confidentiality

Participant's information will remain strictly confidential. Interviews will be conducted in a private room. No names will be recorded anywhere during this research only numbers on the consent form, and the audio recording will not be linked to your name. Only the researcher and supervisors will have access to the information. All your information will be kept under lock and key (electronic data password protected on the computer) for five years after the report has been published then will be destroyed/deleted.

Conditions of participation

Please understand that taking part in this study is voluntary and you are not being forced to participate. The decision to participate is entirely up to you. However, I would appreciate it if you share your views with me. If you make a decision not to participate in the study, this will not affect any care at this clinic. You will get the treatment as needed. If you agree to participate and later decide to withdraw at any stage of the interview or study, you are allowed to do so. There will be no interruption of services during the research project as a private room will be used to conduct the interviews, thus no negative impact on the clinic's service delivery and patient's management will occur.

Expenses

You will not pay anything, and you will not be paid by participating in this study.

Contact details

This research is being conducted by Kupatsa Chigona, a professional nurse now working as research officer/ surveillance officer here at an urban PHC clinic.

If you have any questions about the research study itself, please contact:

Researcher: Kupatsa Chigona

Professional Nurse Matawale Health centre, P/Bag 18, Zomba. 0609098344/0888113425

Email address: kupatsac@gmail.com

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:

Research Supervisor/ Head of the Department of Nursing

Prof. K. Jooste

Cape Peninsula University of Technology

P O Box 1906, Bellville, 7535

Telephone :(021) 959 2271

Email: kjooste@cput.ac.za

ANNEXURE B: CONSENT FORM



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WRITTEN INFORMED CONSENT

Letter of request to participate in the study

Project Title: Nurse support for young adults during a first antiretroviral therapy visit at an urban primary health care clinic in Malawi

The study has been described to me in language that I understand, and I freely and voluntarily agree to participate. My questions about the study have been answered after reading the information sheet. I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way.

Participant's signature.....

I further agree that the interview be voice recorded.

Participant's signature.....

I further agree that the researcher takes field notes.

Participant's signature.....

Witness

Date.....

ANNEXURE C: INTERVIEW SCHEDULE



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Introductory questions

Welcome and explain the purpose of the study
what is age and demographics

Main questions

- What are your experiences of your first visit that was for ART treatment at the urban PHC clinic that you attended?
- How can other young adults be supported by nurses when they first visit the clinic for ART treatment?

Examples of probing questions

- How is it for you to ...
- Tell me more....
- What is your overall impression of the support from nurses to you during the visit to the clinic?
- How was the treatment and education plan supportive to you?
- What information did you receive?

ANNEXURE D: LETTER OF REQUEST TO CONDUCT THE RESEARCH



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October 2017

Request for permission from faculty research committee to conduct research investigation

I hereby request to conduct a research study at an urban PHC clinic in Zomba, Malawi. The study is entitled: Nurse support for young adults during a first antiretroviral therapy visit at an urban primary health care clinic in Malawi. This study is part of the requirements for acquiring a Master of Nursing Science Degree. The study will be done under the supervision and guidance of Professor K. Jooste of the Cape Peninsula University of Technology.

Data collection will be obtained by:

- Individual semi-structured interviews which will be held at an urban PHC clinic in Malawi. Participants invited to partake will be young adults who are HIV positive on ART treatment and nurses' support. Interviews will be held in a private room and it will take not more than 30 minutes for individual interviews.

The researcher will adhere to the rights of participants to privacy and confidentiality. In this study

no names will be attached to the data obtained and the interview transcripts will be numbered. The participants' names will not be linked to the research findings. The research will not harm the participants in any way. Participants will be informed that they can withdraw from the study at any time they wished to. In this study, the researcher will make use of semi-structured individual interviews and field notes to develop a comprehensive understanding of the phenomenon. While conducting the interviews, the researcher will record the views and experiences shared by the participants with their permission. The transcribed data of the interviews, together with the field notes will be triangulated for analysis after translation and back translation. Open coding will be used to organize data collected and an independent coder (experienced researcher and supervisor) will assist in this regard.

I am also attaching the proposal, information sheet to participants as well as the informed consent sheets for your information.

Researcher: Kupatsa Chigona

Professional Nurse

Matawale Health Centre

P/bag 18,

Zomba,

Cell: 0609098344/0888113425

Email address: kupatsac@gmail.com

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:

Research Supervisor

Prof. K. Jooste

Cape Peninsula University of Technology

P O Box 1906, Bellville, 7535

Telephone :(021) 959 2271

Email: kjooste@cput.ac.za

This research has been approved by the Senate Research Committee and Ethics Committee of the Cape Peninsula University of Technology.

ANNEXURE E: LETTER TO THE MINISTRY OF HEALTH, MALAWI.



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The Director,
Ministry of
Health,
Post office Box
30377, Capital-
City, Lilongwe.

Dear Sir/Madam

Request to conduct a study at an urban PHC clinic in Zomba, Malawi.

I write to seek permission from your office to conduct a study at the PHC urban clinic in Zomba District.

I am a nursing student registered for a Master of Nursing at the Cape Peninsula University of Technology. In fulfilment of this course, I am required to conduct a research project. The purpose of the study is to describe nurse support for young adults during a first antiretroviral therapy visit at an urban primary health care clinic in Malawi.

The study population will include young adults aged between 19 and 25 years (both male and female), HIV positive, first visit for ART treatment at an urban PHC clinic in Malawi between January - February 2018. The participants will be interviewed by the researcher herself using a prepared question guide. The researcher will adhere to the rights of participants to privacy and confidentiality. In this study no names will be attached only numbers on the interview transcripts. The participants' names will not be linked to the research findings. The research will not harm the participants in any way. Participants will be informed that they can withdraw from the study at any time they wished to do so. In this study, the researcher will make use of semi-structured individual interviews and field notes to develop a comprehensive understanding of the phenomenon. The interviews will take about 30 minutes in a private room at the clinic. The researcher will record the views and experiences shared by the participants with their permission. The transcribed data of the interviews, together with the field notes will be triangulated for analysis. Open coding will be used and an independent coder (experienced researcher and supervisor) will assist in this regard.

I am attaching the proposal, information sheet to participants and informed consent sheets for your information.

Looking forward to your favorable consideration.

Yours faithfully

Kupatsa Chigona..... Date.....

Supervisor's signature..... Date.....

Researcher: Kupatsa Chigona

Professional Nurse

Matawale Health Centre

Zomba DHO,

P/Bag 18,

Zomba.

Cell: 0609098344/0888113425

Email address: kupatsac@gmail.com

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:

Research Supervisor/ Head of Department Nursing Science, Health and wellness science:

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This research has been approved by the Senate Research Committee and Ethics Committee of the Cape Peninsula University of Technology.